THE MEANING OF SUCCESSFUL AGING

AMONG

OLDER ADULTS WITH LONG-TERM DISABILITIES

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Dedication

To my husband, son and daughter. May you always overcome adversity, cope with strength and demonstrate resiliency.
Acknowledgments

I am grateful to the professors who taught and guided me during my doctoral studies at Indiana University School of Social Work. I am also grateful to my dissertation committee – thank you for the hours you spent reading and offering feedback on this study. I appreciate your genuine interest in the topic and your encouragement throughout the process. Dr. Adamek was the one who led me to the path I needed to follow when I was lost and unsure of a direction. I was meant to study older adults and have learned a tremendous amount from this work. I am grateful to all of the social workers, physicians and agency employees who guided me to the amazing group of older adults who participated in this research. I will always remember the strength and resilience these older adults taught me through their words during these interviews.

I am also grateful to my parents who model successful aging for me, their grandchildren and my siblings. I am most grateful to my husband, son and daughter. You were patient during the days when mommy needed to work.
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In this study, I explore the meaning of successful aging among older adults with long-term disabilities. The study is a review of scholarly literature on the subject of successful aging, with a specific focus on older adults with long-term disabilities. The objective is to shed light on the issue by critically examining what research exists and what research is still needed. The purpose of this study was to investigate the following question: *What does it mean for an older adult with long-term disability to age successfully?* Seven older adults with sensory impairment, either deaf, hearing impaired, blind, visually impaired or a combination of these, were interviewed using qualitative phenomenological research methods. Findings include themes of *aging as inevitable, frequent activity, social and family interaction as essential, sense of worth, acceptance of disability, coping and resilience* as well as *advice to others.*

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Chapter I: Introduction

Demography of Aging and Disability

As the Baby Boom generation ages, more and more attention is being paid to issues involving aging. The Baby Boom generation consists of those individuals born in the post-World War II period between 1946 and 1964. The oldest among this cohort reached age 65 in 2011 and will reach age 85 in 2031; the younger members will reach age 65 in 2029 and age 85 in 2049. Baby Boomers will represent approximately 60 million of the projected 69 million people 65 and over in 2030. In that same period, the proportion of the oldest-old (80 years and older) will increase dramatically (U.S. Census Bureau, 2010).

As social workers, it is imperative that we strive to both meet the needs of this group but to harness their talents to give back to their communities. One specific area for social workers to concentrate their efforts involves identifying what services can assist older adults in aging successfully. The word aging is often associated with the word problem (Hagestad, 1987; Weaver, 1999), yet many older adults are active, healthy and involved in the community. Even in advanced old age, many people function independently (Haber, 2007). Most older adults are not dependent on others and are not a drain on familial and societal resources, but rather are a vastly underutilized social resource (Hagestad, 1987 & Sherraden, Morrow-Howell, Hinterlong & Rozario, 2001).

The following is a review of scholarly literature on the subject of successful aging, with specific concentration on older adults with long-term disabilities. The objective is to shed light on the issue by critically examining what research exists
and what research is still needed. The study also addresses to what extent older adults with disabilities view themselves as able to age successfully. Much of the research available on successful aging does not address older adults with long-term disabilities. This research study proposed addresses this gap in the existing literature. This research addresses, in part, the following question: *What does it mean for an older adult with a long-term disability to age successfully?*

What is an *older adult?* Definitions of the term vary. For the purpose of this project, older adults consist of individuals age 55 and older. In 1900, 4.1% of the United States population was age 65 and older, now that percentage has more than tripled to 12.8 percent of the US population (Administration on Aging, 2001). In 2000, 35 million adults over the age of 65 (13%) were counted in the US Census (US Census Bureau, 2000). The most recent census data show that the 65 and over population was 40.3 million persons or 13 percent of the US population (US Census Bureau, 2010).

In 2011, the United States experienced the first wave of baby boomers turning 65; each day about 10,000 Americans turn 65 (Administration on Aging, 2001). The number of older Americans will double, from 35 million in 2000 to 70 million by the year 2030, increasing the ratio of Americans over age 65 from one out of eight to one out of five (Administration on Aging, 2001; Alliance for Aging Research, 2002). The fastest growing segment within the older-adult cohort is people age 85 and older, this group is expected to more than double by 2030 (Administration on Aging, 2001). In 2000 there were 50,454 Centenarians (people 100 years and older) in the US, up from 37,306 in 1990 (US Census Bureau, 2010).
The rapid rise in life expectancy, coupled with the declining fertility rate during the past century, has accelerated the growth in the elderly portion of the population (Kaplan, Huguet, Orpana, Feeny, McFarland & Ross, 2008). The proportion of older adults (60 years or older) in the world's population is expected to increase from 10% in 2005 to 22% in 2050 (United Nations, 2005).

According to the US Census, in 2000 there were 14.4 million men and 20.6 million women age 65 and over in the US (US Census Bureau, 2010). Within this population, more men than women are married, while more older women than older men are widowed. Accordingly, most older men reside with a spouse while most older women reside alone. Most older adults reside in metropolitan areas. Distributions by race and ethnicity show that Hispanics are the fastest growing older adult ethnic group. Only five percent of older adults reside in nursing homes. Sixty-seven percent of the population age 65 and older have earned high school diplomas and 15% have bachelor's degrees or higher. The majority of older adults have low to middle incomes and poverty affects older adults at about the same rate as it does younger adults; approximately 11.7% of the older population is living under the poverty level set by the federal government, compared to 11.9% of the population between the ages of 18 and 64 (Hawkins, May & Rogers, 1996). More than 12% of the older adult population is involved in the labor force (Hawkins, et al,1996).

The 2000 Census shows that 49.7 million people in the United States age five and over have a disability. This is nearly one in five United States residents. Of those, 5.2 million were between the ages of five and 20; 30.6 million were between
the ages of 21 and 64 and 14 million were 65 and over (US Census Bureau, 2010). This is approximately one of three older adults.

Worldwide, 285 million people are estimated to be visually impaired. Thirty-nine million are blind and 246 million have low vision. Eighty-two percent of people living with blindness are age 50 and above. Globally, uncorrected refractive errors (myopia, hyperopia or astigmatism) are the main cause of moderate and severe visual impairment. Cataracts remain the leading cause of blindness in middle and low-income countries (WHO, 2015a).

According to the World Health Organization (WHO, 2015b) there are 360 million people, over five percent of the population, worldwide who have disabling hearing loss. 328 million of these people are adults and 32 million are children. It may be inherited, caused by maternal rubella or complications at birth, certain infectious diseases such as meningitis, chronic ear infections, use of ototoxic drugs or exposure to excessive noise. Aging is also a cause of hearing loss (WHO, 2015b). The participants of this study all experienced non-age-related hearing loss or complete deafness.

Disability is a demographic variable similar to age, sex, racial ethnicity and socioeconomic status. It is not a negative health outcome. Disability is a method of identifying risk factors that contribute to lessened participation in life. Older adults are often at risk of facing isolation and lessened participation in activities such as working, voting and community life. Disability is strongly correlated with low education, poverty and reduced access to resources (NIDRR’s Disability Statistics Center Website http://www.ed.gov/rschstat/research/pubs/research.html, 2007).
Aging as Decline

Ageism is the systematic stereotyping of, and discrimination against, people because they are old (Butler, 1969). Similar to sexism and racism, ageism fails to look at people as individuals, but instead judges people by virtue of their membership in a social category. Ageism is also known as prejudice and discrimination against older people based on the belief that aging makes people less attractive, less intelligent and less productive (Ferraro, 1992). Ageism is a longstanding phenomenon. Freud (1905) believed, “Psychiatry was not possible near or above the age of 50; the elasticity of the mental processes on which the treatment depends is as a rule lacking – old people are not educable” (p. 149). In the 20th century the predominant stereotype was that the aged were poor and frail, and that their children often deserted them (Quadagno, 1999).

More recent stereotypes depict older adults as a prosperous, selfish and politically powerful group who are gobbling up scarce societal resources (Binstock, 1996). Older adults are also stereotyped as “An unproductive section of the population, one that does not even promise (as children do) one day to be productive” (Fairlie, 1988, p. 19). Recent ageism sees younger people having a tendency to patronize older adults and be overly solicitous (Quadagno, 1999). This could also include attitudes that discourage older adults from taking risks, dissuade them from exercising and even deny their sexuality.

There are many myths related to aging. Quadagno (1999) summarized some key myths and facts:
♦ *Myth:* Most older people are poor. *Fact:* More than 88% of people 65 and older have incomes above the poverty level.

♦ *Myth:* The aged are isolated from family members. *Fact:* The vast majority of older people have regular contact with family members and see at least one child weekly.

♦ *Myth:* Most older people are disabled. *Fact:* Older men and women spend more than 80% of their lives free of disability.

♦ *Myth:* People become more mellow as they grow old. *Fact:* Personality is stable. It does not change with age.

♦ *Myth:* Nearly 1/3 of people 65 and older are in nursing homes. *Fact:* Fewer than five percent of people 65 and older are in nursing homes.

♦ *Myth:* The aged have no interest in sex. *Fact:* Although frequency of sexual intercourse declines with age, men and women continue to find satisfaction and enjoyment in sexual activity as they get older.

♦ *Myth:* Most Americans retire at 65. *Fact:* The majority of men and women are out of the labor force by age 62.

Aging as decline can be seen as a paradigm or common belief. Shifting to a paradigm of successful aging not only improves others’ views of aging but will improve older adults’ views as well, until it is viewed as the norm to age successfully instead of being sick and alone.

*Ableism*

The term ableism evolved from the disabled people rights movements in the United States and Britain during the 1960s and 1970s. It questions and highlights the prejudice and discrimination experienced by persons whose body structure and ability functioning were labeled as ‘impaired’ as “sub-species.” Ableism of this type is a set of beliefs, processes and practices, which favor species-typical normative body structure based abilities. It labels ‘sub-normative’ species-typical biological structures as ‘deficient’, as not able to perform as expected (Barnes, 2011).
There are myths and stereotypes that exist related to people with disabilities. Barnes (2011) highlights the Judeo-Christian religious tradition of judging human imperfections as signs of impurity, divine judgement and diabolical influence. He concludes, rather pointedly, that "prejudice, in whatever form it takes, is not an inevitable consequence of the human condition, it is the product of a particular form of social development associated with western capitalism (p. 52)."

Living with a severe disability can cause you to age faster (Kemp, 2005). Aging is a natural and predictable process of life that begins as soon as the period of maturation and development ends, typically at about the age of 20 years. Aging can be viewed on a number of levels including subcellular, cellular, organ system, performance, psychological and social. Each level has its own measure of aging. The changes people go through reflect gradual decreases in function at the cellular and organ system levels (Forman, Carruthers and Bondner, 2009).

Over the years organ system capacity declines gradually, over a 50 to 60 year period, until it reaches 20% to 40% of peak, at about the age of 75 years. In people with disabilities, this decline is accelerated from an average of 1% per year in the nondisabled person to between 1.5% and 5% per year for the disabled individual. What is seen is that adults who have a disability after maturity seem to age at a rate faster than normal adults from that point forward. Those who face a disability prior to maturity may never reach that peak capacity (Kemp, 2005).

Accelerated aging was first noticed in people with polio and later in those with spinal cord injuries, traumatic brain injuries, cerebral palsy, amputations and other conditions. It does not affect everyone in the same way or to the same degree,
but premature aging is a problem that merits attention (Forman, et al., 2009, p. 271).

Until about 1960, people with cerebral palsy, spinal cord injury, Down Syndrome, polio and other impairments had a much shorter life expectancy. Today, most people with major impairments can expect to live at least into their 60s. Some people can reach a normal life expectancy if given adequate care (Forman, et al., 2009). The potential shorter life expectancy for individuals living with long-term disability influenced the decision to define the participants in this proposed study as age 55 and older.

For the most part, this increase in life expectancy is due to the same factors that contribute to the increase in life expectancy for people without disabilities. However, increased interest and funding for rehabilitation, better trauma care, research and the enactment of pro-disability legislation have had an additional, significant impact. Aging, however, is still harder and often faster for people with disabilities (Forman, et al., 2009).

Despite the gains in life expectancy, people with disabilities still tend to age faster. A general principle appears to be emerging: the 20/40 rule. This means functional issues begin to emerge when a person reaches 40 years of age or has 20 years’ duration of disability, whichever comes first. These issues generally include the following:

- Decline in physical function
- Increase in medical complications
- Changes in caregiver support
Decline in emotional well-being (Forman, Carruthers and Bondner, 2009, p. 271).

Physical causes are usually straightforward and easy to identify, such as overuse of muscles and joints from years of using a manual wheelchair instead of a power wheelchair. Emotional causes may be more subtle, such as depression due to changes in caregiver support. The physical and emotional tolls combine and affect each other and, if left unchecked, can cause a downward spiral for both mind and body (Forman, et al., 2009, p. 271).

Physical causes are relatively easy to fix. For instance, a power wheelchair can be used in conjunction with the manual chair. The use of a self-propelled chair has many advantages, such as strengthening of the heart, lungs and upper body muscles. These advantages must be balanced with the possibility of injury from overuse. Exercise, massage and monitoring of muscles and joints can prevent injuries, misalignments and secondary complications in wrists, elbows, shoulders and neck. The power wheelchair can be used on low-energy days or times when a long distance must be traversed. This way, the best of both worlds are balanced (Forman, et al., 2009, p. 271).

Emotional causes of premature aging, while more complex than the physical ones, can also be addressed and reduced. Most people consider the ability to control and manage their daily activities to be essential to their quality of life. Powerlessness or lack of control over certain aspects of life and the future can be overwhelming. A change in the level of independence with aging has been related to stress, depression and decline in quality of life. Depression often leads people to
neglect their health and lose interest in social activities and work, further increasing the downward spiral (Forman, et al., 2009, p. 271).
Chapter II: Review of the Successful Aging Literature

Successful Aging

What is successful aging? The term first appeared in 1961 in the first issue of the journal *The Gerontologist* (Havinghurst, 1961). The term is often used synonymously with the terms *aging well* and *productive aging*. Interest in the determinants of successful aging is growing. Most studies have focused on the absence of disability or deficits in physical performance as outcomes (Kaplan et al., 2008). Studies show that lifestyle decisions such as quitting smoking, managing diet, exercising and staying active and involved are all vastly more important than one's genetic inheritance in determining how long a person lives as a functioning, independent individual (Vaillant, 2002). John W. Rowe, president of the Mount Sinai School of Medicine and Mount Sinai Hospital in New York City, and Robert L. Kahn, professor emeritus of psychology and public health at the University of Michigan, have amassed and analyzed hundreds of studies in an attempt to depict successful aging. Their book, *Successful Aging* (1998), presents the results of the MacArthur Foundation Study of Aging in America, which shows how to maintain optimum physical and mental strength throughout one’s later years.

The aim of the MacArthur Foundation Study on Successful Aging was to gather knowledge to improve older Americans’ physical and mental abilities. The research group consisted of 16 scientists drawn across interdisciplinary lines – biology, neuroscience, neuropsychology, epidemiology, sociology, genetics, psychology, neurology, physiology and geriatric medicine. The researchers hoped to provide fresh insights into successful aging in America. They aimed to emphasize
the positive aspects of aging. The researchers worked toward a positive understanding of one central theme – effective functioning in later life, from each of the respective disciplines. The authors believe this study provides strategies for middle-aged and older persons to boost their chance of aging successfully, and that the study provides a basis for developing effective policies for the successful aging of American society.

In 1987, an article (Rowe and Kahn, 1987) based on this study appeared in the journal Science entitled “Human Aging: Usual and Successful.” The term successful aging has since become a popular term in the field of gerontology. Defining successful aging as enjoying a low risk of disease and disease-related disability, maintaining high mental and physical function, continuing an active engagement with life, and avoiding unproven "remedies," Rowe and Kahn (1987) show how, and why, growing old, really old, is, for most, an attainable goal. We can grow old not just "gracefully" but happily, productively and successfully. It is this researcher’s underlying assumption that this can also occur for older adults who have a disability.

Rowe and Kahn (1987) indicated successful aging must contain three components: 1) avoiding disease, 2) engaging with life, and 3) maintaining high physical and cognitive function. This conceptualization however, lacks consideration for older adults with disabilities; it assumes that those with disabilities are unable to age successfully.

In their culminating report, Rowe and Kahn discuss several topics. First, they describe aging and the aging process and address a number of commonly held
beliefs, proverbs or idioms, of aging. By contrasting these (e.g., “To be old is to be sick,” “You can’t teach an old dog new tricks,” “The lights may be on, but the voltage is low”) with scientific findings, the authors posit that our society is in denial of some important truths of aging. Second, they describe and explain the terms usual and successful aging. Third, Rowe and Kahn provide persuasive evidence that environment and lifestyle are more important than genes in terms of risk factors associated with aging.

The fourth theme is behavioral issues relating to changing these three key behaviors and avoiding a range of specific diseases and disabilities common in later life (e.g., cancer, heart disease, stroke, osteoporosis). The authors also address the importance of exercise, nutrition and the mind-body connection in maintaining physical and mental health, as well as physical performance.

Rowe and Kahn (1987) argue that the mind-body connection becomes increasingly powerful as we age. For example, weight training, even for the very old, not only tones muscles and maintains bone mass in older adults, it alleviates depression, creating a positive, can-do attitude that adds increased energy and adds years of quality life.

The Whitehall II Study (Wilcox, 2012) began recruiting participants in 1985-1988 for an observational epidemiologic study. The study clinically examined (at intervals of about five years) a cohort of 10,308 British men and women, aged 35-55 years at baseline, for various health outcomes, including diseases and disabilities that typically occur with aging. Sabia and colleagues (2012) used these data and focused on assessing successful aging for 5,100 healthy, middle-aged (42-63 year
old) men and women assessed during the 1991-1994 examination cycle. Strengths of this study include the large number of participants (n = 5,100), a relatively long follow-up (median 16.3 years), detailed analyses and a focus on successful aging as the primary outcome. Most studies of healthy aging have focused on less comprehensive outcomes, such as a particular disease or disability (Depp & Jeste, 2006). Although such studies are important, the collective outcome (maintaining relatively good health and high functional ability) may be most important to the aging patient and, ultimately, is an impact of aging on health care and social systems.

Despite the limitations often seen in large, observational cohort studies, research such as this is valuable for assessing the complex nature of human aging. Interventional studies of aging that can show causation are possible in model organisms with limited lifespans (e.g., yeast, worms and mice), but are impractical to perform with humans (Willcox, 2012). Of note, the fact that only 12% of the participants engaged in all four healthy behaviors (Rowe & Khan, 1987) suggests we may have much to gain by continuing to encourage people to decrease such habits. More work on the social or other determinants as to why so few people engaged in all four behaviors may be required.

In another large study, Vaillant (2002) identified four factors that help predict if a person will age successfully. The factors include healthy aging, retirement, play and creativity and a continual sense of intellectual and social development (“generativity”). Those factors include not smoking (or stopping by age 45), adaptive coping style, no alcohol abuse, health, weight, stable marriage,
some exercise, years of education and cultivation of a rich social network after age 50.

Vaillant (2002) also identified six factors that do not predict aging well/successful aging. These factors include ancestral longevity, cholesterol, stress, parental characteristics, childhood temperament and ease in social relationships. These factors can have a positive or negative effect on aging.

In determining these criteria, Vaillant drew on three long-term longitudinal studies: his study of 268 Harvard men (Vaillant, 1977), a study of 456 inner-city men at risk for delinquency, and 90 women from the Terman study of gifted children. The Grand Study of Harvard men involved participants answering questionnaires every two years, providing records of physical examinations every five years and participating in interviews every 15 years. The sample of inner-city men completed questionnaires every two years. The Terman women were studied for almost 80 years through questionnaires every five years and interviews in 1940 and 1950. All of these studies followed their participants from childhood or adolescence to the present; average dates of birth ranged from 1911 for women in the Terman study to 1930 for the inner-city men. This study is particularly valuable because it permits examination of the predictors of healthy aging from a longitudinal perspective.

