Volunteerism among Older Adults with Mobility-Limiting Disabilities:

An Exploratory Study

By

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Submitted to the graduate degree program in The School of Social Welfare and the Graduate

Faculty of the University of Kansas in partial fulfillment of the requirements for the degree

of Doctor of Philosophy.

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Volunteerism among Older Adults with Mobility-Limiting Disabilities

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Date Approved: 30 April 2018

Abstract

While an extensive research literature has examined participation of older adults in formal volunteer activities in the United States, there is a dearth of knowledge on the experiences of older adults with disabilities. People with disabilities of all ages are less likely to be involved in volunteer activities, compared to those without disabilities (Burr, Mutchler, & Caro, 2007; Butrica et al., 2009; Shandra, 2017). Yet, the extensive physical and emotional health benefits that have been found to be associated with volunteerism for older adults (see Anderson et al., 2014) suggest that the lack of inclusion of older adults with disabilities is a social justice issue worthy of social work's attention. To address knowledge gaps around the participation of older adults with disabilities, this research explores the experiences of older adults with mobility-limiting disabilities who are engaged in volunteer activities. Using naturalistic inquiry (Lincoln & Guba, 1985), in-depth interviews were conducted with 20 older adults (aged 55-80) who self-identified as having serious difficulty walking or climbing stairs and had volunteered with one or more organizations. The constant comparative method of analysis was used to identify themes from the data (Corbin & Strauss, 1990). Findings convey participants' discussions of the challenges but also the benefits that volunteer participation can bring. Seven themes were identified from participants' discussions: Disability Across the Life Course, Meaningful Engagement, Environmental Barriers and Facilitators, Individual Facilitators and Barriers, Organizational Facilitation, Costs of Participation, and Benefits of Meaningful Participation. An additional overarching theme, Importance of Meaningful Participation, illustrates how all of the themes are connected. This knowledge can help to better identify opportunities to increase the participation for older adults with disabilities who are interested in volunteering. Implications of

these findings for social work education, policy, and research are discussed, as well as

limitations of the study.

Acknowledgements

I would like to thank the many people who helped to make this dissertation possible. I am very fortunate to have so many supportive colleagues, friends, and family in my life.

First, to the participants who took part in this study, thank you for sharing your time and ideas. Your enthusiasm and willingness to share personal stories with me were critical to the success of this study and I offer you heartfelt thanks and gratitude.

I would like to thank the members of my dissertation committee, Dr. Rosemary K Chapin, Dr. Terry Koenig, Dr. Chris Petr, Dr. Karrie Shogren, and Dr. Michelle Putnam. I appreciate the guidance and wisdom that you have shared with me. I would particularly like to thank my committee Chair, Dr. Rosemary K. Chapin, for her ongoing support and mentorship throughout my doctoral education. I will forever be grateful to you for helping me to grow both personally and professionally. I also thank my methodologist, Dr. Terry Koenig, for her mentorship and support throughout this process. You have been an amazing methodologist and helped me to understand both the benefits and pragmatics of conducting qualitative research. I also acknowledge several other faculty members who have helped in my personal and professional growth, including: Dr. Deb Adams, Dr. Becci Akin, Dr. Jody Brook, Dr. Nancy Kepple, and Dr. Megan Paceley. I would also like to thank my friends and colleagues, Dr. Skye Leedahl and Dr. Mary Kate Dennis, for their support and mentorship.

I am also grateful to my friends and colleagues at the Research and Training Center on Independent Living, Dr. Dot Nary, Martha Hodgesmith, and Val Renault. Dot thank you being an incredible mentor and helping me as I navigated new waters. Martha and Val, thank you for listening to my ideas and for your ongoing support to me personally and professionally.

Many of my Peace Corps and KU colleagues have also been critical to my success in the program. I am deeply appreciative of the support and encouragement I have received over the years from: Keith and Sandra Adams, Curt Arnow, Jeri Damman, Catelyn Holmes, Hyan Kang, Sarah Landry, Heather Lassman, Dr. Eunji Nam, Dr. Elizabeth O'Neill, Ashley Palmer, Salena Reynolds, Lora Swartzendruber, Sherry Warren, and Dr. Carrie Wendel-Hummel.

Finally, I would like to thank my family for their unwavering support through these many years. I would especially like to thank my father and mother, Gordon and Dulcy Sellon, for encouraging me to get my PhD and for supporting me along every step of this journey. Rachel and Jeremy O'Brien, thank you for all of the love and support you have given. I could not have made it through this process without all of you.

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Chapter I: Introduction and Overview

Researchers have investigated retirement activities of older adults for many years, with considerable attention being given recently to the baby boomers, due to the size and diversity of this cohort. As the baby boomers age, the number of older adults in the United States will increase dramatically in the next few decades (Ortman, Velkoff, & Hogan, 2014). Within this population is a growing number of older adults with disabilities (Ward & Schiller, 2013; Lin, Beck, Finch, Hummer, & Master, 2012). How these older adults, particularly those with disabilities, spend their retirement years has implications not only for their personal well-being but also for their communities and society more broadly.

Due to significant physical and mental health benefits associated with participation in volunteer activities, such as decreased depression and mortality, and the potential contributions that can be made to society, researchers have suggested that increasing participation opportunities should be considered a public health priority (Carr, Fried, & Rowe, 2015; Gonzales, Matz-Costa, & Morrow-Howell, 2015). However, researchers who have examined the participation of older adults in volunteer activities have largely overlooked older adults with disabilities. While older adults with disabilities have many things in common with their non-disabled peers, they have also had unique experiences, shaped by their disability, such as experiencing barriers in their physical and social environments. As a result, it is unclear if knowledge about volunteer activities among non-disabled older adults applies to those with disabilities, particularly those who have aged with a disability. Consequently, the effect of participation in volunteer activities for people in this group needs focused attention (McBride, 2006; Martinez, Crooks, Kim, & Tanner, 2011).

Research indicates that adults with disabilities tend to have lower self-reported health and lower levels of physical activity and are more likely to experience depression and social isolation than their non-disabled peers (Brucker & Houtenville, 2015; LaPlante, 2014). Such findings suggest that older adults with disabilities could potentially benefit from participation in volunteer activities. However, people with disabilities have lower rates of participation in volunteer activities (Shandra, 2017) and we know relatively little about the experiences of older adults with disabilities or the benefits and drawbacks of their participation. Moreover, while there is a considerable literature on social and community participation (Benka et al., 2016; Ginis, Evans, Mortenson, & Noreau, 2017; Hammel et al., 2015; Hawkins, McGuire, Linder, & Britt, 2015; Schur, Kruse, & Blanck, 2013; Whiteneck et al., 2004) and physical activity for adults with disabilities (for systematic reviews see Casey et al., 2017; Hall et al., 2017), there is little research focused specifically on the experiences of older adults with disabilities who volunteer. Volunteerism, in this study, refers participation in formal volunteer activities, which are structured by an organization with little to no financial compensation (Cnaan, Handy, & Wadsworth, 1996; Morrow-Howell, 2010). Further, knowledge in this area is needed to design social work and other interventions to increase the recruitment and retention in volunteer activities of older adults with disabilities.

The purpose of this dissertation is to develop a more comprehensive understanding of participation in formal volunteer activities by people with disabilities. As such, an exploratory qualitative study, guided by social constructionism and naturalist inquiry, is conducted to elucidate the experiences of older adults with mobility-limiting disabilities. Because social workers are involved in health and aging as well as mental health practice-based settings in which older adults with disabilities are being served in growing numbers, this study can provide

the field of social work with a deeper understanding of the needs, strengths, and barriers that older adults with disabilities face. This, in turn, can inform social work practice, research, theory and policy efforts to increase opportunities for members of this population to engage in meaningful, volunteer activities. While there is a broad need to understand the participation of people with different types of disabilities in a variety of social and community activities, this study focuses on participation of older adults with mobility-limiting disabilities in formal volunteer activities. Mobility-limiting disabilities refers to individuals who have serious difficulty walking or climbing stairs due to a health condition or impairment.

This dissertation is divided into five chapters. The first chapter provides an overview of aging, volunteerism, the dimensions of disability in the United States, and the relevance of this topic to social work. The second chapter includes a review and synthesis of relevant theoretical and conceptual frameworks and the literature related to volunteerism among older adults and social and community participation among people with disabilities. The third chapter lays out the paradigm for inquiry and qualitative methods used in this study. The fourth chapter contains the findings from the study, and the fifth chapter discusses their relevance as well as future directions.

Overview

This section provides background information to inform a deeper look into formal volunteerism among older adults in general and volunteerism and community and participation among people with disabilities that will be discussed in Chapter Two. This chapter is divided into four sections. The first section provides background information on the aging population in the United States. The second section gives an overview of volunteerism among older adults. The third section provides information about people with disabilities, including older adults with disabilities

in the United States. The final section discusses the important role that social work can play in increasing opportunities to participate in volunteer activities for older adults with disabilities.

Aging in the United States

In the coming decades, the size and make-up of the older adult population will be substantially different from that of previous generations. In 1970, older adults aged 65+ made up only 9.8% of the population. By 2030, individuals aged 65+ will constitute 20% of the U.S. population (Ortman et al., 2014). This population increase is largely driven by the aging of the baby boomers and increased life expectancy rates. Baby boomers, a cohort of nearly 79 million people, started to reach retirement age (65) in 2011 (Pruchno, 2012). By 2030, all surviving members of this cohort will have reached the ranks of old age. In addition, life expectancy in the U.S. at age 65 has increased from 80.2 years in 1972 to 84.1 years in 2010, and life expectancy at 85 also increased by 6.5 years in 2010 (Ortman et al., 2014). Researchers have estimated that, from 2014 to 2060, the size of the population 65+ could grow from 46 million to 98 million individuals.

The baby boomers will be different in many ways from previous generations of older adults. They are more highly, educated and a larger percentage of women have been in the labor force. The older adult population will also be more racially and ethnically diverse than previous generations of older adults. For example, the percentage of African Americans aged 65+ is expected to grow from 8.8% in 2012 to 10.7% in 2030. Similarly, the percentage of individuals aged 65+ identifying as Hispanic is expected to increase from 7.3% to 11% from 2012-2030 (Ortman et al., 2014).

The health, well-being, and social engagement of the older adult population has been of interest to researchers, practitioners, and policy makers for many years, due to both the size of

this population and increases in life expectancy (Anderson et al., 2014; King, Matheson, Chirina, Shankar, & Broman-Fulks, 2013; Lin et al., 2012; Ward & Schiller, 2013). The risk of developing multiple chronic conditions increases with age (Ward & Schiller, 2013). In addition, compared to previous generations, baby boomers are more likely to be obese, tend to be less physically active, and are more likely to experience diabetes and hypertension (King et al., 2013). Due to both increased rates in disability among recent cohorts of older adults (Lin et al., 2012) and increased survival rates and life expectancy of millions of adults aging with an existing disability (Kemp & Mosquenda, 2004), in the coming decades there will be a larger population of older adults with disabilities. Such findings have raised concerns about rising health care costs and potential limits to the quality of life of older adults. Researchers and practitioners have begun to explore opportunities to help older adults live healthy and meaningful lives, with volunteerism being suggested as an important means of social engagement that could positively impact well-being.

Volunteerism among Older Adults

Rates of participation in formal volunteerism among older adults have increased substantially in the last few decades, and older adults are the most likely age group to volunteer 100 or more hours. Baby boomers have historically had high rates of participation and are predicted to continue this trend during retirement (Foster-Bey, Dietz, & Grimm, 2007). Scholars and practitioners alike view participation in volunteer activities as a potential mechanism for increasing the well-being of older adults and communities (e.g. Anderson et al., 2014; Carr, et al., 2015; Gonzales, Matz-Costa, & Morrow-Howell, 2015). Researchers have examined the health benefits for older adults who participate in formal volunteerism. Their findings suggest that such participation is associated with improved physical and mental health, reduced

depression, and lower mortality rates (Anderson, et al., 2014; Fried et al., 2013; Greenfield & Marks, 2004; Harris & Thoresen, 2005; Lum & Lightfoot, 2005; Parisi, et al., 2015; von Bonsdorff & Rantanen, 2011). Moreover, participation in meaningful volunteer activities can provide a sense of purpose and satisfaction as well as opportunities for socialization and help older adults feel more connected with their communities (Greenfield & Marks, 2004; Morrow-Howell, Hong, & Tang, 2009; van Ingen & Wilson, 2017). On a societal level, it has been estimated that participation in volunteer activities by older adults contributes at least $161.7 billion to the economy (Johnson & Schaner, 2005).

Traditionally, volunteerism has been the domain of more highly-educated older adults who are in good health, with few to no functional limitations. Research suggests that older adults, regardless of race, with higher levels of education and income are more likely to volunteer and tend to contribute more hours (Johnson & Lee, 2017; Wilson, 2012). In addition, being in poor physical health, having higher levels of depression, or having a functional limitation reduces the likelihood that an older adult will start or continue volunteering (Choi Choi, Burr, Mutchler, & Caro, 2007; Butrica, Johnson, & Zedlewski, 2009).

As recognition of the health benefits of volunteerism has grown, so have calls for increasing the inclusivity of participation (Gonzales, Matz-Costa, & Morrow-Howell, 2015). While sub-populations of older adults have received attention in recent years, such as people with lower-incomes, African Americans, and Asian Americans (e.g., Tang, Copeland, & Wexler, 2012), there has been less focus on increasing the participation of older adults with disabilities. Indeed, as noted by Gonzales and colleagues (2015), older adults with a disability, both those aging with and those who developed a disability in later life, are often not included in national (i.e. Senior Corps) or local volunteer programs for older adults.

Moreover, it can be difficult to determine rates or benefits of participation for older adults with disabilities, as many studies do not include a disability measure (e.g. Lee & Brudney, 2012; Morrow-Howell et al., 2009; Morrow-Howell, Lee, McCrary, & McBride, 2014). It is also difficult to distinguish between people aging with a disability and people aging into a disability, as studies of volunteering by older adults have generally lacked information about the age of onset of disability. In addition, the aging literature has tended to focus on older adults' limitations in activities of daily living (ADL), such as bathing and eating, and instrumental activities of daily living (IADL), such as shopping and preparing meals, while the disability literature tends to focus on disabilities that involve specific health conditions, such as spinal cord injury. As having any functional limitation decreases the likelihood that an older adult will start volunteering, it is likely that the majority of older adults with disabilities in studies of volunteering are those that develop functional limitations or disabilities in later life (Butrica et al., 2009).

Disability in the United States

Disabilities can be congenital (e.g., spina bifida), acquired through injury (e.g., spinal cord injury), or resulting from a chronic condition. The Americans with Disabilities Act (ADA), amended in 2008, has the broadest definition and defines disability as a physical or mental impairment that limits activity in important life situations. A person is also considered to have a disability if they have a record of an impairment or are regarded by others as having a disability (American with Disabilities Act, 1990; Americans with Disabilities Act Amendments Act, 2008). In general, a disability tends to be associated with an illness or injury and may limit an individual's ability to do some activities but not others (Freedman, Martin, & Schoeni, 2004).

Because national surveys tend to measure disability differently, it is difficult to estimate the prevalence of disability in the U.S.. For example, based on data from the Survey of Income and Program Participation, which asks about ADL and IADL limitations like eating or shopping, the estimated population of individuals with a disability was 18.7% or over 56 million people in 2010 (Brault, 2012). However, data from the American Community Survey (ACS), which asks specific questions about difficulty with ambulation, vision or hearing, cognition, and self-care or independent living, suggest the population with disabilities to be about 12% or over 37 million people in 2011 (Erickson, Lee, & Von Schrader, 2014). Mobility impairments appear to be the most common type of disability in the United States (Erickson et al., 2014; Schur et al., 2013).

Demographic factors, such as age, gender, and race, are also important to consider in understanding the prevalence and impact of disability. For the non-institutionalized population, risk of disability tends to increase with age, and older adults have the highest rates of disability. Across all ages, women are more likely than men to have a disability (Erickson et al., 2014; Schur et al., 2013). However, estimates of disability among the working-age population suggest that men (10.7%) are slightly more likely to have a disability than women (10.2%) (Erickson et al., 2014). The difference in prevalence appears to be due to the combined effect that disability is more common in later life and women tend to outlive men (Erickson et al., 2014; Schur et al., 2013). There are also important racial differences in the prevalence of disabilities. Erickson and colleagues (2014) report that, among the working age population, Native Americans (17.6%) have the highest rate of disabilities, followed by African Americans (14.2%), and then whites (10.2%). Research suggests that Black and Hispanic women have the highest rates of disability (Kelley-Moore & Ferraro, 2004; Schur et al., 2013; Warner & Brown, 2011). In addition,

African American older adults have a higher rate of disability compared to Whites (Fuller-Thomson, Nuru-Jeter, Minkler, & Guralnik, 2009).

Disability Trends among Older Adults

Findings from an analysis of data in the American Community Survey suggest that 25% of older adults age 65-74 had a disability in 2012 and 50% of older adults 75+ had a disability in 2012 (Erickson, Lee, & Von Schrader, 2014). Twenty-seven percent of people with a disability reported the age of onset as occurring from ages 40-55, and a similar percentage of people with a disability indicate that their disability started after the age of 56 (Kessler/NOD/Harris, 2010). For older adults, mobility-limiting disabilities appear to be the most common form of disability (Erickson et al., 2014).

Data on older adults with disabilities include both those who have aged with and those who have aged into disability. "Aging with a disability" refers to individuals who were born with or acquired a disability early in life (Kemp & Mosqueda, 2004; Verbrugge & Yang, 2002). Estimates suggests that there are 12-15 million adults under the age of 40 aging with a disability (LaPlante, 2014). Older adults who have aged with a disability have likely experienced negative social attitudes and a variety of barriers across their life course (discussed in more detail below). "Aging into disability" refers to individuals who do not develop a disability until mid or later life (Kemp & Mosqueda, 2004; Verbrugge & Yang, 2002). Disability in later life may be from an accident or injury, such as a stroke, or as the result of declines in functioning due to accumulation of chronic health conditions (Molton & Jensen, 2010). Individuals in this group tend to have a decline in functioning over time and largely account for the rise in disability rates in older age (Dixon-Ibarra, Krahn, Fredine, Cahill, & Jenkins, 2016). People aging with disabilities and into disabilities may have similar levels of functioning, but they likely have had

different experiences in living with their disability and in relationships with their environment. Such differences include the length of time with the disability, disruptions to education and employment, and experiences with stigma and social exclusion. In addition, older adults who have aged into disabilities may not connect with or consider themselves to be part of the disability community (Darling & Heckert, 2010).

Health and Wellness of People with Disabilities

In this discussion, health and wellness refers to the physical and mental health of people with disabilities. In general, people with disabilities tend to have lower self-rated health, be sedentary and obese, and are more likely to have trouble affording needed health care services, often skipping or delaying receiving medical care (Brucker & Houtenville, 2015; Froehlich-Grobe, Jones, Businelle, Kendzor, & Balasubramanian, 2016; Krahn, Walker, & Correa-De-Araujo, 2015; LaPlante, 2014). In addition, people with disabilities often face barriers to physical in accessing health care services. Beyond difficulties accessing healthcare buildings in the community, barriers can include weight scales that cannot accommodate wheelchairs or exam tables that cannot be height adjusted, health and wellness programs that are not designed for people with disabilities, and a lack of knowledge or negative attitudes towards people with disabilities on the part of health care professionals (Peacock, Iezzoni, & Harkin, 2015; Rasinaho, Hirvensalo, Leinonen, Lintunen, & Rantanen, 2007).

In addition to primary conditions, individuals with disabilities often develop secondary conditions that can increase the risk for other health conditions and accelerate the aging of organ systems (Hitzig, Eng, Miller, & Sakakibara, 2011). In general, the most common secondary health conditions for individuals with a disability appear to be pain, fatigue, and depression (Field & Jette, 2007; Kinne, Patrick, & Doyle, 2004; Jensen et al., 2013). Reports of depression

are common among people with a disability (Krahn et al., 2015). For example, people with mobility impairments are nearly ten times more likely to be depressed or anxious compared to their non-disabled peers (Iezzoni, McCarthy, Davis, & Siebens, 2001), and estimates of the prevalence of depression among people with disabilities suggest that about one in three experience moderate or severe depression (Kemp & Mosqueda, 2004). Depression is often associated with pain and fatigue, and this can limit the social and community participation of a person with a disability (Alschuler et al., 2013).

Physical activity can also play a major role in the health and well-being of people with disabilities, as it has been associated with reduced risk of chronic conditions and functional limitations and improvements in quality of life (Motl & McAuley, 2010). However, people with disabilities are less likely to engage in physical activity compared to the general public (Motl & McAuley, 2010; Rimmer, Riley, Wang, Rauworth, & Jurkowski, 2004). Research suggests that people with disabilities face a number of barriers to participation in physical exercise activities, including inaccessible physical environments, limitations due to health and secondary conditions, such as pain and fatigue, and fear of embarrassment or negative societal attitudes (Phillips, Flemming, & Tsintzas, 2009; Rimmer et al., 2004).

Health and Wellness of Older Adults with Disabilities

Research suggests that older adults with disabilities are more likely to report lower levels of both physical and mental health and lower physical activity, as compared to their non-disabled peers (Choi, 2017; Furner, Hootman, Helmick, Bolen, & Zack, 2011; Motl & McAuley, 2010; Thompson, Zack, Krahn, Andresen, & Braile, 2012). They are also likely to experience pain and fatigue associated with their disability (Herr & Garand, 2001; Molton, Cook, et al., 2014). For example, in a study of older adults with and without functional limits, Thompson and colleagues

found that, while many older adults with functional disabilities reported being in good physical and mental health, older adults aged 65+ with disabilities had an average of eight more physically unhealthy days in a month as compared to their same-age, non-disabled peers. In addition, women aging with physical disabilities are at increased risk of cardiovascular diseases, such as hypertension, myocardial infarction, and coronary heart disease, compared to their non-disabled peers (Rosso, Wisdom, Horner-Johnson, McGee, & Michael, 2011). Finally, older adults with disabilities, particularly those aging with disabilities, are nearly twice as likely to be physically inactive as compared to their non-disabled peers (Motl & McAuley, 2010).

There are also some unique physical health concerns for older adults who have aged with as compared to those who have aged into disability. For example, chronic conditions are often the cause of disability for those "aging into" disability (Hung, Ross, Boockvar, & Siu, 2012); whereas, people "aging with" disabilities tend to develop chronic conditions on top of their primary impairment (Dixon-Ibarra et al., 2016). Indeed, in a study comparing older adults aging with and into disability, Dixon-Ibarra and colleagues found that people who became paralyzed later in life reported having more chronic diseases as compared to people aging with disabilities. Interestingly, people aging with a disability that causes paralysis may have fewer days of poor mental health compared to individuals aging into disabilities that cause paralysis (Dixon-Ibarra et al., 2016). This difference may be related to the ability of people aging with a disability to develop a sense of resiliency over time, as they have more time to live with and adjust to having an impairment (Bishop & Hobson, 2015; Kemp & Mosquenda, 2004; Yorkston, McMullan, Molton, & Jensen, 2010).

Community and Social Participation of People with Disabilities

While participation in volunteer activities could be beneficial to the health and well-being of older adults with disabilities, across all ages, people with disabilities face a variety of barriers to accessing community resources and social spheres, which include "factors in a person's environment that, through their absences or presence, limit functioning and create disability" (World Health Organization, 2001, p. 214). These barriers may be due to physical impediments, negative social attitudes, limited access to technology, or limited access to private or public transportation. These barriers have led to the social exclusion of people with disabilities and help to explain their high rates of social isolation.

Social Exclusion of People with Disabilities

Social exclusion is a complicated issue, and many frameworks have been proposed to study and address this issue, such as those related to poverty and marginalization (Peace, 2001; Rimmerman, 2013). According to Peace (2001), the term has been used in research, policies, and programs in the European Union and Greater Britain as both a narrow construction in reference to poverty and social cohesions and as a broad construct that refers to a lack of resources and denial of rights. For this study, social exclusion is seen as a multidimensional phenomenon and refers to the educational, economic, political, and social marginalization of individuals (Rimmerman, 2013).

Social exclusion can occur and be maintained at multiple levels. First, at the national level, a lack of enforcement of the ADA or curtailing of policies designed to increase accessibility can make it difficult for people with disabilities to pursue legal routes to reducing exclusion. Second, at the community level, people with disabilities may experience inaccessible

physical and social environments, both of which can lead to the marginalization of people with disabilities (Rimmerman, 2013; Schur et al., 2013).

Importantly, experiences of inaccessible physical environments and negative social attitudes may be different for people aging with as compared to those aging into disabilities. The former may have experienced discrimination and barriers to accessing education, employment, and activities in the community throughout their lives. In contrast, those aging into will likely have experienced negative social attitudes and barriers in the physical environment for a shorter period of time. Both groups may also experience ageism or discrimination based on their chronological age (Molton & Jensen, 2010; Putnam & Wladkowski, 2016).

Importantly, the exclusion of people with disabilities cannot be separated from the social and physical context in which the discrimination occurs. As such, it is important to consider historical, social, and spatial elements which can maintain or increase the social exclusion of people with disabilities. The following elements of social exclusion will be discussed for people with disabilities including stigma, exclusion from community living, barriers to education an employment, barriers to resources in the community, and social isolation.

Stigma. One of the overarching issues that contributes to the social exclusion of people with disabilities is the existence of longstanding, negative views towards disabilities held by the majority of society. Historically, disabilities have been a source of stigma in the United States. Werner and Shulman (2015) define stigma as "a set of prejudicial attitudes, stereotypes, discriminatory behaviors and biased social structures endorsed by a sizeable group about a discredited subgroup" (p. 272). Hence, stigma is created and reinforced through social interactions (Goffman, 1963; Werner & Shulman, 2015).

Stigma towards people with disabilities can range from avoidance of people with disabilities to outright discrimination, such as denying people with disabilities access to areas or services and supports, and has negative consequences for the health and well-being of people with disabilities (Schur et al., 2013). Stigma towards people with disabilities has also resulted in the development of several negative stereotypes, such as people with disabilities being seen as pathetic and weak, as a "Supercrip," or as better off dead (Schur et al., 2013; Switzer, 2003). Supercrip refers to using images or stories of a person with a disability overcoming some obstacle as a way to inspire people without disabilities. This imagery has two negative consequences. First, these images often encourage the public to view people with disabilities with pity. Second, many people with disabilities, leading ordinary lives, have been made to feel inferior because they are not inspiring others (Switzer, 2003). Stigma towards people with disabilities has played an important role in the exclusion of members of this group from many spheres of social and community life, such as community living, access to health care, education and employment, and social and community participation (Fleischer, Zames & Zames, 2012; Schur et al., 2013).

Societal fears of and negative attitudes towards those with a disability have also informed medical care for people with disabilities. Until relatively recently, the medical model of disability has guided medical, social, and political views of disability. This model focuses on the impairment and sees disability as making up the entirety of the person, as an individual responsibility, and as something to be cured or worked around (Schur et al., 2013). The model tends to view people with disabilities as one-dimensional and ignores historical and social factors that influence their lives. While newer models that focus more on the role of social and political systems in creating disability have been developed, scholars have noted that the medical model

approach still informs the practice of many health care professionals (e.g. Galambos, 2004; Haegele & Hodge, 2016). Models of disability will be discussed further in Chapter Two.

Exclusion from community living. As views of disability shifted from being considered as a family issue to a broader societal problem, mental asylums and institutions were developed to house people with disabilities. Proliferating in the early 1900s, and marked by the rise of the Eugenics movement, people with disabilities were institutionalized at unprecedented levels and often sterilized (Fleischer et al., 2012; Schur et al., 2013). Advocacy for moving from institutionalization to community living gained little traction until the 1960s and 70s with the advent of the disability rights movement (Schur et al., 2013).

The disability rights movement sought to counter both social views that saw people with disabilities as a group to be feared or pitied and authoritarian policies that limited the freedom and ability of people with disabilities to live and participate in their communities (Switzer, 2003). Key to the growth of the disability rights movement was the independent living (IL) movement. The IL movement began in the late 1960s when students with disabilities formed the "Rolling Quads" to fight segregation and stigma at the University of California at Berkley. In 1970, the Rolling Quads were given a grant from the Rehabilitation Administration to form the first Center for Independent Living (CIL) (Switzer, 2003). Today, CILs exist all over the United States, are run by people with disabilities, and provide support and information for people with disabilities (Independent Living Research Utilization, 2017). While there has been a significant shift towards supporting people with disabilities to live independently in their communities across the life course, members of this group often have difficulty accessing resources needed to live healthy and independent lives.

Barriers to education and employment. Individuals aging with disabilities often experience unequal access to education and employment opportunities, key resources for financial security and volunteerism in later life. Educational achievement levels of people with disabilities generally lag behind those of their non-disabled peers. Individuals with work-limiting disabilities often have lower levels of education as compared to their non-disabled peers (Clarke & Latham, 2014), and those with a disability have lower rates of high school completion than people without disabilities (Kessler/NOD/Harris, 2010). Similarly, individuals with a disability are less likely (12.4%) than their non-disabled peers (31.7%) to have completed a bachelor's degree or higher (Erickson et al., 2014). However, the number of individuals with disabilities completing some college or attaining a bachelor's degree has increased in the last few years (Erickson et al., 2012; Erickson et al., 2014).

Individuals with disabilities also have different labor force attachment profiles than their non-disabled peers and less accumulated wealth. The employment rate for individuals with disabilities is much lower (33.5%) compared to those without disabilities (79.3%), and employed people with disabilities have higher rates of part-time work (Erickson et al., 2014). Furthermore, people aging with a disability or who experience onset in midlife are likely to retire earlier than those without disabilities (Honarmand, Akbar, Kou, & Feinstein, 2011; Mitchell, Adkins, & Kemp, 2006). In a study comparing employment rates between people with and without disabilities, Mitchell and colleagues (2006) found that, while employment rates for people with disabilities are lower at all age points compared to people without disabilities, there is a sharp decline in employment for those with a disability starting around the 40's age decade.

In addition, many individuals with disabilities must rely on means-tested programs. Nearly 47% of people with disabilities who are not working rely on Social Security Disability

Insurance (SSDI) or Supplemental Security Income (SSI), and the percentage of people with disabilities receiving SSI payments increased from 2010 (18.9% or 3.4 million people) to 2012 (19.9% or 3.7 million people) (Erickson et al., 2012; Erickson et al., 2014; Kessler/NOD/Harris, 2010). These programs limit the income and assets of beneficiaries and can prevent individuals from accumulating wealth needed for later life expenses (Putnam, 2015).

Due to work disruptions and means-tested programs that limit the ability of a person with disabilities to accumulate savings, many people aging with a disability have limited financial resources for retirement (Putnam, 2015). In a study of 4,425 individuals with and without work-limiting disabilities from the U.S. Panel Study of Income Dynamics, Clarke and Latham (2014) described the life-course profile from 1979 to 2009 of adults with work-limiting disabilities. Their results suggest that, for individuals with a work-limiting disability before age 50, employment rates and household income are lower compared to non-disabled peers. Similarly, adults age 45-64 with disabilities are much more likely than their same-age peers to have a household income under $15,000 (LaPlante, 2014).

Barriers to resources in the community. The lack of access to physical spaces in the community can also contribute to the social exclusion of people with disabilities of all ages. While access to the built environment is protected by the ADA, there are exemptions for older buildings, many buildings are built without input from people with disabilities, and much of the responsibility for reporting ADA violations falls on people with disabilities (Gray, Gould, & Bickenbach, 2003; Schur et al., 2013). Researchers suggest that, depending on the type of disability and assistive devices used, people with disabilities can face a number of barriers to participating in their community and even accessing basic services such as banks and grocery stores, due to aspects of the built environment. These include uneven sidewalks or a lack of curb

ramps, or the architectural design of buildings, such as a lack of ramps, narrow doorways, or heavy doors (Eisenberg, Vanderbom, & Vasudevan, 2017; Hammel et al., 2015; Rosenberg, Huang, Simonovich, & Belza, 2012). In addition, features of the built environment can interact with other factors, such as the natural environment, to create disabling environments (Hammel et al., 2015; Rosenberg et al., 2012). For example, metal ramps can help to make buildings or cars accessible, but rain or snow can cause these structures to become slippery and unsafe for wheelchair users.

Access to private or public transportation is an important facilitator for community participation. Private vehicles that can accommodate needs can greatly facilitate participation, but this is often cost prohibitive for many people with disabilities (Hammel et al., 2015). There are also barriers to using public transportation, such as bus or subway stops that are not accessible and routes to needed destinations that require a person to physically travel more distance than they can manage or require advanced scheduling, which can be problematic for individuals with health conditions that flux (Hammel et al., 2015). In addition, people with disabilities who live in rural areas may not have access to public transportation.

Social isolation of people with disabilities. The social exclusion of people with disabilities across many spheres puts them at high risk of becoming socially isolated. Social isolation occurs when a person has little engagement with others, and it is often marked by the lack of meaningful relationships (Nicholson, 2016). Depression is a key risk factor for social isolation (Nicholson, 2016). Social isolation can also have serious physical health consequences and has been associated with a number of health risks, such as an increased risk of coronary disease (Barth, Schneider & von Känel, 2010) and mortality (Holt-Lunstad, Smith, Baker, Harris, & Stephenson, 2015).

Generally speaking, people with disabilities tend to have less social support and higher rates of social isolation than their non-disabled peers (Putnam, 2015; Schur et al., 2013). Social support can include emotional, social, and physical resources provided by family and friends (Berkman & Glass, 2000). Factors that can lead to social isolation of people with disabilities include low marriage rates, smaller social networks, and limited interactions with the community (Kessler/NOD/Harris, 2010; Schur et al., 2013). For example, due to lower marriage rates and smaller social networks, people with disabilities are less likely to have social supports (Schur et al., 2013). In addition, people with disabilities tend to have fewer social contacts and are less likely to be engaged with their community (Kessler/NOD/Harris, 2010; Schur et al., 2013).

Older adults with disabilities are at an increased risk for experiencing social isolation (Havens, Hall, Sylvestre, & Jivan, 2004; Nicholson, 2016). For example, Havens and colleagues found that having four or more chronic illnesses increases the risk of social isolation for older adults. More recently, in a study of 676 older adults, Rosso and colleagues (2013) found that individuals with mobility limitations are less likely to be socially engaged inside and outside of their homes.

Research suggests that social engagement can help to slow declines in physical functioning for older adults with and without disabilities (Lee & Kim, 2013; Mendes de Leon, Glass, & Berkman, 2003). For example, older adults who were more socially engaged reported experiencing fewer functional limitations, as compared to those who were less engaged (Mendes de Leon et al., 2003). In addition, Lee and Kim found that older adults who had more visits from friends reported better health and fewer functional declines. However, older adults with disabilities are less likely to be engaged in their communities as compared to both younger individuals with disabilities and older adults without disabilities (Schur et al., 2013). Hence,

there is a need to increase the social inclusion of people with disabilities in general, but particularly for older adults with disabilities.

Social Inclusion of People with Disabilities

While there are a variety of conceptualizations as to what constitutes social inclusion for people with disabilities (for an overview see Rimmerman, 2013), for this study, social inclusion refers to the "full and fair access to activities, social roles, and relationships directly alongside non-disabled citizens" (Bates & Davis, 2004, p. 194). Research highlights several factors that are important markers of social inclusion for people with disabilities, such as being involved in a variety of leisure and recreational activities in the community (e.g. church, sports, etc.), being accepted for who they are and what they can do, being able to choose how and when they participate in activities, and having the opportunity to develop social relationships with other members of the community (Hall, 2009; Milner & Kelly, 2009).

The ADA has significantly helped to change how society views people with disabilities and has greatly increased their inclusion in education, employment, and social spheres (Rimmerman, 2013). The disability rights movement and accompanying legislation have made major strides in making communities, education, and employment more accessible for people with disabilities. The Rehabilitation Act of 1973 was the first civil rights legislation for people with disabilities. As the precursor to the ADA, the act prohibits discrimination on the basis of disability in federal agencies or programs that receive federal funding. Section 504 of the Act, in particular, requires that organizations that receive federal funding make reasonable accommodations for people with disabilities and make programs accessible. The Rehabilitation Act of 1973 was amended in 1992 and 1998 to bring it more in line with the goals set out in the ADA (Switzer, 2003).

Expanding on the protections provided in the Rehabilitation Act of 1973, particularly

Sections 504, the ADA was designed to provide equal opportunities for full participation in the

community, independent living, and economic well-being. In particular, Title I protects people

with disabilities in the work place, requiring employers to make reasonable accommodations to

support people with disabilities, and Title III prevents discrimination in public and some private

businesses (Americans with Disabilities Act, 1990). The ADA was amended in 2008 to better

address disability discrimination in employment settings. With the amendment, Congress

charged courts to focus on whether employers had made reasonable accommodations rather than

on whether the employee had a legally-recognized disability (Americans with Disabilities Act

Amendments Act, 2008; Schur et al., 2013). Finally, the Supreme Court has also weighed in on

the rights of people with disabilities. In Olmstead v. L.C. (1999), it recognized the right of

people with disabilities to live in the community by requiring that states eliminate unnecessary

institutionalization (Schur et al., 2013). However, despite this ruling and the legal protections

provided by the ADA, people with disabilities continue to experience discrimination and barriers

to community life (McCarthy, 2003; Schur et al., 2013). Thus, additional approaches are needed

to help people with disabilities access and engage their communities.

While social inclusion encompasses the topics discussed above (e.g. education,

employment, and community living), of particular interest in this study is the inclusion of people

with disabilities in their communities, particularly in volunteer activities. Volunteerism is one

way to increase the social inclusion of people with disabilities, particularly older adults with

disabilities. In particular, volunteerism can provide individuals with disabilities with the

opportunity to not just be in their communities but also to be active members who have the

opportunity to engage with others and contribute to the betterment of society. Interaction with

people with disabilities can also help to improve community members comfort level with and knowledge about people with disabilities (Scior, 2011; Kersh, 2011). However, there is limited information available on the experiences of older adults with disabilities in volunteer activities and the potential for participation to improve the social inclusion of this population.

Study Rationale

Given the health benefits associated with participation in volunteer activities, disparities in volunteerism between those with and without disabilities represents a social justice issue. As social workers are charged with working to reduce discrimination and oppression of marginalized populations (NASW, 2017), it is incumbent upon us to work with people with disabilities to reduce barriers to participation in social and community activities. Social workers can play an important role in helping to increase opportunities for older adults with disabilities to engage in volunteer activities. However, there is limited information available to guide practice and policy efforts. In addition, much of our knowledge about people with disabilities has been developed by other fields and in other countries, which may limit the availability and usefulness of this knowledge for social workers (Kattari, Lavery, & Hasche, 2017). This study can play an important role in increasing social work knowledge about the experiences and needs of older adults with mobility-limiting disabilities who are interested in volunteering.

Studies of volunteerism among older adults in the United States have largely only considered disability as a control variable and some studies have not included any disability measure (Lee & Brudney, 2012; Morrow-Howell et al., 2009; Morrow-Howell, Lee et al., 2014). The limited attention given to older adults with disabilities reduces the ability of social workers to respond to the needs of this population as they try to engage in volunteer activities. As social workers increasingly work from the social model of disability and an empowerment approach

(Beaulaurier & Taylor, 2001; Galambos, 2004; Kim & Canda, 2006), this study can help to provide further insights into the challenges that older adults with disabilities face in terms of the social and physical environment. Moreover, this study also highlights the strengths and abilities of older adults with disabilities, which can provide an important reference point to help social workers think about the capabilities of their own clients with disabilities.

The limited information on volunteerism among older adults with disabilities can also hinder the efforts of social workers engaged in policy efforts aimed at increasing inclusivity for people with disabilities and opportunities for older adults to age in place in their communities. Per the Olmstead decision and the ADA, people with disabilities have a right to full participation in their communities. Given the health and social benefit associated with volunteerism, inclusion could be an important way to help older adults with disabilities remain in their communities. However, there is limited research available to help social workers target their advocacy efforts. This study provides important insights into areas that could use particular attention from social workers, such as transportation and design of community programs and infrastructure, in order to help people with disabilities to have the same opportunities to be engaged with and volunteer in their communities.

Hence, to better guide social work practice and advocacy efforts, there is a need for more in-depth research on the experiences of older adults with disabilities. This study is an important first step in helping to understand the myriad of factors that can influence participation of older adults with mobility-limiting disabilities in volunteer activities. This knowledge can help to guide the development of interventions to increase participation and suggest areas for further research. Implications of this study for research, practice and policy are discussed in detail in Chapter 5.

Summary

Despite health benefits of volunteerism for older adults and health disparities faced by people with disabilities across the life course, little attention has been given to the experiences of older adults with disabilities and the potential benefits of their participation in volunteer activities. While there is a considerable amount of information on barriers and facilitators to social and community participation for people with disabilities more generally, there is a dearth of knowledge on the experiences of older adults with disabilities who participate in volunteer activities, particularly those with physical disabilities. By expanding this knowledge base, this study can help social workers better understand how to support this population to the benefit of these individuals, their communities, and society.

Chapter 2: Conceptual Frameworks and Literature Review

This chapter reviews social constructionism, the International Classification of Functioning, Disability, and Health (ICF), the life course perspective and strengths perspective, and the ecological perspective to help develop a conceptual framework to guide the study. Research related to participation in community and volunteer activities by older adults and those with mobility-limiting disabilities is also explored and synthesized to provide background for this study. The chapter is divided into four sections. In the first section, the four conceptual frameworks are reviewed. In the second section, the research literature on volunteerism among older adults and volunteerism and community participation by adults and older adults with disabilities is discussed. In the third section, a brief critique of the literature is provided. Finally, the literature from the second section is synthesized and combined with information from the first section to develop a conceptual model to guide the development of the research questions and methods used in this study.

Conceptual Frameworks

A Social Constructionist Approach

There are a variety of methodological and conceptual approaches available to researchers interested in using a social constructionist approach (see Holstein & Gubrium, 2007). For this study, the discussion is limited to concepts described by Berger and Luckmann (1966) and Crotty (1998). Social constructionism, as described by these authors, serves as the overarching conceptual framework for this study. A social constructionist orientation to research is concerned with exploring how knowledge is created in social contexts, "the view that all knowledge, and therefore all meaningful reality as such, is contingent upon human practices, being constructed in

and out of interactions between human beings and their world, and developed and transmitted within an essentially social context" (Crotty, p. 42). Central to this idea is that language, and the meaning and values that we assign to words, is the medium through which knowledge is developed and shared (Crotty, 1998). Social constructionism came to prominence in Berger and Luckmann's *The Social Construction of Reality* (1966). Over time, two variations have developed, social constructivism and social constructionism. These terms have been used both interchangeably and as distinct forms for studying social constructions. The former is primarily concerned with understanding the cognitive processes of individuals, and the latter focuses on how knowledge is socially constructed and disseminated (Crotty, 1998). This study primarily focuses on the second variation, social constructionism, which provides a particularly useful approach for designing a study to explore the experiences of older adults with mobility-limiting disabilities.

Key concepts. There are three critical and interrelated aspects of social constructionism that inform this study: *the interconnectedness of subjective and objective reality, the social transmission of knowledge, and social constructions are both real and relative.* Social constructionism explores the *interconnectedness of subjective and objective realities* in order to understand how people make meaning from their experiences. This approach goes beyond a purely objectivist or subjectivist approach to the development of knowledge (Crotty, 1998). Objectivist orientations tend to ignore subjective experience and suggest that knowledge is found and not created by humans. Subjectivism, on the other hand, overlooks objective reality and focuses only on the subjective realities of individuals (Crotty, 1998). This is not to say that social constructionism rejects the idea of objective or subjective realities. Rather, social constructionism focuses on the interconnectedness of the two to understand how people develop

knowledge through interactions with the objective world, "because of the essential relationships that human experience bears to its object, no object can be adequately described in isolation from the conscious being experiencing it, nor can any experience be adequately described in isolation from its object" (Crotty, 1998, p. 45). In this understanding, the objective world includes both the natural world (e.g. mountains, trees, etc.) and cultural or societal norms. Social constructionism, then, is concerned with how people interactive with and interpret the objective world (Crotty, 1998). For example, a wheelchair is an object that exists, but its meaning, positive or negative is created and ascribed to it by people and can change over time.

The second key concept, *the social transmission of knowledge*, suggests that how individuals make meaning of new situations is largely based on the knowledge and values that they bring to the experience. This knowledge base, argue Berger and Luckmann (1966), is developed and shaped by the culture and society in which they are raised. Berger and Luckmann suggest that cultural knowledge is developed through a process whereby experiences and knowledge are internalized by groups and this information comes to be accepted as objective reality and part of the everyday workings within a culture or society. This knowledge is then passed on to new generations and solidified into a social understanding that this is the way things are and work (culture). As noted by Crotty (1998), "It is clearly not the case that individuals encounter phenomena in the world and make sense of them one by one. Instead we are all born into a world of meaning" (p. 54).

The third key concept, *social constructionism is both real and relative*, suggests two things. First, that something can be both socially constructed and real (Crotty, 1998). For example, negative views of disability are socially constructed, but they also exist and have very real consequences for people with disabilities. Second, different individuals and groups of people

may have different understandings of what is real, "We need to recognize that different people may well inhabit quite different worlds. Their different worlds constitute for them diverse ways of knowing, distinguishable sets of meanings, separate realities" (Crotty, 1998, p. 64). This then helps explain why stigma towards disability and the disability rights movement can exist at the same time within the same society—different groups with diverse views of what it means to be disabled and the causes of disability.

Applications. Social constructionism, as a kind of meta-theory, has been used in a number of ways to inform studies across many disciplines (e.g. sociology, social work, etc.), in the application of many theories (e.g. life course, discussed below), and, importantly for this study, in understanding disability. Research on the social construction of disability has largely focused on stigma, discrimination associated with having an impairment, and the lived experiences of people with disabilities. Early work by Goffman (1963) argues that stigma plays out when people encounter an individual with a trait (e.g. visible physical impairment) that is not considered desirable by the rest of society and assign stereotypes to and act differently towards the individual with the disability than they would a person without one. Goffman points out that experiencing stigma can cause people with disabilities to internalize those negative views and withdraw from society.

Medical sociologists have also explored how experiences with disease and disability have been socially constructed. In a review of the literature on the social construction of disability, Conrad and Barker (2010) note that this approach has been used to explore how meaning is created and applied to various diseases and impairments. For example, the authors point to a number of studies that have explored such topics as how people come to understand their disease or impairment and how that knowledge influences their identity, the stigma and discrimination

that they experience, and how they deal with discrimination. There are also a number of works from scholars with disabilities who share their own experiences of living with a disability (e.g. Iezzoni, 2003).

Importantly, social constructionism has also helped to inform the social model of disability (Anastasiou & Kauffman, 2011). While the concepts that form the foundation of this model were originally developed by the Union of Physically Impaired Against Segregation in England, the model has come to inform scholarship, policy, and popular discourse more broadly (Shakespeare, 2006). According to Anastasiou & Kauffman, the social model of disability, as it has come to be used by theorists and researchers, is rooted in a social constructionist approach. In brief, as described by Shakespeare, the social model of disability suggests that the concept of disability is socially constructed and reinforced. In this view, there is a distinction between an impairment and the social and physical context in which the person functions. Impairment alone may not be disabling. Rather, social contexts, such as inaccessible environments or negative social views, can cause a person with an impairment to be disabled (Shakespeare, 2006).

While the social model of disability has been instrumental in advancing the rights of people with disabilities, it has been subject to important criticisms. First, it has been criticized as being over general, ignoring the unique experiences of people with different types of impairments. Second, the model lacks a person-in-environment approach, which takes into account both personal and societal characteristics (Shakespeare, 2006). This can limit the usefulness of the social model in exploring interactions between an individual with an impairment and their environment.

Limitations. Concerns have been raised about the usefulness of a social constructionist approach. The primary criticism is that this approach ignores objective reality and does little

more than describe the varied experiences and subjective realities of individuals, limiting its usefulness in identify patterns and phenomena (Andrews, 2012; Crotty, 1998). Others have argued, however, that this criticism is an oversimplification of social constructionism and focuses only on work that takes a subjectivist approach (Andrews, 2012; Crotty, 1998). Interestingly, this criticism is similar to that of the social model of disability where critics have noted that the social model tends to deemphasize the impact of the impairment on an individual in favor of focusing on the social context that creates disability (Schur et al., 2013). Given this criticism, in this study a broad social constructionist perspective is taken, which holds both subjective and objective reality as true. As such, this study draws on the International Classification of Functioning, Disability, and Health developed by the World Health Organization, which focuses on both impairments and how a person with said limitations interacts with the social world.

International Classification of Functioning, Disability, and Health (ICF)

The conceptualization of disability has evolved over time. In contrast to the traditional medical model of disability, new conceptual models have been developed to provide a more holistic understanding of why and how a person is disabled. Such models include the social model of disability discussed above, political frameworks, disability process models, and classification systems (Hahn, 1994; Nagi, 1965; Shakespeare, 2006; Verbrugge & Jette, 1994; WHO, 2001). While all of these models provide important approaches for understanding and studying disability, the ICF framework is used to guide this study.

The ICF, a classification system and framework for investigating health and disability, uses a bio-psycho-social approach that incorporates key ideas and elements of the medical and social models (WHO, 2001). This model of disability revises the earlier WHO model, the

International Classification of Impairments, Disabilities, and Handicaps (1980), by replacing judgmental terms (i.e. handicap) and incorporating personal and environmental factors that could influence the ability of a person with disabilities to participate in life events (Whiteneck, 2006). The major goal of the ICF is to provide a common conceptual framework and language for studying health and disability that will allow comparison within and across countries. In the model, disability is seen as the result of interactions between health conditions and environmental and personal factors (WHO, 2001).

     Key concepts. The ICF model allows for the multidimensional study of functioning and disability by providing a framework for examining the interaction among a person's health conditions, personal factors, and environmental factors (WHO, 2001). The model uses a health condition (e.g., spinal cord injury (SCI)) as a starting point for the possible development of an impairment, activity limitation, or participation restriction. The model has three major components: *body functions and structures*, *activities and participation*, and *environmental factors.* The first component refers to the physical and cognitive functioning of an individual's body systems, such as operation of the nervous system, and secondary conditions, such as pain, fatigue, and depression. The second component includes two broad areas: ability to perform certain activities, such as the ability to perform ADLs/IADLs, and participation in life situations, such as volunteer activities. The third component, environmental factors, refers to natural and built environments and social attitudes that may act as facilitators or barriers to a person's ability to participate (WHO, 2001). While the model also includes a category, *personal factors*, the ICF does not provide definitions or codes for this category.

     Applications. The ICF model has become a popular framework for guiding disability research around the world, and the Committee on Disability in America has supported the

adoption and use of this conceptual framework in the United States (Field & Jette, 2007). The

ICF has been used to guide research and practice in a number of settings (Stucki, 2005;

Kostanjsek, 2011). The model is particularly useful in occupational and physical rehabilitation

and in studying trends in disabilities within and across countries (Field & Jette, 2007;

Kostanjsek, 2011). The ICF has also been used to guide the development of measures of

participation in social and community activities (Noonan, Kopec, Noreau, Singer, & Dvorak,

2009). The most commonly-used measures are the Impact on Participation and Autonomy (IPA),

the Participation Scale (P-Scale), and the World Health Organization Disability Assessment

(WHODAS II).

Finally, the ICF has informed research on aging with a disability (i.e. Barclay,

McDonald, Lentin, & Bourke-Taylor, 2016; Jensen et al., 2012; Kemp & Mosqueda, 2004). For

example, Kemp (2004) uses the ICF to frame a discussion of quality of life, coping, and

depression in people aging with disabilities. More recently, Jensen and colleagues use the ICF to

guide a review of secondary conditions in people aging with a SCI. Indeed, as noted by Jensen

and colleagues, the ICF is now used by researchers and policy makers in the fields of

rehabilitation and aging.

Limitations. There are several well-documented limitations to the ICF. First, the model

does not make clear distinctions between activities and participation. A number of articles have

been published on the identification of characteristics that can help distinguish between the two

dimensions (e.g. Badley, 2008; Jette, Haley, & Kooyoomjian, 2003). In addition, there is wide

variation in how participation is operationalized (Noonan et al., 2009). Some researchers have

suggested defining activities as individual tasks (ADLS/IADLs) and participation as social

activities (Whiteneck, 2006). Second, the ICF includes the component of *personal factors*

without a classification system (Field & Jette, 2007; Kostanjsek, 2011). Hence, there is no

guidance on measuring intrinsic factors, such as self-efficacy and resiliency. Third, the *environmental factors* section does not include a framework for understanding interactions between different environmental factors and participation (Field & Jette, 2007; Hammel et al., 2015). Fourth, there is not explicit discussion of time or the life course; therefore, it is up to researchers to incorporate a time dimension in their study.

The lack of a time dimension is particularly relevant to this study as it can lead to a wide variety of possible definitions for key concepts, such as aging into disability. Much like the variation in defining disability, as noted in the first chapter, there are no standard definitions or inclusion criteria for studying aging with a disability. In general, three main ways to define aging with a disability have been used: *any disability before age 65*, *disability before a certain age*, and *time since onset*. The broadest definition, *any disability before age 65,* has tended to be used in conceptual work (Grassman, Holme, Larsson, & Whitaker, 2012; Kemp & Mosqueda, 2004; Putnam, 2007). Other operationalizations use a narrower time frame. For example, LaPlante (2014) focused on individuals with a disability before age 40, and Clarke and Latham (2014) included people who had reported a work-limiting disability during their prime working years. Several studies have also used *time since onset* of injury as the key inclusion criterion. For example, Bishop and Hobson (2015) included people who had lived with their disability for at least three years, while McColl and colleagues (2004) focused on individuals who had experienced a SCI at least 20 years prior.

Life Course Perspective

A life course approach is particularly useful in understanding the various physiological, psychological, social, and historical factors that influence the health and well-being of people as they age (Giele & Elder, 1998; Elder, Johnson, & Crosnoe, 2004). It offers particular insight into the dynamics that influence the lives of people aging with disabilities, as it provides a framework for considering the impact of the timing of impairment and the historical events that have shaped societal attitudes toward disabilities (Grassman et al., 2012).

Researchers using a social constructionist orientation have taken two approaches to exploring the life course. The first uses the life course as framework for exploring how people make meaning throughout their lives. The second focuses more on exploring the idea of "life course" as socially constructed (Holstein & Gubrium, 2007). For this study, the first approach is used. The discussion of the life course in this study uses key concepts from the work of Elder and colleagues (2004). To this framework, the strengths perspective is added as a way to understand and highlight the skills and resources that older adults with disabilities can bring to a volunteer experience. The strengths perspective is an approach to research, policy, and practice that focuses on the strengths and abilities of individuals and communities rather than deficits or limitations (Chapin, 2017; Saleebey, 2013; Weick et al., 1989).

Key definitions. Several key concepts inform a life course approach and can be grouped into three larger categories: *process of aging*, *timing of events*, and *social connections* (Elder et al., 2004; Grassman et al., 2012). The first category is made up of two key principles: (1) that aging is a lifelong process, with older age influenced by past experiences, and (2) the choices people make throughout their lives will shape their present and future lives (Elder et al., 2004). This first principle suggests that aging begins at birth and continues through the end of life and that later life cannot be understood without knowing the context and events that influenced a person in their youth and as an adult (Elder et al., 2004). The accumulation of experiences can lead to advantages or disadvantages that have important consequences for later life (Dannefer, 2003). However, despite disadvantages, people with disabilities may also develop coping mechanisms and resilience across the life course (Grassman et al., 2012).

The second principle suggests that individuals have the ability to construct their own life through the choices they make, based on the options available to them (Elder et al., 2004). The choices they make help form pathways that influence their present and future lives (Elder et al., 2004). For example, the choice to use a mobility assistive device, such as a cane, earlier in life

could allow an individual to avoid falling; often, however it also means that one shoulder and arm may become worn out sooner.

The second category, *timing of events*, highlights the importance of looking at the impact of time on three levels: the individual, cohorts, and larger historical trends. Individual time focuses on the chronological age of an individual and the age at which major life events or transitions occur (Elder et al., 2004). For example, the age of onset of disability can influence education, work, marriage, and other factors (Molton & Jensen, 2010). The second type of time is the cohort to which a person belongs (Elder et al., 2004). For example, the baby boomer generation is more highly educated and racially/ethnically diverse than its predecessors (Frey, 2010; Vincent & Velkoff, 2010). Third, it is important to consider larger historical trends and events (Elder et al., 2004). For example, the development of the disability rights movement and passage of the ADA have had a profound effect on the lives of people with disabilities (Schur et al., 2013; Molton & Jensen, 2010).

Finally, people are influenced by their *social connections*. Also known as "linked lives", this concept suggests that people experience larger social changes through their interactions with family members and acquaintances (Elder et al., 2004). For example, developing new relationships can change an individual's view or understanding of current events (Elder et al., 2004). In addition, problems can arise when a person does not meet the expectations of their social group (Settersten, 2003). For example, people aging with disabilities may experience negative attitudes from others, due to stigma associated with disability.

Applications. Overall, the life course perspective suggests a holistic approach that looks at the dynamic interactions between an individual and their environment, including the larger social context. This approach has been used to guide studies of cumulative advantage and disadvantage among older adults (e.g., Angela, 1996) and the influence of marital status, divorce, and health across the life course (e.g., Williams & Umberson, 2004).

The life course perspective has also been used in studies on aging with a disability. Grassman and colleagues (2012) use it to frame their work on aging with a disability in Sweden. Similarly, Clarke and Latham (2014) use it as a means for examining the impact of disability and work limitations during prime working years on the financial health of older adults who have aged with a disability. Finally, other researchers have used it as a basis for studying the importance of age of onset of disability (e.g. Bishop & Hobson, 2015) and the ability of people with disabilities to age successfully (LaPlante, 2014).

Strengths Perspective

This approach can further supplement and expand a life course perspective to increase its relevance for exploring the volunteerism of older adults with disabilities, as it can help to think about the skills and resources that individuals develop over time. Key concepts from the strengths perspective that are particularly relevant for this study include: that all individuals have a variety of social, emotional, and cognitive skills and resources; people have a variety of strengths and skills and the ability to continue to grow and learn; and communities also have strengths and are full of resources (Saleebey, 2013). This approach has been used extensively with older adults and highlights the resourcefulness and resiliency that older adults can develop throughout their lives (Chapin & Cox, 2002; Chapin et al., 2013; Chapin, Nelson-Becker, Macmillan, & Sellon, 2015).

Limitations. There are two notable limitations to the use of the life course perspective. First, studies using this perspective, particularly cohort studies, may lead to overgeneralizations that leave out the experiences of traditionally marginalized populations (Hutchison, 2010). Second, concerns have been raised about the ability of this framework to adequately allow researchers to link the individual to larger macro programs and policies (Dannefer, 2003).

There have also been two main criticisms leveled against the strengths perspective. First concerns have been raised that it can place an overly positive spin on negative events or issues (Saleebey, 1996). However, as noted by Saleebey, while the strengths perspective does not

pathologize problems, it also does not ignore them. Instead, working from this approach, the focus is on using personal and community strengths and resources to overcome problems. Second, the strengths perspective has been criticized as being too individualistic (Gray, 2011). However, recent work has expanded its use to guide policy and advocacy work (Chapin, 2017). The focus of this study is on the experiences of members of a traditionally marginalized group and on the social and structural elements that facilitate or impede participation in volunteer activities which not only helps to mitigate some of the concerns raised about these approaches but also reflects their meaningful applicability to this study's population.

Ecological Perspective

An ecological approach draws from concepts in biology and systems theory and has been conceptualized in many ways (see Robbins, Chatterjee, & Canda, 2011). For this study, emphasis is given to ecological models developed by Bronfenbrenner (1977) and translated for use in the profession of social work by Gitterman and Germain (2008) and other social work scholars (Gordon, 1965; Hearn, 1969). The ecological perspective, as described by Bronfenbrenner (1977), builds on ideas from general systems theory and was developed as an expansion of naturalistic inquiries that focused only on a person's or group's immediate environment, and that ignored the influence of larger social structures. Bronfenbrenner's expansion, which he refers to as the "ecology of human development" seeks to develop a richer framework from which researchers can explore the many contexts that influence the everyday lives of individuals and groups. Key ideas are also drawn from Gitterman and Germain's (2008) ecological approach.

Key concepts. The ecological perspective includes four levels, the *microsystem*, *mesosystem*, *exosystem*, and *macrosystem*, which are nested within and interact with each other (Bronfenbrenner, 1977, p. 514). The first level, the *microsystem*, consists of individuals and their immediate setting (e.g. their home and family system). The *mesosystem*, the second level,

focuses on the person's participation in social roles with their immediate social groups. The *exosytem*, the third level, is an extension of the *mesosystem* and focuses on a person's interaction with their larger community (e.g. the neighborhood, transportation services, community organizations, etc.). Due to the similarity of these two levels, the *mesosystem* and *exosystem* levels are merged in this study and focus on a person's experiences in their communities (geographical and social). The final level, the *macrosystem*, refers to the larger cultural and historical patterns which influence the other levels (e.g., policy and regulatory systems, cultural norms, etc.) (Bronfenbrenner, 1977). Hence, the ecological perspective is useful for understanding how a person interacts with and is influenced by various contexts.

Applications. The ecological perspective has made important contributions to our understanding of human development in a social context and has informed work in a variety of fields, such as sociology, psychology, and social work. In particular, an ecological perspective has come to be an important tool in social work practice (Gitterman & Germain, 2008; Robbins et al., 2011). Drawing from Bronfenbrenner's model (1977), Gitterman and Germain suggest that people grow through their interactions and transactions with the variety of environments that they encounter. Indeed, the authors argue that, in order to holistically study individuals and groups, we must look at not only the characteristics of the individual(s) but also the give-and-take relationships that they have with their physical and social environments (Gitterman & Germain, 2008). With this approach, referred to by the authors as the "life model", it is possible to explore persons in their environments and identify when there is a good or incompatible fit between the two. This also allows for an understanding of how people adapt to their environments and how they can also change their environments to better meet their needs (Gitterman & Germain, 2008). Importantly, responding to criticisms of their earlier versions of

the "life model", the authors also recognize that environments can be oppressive and that practitioners and researchers using this approach should be aware of the discrimination that marginalized populations experience.