The first of two more recent definitions of successful aging include, “a favorable outcome as perceived by the individual, and his ability to cope or adapt to the cumulative changes associated with the passage of time, while experiencing a sense of meaning or purpose in life” (Flood, 2002, p. 105). The second is that
“successful aging is not adequately understood as mere longevity. Instead, it implies sufficient well-being in a number of spheres (mental, physical, social, spiritual, economic) to sustain a capacity to function successfully in the changing circumstances of one’s life” (Inui, 2003, p. 391). These definitions take into account the entire person and the systems in which the person interacts. They also seem to be more inclusive of different groups of older adults, including those with disabilities. This is in direct contrast to the Rowe and Kahn definition which states that one must avoid disease and maintain physical and cognitive function. Vaillant also failed to include those with disabilities in his samples, this led him to develop criteria or predictors of successful aging that exclude those with disabilities.

All of these definitions are difficult to operationalize and do not take into account normal aging of people with disabilities. Another problem with the terms successful aging and aging well, is that there are those who are successful, or good at aging and then those who are unsuccessful or bad at aging.

Given the lack of a consensual definition of successful aging, Depp and Jeste (2006) searched for English-language peer-reviewed reports of data-based studies of adults over age 60 that included an operationalized definition of successful aging. The authors categorized the components of these definitions and independent variables examined in relation to successful aging (e.g., gender, education, and social contacts). Depp and Jeste (2006) identified 28 studies with 29 different definitions that met the criteria of having an operationalized definition of successful aging. Most investigations used large samples of community-dwelling older adults. The mean reported proportion of successful agers was 35.8% (standard deviation: 19.8), but
varied widely (interquartile range: 31%). Multiple components of these definitions were identified, although 26 of 29 included disability/physical functioning.

The most frequent significant correlates of the various definitions of successful aging were age (young-old), nonsmoking, and absence of disability, arthritis, and diabetes. Moderate support was found for greater physical activity, more social contacts, better self-rated health, absence of depression and cognitive impairment, and fewer medical conditions as being predictive of successful aging. Gender, income, education, and marital status generally did not relate to successful aging. Despite variability among definitions, approximately one-third of older adults across the 28 studies were classified as “aging successfully.” The majority of these definitions were based on the absence of disability with lesser inclusion of psychosocial variables. Predictors of successful aging varied yet point to several potentially modifiable targets for increasing the likelihood of successful aging. While in general disability is not “modifiable,” this study will examine if older adults who have a disability see themselves as able to age successfully.

Williams and Wirths (2006) looked at styles of life and successful aging as a part of the larger Kansas City Study of Adult Life. They quantified which styles of life (such as working, married, living alone) would make one more likely to age successfully or less successfully. This study did not evaluate those living with a non-age-related disability.

Using a focus group approach, Reichstadt, Depp, Palinkas, Folsom, and Jeste (2007) examined the opinions of older adults about factors related to successful aging. Twelve focus groups were conducted with an average of six individuals per
group. Participants included 72 community-dwelling older adults (age range: 60-99 years) recruited primarily from retirement communities in San Diego County, California. Interview transcripts were analyzed using a grounded theory framework of Coding Consensus, Co-occurrence, and Comparison. Thirty-three factors were identified, out of which four major themes emerged: attitude/adaptation, security/stability, health/wellness, and engagement/stimulation. Every focus group emphasized the need for a positive attitude, realistic perspective, and the ability to adapt to change. Security and stability encapsulated one’s living environment, social support, and financial resources. General physical health and wellness were frequently mentioned, with mixed opinions on their necessity for successful aging. Finally, a sense of engagement, reflected in pursuit of continued stimulation, learning, feeling a sense of purpose in life, and being useful to others and to society, was considered a prominent aspect of successful aging. All four themes appeared to be interrelated such that engagement required a foundation of security and stability while positive attitude and adaptation strategies often compensated for impaired physical health. Reichstadt and colleagues (2007) concluded that older adults place greater emphasis on psychosocial factors as being key to successful aging, with less emphasis on factors such as longevity, genetics, absence of disease/disability, function and independence. The results are similar to those found in other studies related to successful aging. Persons aging with disabilities were not the target population participating in this study.

The literature on successful aging reveals a wide range of definitions, generally reflecting the academic discipline of the investigator. Biomedical models
primarily emphasize physical and mental functioning as successful aging; socio-
psychological models emphasize social functioning, life satisfaction and
psychological resources as components of successful aging. Several studies also
identify these factors as the precursors of successful aging.

For the past four decades, many studies seeking to develop a definition and
identify critical determinants of successful aging have been published. To date, there
is still no consensus on a standard definition or measure of successful aging. Most
constructs have been one-dimensional, although a few have been multidimensional,
none has emerged as standard. The most serious limitation of contemporary
successful aging constructs is the undue focus on physiologic aspects of aging. To
move beyond the limited perspective that stresses disease and impairment, Young,
Frick and Phelan (2009) postulate that successful aging may coexist with diseases
and functional limitations if compensatory psychological and/or social mechanisms
are used. With this premise, these authors present a new definition and conceptual
framework of successful aging, together with an operational definition that
delineates their successful aging concept. The authors examine if successful aging
and chronic illness can coexist in the same individual. By allowing for the possibility
of chronic disease and success to coexist within a given individual, this construct
also attempts to respond to the concern that some published descriptions of success
destine most older adults, who by and large have at least one chronic condition, to
fail at aging successfully.

Moreover, research shows that older people generally consider themselves
to have aged successfully, but classifications based on traditional medical models do
not. Fewer studies have explored lay views, and most of these have been exploratory or restricted to specific groups or areas (Bowling, 2007). Throughout this current research a social-psychological approach is used. None of the existing studies focus on older adults with disabilities.

In a recent issue of The Gerontologist (February 2015), Successful Aging is once again examined as the feature topic. Rowe and Kahn’s (1987) credit remains for pushing forth the term successful aging however, they continue to be criticized for the shortcomings in their research. Several articles in the issue (Riley, 1998; Katz & Calassanti, 2014; Robinstein & de Medeiros, 2014; Snowe & Cooney, 2014) criticize the work as seriously incomplete, as it neglects the structural and social factors that influence successful aging and some call for the term successful aging to be abandoned and others such as healthy, positive, active, productive and effective aging replace the term. The issue’s editorial mentions these and states:

It would be irresponsible for gerontologists to abandon the concept of successful aging. Nearly three decades after Rowe and Kahn’s initial article was published, it is incumbent on gerontologists to use the conceptual and empirical knowledge base that now exists to develop consensus about what successful aging is and how it should be measured. We should approach this goal knowing that our measures will not be perfect, but at least our findings will be comparable. Advancing this work will help us learn how individuals can experience successful aging regardless of their social or health conditions. Finally, with an enhanced understanding of what successful aging is, we will be in a stronger position to develop interventions that will enable more people to age successfully. the sheer number of people comprising the Baby Boom generation transformed academic interest in successful aging to a public policy imperative. Now more than ever it is critical to develop science that empowers people to experience the best old age possible (Pruchno, p. 4, 2015).
Successful aging may be understood from the perspective of several theories. The most known of these theories are activity, disengagement and continuity theories.

The activity theory of aging (Havinghurst & Albrecht, 1953) posits that older adults have the need to stay active, resist role losses and compensate for lost activities with new roles. Activity theory views successful aging as active aging and states that the psychological and social needs of older adults are no different from those of middle aged adults and that it is neither normal nor natural for older people to become isolated and withdrawn. Older adults who remain active are more satisfied and better adjusted than less active older adults. A person’s self-concept is validated through participation in roles that are characteristic of middle age. It is desirable to maintain as many middle age activities as possible in late life. If a person substitutes a new role for one of those lost (due to widowhood or retirement), they will age more successfully. For example, if one is a homemaker while her husband works but then the husband dies, the widow can begin attending a senior center and participate in numerous available social activities. Critics of activity theory (Estes, 1983; Minkler, 1984) argue that it is prescriptive in nature because it advises people what to do and not to do to age well. Critics also argue that adaptation to role loss or role change occurs by remaining active and this is not exclusive to older adults.
The main idea of disengagement theory (Cumming, Dean, Newell, & McCaffrey, 1960; Cumming & Henry, 1961) is that there is a loss of roles and energy due to age that makes people desire to be dismissed from their social expectations of productivity and competitiveness. Disengagement is viewed as an adaptive behavior that allows for the maintenance of a sense of worth and tranquility while performing peripheral social roles. Disengaging is an orderly way of transferring power from one generation to the next. The disengagement process is mutual and has positive consequences for both society and the individual. The passing of a law practice from father to son is an example of disengagement. This theory has been strongly criticized (Hochschild, 1975; Tornstam, 1989; Achenbaum & Bengston, 1994; & Alkema & Alley, 2006), including evidence amassed through studies like the Duke Geriatric Project, which contradicted the theory’s core premises. Today, disengagement is viewed as a process that sometimes, but not always or necessarily, occurs.

Continuity theory (Havinghurst, 1968; Neugarten, Havinghurst, & Tobin, 1968) explores the substitution of roles. Aging persons are advised to substitute new roles for those they have lost. By continuing to maintain typical ways of adapting to the environment, older adults are able to maintain an inner psychological continuity as well as an outward continuity of social and behavioral circumstances. The theory recognizes change but forces the concept of change into one of continuity. Continuity theory assumes that earlier stages of development set the criteria for successful aging. For example, how one adapts to stress early in life may not be the same later in life. The need for continuity may reduce a person’s
self-esteem when physical or mental declines force a change in lifestyles held earlier. For example, if one is sad, one's adaptation style might be to go shopping, although he or she might not be able to afford the purchase. The theory would suggest that this person would not be satisfied with life because of the adaptation choices he or she made when they were younger. Continuity theory gets in the way of a person who wishes to stop or change certain behaviors or roles. Releasing oneself from former roles can be liberating. If one felt he or she needed to behave one way at his or her job, the person might like the change of roles in retirement. The theory's concept of normal and pathological aging has been criticized as failing to focus on the mechanisms people use to create continuity when confronted with disease or disruption, and for defining normal aging around a male model.

In summary, activity, disengagement and continuity theories fall short in explaining successful aging among older adults with disabilities. Burbank (1986) concurs in her critique of the three theories. She identifies problems with each of the theories when the criteria of intersubjectivity of meaning, testability, and empirical adequacy are used in the evaluation process:

An analysis of relevant research shows that none of these three theories is clearly supported by empirical evidence. Because of the tentative nature and lack of conclusive support for each of these theories, further exploration and theory development is needed. It is suggested here that a phenomenological approach may be a more productive way to study the psychosocial aspects of aging (p. 73).

There are two other lesser-known and not as thoroughly researched theories related to successful aging: Socioemotional Selectivity Theory and Selection, Optimization and Compensation Theory (SOC). These are not only more recent but more robust than activity theory. They appear to provide a more accurate
description of why and how older adults make decisions, including those contributing to successful aging.

The first of these theories is Socioemotional Selectivity Theory (Carstensen, 1991). This theory maintains that perceived limitations on time lead to motivational shifts that direct attention to emotionally meaningful goals. The theory posits that increased attention to emotional goals results in greater complexity of emotional experience and better regulation of emotions experienced in everyday life. Essentially, when concerns for the future are less relevant, attention to current feeling-states heightens. Appreciation for the fragility and value of human life increases and long-term relationships with family and friends assume unmatched importance. The theory contends that when perceived limitations on time are made salient, similar shifts begin in people as young as adolescents but because of the inextricable association between age and time left in life, chronological age – on average – is associated with increased preferences for and investment in emotionally meaningful goals.

The second of these theories is Selective Optimization and Compensation Theory (Baltes & Baltes, 1990). Selective Optimization and Compensation Theory contends that individuals who age successfully use three strategies: selection, optimization and compensation to achieve desired goals. Selection includes identifying goals, prioritizing them, establishing criteria and conditions and determining the degree of commitment. Optimization refers to maximizing performance to facilitate success. It involves the degree of focus, the timing and tenacity of goal pursuit, learning new skills, modeling others who are successful,
developing resources and increasing the amount of time dedicated to goals. Compensation refers to adapting to limitations that interfere with goals. It includes the use of assistive technology, obtaining help from others, developing new skills and resources, employing previously discarded skills and resources, devoting more energy or time and modeling others who compensate well. This theory seems the most applicable to successful aging among those with disabilities. It is inclusive of different groups and does not include language that one must be non-disabled in order to age successfully. While both theories are limited by their lack of specificity, Selective Optimization and Compensation Theory appears to be the best fit to guide this study, as it is more inclusive of different groups.

**Successful Aging and People with Disabilities**

The 2000 Census shows that 49.7 million people in the United States age five and over have a disability. This is nearly one-in-five United States residents. Of those, 5.2 million were between the ages of five and 20; 30.6 million were between the ages of 21 and 64 and 14 million were 65 and over (US Census Bureau, 2010). It has proven difficult to obtain the exact extent of the population defined in this study. This will be addressed further later in this dissertation.

While there have been numerous studies related to successful aging, there is little research related to successful aging among people with disabilities. Much research has been done that evaluates age-related disability, but there is an absence of research related to older adults with long-term disability and their view of aging successfully. The following section highlights publications related to successful aging and disability.
In “Successful Aging: A Disability Perspective,” Minkler and Fadem (2002) refer to the “successful aging” paradigm in gerontology and the problems it poses when applied to a growing population of people who are aging with substantial physical disabilities. The primary assertion is that the existing definitions of successful aging do not address those aging with physical disabilities. While this article identifies the issue of successful aging among those with disabilities, it does not support these assertions with empirical evidence.

In “Women with Disabilities Aging Well: A Global View,” Walsh and LeRoy (2004) describe a study that draws on the oral histories of 167 women in 18 countries. The investigators examined what women who have intellectual disabilities (i.e., Downs Syndrome and Autism) experience as they age and explores contributing factors to healthy aging for this population. Using an ecological systems framework, they examined the importance of economic factors, health and nutrition, recreation and relationships, as well as the influence of disability policies and programs on all of these factors. They interviewed participants using a 102 item survey grouped into five topics: demographics, economic and personal safety nets, health, social roles and well-being. The investigators employed collaborators recruited from various countries to assist in interviewing participants. Collaborators were asked to recruit 10 older women with intellectual disabilities to participate in the interviews. While there was no standardization of the recruitment process for obtaining study participants, criteria for participation were set. Only women older than 40 with an intellectual disability were allowed to participate in the study. Both qualitative and quantitative data analysis methods were used.
Participants ranged in age from 40 – 71 years old and the geographic regions represented include: North America (United States and Canada), Europe (Austria, Belgium, England, Finland, France, Ireland, Italy, Northern Ireland, Norway and Scotland), South America (Argentina and Brazil), Asia (Japan and Taiwan) and Oceana (Australia and New Zealand).

Findings revealed that these women were dependent on their external economic and personal safety nets for their existence. Respondents were fairly independent with activities of daily living and instrumental activities of daily living, however, they acknowledged that they receive assistance from informal and formal supports on a daily basis.

As the authors acknowledge, this study was limited by the lack of standardization in the recruitment process of the participants. The study, however, does shed light on women’s experiences with aging and living with an intellectual disability. However, fewer than half were over the age of 65. The study did not look at similarly situated men.

Poon, Gueldner and Sprouse (2003) conducted a study that explored the following questions: How do older adults approach and deal with everyday-life when affected by multiple health problems? What kind of impact do they feel diseases have on their successful aging? How do existent models and theories of coping address these issues? The study was based on a survey of 899 men and women who had responded to a 1999 follow-up of the longitudinal Alameda County Study. These data constitute the second wave of a survey designed to study the influence of health practices and social relationships on the physical and mental
health of a typical sample of the population. The first wave collected information for 6,928 respondents (including approximately 500 women aged 65 years and older) on chronic health conditions, health behaviors, social involvements, and psychological characteristics. The 1974 questionnaire was sent to 6,246 older adults who had responded in 1965, and were able to be located. A total of 4,864 individuals responded in 1974. Respondents were asked about marital and life satisfaction, parenting, physical activities, employment, and childhood experiences. Demographic information on age, race, height, weight, education, income, and religion was also collected (Kaplan, 2006).

Those aged 65 or older who responded to the 1999 follow-up questionnaire in the Alameda County Study were sent an additional questionnaire with items related to successful aging. Fifty of the 899 who completed surveys also participated in qualitative interviews. The study assessed successful aging, physical health and disability, mental health, activities in old age, health behaviors, quality of life, social relationships, religiosity and spirituality, neighborhood and financial problems, hearing impairment and vision impairment while considering variables such as age, sex and ethnicity. The finding most relevant to this proposal is that of those with mobility impairment, only 17% rated themselves as aging successfully. Why? This is the research still needed.

A recent study of older adults looked at severe vision impairment, hearing impairment and successful aging (Wahl, Heyl, Drapaniotis, Hormann, Jonas, Plinkert, & Rohrschneider, 2013). The quantitative study considered a broad range of successful aging indicators and compared older adults with vision impairment,
hearing impairment and dual sensory impairments and without sensory impairment. Participants underwent a wide-ranging assessment, covering everyday competence, cognitive functioning, social resources, self-regulation strategies, cognitive and affective well-being and four-year survival status. All of the participants had late-life sensory impairment, not a long-term disability. One study conclusion, relevant to this research, is that investing in maintaining everyday functioning in rehabilitation programs seems critical. Limitations of this study were that the sample sizes were small and related to this research, did not address older adults with long-term hearing or vision disability.

A few recent studies have looked specifically at those aging with particular diseases: HIV and sickle cell disease. Each study proposes different theoretical constructs in which to evaluate successful aging among people living with HIV and sickle cell disease. The research related to successful aging with HIV proposes using hardiness as a construct by which to evaluate successful aging among those living with HIV. The first of the three HIV-specific successful aging publications (Vance, Burrage, Couch & Raper, 2008) is a review of literature in nursing, gerontology and HIV related to hardiness and how it represents a way to promote wellness and facilitate successful aging with HIV. In this synthesis of the literature, hardiness serves as a psychological resource to describe, explain and hypothesize how people may age successfully with a chronic illness, in this case, HIV. Articles reviewed were selected based on their relevance to the conceptual definition of hardiness and successful aging in reference to HIV. The authors point out that during the selection process, seminal articles were included because more recent studies on this topic
were not available. The authors describe hardy people as those who exert control over circumstances in their lives and remain committed to their lives and intricately involved with their own activities. This study, as well as two similar studies published during 2009 (Vance, Struzick & Burrage; Vance, Childs, Moneyham & McKie-Bell, 2009) offer some insight into the issues that might influence hardiness or successful aging when faced with a chronic illness or disability. Such issues include stigma and social isolation, decreased cognitive and physical functioning and synergistic effects with age-related comorbidity.

Jenerette and Lauderdale (2008) used qualitative methods in a pilot study to inform theory related to successful aging for people with sickle cell disease. They interviewed six older-adult women recruited from two urban sickle cell clinics in the U.S. They concluded that identifying vulnerability factors, self-care management resources and health outcomes in adults with sickle cell disease may aid in developing theory-based interventions to meet the health care needs of younger individuals with sickle cell disease. They concluded that using a life review approach is a useful process to gain insight into successful aging of adults with sickle cell disease and other chronic illnesses.

Dabelko-Schoeny, Anderson and Sparks (2010) performed a pilot study of civic engagement of older adults with functional limitations. They studied participants in two adult day centers. One center was used as a control group, measuring older adult’s civic engagement with usual programing at the center. The other group included interventions of education, service and recognition. These included, among other things, learning about military personnel serving overseas,
packing care packages for them and then presenting the care packages to them. Participants in the study were described as having “moderate functional impairment” with no mention of the type, cause or duration of the impairment. The study was a pilot but did find that those in the intervention group reported higher, yet non-significant, levels of purpose in life, self-esteem and perceived physical health compared to those in the control group.

Romo, Wallhagen, Yourman, Yeung, Eng, Micco, Perez-Stable and Smith (2013) performed a qualitative study of perceptions of successful aging among diverse elders with late-life disability. There were several similarities and significant differences between the Romo et. al. (2013) study and this study. Both use qualitative research methods to interview older adults with disabilities about their perceptions of successful aging. The 2013 study asked a diverse group of older adults four questions:

1. Researchers have come up with the term “successful aging.” What comes to mind when you hear that term?
2. What does it mean to be old?
3. Do you feel you've aged successfully?
4. Do you feel old?

Interviews lasted an average of 30 minutes. Participants all experienced some degree of late-life disability or “age related disability.” A theme in the interviews is that many participants felt like they were “living a new reality” related to their disability. There were those who accepted or acknowledged the new reality of living with a disability and those who rejected this reality. Those who accepted the
new reality view aging as an unavoidable natural process that includes age-related
disability. Those who were viewed as rejecting the new reality of living with a
disability generally did not view themselves as old. They denied dependencies and
view themselves as completely independent.