Limitations. There are three notable limitations to the ecological perspective approach. First, critics have argued that an ecological perspective is primarily descriptive and does not provide for an understanding of why things happen. This limits the ability of practitioners to address issues (Unger, 2002). Second, the ecological perspective has been criticized for being overly abstract and generalized, including vague constructs and providing limited direction for understanding how aspects of the various levels can be connected (Reid, 2002; Unger, 2002). Finally, the idea of culture and its influences on the person is not well-developed in Bronfenbrenner's model (Vélez -Agosto, Soto-Crespo, Vizcarraondo-Oppenheimer, Vega-Molina, & Coll, 2017). However, despite these limitations, for this study Bronfenbrenner's (1977) model provides a useful framework to bring together key ideas from the various conceptual models discussed above and the research literature reviewed in the next section.

Summary

These four models help to provide a foundation and organization for this study. Social constructionism highlights the importance of exploring the lived experineces of older adults with mobility-limiting disabilities. It is also a useful framework for helping to balance objective and subjective realities throughout the study. Both the ICF and a social constructionist approach suggest that it is important to consider both the person's impairment, including how they understand it, and features of the social and physcial environment that can facilitate or impede particiation.The ICF also provides a useful guide for thinking about how aspects beyond the person's impairment, such as their physical and mental health, can influence their participation.

A life course approach suggests the need to consider larger cultural trends that impact the ability of people with disabilities to volunteer and the unique aspects of the individual's life, such as the age of onset of their impairment and the strengths they have developed over time, that can influence participation. Finally, the ecological perspective provides both a framework for organizing and exploring participant's experiences at different levels and for studying how the different levels can influence their participation.

Volunteerism and Community Participation among Older Adults and People with Disabilities

This section explores volunteerism and community participation by older adults and people with disabilities. In the first part of this section, *Dimensions of Volunteerism among Older Adults*, relevant literature on volunteerism among older adults, in general, is surveyed. Since this literature base does not adequately address disability, a second set of literature is reviewed. The second part of this section, *Volunteerism and Community Participation among People with Disabilities*, is reviewed in order to better understand the potential elements that could impact participation for people with disabilities specifically. Due to limited studies on volunteerism among older adults with disabilities, studies on both volunteerism and broader community participation among working age people with disabilities are included. Bronfenbrenner's (1977) ecological perspective is used in this section as a way of organizing the variety of factors that influence participation. Articles reviewed are restricted to 2001-2017 to correspond with the publication and use of the ICF guidelines, which were not developed until 2001.

Dimensions of Volunteerism among Older Adults

This section provides background information on rates and types of volunteering, factors that influence participation, and the experiences and benefits of participating in volunteer activities for older adults. This literature provides a foundation for comparing what we know and

gaps in knowledge about participation in volunteer activity by people aging with a disability. Given the extensive interest in volunteerism among older adults around the world, this review focuses only on studies of older Americans.

Rates and Types of Participation

Volunteer rates among older adults have increased substantially in the last few decades. Older adults are the most likely age group to volunteer 100 or more hours. Baby boomers have historically had high rates of participation and are predicted to continue this trend during retirement (Foster-Bey et al., 2007). In 2015, nearly 27% of adults age 45-64 and 23.5% of adults 65+ volunteered (U.S. Census Bureau of Labor Statistics, 2016). Interestingly, individuals who are involved in formal volunteering also have high rates of informal volunteering (Lee & Brudney, 2012).

Older adults are involved in a variety of volunteer activities. According to the U.S. Census Bureau of Labor Statistics (2016), some of the most common activities older adult volunteer are engaged in include: collecting and distributing food, providing professional or management assistance, fundraising, and teaching. In an analysis of data from the 2002 Current Population Survey Volunteer Supplement, Tang and Morrow-Howell, (2008) found that older adults 65-85 were most likely (44%) to be involved in formal volunteer activities through a religious organization. Older adults were also likely to participate in social service-related opportunities (20.7%), volunteering with health-related organizations (10.8%), and being involved in programs run by civic or political organizations (9.0%). In addition, older adults may participate in specially designed programs, such as peer-mentor programs (Chapin et al., 2013; Mui, Glajchen, Chen, & Sun, 2013) or intergenerational programs like Experience Corps.

Individual Level Factors Influencing Volunteerism

Most of the research on volunteerism among older adults has focused on formal volunteer activities. However, there is a growing body of literature on informal volunteering (Choi et al., 2007; Johnson & Lee, 2017; Kaskie, Imhof, Cavanaugh, & Culp, 2008; Lee &

Brudney, 2012; Martinez et al., 2011) that can be used to supplement the literature on formal volunteering. Previous research suggests that gender, race/ethnicity, age, education, income, employment, and health/functioning are important predictors for volunteerism (Adler, Schwartz, & Kuskowski, 2007; Choi, 2003; Johnson & Lee, 2017; Kaskie et al., 2008; Musick & Wilson, 2008; Tang, 2006; Tang et al., 2012). In addition, motivation and previous experience as well as social connections also appear to influence participation (Choi & Chou, 2010; Musick & Wilson, 2008; Tang, 2006).

Gender, race, and age. Research suggests that women are often more involved in volunteer activities than men (Burea of Labor Statistics, 2016; Musick & Wilson, 2008; Wilson, 2012). Importantly, men and women often volunteer in different roles (Musick & Wilson, 2008; Rotolo & Wilson, 2007). For example, using data from the 2002 CPS and the CPS Volunteer Supplement, Rotolo and Wilson (2007) found that men are more likely to serve on boards or committees or coach and women are more likely to be involved in preparing food or goods and volunteering with social service agencies. In addition, men may be more involved in informal volunteer activities than women (Zedlewski & Schaner, 2006).

Race is also an important predictor of volunteerism. Research suggests that non-Hispanic Whites participate in formal volunteering at higher rates than African Americans, Asians, or Hispanics (Adler, et al., 2007; Johnson & Lee, 2017; Kaskie et al., 2008; Musick & Wilson, 2008; Tang et al., 2012). The higher rates of participation among Whites are likely due to the fact that they are often more likely to be asked to volunteer (Musick & Wilson, 2008). In addition, participation by African Americans often occurs through churches and is therefore often overlooked in studies of formal volunteerism (Musick & Wilson, 2008; Martinez et al., 2011). Interestingly, once involved, African Americans often contribute more hours compared to their White peers (Tang et al., 2012). In contrast to Whites, members of racial or ethnic minority groups are as likely or more likely to participate in informal volunteer activities (Lee & Brudney, 2012; Johnson & Lee, 2017).

In general, younger segments of the older adult population appear more likely to be involved in volunteer activities. For example, in a study of 6,465 older volunteers and non-volunteers from the Asset and Health Dynamics Among the Oldest Old database (AHEAD), Choi (2003) found higher rates of involvement among the young-old, 65-75. More recently, in a study of 4,526 participants from the Health and Retirement Study and the Consumption and Activity Mail Survey, McNamara & Gonzales (2011) found that, after controlling for other factors, volunteer rates remained stable as older adults aged, at least through their 70th year.

Education, income, and employment. Broadly speaking, education and income tend to be the most common predictors of volunteerism (Wilson, 2012). For older adults, education is related to both the likelihood of participation and the number of hours contributed. For example, in a study of 3,617 adults from three waves of data from the Americans' Changing Lives study, Tang (2006) found that education is positively related to the number of volunteer hours provided by older adults. However, education is not significantly related to volunteer hours for middle-aged and younger individuals. In addition, older adults with higher levels of education contribute more hours than their less-educated peers. More recently, Johnson and Lee (2017) found that education was a significant predictor of volunteering for non-Hispanic Whites, Asians, Non-Hispanic Blacks, and Hispanics, with higher levels of education increasing the odds of volunteering for all groups.

Higher income levels and more assets are also associated with volunteering (Adler, et al., 2007; Choi, 2003; Kaskie et al., 2008; Musick & Wilson, 2008; Tang, 2006). In general, older adults with more income are both more likely to volunteer and to contribute more hours (McNamara & Gonzales, 2011). More recently, using four waves of data from the Americans' Changing Lives study, Han and Hong (2013) found that homeownership and liquid assets, such as stocks and bonds, increase the number of hours volunteered by older adults. The use of stipends, particularly to offset transportation costs, has also been shown to improve the rates of

engagement and retention of lower-income, older adults (Hong & Morrow-Howell, 2013; McBride, Greenfield, Morrow-Howell, Lee, & McCrary, 2012).

Finally, employment does not appear to be a barrier to volunteerism for many older adults. For example, in a study of 3,939 individuals who reported volunteering in the 2002 Current Population Survey, Tang and Morrow-Howell (2008) found that older adults who were employed were more likely to volunteer than those who were not employed. More recently, Tang (2016) found that individuals who were not retired or who worked part-time were more likely to volunteer than full retirees and those not in the workforce.

Health and functioning. Three health-related factors: self-reported health, depression, and ADL/IADL limitations also appear to be important predictors of participation for older adults (Choi et al., 2007; Musick & Wilson, 2008; Wilson, 2012). For many older adults, poor health reduces the odds of volunteering (McNamara & Gonzales, 2011) and declining health is a common reason why older adults stop volunteering (Tang, Morrow-Howell, & Choi, 2010). Mental health also has an important effect on participation. For example, in a study of 525 older adults from the 2008 Aging Texas Well Indicators survey, Ahn and colleagues (2011) found that having good or excellent mental health significantly increased the participation in volunteer activities. Interestingly, for men, symptoms of depression may reduce participation in both formal and informal volunteering. In contrast, depression does not appear to reduce participation among women (Choi et al., 2007). Finally, having at least one ADL/IADL limitation reduces the likelihood of starting or staying involved in formal volunteer activities (Burr, Mutchler, & Caro, 2007; Butrica et al., 2009). For example, in a study of volunteer transitions from four waves of data from the Health and Retirement Study, Butrica and colleagues found that onset of difficulties with ADLs/IADLs increases the chances that a person will quit volunteering.

Unfortunately, these studies have not included information about the age of onset of limitations or disability due to the fact that few secondary data sets provide these variables (Putnam, Molton, Truitt, Smith, & Jensen, 2016). This increases the difficulty in distinguishing

between participation among those aging with a disability and those who have developed a disability in later life. In addition, these studies have focused on formal volunteering, making it difficult to determine how functional limitations and disabilities impact informal volunteering or community participation.

Motivation and previous experience. Participation of older adults in volunteer activities also appears to be driven by both altruistic and self-benefit motives. Several studies highlight the importance of being able to give back and make a meaningful difference in their communities as a reason why older adults participate (Cheek, Piercy, & Grainger, 2015; Chen & Morrow-Howell, 2015; Larkin, Sadler, & Mahler, 2005; Martinez et al., 2006; Okun & Michel, 2006). For example, in a study of volunteerism among 653 young-old adults using data from the Midlife in the United States study (MIDUS), Okun and Michel found a positive association between generativity and likelihood of volunteering. Similarly, in a qualitative study of 37 older volunteers preparing for intensive volunteer experiences with faith-based organizations, Cheek and colleauges found that making a meaningful difference was a major reason why older adults continued to volunteer.

The combination of altruistic and self-benefit motives also appears to be common. For example, findings from a study exploring the experiences of 16 older adults involved in a mentoring program for at-risk youth, found that wanting to both have a sense of purpose and give back to others as motivations for this participation (Larkin et al., 2005). Similarly, in a study of 510 volunteers in the Experience Corps program, Chen and colleagues found that altruistic (33%) and a combination of altruistic and self-benefit (36%) motivations were the most common reasons given for volunteering. Their results also suggest that African Americans are more likely to report altruistic motives as a reason for volunteering.

Research also suggests that volunteer experiences before retirement can increase the likelihood that an older adult will be involved in volunteer activities (Chambré & Einolf, 2008). For example, in Chambré and Einolf's multivariate logistic regression model of volunteering, the

authors found that the strongest predictor of volunteerism for retirees was whether the individual had previous volunteer experience.

Social connections. In addition to these key predictors, research also suggests that social connections and having a spouse who volunteers play an important role in helping older adults learn about and participate in volunteer opportunities (Choi & Chou, 2010; Musick & Wilson, 2008; Tang, 2006). For example, the number of friends and informal social integration significantly increases the likelihood of volunteering (Tang, 2006). In addition, in a study of individuals age 50+, McNamara and Gonzales (2011) found that individuals who like to spend free time with their volunteer spouse were more likely to be engaged in volunteering, contribute more hours, and were less likely to stop volunteering compared to unmarried individuals. As being asked to participate is the one of the most common ways for people to become involved in volunteer activities, a larger number of social connections can increase the likelihood of being asked (Morrow-Howell, 2010; Musick & Wilson, 2008; Tang, 2006; Tang & Morrow-Howell, 2008).

Meso Level Factors Influencing Participation

Studies of community-level factors that influence volunteerism among older adults have largely focused on approaches organizations can take to recruit, support, and retain these volunteers. Research suggests that a personal invitation to participate from the organization or a friend or family member who is involved with the program are the most common ways for older adults to become involved (Cheek et al., 2015; Martinez et al., 2006; Tang & Morrow-Howell, 2008). Program characteristics that may influence participation of older volunteers include: role flexibility, staff supervision and training, recognition, and the use of stipends (Sellon, 2014). Role flexibility, in terms of both scheduling and tasks, has been associated with a higher level of perceived benefits (Hong & Morrow-Howell, 2013; McBride, Greenfield, Morrow-Howell, Lee, & McCrary, 2012; Tang, Choi, & Morrow-Howell, 2010). For example, in a study of 401

volunteers across 13 volunteer programs, Hong & Morrow-Howell found that role flexibility was significantly associated with perceived benefits. Similarly, Tang and colleagues found that choice of tasks and schedule were associated with both retention and perceived benefits. In addition, support and training offered by staff, as well as recognition of service by the organization, can help in the retention of volunteers (McBride et al., 2012).

Macro Level Factors Influencing Participation

Recognizing the importance of volunteerism and the contributions that older adults can make, formal volunteer programs have been developed at the federal level and by large-scale non-profits. For example, the Domestic Volunteer Service Act mandates the development and operation of the three programs specifically for older adults: the Retired Senior Volunteer Program (RSVP), the Foster Grandparents Program, and the Senior Companion Program. These programs currently operate under one agency, Senior Corps, and support more than 270,000 older adults (Corporation for National &Community Service, 2015). Finally, AARP operates an Experience Corps program in many cities. This program recruits and supports older adults to act as tutors and mentors for children during the school year and has shown success in terms of both student skill development and the recruitment and retention of low-income older adult volunteers (Morrow-Howell, Hong, & Tang, 2009)**.**

Benefits and Disadvantages of Volunteering for Older Adults

Many studies suggest that volunteering can have important physical, emotional, and cognitive health benefits for older adults (Anderson et al., 2014; Carlson et al., 2008; Carlson et al., 2009; Fried et al., 2013; Greenfield & Marks, 2004; Harris & Thoresen, 2005; Hong & Morrow-Howell, 2010; Lum & Lightfoot, 2005; Parisi et al., 2015; Tang, Choi, & Morrow-Howell, 2010; von Bonsdorff & Rantanen, 2011). For example, in a study of 7,527 older adults from the Longitudinal Study of Aging, Harris and Thoresen found that volunteering is associated with a reduced risk of mortality. In addition, Lum and Lightfoot, using data from seven waves of

the AHEAD database, found that volunteering can slow both increases in depression symptoms and self-reported declines in functioning levels. Similarly, Tang and colleagues found that perceived contributions to the community and others were positively and significantly associated with mental health. In two studies exploring the benefits of participation in the Experience Corps program for older adults' cognitive health, Carlson and colleagues found that participation in volunteer activities may provide an important opportunity for older adults to increase their cognitive engagement improve executive functioning. More recently, two randomized control studies of the benefits of participation in Experience Corps have found improvements in physical functioning (Fried et al., 2013) and increases in physical activity (Parisi et al., 2015).

Volunteerism has also been associated with improvements in well-being, such as increases in life satisfaction, self-esteem, self-efficacy and having a sense of purpose (Anderson et al., 2014; Arnstein, Vidal, Wells-Federman, Morgan, & Caudill, 2002; Greenfield & Marks, 2004; Han & Hong, 2013; Kahana, Bhatta, Lovegreen, Kahana, & Midlarsky, 2013; Larkin et al., 2005; Li, 2007; Morrow-Howell et al., 2009). For example, findings from a study of 373 older adults (aged 65-74) using the MIDUS data set suggest that volunteerism is associated with having a positive affect and that volunteerism can act as a protective factor for older adults who experience role losses, such as feelings of loss of self-identity due to retirement (Greenfield & Marks, 2004). Arnstein and colleagues examined the experiences of seven individuals aged 41-70 who completed a training course on pain management and then volunteered to be peer leaders of the program. Their findings suggest that acting as peer volunteers can help to reduce the experiences and intensity of pain and improve self-esteem. More recently, in a study using two waves of data collected three years apart of 585 older adults (aged 72 +), Kahana and colleagues found that volunteerism was a significant, positive predictor of positive affect and life satisfaction.

While the focus of much of the research on volunteerism among older adults has been on health benefits, research suggests that volunteerism can also help to increase older adults' social

networks, feelings of connectedness to the community, and increased odds of going back to work (Arnstein et al., 2002; Brown et al., 2011; Cheek et al., 2015; Gonzales, Nowell, Brown, & Goettge, 2015; Larkin et al., 2005; Morrow-Howell et al., 2009; Mui et al., 2013). For example, in a grounded theory study with 40 older adults who volunteered with Habitat for Humanity, participants discussed how volunteering provided them with an important opportunity to connect and give back to other people and their communities. In addition, results from a follow-up study of 338 individuals who volunteered with Experience Corps in 2006 and 2007 found that 16% of participants reported that they started a new job and over 90% engaged in new volunteer or community activities (Morrow-Howell, Putnam et al., 2014). Similarly, analyzing ten waves of data from the Health and Retirement Study, Gonzales and colleagues found that participation in formal volunteer opportunities increased the chance of returning to work.

In addition to benefits to individuals, volunteerism by older adults has also been associated with benefits to the community (Larkin et al., 2005; Lee, Morrow-Howell, Jonson-Reid, & McCrary, 2012; Morrow-Howell et al., 2009; Mui et al., 2013; Rebok et al., 2004). For example, in a study of 401 older adult volunteers from 13 different programs, the majority of participants believed that they had contributed to the well-being of others and their community more broadly (Morrow-Howell et al., 2009). In addition, the Experience Corps program has helped to increase literacy levels and grade completion for children involved in the program (Lee et al., 2012; Rebok et al., 2004).

While research has identified a number of benefits associated with participation in volunteer activities, there are also some potential disadvantages. The financial costs associated with volunteering could become a burden to older adult volunteers, particularly if stipends are not provided (Tang, Morrow-Howell, & Choi, 2010). In addition, the amount of time required to be a volunteer at some organizations may be more than an older adult can physically handle. Similarly, the amount of work expected of older adult volunteers may cause stress or fatigue

(Martinez et al., 2011). Finally, participating in volunteer activities may also take time away from other activities of interest (Tang et al., 2010).

Summary of Volunteerism among Older Adults

Findings from research on volunteerism among older adults in the United States suggest that there are a number of important dimensions to explore when considering participation among members of this population. First, there are several aspects at the individual level that impact participation including: gender, race, age, education income, physical functioning and physical and emotional health. Older adults also have both altruistic and self-directed motivations for volunteering, and having social support and more social contacts increases the likelihood that members of this group will volunteer. There are several things that organizations can do to better recruit and retain older adult volunteers, such as directly asking older adults to participate, providing support and training, allowing the person to have flexibility in terms of their role and schedule, providing stipends, and recognizing the contributions of volunteers. Third, there are many benefits associated with participation for older adults, such as increasing physical activity and physical and cognitive functioning, decreasing symptoms of depression, and decreasing risks of mortality. In addition, volunteering can provide older adults with a sense of purpose and can help to increase their satisfaction with life, self-esteem and self-efficacy. Including older adults in volunteer activities can help organizations serve their clients and help communities more broadly. Finally, there are some drawbacks to participation, such as the financial costs associated with participation (e.g. transportation), being asked to do too much and experiencing stress and fatigue, and not having as much time for other valued activities.

Dimensions of Volunteerism and Community Participation among People with Disabilities

This section provides background on rates and types of volunteer and community participation, factors that influence participation, and the experiences and benefits of

participating in volunteer activities for adults and older adults with physical disabilities who live in non-institutional settings. This section reviews existing studies in the U.S. and supplements this knowledge with international findings.

Rates and Types of Participation

People with disabilities appear less likely to participate in volunteer and community activities compared to people without disabilities. For example, in a study of 213,770 volunteers in North America, Miller and colleagues (2005) found that only 4.5% of the volunteers had a disability. More recently, a study by Shandra (2017), using nationally representative data from the Current Population survey, suggests that adults with physical disabilities are 28% less likely to be involved in formal volunteer activities, as compared to the general population. Finally, in a study of older adults with disabilities, Freedman, Stafford, Schwarz, Conrad, & Cornman (2012) found that older adults with physical, cognitive, or sensory disabilities were less likely to have volunteered in the last week, as compared with their non-disabled peers.

While there are many programs designed to increase the participation of people with disabilities in exercise programs (e.g. Ravesloot et al., 2006), there is limited information on how to improve participation in volunteer activities, and research on what is available has primarily been based in Australia (e.g. Stancliffe, Bigby, Balandin, Wilson, & Craig, 2015). More work is needed to both understand and improve participation rates, especially for older adults with disabilities in the United States.

Adults with disabilities take part in a wide range of activities. Volunteering for social service agencies and through churches appear to be the most common ways for individuals with disabilities to become involved (Balandin, Llewellyn, Dew, & Ballin, 2006; Stroud, Miller, Schleien, & Merrill, 2005). Volunteering or membership with organizations focused on people with disabilities is also common (Rak & Spencer, 2016; Raymond, Grenier, & Hanley, 2014). In studies from Australia, many volunteers use their past experiences or unique experiences to aid their volunteer work. For example, a volunteer in the study by Trembath et al., (2010) used his

experience with cerebral palsy and using a power wheelchair to teach others about how to access and use this resource. In addition, a volunteer in the study by Balandin and colleagues used her experiences of having lived in a rural area to help people transition from small country hospitals to large urban hospitals.

Individual Level Factors Influencing Participation

While few studies have looked specifically at factors associated with participation in volunteer activities by older adults with disabilities, more research has been done on community participation by adults with disabilities. The existing research on individual-level factors that influence volunteerism and community participation of working-age and older adults with disabilities suggests that motivation, gender, race, age, secondary conditions, self-esteem and self-efficacy, social support, and coping strategies and use of assistive equipment may also influence participation in volunteer activities.

Gender, age, and race. In terms of gender, women with disabilities are more likely to be involved in volunteer activities than men (Campolieti, Gomez, & Gunderson, 2009; McColl, Charlifue, Glass, Lawson, & Savic, 2004). For example, comparing matched samples of men and women living with SCI, McColl and colleagues found that women spend more time volunteering than men.

In general, younger people with disabilities are more likely to be involved in volunteer activities. For example, Schur and colleagues (2013), using data from the 2008 Current Population Survey Civic Engagement Supplement, found that participation in community groups was more common among younger adults with disabilities age 18-34 compared to older people (35+) with disabilities. This may be due to greater emphasis placed on community participation for youth and because volunteering and other programs are often seen as providing a way for young people to enter the labor force. In addition, fewer social interactions after leaving the labor force may make it more difficult for older people with disabilities to learn about and become involved in civic activities (Rak & Spencer, 2016; Schur et al., 2013).

Despite the high prevalence of disabilities among African Americans and Hispanic/Latinos, there is relatively little information on their participation rates in volunteer activities. The limited research available comes from studies of adults with SCI and suggests that Whites tend to be more engaged than non-Whites with disabilities. For example, in a study of 2,726 people with SCI, Whiteneck et al., (2004) found that non-Whites were more likely to report barriers to participation than Whites. Similarly, Krause and Coker (2006) found that among individuals with SCI, Whites reported higher rates of engagement and subjective well-being, as compared to African Americans, American Indians, and Hispanics.

Education and income. For both volunteering and community participation, higher levels of education appear to be associated with a greater likelihood of participation for people with disabilities (Campolieti et al., 2009). In a study of working-age adults in Canada's Participation and Activity Limitation Survey, Campolieti and colleagues found that higher levels of education increased the likelihood of volunteering, with the highest levels reported among those who had a college degree.

Higher levels of income are also associated with a greater likelihood of volunteering and participation in civic groups. For example, Rak & Spencer (2016) found that, for people with and without disabilities, higher household income and being employed were positively associated with volunteering. In addition, Campolieti et al., (2009) found that homeownership increases the likelihood of volunteering. Campolieti colleagues also found that federal disability payments were associated with increased participation, so long as stipends received from volunteer work did not disqualify or reduce these benefits. Finally, expenses associated with volunteering and community participation, such as transportation costs, can make it difficult for many individuals aging with a disability to become and remain engaged (Balandin et al., 2006).

Secondary conditions. While there do not appear to be any studies comparing rates of community participation and volunteerism based on diagnostic condition, it seems that secondary conditions influence participation. In general, pain, fatigue, and depression appear to be

associated with lower social participation rates. For example, in a study of individuals from the Netherlands with a variety of disabilities, Cardol and colleagues (2002) found that individuals with stroke, RA, or fibromyalgia perceived more restrictions to participation than people with SCI. This difference may be due to flare-ups in pain for individuals with RA and fibromyalgia. Similarly, exploring participation among 157 Slovakians with RA, Benka and colleagues (2016) found that those who experienced more pain, fatigue, anxiety, and depression were less likely to be socially engaged. Silva and colleagues (2016) found a statistically significant correlation between depression and participation in post-stroke adults, with individuals experiencing depression reporting lower participation scores. In a study of 179 adults in the Netherlands with spina bifida, Barf et al., (2009) found that depression and anxiety reduced participation levels. And, in a study of 1,271 adults with MS and 620 with SCI, Yorkston and colleagues (2012) found that satisfaction with participation was associated with less fatigue and pain. Finally, findings from a study of adults with with MS suggest that depression and feeling burned out from having to constantly manage their MS and secondary conditions can make it more difficult to be engaged in social and community activities (Silverman, Verrall, Alschuler, Smith, & Ehde, 2017).

People with disabilities use a number of coping strategies to help manage secondary conditions so that they can participate in meaningful activities (Lynch et al., 2008; Silverman, Verrall, Alschuler, Smith, & Ehde, 2017). For example, findings from focus groups with nine long-term stroke survivors and their caregivers suggest that staying positive, being persistent, and using problem solving strategies to work around physical limitations are important for re-engaging with life after stroke (Lynch et al., 2008). More recently, in focus group discussions of the effect of MS on participation, study participants discussed using humor and being optimistic as ways to help cope with their condition. In addition, participants noted that it was important to plan ahead and be selective about choosing which activities they participated in as a way to conserve energy (Silverman et al., 2017).

Self-esteem and Self-efficacy. Self-esteem and self-efficacy also appear to have an impact on participation (Benka et al., 2016; Mikula et al., 2017). For example, in a study of two samples of RA patients with recent and long-term disease duration, Benka and colleagues found that people who had lower social participation had higher rates of pain, fatigue, anxiety and depression, and lower self-efficacy. More recently, in a study of 118 Slovakians with MS, Mikula and colleagues found that self-esteem fully mediated the relationship between participation and mental health.

Modifications to the home environment. Having a home environment that fits a person's needs and abilities can help facilitate participation (Greiman, Fleming, Ward, Myers, & Ravesloot, 2018; Hammel et al., 2015). Home modifications, such as installing a lift or ramp and modifying bathrooms, can facilitate participation (Hammel et al., 2015). In addition, in a study of 6,002 people with mobility impairments using data from the American Time Use Survey, Greiman and colleagues found that people with mobility impairments who report having to spend extra time and energy on tasks related to bathing are less likely to participate in social and community activities. Hence, more home modifications related to bathing and hygiene may be needed to facilitate participation for people with impairments that reduce mobility.

Social Support. Research also suggests that social support can play an important role in facilitating participation (Beckley, 2006; Hawkins et al., 2015; Hammel et al., 2015; Jellema et al., 2016; Lynch et al., 2008; Trembath, Balandin, Togher, & Stancliffe, 2010). In a study of community reintegration after injury and discharge among nine former service members, Hawkins and colleagues found that emotional support from family and friends was positively associated with social participation (Hawkins et al., 2015). In addition, having someone to talk to and provide support when volunteering becomes difficult or stressful appears to be important for the well-being of older volunteers with disabilities (Trembath et al., 2010). Finally, findings from a systematic review of qualitative and quantitative studies of the factors that can facilitate

participation after a stroke suggest that social support is critical to stroke survivors ability to navigate barriers and become reengaged with their communities (Jellema et al.,).

However, not all social support is positive, as many people with disabilities have reported having strained relationships or losing support from friends and family members due to the difficulties of managing the disability (Lynch et al., 2008; Silverman et al., 2017). For example, participants in the study by Lynch and colleagues discussed how their own family members' attitudes changed towards them after their stroke. Similarly, participants in Silverman and colleague's study said that they had lost friends or experienced frustration with friends who did not understand what it was like to live with MS.

Coping strategies and use of assistive equipment. Coping strategies and use of assistive equipment can increase opportunities for participation (Carver, Ganus, Ivey, Plummer, & Eubank, 2016; Kirchner, Gerber, & Smith, 2008; Pettersson, Törnquist, & Ahlström, 2006; Schur et al., 2013). For example, in a study of 134 adults with visual and mobility limitations, Kirchner and colleagues found that participants coped with known barriers in the environment by planning routes ahead of time, slowing down and taking more time to navigate barriers, and choosing to wait until later dates to participate in activities. In terms of assistive technology, findings from a study of the effect of an outdoor powered wheelchair on activity levels and participation among people who had experienced a stroke suggest that a powered chair greatly increased the ability of participants to engage in social and civic activities (Pettersson et al., 2006). More recently, findings from a study of the use of mobility-assistive technology devices, such as wheelchairs, suggest the use of such devices can help to overcome many environmental barriers to participation (Carver et al., 2016).

Motivation. Like the overall population, people with disabilities become involved in volunteer activities for both altruistic and self-benefit reasons. Several studies suggest that a major reason that individuals with a disability participate in volunteer and community activities, is to give back and contribute to society (Balandin et al., 2006; Hammel et al., 2008; Trembath et

al., 2010). For example, in a study of 14 older Australian workers in supported employment settings, Balandin and colleagues found that many participants saw volunteerism as a way to help people and give back. Similarly, findings from a study of 24 adults with disabilities and complex communication needs in Australia suggest that the desire to help other people was the main reason that participants volunteered (Trembath et al., 2010). In addition, many of the study participants hoped that their participation would improve peoples' understanding and acceptance of disabilities. Similarly, in interviews with 63 people with disabilities, Hammel and colleagues found that many people with disabilities see community participation and volunteering as a way to counter negative assumptions about people with disabilities, particularly beliefs that people with disabilities are the recipients and not the providers of services.

Personal growth, involvement in meaningful activities, and a chance to meet new people are also important reasons for people with disabilities to become involved in volunteering and with community groups (Hansji, Wilson, & Cordier, 2015; Hjelle & Vik, 2011; Trembath et al., 2010). For example, in a qualitative focus group study with six people who use wheelchairs in Norway, participants discussed the desire to be involved in their communities and felt that they should have the right to participate just like an able-bodied person (Hjelle & Vik, 2011). Volunteering can provide adults with disabilities an opportunity to meet new people and as a way to develop new skills that could lead to future employment (Trembath et al., 2010). More recently, findings from interviews with Australian men with disabilities who participated in Men's Sheds (a place for retired men to get together and socialize and work on community projects), suggest that these clubs can be an important way for older men with disabilities to meet new friends and to engage in meaningful activities (Hansji et al., 2015).

Meso Level Factors Influencing Participation

Aspects of the natural and built environment, as well as social attitudes, can act as facilitators or barriers to participation for adults with disabilities (Hammel et al., 2015; Ripat, Brown, & Ethans, 2015; Ripat & Colatruglio, 2015; Whiteneck et al., 2004). In a study of

environmental barriers that impact participation among those with SCI, the natural environment was listed as the most important (Whiteneck et al., 2004). One example is rain and snow making ramps inaccessible (Ripat & Colatruglio, 2015). In a study of 99 wheelchair and scooter users, Ripat and colleagues found that participation decreases during the winter months.

Focusing specifically on the built environment, people with major physical impairments and wheelchair users may face unique barriers (Clarke, Ailshire, Bader, Morenoff, & House, 2008; Hammel et al., 2015; Harris, Yang, & Sanford, 2015; Rosenberg et al., 2012; Schur et al., 2013; Trembath et al., 2010) In a study of 1,195 individuals with a range of physical disabilities, Clarke and colleagues found that streets with cracks and broken curbs can greatly reduce the ability of individuals with moderate to severe lower limb impairments to participate in their communities. Similarly, Harris and colleagues found that many community environments may be inaccessible to wheelchair users, due to the construction of sidewalks, intersections, curb cuts, and ramps. Their results also suggest that older wheelchair users experience more barriers as compared to younger wheelchair users.

Inaccessible architectural features of buildings, such as bathroom stalls that are not ADA compliant, narrow doorways, and a lack of ramps or elevators, limit participation among people with disabilities (Hammel et al., 2015; Nilsson, Iwarsson, Thordardottir, & Haak, 2015; Schur et al., 2013). For example, in a focus group study of participation with 29 people with Parkinson's disease in Sweden, participants discussed how on bad days they cannot go up or downstairs or open heavy doors (Nilsson et al., 2015). In addition, in a case study of a community-based writing group for older adults in Canada who had lived with a hearing, vision, or mobility impairments since birth or early adulthood, participants discussed how trying to be involved with community groups was challenging, as they often had to request that meetings be switched to accessible locations (Raymond, Grenier, & Hanley, 2014).

Transportation. While private and public transportation can facilitate participation in community and volunteer activities, there may also be barriers to their use. Unreliable and

expensive transportation can limit the participation of people with disabilities (Barclay et al., 2016; Hammel et al., 2015; Reinhardt, Ballert, Brinkhof, & Post, 2016; Trembath et al., 2010). For example, findings from a study that analyzed transcripts from 36 focus groups suggest that many people with disabilities are not able to afford to modify vehicles to make them accessible and often have to rely on friends and family for rides. Participants in this study also noted that many bus and train stops are not accessible (Hammel et al., 2015). In addition, a lack of available disability parking can make it more difficult for people with mobility impairments to participate. For example, in a study of 35 adults over the age of 50 with mobility limitations, Rosenberg and colleagues (2012) found that lack of disability parking spaces and parking being too far from destinations were barriers to participation.

 Social attitudes. Participation in volunteer and community activities can also depend greatly on social attitudes towards disabilities. Negative social attitudes can reduce opportunities for people with disabilities to participate in social and civic activities (Barclay et al., 2016; Hammel et al., 2008; Hammel et al., 2015; Reinhardt et al., 2016; Trembath et al., 2010). For example, in semi-structured interviews with 17 adults with SCI, several participants discussed how people in the community often held negative views towards them and their wheelchairs, often ignoring them or acting hostilely towards them. In addition, many participants discussed how employers often assumed that people in wheelchairs could not contribute (Barclay et al., 2016). Similarly, most of the participants in the study by Trembath and colleagues had experienced negative attitudes and assumptions from others that they could not participate. Indeed, one participant noted that she was excluded from voluntary work in schools. In contrast, staff who are knowledgeable and sensitive to the needs of people with disabilities can facilitate participation for people with disabilities (McDonald, Williamson, Weiss, Adya, & Blanck, 2015; Trembath et al., 2010). In particular, staff who are knowledgeable and can help access resources and assistive technology can increase opportunities for participation (Hammel et al., 2008; Trembath et al., 2010).

Macro Level Factors Influencing Participation

There are several macro level policies and programs that can influence the ability of adults with disabilities to participate in volunteer activities. Similar to older adults without disability, people aging with disabilities could participate in the various Senior Corps programs or in Experience Corps. However, they may face unique challenges. For example, while the ADA mandates the accessibility of commercial buildings, many environments contain elements that are not accessible. While the Senior Corps programs are supported by federal funds and are therefore required to provide accommodations, aspects of some of its programs may make it difficult for people with disabilities to participate. For example, volunteers in the Senior Companion Program often visit homebound older adults. Homes that are inaccessible will make it difficult for wheelchair users to volunteer with this program. Finally, as many people with disabilities rely on SSI and SSDI, the potential use of stipends to support engagement, such as those used in Experience Corps, will need to be explored further to ensure that they do not interfere with the receipt of benefits.

Benefits and Disadvantages of Participation for Adults with Disabilities

Participation in volunteer and community activities appears to have many benefits for adults with disabilities, such as increasing opportunities for socialization, fostering a sense of purpose, and learning new skills (Balandin et al., 2006; Hansji et al., 2015; Hjelle & Vik, 2011; Silverman et al., 2017; Stancliffe et al., 2015; Trembath et al., 2010) For example, in Silverman and colleagues' study of adults with MS and their caregivers, participants and caregiver discussed the importance of participation in meaningful activities as a way to develop a sense of purpose and stay engaged in life. In a mixed methods study evaluating a mentorship program between Australian adults with disabilities and community partners, Stancliffe and colleagues found that most of the participants were able to attend their community group once a week for at least half a year and that they also increased their level of community participation. Similarly, many volunteers noted how volunteering allowed them to meet people and develop new

friendships (Balandin et al., 2006; Hansji et al., 2015; Trembath et al., 2010). In addition, volunteers noted how important it was to use their own skills and knowledge and to feel like they could contribute and make a difference (Balandin et al., 2006; Trembath et al., 2010). Finally, the majority of volunteers in the study by Trembath et al., (2010) discussed skills they had learned, such as reading reports and how to serve as board members, that they felt could help them transition into paid positions.

Research has also identified potential drawbacks to social and community participation, particularly volunteerism, among adults with disabilities. Similar to the literature reviewed in previous sections, financial costs associated with volunteering may become a burden for adults with disabilities (Trembath et al., 2010). Participation may also exacerbate secondary conditions, such as pain or fatigue, or interfere with care routine (Balandin et al., 2006). People with disabilities may also experience negative social attitudes or structural barriers to participation that cause emotional stress (Raymond et al., 2014). Finally, volunteering may take time away from other activities of interest or from paid employment (Balandin et al., 2006).

Summary of Volunteerism and Community Participation among Adults with Disabilities

Review of the literature in this sub-section suggests people with disabilities are less likely to be involved in formal volunteer activities as compared to their non-disabled peers and that there are several important elements at the individual and community level that can facilitate or impede participation. First, intersections between gender, race, age, education, income, and disability appear to impact participation. Second, the primary impairment and secondary health conditions, such as pain, fatigue, and depression, can make it more difficult to participate. Third, physically inaccessible environments and negative social attitudes can impede participation. However, there are also several factors at the individual level that can facilitate participation, such as higher levels of self-esteem and self-efficacy, coping skills, use of assistive devices, social support, and modifications to the home environment.

In terms of activities engaged in and benefits of participation, people with disabilities are often involved with disability-related organizations. However, they may also volunteer with religious organizations and other non-profits. Participation can help people with disabilities to meet new people, feel more connected with their communities, help them develop a sense of purpose, and help them to develop new skills. However, participation can be financially expensive, it can take time from other valued activities, and it can exacerbate health conditions or hurt a person's self-esteem if they experience negative social attitudes.

Critique of the Literature

This section provides a critique of the quantitative and qualitative literature on volunteerism among older adults and volunteerism and community participation of adults with disabilities reviewed in this chapter. In particular, the use of theory, quantitative methods, and qualitative methods are evaluated in this section.

Critique of Quantitative Studies

Use of theory. In quantitative research, theories can provide a systematic view and conceptual framework for exploring topics and are often used to develop the hypotheses and relationships between variables that will be tested in a model (Creswell, 2014). The quantitative studies reviewed in this paper generally use one or more of the conceptual frameworks discussed in this chapter as a rationale for the study (i.e. Clarke & Latham, 2014; Krause & Coker, 2006; Tang, 2006) or to help explain phenomena (Yorkston et al., 2010). For example, several studies used the life course perspective as a rationale for the study (Clarke & Latham, 2014; Tang, 2006). In addition, the majority of studies on participation by people with disabilities are guided by the ICF conceptual framework. Finally, several articles did not explicitly use a theory. For example, some of the quantitative studies on aging with a disability (Cook, Molton, & Jensen, 2011; McColl et al., 2004; Rosso et al., 2011; Molton, Cook et al., 2014; Molton, Terrill et al., 2014) and a few of the studies on volunteerism among older adults or participation among people

with disabilities (Ahn, Phillips, Smith, & Ory, 2011; Butrica et al., 2009; Kaskie et al., 2008; Rak & Spencer, 2016; Tang, Morrow-Howell, & Choi, 2010) did not explicitly use any theory.

Methodological Issues

Research design. Overall, the strength of studies varies considerably, ranging from randomized control trials to cross-sectional studies without representative data or comparison groups. The literature on volunteerism among older adults includes some of the strongest studies, with two randomized control trials of the Experience Corps volunteer program (Fried et al., 2013; Parisi et al., 2015). A randomized control trial is particularly useful in reducing spurious causality and bias (Singleton & Straits, 2010). Several studies use a longitudinal design, with multiple waves of nationally representative data, often controlling for gender, race, education, income, and ADLs/IADLs (Butrica et al., 2009; Choi, 2003; Han & Hong, 2013; McNamara & Gonzales, 2011; Tang, 2006). While longitudinal designs do not allow for the determination of causality, they can be useful in studying changes over time (Singleton & Straits, 2010). One study used a quasi-experimental, pre-test/post-test design with a matched control group, allowing for the elimination of prior differences (Hong & Morrow-Howell, 2010) whereas others did not include a control group (e.g. Chen & Morrow-Howell, 2015; Hong & Morrow-Howell, 2013; Tang, Choi, & Morrow-Howell, 2010). Several studies used a cross-sectional design with nationally representative samples (e.g., Johnson & Lee, 2017). In addition, some studies used a cross-sectional design with (Tang et al., 2012) and without (Kaskie et al., 2008; Lee & Brudney, 2012; Rak & Spencer, 2016) matched comparison groups. Cross-sectional designs are useful for describing relationship patterns between variables rather than establishing causation (Singleton & Straits, 2010).

In the aging with disability literature, articles reviewed used a range of research designs. Two articles used longitudinal designs. The first used multiple waves of data from nationally representative secondary data sets (Clarke & Latham, 2014), and the second used survey data collected from individuals over 30 years (Krause & Coker, 2006). Another study collected data

for four years from a convenience sample (Silverman et al., 2015). Two studies used a cross-sectional design, with a matched comparison (Cook et al., 2011; Molton, Cook et al., 2014). Finally, articles reviewed in the social and community participation literature often use convenience samples without matched comparison groups, reducing the generalizability of the findings (Benka et al., 2016; Cardol et al., 2002; Silva et al., 2016; Yorkston, Bamer, Johnson, & Amtmann, 2012).

Sampling. Across the studies reviewed, sample sizes and representativeness varied greatly, from large nationally representative samples to small convenience samples. For example, several studies used secondary data sets to draw large, nationally representative samples (i.e. Clarke & Latham, 2014; Han & Hong, 2013; McNamara & Gonzales, 2011; Silverman et al., 2015; Tang, 2006). Others drew from large convenience samples from volunteer programs (i.e. Chen & Morrow-Howell, 2015; Hong & Morrow-Howell, 2013) or from participants in a larger longitudinal study (McColl et al., 2004; Silverman et al., 2015). A few studies included small convenience samples (Mui, et al., 2013; Silva et al., 2016), making it difficult to generalize to a larger population.

In addition to a range of studies with varying sample sizes, there was also a wide range of diagnostic conditions included. For example, some studies focused only on one diagnostic condition (i.e. Barf et al., 2009; Benka et al., 2016; Silva et al., 2015). Others included multiple conditions (Cardol et al., 2002; Yorkston et al., 2012). Finally, within the volunteer literature, many studies focused on or included Experience Corps participants (Chen & Morrow-Howell, 2015; Fried et al., 2013; Hong & Morrow-Howell, 2013; Martinez et al., 2006; Parisi et al., 2015). As this is an intensive, education-focused volunteer opportunity, results may not be representative of many older adult volunteers.

Measurement. The studies reviewed have several measurement issues. As noted earlier, some of the articles on volunteerism among older adults lack any measure of functional limitation or disability (Lee & Brudney, 2012; Morrow-Howell et al., 2009; Morrow-Howell,

Lee, McCrary, & McBride, 2014). The social and community participation literature often uses one of three measures: IPA, P-Scale, and WHODAS II. While all of the measures have been shown to be valid and reliable (Noonan et al., 2009), the studies include different sub-categories and examine aggregate participation instead of unique aspects of participation (i.e., informal volunteering). For example, the IPA includes a specific section on formal volunteer work and includes a question about informal volunteering, the P-Scale only includes one question on informal volunteering, and the WHODAS II only asks about difficulty accessing services and institutions in the community (Chisolm, Abrams, McArdle, Wilson, & Doyle, 2005; Noonan et al., 2009; Van Brakel et al., 2006). This makes it difficult to determine what factors might be associated with different forms of social and community participation.

Critique of Qualitative Studies

Use of theory. In qualitative studies, theory may be used as a broad explanation of phenomena or as a theoretical lens to study experiences of marginalized populations (Creswell, 2014). Of the qualitative articles reviewed in this paper, one used the life course perspective to help explain aging with a disability (Grassman et al., 2012), one used the ICF to guide study of what participation means to people with disabilities (Hammel et al., 2008), and several did not include a theoretical framework (Balandin et al., 2006; Hansji et al., 2015; Trembath et al., 2010).

Methodological Issues

Research design. Qualitative studies reviewed generally use focus groups and in-depth interviews (Balandin et al., 2006; Bishop & Hobson, 2015; Hammel et al., 2008; Trembath et al., 2010). One study tracked participants for 30 years (i.e. Grassman et al., 2012), and another used an ethnographic design to observe the participation of men with disabilities (Hansji et al., 2015). Several of the studies combined different types of disabilities, such as intellectual and developmental disabilities, physical disabilities, and mental-health-related disabilities (Balandin et al., 2006; Bishop & Hobson, 2015). While this provides useful information about the

experiences and challenges of aging with a disability and participation, it may lead to over-simplification, as some types of disabilities may face unique barriers as compared to others. A potentially more useful approach would be to explore experiences by type of disability and then compare and contrast experiences to present a larger picture.

Recruitment. Qualitative studies reviewed used purposive samples. One included participants from a single program (Hansji et al., 2015), and others were recruited with the help of disability organizations (Bishop & Hobson, 2015; Balandin et al., 2006; Stancliffe et al., 2015). The use of a single program may limit the transferability of the findings to other population groups.

Rigor. The rigor or trustworthiness of articles varied, with some having a high level of rigor (Balandin et al., 2006; Hansji et al., 2015; Trembath et al., 2010) and others having a lower level (Bishop & Hobson, 2015). The article by Trembath et al., (2010) is an example of a rigorous qualitative design. The authors included a statement about their backgrounds and beliefs to help the readers understand both the expertise of the researchers and any potential biases. In addition, the researchers ensured the credibility of their work by having participants review data collected and interpretations made by the authors. However, some of the articles reviewed do not provide enough detail to reliably follow methods used or to repeat the study. For example, Bishop and Hobson (2015) used focus groups and follow-up interviews. However, in their analysis they often did not explain which data came from the focus groups and which from the individual interviews. This lack of clarity makes it difficult to determine what topics were brought up in the focus group and which responses were the result of questions asked in the interviews.

Critique Summary

Overall, the research studies reviewed in this paper varied from strong studies using randomized control trials or rigorous qualitative designs to weaker studies using cross-sectional designs and convenience samples or qualitative studies with limited trustworthiness. As many of

the studies reviewed are cross-sectional, it is not possible to determine causality, hence much of the knowledge base is built on correlations. Limitations of the literature reviewed include: lack of use of theory, less robust research designs, samples that combined different types of disabilities, and use of a variety of participation measures. In order to better understand participation in volunteer activities by people aging with a disability, these limitations need to be addressed. In particular, a qualitative design that can explore the experiences of older adults with mobility-limiting disabilities is needed.

Synthesis and Conceptual Model

In order to develop a more comprehensive understanding of participation in volunteer activities by older adults with disabilities, a synthesis of the preceding review will highlight similarities and differences in findings and identify gaps in our knowledge base. The results of the synthesis will be used to suggest important questions that could be examined in a study of volunteerism among older adults with disabilities.

Similarities

Overall, there is considerable consistency in terms of the findings between the literature on volunteerism among older adults and that on volunteerism and community participation by adults with disabilities (see Table 1). Motivations for participation and individual level factors including gender, race, age, education and income, self-esteem and self-efficacy, social support, and mental health appear to be common factors associated with participation in both literature bases. For example, motivations for participation, such as a desire to give back to others and to meet new people, appear to be similar for people with disabilities and other older adults. In addition, women with and without disabilities are more likely to be involved in formal volunteer activities than men, and Whites, both with and without disabilities, are more likely to be involved in formal volunteer activities than African American or Hispanics. Interestingly, African Americans and Hispanics appear to participate in informal volunteer activities at a similar rate to Whites. However, as the studies reviewed did not focus on the intersection of race and disability,

it is unclear whether these trends hold true for the population aging with a disability. For both older adults and people with disabilities, it appears that younger segments of the older population are more likely to volunteer. In addition, education and income are strongly related to participation among people with and without disabilities. Having better physical and mental health and more social support also appear to be important factors for participation for older adults with and without disabilities.

There are also similarities in the findings on benefits and drawbacks of participation. While the literature on volunteerism among all older adults has studied potential physical and mental health benefits in more depth, both literature bases suggest that individuals who volunteer can gain useful skills and develop new friendships. In addition, volunteering appears to provide a sense of emotional fulfillment, as participation provides an opportunity for volunteers to give back to their communities. Finally, the literature also suggests that the potential drawbacks to volunteering are similar. For example, the financial costs, the possibility of overworking oneself, and the time commitment associated with volunteering are similar between the two literature bases.

Differences

While there appears to be some consistency across the literature, there are also notable differences and gaps (see Table 1). First, while many studies emphasize the importance of being healthy, the literature on disabilities includes a focus on secondary conditions that is absent from the literature on volunteerism among older adults. In addition, the literature on people with disabilities includes a discussion of coping strategies to deal with environmental barriers to participation that is absent from literature on volunteerism among older adults.

Second, while the literature on social and community participation and disability in later-life provides a wealth of information about the role of the natural and built environments in facilitating participation in general, there has been less focus on their potential impact on volunteerism specifically. Moreover, these topics are largely absent from the literatures on

volunteerism among older adults. While organizational facilitation has been studied within the literature on volunteerism among older adults, there is not specific information on how volunteer organizations could accommodate and support older adults with disabilities. Findings from the literature on participation by people with disabilities suggest that negative social attitudes can be a barrier to participation. This topic is largely absent from studies of facilitators of participation for older adults more generally. While the literature on volunteerism among older adults has explored the topic of including stipends, particularly to offset transportation costs, the focus in the disability literature has been on the accessibility of transportation. Finally, the role of assistive technology in facilitating participation has been explored in the disability literature, but is largely absent from the literature on volunteerism among older adults.

Table 1 *Similarities and Differences in Findings between Older Adult Volunteerism and Volunteerism and Community Participation for those with Disabilities.*

Similarities	Differences
• Motivation • Impact of Gender • Race • Age • Education and Income • Social support • Self-esteem and Self-efficacy • Health • Benefits • Drawbacks	• Role of secondary conditions • Coping strategies • Role of the built and natural environment • Organizational facilitation • Role of social attitudes • Role of transportation • Role of assistive technology

Knowledge Gaps

Thus, while the literature provides some guidance, there are still many outstanding questions at the individual, community, and macro levels (see Table 2). There is a need to look more closely at how the concepts in Table 1 are applied to the experiences of older adults with mobility-limiting disabilities who are engaged in volunteer work. In particular, there is a need to explore how these concepts are similar or different for those who have aged with a disability and

those who have aged into disability. First, information is needed on how motivations for older adults with disabilities compare to both older adults in general in the United States and to the motivations noted in the studies of older adults with disabilities in Australia. Knowledge about how motivations compare between those who age with and into disabilities is also needed. Second, while we have knowledge about the factors that could impact volunteerism among older adults and social and community participation for people with disabilities in general at the micro, meso, and macro level, we need more specific information about how these elements impact volunteerism for older adults with disabilities. Volunteerism is different from general social and community participation as it requires a regular schedule, educating others about disabilities, and being seen and accepted as someone who can volunteer. Developing this knowledge base is especially important for developing interventions that can increase the recruitment and retention of older adults with disabilities in volunteer activities.

Table 2 *Knowledge Gaps in Studying Volunteerism among Older Adults with Mobility-limiting Disabilities*

Micro Level	Meso Level	Macro Level
• How motivations are similar or different	• Influence of social attitudes at the community level and within volunteer organizations	• Cultural/societal views towards disability
• Role of physical and psychological impact of impairment		• Policy and regulatory systems
• Role of age of onset	• Influence of the physical environment in the community and within volunteer organizations	
• Role of secondary conditions		
• Coping strategies used	• Organizational facilitators of participation	
• Role of assistive devices used	• Benefits to community and organizations	
• Individual strengths	• Drawbacks for community and organizations	
• Benefits for people with disabilities		
• Drawbacks for people with disabilities	• Role of transportation	

Literature Review Chapter Summary

When they retire or are forced to leave the labor force, people with disabilities may lose access to social connections and opportunities to participate in personally meaningful activities. In addition, people with disabilities who have not been in the labor force are often socially isolated (Schur et al., 2013). Participation in volunteer activities could help fill that void. People with disabilities have valuable insights and abilities that could be an asset to many organizations and community groups (Miller et al., 2005). However, there is relatively little information on volunteerism among older adults with disabilities. This chapter reviewed and critiqued four

conceptual frameworks and literature related to volunteerism among older adults and social and community participation among people with disabilities. This analysis suggests that there is limited information on what volunteerism looks like for older adults with disabilities, particularly those with mobility-limiting disabilities. In order to begin to address this gap in knowledge, a qualitative study, guided by the conceptual framework, presented earlier in this chapter, and review of the literature, is proposed. The purpose of this study is to explore in much greater depth the experiences of older adults with mobility-limiting disabilities who engage in formal volunteer activities. The following key research questions will be examined:

1. Why do older adults with mobility-limiting disabilities engage in formal volunteer activities?
2. What characteristics, at the individual or environmental level, might facilitate participation of older adults with mobility-limiting disabilities in formal volunteer activities?
3. What characteristics, at the individual or environmental level, might prevent participation of older adults with mobility-limiting disabilities in formal volunteer activities?
4. How do older adults with mobility-limiting disabilities describe the benefits and drawbacks of participating in formal volunteer activities?

Chapter 3: Methods

This chapter presents the research methods used in this study. The chapter begins with an overview of the rationale for a qualitative approach and the paradigm and research methodology used for the inquiry. The next section presents the research questions and key concepts of the study and their definitions. The third section discusses the methods used in this study and is organized by: study preparation, data collection, quality criteria, and data analysis. This exploratory qualitative research design draws from naturalistic inquiry (Erlandson, Harris, Skipper, & Allen, 1993; Lincoln & Guba, 1985) and uses in-depth interviews with older adults with a mobility-limiting disability to explore their experiences and perceptions relating to engaging in volunteer activities. Mobility-limiting disability refers to individuals who identify as having serious difficulty walking or climbing stairs (Brault, Stern, & Raglin, 2007).

Research Design and Paradigm for Inquiry

Rationale for the Research Design

A qualitative design is used for this study for three reasons. First, as seen in the literature review, there is little information about volunteerism among older adults with mobility-limiting disabilities. Creswell (2014) suggests that qualitative methods are particularly useful for exploring topics where little information is available or if previous knowledge may not apply to certain groups. Given the limited information about the experiences of older adults with mobility limiting-disabilities and the potential differences between those who have aged with and into disabilities, a qualitative approach may help to better our understanding of how findings from the literature on older adults in general may or may not apply to those with disabilities.

Second, volunteerism among older adults has largely been explored with quantitative methods. While these studies have provided a wealth of information, a qualitative inquiry allows

for a deeper and potentially more holistic investigation of volunteerism (Padgett, 2008). In particular, qualitative methods can help to expand on some of the quantitative findings in the existing literature, for example, that functional limitations or poor health reduce the likelihood of volunteerism (Butrica et al., 2009). Qualitative methods may also provide a better understanding of underlying processes behind some of these findings, e.g., having an inaccessible home or intermittent physical pain that may make volunteering difficult. Qualitative methods may also help to identify ways of overcoming some of the potential barriers, such as functional limitations, highlighted in the literature.

Third, the intent of this study is to gain rich information on the facilitators and barriers to participation from the unique perspectives of older adults with mobility disabilities. Qualitative methods are particularly useful for exploring how individuals understand and make meaning from their lived experiences (Padgett, 2008). A qualitative approach is also helpful for ensuring that the study includes the voices and ideas of people with disabilities. In this study, qualitative methods can help us learn how participants have understood and come to terms with their mobility limitations and how this impacts their health, well-being, and ability to participate in volunteer activities.

Research Design: Paradigm for Inquiry

In order to understand the volunteer experiences of older adult with mobility-limiting impairments who engage in volunteer activities, the paradigm or conceptual foundation for this study is social constructionism. The research methodology used in this study is drawn from naturalistic inquiry (Erlandson et al., 1993; Lincoln & Guba, 1985) and is consistent with social constructionism.

Like the social constructionist paradigm, naturalistic inquiry is founded on the assumption that reality is created through our interactions and interpretations of our involvements with the natural and social world, with the researcher working to understand both the unique experiences of individual participants and how those experiences come together to paint a picture of a shared reality (Erlandson et al., 1993; Lincoln & Guba, 1985). As noted by Erlandson and colleagues (1993), "Because all the "parts" of reality are interrelated, an understanding of the "whole" can begin with a holistic investigation of any portion of it" (pg. 14). This study is naturalistic in that it explores the experiences, both negative and positive, of older adults with mobility-limiting disabilities. The nature and meanings ascribed to those experiences are uncovered through interviews with the participants (Patton, 2015; Padgett, 2008).

The goal of naturalistic inquiry is not generalizability, but rather to develop a rich and holistic understanding of a particular phenomenon within certain contexts; other scholars and practitioners may instead examine these qualitative findings to determine if they are transferable to their particular context (Erlandson et al., 1993; Lincoln & Guba, 1985). There are several key concepts to consider when conducting a naturalistic inquiry. First, naturalistic studies follow an emergent design. This means that the researcher develops some structure to guide the study but that much of the study is emergent (Erlandson et al., 1993; Lincoln & Guba, 1985). For example, in contrast to other approaches, in a naturalistic design, participants are not selected prior to beginning the study, rather they are identified based on the potential information they can add to the study as part of an iterative process between preliminary data analysis and selecting new participants (Erlandson et al., 1993; Lincoln & Guba, 1985). An emergent design is particularly

useful both for addressing complex issues and for working with groups who have not been included in mainstream discourse (Hesse-Biber & Leavy, 2010).

Second, while theories or conceptual frameworks are often used to help inform naturalistic inquiries, studies using this approach focus on developing emergent theory grounded in the data collected, instead of directly applying and testing existing theories (Erlandson et al., 1993; Lincoln & Guba, 1985). Theories and perspectives may be examined more closely once the study is conducted for their applicability, consistency, and differences with the findings.

Third, this orientation to research recognizes that the researcher and participants interact with each other as part of the research process and that this collaboration informs the study (Erlandson et al., 1993; Lincoln & Guba, 1985). As noted by Lincoln and Guba (1985), the researcher's role in shaping the study and interacting with participants can create bias, and the researcher must acknowledge and take steps to control the bias (see Research as Instrument discussion below).

Fourth, naturalistic inquiry is best conducted within natural settings, such as homes or places of work, instead of in laboratories or other controlled settings (Erlandson et al., 1993; Lincoln & Guba, 1985). More familiar setting can help put the participant at ease and provide important information about the individual's lived experience.

Finally, the quality of a naturalistic study is judged on the trustworthiness of the investigation (Erlandson et al., 1993; Lincoln & Guba, 1985). Trustworthiness, discussed in greater detail below, focuses on the authenticity of the findings and is evaluated by looking at the truthfulness, the applicability, and the consistency of the findings (Erlandson et al., 1993; Lincoln & Guba, 1985).

Social constructionism and naturalistic inquiry help the researcher to explore the experiences and meaning-making of participants. One specific strategy chosen for this study is in-depth, semi-structured interviews. This approach to data collection is consistent with naturalistic inquiry and is a useful way to explore complex topics, as interviews can help "the researcher to understand and put into a larger context the interpersonal, social, and cultural aspects of the environment" (Erlandson et al., 1993, p. 85). In addition, unlike observational or survey studies (with close-ended questions), interviews provide an important forum for participants to directly share the complex nature of their experiences and for the researcher to follow up with participants to explore areas that emerge from the participants' responses to initial interview questions.

My research, including the construction of my interview guide, and my presentation of findings are informed by the theoretical frameworks or concepts reviewed in Ch.2. These are: social constructionism, the International Classification of Functioning, Disability, and Health (ICF), the life course perspective and strengths perspective, and the ecological perspective. These theoretical underpinnings, which focus on both the individual and systems level, as well as the interactions between levels, helped to synthesize findings and to develop a more holistic picture of both the individual who volunteers and aspects of the social and physical environment that influence their participation. Findings from this study also provide insights into how use of these theoretical concepts can aid in understanding volunteerism among older adults with mobility-limiting disabilities.

Re-Statement of the Research Questions

As stated earlier, the purpose of this study is to explore the experiences of older adults with mobility-limiting disabilities who engage in formal volunteer activities. The research questions used to guide the investigation of participants' experiences include:

1. Why do older adults with mobility-limiting disabilities engage in formal volunteer activities?

2. What characteristics, at the individual or environmental level, might facilitate participation of older adults with mobility-limiting disabilities in formal volunteer activities?

3. What characteristics, at the individual or environmental level, might prevent participation of older adults with mobility-limiting disabilities in formal volunteer activities?

4. How do older adults with mobility-limiting disabilities describe the benefits and drawbacks of participating in formal volunteer activities?