These recent studies offer some insight into the issue of disability and
successful aging, but do not fully explain successful aging and living with long-term
physical disabilities among the broader population of aging men and women.

The above-mentioned studies fail to address a significant gap in the literature
related to persons with long-term disabilities aging successfully. Previously, I
completed a pilot study of successful aging and involvement in senior centers. An
outline of that study follows.

Pilot Study

I completed a pilot study during the 2003/2004 academic year in which I
completed interviews with three non-disabled older adult members of a senior
center. I sought to find out their lived experience of aging and what aging well
means to them. The interview questions were as follows:

1. Tell me what it means to age.

2. Describe for me a typical day in the last two weeks. How is that different
from how you felt on a typical day 30 years ago?

3. Think of a great day you have had in the past few months. Walk me
through that day.

4. Do you see yourself as aging successfully? What does that mean for you?
What does it look like for one to age well?
5. If you could pick the perfect age to live forever, what age would that be and why?

6. What advice could you give me that would help me age well?

7. Is there anything else you would like me to know about aging?

Prior to interviewing the three older adults, I contacted an informant at the Indianapolis Senior Center. I discussed this study with her and observed active older adults at the center. I completed an interview with the informant and reviewed the interview questions with her. I incorporated her suggestions into my interview plan. The informant also gave me the names and contact information of potential interview candidates for this study. The Indianapolis Senior Center requires that members are 55 years of age or older – therefore my study participants were at least 55 years of age. I asked the informant to suggest interview participants that she perceived as aging well.

Findings from Pilot Study

The target group included adults age 65 and over who were members of the Indianapolis Senior Center. My participants included three women aged 70, 78 and 78. All were widowed, Caucasian and mothers. The three women participated in approximately one to two hour recorded interviews at the senior center.

Upon transcribing the interview tapes and evaluating those transcripts, several themes emerged. The themes I identified included the following:

- being needed
- interaction across the generations
- impact on others
• feeling young
• influence of others on self worth
• church/spirituality/religion
• family
• transition
• charity work/volunteer
• keeping busy
• giving back
• friendship/social interaction
• activity
• lack of structure
• touching – social interaction
• health
• aging
• family history
• personal history
• coping style
• age
• belonging

I then narrowed these themes to a few broader themes: activity, social interaction, spirituality, health, coping, sense of worth and freedom.
Many of the interview responses related to activity. These activities included activities at the senior center, choir practice, exercise, dance and driving. For example, when asked what a typical day was like for her, one participant stated,

Well, Monday is a really busy day. I’m up here all day. 10:00 is a meeting on season swimmers which is a healthy lifestyles group. 11:00 is the piano lesson and then I do my exercises from about 11:45 until 12:30. And then sometimes I usually have a meeting of some type at around 1:30 so I’m usually here until about three. Other than that a typical day… I’m always up at 6:00. That’s when the alarm goes off. I take a daily paper and read it and do the crossword puzzle – religiously. Then I may get onto the computer. 9:00 there is an hour of crafts with Carol Duval that I watch. Her program now is at 9 and 9:30. Which is okay. Let’s see, I have Bible study on Tuesday mornings that I’ll go to at 10:15 and that’s out at about 11:30. Then I’ll go to the thrift store to see what bargains are there...

Another theme was social interaction, which included mention of friendships, group activities, and family support and interaction:

[agering successfully is] “Being able to meet new friends and keep the old ones. Having friends. Staying social.” Another woman described a special friendship formed at the senior center. “I met Emma here and I pick her up and we go dancing…she always watches the bulletin boards here for us to go to the different places that are free for us to go to. I like her as a friend because she always watches the bulletin board.

The next theme identified was spirituality. The women discussed how God helps them in times of trouble. They all mentioned that they are all “religious” but not all attend church regularly. All three mentioned that they pray. “Of course, I had a little help. [points toward heaven] A lot of help. If it hadn’t been for that I don’t know what I would have done.” “I believe in God that’s for sure.” “I believe in God through Jesus Christ. So, we are supposed to glorify the Lord aren’t we, in all we do and all we say.”
Another theme mentioned by each woman regarding aging successfully was health. This included exercise, eating right and resting when needed. All concurred that poor health can slow them down. Two were speaking from experience as they described having joint problems that occasionally limited their activity.

If these (knees) didn’t hurt that would be great. I think when you start and get to 55 that is when you start to feel...you had aches and pains when you were young but you are starting to realize that they do hurt. Sometimes you get upset because you think ‘I’m getting older so I can’t do this or that.’ I try not to say can’t but sometimes you can’t. It’s impossible because it hurts bad.

An additional theme throughout the interviews was coping. The women described how they dealt with the loss of loved ones, specifically loss of children and spouses. The dominant theme in their coping experience is that they move on – they do not dwell on their problems. Each also mentioned prayer as a significant method of coping. “It was hard for a while but you survive. You can’t just dwell on things – you’d be lost.” “If I can do something about it I do it. If I can’t I sleep on it. You know, if you lose your job you go out and find another one. If you lose your son there’s nothing you can do so you sleep on it. You do things to remember them in the best light that you can. I don’t know – stressful times...If I can do something about it, I do it. If I can’t I sleep on it and have a new outlook the next day. And God helps, some prayers.”

Another theme expressed by the women was a sense of worth. Several things were mentioned by the women as important to influencing their positive sense of worth. These included volunteering, giving back to others, being needed, interaction across the generations, impact on others (children), feeling young and the influence of others or self worth “you’re as young as you feel.” “There is so much
work that can be done to be helpful.” “I think the nicest thing was her (child she was mentoring) asking my advice on things. I think it is nice to feel that they still respect your opinion.”

The final theme that emerged during the interviews was a sense or feeling of freedom to choose their actions. “Now I’m a little freer to not do the dishes if I don’t want to for a couple of days.” “I did not join until after my children were older...well I thought now I have done that job so now I’m going to do something for me. So that’s why I do it.”

The pilot study provided valuable information related to what older adults view as successful aging. Hearing directly from these women added to my understanding that these older adults did not necessarily see themselves as “aging successfully,” however, they described similar themes related to why they might be perceived by others as successfully aging. They shared common ideas and lifestyles related to activity, social interaction, spirituality, health, coping, sense of worth and freedom. Upon completion of this pilot study, I searched the literature to determine if older adults with disabilities would have the same outcomes as those living without disability and found very little information. The pilot study did not consider disability as a variable when selecting the study participants. This study could be taken further, however, and address the gap in the current literature related to older adults with long-term disabilities. Do both groups view aging successfully similarly? Do both groups perceive themselves as aging successfully? Evaluating these perceptions among older adults with long-term disabilities is the focus of my dissertation research.
Chapter III: Research Method

The participants of this research differ from the pilot study in that they are all older adults who have some type of long-term physical disability. The definition of disability I used as the operational definition for this study is that of the Americans with Disabilities Act (ADA), Public Law 101-336. The ADA's protection applies primarily, but not exclusively, to individuals with disabilities. The term *disability* means, with respect to an individual:

- a physical or mental impairment that substantially limits one or more of the major life activities of such individuals such as caring for oneself, performing manual tasks, walking, seeing, hearing, speaking, breathing, learning, and working;
  - a record of such an impairment; or
  - being regarded as having such an impairment.

The participants in this study all have a long-term disability lasting approximately 20 years or longer. This distinguishes the study population from older adults with age-related disability. Disabilities that limit cognition were not included in this study because I conducted interviews; the participants of this study needed to have cognitive capacity to answer questions. A limitation I previously pointed out when describing current literature available related to successful aging among older adults with disabilities is that study participants have mostly been women. I was able to include men in the sample of research participants. Participants shared their thoughts about successful aging and the lived experience of aging with a disability.
This is a phenomenological study of older adults and their views on aging. Information was gathered through open-ended interviews with older adults with disabilities. Following phenomenological research methods, I sought an understanding from in-depth interviews about what it means to age well. I wanted to find out their lived experience of aging and what aging well means to them. The study participants illustrated disabled older adults’ perceptions of aging successfully. These perceptions included both positive and negative components.

Through this study, I hoped to gain an understanding of what aging well means to older adults with a long-term physical disability. I hoped to gain knowledge of what aging well means to older adults with disabilities and how they perceive other’s views of them. This inquiry is important because, as stated, the word aging is often associated with the word problem due to a dominant image of old age as one of inevitable decline, senility and dependence. While some older adults suffer decline, is it inevitable for all older adults with disabilities or do some perceive themselves as aging successfully? As social workers it is important that we have accurate knowledge of the reality of aging. It encompasses our profession’s focus on the strengths perspective. Finding out what aging well means to those who are living the experience gives social workers the tools to work with all older adults.

I hoped to identify those aspects of older adults’ lives that influence whether or not they believe they are aging successfully. This project addresses the question: What does it mean for an older adult with a long-term disability to age successfully? Prior to this study, I did not know if I would find themes different from the pilot study. A bias I hold is that it is possible for older adults with disabilities perceive to
themselves as aging successfully. I managed this bias by bracketing this notion and learning the reality of the perceptions from my participants. I expected that I might discover different themes in their statements of what influences their perception; I also, however, expected that regardless of ability, the themes found in the pilot study and existing other research mentioned in this proposal would be consistent. I believe that one likely needs to have some amount of activity, social interaction, spirituality, health, coping, sense of worth and freedom in order to age successfully. There are varying degrees of each of these, of course. I looked forward to finding out where older adults with long-term disabilities perceive themselves as fitting along this continuum.

This is a phenomenological study of older adults with disability and their views on aging well. A phenomenological study describes the meaning of the lived experiences for several individuals about a concept or the phenomenon (Creswell, 1998). Through individual interviews, I explored, from participants’ perspective, what it means to age well. I selected phenomenology because I wanted to find out from the participants their perceptions and the meaning of those perceptions, in their own words and based on their lived experiences. Because aging is often seen as “decline,” I wanted to find out if those who are already living under certain limitations handle aging differently or have a different perception of aging successfully.

Phenomenology is a process of exploring one’s interests and understandings of a phenomenon, uncovering the essence of that phenomenon by gathering stories from those living it, interpreting those stories and offering implications for practice.
This method offers a unique approach to understanding and interpreting individual experiences. Phenomenology is rooted in the idea that everyday experience is worthy of examination. For example, aging is an everyday experience worthy of examination. The raw data of phenomenological study are personal experiences. Such experiences may be gathered through interviewing, observing, reading, writing and living (Glesne, 1999).

Those who use the phenomenological method are called to recognize and live in the strain between subject and object. The scientific paradigm expects researchers to be objective about the participants of their study. Yet, a researcher who is phenomenologically-oriented believes that there is no such thing as objectivity. Phenomenologists recognize the researcher’s role in shaping the research process and interpreting themes. Thus, the role of the researcher is examined within a phenomenological study. The participants the researcher talks with to gain a better understanding of their everyday experience are not “subjects,” but active participants in the study. The goal of the research process is not just to examine the participants’ experience, but to create a situation in which reciprocal learning can occur (Glesne, 1999).

Phenomenologists explore the structures of consciousness in human experiences (Polkinghorne, 1989). Glesne (1999) summarizes the major procedural issues in using phenomenology:

- The researcher needs to understand the philosophical perspectives behind the approach, especially the concept of studying how people experience a phenomenon. The concept of epoche is central, where the researcher brackets his or her own preconceived ideas about the phenomenon to understand it through the voices of the informants.
• The investigator writes research questions that explore the meaning of that experience for individuals and asks individuals to describe their everyday lived experiences.
• The investigator then collects data from individuals who have experienced the phenomenon under investigation. Typically, this information is collected through long interviews with informants ranging in number from three to ten.
• The phenomenological data analysis steps are generally similar for all psychological phenomenologists who discuss the methods. The original protocols are divided into statements or horizontalization. Then, the units are transformed into clusters of meanings expressed in psychological and phenomenological concepts. Finally, these transformations are tied together to make a general description of the experience, the textural description of what was experienced and the structural description of how it was experienced.
• The phenomenological report ends with the reader understanding better the essential, invariant structure of the experience, recognizing that a single unifying meaning of the experience exists.

In phenomenological study, the participants may be located at a single site, although they need not be. They must be individuals who have experienced the phenomenon being explored and able to articulate their conscious experiences. For the purpose of this study, the older adults who participate are age 55 or older and have a disability that fits the Americans with Disabilities Act definition. The participants must be able to mentally and physically participate in the interview. They all therefore, have experienced the same phenomenon becoming an older adult with a disability.

A criterion sampling method was used. I am fortunate to have close ties to the medical, academic and social services in my region. I reached out to physicians, service clubs and service agencies inquiring about potential participants for this study. I was hopeful that those groups would refer me to other potential
participants. I anticipated I would have adequate access to participants to recruit within a 150-mile radius of where I reside. For a phenomenological study, the process of collecting information involves primarily in-depth interviews with as few as three and as many as 10 individuals. The important point is to describe the meaning of a small number of individuals who have experienced the phenomenon (Glesne, 1999). With an in-depth interview lasting as long as two hours, ten participants in a study represents a reasonable size (Polkinghorne, 1989).

I spoke with people with disabilities and those who work with people with disabilities while planning this project. I asked them to review the interview questions and assist me in revising these questions based on their knowledge and experience of working with older adults with long-term disabilities. I also received feedback from my dissertation committee and modified the questions based on that feedback. I hoped to interview between three and ten participants for this study and obtain those participants through snowball sampling, based on the criteria explained in the previous paragraph. The questions I asked included:

1. Tell me what it means to age.
2. Describe for me a typical day in the last two weeks. How is that different from how you felt on a typical day 30 years ago?
3. Think of a great day you have had in the past few months. Walk me through that day.
4. Do you see yourself as aging successfully? What does that mean for you? What does it look like for one to age well?
5. If you could pick the perfect age to live forever, what age would that be and why?
6. What advice could you give me that would help me age well?
7. Is there anything else you would like me to know about aging?
8. Do you face any barriers related to your disability? If so, what?
9. What effect do you think your disability has had on your aging?
10. What effect has aging had on your disability?
11. What advice would you give to a younger person with a disability to guide them to age well?
12. What do you think contributed to your aging well?
13. What do you wish people know about aging well with a disability?

I also asked participants to complete a brief demographic questionnaire (Appendix A).

All of the interviews were audio-recorded with the participants’ permission. I completed member-checks where I asked participants to review the transcript from their particular interview to check for accuracy. I also aimed for use of thick description when writing the narrative of participant’s comments. Thick description is providing the participant’s verbatim comments, as well as things such as the participant’s manner of dress and use of assistive devices, in rich detail. The interviews took place wherever the participant felt most comfortable. I offered to meet them in their home or in a public location with a private room, such as the public library. Participants were not compensated financially for taking part in this
study. Other details involving participant benefits are described in the Informed Consent (Appendix B).

*Data Analysis*

In phenomenological research, there are several steps in the analysis process which Glesne (1999) summarized as follows:

- The researcher begins with a full description of his or her own experience of the phenomenon.
- The researcher then finds statements in the interview transcripts about how individuals are experiencing the topic, lists out these significant statements and treats each statement as having equal worth, and works to develop a list of nonrepetitive, nonoverlapping statements.
- The statements are then grouped into “meaning units.” The researcher lists these units, and writes a description of the “textures” of the experience—what happened—including verbatim examples.
- The researcher next reflects on his or her own description and uses imaginative variation or structural description, seeking all possible meanings and divergent perspectives, varying the frames of reference about the phenomenon, and constructing a description of how the phenomenon was experienced.
- The researcher then constructs an overall description of the meaning and the essence of the experience.
- This process is followed first for the researcher’s account of the experience and then for that of each participant. After this, a “composite” description is written (p. 150).

I used phenomenological data reduction, which proceeds through the methodology of reduction, the analysis of specific statements and themes, and a search for all possible meanings. I did my best to set aside all prejudgments, bracketing my experiences and relying on intuition, imagination and universal structures to obtain a picture of the experience (Creswell, 1998).

The data analysis process I followed for this research study is as follows:
I obtained IRB approval from the Indiana University Institutional Review Board. I contacted service agencies, healthcare providers, government agencies, senior centers and housing programs requesting their assistance in finding participants for the study. Several interested persons did not meet study criteria and were not interviewed. All of the individuals who met the study criteria and participated in interviews were, blind, hearing impaired or a combination of these.

I asked older adults with disabilities to participate because I believe that their ideas and feelings about aging well will help me to better understand these older adults and what aging well means to them. The benefits of participating in this study include learning some new things about themselves, enjoyment from sharing their ideas and feelings about aging well. In addition, their participation in this study helps enhance an understanding of how to help older adults age well. There was, however, a risk that, for some people, talking about aging and how they see themselves can be upsetting.

I explained to each participant that their personal information will remain confidential. Prior to interviewing each participant I obtained their permission to tape-record the interviews, and also take notes as reminders of what was discussed during each interview. I informed each participant that in this situation, he or she is the expert, or teacher, and they are explaining to me what aging well is for them. I also informed each participant that he or she can decide to not participate in this study, or stop doing so at any time. The Informed Consent (Appendix B) details this information further.
Chapter IV: Findings

A total of seven people completed interviews. The interviews took place in participant’s homes and at a public library in a Midwestern state. Participants ranged in age from 63 to 83 years old. Three were male and four were female. Four were married, one was separated, one was single, and one was a widow. Four lived with their spouses and three reside alone. All had completed at least one year of college or technical programs. Five had graduated from college or technical programs and one had earned credits beyond her bachelor's degree.

All of the participants were blind, deaf, hearing impaired or a combination of the three and all meet the definition of the Americans with Disabilities Act. All but one of the participants who are deaf have had a Cochlear Implant, allowing them to hear when the implant is in use, otherwise they are deaf without it. Jim attempted to have a Cochlear Implant surgery, however it was unsuccessful. Jim’s wife assisted in communicating during his interview, when he could not hear me, or we used a notepad between us to communicate. All have lived with their disability between eighteen and fifty years. Most described their overall physical and mental health as good or excellent. None identified needing assistance from a caregiver. All were assigned pseudonyms to protect their identity. The demographic information is described in Table 1.
**Table 1: Demographic Information**

<table>
<thead>
<tr>
<th>Name (pseudonym)</th>
<th>Age</th>
<th>Marital Status</th>
<th>Living Status</th>
<th>Education</th>
<th>Disability</th>
<th>Years</th>
</tr>
</thead>
<tbody>
<tr>
<td>Jim</td>
<td>83</td>
<td>Married</td>
<td>With Spouse</td>
<td>Two-year College Degree</td>
<td>Hearing Impaired Vision Impaired</td>
<td>50</td>
</tr>
<tr>
<td>Sara</td>
<td>68</td>
<td>Married</td>
<td>With Spouse</td>
<td>Two-year College Degree</td>
<td>Vision Impaired</td>
<td>18</td>
</tr>
<tr>
<td>Seth</td>
<td>66</td>
<td>Single</td>
<td>Alone</td>
<td>Two-year College Degree</td>
<td>Deaf</td>
<td>50</td>
</tr>
<tr>
<td>Laura</td>
<td>63</td>
<td>Separated</td>
<td>Alone</td>
<td>Three-years of college</td>
<td>Deaf</td>
<td>26</td>
</tr>
<tr>
<td>Lois</td>
<td>77</td>
<td>Widowed</td>
<td>Alone</td>
<td>Bachelor's Degree</td>
<td>Vision Impaired</td>
<td>40</td>
</tr>
<tr>
<td>Lester</td>
<td>78</td>
<td>Married</td>
<td>With Spouse</td>
<td>Two-year College Degree</td>
<td>Deaf Vision Impaired</td>
<td>55</td>
</tr>
<tr>
<td>Jill</td>
<td>63</td>
<td>Married</td>
<td>With Spouse</td>
<td>Secretarial School</td>
<td>Blind</td>
<td>38</td>
</tr>
</tbody>
</table>

Data analysis aimed to answer the research question: *What does it mean for an older adult with long-term disability to age successfully?* Data analysis revealed the meaning of this question for those interviewed.