Key Concept Definitions

There are several key concepts that guide this study including: formal vs. informal volunteerism, aging with vs. into disabilities, barriers to participation, facilitators of participation, individual level, environmental level, benefits of participation, and drawbacks to participation. Definitions for these terms are provided to help contextualize participants' responses.

Formal volunteerism vs. informal volunteerism. As noted earlier, formal volunteerism refers to activities done for little to no compensation through the auspices of an organization. Organizations may include for-profit, non-profit, or civic groups aimed at providing guidance or

services to individuals or the community. Informal volunteering, in contrast, refers to helping friends and neighbors and is not done with or for an organization.

Aging with disabilities vs. aging into disabilities. Many studies have used a variety of definitions or approaches to distinguish between those aging with and into disabilities. Based on discussions with the key informant, who has aged with a disability (see discussion below), this study uses the conceptual definition suggested by Kemp and Mosqueda (2004) and Verbrugge & Yang (2002) that "aging with disabilities" refers to an individual who was born with or acquired a disability early in life and "aging into disability" refers to a person who developed a disability in mid or later life. This definition was chosen as the key informant felt that there would likely be differences between those who were born with or acquired a disability in their 20s and those who acquired a disability in mid or later life in terms of their access to education and employment and experiences growing up with a disability in a pre-ADA world.

Barriers to participation. Following the WHO (2001) definition noted earlier, barriers to participation in this study include any physical structures, negative social attitudes, or limitations to accessing resources, at either the individual or environmental level that make it difficult or impossible for study participants to volunteer with organizations.

Facilitators of participation. As with barriers, the WHO (2001) definition informs the facilitators of participation. In this study, this term refers to both the absence, intentional or otherwise, of barriers to participation and to the approaches or resources that participants use to overcome any impediments encountered.

Individual level. Drawing from the ICF (WHO, 2001) and the ecological perspective (Bronfenbrenner, 1977), this term refers to both the person themselves and any facilitators or barriers to participation that the person may experience in the home or immediate social

environment. Starting with the person, this term includes the person's health condition, secondary conditions they may experience, and any coping skills that they employ. The person's immediate social milieu includes any support that the person receives from family members.

Environmental level. Informed by both the ICF (WHO, 2001) and the ecological perspective (Bronfenbrenner, 1977), this term refers to the broader social and physical structures that influence a person's life. For this study, the environmental level focuses on the volunteer organizations, the geographic community in which the person lives, and the person's connections to larger communities, such as the disability community or aging community.

Benefits of participation. As noted in the literature, there are many potential benefits to participation. This term includes benefits to the individual, the volunteer organization, and the community. Benefits are defined as any positive outcomes that participants believe have come as a result of their participation.

Drawbacks to participation. In this study, drawbacks can be to the individual, the organization, or the community. This term refers to any negative experiences or costs associated with the person's participation as defined by the research participant.

Study Methods

The methods for this study, as noted above, are informed by naturalistic inquiry (Erlandson et al., 1993; Lincoln & Guba, 1985). Strategies presented by Padgett (2008) and Patton (2015) also guide the methods. This section reviews the following topics: phases of inquiry, protection of human subjects, data collection, and data analysis.

Phases of Inquiry

This study was conducted over the course of one year and six months (See Appendix A for study timeline). During the first phase, which lasted seven months, the interview guide and

recruitment flier were developed and approval of the study was sought from the Human Subjects Committee at the University of Kansas, Lawrence Campus. A pilot of the interview was conducted (discussed below) to test the interview guide.

In the second phase, study participants were recruited from three Midwest towns via fliers posted at libraries and online and with the assistance of the key informant, and interviews were conducted. During this phase, participant recruitment and data analysis occurred in an iterative fashion, with the researcher identifying tentative codes and ideas to explore in greater depth. The second phase lasted eight months and is inclusive of both initial and follow-up member checks to review and clarify comments. Two audit checks occurred during this phase with the research methodologist, Dr. Koenig, and peer debriefings with two doctoral students occurred during this phase for the purpose of processing the data collection and analysis process and for examining the researcher's own reactions and reflections on the findings.

The third phase, data analysis, occurred over five months. During this phase, the researcher refined the coding guide and conducted an in-depth analysis of the data using the constant comparative method (Corbin & Strauss, 1990). The constant comparative method involves using an iterative process of moving back and forth between tentative codes and transcripts to compare, contrast, and develop a preliminary coding guide that incorporates analyses both within and across interviews. A final coding guide was then developed and used to re-code the pilot interview; the researcher and the participant from the pilot study reviewed the final coded transcript to ensure that thoughts and ideas were reported accurately. A final audit check with the methodologist and a review of the findings with the key informant were also conducted during this phase.

Protection of Human Subjects

In order to insure that necessary safeguards were in place to protect the well-being and confidentiality of participants, approval for the study was obtained from the University of Kansas, Human Subjects Committee Lawrence (HSCL) (see Appendix B for Human Subjects permissions). Three forms were submitted to and approved by the HSCL: the informed consent letter (see Appendix C) recruitment flier (see Appendix D), and the initial interview guide (see Appendix E). Written informed-consent forms were developed in accordance with HSCL requirements, and signed informed-consent forms were required by all participants prior to the start of any data collection activity. These forms ensured informed consent of participants and addressed several topics, such as study procedures, risks, benefits, payments, confidentiality, and right to terminate the agreement.

Data Collection

In this study, data collection included several steps and considerations. The following subsections explain the data collection process: the researcher as the instrument of data collection, the selection and recruitment of participants, the use of a key informant, the development and use of the interview guide, and steps taken to ensure the quality of the study.

Researcher as study instrument of data collection. As the researcher, my worldview and experiences as both a Peace Corps volunteer and in working with older adults and people with disabilities shaped the development and implementation of this study. In addition, my experiences as a person without functional limitations has shaped my interactions with the environment and with people with disabilities. This section addresses what I bring to the study in my role as researcher as instrument (Patton, 2015).

My interest in this topic stems from my experiences as a Peace Corps volunteer and my work with older adult volunteers and people with disabilities. As a volunteer, I was able to work with several older women in my Jamaican village to start a women's group. My work with them helped me realize that I wanted to pursue a career in social work, centered on older adults. As such, my MSW program course work and practicums focused on working with older adults. I also had the opportunity, through volunteering, to work with older adult volunteers who had developed the LGBT Elder Initiative to help support LGBT older adults in Philadelphia. My work with older adults, particularly those involved in volunteer activities, helped me to realize that this was a topic that I wanted to explore in more depth.

Throughout my PhD work, I have focused on volunteerism among older adults. However, in working on a project with people with disabilities, my focus changed slightly. During focus groups and interviews with people with disabilities as part of this project, I heard participants discuss how much they wanted to be involved in their communities. They wanted to be employed or volunteering, but they were not given the chance to do either. This helped me to reflect on my own work and our social work knowledge base to better understand what we were doing to support people with disabilities, particularly older adults with disabilities who wanted to volunteer. In reviewing the literature, I found that there was very little information about or guidance on how to include older adults with disabilities.

This discovery formed the basis for the rationale for this study. My life experiences and perspectives have also shaped the development of this study in several ways. First, as a former Peace Corps volunteer, I recognize that volunteering can have a wide variety of benefits for individuals, but that it can also be a very challenging endeavor. I believe that volunteering can be a great experience for an individual. However, I also recognize that volunteerism is not a one-

size-fits-all situation and that volunteering can have negative consequences, such as detriments to a person's physical or mental health. Second, I believe that volunteer opportunities should be made available to anyone who is interested, but I also recognize that there might be many social and financial challenges to including everyone. Third, I recognized at the start of the study that, as a person without a physical disability, I have not had the negative experiences or challenges that the participants in my study have had. As such, I have tried to develop rapport with the participants, learn from the participants, and create a safe space for them to talk about both their success and their challenges. I have also, as seen below, taken steps to ensure that my interpretation of the findings are an accurate reflection of their experiences.

Selecting participants. Naturalistic inquiry focuses on purposeful rather than representative sampling, with participants selected based on the belief that they can provide new and important information (Lincoln & Guba, 1985). To qualify for the study, participants had to meet the following initial selection criteria:

1. Identify as having serious difficulty walking or climbing stairs due to a health condition or impairment;

2. Be 50-80 years of age at the time of the interview;

3. Have volunteered in the last year;

4. Live in a non-institutional setting (e.g. not in a nursing home);

5. Communicate in English;

6. Does not have a legal guardian and is cognitively capable of participating in the interview.

This definition is similar to the one used in the American Community Survey to identify people with mobility impairments, but the term "due to a health condition or impairment" was added by

the researcher in order to increase the likelihood of recruiting individuals with a physical

impairment. Further, the term disability was not used in the recruitment flier, as both the

researcher and key informant felt that this term might not be inclusive for older adults with

mobility-limitations who may not consider themselves to have a disability. The researcher chose

the age range of 50-80 for two reasons. First, the onset or worsening of some health conditions

associated with mobility-limiting disabilities, such as Multiple Sclerosis (MS) and post-polio,

cause individuals to transition out of the labor force in their 40s and 50s (Mitchell et al., 2006).

Second, while the life expectancy for many people aging with disabilities has increased, it still

tends to be lower than that of people without disabilities (Kemp & Mosquenda, 2004). The lower

age range allows this study to be more inclusive of the experiences of both people aging with and

into disabilities.

15-20 interviews were planned in order to be able to compare findings between those

aging with and into disability and was able to complete 20 interviews. An iterative process

between initial analysis of data and selection of new participants was used, with new participants

recruited after every two to three interviews. Participants in this study were also selected

purposively according to the following criteria: (a) type of health condition and age of onset; (b)

gender; (c) race; (d) age; and (e) education level.

Priority was given to the first criterion in order to develop a sample that was both

balanced between those aging with and into disability and included a variety of health

conditions. Criteria two to five were selected since the literature (reviewed in Chapter 2)

suggests that there are differences in terms of participation based on gender, race, age, and

education. For this study, the researcher sampled for maximum variation in terms of gender,

race, age, and education in order to include multiple perspectives and to better understand the

intersection of these criterion with having a disability. Maximum variation refers to attempts by the researcher to develop a heterogeneous sample based on the selection criteria, such that a variety of experiences and viewpoints are represented in the sample (Padgett, 2008).

Participants were recruited in four ways. First, seven potential participants were contacted via the key informant (see below) and the initial participant who completed the pilot study. The key informant and initial participant sent the flier to people that they believed would be interested in participating. Second, fliers were placed in community libraries, recreational facilities, a local senior center, and at area Centers for Independent Living. Third, the flier was posted by a Facebook group focused on supporting the health and well-being of people with disabilities in the state. Fourth, participants were asked to identify and pass on the study fliers to acquaintances. On the recruitment fliers, participants who were interested in participating were asked to contact the researcher via email or phone.

The combination of primary and snowball sampling yielded 20 in-depth interviews. Six potential participants were not included in the sample because they did not meet the inclusion criteria of identifying as having serious difficulty walking or climbing stairs. Padgett (2008) suggests that sampling of participants ideally ends when saturation is reached, that is no new information is yielded from additional interviews. Selection of participants was stopped at 20, as the researcher believed that based on a preliminary analysis of the interviews that a depth of understanding corresponding to the overarching purpose of the study had been achieved.

Key informant. A key informant is an individual who is knowledgeable about the topic, has important professional or social connections, and is willing to share expertise and help the researcher make useful connections (Padgett, 2008). For this study, a key informant who has aged with a disability and has knowledge and connections with the aging and disability

communities in the state helped in the development, implementation, and evaluation of the study. First, the key informant suggested potential participants and distributed the recruitment flier to their social network. Second, the key informant reviewed the initial findings and main findings and provided feedback through face-to-face and phone interviews with the researcher.

Interviews. In order to explore the experiences of participants, face-to-face, semi-structured, in-depth interviews (for final interview guide see Appendix G) were conducted with 20 individuals who met the inclusion criteria. A semi-structured interview guide approach (Patton, 2015) provided some structure to ensure that discussions covered similar topics, while also giving enough flexibility to probe more deeply as needed. An initial pilot interview was conducted with a participant who met the inclusion criteria and could provide detailed feedback on the adequacy of the questions. Data from the pilot interview was analyzed and included in the findings.

The researcher spoke to each potential participant in order to determine if they met the inclusion criteria. Interviews were scheduled with those that met the inclusion criteria. Once their interview had been scheduled, participants were sent, via email or read over the phone, an information letter (see Appendix F) about the purpose of the study and the types of questions that would be asked so that they had time to reflect on their experiences before the interviews. Participants were asked to identify where they would like to meet for the interview. The researcher chose this approach in order to ensure that locations would be both accessible and comfortable for participants. Locations included the individual's home, places of employment, at volunteer agencies, and at local libraries or coffee shops. Prior to beginning the interviews, participants were asked to read and sign the consent form and complete a brief demographic

profile. Questions on the profile asked a variety of questions (see Appendix H), such as age, race, type of impairment, age of onset, type of volunteer work, and hours volunteered.

The interviews lasted between fifty minutes and two hours. All interviews were audio recorded. Transcription of the interviews was done by a professional transcriptionist. Participants were provided with a $40 debit card to compensate them and thank them for their time. Follow-up communication and member checks were conducted with fifteen participants via email or by phone for clarification and expansion of ideas. The researcher was unable to get in contact with five of the participants to ask follow-up questions. The researcher transcribed additional data from phone interviews. All information from the first and follow-up interviews are included in the analysis.

Field notes were recorded during interviews and throughout the research process. Field notes are useful for recording the researcher's experiences and understanding of the context and in providing an important source of triangulation (Padgett, 2008). The notes included handwritten and electronic notes. Field notes centered on the major purpose of the study and included observations about the home environment, ability of the person to navigate built environments where interviews took place, and observations of other people's interactions or reactions to participants.

Interview guide. The conceptual framework and literature review (see Chapter 2) informed the development of the interview questions and probes. Example questions asked during the interview that are based on the overarching research questions for the study included:

- Can you tell me a little about why you volunteer?
    - When did you start volunteering?
    - Are there aspects of being a volunteer that you particularly like?

- At a personal or individual level, what factors might help you or a person with a mobility limitation in their volunteer work?

  o Do you use any assistive technology or other resources?

  o Family or other supports?

  o What kind of help or support might an older adult with a mobility impairment need to volunteer?

- At a personal or individual level, what factors related to your health or mobility limitation could make it difficult to volunteer?

  o Are there health related factors that limit your ability to volunteer?

  o What challenges in your volunteer work are due to age and which might be due to your impairment?

Participants were encouraged to both share their own experiences and to extrapolate on the barriers and facilitators of participation for other older adults with mobility-disabilities. This was done in order to make things less personal for those who were uncomfortable with sharing their own experiences and to further probe into the opinions and ideas of participants. The interview guide was piloted with a staff member at the Research and Training Center on Independent Living at the University of Kansas. Following an emergent design, the interview guide was adjusted five times as new participants added additional ideas and areas that were worthy of exploration, e.g., questions were added about neighborhood quality and about how organizations could better recruit and support older adults with mobility impairments. Phone calls and emails were used to contact early participants in order to provide them with the opportunity to share their ideas on the new questions.

Design Rigor

In qualitative inquiry, it is important to document and justify that findings presented are based on the data collected. This section describes the steps taken to increase the rigor and trustworthiness of the study.

Trustworthiness

In a naturalistic study, trustworthiness serves a similar function to the concepts of internal and external validity seen in quantitative studies (Lincoln & Guba, 1985; Padgett, 2008; Patton, 2015). According to Padgett, there are three main threats to trustworthiness in qualitative researcher: reactivity, researcher biases, and respondent biases. Reactivity refers to the impact that the researcher's presence can have on an environment, such as causing participants to change their behaviors. Researcher bias can occur when a researcher has preconcieved notions or opinions about the topic and these beliefs cloud their interpretations of the data. Respondent bias refers to the idea that participants may withhold information or may respond in ways that they believe the researcher wants. There are several steps that a researcher can take to protect against threats to trustworthiness, and these are discussed as part of the criteria for judging the trustworthiness of a study including: credibility, transferability, and dependability and confirmability (Lincoln & Guba, 1985).

Credibility. This term refers to the accuracy with which the findings presented are representative of participants' experiences (Lincoln & Guba, 1985). An important aspect of this critierion is recording both where themes are consistent across participants and also where they diverge (Erlandson et al., 1993; Lincoln & Guba, 1985). As the researcher plays a central role in interpreting the realities presented by participants, several steps can be taken to increase the

accuracy of their findings, such as prolonged engagement, member checking, triangulation, negative case examination, field notes, thick description, peer debriefing, and audit checks.

Prolonged engagement provides an important way for the researcher to understand the topic and areas where the researcher may bring in bias and can be done through persistent observation (Erlandson et al., 1993; Lincoln & Guba, 1985). While the researcher did not have the opportunity for ongoing, persistent observation, the researcher was able to connect with participants beyond the initial interview through follow up emails and phone calls in which member checking occurred with participants on their views of tentative themes and inferences. This more extensive engagement assisted the researcher in developing a more holistic picture in which to understand participant interviews.

Member checks serve as an important way to ensure that the researcher's interpretations are an accurate reflection of the participants' experiences (Erlandson et al., 1993; Lincoln & Guba, 1985). In addition, member checks help to protect against all three threats to trustworthiness (Padgett, 2008). The researcher conducted member checks during the interviews by paraphrasing participant's responses throughout the interview and also asking the participant if the summary at the end of the interview was correct. The researcher also conducted member checks with fifteen of the participants through follow-up contact in phone interviews and electronic exchanges asking for clarification and further detail. The researcher was unable to reach or did not receive a response from five participants. The researcher also reviewed the final coded transcript with the participant who participated in the pilot study to help ensure that the codes were a reflection of what the participant discussed. The participant had the opportunity to review the final coding guide, how each of the codes was defined, and how themes were developed from the codes. The participant provided important critical feedback, disagreeing with

the assignment of one of the codes, i.e., walking away. The researcher and participant discussed the code, narrowed the definition of the code, and recoded the section to better reflect the participant's experience. The remaining transcripts were re-coded after the final coding guide had been developed and reviewed with the participant in the pilot study. Finally, the researcher reviewed the findings with the key informant.

Triangulation refers to comparing the researcher's interpretations of the findings with other relevant sources of data or information to achieve a more comprehensive picture (Erlandson et al., 1993; Lincoln & Guba, 1985; Padgett, 2008; Patton, 2015). Triangulation is an important aspect of credibility because it can help to protect against all three threats to trustworthiness. There are several approaches that can be used to triangulate data: *methodological triangulation, data triangulation, analyst triangulation, and interdisciplinary triangulation* (Padgett, 2008; Patton, 2015). The first, *methodological triangulation*, refers to using multiple methods to collect data. The researcher used multiple methods to collect data including in-person interviews, field observations, a demographic data collection sheet, and member checks via telephone and email. The process of checking the findings with the key informant added an additional level of triangulation and led to building credibility of the findings and further insights.

Data triangulation refers to using multiple sources of data. This study compared data from people with different disabilities, experiences, and points of view (e.g. those who did more hands on volunteer work and those who served on boards). Second, the researcher also asked participants to provide information about the age of onset of their disability, assistive devices that they used, and the number and types of organizations that they volunteered with. Third, the researcher recorded field notes and observations for each interview. These field notes consisted

of the researcher's view of their ability to navigate spaces (e.g. walk or wheel in the area where the interview took place), the assistive equipment that the participant used, and negative or positive social interactions that occurred (e.g. people asking to pet a participant's service dog). The researcher compared these notes with the information participants provided on their demographic worksheet and during the interviews. For example, several participants listed that they used a cane or walker and, while they did not use a cane or walker to for assistance during the interview, it became clear that they would use assistive devices only on some occasions such as when they had to walk long distances or were experiencing a lot of pain or fatigue.

Analyst triangulation refers to having multiple analysts review the process and findings. The researcher met with the methodologist and key informant throughout the study to discuss recruitment, interviews, preliminary findings, and final findings. The researcher also conducted three audit trail reviews with the methodologist (discussed in detail below). The audit trail and meetings with the key informant provided the researcher with the opportunity to demonstrate how codes were developed and organized into themes and provided an opportunity for the researcher to receive critical feedback on the development of the coding guide and themes.

Interdisciplinary Triangulation refers to having insights from more than one discipline guide the study. The key informant in this study was chosen due to her experience in disability studies and law and her extensive experience with the disability community. She provided important insights throughout the process, in particular in review of the findings, and helped the researcher think through the development of the overarching themes in this study.

Peer debriefing provides an important opportunity for the researcher to take a step back from the study and receive critical feedback from individuals who have not been as intimately involved in the data collection or analysis. According to Padgett (2008), this is an important

approach to for reducing researcher bias. This approach provides the researcher with the opportunity to test inferences, tentative conclusions, and developing perspectives arising from the data and to discuss potential next steps in the emergent design (Erlandson et al., 1993; Lincoln & Guba, 1985). Importantly, peer debriefing can also challenge the researcher to identify any biases and help ensure that their findings are grounded in the experiences described by the participants (Erlandson et al., 1993; Lincoln & Guba, 1985). For this study, peer debriefing was conducted with two doctoral students and the key informant. Throughout the study, the researcher discussed aspects of the project with one PhD student who has extensive practice experience with the disability community. A second doctoral student, who was less familiar with the topic, provided a critical review. According to Patton (2015), in this type of review a trusted colleague is asked to review the methods and findings and asks critical questions about how the researcher arrived at their conclusions and if there are other ways to interpret the data. Both provided important critical feedback and helped in the development of new insights.

Transferability. This criterion refers to the applicability of the findings to informing other studies. This is not to say that naturalistic inquiry is concerned with generalizability, but rather that knowledge gained from studies using this methodology can be useful if researchers consider the context that informed the study (Erlandson et al., 1993). For this study, the transferability of findings is increased through the use of both purposive sampling techniques to identify information-rich participants and thick descriptions of participants' experiences obtained through initial and member checks (Erlandson et al., 1993; Lincoln & Guba, 1985; Patton, 2015). In part because of thick description, other researchers will be able to gauge whether the findings reported in this study are useful for understanding volunteerism among older adults with mobility-limiting disabilities in other communities and settings.

Dependability and Confirmability. These criteria refer to the degree to which the study's findings are both reliable, the product of participants' experiences and not bias of the researcher, and traceable. Hence, dependability and confirmability rely on a clear accounting of the research process (Lincoln & Guba, 1985; Padgett, 2008). The confirmability of a study depends on the dependability or auditability of the studies procedures.

Dependability is primarily concerned with the process of designing and collecting data and how well these procedures are documented. Dependability was enhanced through peer debriefing, presentation of findings to social work educators at various universities, and discussions with the key informant and methodologist. Presentations and discussions with these groups helped the researcher to think through research issues and refine the coding guide.

The dependability and confirmability of a study is also reliant, in part, on the review and verification of the research process through the use of an audit trail (Lincoln & Guba, 1985; Padgett, 2008). An audit trail includes raw data, field notes, coding, memos of coding decisions, and analysis. The audit trail provides documentation of steps taken and decisions made, for example selection of new participants or choices made during the analysis of the data, such as organizing several of the initial codes into the category "self-esteem", in the course of the study (Erlandson et al., 1993; Lincoln & Guba, 1985). The contents of the audit trail are listed in Appendix I. Dr. Koenig performed three audit checks. The first audit check occurred after nine participants had been interviewed and the review focused on detailing how participants were recruited and how the interviews were proceeding. This audit check led to the inclusion of an additional research probe after the question in the interview guide that asked participants what advice they would give to an older adult with a mobility-limiting disability who was interested in becoming a volunteer. Responses to the initial question were all very similar and somewhat

simplistic "just go for it". A probe was added to this initial question asking participants how they would support or mentor another older adult with a mobility-limiting disability who was interested in volunteering. The second audit check focused on reviewing the initial coding guide and discussing preliminary findings. This discussion helped the researcher to better refine codes into categories (e.g. self-esteem) and themes and to begin to think about how the themes fit together. The final audit check included a detailed demonstration of how the codes were developed (e.g. review of codes in actual transcripts) and organized into categories and themes (e.g. tracing the code from the raw data to how it fits with other codes to form categories and the overall themes). The researcher and methodologist also reviewed the field notes and data collected from the member checks.

Data Analysis

For this study, the researcher used the constant comparative data analysis method from the grounded theory framework of Corbin and Strauss (1990). This approach to data analysis is consistent with naturalistic inquiry (Patton, 2015). Using the constant comparative method, a researcher constantly compares units of text within an interview and across interviews with the purpose of identifying codes and themes. This approach to analysis includes three levels of analysis: open coding, axial coding, and selective coding (Corbin & Strauss, 1990).

Using an inductive approach, the researcher begins by *open coding* or reviewing each unit of text (which can be a phrase or larger segment of text that makes up a meaningful whole) and comparing it to other units of text within the section and within the interview to identify potential codes or themes (Corbin & Strauss, 1990). In this study, open codes and hypothetical categories were developed throughout the data collection process, and three substantive first interviews were selected to conduct the initial open coding. In the next stage, *axial coding,* the

researcher organizes the codes into categories, defines the categories, and creates a tentative coding guide. In this study, after the initial coding guide was developed, the remaining interviews were compared against it. The coding guide was adjusted as new codes were created from the coding of the remaining interviews. After this was completed, a final coding guide was created and the initial pilot interview transcript was recoded and reviewed with the participant. The final coding guide was adjusted to redefine one code. All the interviews were coded with the final coding guide. In the final stage, *selective coding,* the researcher connects the categories together to create sub-themes and overarching themes (Corbin & Strauss, 1990). In this study, Microsoft Word and the software program Atlas ti. 6 were used to organize, manage, and store the data.

Summary

This exploratory qualitative study was conducted with 20 older adult volunteers who identified as having serious difficulty walking or climbing stairs. Qualitative methods were chosen because there is both a dearth of knowledge available on the topic and as a means of capturing the complex contexts which they must negotiate in order to engage in formal volunteer activities. Naturalistic inquiry guided the methods, and in-depth initial and follow-up interviews were chosen in order to develop a richer understanding of the experiences of this population. A number of steps were taken to assure the trustworthiness of the study including member checks, peer debriefing, field notes, review of findings with a key informant, and audit checks. These methods allowed the researcher to consider multiple perspectives when analyzing the data and developing implications.

Chapter 4: Findings

This chapter provides background information on the participants and a discussion of the major findings from the study. The first section of the chapter provides an overview of the sample and an explanation of how participants were organized and categorized for the analysis (i.e., aging with or aging into). The second section presents the findings from the interviews that address the four research questions. Analysis of the interviews identified seven categorical themes: Disability Across the Life Course, Meaningful Engagement, Environmental Barriers and Facilitators, Individual Facilitators and Barriers, Organizational Facilitation, Costs of Participation, and Benefits of Meaningful Participation. An additional overarching theme, Importance of Meaningful Participation illustrates how all of the themes are connected.

Demographic Characteristics of Participants

Interviews were completed with 20 individuals. Prior to beginning the interviews, participants completed a demographic survey (see Table 3). Due to the fact that, even with the use of pseudonyms, several of the participants could be easily identified, demographics are reported as an aggregate. Participants in this study tended to be younger with an average age of 66. The youngest participant was 55 and the oldest was 80. The sample consisted of more women (70%) than men (30%) and tended to be non-Hispanic White (75%), more highly educated (75% with college or more) and higher incomes. Half of the participants were married or in a domestic partnership, and half rated their health as good or very good. In terms of employment status, nine of the participants said that they were retired; this included individuals who are on disability and considered themselves to be disabled and retired. In the other category, two participants listed themselves as on disability, and one said that he was a part-time student.

Table 3: Demographic Characteristics of Participants

	(N) %		(N) %
Average Age	66 (55-80)	**Employment Status**	
Sex		Employed full time	(3) 15%
Male	(6) 30%	Employed part-time	(4) 20%
Female	(14) 70%	Unemployed	(1) 5%
		Retired	(9) 45%
Race/Ethnicity		Other	(3) 15%
White Hispanic/Latino	(1) 5%		
Black/African American	(2) 10%	**Education Level**	
Native American	(2) 10%	High school or less	(2) 10%
White (non-Hispanic)	(15) 75%	2 years college or associates degree	(3) 15%
Marital Status		College degree	(7) 35%
Married/domestic partnership	(10) 50%	Master's degree or more	(8) 40%
Widowed	(3) 15%	**Average Annual Household Income**	$ 41, 548 (10k-120k)
Divorced	(3) 15%		
Single/Never married	(3) 15%	Low (0-25k)	(5) 25%
Refused to answer	(1) 5%	Middle (25-60k)	(9) 45%
		High (61-120k)	(6) 30%
Self-Reported Health			
Very good	(2) 10%		
Good	(8) 40%		
Moderate	(9) 45%		
Bad	(1) 5%		

Participants are divided into three groups, based on the age of onset and type of

impairment (see Table 4). Those who were born with or acquired a disability in their twenties are

categorized as *aging with* a disability. Eight of the participants are classified as *aging with*.

Seven members of this group were born with a disability or acquired one early in their youth

(polio), and one participant acquired a spinal cord injury when he was 26. While he does not use

a wheelchair, the injury and rehabilitation affected him during his life course and so he was

included in this category. Of those born with a disability, one participant was blind and also had

mobility impairments due to her limited vision and arthritis. Given the discrimination that she

experienced throughout her life and the difficulty of distinguishing between issues related to her

vision and issues related to her arthritis, she is included in the aging with disabilities group. As several of the participants within this group could be identified by their disability, only a discussion of the assistive equipment that they use is included. Of the aging with disabilities group, four used a wheelchair some or all of the time, and three used canes.

Those who have acquired or developed mobility limitations due to the progression of a disease are categorized as *aging into* disability. Participants with rheumatoid arthritis lived with the condition for many years and often decades before they began to experience mobility limitations. They were classified as *aging into,* as they had only begun experiencing mobility limitations after midlife. One participant with MS was included in the aging into group as she was diagnosed with the disease in her early 40's but did not begin experiencing mobility limitations until she was in her 50's. She is included in this group due to the fact that her mobility has declined over time, instead of a sudden loss, as compared to the other participants who are classified as acquiring in midlife.

A third group was identified in this study, those who acquired a disability in midlife *(acquired midlife)* and use a wheel chair. Three participants are included in this group. They are distinct from those in the *aged into* group in two ways. First, they use power or manual wheelchairs and have experienced barriers related to using a chair; whereas those in the *aged into* group do not use wheelchairs. Second, their volunteerism includes a specific disability focus, with the three participants discussing how they hoped their volunteerism could improve things for people with disabilities.

Table 4: Pseudonyms of Participants Organized by Group

Participant	Length of time with Impairment	Assistive Device Used
Aging With a Disability		
Chris	55 years	Manual wheelchair and forearm crutches
Elizabeth	61 years	Manual wheelchair
Lewis	30 years	Cane and braces
Nancy	69 years	Manual wheelchair with power assist, cane, support animal
Paul	67 years	Manual and power wheelchairs, cane, and braces
Randy	69 years	Cane
Stacey	66 years	Cane
Acquired in Midlife		
Alice	4 years	Powered wheelchair
Ben	20 years	Powered wheelchair
Martha	20 years	Powered wheelchair
Aging into		
Ashley	20 years (limited mobility in last 10 years)	Cane and braces
Barb	20 years	Cane
Emily	6 years	Cane and Walker
Erin	8 years	Cane
Jane	8 years	Cart that can be used for shopping
Lacy	16 years (limited mobility in last 12 years)	Cane, Walker, Braces
Rachel	4-5 years	none
Sarah	20 years (limited mobility last 10 years)	Cane and Walker
Susie	43 years (limited mobility last 10 years)	Cane and Braces
Stan	6 years	Cane

Findings

I identified seven themes and one overarching theme from participant's discussions. The themes: Disability Across the Life Course, Meaningful Engagement, Environmental Barriers and Facilitators, Individual Facilitators and Barriers, Organizational Facilitation, Costs of Participation, and Benefits of Meaningful Participation, and corresponding sub-themes are presented. The overarching theme, Importance of Meaningful Participation highlights the

importance of having opportunities to participate in formal volunteer activities and helps to connect the seven themes.