Following the steps of phenomenological research analysis, I begin with a description of my own experience of the phenomenon. I am forty-one years old and do not live with a disability therefore, my understanding of being an older adult living with a long-term disability does not come through experiencing this phenomenon. My experience is only the perceptions I have of observing others throughout my lifetime. My grandfathers both died of heart failure close to the time I was born. I spent a lot of time with my grandmothers, as both lived in my house
for several years while I was growing up. My maternal grandmother died with Alzheimer’s disease and my paternal grandmother lived with schizophrenia until she died a few years ago. I watched both of them live through these illnesses for many years. These were the older adults in my life who made the largest impression on me related to aging.

When I began the PhD program, my research interests did not include successful aging or anything related to aging. I had worked as a medical social worker for several years and my perception of older adults was largely that they were frail, ill and in need of help and resources. During my coursework, I discovered literature related to successful aging, which made a significant impact on me and changed the course of my studies. It was fascinating to me to begin to think of older adults as successful agers.

The pilot study and research leading up to it expanded my knowledge of successful aging. I was delighted to learn that these women, despite experiencing many hardships, were aging successfully. There was a large focus in the literature on activity and absence of disability being requirements of successful aging. This intrigued me, as I did not know if people with disabilities could age successfully. My assumption was that they could, based on what I had learned from others who had faced adversity and aged successfully.

The second step of phenomenological research analysis is finding statements in the interview transcripts about how individuals are experiencing the topic. These statements are grouped into “meaning units” or themes. The themes found in the analysis of this study’s transcripts are as follows:
• Aging as inevitable
• Frequent Activity
• Social and Family Interaction as Essential
• Sense of Worth
• Acceptance of Disability
• Coping and Resilience
• Advice to Others

Several themes emerged throughout this study. From those themes, came codes and examples of those themes and codes. The final coding system, including major themes, codes and examples, is described in Table 2.
<table>
<thead>
<tr>
<th><strong>Meaning Units/Themes</strong></th>
<th><strong>Codes</strong></th>
<th><strong>Examples</strong></th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Aging as Inevitable</strong></td>
<td>Feeling young Negative Positive Transition Acceptance</td>
<td>Forgetful Wiser Natural Process Slow Down Comfortable Content Happy Independence/Freedom In Control It’s Happening so Accept it It’s Change, Loss</td>
</tr>
<tr>
<td><strong>Frequent Activity</strong></td>
<td>Hobbies Charity work/volunteer Giving back Keeping busy Structure</td>
<td>Golf/Walk/Bike/Horse Riding/Cards/Woodworking Crafting Farming Employed Volunteering at Church, Senior Center, Service Agencies Household Chores</td>
</tr>
<tr>
<td><strong>Family and Social Interaction as Essential</strong></td>
<td>Joy Strength Damaged Relationships Relationships Belonging Source of Strength</td>
<td>Love of Spouses, Parents, Siblings, Children and Grandchildren Coping with Disability was Positive and Negative Friends Coworkers</td>
</tr>
<tr>
<td><strong>Sense of Worth</strong></td>
<td>Being Needed Interaction Across Generations Impact on Others Influence of others or self-worth Uniqueness</td>
<td>Working with Young Adults Maintain Employment Maintain Social Network Learn Technology Respected by Younger People</td>
</tr>
<tr>
<td>Acceptance of Disability</td>
<td>Uniqueness Fitting in Limitations Lack of Freedom Acceptance</td>
<td></td>
</tr>
<tr>
<td>--------------------------</td>
<td>-------------------------------------------------------------</td>
<td></td>
</tr>
<tr>
<td>Acceptance</td>
<td>Disability Sets You Apart Limited Driving Limited Vacations Limits Social Interaction Could no Longer Work or Limited Job Opportunities Fit in Among Peers Now Better Than When Younger with Disability Refused to Use Adaptive Equipment at First Acceptance</td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Coping and Resilience</th>
<th>Overcoming Loss Determination Persistence Success Resilience Family History Others in worse shape None see their situation as “that bad” Church Religion</th>
</tr>
</thead>
<tbody>
<tr>
<td>Acceptance</td>
<td>Death of Friends and Family Parents Influenced Their Determination Find Equipment That Works for You No one Else Will do It For You so You Have to Do it For Yourself One Bad Day Doesn’t Define Me If I Were Ill My Disability Isn’t Like Others’ I’m Not in a Wheelchair or Anything There are so Many Others Who Have it a Lot Worse Than Me Blessed My Purpose Belief in God God Still Accepts Me Integrity Modesty</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Advice to Others</th>
<th>Activity Friendships Determination Seek Help Use Adaptive Equipment Self-Advocacy Sense of Humor Positive Attitude</th>
</tr>
</thead>
<tbody>
<tr>
<td>Acceptance</td>
<td>Just Keep Pushing Try to Overcome Disability Don’t Let it Stop You From Doing Anything Enjoy Life</td>
</tr>
</tbody>
</table>
The following section illustrates the “textures” or codes and examples of these themes.

*Aging as inevitable*

The seven participants shared similarities and also significant differences. All participants stated that they feel they are aging successfully. The following is a brief introduction to each of the seven individuals and their answers to the first question. The interviews began with a simple, open-ended question, “Tell me what it means to age.” One theme is that they all feel aging is inevitable and they are trying to make the best of it. Some could answer the question immediately while others considered their responses carefully.

Jim and his wife, Mary, met with me in their comfortable townhome in a newer subdivision of a mid-sized Midwestern city. Jim is 83 years old and has been married to Mary for 55 years. They spend half of each year in the Midwest and the winter months at their home in a southern state. Jim is hearing impaired and has been for 50 years. He also has macular degeneration and cardiac issues. Jim’s hearing impairment made the interview difficult at first but we adapted by using written materials and having his wife assist in interpreting, at times. Jim shared few words in the beginning of the interview, when asked what aging means to him. “Natural process I guess. What else can you say about it? I don’t like that you lose your hearing and all that. That’s about all.”

Sara’s interview took place on the sun-porch of the beautiful single family home she shares with her husband of 48 years. Sara is 68 years old and lost one-third of her eyesight in both eyes after experiencing two strokes at age 50.
As I started aging, I felt like I was in a good place. I felt that, you know, you get wiser as you get older. But, as I’m aging, I’m finding I don’t like it. You just, you get a little forgetful. It’s not a big thing.

Seth’s interview took place at the kitchen table in his single family home. Seth is 66 years old and has never married. He has lived with a hearing impairment since he was in elementary school.

That’s something that’s interesting. You know I am still working. A lot of people at work know I can retire and wonder why I’m still working. I plan to continue working until I find my next page or chapter in my book. You know, as far as why I’m going to do next. I’m pretty content with what I’m doing. Age – you’re always picking up on things you couldn’t do before. Age is something, you know, quality of life. I noticed with my mom now (100 years old), she’s starting where she can’t see and she can’t hear. She’s getting a little more flustered, you know, aging. I think as long as you are able to do the things you enjoy doing, then aging isn’t really a big deal.

Laura’s interview took place in a public library’s private conference room. She lives on a farm in a remote area and agreed to meet with me in town when she was there visiting the disability office. Laura is 63 years old, tall and athletic looking. She has been deaf for the past 26 years. She is currently divorcing her husband of 42 years. Her response when asked to describe aging is as follows,

It bites. There are so many things, I shouldn’t say there are so many things, that I can’t do anymore. I just don’t have the time. My days are numbered and I know it. Physically I’m doing amazingly well, I think, for my age. I can still, I ride my horse. I’m able to get off and on her. I do all my own chores. Like I said, physically I’m not, with the exception of my hearing, there are certain things I can’t do, like jump up and down off the back of a pickup truck or bail rack. Other than that I’m doing pretty well.

Lois’s interview took place in her lovely condominium in a large Midwestern city. She is 77 years old and has an artificial eye and partial vision in her other eye. She has been disabled for 40 years. She has a college degree and worked as a
teacher for many years. She is a widow and has several children who reside within the same state. Lois describes aging below,

It means, that’s really hard to describe. I feel very freed, I guess from a lot of life’s struggles. It’s not an unhappy time. It’s a happy time. I’m not lonely. I don’t really know how else to describe it. I’m not fearful. I feel in control. I don’t know what more to say.

I asked her to explain more about “free from life’s struggles” and she replied,

“I suppose if I were ill, I’d have a different viewpoint. For instance, living alone. I don’t have to make sure I have dinner ready. I can basically do whatever I want to whenever I want to type of thing. I guess that’s why I feel free.”

I interviewed Lester and his wife, Mandy, in their home on their large farm. Lester is 78 years old and has been deaf since he was in his 20s and also has macular degeneration, which has significantly decreased his vision. He also has a blood disorder and cardiac issues. “I guess you just have to take it day by day and hope everything goes okay. Get plenty of rest and enjoy everything that’s around you. Go to all the grandkids’ stuff. I have thirteen grandkids.”

Jill’s interview took place in her lovely two-story home in a mid-sized Midwestern town. She is 63 years old and has been married for 40 years. She lost complete vision at age 25 as a complication from Type I Diabetes. Jill had a smile on her face throughout our entire conversation and is one of the most positive people one could ever hope to meet.

You know Victoria, I don’t know. I don’t feel old! I laugh about it because the last time I saw myself I was 25 years old. If I could see tomorrow, and look in the mirror, I’d wonder, “who is that little old lady?” Because I don’t feel old. I don’t feel that. So what does it mean to age? I think a person gets more content in their life. Things that you used to think were really important aren’t probably so important anymore. I think your priorities as you age are different than what
they were when you were young. So I think I'm more comfortable getting older. I'm more confident with myself. I'm not so critical with myself. Or with others. So I think it's great getting older.

Fitting the theme of aging as inevitable, the question “Is there anything else you would like me to know about aging?” yielded candid replies from a couple of participants. Jim stated, “It’s not good. Too bad it has to happen. Sara stated, “It’s really for the shits. Oh, I probably shouldn’t say that. Um, no, I just think you have to take it gracefully and you have to realize that you do age and there’s nothing you can do about it. It gets scary, as we get older, about how it’s going to end. But no, just enjoy life and stay healthy.”

Seth’s response was a bit different: “I’m starting to learn things myself. I think that’s the biggest thing I’m learning.” Finally, Lois stated, “It’s happening. It’s inevitable. Just go with it. You can’t do a thing about it so embrace it I guess.”

Frequent Activity

All of the participants described very active lifestyles. The meaning of “active” was different for all. Sara is very active and described a typical day in her life.

Today? Okay, on Tuesdays I get up in the morning, pick up around the house. Maybe do some wash. At 11:00 in the morning I go play Maijong until we have lunch, I play until about 4:00 in the afternoon. Come home, fix dinner, enjoy television or read; or games on the computer.

Probing a bit deeper, I asked, “So the other time I called, you were golfing during the day. Do you have a lot of things, social things you do?” to which Sara replied,

Yes, we keep very active. I've got something to look forward to, that will be a great day. In two weeks there's a group of us, there's eight
girls that go to a different city and we golf. We’ve done this for the last 20 years. We go over there and we golf and go out for dinner and have a few cocktails and golf again the next day. That will be a great day, or a great weekend. I’m trying to think, oh, golfing again. The day that you tried calling me. That was another day that the eight girls in this group. Three months on the summer, June, July and August, we have a get-together and we get out of town and go to different places. And what we do is we golf and we have started a book club. We go to someone’s home after we’re done golfing. We do a book club and have dinner and a couple of cocktails. And that was a good day. That was a great day. That was fun.

Jill, who is blind, described a typical day: “Mondays are my wash days. I tell everyone, people assume that my husband does the housework but I do. I do the cleaning, I do the cooking. Hey, I even iron.” Jill continues describing some of her activity and interests,

I don’t have a fancy home but I love decorating. I get on the floor on my hands and knees and wash and wax the floors. I probably go over the same spot many times because I can’t see. I’ve lived in the house 40 years and lost sight one year later, after being married one year. I did know the layout of the house. I can pick out colors and coordinate (carpet and wall colors). I’m so thankful that I had sight at one time because I can visualize so many things in my head. I’m not saying they always turn out right, but I have a really good idea of what I want and what I like.

Seth continues to work a full-time job as a custodian at a local college. He has no plans to slow his life down anytime soon.

I’m a person who likes routine. On the weekends I usually get up around 9:00 or 10:00 in the morning. Because I work 3:00 -11:30 so usually when I get off work, I read or watch TV; something to relax. I don’t necessarily go to bed right away. And then a lot depends on what the situation is with my mom. I usually go up and check on her. I clean her quilt for her or little odds and ends things I do. I typically get up in the morning and you know, do some odds and ends things. Mow the grass or something to keep active. Then I’ll have lunch. Often I have lunch with friends. Yesterday I had lunch with a friend of mine and we haven’t seen each other for about a month or so. I try to keep in contact with people and everything. My afternoons are usually
getting ready for work. I usually go to work around 2:30 then I do my work. I try to keep everything fairly routine. Weekends I usually try to spend time with mom and then I play golf or do something like that. I try to balance everything. I don’t think I’ve changed that much as far as 30 years ago. I’ve always been single. Let’s see, that would’ve been 1984. I guess 30 years ago I was going on cruises and different things like that. I went on a couple of singles cruises. I have a friend who got me started on that sort of thing. 30 years ago I guess I just found out that as you get older, things start to slow down a bit and sometimes you need to… I’m trying to work in naps and things like that. I try to make some compensation for being older. Otherwise I don’t think I’ve changed much in 30 years.

Laura’s describes her divorce and the time it consumes in her life. “I get up and eat breakfast. Depending on what’s going on, divorce has been almost a full-time job for me. I’m parish secretary at our church. Not a high-paying job. I’ve had it for quite a few years.”

Lois is one of the more active of all of the participants. She describes some of this activity below:

I get up about 6:00 or 6:30. Make myself coffee and a little breakfast. I’ve been doing a Bible study in the morning. And then I maybe go and get my hair done, meet a friend for lunch, go shopping. Right now I’m looking for new furniture so I’ve been doing that. Of course I would do household chores. I do have someone who comes and cleans the floors and those types of things. I do my own washing, dusting that sort of thing.

Lester and his wife reside in a home on their large farm. He is living with hearing and vision loss.

We’ve got grass, you wouldn’t believe how much we have to mow. I do a lot of mowing. I’ve got a John Deere lawnmower with a six foot deck. We’ve got a garden with beans, tomatoes, peppers, beets, lettuce, watermelon, cabbage. Everything is good. I till that with the tiller that’s on the tractor. We have two swings that, in the evenings when it’s so nice, I’ll sit on and rock back and forth. We have this little female dog, a Boston Terrier. She’s right there with me constantly. There are three cats. A tom cat and a female and another guy that isn’t anything easy to look at. They call him pirate because he’s blind in one
eye. He'll jump right up on me. They like to rock too. Every morning I go up and go through my routine. Take my pills and have my oatmeal. I like my coffee. Take care of all of the dog chores. Three times a week I go to town and go to cardiac rehab. Wife drives. We have 25,000 turkeys and these buildings are 560 feet long so I always said I didn’t need any exercise. I get plenty out there. Now our son runs the business. We have 13,000 pigs. There are semis coming in with feed. Yesterday they loaded at least two semi loads of market pigs. There’s always something. (He ran the business until recently.) I still know what the hell is going on. My vision limits me. For safety reasons I stay mostly in the yard. There’s always something to fix.

Laura’s horses hold deep meaning in her life and describes activity related to them:

That would be a day where I went to the County Fair with my mare and I got to show her and I was with a lot of like-minded people, horse people. We inhabit a different universe. It was fun, not only to participate, but also to watch and have someone to talk to. That was a great day.

The State Fair is mentioned as an important activity in Lois’ “great day” as it relates to the award one of her creations received at the Fair:

Last week, the first day of the fair. I went with my son and his wife. I was a little on the apprehensive side because I wasn’t sure how I did on the project that I entered. We ate breakfast and I’m always anxious to get into the creative activities building. Anyway, to get there and see that there was actually a blue ribbon on something that I’d done. The other years someone had helped me whereas this one, I did all by myself. So, I was really wondering how I would do on my own and to get a blue ribbon for it was really a fun thing to experience.

Once again, the State Fair is an important part of Lester's “great day” and demonstrates activity in his life,

They’re all great days. The kids took me to the State Fair. They put me in a wheel chair and took me all over. We went in different agricultural buildings and buildings with different flowers and animal barns. Looked at all the craft booths. Yeah, it was pretty good.
Jill’s positivity continues as she describes her activities when answering the “great day” question:

That’s really hard because there are so many great days. Well I had a really great day on Saturday. I’m a Lion and my husband is too. We went to the diabetes expo. And that was really informative. It was educational. There were 24 people who boarded the bus and we met a lot of really neat people up there. I’m really involved in diabetes. I’ve really been focusing on it. I do a lot of speaking engagements, hoping someday there will be a cure for this disease. It’s always good to learn more about it and about what new products are available. That was a great day. We spent all day at the expo and we sat at the Lion’s booth. People could come by and we got to meet a lot of people. That’s what I love is sitting and visiting with people. I came home the end of the day very happy. I guess for most people maybe it wouldn’t be that exciting but I love just the contact with other people.

Jim and Sara stated that activity and health are important aspects of successful aging, “I think so. I still get around pretty good. I’m 83 years old. Retired. I feel comfortable with my lifestyle, I’ll say.” Sara stated:

I have my health. It means I have friends. It means I keep busy. I just am very fortunate. I think to age well you have to have your health. I really do. I think that is very important. But you also have to have your friends and you have to have interest in life. I mean you can’t just sit back and not have any interest in anything. I have a lot of interest in a lot of different things. I think that means a lot too.

Seth’s response is further demonstration that he plans to continue an active and productive lifestyle,

Yes, I think so. In fact the big thing now is, I’m trying to see what I want to do next. I know some things that I used to like to do. Like I said, taking care of seniors, taking them to the doctor or something, but I think I’m going to age successfully. I’m going to find things to do. I’m going to check out the senior center or someplace like that and find a place where seniors hang out and that kind of stuff. And then I’m going to try to get involved, either volunteer or find a part-time, 20 hour a week job. Right now I will continue to age successfully. I think it’s a quality of life and how comfortable you are. You know, all I went through with my dad and the hospice thing. I’ve seen other people. I think as long as they can stay active. As long as they can keep
doing things. I don’t think we always have to be crazy and try to find a new bucket list or anything like that but I do think we need to maintain our activeness and everything like that. As long as we aren’t restricted in any way. I saw the same thing with my grandma. She had diabetes and lost her leg and started to go downhill when she lost her health. I think as long as you can stay active and your life is somewhat normal, I think you’re fine. I think it’s just when disabilities and, you know, health things are effecting you that you really start having more trouble.

All of the participants highlighted the theme of activity and the meaning that holds for each of them. The result is that all are active, in their own way, and credit activity as a contributor of their ability to age successfully.

*Social and Family Interaction as Essential*

All of the participants described family and social interactions as an essential part of successful aging. Seth described the special relationship he has with his mother and the meaning that his family holds for him,

Labor Day was kind of a good day. I went and picked up mom from the nursing home. We went out for lunch. She likes to go out for Culver’s chicken. Where she’s staying they make things a little dryer and blander. She likes to go for chicken. Then we come home. She likes to spend time at the house. My dad built this house. This is kind of one of those things where off and on I’ve lived in the house almost all my life. Back in the 1990s when my dad had the cancer and the prognosis didn’t look that good, I took over the house. I’ve been taking care of folks ever since. That’s probably something I’ll do when I retire. Do some kind of caregiving, taking people to doctors or anything. So getting back to what mom has... so we came back here and we played about three or four games of cribbage. Mom checked on the house and made sure I’m keeping the house right and that sort of thing. Then at about 4:00 or 4:30 we went out to Baker’s Square. She likes their supper. She likes their pancakes and I think she likes their eggs too. I think they get powdered eggs where she’s at. So anyway, we had that and then I came home and watched a baseball game. That was a good day.

Seth also described that a social network is important to him. “I try to find out where I fit in. Start getting my social network of friends and acquaintances and
that sort of thing. I think if I can learn to be happy and content.” Jim also finds his friends an important part of his life, “We have a nice group of friends and we are always with our friends and have a good time.”

Lois’ circle of friends hold meaning to her and influence her thoughts of aging successfully.

Yes. I have multi-generational friends. I think it’s really important to have friends who are my age and older and to have friends who are younger. I feel respected by a younger person and I feel loved by family members and friends. Friends are really important to me so that’s probably what I would view as aging well. Having activities in my life. I don’t sit home and wish somebody would call me or wish somebody would do something with me. If I ever felt lonely I would call somebody myself and make arrangements to do something with someone. For me that’s aging successfully but I think that’s probably an individual thing. I think to have fairly decent health would be a way to age successfully. However, if you are ill and you still have a good outlook on life, I think you’re aging successfully also.

Relationships with family and friends was a theme throughout the interviews. It was evident that this is a foundation of successful aging for these older adults.

 Sense of Worth

Participants described the development of their sense of self-worth in their responses to the question, “If you could pick the perfect age to live forever, what age would that be and why?” Their answers did not involve a uniform age or even decade. The answers were each unique and illustrated their individual sense of worth. A few generally involved a time when participants were actively rearing their children or when they felt they had more energy. Sara’s response involved the feeling that she had successfully reared her children,
I would say, I’m trying to think of what age I was when the girls left. The perfect age I think would be between 50-60. I really would. Because then you, your kids have done college and hopefully have established their lives. You can get on with your own life and don't have to worry about them so much and you aren't responsible for them as much.

Seth does not have children and responded,

That’s a good question. You know now that I work up at the college and I see these kids, you know, I used to think it would be fun to be 17 to 25 years old and I think, no, I don't think I'd want to be that age again. I think right around your 30s would probably be the best. You know, 30 years ago right around my 30s because then I think you are right around that age where you just start knowing who you are. You know how to handle certain things. You’ve got a little bit of maturity. I think someplace in your 30s would be the perfect age to live.

Laura described the time when she was rearing her family,

Probably, well, probably 35. It was the best time in my life. I was raising my family. Those were the happiest days of my life. That’s the age I’d like to be. I’d have had ten kids if I could’ve. As I said, I was a stay at home parent because my husband always told me that I couldn’t have it all. Meaning, I couldn’t have a career and a family. That was sort of his mantra. I tried to finish my college degree when my oldest daughter was still at home and after she graduated high school, I had no help and no support. So I never did. Anytime I did have any kind of meaningful job, he was upset. Somehow it was a reflection on his manhood, that he wasn’t able to provide for his family. He was upset when I took the job at the church. But I digress, I think 35 I’d say was probably the perfect age.

Lois has children but described a time when she had more energy. “I think it would be between 60-65. You have more energy. I had more energy. I had more strength. I had a husband at that point too so that made a difference. I plan to live to 100 but if I could just stay at one age it would be 65.”

Lester described a time when he was very active and began to experience independence. He also describes time when his children were younger,
I suppose 21. You can go in anyplace. You can show your ID and you’re still old enough to go in and sip a few. Even then you have to shop around and see if you can find a mate. A good age is any age if you’re feeling pretty good and healthy enough to keep being in society or whatever. I mean, I was on the church board and on the county board for years. I was on the school board, I’m just guessing, at least 26 years. I gave all six of our kids their diploma at graduation. We’ve always been pretty active. Even just as quick as our world has grown and our boy, the one who got killed, when they got their drivers license they would drive sows to the stockyards. They would really help me a lot. We were mixing feed constantly and cultivating. A lot of times I had the windows open on the cab and had kids sitting all around in the cab. If we saw a stone they’d jump out and get it.

When asked about the best age to live, Jill did not give an age but describes a time when she was rearing her daughter:

I guess my mid-thirties. I was married. I had our daughter. We were, I don’t know. That’s a real hard one because I like almost every age. That’s a very hard one. I could pick my early 20s when I could see. And used to drive my convertible mustang. I could pick now at the point where I’m at because now I’m going to be a grandmother. That’s a real hard question to answer.

These responses describe how each developed their self-worth through meaningful times in their lives.

Acceptance of Disability

All of the participants described how they have coped with challenges and losses during their lives. Specifically, they were asked to describe the impact their disability has had on their lives. A theme for all was the coping and resiliency illustrated by each participant when asked to describe the impact their disability has had on their lives.

While the first half of the questions related to aging, the second half of the questions were related to living with a disability. The first of these questions was,
“Do you face any barriers related to your disability? If so, what?” Jim replied, “Oh my goodness. All kinds of them.” His wife Mary elaborated for him:

I can tell you some too because he can’t hear on the phone. I have to do all the phone stuff. And a lot of it is technical stuff, like computers and stuff, that, well I know how to operate the computer but I don’t know anything about how it works or anything. So if he has a problem on the computer, he calls a technician or something and he can’t hear what they are saying (he laughs). So I have to get on the phone and they tell me and I have to relay it to him. I have no idea what I’m talking about. It doesn’t make any sense to me so I think that’s a big problem. I have to do so much of everything. He has a lot of phone contact and stuff. He gets a lot of magazines and stuff. Every time there is something he needs to know about I have to call.

Jim interjected, “Even when I go to the store or something you know and have to ask questions, she has to be here to answer.” Mary then continued,

I’m always his ears no matter where we go. He’s better now but right after he had the Cochlear Implants, we had such high hopes for that. He got very frustrated after that, that it didn’t work at all. He’s kind of coming out of that a little bit now. And we write a lot of notes back and forth if he can’t understand what I’m saying. But he still now, I think, he’s handling it a little bit better than he did before. I think he’s got a good sense of humor, you know and that kind of helps him get along and that’s why everybody really likes him and they like his sense of humor and a lot of our friends have a good sense of humor too and they get together and laugh and stuff and so I think that part is helping you. As long as you keep your sense of humor.

Laura explained, “When I wake up in the morning I have to make sure I put on my implants right away because I have absolutely no hearing without them.”

Sara stated,

Yeah. With my eyesight I do. I don’t drive at night. I mean, and these are so minimal compared to anyone else’s. It took me a long time to be able to recover from the loss of the eyesight. I had to, when I look at you right now, right now I’m looking at you straight ahead. All I see is that eye and a little bit of that part of your head. But now what I’ve done, I move my head and you might not notice this, but I’ve moved my eyesight just a little bit and now I see your whole face. So I’ve learned to adapt. It’s the peripheral side that I don’t see out of but
because of that adaption that I've taught myself, I mean I don't know how you'd do that, I really don't. It's just something that I taught myself. Now I have a very big visual field. I have gotten so I don't look straight ahead anymore. I would say 99% of the time I look that way. When it came time to read, I couldn't follow the line, I couldn't read and that was devastating. One of the big things that really ticked me off was Wheel of Fortune because I couldn't see all of the letters. That really ticked me off. And with the reading, I just had to force myself to do it and never gave up on it. I never felt “oh woe is me.” I didn't think I would ever drive again so my next thought was “okay I'll just ride my bike” and I rode my bike all over town. You know, I never let any of that get me down. It seemed like, if there was a handicap, I wasn't even paying any attention to it. I was going to take care of it and work my way through it. Except, the first time I went out on a bike ride, like, oh it must have been about 8:00 in the morning, and I realized, because at that time I hadn't learned to adapt my eyesight yet. I didn't realize that people were on their way to work and backing out of their driveways and I wasn't seeing them. So then I had to wait. I mean, nothing happened but I discovered that that is what was happening so I had to wait until everybody went to work before I went on my bike ride.

I asked Sara if she participated in vision therapy or other treatment programs to improve her vision and she stated that she did not. She taught herself.

There was nothing they could do for me. What happened was the stroke was in the oxibatal lobe so the eyes are fine. It's just that there is a ball about that big that is just dead matter. They told me that if it didn't come back within a few days it would never come back. It never did. What happened is that one of the things that was really ironic, you could almost figure out how Picasso saw things. Because I remember laying in the hospital and like, if my daughter would come in to see me, and my husband was standing there, I'd look at her and then I'd go to look at him and her hair would follow on his head. It must've been like a latent image or something. There were a lot of weird things that I saw after the stroke but then they all eventually worked out more. I pretty much only drive where I know I'm going. If I know where I'm going then I'm okay but if I have to be looking for roads and finding roads then I can't do it. I'm comfortable if I know where I'm going and if I've been there before. I haven't had any accidents and can still get a driver's license. The first time I had to do the eye test I was petrified but passed it with flying colors.

Seth also identified barriers he faces related to his disability:
That’s always been a frustration of mine, not being able to hear. It’s troublesome. Environments are a big deal. Like when I’d try to take someone on a date. If you go somewhere where the acoustics are really bad and you can’t carry on a conversation. I mean, I do real well in a one to one conversation as long as it’s an environment where the background is controlled. You know I do real well. Sometimes when you are outside and the wind is blowing and there is bad acoustics, everybody’s talking, that does make it challenging. You have to pick places where you’re comfortable. Friends of mine usually understand that. I think also that some of my friends know that I don’t hear real well so it’s part of the thing. You know my brother has the same thing. Working, you know, he’s up on the roof and I’m trimming the branches and I’m talking to him or he’s talking to me, we don’t always hear. It’s just one of those things where it all part of life. You know, if you can accept your disabilities and accept your limitations, no matter what they are, I think that’s the key to being successful.

Laura described many barriers:

Absolutely, all the time. Even with the bilateral implants. The telephone is still a challenge. With the bilaterals I still only have 70% hearing. I got my first implant in Feb of 2011 and my second one in Feb of 2012. Maybe it was 2012 and 2013. Within the last five years. There are certain jobs I absolutely can’t do. It limits my employability in that regard. It’s difficult if people don’t understand that they have to look at me when they talk. That’s a huge thing because even with the implants, this is perfect room because acoustically it’s good, there’s no other noise, I’m not having a problem talking to you. I still rely on lip-reading. There is just so much stuff I have to drag around with me and it has to be working. Since I’ve been living alone, it dawned on me how vulnerable I am. Once I take these off I can’t hear anything. I just recently, within the last two months, got adaptive equipment that will warn me if the smoke detector or carbon monoxide detector goes off, or if the doorbell rings. All winter I relied on my dog. What bothered me was that their wasn’t a sole in my family that was concerned about it. Last year I realized how vulnerable I am.

Lois modestly described her barriers:

Yes. Depth perception would be one. Missing things on my left side. Bumping into things. Missing things. When someone hands me something like a credit card I don’t always get it right. I might put my hand underneath it or something like that. Nobody notices it but I notice it.
I inquired further, asking if her vision impairment has had an impact on her driving. Lois responded, “No, well maybe a little bit but I think I’ve adjusted to that. I remember when I first lost my eye. They said “be sure to turn your head” so I think I’ve learned enough to do that to hopefully make a difference.” I asked if it has impacted her ability to read and Lois stated, “There’s no problem with reading. My right eye has macular degeneration. Then there was a real disability because, at times, it was almost blind. I lose people when I’m in a crowd. I tell my family so they watch out for me.” I asked her to explain her statement “then I almost had a real disability.” Lois laughed and replied, “I don’t think of it as a disability. That’s the difference I guess.” I asked if she thought of it as a disability when if first occurred and she sated,

When it first happened I went to the ophthalmologist and he said ‘there is something going on behind your eye and glasses won’t help. I want you to go to a specialist soon, as soon as tomorrow.’ And then the specialist, we went to see him and he must have had a resident or someone with him. He examined and then took my husband and I in his office into his office. He was sitting across from us at his desk, playing symphony music, brown walls and the drapes were pulled. He had a lamp on his desk, had a beard and said, ‘Mrs. X (Lois) has a tumor in her eye the size of a dime in circumference, three dimes in thickness and I believe her eye will have to be removed.’ At that point I was relieved because I thought it was a brain tumor and was relieved that it wasn’t. My uncle had lost an eye and so I knew you could get along just fine without one. At that point I was relieved and thankful that it was just my eye and nothing more.

Lester described his barriers:

You just have to be careful if you can’t navigate like you used to you know what you can do and what you can’t do. If you can’t do it then stay the hell out of there. There’s a lot you can do too. When you see the ones with the white cane. At least for this generation, you don’t loose your complete vision. I’ve lost most of it. Attempted to get a new surgery but didn’t qualify because my eye was too small. My adaptive
equipment (glasses, a watch that talks). Working with audiologist to get reading books. This winter I can use them. I used to love to read.

Jill stated:

The only one probably is transportation. You know if I’m going to make something here at home, years ago I could just get in my car and go get it. The independence of transportation. I have a very good friend of mine who is completely blind like I am. We often talk about, you know, years ago she was seeing a young man. She’d have to depend on a friend to take her to the post office to mail him a package. You’ve lost your privacy factor. Her friend would always say, “what are you sending him? Why are you sending him that?” why do you have to feel that you have to tell your friend everything? Maybe she wanted to keep that to herself. I’m just the opposite. I tell everybody everything! No secrets! But I understand her. It’s your privacy, your independence. Sometimes I, I guess I used to...sometimes people, when I first lost my sight, people didn’t know I lost my sight. A lot of people thought I was aloof. I’m not aloof, it’s just that I couldn’t see them and once they understand that, you know. I remember on person said, "I'd always wave at you and you'd never wave. Now I understand. Things like that were more of a barrier. When people realized that I couldn’t see. There was no eye contact. There was no interchange of expression. That was kind of a barrier but once people know, that is not a barrier at all. In fact, to be honest with you Victoria, I feel that the blindness is a blessing because, as you can tell, I love people. If you had ten people that were outgoing but one of those people were a blind person, who would you remember? The blind person, right? I count that blindness as a blessing because so many people remember me. No matter where I go, there’s always somebody who comes out of the crowd and gives me a hug. You know? That’s the silver lining to my cloud. People wouldn’t have to come out and say hello. I wouldn’t know that they’re there, you know? And they always do and I think, “they remember me.” It’s people that I don’t even know that well sometimes. But they do. I know it’s because of the white cane and I think, “thank you Lord.”

When asked, “What effect do you think your disability has had on your aging?” most of the participants thought that their disability had had little or no effect on his or her aging. Sara elaborated on barriers related to her disability “I'm not able to just take off and go where I want to go. I can’t. Luckily I have good friends who will drive me. I can’t get in the car and just take off and go where I want
to go. Also, I had to quit work. I could no longer work. That was hard. That was very hard.” Seth stated:

I think in some ways it’s a blessing in disguise. It’s one of those things where you, you know maybe when I was in my teens, 20s or 30s, I felt like I focused on my disability. I finally came to peace with my disability and that this is who I am. I think it helped me look at other people too. You know, everyone is not perfect. I think the same thing with me. I realized, okay, you go with what you can go with. You don’t try to, obviously, with hearing there were certain things, you know, I wouldn’t be a telemarketer or something like that. Although now the phones are getting better. I have a caption phone so can hear better. I think because I had a disability when I was younger that’s easier than some people who start to lose their hearing now. They get frustrated, adapting to hearing aids or something. I didn’t have to go through that. In some ways it’s kind of nice now, as seniors, because I can’t hear very well, I fit in better than when I was younger. Now I’m kind of on the same level with them now.

Laura did not feel her disability impacted her aging.

I don’t think it’s had an effect on my aging. But it certainly had an effect on my relationships. As I was losing my hearing my family was essentially unwilling to learn anything more about people who suffer hearing loss. Especially my two younger sons. I’m finding this out now as they get older. When they thought I was ignoring them and then when I talked to them they thought I was always yelling. What people don’t understand is that as you lose your hearing, you can’t hear yourself either. It made it really hard. I spent the last 25 years of my marriage, because as I said, I got my first hearing aid when I was 37, having to remind my husband that he needed to look at me when he talked to me. My friends could remember and he couldn’t. You grieve, as you lose your hearing. Unless you’ve been in that spot, you withdraw because you realize your saying stupid things when you hear one thing and you realize it’s not. You try to get involved in a conversation and realize it has nothing to do with what they were talking about. Eventually you just don’t talk anymore.

I asked Laura if she believes there is a difference in this between when she first became disabled and now. She stated:
It was progressive. I didn’t realize it myself until I got my first implant. It was activated two days before my mom’s 80th birthday party. When my family got together to celebrate, people were asking me to repeat myself and speak up. It had been so long since I could hear myself that I had been talking to loudly most of the time. That was a pretty radical moment for me. I know the audiologist said I was a perfect candidate for a Cochlear Implant surgery because I had hearing and I was highly motivated. In fact, the day she activated the first implant, it happened I’d seen a documentary about a woman who’d received Cochlear Implant and it was a lot like me. Her audiologist had used an embroidery hoop covered with fabric to cover her mouth so this woman couldn’t lip read. She didn’t do nearly as well as I did. I was able to understand what she said. She was amazed how well I did.

When asked what made her “highly motivated” to get the Cochlear Implant, Laura responded,

I wanted to be able to hear my grandchildren. I wanted to be able to talk to them and that was a range of hearing that, those frequencies are among the first you lose. It was funny, after I got my implant, my one grandson, God bless him, said “grandma I want one of those when I grow up.” He realized what a difference it made. When I take them off I tell him I can’t hear you.

Jill’s positive response was, “I think it’s been great! I can’t see myself with the wrinkles! Like I said, I don’t see myself aging so I think it’s been a blessing. I can’t see any negativity in it whatsoever.”

Similar to the preceding question, the following question, “What effect has aging had on your disability?” did not prompt most of the participants to answer affirming that aging had significantly impacted his or her disability. Seth stated, “In some ways it’s better because now I’m starting to get a peer group that doesn’t hear well like me. In some ways I’m getting closer to my peer group then I was when I was younger.”

Laura stated:
As I got older, I got my first implant at age 37 and it progressed over time. It became a necessity to get Cochlear Implant. It has affected me all of these years. 25 years. It so impaired my ability to interact with other people. I read a quote by Helen Keller and she was asked if she had a choice to be either deaf or blind which one would she choose? 'Would rather be blind because speech is what connects you to other people.' That is true. That's what connects you. My disability hasn’t affected me as I’ve aged, I’ve reached a plateau here. Even now when I’m trying to establish new relationships, I make it crystal clear from the beginning. If you don’t have the patience or the understanding to look at me when I talk, I’m not interested in beginning a relationship with someone. It's too much work.

I asked how that was received by people and Laura responded,

Some people are very understanding and others aren’t. I went on an on-line dating site. My husband essentially abandoned me years ago. I can almost pinpoint it to the time I began losing my hearing. He was never able to accept the fact that he had a wife with a disability and my disability sent me, over the years, as in fact I went on my first antidepressant when my daughter was a junior in high school. As my kids left home, I saw the handwriting on the wall, because my husband was a workaholic and I knew that and I knew I was his enabler. But I kept waiting. I waited for him my whole life. I said, now, it was for nothing. When I went on this website I made it crystal clear in my profile that I have bilateral Cochlear Implant and I’m deaf without them. If that’s not important enough and you aren’t patient enough to remember to look at me when I talk, don’t bother to contact me. It impacts pretty much every aspect of my life. When I got back in the show ring after being out for a long time, I actually had to get a letter from my surgeon and audiologist that I have to give the judge because the rules require that you wear a helmet. I can’t because there is a high risk of the skin eroding where these attach. The hat has to be tight to keep it on and if they are covered up by the helmet then I can’t hear. They make a reasonable accommodation for me because of the ADA. They are also required to have closed captioning for me during the divorce proceedings. The one person I can’t hear is the judge. That’s another thing, it was years that I didn’t go to movies. I never went to concerts. Although, I think my music is coming back. It’s not the way I remember it. There are certain things I can hear and certain things I can’t. Losing the music was huge.

Hearing how important music is to her, I asked Laura if she plays any instruments and she stated that she does not. “My parents were too poor so I always swore I
would have my kids play an instrument. Both my girls sing beautifully and play the piano. I used to love listening to them. My oldest daughter majored in music. It wasn’t until I got the implants that I lost the music. For some reason they haven’t been able to tweak them to make that any better."

Hearing what Laura said about withdrawing at 37, when she lost her hearing, I asked her if she thinks the experience would have been different had she lost her hearing at her current age versus age 37 and she replied,

The experience would be completely different because, like I said. My children’s impression of me would be completely different. I wonder how their relationship would be with me if they didn’t have the impression I was ignoring them and yelling at them all the time. I went back to school. I was going to be a social worker. I wanted to go into hospice and my advisor asked me if my family would be interested in learning ASL. I said they wouldn’t even bother. It impacted what I wanted to do. I got far enough into it to know that people who are dying...I worked at a nursing home. I had a hard time interviewing the residents because I couldn’t hear them. My days were numbered there anyway but it makes you aware that it effects every aspect of your life. You grieve the loss of your hearing. It has really struck me and my family never understood that. My friends did. If my family would have been supportive, my whole life would’ve been different.