Disability Across the Life Course

This theme refers to how disability has impacted participants across the life course. Central to this theme is that while participants now have similar experiences in terms of secondary conditions and the barriers that they experience in their physical environment, their pathways have looked very different. Seven participants have aged with a disability, and four of them use a wheelchair some or all of the time. Those who use it some of the time noted that they will often use crutches at home but use a wheelchair when they are out in the community. The other participants who have aged with a disability use a cane or other assistive device. Three participants acquired a disability in midlife, and all three use a powered wheelchair. Ten have aged into disability, due to progression of chronic conditions, such as rheumatoid arthritis, or development of impairment, such as back pain. None of the participants who aged into disability use wheelchairs, but Lacy (aged into), who has MS, often uses a scooter when she is in the community. Unlike the participants in other groups, those who have aged with a disability experienced a world pre-ADA and have had to deal with many environmental and social barriers throughout their lives. Those who acquired in midlife or who have aged into have largely experienced disability in a post-ADA world. Despite these differences, the three groups described similar experiences in terms of barriers in their physical environment and in dealing with having a disability and getting older. Two sub-themes were identified: *Disability and Dealing with Challenges to Social Engagement* and *Understanding Aging and Disability.*

Disability and dealing with challenges to social engagement. This sub-theme refers to participants' descriptions of living with a disability and the major challenges that they have

faced. It emerged inductively from participant's personal stories. Participants have had different experiences with disability and aging, but they also experience many of the same barriers to volunteering and all share a desire to be engaged. As Elizabeth (aged with) explained:

> There are probably some differences between people who have been disabled either from birth or at a young age and those transitioning but some of the issues are the same… Barriers, accommodations, wanting to contribute, and being respected for what you can offer.

Similarly, Erin (aged into) noted that there may be differences between people who have aged with a disability and those who have not, with many in the first category having a better understanding of their limits and abilities. Susie (aged into) discussed how important it is for all older adults to stay active and engaged:

> Yea I can see myself [reducing volunteer hours], but at the same time I am not interested in being a person who secludes him or herself and reduces social activity. I think that is a killer for older people. It leads to depression and just a lot of bad emotions. So I think being active is one of things we do for ourselves.

Participants who aged with a disability discussed the lifelong barriers and discrimination that they and other people aging with disabilities face. These challenges are related to policy enforcement, stigma, having to work around barriers, and coming to terms with using assistive devices. For example, Elizabeth (aged with) noted that people aging with disabilities often have difficulty accessing education and employment. Similarly, Paul (aged with) said "the ADA and things like [it] hasn't accomplished all of its goals, certainly not employment wise. I mean that's the really slowest pace thing to come along." He also noted that more needed to be done with

vocational rehabilitation, so that youth aging with disabilities were more equipped to find employment.

Participants also discussed the challenges around aging with a disability. Participants noted that many people with disabilities feel isolated. Elizabeth (aged with) explained that people with disabilities are often unaware of the disability rights movement and that they are part of a larger community. Paul (aged with) noted that he was bullied in school due to being the "crippled guy." Similarly, Nancy (aged with) commented on stigma around disability when she was growing up:

> By high school, I no longer had the leg braces, though I was in and out of the hospital with surgeries. My family and I think with the definition of polio that generation pretty much was not allowed to identify as disabled. When I said something about disability, about braces my mother's response was, "well, your cousin has braces on her teeth and she is not crippled." Ok. Yea. So, it was not a mindset in our family that I was disabled. Because I could move I didn't consider…. the rest of the world pretty much did… but I did not see it.
>
> Interviewer: Were you ever treated differently?
>
> Nancy: Yea. I mean. All the time. "Poor little girl." Actually, I was chosen for a March of Dimes Poster Child but my mother did not want the attention to go my disability so she refused.

Participants aging with a disability also discussed how physically demanding living with a disability could be. For example, Randy (aged with) said that, as most cars did not accommodate him when he was younger, he had to overextend his body to operate them. He noted that he now has a lot of pain in his joints due to overusing parts of his body. Paul (aged

with) noted that in the disability community there was a belief that, if you did not push yourself, you would lose strength or functioning. It can also be difficult to become comfortable with using assistive equipment. As one participant noted, although she was having trouble walking, she did not decide to use a wheelchair until she saw other people with disabilities have a good quality of life because of the chairs.

Participants who acquired a disability in mid-life primarily discussed the challenges of adjusting to both the new level of functioning of their bodies and to using a wheelchair. For example, Martha (acquired midlife) said:

And it's like you have to redo everything in your life…The funniest thing I remember was when I first came home from the hospital. My husband took me out of my wheelchair and set me on the couch and I'm sitting there and all of a sudden I hear the dryer go off. And I'm so used to jumping up and just and I'm like, I can't get off the couch by myself and I can't go to the dryer and do that and it was just like, oh, gosh.

While many people may be uncomfortable with or afraid of ever having to use a wheelchair, participants who acquired disabilities in midlife discussed how their wheelchair allows them to participate. For example, Alice (acquired midlife) discussed how recovery after the accident was difficult, personal growth that she has experienced as result of the accident, and how she sees herself and her wheelchair: "I don't feel disabled and I don't let my wheelchair define me. It is my mode of transportation."

Participants who aged into disability discussed encountering barriers for the first time when they experienced the onset of disability or worsening of health conditions. As Susie (aged into) said: "There are some structural limitations that didn't use to be there." Barb (aged into) discussed struggling to step up onto the curb of sidewalks until a bus driver pointed out that there

was a curb cut (concrete ramp) a little ways away that she could use. For some participants, coming to terms with their decline in functioning was emotionally challenging. Jane (aged into) had difficulty getting disability benefits: "I went to the disability people and I tried to fill out their [forms] and I was just like balling. Because to sit down and talk about what has happened from the physical limitations…is just infuriating to me." Identifying as a person with a disability can also be challenging for people aging into disability. For example, Rachel (aged into), discussed how, unlike people who use wheelchairs, she was not fully disabled.

Understanding aging and disability. This sub-theme refers to participants' discussions around the impact that having a disability and getting older have on their participation in volunteer activities. Many (12) of the participants saw participation limitations as being due to a combination of aging and having a disability. For example, Elizabeth (aging with) noted that looking after her health is taking a lot more time than it used to. Nancy (aging with) who experiences limitations due to post-polio and cerebral palsy said:

> Well my husband reminds me that aging [is] for the brave. Aging is the pits no matter who you are unless your body is very wonderful. I am much more aware of my disability. I look at people at my own age and in this day… age 69 is not old. I feel older than 69. I feel the lack of energy and I feel that fact that I can't do as much exercise as other people my age do to keep in better shape. That is one of the things I feel about the aging and the disability. The disability, post-polio, kicked in like, "Oh, yea, it came back."

Two of the twelve participants discussed how it was hard to untangle the two. For example, Ben (acquired midlife) said it was difficult to tell whether his fatigue was due to his disability or getting older. Similarly, Paul (aging with) noted that having post-polio meant that his muscles

became weaker over time, and he could not tell if his reduced endurance was due to loss of muscle mass or if he was slowing down due to age.

Seven participants felt that limitations were due primarily to their disability, and one participant discussed aging as the main reason why she felt that she was slowing down. For example, Martha (acquired midlife) explained "Most [limitations] are disability, I don't feel that age part. To me, I'm still 30 years old, just in this body that's getting older. Barb (aged into) noted that she believed that most of her limitations were due to her stroke and not aging. Conversely, Sarah (aged into) noted that she was having more difficulty balancing but felt that this was largely due to aging.

Summary of disability across the life course. While participants have had different experiences due to the length of time with their impairments, they now experience many of the same barriers to social participation. Across all three groups, participants also shared a desire to be engaged with others and their communities. They also discussed the challenges of having a disability and aging, with many of the participants experiencing limitations to engagement due to both their disability and the fact that they were getting older. Some of the participants felt that any limitations they experienced were only due to their impairment, and one felt that aging was the main reason for the limitations she experienced.

Meaningful Engagement

This theme refers to the participants' motivations for volunteering. Participants in this study identified being part of and giving back to the community as the main reasons for their involvement in volunteer activities. Most of the participants had volunteered earlier in their lives and discussed becoming involved through their school or church. However, one participant, Emily (aged into) discussed seeking out volunteer activities after she retired. As a first step to

getting involved in volunteer activities, participants emphasized how important it is to find something that you are passionate about. Participants volunteered for a variety of organizations, such as churches, schools, and civic groups, and focused on a wide array of issues, including homelessness, senior services, disability rights, and food insecurity. Participants were involved in a wide range of activities, such as serving on committees or boards, working with children in schools, participating in various church programs, taking care of animals, and helping people through various non-profit organizations. When asked about why they volunteer, five sub-themes were identified: *Making an Impact*; *Giving Back to the Disability Community, Coping with Condition, Connecting with Others*; and *Staying Busy*.

Making an impact. Contributing to the lives of others was a major reason why participants became involved in volunteer activities, and participants discussed wanting to have both a broad and more focused impact. Central to this theme is participants' being able to be actively engaged in helping others, rather than functioning as passive volunteers. Being able to make a positive impact in their community and on the lives of others was a major reason why participants became and stayed involved in volunteer activities. Participants discussed how they hoped that their efforts contributed to betterment of others and society. Across all groups, eight of the participants discussed wanting to make their world or communities a better place. One participant, Jane (aged into), discussed the current political climate and how she hoped her volunteerism would improve things for everyone. Another participant, Elizabeth (aged with), discussed how she volunteered as a way of impacting her community "I think the first is just a kind of a belief that you have to create the community you want to live in."

In addition to making the community a better place, nearly all of the participants also discussed how they volunteered as a way to help others. One participant, Rachel (aged into),

discussed how she sought out a volunteer opportunity at a food bank as a way to give back: "I want to help other people. I thought it would be a good place to help other people, which I'm finding that it is." Stan (aged into) discussed how it was hard to find help in town and that he volunteered to help others. Another participant, Martha (acquired midlife), noted that she had the resources to volunteer and discussed how volunteering was an important way to help other people like her:

> Um, because I enjoy doing stuff that helps people that are disabled or elderly. I like helping the elderly and disabled, basically, and I have the time to do because I'm not employed because I'm basically retired and disabled. I consider it retired, so, but uh I do a lot of that.

One participant, Ashley (aged into), noted that she mostly volunteered at the animal hospital as a way to spend more time with cats; however, she also noted that she enjoyed being able to help out the staff.

Throughout the interviews, participants noted how their volunteerism improved the lives of others. Integral to this was the opportunity to be actively engaged as volunteers. For example, one participant, Susie (aged into) delivered shawls that had been hand-knitted by the church group she volunteered with to residents in a local nursing home:

> Whenever I am going to a person whose [has] just totally lost their health and found themselves in a nursing home or in assisted living or something– they are looking at a whole new world. Maybe they have memory problems and so on. I always take two shawls in a bag. The reason is because I give them the choice. Which one would you like to have? They don't get to choose anything anymore. Not when they eat, not when they take a shower. Nothing. And you would be surprised how long it takes those little old

ladies to choose, they put them on, they take them off, put them on, take them off, and they finally choose one. I just feel like I have made a difference in that person's day and that is a good feeling.

Giving back to the disability community. For participants who had aged with and those who acquired midlife, the opportunity to advocate for and give back to the disability community was also an important reason why they volunteered. Five of the participants in these two groups discussed how they hoped their volunteering would help other people with disabilities. Two participants who had aged with a disability talked about being role models or positive examples for other people with disabilities. For example, Elizabeth (aged with) discussed how she did not have many role models with disabilities growing up. She hoped that, through her volunteer work, other people with disabilities would see that you can be active and contribute even with a disability. Chris (aged with) said: A lot of times it helps if I say, "I do this, this and this." And they look at me and say, "if you can do that, I can probably do that."

Two of the participants spoke about helping the health and well-being of others with disabilities as an important part of their volunteer work. Paul (aged with), who volunteered with people with disabilities, noted that he hoped his volunteerism helps those that he works with:

Well hopefully it keeps these guys somewhat more fit than they would be and I am saying that people that have had the opportunity and have not stuck with it are marginalized. Their health is horrible. And even some of them that are in the program, their health is not good. And I am looking at a lot of pre-diabetic people and I am going, you know you got to do something about this.

Similarly, Alice (acquired midlife), discussed how she hoped that some of her work would help to make school playgrounds more accessible for children who use wheelchairs. She noted that

many schools have woodchips or other impediments that make it so that children in wheelchairs have to restrict their activities or cannot play with their friends in some areas.

Four of the participants who are aging with a disability and the three participants in the acquired in midlife group also discussed participating in advocacy efforts through their volunteer work and in the course of their day-to-day lives in order to address barriers in the physical and social environment and as a way to give back and make positive change for other people with disabilities. For example, Nancy (aging with) and Martha (acquired in midlife) discussed being involved in advocacy work through their volunteer activities. Nancy explained: "With the [organization] I feel I have something to offer and therefore it a way to continue essentially doing what I have done all my life which advocate for people with disabilities." Similar, Martha noted:

> With the Independent Living [organization] and the AARP, we kind of have the same, trying to push the same agendas, you know, for disabilities and, and caregivers and all that other stuff. Yeah, that's what somebody was telling me, it's amazing how you are able to find these organizations and you kind of get involved with them and they overlap each other. That, that way I'm still pushing my agenda.

Elizabeth (aging with) discussed how she approached a situation in the community where a restaurant had put up tent and blocked off the accessible parking spaces:

> You are not going to change everybody. But kind of approaching the situation is okay. Do I come in as an advocate? Do I come in as an ally? Does a person need education? Do they need to have the law sited? Last night I cited the law. At 11:00 last night I was e-mailing the city manager giving him the history and this is illegal and that I am requesting that the city speak [to] the restaurant about removing the tent and that a permit

never be issued to them again without a city personnel being there to see where it is

erected. So my question was, are they going to get ticketed for misusing the accessible

spaces? They said no because it is only when a vehicle in them. I said that was bullshit.

Then I asked if they are going get fined and then they have to have a chance to respond

so there is due process. I said I would be happy as they are put on notice that as soon as

they can get it taken down that maybe tomorrow they get it taken down and they be

cautioned doing that in the future because they would we warned then. So you have to

mediate the way you deal with the barrier based on the barrier, the people involved, their

awareness level, how important it is, etc.

Elizabeth also noted that she tries to balance the need to educate and make change with the

knowledge that her approach can impact other people with disabilities:

So I don't hesitate to make an issue if it is warranted, but if I can educate by not making

an issue, I probably paint the way for other people. I am very conscious that I may be

creating or preventing opportunities for other people.

Finally, Paul (aging with) noted that he has been involved in advocacy efforts for much of his

life and discussed his approach to advocating for change when organizations or the city was not

supporting people with disabilities in the way that they should:

Because they are not fulfilling their responsibilities as an organization and we need to

make a point here. The city is not doing what it is supposed to do. I am not an ADA

lawsuit guy. I am a let's go in, roll up our sleeves and figure out what is wrong.

Coping with condition. This sub-theme comes from one of the respondent's expressions.

Ben (acquired midlife) discussed how he volunteers as a way to connect with others, but that he

initially became involved as a way to better understand how to manage his condition. Due to the

worsening of a previous injury to his back, Ben began using a wheel chair in his early 50's.

Indeed he noted the onset date of his disability as when he began to use his chair. When asked

about why he volunteers, Ben said:

> Well first of all I want to learn more about how to cope with my own situation. So I have
>
> found that is the best way. I am trying to be involved with others, contribute to the lives
>
> of other people. I have learned something myself. It has been helpful.

Connecting with others. While giving back to others is an important motivation for

volunteering, so too is having the opportunity socialize with others. Across all groups,

participants discussed how volunteerism gave them a chance to connect with other people and

with their community. Eighteen participants discussed getting to meet people and spend time

with people as a major reason why they volunteered. For example, Emily (aged into) said that

she volunteered "Because I like to be around people. I like to help people." Sarah (aged into)

noted that it was a way to meet new people. Two participants, Erin (aged into) and Randy (aging

with) discussed how volunteerism gave them a chance to interact with people in less intense and

formal ways. For example, Randy said: "I volunteer to experience community in a different way

than professionally. It gives me different roles and uh allows me to develop different kinds of

relationships." Other participants discussed how getting involved helped them to feel closer to

their community. For example, Elizabeth (aging with) discussed how she served on a board at

her church as a way to stay connected with that community. Another participant, Alice (acquired

midlife), said: "I like the connections back with the people I used to work with. Like I know

several people at both of the schools. I run into subs that were teachers. I run into people like

that."

Staying busy. The opportunity to keep busy, particularly for those who had retired or had work limitations due to their impairment, was also an important reason why participants volunteered. Across all three groups, seven participants discussed volunteerism as a way for them to keep busy and engaged. For example, Stacey (aged with), who was employed part-time, said that she volunteered because she did not do well with unstructured time. Erin (aged into), who was fully retired, said: "What would I do if I did not volunteer? It is a totally selfish reason. I would probably sit at home and read and be very sedentary and very uninvolved because I don't enjoy being in large groups."

Summary of meaningful participation. Across all three groups, participants described both altruistic and self-directed motivations for volunteering. They described a desire to give back to others and their communities. Participants in the "aging with" and "acquired midlife" groups also discussed wanting to give back to the disability community. In terms of self-directed motivations, participants discussed wanting to both connect with others and stay busy. One participant also noted that he volunteered as a way to learn how to better cope with his condition.

Environmental Barriers and Facilitators

This theme refers to both features of the physical environment and social attitudes that can impede or facilitate participation. Participants described how the community can play a major role in a person's ability to volunteer. In particular, inaccessible environments not only made it difficult for them to access buildings and areas in their communities but also required them to spend extra time and effort working around those barriers. Regardless of group, participants discussed experiencing similar barriers in the physical environment. Aspects of the physical environment included architectural designs (built environment) of sidewalks, parking lots, and buildings and the weather (natural environment). Participants also discussed how social

attitudes could impact their ability to participate. Participants described having different experiences with and responses to other people in the community and at volunteer organizations. In addition to the physical and social environment, participants also discussed the important role that transportation can play in facilitating participation, but noted some limitations in their current system. Participants were asked about barriers in the community that could make it difficult for them or another older adult with a mobility-limiting disability to volunteer. Three sub-themes were identified: *Built and Natural Environment*, *Social Attitudes, and Transportation*.

Built and natural environment. This sub-theme refers to features of the built or natural environment that could make it easier or more difficult for participants to volunteer. The accessibility of both the community and organizations played a major role in participants' ability to volunteer. As Elizabeth noted: "You can spend a ton of energy on just negotiating your everyday environment if it is not accessible. And that takes the energy that you could put into volunteering, working, achieving employment." Across all groups, participants discussed experiencing a variety of barriers in the built environments that they interacted with in the community and at volunteer organizations. In the community, seven participants noted that obstructions on or uneven sidewalks could make it difficult for them to access parts of their community. For example, when asked about features of the community that could create problems for him physically, Ben (acquired midlife), who used a power chair, said: "Yes, obstructions, quality plus people if it is a crowded time of day. You usually have to follow someone so that they can clear the way." Jane (aged into) and Randy (aged with) noted that uneven sidewalks are a tripping hazard for them. The absence of sidewalks, particularly in rural areas or suburbs, can also make it difficult for people with disabilities to participate in those

areas. For example, Nancy (aged with) noted that the absence of sidewalks in her neighborhood meant that she could not be involved in volunteer work around her home. Martha (acquired midlife), noted that dirt roads and a lack of sidewalks had made it more difficult to operate her chair and participate in her community, though things had improved since they paved them:

> No, we've got paved roads finally, which is really nice. I remember back when they weren't paved, there's uh it's basically in the dirt. A lot of people have dirt driveways and dirt yards like me….that's what I hate when it's wet and rainy and I get all muddy tires and stuff and I have to come into the house and then sweep it up and clean it up afterwards.

Seven participants discussed how important accessible parking is for older adults with mobility-limiting disabilities but also noted that there are challenges even with accessible parking. For example, two participants discussed how too much distance between the parking spaces and the building was a barrier for them. For example, Susie (aged into) noted "Long walks for parking is another issue."

While accessible parking spots are an important facilitator of participation, misuse of the spots by organizations or other people with disabilities can limit their usefulness. Two participants who use wheel chairs, Ben (acquired midlife) and Elizabeth (aged with), noted that accessible parking places, particularly ones that have space for a chair lift, can be misused or are taken by people who do not have a lift. For example, Ben explained:

> It has been very frustrating because so many people. A lot of it of ignorance. Even people who are handicapped themselves…or even parking in the accessible aisle which is marked yellow stripes…so then I can't get in and out of my vehicle– I have a ramp van. So I take 8 feet to get in and out of my vehicle. If they park in there [spots with an

accessible aisle] then I have to get someone to come and back my vehicle out of the space so I can get in.

Participants also discussed a number of features in the interior and exterior of buildings that could limit their accessibility. Across the groups, participants discussed how ramps, elevators, doors, and bathrooms can all facilitate or impede participation. All of the participants in this study had serious difficulty or could not climb stairs. For example, Ashley (aged into) said "They take more time I guess. You ever see those little kids that go step, step, step. That's pretty much how I do them" and "I look for elevators." Elizabeth (aged with), who uses a wheelchair, described requiring assistance from others to enter buildings that had stairs and no ramps.

Fifteen participants, across all three groups, discussed how ramps could make buildings more accessible but also noted that sometimes ramps were not well-placed or were made inaccessible by other people. For example, Paul (aged with) discussed how, when he reviews ADA accessibility for organizations, he makes sure that they have ramps for buildings that need them and that they are up to code. While having a ramp can be helpful, Sarah (aged into) noted that some ramps are not usable "They built this huge ramp outside and then they found that that just didn't take care of it for a lot of people. It is pretty steep and long to get to from the front." Nancy (aged with) also noted that people can inadvertently cause ramps to be inaccessible by putting or storing objects on a ramp. Elevators or stair lifts were also an important way to make multistory buildings more accessible for participants. Ben discussed how one of the churches he volunteered with put in a stair lift that he could drive his wheelchair onto. Participants were very appreciative of organizations that put in the money and effort. However, Sarah (aged into) also noted that, because buildings often only had one elevator available, they were not able to use the building when the elevator broke.

In addition to these features, participants also discussed how the design of doors and bathrooms could make it difficult to participate. For example, ten of the participants discussed how the width and weight of doors could make it difficult for them to enter buildings and bathrooms. Participants also noted that buildings with automatic doors facilitated participation, but that heavy or narrow doors made it much more difficult to access buildings in the community and volunteer organizations. For example, Alice (acquired midlife) said "Downtown doors. I can't get in downtown doors by myself. They are so heavy. And the opening is small so I still go up and this arm is not long enough to hold the door open." Similarly, Susie (aged into) and Jane (aged into) noted that heavy doors or door knobs that required twisting were difficult to manage. Finding usable bathrooms was also a challenge for participants, as many bathrooms met accessibility standards but were not convenient for the participant. In particular, the weight of bathroom doors was noted as a problem. For example, Ben (acquired midlife) said:

> I've been to other places, another [coffee shop], a new one on the west end which a lot of the issues are so simple like the restroom doors have too much pressure on them. If I get in, I can't get out. All it takes is a screwdriver to adjust. I could never persuade the manager. Oh I have to call corporate, blah, blah, blah….He finally got it done.

The layout of the bathrooms themselves can also make them unusable for people with disabilities, particularly those who use wheelchairs. Chris (aging with) noted that while a bathroom might meet ADA standards, the shape and layout can make it difficult to navigate for people in wheelchairs.

Across all groups, four participants discussed how homes are often not accessible and how this can reduce the ability of a person with a mobility-limiting disability to visit such homes. For example, Jane (aged into) shared a conversation she had with a friend:

And if you go over to the part of [east part of town], like my friend James has property over there, and he says, "why are all these people coming out here west?" He doesn't understand that when you have private older properties there are a million things on it that can make you fall.

Similarly, Martha (acquired midlife) explained "Oh, gosh, um basically you can't go to people's houses. You have to call them or meet them some place because houses aren't accessible."

For participants, the natural environment did not pose as much of a barrier to participation. They all said that hot and cold weather were not something that would keep them from participating, and they discussed how they carried on just like anyone else. However, two participants noted that rain and snow could make it more difficult to use their assistive equipment. Martha (acquired midlife) said "Yeah, when it's like snowing out and it's slippery, and, I don't want to have to try to get in my van. And even when my tires are wet, the ramp, I slide on it, you know, trying to get in the van."

Social attitudes. This sub-theme refers to participants' social encounters in the community and at volunteer organizations that could facilitate or make it more difficult for them or another older adult with mobility-limiting disabilities to participate. Social barriers to participation is a complex topic. While participants described their communities as generally open, they also discussed how people often assume that those with disabilities are incapable of doing things and negative encounters that they or another person with a disability had experienced. For example, Elizabeth (aged with) described her community as open and that most people at her volunteer organizations saw her as competent and able to contribute and that she would probably raise the issue if she felt like she was being discriminated against. However, she also discussed how there is often a perception or assumption that a person with a disability will

not be able to contribute or that they will cost more than they are worth. She also shared a negative experience of trying to participate at a community event and being disrespected and ignored:

> I don't think so much now, although, yea it probably happens. I guess I don't see as much of it as an issue because I would probably say something if it was that much of an issue. But I was just thinking of one. A couple of years ago, I offered to volunteer at a community event, and I didn't know the people well. It was [to be] a bike valet. If you rode your bike down you could park your bike and we would take care of it and give you a check and you could come back and get it. So, I went to volunteer and everybody had these vests on that designated [that] they were part of this effort and they had things to do. They didn't give me a clipboard to put names down for support. They didn't give me a vest and it was kinda like, why did you ask me to come if I am not a full fledge volunteer? I would not encourage other people with disabilities to come down to help you out. For example, you now they doing the bike and the pedestrian counts. I haven't volunteered because I am not going to be treated that way.

In another example, Alice (acquired midlife) said that she felt that schools were fairly open to having her volunteer and that the major barrier for people with disabilities was in working up the confidence to get involved. She also described having to educate teachers about disabilities and noted that parents were often less comfortable around her than the children, but she felt that educating others was an important part of her work. She also discussed having some negative experiences in the community, such as strangers staring at her "It's like people seeing me on the street. And they keep staring." Lacy (aged into) discussed how she thought that people often had

difficulty interacting with someone who used an assistive device because they were not sure what to say:

> I mean, um, whenever you see someone that is walking a cane or in a wheelchair, I think that people don't know how to interact. They are afraid they are gonna, I don't know, offend you in some way or something.

> Across all groups, (17) of the participants discussed how people with disabilities may face barriers to volunteering because organizations may not know how to work with a person with a disability or may assume that people with disabilities were not capable of volunteering. Participants also stressed that the negative social attitudes were likely due to people's lack of knowledge and experience with people with disabilities. Participants also described experiencing stigma related to the assistive equipment they used and also encountering ageist attitudes. Participants who use wheelchairs described having negative experiences in both the community and at volunteer organizations. Negative interactions in the community often involved others avoiding talking to the person in a wheelchair or expressing pity and fear. In one particularly negative experience, Ben (acquired midlife) said of a friend who also used a wheelchair: "He was going to a lot of water classes and [a] new guy came in, he must have been around 80 or so but, one day he just said, "If I were like you, I would shoot myself." Chris (aged with) also noted that, when you use a wheelchair, people often assume you also have a cognitive impairment and you have to work to convince volunteer organizations that you have something to contribute.

> Participants in wheelchairs were not the only ones to experience discomfort or avoidance from people in the community. Three participants, who had aged into disability, discussed how

they felt that people in the community both noticed and were uncomfortable with their disability.

For example, Rachel said that she avoided using ramps, struggling up stairs instead:

>There is also a ramp that you go up in the back, but I feel it is one of those things that I
>
>feel, I don't know being disabled, you just feel that people are noticing you going up the
>
>ramp, but people you know, it's a weird kind of feeling.

Jane (aged into) discussed how it could be less uncomfortable for people to use the store carts or

a smaller shopping cart that she had purchased to support themselves when they were in the store

or the community instead of canes or scooters "So actually I am saying these carts and the

grocery store carts are key to rather than canes; these are better supports because most people can

handle them emotionally. The cane thing is hard for most of us and that sitting in that thing

[scooter]." However, Barb (aged into) said that while she was sure that it happened to other

people, she had not experienced any social barriers in the community or at her volunteer

organization and thought both environments were fairly open and inclusive.

Participants also discussed experiencing ageist attitudes or negative experiences related to

aging. For example, two participants, who aged into, discussed how they had difficulty finding

volunteer positions due to their age. Sarah (aged into) said that she though some organizations

just were not looking for older people. Erin (aged into) noted that organizations seemed to make

assumptions when they saw a mobility-limited older adult:

>It is kind of a pre-conception that probably you are, well you are going to be more
>
>restrictive physically and you're going to be more, I don't know. There is just a certain
>
>aspect once you get past a certain age that you are …. People call you sweetie.

Two participants also discussed how they had experienced discrimination due to their race or

sexual orientation. Jane (aged into) said that she had experienced a lot of discrimination within

the LGBT community and was also not openly gay in her apartment complex or with some of the churches and organizations she worked with. She felt that the discrimination in the LGBT community was due, in part, to the weight that she had put on as a result of her disability. She feared losing access to services or her support network in town if she came out.

Participants also noted experiences that could help people with disabilities feel more included. For example, three participants discussed how going to church could be uncomfortable for people who use wheelchairs, as they are often made to sit in the back and receive communion last, and as Ben (acquired midlife) said "Who wants to be last?" However, churches that have created accessible seating at the front or throughout were more inclusive, such as one Nancy (aged with) discussed "It's just a whole different attitude. They have installed some pews in front so the wheelchairs, if they choose, can come to the front, instead of at the back."

Participants also shared different views on receiving offers of help from others in the community. For example, Susie (aged into) in discussing difficulties opening doors said:

When I encounter barriers I do the best I can and I just go ahead and get that door open. But it is surprising in [town] how many people are so helpful. I seldom walk in the library doors and there is a disability entrance but I usually go to the doors anyway. There is almost always somebody that just….hold[s] it open.

Similarly, Elizabeth (aged with) explained that she often appreciated receiving help from another person to get her wheelchair over a stair that would otherwise be a barrier to her using the local senior center. However, Chris said that, while he appreciates people's kindness, he preferred that people did not make assumptions about what he can and cannot do, saying:

I usually just say, "thanks for the offer, but I have got this." Everybody wants to hold a door for you which is fine and I appreciate that. In our groups we always say we celebrate

the things that we can do. We don't want people to do those things for us because we

want to do the things we can.