When asked what effect aging has had on her disability, Jill answered,

Well, it’s aging, like I said, it’s the long-term diabetes, I have the autonomic neuropathy, I have the hypoglycemia unawareness. Those are from long-term, you know, dealing with this disease long-term. So those diseases have created issues for me but there again, I’ve got ten friends that have died from this disease. So, I felt very fortunate. I’m here. So it’s very hard for me to, um, I know I sound too Pollyannaish, I’m aware of that. I am just so grateful.
Coping and Resilience

The participants illustrated coping and resilience as themes in many of their statements. All described some type of loss during their lives and how they managed to cope through that loss and other challenges.

Lester describes losses he has faced,

I feel like I’m 90 instead of 78. It feels like I might make it to 100. It’s a change. It’s a loss. I was busy all day every day. I did all the corn, spraying, harvesting, combining and chisel-plow in the fall. We used to have 400 plus cattle and two big silos. I basically took care of them all the time. We had pure-bread black angus cows and when the kids were younger they were in 4H and in fairs. We won all the awards. Our oldest son had the grand champion steer at the county fair. He was driving home in the fog the next day and a semi hit him and killed him and our nephew both. He was 18. He’d been homecoming king and had his room ready at the University. Now that was a son of a gun. They were both killed. That took a large part of our life. Kids used to show pigs and we had 200 plus ducks. Kids won grand champion at fair. We had a very active place. I used to make five trips to the State Fair in the semi.

Lois lost her husband approximately ten years ago and stated,

Thirty years ago I had a husband. I had one child living at home. We lived part-time in Florida and part-time here so it was quite different. I was happy and content and felt fulfilled then and now. Probably it was a little more, my son was a teenager and giving us a little bit of a problem, he was a little hard to deal with. That was probably a little more stressful than it is right now. I have a pretty stress-less life right now.

Laura is currently coping with the loss of her marriage. Laura’s divorce proceedings weigh heavily on her mind and influenced her answers to most questions:

I’m only employed part-time but when I wake up in the morning, I spend my first waking moments thinking of what I’m going through right now. Thirty years ago, my first thought in the morning wasn’t that I couldn’t understand how this could happen to me. I found out
right after we had our 42nd anniversary. Thirty years ago I was busy raising our children. That was a full-time job. Because my husband was never home, I was essentially a single parent. We had four children and our 3rd child wasn’t the best boy, he’s on the autistic spectrum. I spent about 15 years working with him. Thirty years ago when I’d work in the field, I’d work in my husband’s business. Things are a lot different now.

Laura stated, “I think it’s cruel that when you are young and healthy you don’t have the money to do the things you want to do and when you get older and do, lots of times, you are dealing with some type of disability that doesn’t make it possible for you to enjoy what you’ve been waiting your whole life to do.” When asked what types of things she wished should could be doing, she talked about her love of music and how her hearing loss has impacted this.

Something I really miss is being involved with music. It was a huge part of my life, I got my first hearing aid when I was 37 but from that point on, I used to do a lot of solo work. I sang with a choir, I did weddings and funerals. When I lost my hearing and started using a hearing aid it was just enough difference that I couldn’t sing in a group anymore or even by myself because you are just a hair behind the accompaniment. Music, I loved listening to music. I had very musical children. That’s a huge thing that’s been taken away from me.

Despite many challenges and losses, the participants all demonstrated remarkable resiliency and feel this resilience contributes to their successful aging.

Seth stated,

I don’t think I can go real crazy and look too far into the future. I don’t think I can come look to living to be 80, 90 or 100 years old. I just think, well, I’m 66 and what is life going to be like at 70? Maybe at 75? There’s a part of me that still thinks I’m 50 years old or something. I’m still a kid sometimes. I go out and play golf, I play 18 holes of golf and I’m stiff the next day. My brother came down last weekend and we did some yard work. I’m realizing I can’t do the same things I used to be able to do physically.
Laura also sees herself as aging successfully despite many challenges she has faced,

I’m aging as successfully as I can. I’m still healthy. I consider that successful aging. I’m still active. My life hasn’t turned out the way I thought it was going to. I read a quote by Maria Shriver that said, “When the life you are clinging to gets taken away you are given the life you were meant to have.” I look in the mirror and I look at my skin and I wonder how I ended up like this because I don’t feel any older. I know there’s a book “Girls with the Grandmother Faces.” That’s appropriate. I guess if I had problems, if I had high blood pressure, or I had arthritis or something impairing me, maybe I’d feel older, but I don’t.

Sara described how she has adapted after rearing her children,

It’s much more enjoyable now. 30 years ago I was working. I was working and trying to raise a family and all that. Now I can relax and not worry exactly about what time I have to get up in the morning. I don’t have to worry about my job or that I only have two or three weeks of vacation. I don’t have to hoard all of those days of vacation. Every day is vacation now.

Seth described how he has adapted to the challenge of his changing social network throughout the years while he maintained a positive attitude,

I’ve adapted to some people. I’ve learned too that some of my friends have changed too. Some have either gotten married or moved on and that’s a real challenge for us to stay connected. I think that’s a part of life no matter where we are. How to find friends and how to move on. You know, suddenly our friends get married or move on or get involved in things…sometimes we do find out that coworkers are not friends. Sometimes when we retire our social network has changed. People that we used to identify with and work with, suddenly they are retired and they are still working there and it changes. I don’t have the answer to that, I’ll be very honest with you. That’s one of the things I’m searching for right now is trying to find a group. Now that I’m working nights again, I try to search and maybe connect with the senior center and search myself. I kidded my neighbor next door now that he’s retired too that we need to find where the seniors hang out. Do we need to go to the cafe in the morning and have coffee? I think sometimes you need to do that sort of thing. You need to challenge yourself and say, okay, I can either stay at home and feel sorry for myself or I can start looking around for people. You know that’s part
of finding what seniors do now. It’s almost like being the new kid in
town. Maybe that’s why I’m still working. I don’t have that alternative
presented to me. I did hear some friends of mine tell me that when
you work at the senior center they all get along. That’s one of the
things that I’m going to do, if I connect with the senior center or find
my second job or something I enjoy doing and doing it with people. All
my life I’ve needed a job. The next time I have a job or something, I
want to do something around people I enjoy being around. That’s one
of the things I enjoy about still working at the school is the energy the
kids have and all that. Even the staff has a certain energy there. Even
when you’re not having a good day or something, you can go there
and suddenly the environment there picks you up.

A positive attitude is something that was evident throughout every every
interview and contributed to the coping styles and resilience of each participant.

When asked if she has a good outlook on life and what that is, Lois replied, “I believe
I do, yes. Not being depressed. Counting my blessings as opposed to thinking of the
negatives.”

A form of coping illustrated by the participants is comparing themselves to
others whom they feel are less fortunate than they are. Lester sees himself as aging
successfully when he compares himself to others.

Well I tell you. When we go to cardiac rehab at the hospital. When I
come out I tell my wife, sometimes I think I’m in bad shape but when
you look at the others, Holy God, compared to the other people, I’m
pretty good. So many people, I mean, you can get hurt just like that in
an accident or fall down and break your hip. Like I say, then you’re
history. A lot of times my wife will wait in the car in the parking lot
and all the people going in and coming out with walkers, wheelchairs
and canes. We have one in our family, it’d be my sister’s son. He just
had a brain tumor taken out of his head. When they sent it in and got
the results, supposedly it’s cancer. He has to go for radiation and stuff
like that. And then a good friend of ours, just this week, he had heart
surgery, a four-way. Anyway, he survived. He lost a lot of blood and
stuff. We have friends who are already in the nursing home or assisted
living facility.
Jill’s positive outlook on life shines through in her response to the question of whether or not she feels she is successfully aging,

Absolutely I do. First of all, I have no problem, like even in my speeches, I tell everybody my age. I don’t mind telling that because I feel like I’ve worked darn hard to get this far and I consider it a goal. I’m still independent and still doing many things around my home. I just feel aging is such a gift. I look at it as a blessing because there are so many people who haven’t gotten this far. I think what a blessing it is to enter into the golden years. I know there are a lot of people that have a heck of a lot harder time than I do with all sorts of medical issues. I just feel, aren’t we blessed to be this far? Successful aging is accepting life. Accepting that there are things that perhaps you cannot do. You’re not going to have the energy you had in your 20s. You’re not going to be able to probably do some things. I just think of myself, Victoria. I try to do everything. If I can’t do it myself I’ll try it again. If I can’t do it I’ll try it again. If I can’t do it I’ll ask for help. You gotta come to the realization sometimes that you do need some help. But don’t be bitter about it. Don’t get angry about it. You can get a little frustrated but don’t hold the frustration, you know? I just think you’ve gotta go through life with an attitude of gratitude.

When asked to describe thirty years ago, Jill replied:

I had our daughter and was busy with her. Joy of my life. Things have changed. Now I’m going to be a grandmother. When baby comes, they live in London, she and her husband are coming home for Thanksgiving. Baby isn’t due until March but I can’t wait until baby comes.

Each participant was asked to, “Think of a great day you have had in the past few months. Walk me through that day.” This question was designed to gain a deeper understanding of activity level and what in their lives, mattered to these individuals. Ultimately, the question again, highlighted the positive attitudes contributing to their successful aging. Jim’s brief response is typical of what you would expect of someone who is often thought of as aging successfully, “Any day above ground is a great day. What else? Never really any bad days.” Sara also
responded very positively, “They are all great days. They really are. I mean, every
day is great.”

I asked all participants “What do you think contributed to your aging well?”
Their answers illustrate what contributed to their coping style. Jim’s response
highlights his positive attitude, “Enjoying life, I guess. A happy marriage. And always
trying to laugh, you know. Have fun. We even have fun talking about my hearing
sometimes.” Sara said, “It was probably my attitude. I think that I do enjoy life. And
that I have many Interests. I have good friends. I don’t know. It’s my nature to be up
I think.” I asked her to describe her attitude and she said, “I think I have a great
attitude. I don’t let things get me down. Well, I do. I mean I worry and stuff like that.
But I don’t let anything with my disability get me down. I’ve had a good attitude
about it all along. And I’ve had support from my husband, he’s always been, you
know, right there for me too.”

Laura initially responded with “I’m a tough Norwegian.” When I asked what
that meant she stated, “I’ve always had livestock. I grew up on a farm. I know what it
is to work hard. I’ve always had horses. I’ve stayed active. My animals have actually
kept me younger because having to do chores: lift feed bags and hay bales and do
things like that helps keep you in good shape.”

Lois described her mother’s influence on shaping who she is. “I think my
mother because she aged well. I think that’s probably where I developed it. It’s in
the genes. Otherwise I don’t really see that I’ve done anything.” I asked her what she
saw her mother do or demonstrate that was aging well and she responded,

At age 80 she was diagnosed with breast cancer and had her breast
removed. She had practiced, before she had the operation, moving her
arm up in the air because they claim that you can’t lift as well or use your arm as well after the surgery because of the depleated muscles after a mastectomy. So she did that right away in the hospital and got along very well with that. My daughter often says to me, ‘Remember grandma’ whenever I’ve had anything to deal with. And I think my children have helped me age well.

I asked her how she thinks her children have helped her age well and she responded:

Okay, I’ll give you a couple of for instances. I have our third child and his wife, they think I’m getting old. I get the feeling that they are watching for me to make some mistakes and be old. My daughter, on the other hand, says ‘go for it.’ I’m a leader in bible study fellowship. At 78 I didn’t know if I should continue doing that. So I called her and asked if I should continue. She said, ‘Of course. Absolutely.’ That was her response immediately. I asked my leader, the person that’s the teaching leader, if I should continue. She just turned 50 this year. She said ‘Yes. And when you feel you shouldn’t, you let me know. I’ll leave that up to you.’ Last year and this year I have a multi-generational group which means the youngest is 44 and I’m the oldest and various ages in between. My son and daughter-in-law moved to a townhome and chose one with a bedroom on the main floor because maybe I’m to a point where I shouldn’t be living alone anymore. And when my husband was ill, he said I should sell the house and move in with our daughter. My daughter said, ‘Mother I think you should remain independent as long as possible.’ I told my husband that and he said, ‘Well you’re independent all right.’ I’m keeping active, for sure.

Jill told of the many challenges she has faced during her lifetime and how these challenges contributed to her successful aging,

When I was 19 I lost a brother, Joe. He was 21. I was quote the ‘sickly child’ in the family. I was the youngest of five children. At that time, shortly after that, I was 25 when I lost my sight. I kept on thinking, ‘You know what, Joe would love to be here so don’t complain. You are alive. You are going to make it through this. He’s always been my mentor. In death he’s been my mentor. When he was alive he was my mentor. When I got older I had a sister that was five years older than me. She died of ovarian cancer at the age of 49. I had a sister 12 years older than me, she developed lupus. That’s an autoimmune disease just like Type I Diabetes. I think our lifeguard was out to lunch at my gene pool. She went into a vegetative state at the age of 47 and she died when she was 54. I’m 63 and people say I have a good attitude.
That’s why. I’ve seen it personally. I’ve seen how, you know I want to use the word ‘blessed’ but I hate to use that word. God has blessed me but he blesses everyone. Everyone is special in his eyes. I don’t know how you are with your faith but I have a very strong faith and I feel we are all special. I hate to use the word blessed because they were blessed too. He took them home but he’s allowed me to be here and that’s what gives me strength. That’s what gives me the attitude I have. I look around and I think, oh gosh. Everybody’s got problems. No matter what they are. Some pretty minor and some pretty major. But I think when you think you have a problem, there is somebody dying right now who would love to have your problem.

Jill illustrates how faith is a foundation to her ability to age successfully. She also highlights that she feels she has nothing to complain about, when comparing herself to others. I asked Jill about facing adversity and moving on and not allowing challenges to incapacitate her. She continued,

I feel sorry for the people who’ve never faced a challenge because when you get older, and you’ve never faced adversity, my gosh. I wouldn’t wish that on anyone. I think once you’ve had to face it that you become more courageous in the face of the future. I’ve seen too many people, as they age and something major happens, and something will in our lifetime, they don’t have the stability to deal with it. They do fall apart more easily. They have a harder time accepting what’s happening. I feel so sorry for them. You know it would be wonderful if we all could live to be a certain age and never have anything hit us but sometime along the way something will. If you find out, if you’ve gone through different things...if I live until November I’ll have outlived my mother. My dad lived until he was 86 and I have a brother that is 74. I always tease my brother. I hope he lives to be 100 but my goal is to outlive everyone in my family. They day he dies I know I’ll have 11 more years to go. I just think it would be so horrible for me to sit and complain about my life when I know my siblings would love to be here. Adversity teaches us to grow.

Each participant described what they wish people knew about aging well with a disability. Their responses involved things they had previously stated, such as “have a positive attitude, stay active and have friends.” Jim stated, “I think you have to keep a sense of humor. You just can’t, even though you get frustrated, you
just can’t let it get you down. It’s just something you’ve gotta accept, you know.

Nothing you can do about it.”

Similarly, Sara stated, “Well there’s nothing you can do about aging because that’s always going to be there. You just keep on with your life and keep going. Enjoy life. You have to have a good attitude and not let things drag you down.” I probed for more depth and obtained it in many of the responses.

Seth’s response is as follows,

For me, my disability was kind of, now that my hearing was going bad, I’m starting to fit in a bit. For some people who are starting to lose their hearing or starting to lose their site, particularly my mom. She’s starting to lose her site and can’t read the paper. That’s something she enjoys doing. I think as seniors, if you take something away from them or you eliminate that from their lifestyle, it makes it challenging for them to replace that. I think the same thing with my dad. I have to chuckle. He went to the VA and they gave him some hearing aids. He came home and threw them in the box and threw them in the drawer and never wore theme again. I think that’s one of the things for seniors that they try to adapt to little things. He did have a good thing. As he got older and tried to get out of the car he’d say ‘Come on old man, let’s get going.’ I now think that’d be a good phrase for me to say as I got older and I’m trying to get out of the car or I’m a little stiff, ‘Come on old man, let’s get going.’ You know, encourage yourself. Challenge yourself, so to speak. I don’t know what advice you can give to seniors. Everyone handles it differently and not everyone wants help. A couple of my nieces and nephews are on my LinkedIn page. They like my advice. You have to encourage younger kids. Be there to pick them up when they fall. Connect younger people with seniors who can be good role models. I like programs that connect daycare centers with senior centers and would like to volunteer when I retire.

Laura described the current struggle of her divorce but also optimism for the future.

Physically I’m doing alright but emotionally, I’m not. I’m still trying to get back on solid footing and realize that I do have a life to live yet. I should’ve gotten out of the situation I was in 20 years ago. I’ve never feared death. My philosophy has always been to go as hard as I can for as long as I can. I told my kids that if I die because I’m driving my
sports car too fast or riding my horse, it will be with a smile on my face.

As with most of her responses, Lois modestly describes her situation when asked what she wished others knew about aging well with a disability. She stated, “That they can do it. That it isn’t an end-all. Now remember, my disability isn’t like somebody else’s. I’m not in a wheelchair or anything.” I asked Lois how different she thinks her experience would have been if she had lost her eye at 77 versus at age 39 and she replied, “That’s a good question. When you’re young I think you can accept things better. I think it would’ve been harder. I think I would’ve felt sorry for myself more so than I did at that time. I think it would’ve been more difficult.” Lois’ daughter had entered the room for this part of the interview and asked her mother, “Think about when you were losing your vision in your good eye. What else did you do?” Lois responded that she bought adaptive equipment and dealt with it. I then asked, tongue-in-cheek, “When did you feel sorry for yourself?” Lois then laughed and her daughter stated, “You always just go on. You find a way to deal with it and you go on.” Lois then told the story of when she lost the vision in her eye and how she dealt with it.

I had a doctor once in Florida who said he saw spots on my eye and I could go blind. It scared me a lot. I tried putting makeup on in the dark because I thought I should practice before it happened. That was when I was a lot younger. I guess I would do that again now if it happened now. I always said I’d get a seeing-eye-dog if I went blind. I’d do whatever I could to get help. I’m really blessed with a good family.

Jill’s positive attitude and resilience are evident, once again, in the following statement,
We all have the power within us to make choices. That’s why I tell people, you know, it’s okay to feel frustrated. It’s okay to be angry. It’s okay to be sad but don’t hold onto those moments. You know you’ve gotta let them go and go forward and keep on going forward. And like I said, keep on remembering all of the things you have and not all that you’ve lost, which you have. It’s not really important what you’ve lost. I always look at myself and think. People are multifaceted. Lack of sight is just a small part of me. I often tell people too, if you blindfold yourself right now, you are still the person you are. Whether you have sight or not. You still like the same things, you still think the same things, you still want to be engaged. If you are a shy person you’re still going to be a shy person. If you are outgoing you are still going to be outgoing. It’s just a small part of you. We are all multifaceted. But I do feel sorry for the people who can’t move beyond because if you can’t you are going to dig yourself in a hole. If you can’t change your ways or your attitude. I know there are a lot of people out there who have it a lot worse than I do so I shouldn’t talk so smugly. I faced a little bit of a challenge two years ago. I lost my hearing on my left side. Was that ever scary. I’d be cooking a meal and I know that the frying pan is right in front of me but the sound is coming over here. What happened to me, it was my autoimmune system. I got it back 80 percent but I had lost total hearing on the left side. It was scary because I thought, what if I lose total hearing? How am I going to take care of myself with everything? My daily routine? My insulin injections? I need to know what my glucose level is. I need to hear the clicks of the insulin as I inject. I thought, what in the world would I do without hearing? Well thank God I didn’t find out. I kept on telling myself, there’s got to be some way. And I’ve got neuropathy too so I can’t read braille. I’d really be up a crick. I was concerned about that. So I shouldn’t talk so smugly. I’m sure there are people like me that that has happened to.

I asked her how she would have handled it if this had been permanent.

I would have. I’m persistent. You know, simple things like writing a grocery list. I would have to manually sit down and write the grocery list. A lot of times I’d forget what I had on there and probably write it over again and sometimes I’d write it over something else so he couldn’t read it because I didn’t know I’d written on top of something else. Now I just keep a document on my computer and a running list of groceries. If he’s going to get groceries I print it out for him. Simple things like that I’m just so grateful for. So many things.

Spirituality, as a foundation for coping, was important to many of the participants. Seth stated,
I realize that I’m looking at my life as a book with different chapters. Some are longer, some are shorter. Some are happy, some are sad. You know I think I just have to figure out, okay, what does God have for me to do in my life. If I can find out what my purpose is for the next five years or ten years, I think that’s fine.

Seth continued to explain how his religion and relationships he has had have influenced his successful aging:

I think being a Christian and believing in God and believing that God has a purpose for you helps a lot. If you’ve got some kind of spiritual base, that does help you. Then you realize that when you have your bummer days and you’re not feeling so good, you realize that God still accepts you. I think that’s good to have a good spiritual base. I guess, like I said, it’s good to have a good group of social friends that accept you. I think that’s always good. You know, just having that perseverance and intelligence to go on and say ‘this bad day doesn’t define me’ and that sort of thing. I think sometimes it’s nice that people come along and encourage you or something like that. We are all going to have our frustrations and struggles, especially as we get older. I think that’s one of the things you need to do is have some type of social contact with people. In fact, I think that’s one of the things people don’t know how to deal with. Older people. Sometimes they are afraid because some senior areas cost and maybe as you get older you don’t have the finances to be able to do stuff. I think it’d be nice to be able to get involved in things. Sometimes church’s focus on youth and younger people and don’t always focus on older people. I think it’s nice there are studies to look at how seniors can live well. I do think that some seniors, after a while, especially, I did this thing on stress one time and losing a spouse is a very stressful thing. Some people, you know, they’ve been connected with somebody for 40 years and suddenly they don’t have anybody and maybe it’s their social friends or were dependent on their work. I don’t know if there’s answers because I’m kind of looking for those answers of how to connect with people when they are older. I think some people when they are older, you know they weren’t raised in the computer/Facebook age so some of that stuff is foreign for us. We don’t go to computers and stuff to look for connections. It does get to be a challenge on seniors to find out how to connect.

Advice to Others
Advice to others included many of the items the participants highlighted in the above themes related to successful aging. The question, “What advice could you give me that would help me age well?” yielded various answers from each participant.

Jim stated, “Well I suppose I stay busy. I have hobbies. I used to like working with wood and stuff like that. I built my own furniture. I haven’t done that lately. Still do some.” Jim continued, “I think too what helps you age good is keeping active with your friends. We still have a lot of friends and relatives around here.” Jim finished answering the question with this statement, “You don’t want to become isolated. Which this tends to become. You tend to isolate yourself when you can’t hear anymore. You like to avoid communicating with people and stuff like that. That’s the bad part. So anyway.”

Sara’s advice included “Keep active. Have friends. Let’s see, stay healthy. And just have a good outlook on life. I think that’s real important.”

Seth’s advice involved being comfortable with who you are:

I think first of all, find out who you are because that’s the most important thing. We all go through self-discoveries and things like that. I think find something you enjoy doing. Find someone you enjoy spending life with. Do those sorts of things. Just learn to enjoy the days. I think that’s one thing that I always disliked when I worked at different jobs and people would say ‘you know I’ve got another 20-30 years until I can retire.’ You know they had goals. Just live life each day and try to be content with who you are. I think it’s fine. You can always try to improve yourself. Knowing who you are and being at peace with yourself.

Laura’s advice was to “Stay active and stay involved. I think those are the two best. Don’t count on someone else for your happiness. I made that mistake.”
A few participants provided advice when I asked if there is anything else they would like me to know about aging. Lois’ optimistic answer was, “Look at the bright side of life. Don’t dwell on negatives. That really tears you down and doesn’t help you one bit. In my estimation I guess. That’s what I would advise.” Jill’s answer was similar, “Accept it. Keep going forward. You can’t reverse time. I’d just keep going forward and embrace it. Again, just be so grateful that you’ve had the opportunity to reach that level.”

When asked, “What advice would you give to a younger person with a disability to guide them to age well?” Most responded stating that one should accept his or her disability and maintain a positive attitude. Sara stated, “To just keep pushing. To try to overcome that disability. Don’t let it stop you from doing anything. Try different ways of however you can to do what you want to do.”

Seth’s sentiment was similar but he expanded his response with a powerful personal story:

I think the first thing is to accept the disability. You know when I was younger sometimes I wouldn’t wear my hearing aids and then I’d go to class or something and I’d be self-conscious and I’d defeat my whole purpose. I think I’ve learned to accept it. Wear my hearing aids and do my stuff. I’ve realized that that if people are rejecting you because of your hearing, if people are giving you a hard time or something like that, they just don’t understand and realize that you have to have peace with yourself and that sort of thing. It’s a part of you, your uniqueness, not being able to hear. You have to kind of realize that some things are going to be more challenging than others. I mean, you can’t go out in social groups where there’s a lot of noise and everything. But at the same time that doesn’t necessarily mean you don’t try. No doubt there will be some jobs that are harder for you to do. But at the same time that doesn’t necessarily mean, you know like cell phones and that sort of thing that aren’t very good for people who don’t hear very well, that doesn’t mean they won’t be able to find something that’s adaptable to you.
Laura responded:

Use every type of support or device or assistance that’s available to you. Try to connect with other people who have gone through the same thing. My disability doesn’t effect my ability to function on a day-to-day basis, you know, self care and all of that. I think that would be the best advice I could give them.

Lois stated, “I guess to learn to live with it and to almost ignore it. Accept it. If you don’t accept it how would you get along very well?” I asked her how one does that and she said, “You just make up your mind you’re going to and you do. I don’t know. How would you do that? It’s mind over matter! In life so many things are mind over matter.”

Lester responded, “You’d better try to take care of yourself because it’s going to get worse. The best thing about if you lose your hearing, you can have these implants in each ear and you get along really good. Supposedly, there isn’t really any fixing the eyes. You’ve got to keep up with the modern technology for your help. Follow-up and get help immediately.”

Jill describes the need for a positive attitude as well as perseverance.

Again, you’ve gotta work on your attitude. Just keep on trying. Don’t let other people underestimate what you can do. Always have self worth. Know that you’re capable of doing something and don’t assume that you cannot. Try it. Give it a try. Perhaps maybe you can’t but the worst thing is not trying. And as you age, well, again, work on that positive attitude. It opens so many doors for you that probably you didn’t even realize that you could do something. To me that’s so very important.

I asked her to clarify what she meant by “open doors” and Jill responded,

You know, don’t assume that you can’t do something. Don’t let other people assume that you cannot. My greatest experience is, I always wanted a computer. When I considered the cost and training and the jobs program that would go with a computer I thought, wow, that’s just overwhelming. That’s a lot of money and it would be just for my
entertainment. It wouldn’t be job-related. I kept pushing it on the back burner. I kept thinking that it was something I really didn’t need. Well then I met someone at Services For the Blind and she helped me and got me training. The first product didn’t work for me. A friend recommended another product. I hated to complain but thought I needed to be an advocate and stand up for myself and say, you know, this isn’t working. After complaining a little bit, the woman at Services For the Blind helped me get a new program. Within two hours I was doing documents and emails. It was like a whole new world opened up to me. But, you need to be assertive. You need to keep on trying to reach your goal. If you’re really insistent and work on it. And you have to have the courage to do it. I think it’s important to have a goal. To have visions of what you want. Where you see yourself and work towards it. And despite what other people say, unless it’s going to be harmful to you. I think you just have to be your own advocate and have the courage to step up and say no, I really want to try this. Give me a chance.

All of the participants illustrated themes of what it means to them, as individuals, to age successfully. These themes included aging as inevitable, frequent activity, social and family interaction as essential, sense of worth, acceptance of disability, coping and resilience as well as the advice to they would offer to others.
Chapter V: Discussion

This study examined the question: *What does it mean for an older adult with long-term disability to age successfully?* Seven men and women participated in recorded interviews with the researcher. The recordings from these interviews and memos written by the researcher became the data that produced findings to answer the research question. Several themes emerged from the data.

Participants ranged in age from 63 to 83 years old and had lived with a disability for approximately 20 years or longer. Three were male and four were female. Four were married, one was separated, one was single and the other was a widow. Four lived with their spouses and three resided alone. All had completed at least one year of college or technical programs. Five had graduated from college or technical programs and one had earned credits beyond her bachelor’s degree.

All of the participants were blind, deaf, hearing impaired, vision impaired or a combination of these. All have lived with their disability between eighteen and fifty years. Most described their overall physical and mental health as good or excellent. None identified needing assistance from a caregiver. All were assigned pseudonyms to protect their identity.

In this study, participants shared their thoughts about successful aging and the lived experience of aging with a disability. This is a phenomenological study of older adults and their views on aging. Information was gathered through open-ended interviews with older adults with disabilities. Following phenomenological research methods, I sought an understanding from in-depth interviews about what it means to age well. I wanted to find out their lived experience of aging and what
aging well means to them. The study participants illustrated disabled older adults’ perceptions of aging successfully. These perceptions included both positive and negative components.

Respondents’ everyday experiences came forward to describe several themes and thick description of what this means to them. This phenomena has not been previously examined among this population.

When I began this research, I was unsure if I would find that those with long-term disabilities are aging as successfully as those without disabilities. One possibility I expected to encounter is that they would not be aging as successfully, due to their limitations. What I found was the opposite. The participants of this study view themselves as successfully aging and much of this might be due to the disability to which they have adapted or overcome. The themes in this study are similar to other successful aging studies of non-disabled older adults (Baltes & Baltes, 1990; Ben-Zur, 2002; Hardy & Concato, 2004; McMullin, 2004; Lamond & Depp, 2008; Ouwehand, de Ridder & Bensing, 2007 & Troutman-Jordan & Staples, 2014).

_Aging as Inevitable_

Aging emerged as a theme as it was directly related to the research question and questions asked to all participants. The participants identified both positive and negative aspects of aging. Many of the participants directly stated that they do not feel old and many feel young. They see age as something one must accept and not something on which one should dwell. They see aging as a natural process and a transition all must experience. The positive examples included not only feeling
young, but also feeling wiser, comfortable, content, happy and in control. Negative examples included a sense that they were slowing down; however this was also viewed as positive and contributed to their being in control. The participants felt that they now have more independence and freedom from responsibilities such as rearing their children, being employed and worrying as much about finances. These findings are consistent with successful aging studies of non-disabled older adults (Baltes & Baltes, 1990; Ben-Zur, 2002; Hardy & Concato, 2004; McMullin, 2004; Lamond & Depp, 2008; Ouwehand, de Ridder & Bensing, 2007 & Troutman-Jordan & Staples, 2014).

Frequent Activity

Activity emerged as a theme and is consistent with the successful aging literature as a contributing factor to those aging successfully. Activity included hobbies such as golfing, walking, biking, riding horses, playing cards, woodworking, farming and crafting. Activity also included charity and volunteer work. This included volunteering at churches, senior centers, youth centers and service agencies. Participants found that they enjoyed volunteering because it not only kept them busy but it made them feel that they were giving back to others. All participants identified a routine to their days but also enjoyed the freedom to vary from this structure when they chose. Two of the participants are employed and all maintained some level of household chores. None of them relied on outside support for their activities of daily living or instrumental activities of daily living. These findings are consistent with successful aging research conducted on non-disabled older adults (Baltes & Baltes, 1990; Ben-Zur, 2002; Hardy & Concato, 2004;
McMullin, 2004; Lamond & Depp, 2008; Ouwehand, de Ridder & Bensing, 2007 & Troutman-Jordan & Staples, 2014). The theme of frequent activity overlaps with the following theme of family and social interaction, as the participants all found meaning in activities involving friends and family.

**Social and Family Interaction**

Social interaction with friends and coworkers was very important to all participants and remained a constant theme throughout the interviews. Codes included relationships with family and friends as a source of strength, activity and belonging. Having friends, being socially active and having a connection to others was mentioned. This is consistent with successful aging literature that those who are more socially engaged, tend to age successfully (Baltes & Baltes, 1990; Ben-Zur, 2002; Hardy & Concato, 2004; McMullin, 2004; Lamond & Depp, 2008; Ouwehand, de Ridder & Bensing, 2007).

Family was a thread woven into many answers to the interview questions. For all, their close family was the source of great joy and support. They maintain positive relationships and spoke of occasions when they see their children and grandchildren. These times mean a lot to them and significantly impact their positivity. Jim spoke of attending all of his grandchildren’s basketball games and sharing his farm with his son. Lois, Jim, Seth and Lester all described their “great day” as a day they recently spent with their families.

One participant was separated from her spouse and in the process of divorcing. This was a challenging situation for her but one could understand, throughout her answers, how she is able to cope with this situation as she has
during many other challenges of her life. Her family has had a difficult time adjusting to her hearing loss and has not demonstrated the support evident in the lives of the other participants. She has demonstrated resilience and has sought that support in relationships with her friends. She finds great joy in her children but there have been challenges with these relationships, as will be discussed more in a following theme of acceptance of disability.

Sense of Worth

Feeling that they matter in the world is also a theme that was prevalent throughout the interviews. All want to feel they are making a contribution and are needed. Their volunteer work, employment, assisting others, friendships and ability to use technology all contribute to their feelings of self-worth. Several also mentioned feeling “only as young as you feel” and that how others perceive them being very important. They feel it is important to remain engaged with people who are younger than they are. They take great pride in being respected by younger people. Lois finds this in the church Bible study group she leads. Seth finds this in his work at a college and in his nieces and nephews seeking his advice on social media. The participants reflected on rearing their children, working and civic engagement activities during times that were meaningful in their lives.

Acceptance of Disability

All of the participants in this study became disabled as children or as younger adults. They each have a story of how their disability has impacted their lives. They all experience certain limitations, including a lack of freedom. Conversely, as noted above, freedom was also mentioned as something they all experience more of in
certain ways, unrelated to their disability, as they have aged. This is perceived differently as it relates to their disabilities. Many face limitations related to driving, communicating, and social interaction. Some faced limited or complete loss of employment as a result of their disability. Some experience a limited ability to travel as they used to while others continue to travel, sometimes more than when they were younger.

Acceptance of the disability was a constant theme among these individuals. They all grieved, then moved on. A part of that moving on was discovering adaptive equipment. Some felt they would be embarrassed to use the equipment; and others wanted to try to manage without it. During the grieving period, some reported they refused offers of adaptive equipment however, all of the participants spoke of adaptive equipment they have used to assist them with the limitations caused by their disability. This equipment has been an important part of their lives and noted contribution toward their successful aging. The equipment was used to adapt to their disabilities, but gave them the freedom to be active and engaged, which they all cited as important components to aging successfully.

As outlined in the preceding “family” theme section, most found their families to be very supportive as it relates to their disability. One participant did not share this experience. She lost her hearing in her thirties, when she was rearing her children and married. She believes the impact of her disability contributed to the strained relationship with her children and the end of her marriage.

A surprising and interesting finding in this research was the sense the participants shared of their disability being their “uniqueness.” It is something they
feel sets them apart from others, in a positive way. A few of the participants identified their disability, while having its challenges, as a positive aspect of their lives and feel fortunate to have the disability as a part of their identity.

Another surprising and interesting finding is that several believe they now fit in better with their peers than when they were younger. Seth mentioned that he did not want to wear his hearing aids when he was in high school because he would have been embarrassed in front of his classmates. He now wishes he could go back and wear them during that time because he missed out on a lot of his education because he could not hear his teachers. Now, as he is getting older, many of his friends are facing hearing loss and he seems to fit in better.

*Coping and Resilience*

Coping is another theme prevalent throughout the interviews. The manner in which these older adults cope is consistent with the literature supportive of successful aging (Baltes & Baltes, 1990; Ben-Zur, 2002; Hardy & Concato, 2004; McMullin, 2004; Lamond & Depp, 2008; Ouwehand, de Ridder & Bensing, 2007 & Troutman-Jordan & Staples, 2014). All experienced loss as it relates to their vision or hearing. Many participants told stories of deaths of friends and family members. Participants lost parents, siblings, spouses and children throughout their lifetimes and, consistent with the pilot study participants, coped with this loss in a positive manner. The interview comments from Jill, regarding the loss of her siblings, and Jim’s loss of his son, show that they grieved but were able to move on after these difficult losses.
Determination and persistence played a role in the participants’ use of adaptive equipment and technology. They told stories of how they were initially challenged by the use of the equipment, or lack of such equipment and were persistent in mastering the skills required to overcome a challenge. Often these situations involved them advocating for themselves to find a solution to the challenge.

Several gave examples of strong family role-models who influenced their coping style. Lois’ mother practiced moving her arm up and down when she was told this would be difficult to do following a mastectomy. Lois remembered this when she was told she would lose her vision and practiced putting on makeup in a dark bathroom. Seth told of his father’s determination to complete even simple tasks for himself while on hospice. Seth has since repeated his father’s mantra, “Come on old man. Let’s get going.” to himself when he is having a difficult day. He often says, “This bad day doesn’t define me.” Many credit their parents for giving them the strength and resilience that contributes to their ability to age successfully.

The older adults interviewed for this study all mentioned that they perceive others experiencing greater hardship than the disability they experience. None see their situation as “that bad.” They made statements such as “If I were ill,” “My disability isn’t like others’” and “there are so many others who have it a lot worse than me.” This highlights their modesty and resilience in the fact that their situations are not preventing them from living their lives and not feeling sorry for themselves.
Research related to successful aging includes coping and resilience (Baltes & Baltes, 1990; Ben-Zur, 2002; Hardy & Concato, 2004; McMullin, 2004; Lamond & Depp, 2008; Ouwehand, de Ridder & Bensing, 2007 & Troutman-Jordan & Staples, 2014) as mechanisms that help foster and maintain a state of perceived well-being, high self-assessed quality of life and a strong sense of personal fulfillment that reflects successful aging. Coping, resilience are essential in older adults’ views of successful aging (Young, Frick & Phelan, 2008).

Spirituality, as a foundation for coping, was important to all participants. Most regularly attend church, identify as Christian and have a strong faith in God. Many described themselves as being “blessed.” There was also a consistent message among most that God holds a purpose for them and this purpose guides them to help others. This took the form of volunteering for senior centers, service organizations and churches. It also involved helping family and friends, without hesitation. There was a modesty reflected in each of the participants when they spoke of their situation. There was never boasting or bragging about all they do for others, or regarding their accomplishments. Their comments focused on how they felt that they are servants and should assist others. They all made their accomplishments sound as if they were “nothing special” which is also consistent with findings from the pilot study.

Critics argue that successful aging research neglects largely spirituality as a factor which contributes to successful aging (Crowther, Parker, Achenbaum, Larimore & Koenig, 2002; Depp; Daaleman & Frey, 2004 & Jeste, 2006). A missing component to Rowe and Kahn’s three-factor model of successful aging is identified
by critics and they propose strengthening the model with a fourth factor of positive spirituality (Crowther, Parker, Achenbaum, Larimore & Koenig, 2002). Positive spirituality involves,

A developing and internalized personal relation with the sacred or transcendent that is not bound by race, ethnicity, economics or class and promotes the wellness and welfare of self and others. Positive spirituality uses aspects of both religion and spirituality (Crowther, Parker, Achenbaum, Larimore & Koenig, 2002, p. 614).

They assert that spirituality is an important component of health and well-being outcomes among older adults and that interventions incorporating spirituality with underserved populations as a guide to health professionals, religious organizations and governmental agencies will improve outcomes successful aging among these older adults (Crowther, Parker, Achenbaum, Larimore & Koenig, 2002).

Advice to Others

The advice the participants gave to others who face disability is how they described themselves living. They recommend that others with disabilities remain active, have friends, be determined, seek help when needed, use adaptive equipment and do not worry what others think of you. They also recommend that others advocate for themselves, try to overcome their disability and do not let it stop you from doing anything. They also recommend having a positive attitude, keeping their sense of humor and enjoying life.

One of the criteria of successful aging identified in the first and most referenced literature on the subject (Rowe & Kahn, 1987) is the criteria that one should be “free from disability.” The research says one should not become frail, elderly, or have an age-related disability if one is to successfully age. I did not find
anywhere in the literature that research was being conducted examining how people with long-term disability were aging. It piqued my interest and became what I wanted to discover next. Many themes were consistent between the pilot study, and other research with non-disabled older adults, and this study. One particular theme was related to how successful agers behave when they face adversity. They are resilient when faced with challenges. This was another reason I wanted to study older adults who had faced a challenge, such as a long-term disability. All of the participants of this study reported that they are aging successfully. Everyone I interviewed had something happen to them earlier in their lives that caused their disability. It is not because I selected it that way; it is how it happened. What do successful agers who experience blindness or deafness do when they face this life-altering disability? As illustrated in this study, successful agers can recover and move on. They are very strong and resilient people. These findings present a positive picture of successful aging among older adults with long-term disability, where they were mostly ignored in previous research.