Similarly, Ben (acquired midlife) noted that people's attempts to hold the door for him often

were unproductive as they were then in the way of his chair.

Transportation. While many (fifteen) of the participants in the study had personal

transportation, they also discussed how important a good public transportation system is for older

adults and people with disabilities. For example, Elizabeth (aged with) said" I think we have a

good public transportation system but it's got limitation because we need to get more people to

use it so they have can pull down more federal money to make it more comprehensive. We are

getting there. Someone told me the other day that people are retiring here because it has a public

transit system." The five participants who used the bus system discussed how it allowed them to

access the community and their volunteer work. However, they also noted that there were some

limitations to the local bus system, such as the fact that buses were not always available and that

it could be expensive to use the service. For example, Sarah (aged into) discussed how she uses

the bus sometimes but that, on Sundays, the buses do not run, so she has to try to get rides with

people from her church. Barb (aged into) said that due to the bus schedule, she sometimes had to

cut her volunteer work short in order to catch her ride:

>That is a challenge for me if… I haven't quite finished my 56 to 59 minutes then I may

>have to cut out but I try to make sure I have plenty of time [to get to my bus which is

>downstairs]. That has been the biggest challenge for me.

 Finally, Jane (aged into) also pointed out that the cost of using the bus system can be prohibitive

for people with limited or fixed income.

Summary of environmental facilitators and barriers. Across all three groups, participants identified key aspects of the built environment that could facilitate or impede participation. Participants noted that, while some things were designed to improve accessibility (e.g. ramps or accessible parking), issues with their construction (i.e. being too steep) or misuse by others could make them unusable. Participants also discussed how the weather could interact with the build environment or assistive technology to make them less usable. Regarding social attitudes, participants described mixed experiences, often having both positive and negative interactions with others. Finally, they indicated that public transportation could facilitate participation and community engagement for many people but they also noted many limitations with their current systems that impeded participation.

Individual Facilitators and Barriers

Beyond barriers in the environment, this theme refers to aspects at the individual level that can facilitate or impede participation. Participants discussed a number of challenges that they experienced in their daily lives and how they overcame or worked around them. First, they noted that their physical and mental health played a major role in their ability to participate. Indeed, most (19) said that the main reason why they would stop volunteering was because of a serious decline in their health. One participant noted that difficulty managing depression would be the main reason why he would stop volunteering. Interestingly, participants also discussed factors beyond their health that could play an important role in facilitating or impeding participation for themselves or another older adult with mobility-limiting disabilities. These include: a person's self-esteem and self-confidence, the accessibility of their home environment, a person's coping skills, and their social support and social network. Participants were asked about factors at the individual level that could facilitate or impede participation and how they

overcame barriers to participation, and six sub-themes were identified from their discussions: *Physical and Mental Health, Self-Care Takes More Time, Self-Esteem and Self-Efficacy, Accessible Home Environment, Coping Strategies, Social Support and Social Network.*

Physical and mental health. Across all three groups, participants all experienced one or more secondary conditions (pain, fatigue, and depression) that made it more difficult to volunteer. Thirteen participants described experiencing pain some or all of the time. For example, Lewis (aged with) and Emily (aged into) noted that they were always in pain. Participants also noted that pain could make it difficult to do a range of activities, such as climbing stairs, squatting or stooping, and lifting or carrying objects. Lewis (aged with) said that doing anything where he had to lift his arms above his head was challenging and could make the pain "excruciating." Stan (aged into) and Rachel (aged into) said that they could not lift things that were very heavy. Rachel also noted that pain made it difficult for her to stay in one position for too long "I am able to stand and stuff but it hurts when I stand or it hurts when I sit down or I have been sitting for a long time. I can't very long."

Thirteen of the participants also described experiencing fatigue or a lack of stamina. For example, Jane (aged into) explained that fatigue was a major issue when you have MS and that it really reduced her ability to get out of her house. Susie (aged into) discussed how her fatigue can fluctuate from day to day and how that can make it challenging to participate:

> And it depends on the day. So sometimes when I say to somebody, yes, I will do this on such and such a time on such and such a day next week, I try to do that but at the same time it's getting to where I can't anticipate what that day is going to be like a week from now. So that's kind of surfacing more.

Participants also discussed challenges of taking care of their health and the chronic conditions or other health issues that they developed on top of their disability. For example, Randy (aged with) noted that people with disabilities often have a narrower margin of health. Martha (acquired midlife) explained:

Uh, yeah, my blood pressure is messing up or if there's something my body, on my body that's painful and I don't know where it's at, so it makes my blood pressure spike. So sometimes I don't feel up to it, but I'll usually know ahead of time cause I'm not feeling good to begin with. And so then all of a sudden oh, I can't go and I'll be not be able to go. But that usually doesn't happen too often because I usually try to keep that at bay. You know?

Alice (acquired midlife) and Emily (aged into) also discussed how health issues unrelated to their disability, such as stomach issues, could be more challenging to manage and that they choose to stay home when they experienced an upset stomach.

When asked about why they would stop volunteering, 19 of the participants responded that it would be because their health declined to point where they could no longer participate. For example, Lewis (aged with) explained that he stop volunteering if he was "Too crippled to get up in the morning." Martha (acquired midlife) said "It would have to be my health because other than that I have no reason why I would want to because I really enjoy it." Similarly, when asked Stan (aged into) said "health reasons" and Ashely (aged into) "I don't know. I can't imagine…Well it would probably have to be health related."

In addition to physical health, two participants discussed how difficulty with symptoms of depression could cause make it difficult to volunteer, and one participant noted that it would

be the main reason why he stopped volunteering. For example, Alice noted that sometimes

having a disability causes her to feel down and need to take a break, but that she keeps going:

> Sometimes having a disability can be pretty darn depressing. Let's face it. But I think it is
>
> important to give our bodies a break and give our minds that break. You know, I feel
>
> down today. Ok. I am going to give myself permission to be down today. Tomorrow
>
> morning I am going to wake up and I'll be fine.

 Ben (acquired midlife) explained that the main reason why he would stop volunteering was

because of his mental health:

> Probably depression, body pulling me down. I struggle with depression too. Mental
>
> health is a big part it. Even when I am healthy there is some issues. When I am hurting
>
> you can't get out and do things it gets worse then.

Self-care takes more time. This sub-theme refers to participants discussions of having to

spend more time on self-care activities, as compared to people without disabilities. This theme

emerged inductively during the analysis. Five participants discussed that having a disability

means that self-care and other activities can take longer for people with disabilities. For example,

Randy (aged with) noted:

> Well, and I think the other thing too, the amount of time it takes people to maintain
>
> themselves, the self-care and the time you invest in yourself is different in people who
>
> don't have disability issues.

Similarly, Elizabeth (aged with) explained:

> It takes more energy to do self-care with a disability for me. It takes me longer to get in
>
> and out of the van. It takes me longer to take a shower. It takes me longer to do house

work. I have also learned to decline volunteer activities that either somebody else could

do that don't use my skills well or that's not a win win.

Susie (aged into) also noted that she needs to have her mornings free so that she does not have to

rush to get ready, as that can cause pain and result in her not being able to do anything for the

rest of the day.

Three of the participants discussed how receiving help from various programs facilitated

their ability to participate. For example, Emily (aged into) and Sarah (aged into) discussed

receiving help from home care agencies and Meals on Wheels. Emily said "I have visiting nurses

come out once a day in the morning with the bathing and dressing and they clean the house and

things like that so that is really helpful too. And I have meals on wheels." Alice has a personal

health attendant, who provides transportation and support, with her most of the time.

Self-esteem and self-efficacy. Participants discussed the role that self-esteem and self-

confidence can play in facilitating or impeding volunteerism. This sub-theme formed inductively

as interviews were analyzed. Participants discussed their own self-esteem and instances where

they felt confident in speaking with people and educating them about disabilities. For example,

Emily (aged into) noted that she had skills to offer organizations. Similarly, Paul (aged with)

discussed how organizations will seek him out and ask him to review things for accessibility

when they are planning to build or change things.

Volunteerism can increase self-esteem and self-efficacy. For example, Alice (acquired

midlife) noted that volunteering had increased her self-esteem. Similarly, Chris (aged with) said

that he believed that volunteering could help build up the confidence of people with disabilities.

Ben (acquired midlife) discussed how, after doing some volunteer work with churches and

educating them about accessibility issues, he felt confident enough to address inaccessible environments in the community:

I did a project by myself with [coffee shop] downtown because I could not get into their restroom simply because [of] their benches. There is not much space and then there was a bench, one of these Van Gough, beautiful bench, you know. So I emailed him and explained the problem and he said let's get together and talk about it. So when I showed him the problem he said we could do something about that. He just picked the bench up and moved [it] to another location and problem solved.

Participants, also discussed how having low self-esteem and self-efficacy could be a barrier to participation. For example, Randy (aged with) and Chris (aged with) noted that many people aging with disabilities have been told their whole lives that they cannot do things and have internalized this stigma. Similarly, Paul (aged with) explained "And too many people, I think, with disabilities wind up being unappreciated and not really having much in the way of self-esteem."

Lower self-esteem and self-efficacy can also be an issue for those who develop disabilities later in life. Ben (acquired midlife) discussed how much your self-esteem can go down after acquiring a disability: "Especially people do not realize, especially for men, if you can't walk or stand you feel down, at least one down from everybody else. Your self-esteem and everything, especially when I was new to the wheelchair." Erin (aging into) also discussed how many people like to do things for older adults and how this can develop or contribute to a sense of dependence in older adults, particularly those with disabilities.

Interestingly, dealing with barriers and negative attitudes and getting older may increase self-esteem and self-confidence for some people with disabilities. For example, Nancy (aged

with) noted that a lifetime of dealing with barriers has given her more confidence in addressing stigma: "I'm old enough and been bullied enough that I speak up a lot more, but depends on the situation." Similarly, Ben (acquired midlife) noted that, with his ministerial background and now being older, he does not care what people think, so he is more confident in sharing his opinions "Well with my background and my age I don't care what people care about me." Hence it may be important to not only reduce barriers to participation, but to also learn how people with disabilities have developed self-esteem and resilience despite the negative experiences they have had across the life course.

Accessible home environment. Another important factor identified that can facilitate or impede participation is the accessibility of a person's home. As Elizabeth (aged with) explained:

> If I had to go home and drag myself upstairs or risk falling in the bathroom that would be different because that would take up a significant portion of my energy. What I have, we have created a home environment that quite accessible so I can take the energy that I do have to spend fighting barriers and fight them in the community.

Across all groups, participants discussed different aspects of their home and environment that made it easier to participate. Nine participants had the financial resources available to modify their homes. For example, Erin (aged into) noted that she and her husband had remodeled their house before she had knee surgery, so that she could live on the first floor. Chris (aged with) discussed widening doorways and Ben (acquired in midlife) said that his family had put in a stair lift so that he could get downstairs. Sarah (aged into) and Lacy (aged into) discussed avoiding certain parts of their home, with both living almost exclusively on the first floor, as a way to save energy and avoid pain. For example, Lacey noted "I haven't been upstairs or downstairs for a long time." Lacey also discussed how her husband had helped to modify their home and find

equipment that she could use to help her exercise. Stan (aged into) and Jane (aged into) noted that their apartments were accessible for them. In particular, Jane noted that while the rent was expensive, her apartment was really well-designed for someone with mobility limitations and she hoped that she would not have to move to a less accessible building.

Coping strategies. This sub-theme refers to ways that participants dealt with environmental and social barriers and their own body limitations. This sub-theme was formed inductively from the analysis. Across all groups, problem-focused approaches, reframing strategies, and avoidance of difficult or painful issues were the most common types of coping strategies that participants used when they encountered challenges. Problem-focused approaches refer to the myriad of ways that participants found to address or work around barriers. Problem-solving, education and advocacy, and planning ahead were identified as the most common strategies. Reframing strategies refer to how participants put a positive spin on negative or difficult situations.

Across the three groups, all of the participants used problem-solving skills to work around barriers to participation. They described using problem-solving skills to work around barriers created by their bodies and encountered in the community or at volunteer organizations. Participants figured out a number of ways to help manage their secondary conditions. For example, Susie (aged into) explained:

> But also there are little tricks you learn. Like I might be feeling really lousy, but if I have a 15 minute rest period, all of the sudden bingo I can go again for a couple of hours. So I have discovered a lot of those things.

Participants also discussed the importance of asking for help or seeking other resources to help them overcome barriers. For example, Elizabeth (aged with) and Paul (aged with) discussed a

number of resources that could help individuals with disabilities and organizations, such as local CILs and vocational rehabilitation agencies. Barb (aged into) and Ben (acquired midlife) discussed how it is important to ask for help when you experience barriers to participation or just in the course of your day-to-day life.

Educating others was a way for participants to not only deal with negative interactions but to also try to exert control over the situation and remove the barrier for themselves and other people with disabilities. Across all groups, eight of the participants discussed educating others and advocating for change when they experienced barriers. For example, Ben (acquired midlife) discussed a frustrating experience at the local theater and why it is so important for him to continue to educate others:

> Yes, raising awareness and education are the step stones to change. And it is a slow go. And I have noticed with the volunteer system at the [theater] like they do at churches for ushers. Well, how many times I have been at the [theater] and when they look at the ticket the ladies will say, "I have no idea where this is." I say, "Well, I do." And she will say, "Wait here." And just make me wait. Until she runs around and gets… oh yea, oh yea. "Oh you know where it is"? "Yes, I know where this is"? "Yes I do." "Yes, it is right over here." "Oh you know you are right."

Discussing his work with churches and encounters with people in the community, Ben explained: "I call it attitude and perception re-education. Because they are the two main reasons why people with disabilities don't go to church." Randy (aged with) discussed how interacting with and educating others about disabilities helped reduce barriers:

> Well, they'll they (people in the community) learn how to stand, they learn how to like not be uneasy, they learn how even to assist. Like the other day I was buying flowers at a

place and they had the, you know, the sign where credit cards [are], and I hadn't paid

yet, so the guy just reached over and took some flowers off of a stand and set it…[aside]..

Because I've been there enough and he was like wait, I know you can't reach that.

Susie (aged into) also noted that it can be challenging to educate others and advocate for change

as there are many types of disabilities, but that it is vitally important that this education happens:

There are so many kinds of disabilities. There are emotional disabilities. There are

mental disabilities. There are physical disabilities of various magnitudes and there are

genetic disabilities. I mean you can just list … And so to try to decide… how to

advocate for people with disabilities, you have to think about [it]. What are we talking

about? It is a huge topic. It is huge.

Planning ahead also appears to be an important coping strategy for participants in the

study, as Elizabeth (aged with) explained "life with a disability is a lot less spontaneous."

Participants discussed various ways that they plan ahead, such as deciding if they will physically

be able to participate that day, checking if the building and bathrooms are accessible and usable,

taking medications and bringing needed equipment, and negotiating transportation. For example,

participants indicated that there are some days that they do not volunteer because they need to

stay home and take care of themselves. Ben (acquired midlife) discussed how important it is to

know ahead of time if the building where the volunteer event is at is accessible, so that they can

make alternative arrangements. Ben also noted that it is important to know where bathrooms are

in a building and whether they will be accessible. Marie (acquired midlife) said

Yeah, exactly or bring my nieces and nephews with me and have them run in and scout

out places. Is the bathroom accessible in there? Can I get in there? Are the doorways

wide enough? And they'll run in and find out and come out and tell me.

Two participants also talked about managing their medications, particularly pain medications, so that they could volunteer. Similarly, Elizabeth (aged into) discussed the various equipment that she brings on shorter and longer trips, such as her medicine and ostomy supplies. Barb (aged into) and Sarah (aged into) talked about needing to plan ahead and set up their schedules around buses. For example, Sarah (aged with) discussed calling her social network to see who was going to meetings at the volunteer organization or who could provide her with a ride to church.

Participants also used reframing strategies as a way to help them come to terms with having a disability and when they encountered negative experiences. For example, Lacey (aged into) explained that it is easy to feel sorry for yourself when you have a disability, but that you have be optimistic: "I mean, I look at it that way. That, you know, this is what I have been dealt. You gotta figure out how to work around it." Similarly, Susie (aged into) said "I think people are affected mentally and emotionally by disability. I think it [is] just a constant re-evaluation and it's a constant wanting to go in a positive direction." Participants also described reframing negative experiences with other people to try to focus on the good or ways to improve things. For example, Elizabeth (aged with) said "You know everybody who poses a barrier is not a bad person. They may be simply unaware. They need to be educated." Three participants also discussed using humor as a way to cope with the challenges of living with a disability. For example, Martha (acquired midlife) said " …anytime I run into any type of a barrier I try to find the humor in it. I find humor in a lot of different things."

Participants also described when they or another older adult with a mobility-limiting disability might use avoidant coping strategies as a way to protect themselves. Participants discussed making decisions to walk away from volunteer activities that were nor inclusive or that wasted their time. For example, Elizabeth (aged with) described a volunteer event in the

community where one of the organizers treated her disrespectfully, and noted that she would not volunteer with this organizer again for risk of being treated badly. Ben (acquired midlife) also discussed how people with disabilities, particularly men who have aged into disability, may avoid using assistive equipment in the community as doing so could harm their self-esteem and pride. Interestingly, one participant in the study also discussed avoiding using assistive equipment as a way to protect self-esteem. Rachel (aged into), when asked about using a cane or other assistive device, said that she choose not to and that it was "probably a vanity thing."

Social support and social networks. Social support from family and friends and connections with other people in the community can facilitate participation. Thirteen participants discussed receiving support and encouragement from their friends and families. Sometimes this was in the form of more direct or physical support. For example, Nancy (aged with) explained "The getting up and getting ready, my husband helps [with]. I could do it, but it would take longer and he does help." For others, knowing that their family supported their volunteerism was also important. For example, Chris (aged with) noted that his family also volunteers and sometimes they participate together. However, people with disabilities may not have strong social support networks or may not discuss their volunteerism with them. For example, Alice (acquired midlife) said "My support network is interesting and it's necessary. So if you have people that don't have that I think it is important to help them build a support system." Lewis (aged with) noted that he did not talk about his volunteer work amongst his friends and that he would feel like he was bragging if he talked about it with them.

Social networks were also important for participants. Having a good social network helped participants learn about new volunteer opportunities and volunteering helped them grow their social network. For example, Randy (aged with) explained "I use social networks as

gateways." Similarly, Paul (aged with) discussed all of the activities and organizations that he has become part of through his social network and also discussed how he tries to use his resources to connect other people with disabilities. Rachel (aged into) learned about her volunteer organization by attending an event in the community. For those without their own vehicle, such as Sarah (aged into), a social network can also be important for transportation. Chris (aged with) explained that one of the benefits of volunteering has been the expansion of his social network: "Well it is really great for networking. You get to know people in different parts of the city, county, state, whatever." However, while social networks can be beneficial, there are also downsides. For example, Erin (aged into) was rather frustrated by the fact that it is often an expectation that you will have wealthy social contacts who can help with fundraising.

Summary of Individual Facilitators and Barriers

Across all three groups, participants discussed a number of aspects related to their bodies and immediate environments that could facilitate or impede participation. In terms of barriers, participants discussed how secondary conditions (e.g. pain, fatigue, and depression) could make it more difficult to participate. All of the participants discussed how declines in their physical or mental health would be the main reason that they stopped volunteering. Several participants also noted that people with disabilities often have a narrower margin of health and that self-care can take more time for members of this population. Participants also noted that people with disabilities who had lower self-esteem and self-efficacy were less likely to volunteer.

In terms of facilitators, participants discussed using a myriad of coping skills to navigate barriers to participation. They also discussed how having an accessible home environment could save energy and facilitate participation. Finally, participants discussed receiving support from

family and close friends, as well as their wider social network, that helped them to remain engaged.

Organizational Facilitation

This theme refers to steps that organizations can take to better recruit and support older adults with mobility-limiting disabilities. Participants have a wealth of knowledge and skills that they can contribute to volunteer organizations; however, a lack of knowledge of the needs of older adults with mobility-limiting disabilities can make it difficult for organizations to recruit and adequately support these volunteers. When asked about how organizations could be more inclusive of and support people with disabilities, participants discussed how there is often an assumption that they cannot contribute or that it will be too difficult to have them as volunteers. Participants believed that, with a little education and creativity, organizations could become more receptive to including older adults with mobility-limiting disabilities. Participants had several suggestions for how organizations could better recruit and support older adults with mobility-limiting disabilities, and five sub-themes were identified from the interviews: *Inclusive Advertisement, Learn from People with Disabilities, Flexibility and Creativity, Support and Training, Focus on Strengths*.

Inclusive advertisement. Eight of the participants discussed how people with disabilities would be more likely to volunteer if they knew that organizations would accommodate them. This sub-theme formed inductively from participants' discussions. People with disabilities already experience many barriers just getting to a volunteer agency. Participants noted that there can be a fear that organizations will not accept or support volunteers with disabilities. To help counter this, participants suggested that organizations should let people know and advertise that

they are willing to accommodate and work with people with disabilities. For example, Martha (acquired midlife) said:

> Yeah, if they just advertise more that they would like to have people come in and they are opened to… disabled people. You know just to make themselves. You know cause most places they don't say anything and they don't put anything in the paper about it. Yeah, I think if they knew, they would be more apt to reach out. You can't just call some organization, do you have anything for volunteering, you know?

 Similarly, Paul (aged with) noted that organizations should state that they are willing to accommodate volunteers. Ben (acquired midlife) also said that it would be even more helpful if organizations provided more detailed information and let people know some of the specific tasks that would be expected of them. For Ben, this would allow a person to decide if the volunteer task was something that they could do, and thus they could avoid the discomfort and frustration of starting a volunteer opportunity and finding out that they were unable to contribute. Ben noted that this was particularly important for the mental health and self-esteem of people with disabilities.

Learn from people with disabilities. This sub-theme refers to organizations willingness to both learn from people with disabilities about their needs and make appropriate accommodations. A lack of knowledge and familiarity with people with disabilities can cause people in the community and staff at volunteer organizations to be uncomfortable around and discriminate against people with disabilities. For example, Nancy (aged with) also explained that many people are not used to seeing people with disabilities working or volunteering, and so there is an automatic assumption that a person with a disability could not contribute "it is always harder as soon as they see a disability. It is like I think often an initial sense that perhaps there

might be a mental impairment along especially if a person has a combination of mobility and speech." Paul (aged with) and Elizabeth (aged with) also noted that because of a lack of knowledge about disabilities. Elizabeth suggested that it was important to "ask the person what is needed before making assumptions about what will facilitate their inclusion." She also noted that organizations could seek out resources to become more knowledgeable about disabilities and the disability community, such as connecting with their local Center for Independent Living.

Flexibility and Creativity. Seventeen of the participants discussed three things that could help support people with disabilities: flexible hours, openness to doing things differently, and learning about and using assistive technology. Seven participants discussed how having flexible hours made it easier for them to volunteer. This flexibility ranged from having meetings start later in the day, for people who worked and for those who needed more time in the morning to get ready, to being able to select days and how many hours they volunteered. For example, Susie (aged into) explained that it would be very hard for her to volunteer in the morning or late at night:

> Pain level is, enough of a factor that, for instance, it is hard for me to do anything in the mornings. I have a routine that I go through and if I try to rush around and hurry I end up crying from the pain. And so I just need to be like a locomotive. I need my time in the mornings and then the afternoons I am pretty active and early evenings. I like to be home in the later evening and put my feet up.

Similarly, Ben (acquired midlife) noted that the medications he takes make it difficult for him to concentrate in the mornings and that he is able to contribute much more in the afternoons. Martha (acquired midlife) also explained that it was important for organizations to be clear that they do not expect the person to do more than they can physically.

For participants, it was also important to not only be flexible in terms of hours but also in terms of how tasks were done. While organizations often have a set way of doing things, a willingness to be creative and open to change can allow a person with a disability to participate. Paul (aged with) explained:

> I think it is just along the same spectrum…along the same continuum as people thinking a person can't do "X" and in order to work here you have to be able to do "X." And their only view is you have to do "X" the way everybody else does "X."

In addition, Rachel (aged into) and Erin (aged into) discussed how they needed organizations to be flexible and allow them to take short breaks or be able to move around in order to participate. For example, Rachel (aged into) discussed how she needed to be able to move around in order to alleviate pain and how she would not be able to volunteer at a place that would not accommodate that "It depends if the place wants you to sit down all the time. That would be hard. If they would expect [that]. There are probably [volunteer] jobs out there that I wouldn't just even bother with because they would be too much. Erin discussed having to give up a volunteer position as an usher because she could not stand for the period required and the organization did not allow volunteers to sit during performances.

While it can be hard for organizations to think about doing things differently, a little creativity can go a long way. For example, Alice (acquired midlife) discussed how much help teachers need and that people can volunteer with a school without having to leave their home:

> Two hours a month for a teacher could be cutting things out. Volunteering does not mean you are in the school. They need to know that. There are volunteering jobs that teachers have that you could take home and do and bring back.

Similarly, Lacy (aged into) discussed that while MS often made her tired and reduced her mobility, she was still able to do all of her volunteer work, serving on a board that oversaw scholarships for high school students, because they allowed her to work from her home. She was able to review documents and applications and call in for meetings.

Finally, participants noted that many organizations and people with disabilities themselves are not aware of the wide range of assistive technology that is available. Moreover, volunteers and agencies may not be aware that many things can be adapted. For example, Nancy (aged with) noted:

> People don't know… [that] I was into assisted technology, they just don't know that there are so many other things available...Lack of knowledge for both the volunteer and the agency that they can borrow things. That things can be adapted easily.

With a little creative thinking, it is also possible to adapt many volunteer experiences to allow older adults with mobility-limiting disabilities to participate. For example, Erin (aged into) suggested an alternative to a traditional meals on wheels program might be to have older adults with mobility impairments pair up with another person, such as someone with an intellectual or developmental disability, who can physically handle carrying heavy objects up stairs. She noted that this would not work for people who use wheelchairs, but that it could be a way to get older adults like her involved.

Support and training. Seven participants discussed the importance of organizations providing support and training to volunteers. Support referred to both providing information and recognition of the work the volunteer was doing. For example, Barb (aged into) discussed how getting a positive evaluation and ideas for ways to improve her work was important to her

And my boss is real nice. So, I think as far as what I bring to the table just my familiarity with words after being a medical transcriptionist. I don't stumble too much. And I did get a good rating after a half a year. Once she listened to me my evaluation was pretty good overall very good. Well then she gives you some pointers though. There is always going to be something you can work on right?

Rachel (aged into) discussed how a lack of support could be frustrating for volunteers "We sometimes have meetings but not often enough. And the new gal that is in the warehouse wants everything new, different. She has great ideas, but she wants it all right now. All at once." But Rachel also appreciated when staff recognized her work "There used to be someone that worked there six months that gave a lot of feedback as, "you're doing a great job," stuff like that. That really helps." Randy (aged with) also explained that it is important for organizations to provide support and "Good supervision and evaluation, and management, just like an employee." Finally, Elizabeth (aged with) noted that sometimes people with disabilities are included as volunteers as "tokens" and that this could perpetuate negative stereotypes. She also explained that organizations had a responsibility to engage and support the person in order to avoid this:

Well you might need to include [a person with a disability] on the board but then you have an obligation to help that person to develop into a good board member…and contribute. And that might mean training. It might mean development opportunities. It might mean doing a board training on diversity to be inclusive.

Focus on Strengths. All of the participants in this study suggested that an important way for organizations to facilitate the participation of older adults with mobility-limiting disabilities is to focus on the strengths and abilities of the individual. This sub-theme was developed inductively from participants' discussions of how organizations could better support older adults

with mobility–limiting impairments and people with disabilities in general. Participants in the study described a wide variety of strengths that they and other older adults with mobility-limiting disabilities could bring to organizations, such as farm-related skills, ability to handle accounting and tax-related issues, experience teaching and public speaking, past work experience in human resources, and creativity and problem-solving skills.

In order for organizations to tap into these skill sets, they need to avoid assumptions that a person with a disability could not do particular tasks or contribute to the organization. Indeed, sixteen of the participants suggested that organizations ask them what they can do and match them with tasks or activities that match those abilities. For example, Stan (aged into) noted that organizations should look at what he, or another person with a disability, can do and work with him to find tasks that fit his skill set. Nancy (aged with) shared a particularly powerful example of how organizations can adapt things to fit the abilities of people with disabilities. She explained:

> Recently I volunteered for Habitat for Humanity. They had unfortunately, the cement company had yet to pour the walks and the porch so they couldn't have the ramps that they had planned but they knew that several of us were coming in chairs and we lucked out in having sun and they found beams that we work on in the street under the shade and that it was just fun and the people we worked with had a very positive attitude about letting people do what they could do.

Nancy also noted how she felt that all of the volunteers were treated with respect and that she liked that they were given real tasks to do, instead of just token work.

While organizations can do a lot to match volunteers with activities that use their strengths and abilities, it is also important for people with disabilities to be aware of their

strengths and limitations. Three participants recognized that it was also critical for the person to be self-reflective and analyze what their own limitations were and what types of activities would not work for them. For example, Susie (aged into) explained:

> I think people need to, I mean the organization can't do it all for you. Whatever this goal that a person has… you have to be a little bit self-evaluat[ive] You have to think, what can I do to help and what can I not do. And then kind of go with what you can do. Because I have experienced that in my own life where I have had to adjust over time to what I can do.

Similarly, Elizabeth (aged with) said that she is aware of what she can and cannot do physically and volunteers for tasks accordingly. For example, she noted that she can make cookies for events or is willing to speak at events and serve on boards, but that she would avoid activities that required her to lift or move heavy objects.

Summary of organizational facilitation. Across all groups, participants discussed a number of strategies that organizations could employ to better recruit and support older adults with mobility-limiting disabilities. Participants discussed the importance of making it clear in advertisements that organizations were open and willing to work with people with disabilities. Participants also suggested that to help facilitate participation, organizations should be willing to both learn from people with disabilities and provide flexibility and accommodations that work with the person's needs and abilities. In addition, participants noted that providing support and training was helpful to volunteers. Finally, across all groups, participants suggested that organizations should look at the strengths and abilities of people with disabilities and match them with tasks that fit their skills.

Costs of Participation

This theme refers to participants' discussions of both the costs of volunteerism for themselves and the costs that organizations may incur in order to include people with disabilities. While participants were reluctant, at first, to discuss drawbacks of volunteerism to themselves, additional questions helped to identify some possible downsides to participation. Volunteerism can require a considerable commitment, which can have costs for volunteers. Being a volunteer can mean spending less time on other valued activities, and it often requires an individual to spend their own money to participate. The time and financial costs can be challenging for individuals with disabilities, particularly those who are working or are on fixed incomes. In addition, while giving back to an organization and others can be a wonderful feeling, volunteers may sometimes push themselves too hard. At the organizational level, it is important for organizations to be as inclusive as possible, but participants also recognized that this could be an expensive proposition. Through discussion of the drawbacks of participation and what organizations could do to better facilitate participation of people with disabilities, three themes related to costs for the individual were identified: *Takes Time from Other Things*, *Financial Costs*, and *Sometimes do Too Much*. An additional theme related to costs to organizations, *Cost of Inclusion*, was identified.