Selective Optimization and Compensation Theory (Baltes & Baltes, 1990) contends that individuals who age successfully use three strategies: selection, optimization and compensation to achieve desired goals. Selection includes identifying goals, prioritizing them, establishing criteria and conditions and determining the degree of commitment. Optimization refers to maximizing performance to facilitate success. It involves the degree of focus, the timing and tenacity of goal pursuit, learning new skills, modeling others who are successful, developing resources and increasing the amount of time dedicated to goals.
Compensation refers to adapting to limitations that interfere with goals. It includes the use of assistive technology, obtaining help from others, developing new skills and resources, employing previously discarded skills and resources, devoting more energy or time and modeling others who compensate well. Prior to beginning the interviews, this theory seemed the most applicable to successful aging among those with disabilities. Upon completion of the research, it appears to be a solid theory upon which to base these results. It is inclusive of different groups and does not include language that one must be non-disabled in order to age successfully.

Selective Optimization and Compensation Theory appears to be the best fit to the study’s findings, as it is more inclusive of different groups. The participants in this study illustrated their use of the three strategies: selection, optimization and compensation.

Illustrating this theory, each told stories of their disabilities and how they did not allow them to limit every aspect of their lives. Related to selection, they all told of the impact their disability had on their lives and the goals they each set to overcome limitations related to their disability. Related to optimization, they each told stories of their degree of focus, the timing and tenacity of goal pursuit, learning new skills, modeling others who are successful, developing resources and increasing the amount of time dedicated to their goals. Finally, related to compensation, each told stories of their adapting to limitations that interfered with their goals. This included the use of assistive technology, obtaining help from others, developing new skills and resources, employing previously discarded skills and resources, devoting more energy or time and modeling others who compensate well.
A newer theory, Gerotranscendence, also applies to the findings of this study. Gerotranscendence theory describes a “natural” alteration of consciousness in old age leading to “wisdom” and a qualitative break with a mid-life rational and materialist world-view. According to the theory, gerotranscendence is obstructed by a lack of alternative values and roles in old age in Western societies. Theoretically and in clinical practice, Gerotranscendence theory has been linked to psychoanalysis (Jonson & Magnusson, 2001). Several of the study participants mentioned that they are more peaceful and have less stress in their lives. They mentioned the difficult years when they were younger of trying to meet employment demands and rear their children. I think many would feel they have gained “wisdom” in old age and have broken from the materialistic world-view of their mid-life years. Jim, Sara, Lois and Jill mentioned that they now feel more independent and “free” from difficulties and obligations of their mid-life years. Seth remains employed but demonstrated he is transitioning toward this “break” from mid-life as he considers retirement and what the next chapter of his life will be. Critics argue that the theory is “empirically weak, has parallels in the New Age movement as well as in romantic Orientalism and can be understood as an attempt to re-enchant aging” (Jonson & Magnusson, 2001, p. 317).

**Study Limitation**

A criterion sampling method was used. I am fortunate to have close ties to the medical, academic and social services in my region and I reached out to physicians, service clubs and service agencies inquiring about potential participants for this study. I was hopeful that those groups would refer me to other potential
participants. Word spread rather quickly among the deaf and hard of hearing as well as the blind and hearing impaired community and I was able to engage qualified participants. I did not have as much success finding participants with other disabilities who qualified for the study, which could be a limitation of the study.

Implications for Future Studies

Based on the limitation cited above, future research on successful aging among older adults with long-term disabilities, other than sensory impairments, could shed light on potential differences among disabled individuals.

Implication for Social Work Practice, Policy and Education

This study can contribute to knowledge and skill development in the areas of social work education, research and policy. As the baby-boom generation ages, the country is preparing for the next generation of older adults. As social work educators it is imperative that we strive to prepare students to meet the needs of this large group of older adults. This will be accomplished through teaching social work students about aging across the curriculum. Aging content is lacking in some of the current social work core curriculum. Most social workers will be involved in work with older adults at one time or another and will need the tools in which to provide appropriate support and services. Finally, this study illustrates how those with long-term disabilities are able to age successfully. Social workers can provide resources and education to assist older adults with long-term disabilities age successfully. We can also influence policy decisions that support funding, support and services for people with long-term disabilities.
Re-Conceptualizing Definitions

Successful aging, productive aging and aging well are just three of the terms used to describe the phenomena researched in this study. All of the terms have been researched over the past several decades and their definitions routinely debated. There have been meta-analysis of the definitions of these terms with many suggestions for alterations. As this study highlights, these definitions do not usually refer to older adults with long-term disabilities. A recommendation from this research is to re-conceptualize definitions of successful aging to incorporate older adults with long-term disabilities.

Conclusion

This dissertation outlines the extent of population aging and long-term disability in late life. It also addresses various definitions of what it means for one to successfully age. This study illustrates the lived experience of older adults aging with a long-term disability. Even in advanced old age, millions of people function independently. This study identified those aspects of older adults’ lives that influence whether or not they see themselves as aging successfully. This project addressed the question: What does it mean for older adults with long-term disabilities to age successfully?

This study offered insight into what factors contribute to successful aging in this population. I would like to use the information from this study to contribute to the literature regarding positive aging and what it means to age well. This study will contribute to the literature illustrating that many older adults, even those with long-term disabilities, are active, resilient and involved in the community.
Appendix A
Demographic Questionnaire

Age: _____

Gender: _____

Marital Status:
Divorced    Living with Another    Married    Separated    Single
Widowed    Would Rather Not Say

Living Arrangement:
Alone    With Spouse/Significant Other    With Adult Child    Congregate
Living
With A Family Member that is Not My child    Would Rather Not Say

Highest Level of Education: _______________________

Type of Disability: _________________________________

__________________________________________________________________________________________

Length of time you have been disabled: _________________________

Overall Physical Health:
Excellent    Good    Fair    Poor

Overall Mental Health:
Excellent    Good    Fair    Poor

Number of medications: ________

Other Chronic Conditions:
__________________________________________________________________________________________

Do you require assistance from a caregiver?    Yes    No
If yes, how many hours a week do you require informal or formal support?
Appendix B

Informed Consent

IUPUI and CLARIAN INFORMED CONSENT STATEMENT FOR

Promoting Successful Aging among Older Adults with Disabilities

STUDY PURPOSE:

You are invited to participate in a research study of older adults aging well. The purpose of this study is to find out from older adults what it means to age well.

NUMBER OF PEOPLE TAKING PART IN THE STUDY:

If you agree to participate, you will be one of approximately ten subjects who will be participating in this research.

PROCEDURE FOR THE STUDY:

If you agree to be in the study, you will do the following things:

You will be invited to participate in three interviews. The first interview will be a brief meeting (less than one hour) to discuss the study and your rights as a research participant. During the second interview you will be asked a series of questions about aging. This interview will last approximately one to two hours. This interview will be audio taped and will take place as a location that is convenient for you, such as in your home or in a private room of a public location, such as the library. After the interview has been transcribed, you will be contacted a third time to review the comments you made during the second interview. During this time you will have an opportunity to add additional comments or correct any errors in the transcript.
RISKS OF TAKING PART IN THE STUDY:
While on the study, the risks are that you might feel uncomfortable discussing certain aspects of aging and the risk of loss of confidentiality. While completing the interview, you can tell the researcher that you feel uncomfortable or do not care to answer a particular question.

BENEFITS OF TAKING PART IN THE STUDY:
The benefits to participation are that you might learn some new things about yourself, and you might enjoy sharing your ideas and feelings about aging well. In addition, your participation in this study might help me and others better understand how to help older adults age well. You will not receive payment for taking part in this study.

ALTERNATIVES TO TAKING PART IN THE STUDY:
Instead of being in the study, you have the option of not participating in the study.

CONFIDENTIALITY:
Efforts will be made to keep your personal information confidential. We cannot guarantee absolute confidentiality. Your personal information may be disclosed if required by law. Your identity will be held in confidence in reports in which the study may be published.
Organizations that may inspect and/or copy your research records for quality assurance and data analysis include groups such as the investigator and his/her research associates, the study sponsor and the IUPUI/Clarian Institutional Review Board or its designees.
CONTACTS FOR QUESTIONS OR PROBLEMS:

For questions about the study contact the researcher Victoria Hanson at XXX-XXX-XXXX or Margaret Adamek at XXX-XXX-XXXX.

For questions about your rights as a research participant, contact the Indiana University Office of Research Compliance Administration at 317-274-8289.

VOLUNTARY NATURE OF THE STUDY:

Taking part in this study is voluntary. You may choose not to take part or may leave the study at any time. Leaving the study will not result in any penalty or loss of benefits to which you are entitled.

SUBJECT'S CONSENT:

In consideration of all of the above, I give my consent to participate in this research study.

I acknowledge receipt of a copy of this informed consent statement.

SUBJECTS SIGNATURE:________________________DATE:_______

SIGNATURE OF PERSON OBTAINING CONSENT:_________DATE:____
References


Disability Policy Studies, 12, (4), 229-235.

NIDRR’s Disability Statistics Center Website


Troutman-Jordan, M. & Staples, J. (2014). Successful aging from the viewpoint of


EMPLOYMENT EXPERIENCE

Mayo Clinic Health System, Southwest Minnesota Region

Chief Operating Officer (August 2014 to present)

✦ Oversee operations of six hospitals and 26 ambulatory care centers.

Mayo Clinic Health System, Southwest Minnesota Region

Vice President of Practice Administration (January 2013 to August 2014)

✦ Oversaw practice operations of six hospitals and 26 ambulatory care centers.

Mayo Clinic Health System, Southwest Minnesota Region

Director of Clinical Institutes (October 2010 to January 2013)

✦ Operations administration of all Perioperative and Surgical, Women’s and Children’s Services.

Immanuel St. Joseph’s – Mayo Health System, Mankato, MN

Director of Hospice, Palliative Care, Family Focus, Social Services and Caregiver Education (April 2010 to November 2010)

✦ Oversaw operations administration of the departments across the southwest Minnesota region.

Immanuel St. Joseph’s – Mayo Health System, Mankato, MN

Director of Behavioral Health Services (March 2008 to April 2010)
Operations administration of Outpatient Behavioral Health Services located in Primary Care and Specialty Clinics; an Inpatient Behavioral Health unit; three outpatient Chemical Dependency Treatment Clinics (Family Focus) as well as the Social Services Department.

- Develop, maintain and evaluate patient care processes that promote desired outcomes.
- Evaluate the quality and effectiveness of patient care practice and patient care services administration.
- Partners with Physician leader to ensure operational success of Inpatient Behavioral Health.
- In partnership with Physician leader, develop Inpatient Behavioral Health strategic and tactical plan, including operational and capital planning request.
- Provide administrative leadership in the development of an integrated behavioral health practice.
- Ensures the competency of all employees in area of accountability.
- Acquire and allocate human, material and financial resources for the effective provision of patient care.
- Develop, maintain and evaluate organizational systems to facilitate the delivery of patient care.
- Provide leadership for assigned divisional, department and institutional initiatives to enhance patient care outcomes.
- Develop, maintain and evaluate an environment that develops and supports professional practice.
- Facilitate and support research and integrate it into the delivery of patient care and/or the advancement of professional practice and other disciplines.
- Provide leadership to the design and operation of the systems to ensure continuous compliance of regulatory standards, quality improvements and innovation in patient care.

Immanuel St. Joseph's – Mayo Health System, Mankato, MN

Social Work Services Director (July 2005 to October 2010)

- Develop, maintain and evaluate patient care processes that promote desired outcomes.
- Evaluate the quality and effectiveness of patient care practice and patient care services administration.
- Acquire and allocate human, material and financial resources for the effective provision of patient care.
- Develop, maintain and evaluate organizational systems to facilitate the delivery of patient care.
- Provide leadership for assigned divisional, department and institutional initiatives to enhance patient care outcomes.
- Develop, maintain and evaluate an environment that develops and supports professional practice.
- Facilitate and support research and integrate it into the delivery of patient care and/or the advancement of professional practice and other disciplines.
- Provide leadership to the design and operation of the systems to ensure continuous compliance of regulatory standards, quality improvements and innovation in patient care.

**Minnesota State University, Mankato, MN**

**Adjunct Instructor** (October 2004 to present)


**Indiana University School of Social Work, Indianapolis, IN**

**Adjunct Instructor** (May 2003 to June 2004)

- Faculty Field Liaison for MSW students participating in practicum placement, fall semester 2003 and spring semester 2004.
Community Hospitals and The Indiana Heart Hospital, Indianapolis, IN

Clinical Social Worker (October 2001 to June 2004)

- Performed comprehensive assessment of patient/family goals as well as assessment of biophysical, psychosocial, environmental, financial and discharge planning needs.
- Implemented discharge plans for patients, including referrals to home health agencies, placements in extended care facilities as well as provided safe and appropriate transition to the next level of care.
- Procured services and served as an advocate on behalf of patients and families.

Domestic Relations Counseling Bureau, Indianapolis, IN

Clinical Social Worker (February 2000 to January 2003)

- Conducted custody and parenting time evaluations in cases of divorce and never-married parents; made recommendations for treatment and services; conducted custody and parenting time mediation to assist clients in resolving disputes.
- Researched and prepared recommendations, referrals, and evaluations for assigned cases including recommending treatments, services, and actions pertaining to family members and effected parties; submitted reports to the court; testified in court as an expert witness.
- Elicited pertinent information from other professionals involved in serving the family; acted as an agency representative, informed others of agency services; discussed alternatives and recommendations for the family.
- Developed training curriculum and education materials for clients and staff.
- Facilitated training to community agencies.

Midtown Community Mental Health Center, Indianapolis, IN

Psychiatric Social Worker (August 1999 to February 2000)

- Provided psychotherapy services to individuals with mental illness.
- Provided consultation and education services to agencies and the community.
HealthEast Hospitals and Hospice, St. Paul, MN

Medical Social Worker (March 1998 to July 1999)

- Performed comprehensive assessment of patient/family goals as well as assessment of biophysical, financial, psychosocial, environmental, and discharge planning needs.
- Implemented discharge plans for patients, including referrals to home health agencies, placements in extended care facilities as well as provided safe and appropriate transition to the next level of care.
- Procured services and served as an advocate on behalf of patients and families.

Minnesota Citizens Council on Crime and Justice, Minneapolis, MN

Crime Victim Liaison/Specialist (June 1996 to December 1997)

- Assisted crime victims and advocated on their behalf during their involvement with the criminal justice system.
- Recommended course of action to prosecutors consistent with both the Victim's Rights Statute and the desires of the victim.
- Provided emergency assistance and crisis intervention to crime victims in conjunction with law enforcement.

Women of Nations Eagle’s Nest Shelter, St. Paul, MN

Advocate (June 1996 to September 1997)

- Provided support, individual and group counseling, advocacy, crisis intervention and access to resources for battered women and their children.
- Worked a variety of shifts in all areas of the shelter including administration, facilities and the women and youth programs.
EducatIon

Indiana University, Indianapolis, IN
PhD in Social Work received October 2015

♦ External Minor is Gerontology.

Augsburg College, Minneapolis, MN
Master of Social Work received June 1999

♦ Completed Master’s coursework with emphasis on family practice.
♦ Completed Master’s thesis on family violence.

University of South Dakota, Vermillion, SD
Bachelor of Science received May 1996

♦ Completed dual major in Criminal Justice and Sociology.

Northern Arizona University, Flagstaff, AZ
National Student Exchange Participant, 1995-1996

♦ Completed senior year of undergraduate study as a National Student Exchange participant.

LicEnsUre/CeRtificAtions

♦ Minnesota Licensed Independent Clinical Social Worker
♦ Indiana Licensed Clinical Social Worker
♦ Certified Hospice Administrator
♦ Certified Basic Life Support Instructor
♦ Certified Crucial Conversations Trainer
♦ Certified Critical Incident Stress Management Facilitator
♦ Certified Psychological First Aid
♦ Indiana Certified Family and Civil Mediator
AWARDS/FELLOWSHIPS

Recipient, Graduate Minor in Aging Fellowship, Indiana University School of Medicine (March 2004)

Recipient, University Travel Fellowship, Indiana University Graduate School (April 2004)

PROFESSIONAL ORGANIZATION MEMBERSHIPS

♦ Member, Minnesota Board of Social Work Advisory Committee
♦ Member, Minnesota State University Master of Social Work Advisory Board
♦ Member, Society for Social Work Leaders in Healthcare
  ▪ President 2008
♦ Member, National Association of Social Workers
♦ Member, Minnesota Social Service Association
♦ Member, Gerontological Society of America
♦ Member, Association for Gerontology in Higher Education
♦ Member, AGE Social Work

RESEARCH EXPERIENCE

♦ Research Intern, Connecting Adolescent and Parents: Parents Talking to Their Teen with Cancer, Indiana University (July 2003 to June 2004)
♦ Research Assistant, Evaluating the Division of Family and Children’s Customer Services, Indiana University (January 2003 to June 2003)
♦ Research Assistant, Office of Research Services, Indiana University School of Social Work (December 2002 to June 2003)

RESEARCH PRESENTATIONS

♦ Effectiveness of a Support Group for Hospice Caregivers,” presented to Quantitative Methods class (2003)
The Male and Female Response to Miscarriage: Does Counseling Help?” presented to Interactive Seminar Scholarship Skills class (2002)

PROFESSIONAL WORKSHOPS PRESENTED

- Professional Boundaries when delivering Homecare and Hospice Services” Will Present to Area Homecare and Hospice Providers (February 15, 2007)
- “Ethics of Aging” Presented at Elements of Ethics Conference (January 2006)
- “Successful Aging” Presented to Senior Network Providers (September 2005)
- “Promoting Successful Aging Among Older Adults,” 57th Annual Scientific Meeting of the Gerontological Society of America, Washington, DC (November 2004)
- “Promoting Successful Aging Among Older Adults,” Indiana University Spring Symposium, Indianapolis, IN (April 2004)
- “Sex, Dating and Intimacy in Late Life: Implications for Education and Practice,” one and one-half hour workshop presentation at CSWE/NGSSW, Anaheim, CA (February 2004)
- “Effectiveness of a Support Group for Hospice Caregivers,” Indiana University Spring Symposium, Indianapolis, IN (April 2003)
- “Mediating Parenting Time and Child Custody,” Marion County Prosecutor’s Office Annual Conference, Indianapolis, IN (February 2001)
- “Mediating Parenting Time and Child Custody,” Fathers and Families Annual Conference, Indianapolis, IN (December 2000)

PUBLICATION


SPECIAL TRAINING

- Building a Foundation of Management Skills, Mayo Clinic (Fall 2005)
- Preparing Future Faculty, Office for Professional Development, Indiana University, Indianapolis, IN (2002 – 2004)
- Member and Program Participant, (April 2003 to June 2004)
- Hennepin County Child Protection, Minneapolis, MN
- M.S.W. Intern (August 1998 to April 1999)
HealthEast Hospice, St. Paul, MN
M.S.W. Intern (December 1997 to March 1998)

Children’s Inn Women and Children’s Shelter, Sioux Falls, SD
B.S. Intern (May 1995 to August 1995)

COMMUNITY SERVICE

- **Board Member, March 2008 to October 2013**
  CADA, Mankato MN

- **Harry Meyering Center, Mankato, MN**
  Board Member, (July 2007 to October 2011)

- **VINE, Mankato, MN**
  Advisory Board Member, (July 2007 to July 2008)

- **Mankato Area Domestic Violence Task Force**
  Member, (January 2006 to June 2011)

- **Mankato Area Sexual Assault Response Team**
  Member, (July 2005 to June 2011)

- **Faith In Action, Sleepy Eye, MN**
  Volunteer (September 2004 to October 2007)

- **Ph.D. Committee, Indiana University School of Social Work, Indianapolis, IN**
  Student Representative (August 2003 to June 2004)

- **St. Vincent Hospice and Pediatric Hospice, Indianapolis, IN**
  Volunteer (February 2000 to June 2004)

- **Big Sisters of Central Indiana, Indianapolis, IN**
  Volunteer (March 2000 to June 2004)

- **Sexual Offense Services, St. Paul, MN**
  Volunteer Advocate (September 1996 to July 1999)