Takes time from other things. Volunteers often contribute a lot of time and energy to their organizations. However, for individuals with less stamina or time available, volunteering can take significant time away from other activities. Twelve participants noted that volunteerism often means you have less time available for other activities. For example, Erin (aged into) said "The biggest drawback I would say is that you get so over involved that your time is spent on

that instead of things that you should be doing for your own self." Similarly, Elizabeth (aged with) explained:

> It can take energy and time from other pursuits. I don't read books for fun as much as I would like. You get on lists where people ask you for lot of stuff. I have gotten better for setting limits. You have to set limits and sometimes that is hard because oh they want me to be on this, you can't be at a board meeting every week. It involving protecting your time and energies and setting limits.

In addition, three participants noted that a person with a disability may need to spend the time and energy that they have available on employment-related activities. For example, Paul (aged with) explained that volunteering can be a great pre-employment strategy to develop skills and a resume, but that it is also important for people with disabilities to move from being volunteers to employees if they want to be able to afford to live on their own.

Financial costs. While there are benefits to being a volunteer, participation can also be expensive. This sub-theme refers to participants' discussions of the financial cost of volunteering. While volunteering has many benefits, five participants explained that people with disabilities may not be able to afford to be a volunteer. For example, Elizabeth (aged with) said "If you are needing to make a living you probably can't volunteer." In addition, Lewis (aged with) noted that many other people get paid to do the same work that he does as a volunteer, and that "it would be nice to get paid" for some of his efforts. Jane (aged into) discussed how volunteerism can be expensive and unaffordable for people on reduced or fixed incomes: "I have to take the [bus]. I need the $4 bucks so you are asking me to pay for $4 to volunteer?" Similarly, Nancy (aged with) noted that transportation can be too expensive for someone who

takes the bus and volunteers several days a week and suggested that stipends or a bus pass would make it easier for people with lower incomes to participate.

Sometimes do too much. While volunteerism has many benefits, sometimes people overextend themselves. This sub-theme refers to participants' discussions of when they or other volunteers pushed themselves too much. Eight participants noted that it is easy to become very involved as a volunteer, but that it is also important to set limits. Lewis (aged with) and Susie (aged into) said that they knew other volunteers, not necessarily those with disabilities, who had become burnt out from trying to do too much. Nancy (aged with) noted that sometimes there are consequences for her health:

Well, as my husband tries to beat me over the head about it, reminds me, I usually don't feel the pain till afterwards and so he tries to protect me from that since I am a little bull headed. Generally, pain does not start out keeping me from volunteering.

Similarly, Alice (acquired midlife) discussed how she initially pushed herself to do as much volunteer work at the school as possible because she was excited to be back and also wanted to return to a sense of normality after acquiring her disability. However, she also explained that it became too much and she had to learn to prioritize her schedule:

Sometimes it is too much. And I don't think we look at that….Especially if I have a board meeting that night. That's just like I can't go. I am just exhausted….Sometimes too much is too much. We do have to listen to our bodies.

Costs of inclusion. For organizations, especially smaller non-profits, it can be expensive to accommodate and include people with disabilities. However, according to participants, the benefits are worth the cost. This sub-theme was developed inductively during the analysis of the interviews and reviews participants' discussions of the costs of inclusion. All of the participants

noted that organizations should be accessible; however, five participants noted that it can be challenging for organizations to include people with disabilities due to financial costs. For example, Ben (acquired midlife) discussed how many churches, particularly those in older buildings, may be reluctant to put in elevators due to construction and maintenance costs. Stacey (aged with) believed that she had missed out on work and volunteer opportunities due to her disability because organizations were afraid of the money they would have to spend to include her: "I think they were really afraid of having to make accommodations." In addition, Elizabeth (aged with) and Randy (aged with) discussed how more training and staff time may be required to properly support a person with a disability.

While there are costs associated with including people with disabilities, these participants also stressed that including people with disabilities is worth the investment. In particular, four of the participants felt that many organizations had a responsibility to be inclusive, particularly non-profits and churches who have a mission of serving the community. For example, Paul (aged with) noted that organizations need to follow the ADA and make reasonable accommodations. Elizabeth (aged with) and Randy (aged with) went a bit further, explaining that organizations that serve the community have a responsibility to include people with disabilities if they are going to truly fulfill their mission statement. Finally, Ben (acquired midlife) discussed how churches should be an example and work to be as inclusive as possible. He also noted that making things more accessible, such as putting in an elevator, can be helpful to the whole congregation.

Summary of costs of participation. Across all groups, participants described several drawbacks to partition in volunteer activities. They noted that being a volunteer could take time away from other valued activities that you can sometimes do too much and exacerbate your

secondary conditions, and that participating can be financially expensive. In addition, participants also noted that organizations may be fearful of including people with disabilities due to the costs associated with making accommodations.

Benefits of Meaningful Participation

This theme refers to benefits to the participants, organizations, and community that were identified in the interviews. Being involved in a meaningful activity gave participants reasons to both get up in the morning and to look after their health. As noted earlier, research has suggested that volunteerism can have a number of benefits for the physical and mental health of older adults more generally. When asked about benefits for their physical and mental health, participants in this study discussed how volunteering helped them to be more active, to better cope with depression and pain, to stay cognitively engaged, and to feel that they had made a meaningful impact on their community.

In addition to being important for the health of individuals, volunteerism can also help organizations and communities. Participants were asked about their perceptions of the impact of their volunteerism on the communities to which they belong, and they indicated that their volunteer work helped organizations to understand how to better work with and support people with disabilities. They also discussed how their participation could benefit people aging with and into disabilities and the community more broadly. Seven sub-themes were identified from participants' discussions of the benefits and impact of their volunteer work: *Increasing Physical Activity and Functioning, Coping with Pain, Cognitive Engagement, Sense of Purpose, Increasing Organizational Inclusivity, Positive Perceptions of People with Disabilities, and Making things more Accessible for Everyone*

Increasing physical activity and functioning. This sub-theme refers to participants' discussions of the benefits of participation in volunteer activities in relation to their physical health and functioning. Participants were asked about perceived benefits for their physical and emotional health. Across all groups, eleven of the participants noted that volunteering gave them a reason to get out of their homes and engage with community. For example, Elizabeth (aged with) said that many older adults and people with disabilities would probably stay in bed or watch TV all day if they did not volunteer. This idea was echoed by Erin (aged into) who said that she would probably be very sedentary if she did not have her volunteer activities to keep her engaged. In addition, Martha (acquired midlife) pointed out the importance of keeping busy for wheelchair users: "just getting out and doing stuff. You are always moving around, and keeping busy and that's, you have to. Otherwise, you get those darn pressure sores." Erin also noted that she had met many nurses through her volunteer work and that she felt that she could call them if she ever needed help.

Volunteerism may also be a particularly useful addition to physical or occupational therapy approaches for helping people with disabilities regain strength and functioning. For example, Alice (acquired midlife) explained that working with children in her school provided a fun environment for her to develop more strength and learn new skills after her accident. Alice stated:

And volunteering has actually been my OT/PT. I have learned how to write better. I have learned how to dribble a basketball. I have learned how to shoot basketballs. Who do you think taught me all those things? The children, that is the best OT/PT that I have ever had. The kids just, "here miss, try this ball", "well this one is too heavy guys. We'll try this ball." And we would throw balls and I would catch. They taught me all those skills. I didn't learn that in OT or PT.

Coping with pain. Pain is a common experience for many people with disabilities. However, in discussions of the benefits of volunteerism for their physical and emotional health, seven of the participants discussed how volunteering helped them to cope with pain. This sub-theme developed inductively. Three participants talked about how volunteerism helped them push through pain. For example, Martha (acquired midlife) explained "I always have to push myself. I'm like you don't feel like doing it, go do it you will feel better later. I find that if you stay active you don't pay attention to your aches and pains." Lewis (aged with) noted that he has a "happy mind and an unhappy body." For four other participants, volunteerism was a way to take their mind off of the pain. For example, Ashley (aged into) and Rachel (aged into) both noted that volunteering helped them to focus on other things besides their pain. Ashley said "I tend to, almost like out of body, even I can just like not even be here. It is just like, I don't even know what you would call that. I can distance myself from pain." Similarly, Nancy explained that in addition to helping to take your mind off of your pain, volunteering also reminds you to be grateful for what you have, as there are others that are worse off than you.

Cognitive engagement. In addition to increasing physical activity, volunteerism can also help participants to stay cognitively engaged. This sub-theme formed inductively. Six participants discussed volunteerism as a way to keep their minds active and four participants noted that volunteerism provided them with the opportunity to develop new skills. For example, Paul (aged with) also explained that volunteerism "keeps you out in the community. It keeps you interesting and interested and if you don't do that, unless you are inclined to be a hermit, you wind up just dwindling as a human being." Barb (aged into) also explained that volunteerism was good for her cognitive health and hoped that it would help her to avoid developing dementia.

Sense of purpose. The opportunity to be involved in meaningful activities also has important benefits for participants' emotional and mental health. Giving back and helping others were important reasons why participants' want to be involved in volunteer activities, and seeing the fruits of their labor provides them with a sense of purpose and satisfaction. For example, Ben (acquired midlife) said "That is where I get a lot of my satisfaction, purpose in life." Similarly, Barb (aged into) explained that she took a lot of pride in her work and that it was very satisfying to provide a service that helped so many people. Participants also described feeling good about their work. For example, Stan (aged into) said "Well, it makes me feel better inside myself." Similarly, Chris (aged with) explained that volunteering was a great way to meet people and that giving back was a really good feeling.

Four participants discussed how volunteering helped them better manage or avoid mental health problems. For example, Alice (acquired midlife) noted that having a disability "Can be pretty depressing", but that working with kids helps her. Similar, Ben (acquired midlife) said depression could make it more difficult for him to volunteer, but that he would feel worse if he did not participate. Finally, Jane (aged into) Emily (aged into) discussed how volunteering helped them to avoid feeling depressed.

Increasing organizational inclusivity. When asked about how their volunteerism impacts their communities, participants discussed how including older adults with mobility-limiting disabilities can help organizations not only complete tasks but also to become more inclusive and connected with the community. For example, Chris (aged with) and Deb (acquired midlife) volunteer with schools and both noted how their participation not only helped students learn but also helped everyone at schools, including teachers and parents, become more comfortable with people with disabilities. In addition, including people with disabilities can also help staff at the

organization to better understand how to interact and work with people with disabilities. For example, Randy (aged with) explained

> Well, I certainly have assets and skills and it also gives an opportunity to, in a safe environment, to interact with me as a person with a disability. And to interact with a person with a disability who doesn't fit the general stereotypical perception of disability.

Randy also noted that including people with disabilities could improve the perception of an organization and help them connect and network with more groups and organizations in the community, particularly those that served people with disabilities.

Positive perceptions of people with disabilities. In addition to helping staff and others connected with the organizations that they volunteer with, inclusion of older adults with mobility-limiting disabilities can help improve community members' knowledge about and attitudes towards people with disabilities. For example, Alice (acquired midlife) said "If you want to be accepted with a disability in the community you have to get yourself out there or you will never ever change people's thoughts. We have to change peoples' minds." Alice is also noted that volunteer work helped to educate children about people with disabilities and that she hoped this would improve things for the future. Similarly, Randy (aged with) discussed how his participation and the inclusion of people with disabilities was an important way to break down barriers for future generations: "….[It's] kind of like creating opportunities that will sustain themselves for the next coming generation, so they don't have to fight all of those attitude and perception issues."

For Nancy (aged with) and Alice (acquired midlife) their volunteerism was also a way to show people who may acquire a disability that life does not stop just because you have a disability. For example, Nancy discussed how her interactions with others and her volunteer work at church could show people how to manage their disability and continue to be engaged:

I am not trying to set myself up as a shining example, but what I am saying, is people have told me that they perceive that. I help them build some resilience and I think when you talk about aging into a disability I think it helps as I'm getting older. I don't stop. I think that['s] just another reason why it is important for me to continue lecturing, not because it was something I thought I could do, but the fact that it is very public means that people see me doing it.

Similarly, Alice explained that she hoped her volunteer work would help others who acquired a disability:

It's walking the walk not just talking the talk. But I have seen it before and I have the… and here is what I see for my future. It is showing people that there is a past, there is living in the moment, and then there is your future. You need to live in the moment. And be grateful.

Making things more accessible for everyone. With the aging of our population, we will see older adults with mobility limitations, and we need to find ways to help them stay active and engaged. Many cities and countries have already begun this work, through the development of age-friendly communities. However, more work needs to be done to educate people about why it is so important to make things more accessible. For example, Ben explained:

Sometimes I explain that people are trying to make me happy, I say, "that's not for me", I am just one person, you know. There is a legion. Just think of the future. And then [the city], you say you want retired people here, well you better wake up and get ready.

The more we listen to and learn from people with disabilities, the more likely we are to be able to develop communities where everyone can participate. As Elizabeth (aged with) said:

We are way beyond the point where people should be excluded. It doesn't help anybody. It doesn't help community. It doesn't the individual. It doesn't help the organization. There are so many people surviving accidents, coming back from war, living to old age, surviving low birth weight. A lot of people living with different issues. So how we are we going to create a community where everyone's skills and talents are used?

Summary of the benefits of meaningful participation. Participants perceived a number of benefits from their participation in volunteer activities. At the individual level, they discussed how volunteerism helped them to increase their physical activity and functioning, cope with pain, stay cognitively engaged, and provided them with a sense of purpose. At the organizational level, participants also discussed how their volunteer efforts helped staff become more knowledgeable about people with disabilities. Participants also believed that their involvement as volunteers helped to show others that people with disabilities had skills and abilities and could make positive contributions. Finally, they discussed how their involvement helped to make things more accessible and inclusive for everyone.

Overarching Theme: The Importance of Meaningful Participation

For the participants in this study there was a strong connection between being involved in meaningful activities and the benefits of participation in these valued activities. Participants described wanting to be actively involved, to give back to the disability community, and to have opportunities to have meaningful interactions with others, and they perceived many important benefits to being included in volunteer activities. Participants discussed experiencing many barriers to participation at the individual, community, and environmental level. In particular, participants who used a wheelchair discussed how they had to overcome and work around discrimination and stigma towards disabilities in order to be able to volunteer. As, Martha

(acquired midlife) explained "they think that everybody that's disabled is just sitting at home, you know, chain smoking, sitting in front of the TV, you know." Similarly, Chris noted "Honestly convincing people that someone sitting in a wheelchair does have intelligence. That is difficult."

Despite the barriers and the work they had to do in order to volunteer, participants felt that it was worth the effort. For example, Emily (aged into) explained:

It keeps me engaged. It keeps me active. It keeps me involved in my community. So in my mind it is just all good and it overrides [the bad]. If you have had a busy day volunteering, like for myself, I might come home and be tired and I might want to put my feet up that night but the benefits outweigh the effort. I go back to thinking that it's real easy when you get older… if you don't feel very good some of the time, it is so easy for people to get in their own little space and turn the TV on when they get up and turn it off when they go to bed. I think those interactions with others are what keep people healthy.

Hence, inclusion of people with disabilities in volunteer activities gives them an opportunity to be active, involved in meaningful activities, and to help counter negative stereotypes. While there are some drawbacks for individuals, such as financial costs, doing too much, or taking time away from other valuable activities, participants expressed a desire to continue to volunteer. Participants also noted that, while organizations may be concerned about costs associated with including people with disabilities, participants noted that it was often less expensive than organizations had thought and that many accommodations, such as elevators, would be useful for everyone. Finally, Alice (acquire in midlife) summed up other participants feelings well: "We are vital. You are missing out on the biggest thing in the world by not using us as volunteers."

Conclusion

This chapter reviewed the major findings from the 20 participants' interviews about their experiences as volunteers. The participants were organized into three groups "aging with", "acquired midlife", and "aging into". While there were differences between the three groups in terms of age of onset of disability, adjustment to having an impairment, and experiences with negative social attitudes, participants in the three groups shared many things in common. In addition, across the three groups, participants shared many similar motivations for participation and experienced many of the same challenges in dealing with secondary conditions and the physical and social environment. Indeed, in both the aging with and acquired in midlife groups, participants discussed being involved in a variety of advocacy efforts and wanting to give back to the disability community. Participants noted that there were some drawbacks to being a volunteer, such as not having enough time for other activities, the potential to exacerbate their secondary conditions, and financial costs associated with participation. They also noted that including people with disabilities could be a challenging and sometimes expensive proposition for organization. However, they provided several strategies to help organizations to better recruit and retain older adults with mobility-limiting disabilities and also noted that the costs of accommodations were often not as high as organizations believed and that making things more accessible could benefit everyone. Importantly, participants across the three groups perceived a number of benefits from their participation for themselves, the organizations the volunteered with, and their communities more broadly.

Chapter 5: Discussion

This chapter provides a synthesis of the main findings from this study. Discussion of the findings and implications incorporates a focus on their relationship to the conceptual framework developed in Chapter Two and previous research. The major sections include: the relationships of findings to the conceptual frameworks, disability across the life course, meaningful participation, environmental and social facilitators and barriers, individual facilitators and barriers, costs of participation, and organizational facilitation. The chapter then discusses the implications of this study for social work theory, research, practice, and policy. Finally, the chapter reviews the limitations of this study and highlights key takeaway points.

Relationship of Findings to Conceptual Framework

This section reviews the findings from this study in relation to the conceptual framework. A discussion of how the conceptual framework informs the interpretation of the findings and how the findings expand on the use of the approaches within the framework (social constructionism, ICF, life course perspective, strengths perspective, and ecological perspective) is provided.

Social Constructionism

A social constructionist approach, as described by Berger and Luckmann (1966) and Crotty (1998), is a useful lens for understanding the experiences of older adults with mobility-limiting disabilities, as it provides a foundation for exploring the impact of the age of onset of disability and the experiences of people with disabilities across their life course as they encounter and navigate barriers to participation. In this study, participants shared that they experienced barriers in their environments (objective reality) but also discussed how they worked around those barriers or reframed negative experiences (subjective reality). For example, participants

shared varying views on how they and other people viewed assistive equipment, with some participants describing wheelchairs as important to their freedom while others had difficulty adjusting to the use of assistive equipment. Some participants also shared that they had negative experiences with community members due to this same equipment.

While much of the literature on volunteerism and community participation by people with disabilities reviewed in Chapter 2 has used ICF as the main conceptual framework (e.g. Hammel et al., 2015), the results of this study suggest that it may be useful, going forward, to more explicitly use a social constructionist lens to explore the experiences of people with disabilities as they encounter, make sense of, and work around barriers. While ideally we will continue to work towards building and designing for everyone, there will likely still be barriers for people with disabilities, as many things may be accessible but not usable for everyone. Therefore, exploring how individuals make sense of and work around barriers can provide important insights for social workers and other helping professionals that are working with older adults with disabilities, particularly those who have aged into disability and are having difficulty adjusting to their changes in their body.

Life Course Perspective

Findings from this study fit in well with Elder and colleagues' (2004) conceptualization of the life course, particularly discussions of the importance of considering the timing of events and how social contacts shape a person's understanding of disability. An important consideration for future studies using the life course perspective is how major disruptions or changes, such as acquiring a disability in midlife, impact a person's understanding of their past and future selves. For example, in this study, Alice discussed how acquiring a disability drastically changed her life, both in terms of her body but also in terms of her self-identity and understanding of the

world. Her accident and resulting impairment caused her to reflect on and make sense of her previous life experiences, such as her lack of knowledge about disabilities and the disability community and how she planned to use her newfound knowledge.

Strengths Perspective

Based on participants' discussions, the strengths perspective appears to be a particularly useful framework for expanding on both the life course perspective and the ICF. While the life course perspective is important for thinking about the importance of the timing of a disability and the impact of larger historical events, such as the ADA, the strengths perspective helps to enrich this approach as it provides a valuable lens for exploring how people with disabilities have dealt with and grown from their experiences. Importantly, the strengths perspective does not pathologize the person's impairment but also does not ignore that the person's impairment and barriers in the physical and social environment can limit participation. Rather, this orientation allows for the exploration of how the person has grown and adapted when facing obstacles.

In addition, this approach is also important for recognizing the strengths and abilities that a person with a disability has and how these could contribute to a volunteer organization. The inclusion of the strengths of an individual is an important consideration for the personal factors section of the ICF (discussed below). While the strengths perspective has been used with people with severe and persistent mental illness (Rapp, 1998) and older adults in general (Chapin et al., 2015), its application to older adults with mobility-limiting disabilities is incomplete. Moreover, there is limited discussion of the strengths of older adult volunteers in the current literature (Sellon, 2014). Given participants' discussions of coping strategies, skills that they can draw upon from their personal and work life, and the discussions of matching a person with a

disability to volunteer activities based on their strengths and abilities, a more explicit study of the strengths of older adults with mobility-limiting disabilities, particularly those who have aged with a disability, could provide important insights to current research exploring the resilience of people aging with disabilities and volunteerism among older adults.

ICF and Ecological Perspective

The ICF (WHO, 2001) and ecological perspective (Bronfenbrenner, 1977) provide an important foundation for thinking about how different aspects of the individual and the environment can facilitate or impede volunteerism. As the ICF demonstrates, it is important to consider both the individual's health condition and their environment when exploring participation limitations. However, as noted by Hammel and colleagues (2015), the ICF does not look at transactions across levels, and that can limit its usefulness in studying the lived experiences of people with disabilities. Indeed, findings from this study demonstrate the importance of exploring transactions across levels, particularly how people with disabilities work around barriers in their physical and social environment and how these obstacles can, in turn, reduce a person's energy and self-esteem levels.

The ecological perspective, particularly Gitterman and Germain's "life model" (2008) provides a useful framework for exploring transactions across levels and how environments can be oppressive for people with disabilities. Going forward, it may be useful for researchers using the ICF to consider applying aspects of the "life model" to better understand the fit between persons and their environment. Similar to Velez-Agosto and colleagues (2017), this study supports the notion that more consideration needs to be given to the influence of the macro environment on the meso and micro levels, as the findings in this study suggest that macro influences such as historical events (passing and implementation of ADA) can influence the day-

to-day lives of people with disabilities as they fight for access to education, employment, and their communities. Hence, it is important to not only explore the fit between persons and their environment but to also explore how larger forces shape that environment.

Discussion of Key Themes

This section discusses the relationship of the themes and their sub-themes to findings from other research. Attention is given to how the findings from this study are similar to previous work and how they expand on current knowledge.

Discussion of Disability Across the Life Course

A life course approach provides a useful framework for organizing the three groups of participants in this study and for exploring how the age of onset of disability impacted participants throughout their lives. Similar to previous discussions about aging with and into disability (Molton & Jensen, 2010), participants in this study arrived at a similar place through very different paths. Participants in this study who aged with a disability have dealt with barriers throughout their lives. In contrast, those aging into have only recently begun to experience barriers, and some discussed having a hard time adjusting to limitations and dealing with social stigma. This suggests that future research using the ICF or an ecological approach could benefit from using a life course approach in order to more holistically understand the interconnections between aging and living with a disability and the challenges that older adults with disabilities may face when they encounter barriers in the physical and social environment. For example, individuals who have aged with a disability have likely figured out a number of ways to work around barriers in their physical environment. In contrast, adults who age into disability may not have had time to develop the same knowledge or coping skills and may find barriers to be insurmountable.

Interestingly, the categorization of aging with and aging into, put forth by Kemp and Mosqueda (2004) and Verbrugge and Yang (2002) did not fit all of the participants in this study. The three participants who acquired a disability in midlife and use a wheelchair seem to have a foot in both worlds. They are connected to the disability community and have had to adjust to using a wheelchair, similar to many participants who aged with a disability. However, they also share many things in common with those who have aged into, such as searching for a new role due to disability-enforced early retirement and having less time to adjust to new circumstances compared to those aging with. As we consider further ways to distinguish between groups as the field grows, it may be important to develop a multidimensional construct that looks not only at age of onset but also length of time with impairment, type of assistive device used, and coping strategies.

Discussion of Meaningful Participation

This section reviews study findings related to the benefits of including people with disabilities in meaningful activities. Participants expressed a strong desire to be involved in volunteer activities and to have the opportunity to socialize with and give back to others and their communities. Their inclusion appears to have positive benefits for themselves, other people with disabilities, organizations, and the community more broadly.

Desire to be involved. Through the discussion of their motivations for participation and the volunteer activities they were engaged in, participants expressed a desire to be involved in meaningful activities and have meaningful engagement with others. Participants not only chose activities that they were interested in but also where they had the opportunity to contribute in meaningful ways, leveraging their personal strengths and abilities. This is consistent with literature on volunteerism among older adults which suggests that desire to give back to others

and to be involved in meaningful activities is an important motivation for participation (Brown et al., 2011; Cheek et al., 2015; Martinez et al., 2006; Morrow-Howell et al., 2009; Tang & Morrow-Howell, 2008; Villar, 2012).

Findings from this study are also consistent with results from studies of older adults with disabilities in Australia (Balandin et al., 2006; Trembath et al., 2010), as several participants in this study discussed having a desire to give back to the community in general and to also improve other peoples' understanding and acceptance of people with disabilities. Unique to this study, one participant discussed his primary motivation for volunteering as learning about how to better manage his condition. Hence, it may be important to not only find opportunities for older adults with mobility-limiting disabilities, particularly those who have aged with or acquired in midlife, to be engaged in activities that can contribute to others with disabilities but to also take steps to include those with disabilities as a way to help them cope with the onset of a new disability.

The findings from this study are also consistent with discussions of volunteerism and social inclusion of people with disabilities. According to Milner and Kelly (2009) and Hall (2009) inclusion is about more than just being in the community; people with disabilities need to be a part of the community and have a chance to engage with others and contribute to the wellbeing of others. As participants in this study discussed, volunteerism is a way for them to expand their social networks and participate in activities that made meaningful differences in their community. In addition, participants had the opportunity to employ various skills and abilities that they had developed throughout their lives.

Benefits of inclusion. Inclusion of people with disabilities in meaningful activities can have important benefits for the individual, organizations, and communities. Participants in this

study discussed a number of benefits for themselves in terms of their physical and emotional health, such as increasing physical activity, coping with pain, and having a sense of purpose. In addition to individual benefits, they discussed how their inclusion helped organizations and their community to be more knowledgeable and responsive to people with disabilities. These findings help to expand on previous research related to volunteerism among older adults in four areas: increasing physical activity and functioning, coping with pain, sense of purpose and positive interactions.

Increasing physical activity and functioning. Findings from previous studies of volunteerism among older adults suggest that participation in volunteer activities can increase physical activity, improve physical functioning, and decrease depression (Greenfield & Marks, 2004; Fried et al., 2013; Lum & Lightfoot, 2005; Parisi et al., 2015). In addition, a study by Kim and Konrath (2016) suggests that older adults who engage in volunteer activities are more likely to look after their health. While these studies were conducted with older adults who were in good physical health, with few to no physical disabilities, findings from this study also suggest that inclusion in volunteer activities by older adults with mobility limiting-disabilities may provide similar benefits.

This study expands on previous research in three ways. First, findings in this study demonstrate that volunteerism also be beneficial for older adults with mobility-limiting disabilities, as it can help increase physical activity for this population. Second, participation in volunteer activities can be particularly important for wheelchair users and people with disabilities who have a narrower margin of health, as participants in this study discussed not only taking better care of their health so that they could volunteer but also how keeping busy helped one participant to avoid pressure ulcers. Third, findings from this study suggest that volunteerism

could help older adults with mobility-limiting disabilities both avoid further functional declines and actually increase some strength and functioning. Thus, inclusion in volunteer activities could be an important extension to physical and occupational therapy practices, as it helped a participant in this study regain strength and practical skills. Given the high rates of obesity and sedentary behavior and reports of lower physical health among people with disabilities (Brucker & Houtenville, 2015), it seems particularly important to begin to identify strategies to increase opportunities for participation for interested older adults with disabilities.

Coping with pain. While coping with pain has not been explored in depth in the literature on volunteerism among older adults, evidence from two studies suggests that that this can be a benefit of participation for older adults who experience chronic pain. For example, in a study of twenty-two older adults with arthritis who were trained volunteers leading an arthritis self-management program in the United Kingdom, Barlow and Hainsworth (2001) found that participation helped some of the participants cope with pain. A second study, by Arnstein and colleagues (2002), examined the experiences of individuals who completed training on pain management and then volunteered to be peer leaders of the program. Their findings suggest that, for the seven individuals who completed the training and acted as volunteers, participation in volunteer activities can help to reduce the experiences and intensity of pain. Findings from this study are consistent with these two studies and help to expand on them by showing the different ways that volunteering helped participants to cope with pain (e.g. pushing through the pain and taking mind off of pain). Findings from this study are also consistent with the literature on using non-pharmacological approaches to pain management, such as distraction and active coping strategies (e.g. staying busy) (for an overview of non-pharmacological approaches see Makris, Abrams, Gurland, & Reid, 2014).

Sense of purpose. As noted above, older adults and people with disabilities are motivated to volunteer as a way to contribute to and give back to others. Both prior research and findings from this study suggest that helping others is both a motivation and a benefit of participation. Research suggests that volunteerism can be a protective factor for and improve the psychological well-being of older adults, with well-being referring to life satisfaction and providing a sense of purpose (Greenfield & Marks, 2004; Morrow-Howell et al., 2003). Similar to previous findings, results from this study show that participation in volunteer activities can have an important impact on mental health and emotional well-being, as it helps to provide individuals with a sense of purpose. As older adults transition out of the labor force, they may feel a sense of loss of identity and connection to others and their communities. However, research suggests that volunteerism can provide a new identity and purpose for older adults (Greenfield & Marks, 2004; Morrow-Howell et al., 2003; van Ingen & Wilson, 2016). Similarly, this study highlights the importance of formal volunteer opportunities for older adults with mobility-limiting disabilities who have retired, as it provides them with a new role and identity. In addition, findings from this study suggest that volunteering can help older adults, who acquired a disability in midlife and were forced to retire early to develop a new role and identity, which may help their mental health and emotional well-being.

Positive interactions. Participants in this study felt that their volunteerism had several important impacts on organizations and the community. Participants in this study discussed having the opportunity to use strengths and skills that they had acquired across their life course and that this demonstrated that people with disabilities are capable of learning new skills. Their inclusion in volunteer activities provided staff and community members with the opportunity to see people with disabilities being active and contributing members of the organization and to

learn about and from the participants. These findings appear to fit with previous research which suggests that learning about people with disabilities and having the opportunity to interact as peers can help to improve attitudes toward and awareness of people with disabilities (Kersh, 2011; Schur et al., 2013; Scior, 2011). Hence, from an ecological perspective, there appears to be a positive transaction between the participants in this study and their social environments, with their participation both helping to educate others about people with disabilities and demonstrating the contributions that people with disabilities can make.

Interestingly, participants in this study, particularly those who aged with or acquired in midlife, also discussed how they could serve as role models not only to other people with disabilities but also to older adults aging into disabilities in particular. They discussed how they could share their wisdom about living with a disability, adjusting to using a wheelchair, and coping strategies that they used to continue to stay active and engaged in their communities.

Discussion of Environmental Facilitators and Barriers

This section reviews study findings related to participants' discussions of environmental and social facilitators and barriers. In general, findings from this study are consistent with results from studies of community participation and volunteerism among people with disabilities (Clarke et al., 2008; Hammel et al., 2015; Harris et al., 2015). Similar to findings presented by Hammel and colleagues (2015), participants in this study discussed how meso level factors, such as aspects of the physical and social environment, could facilitate or impede participation. For example, participants discussed how ramps can facilitate participation, but that ramps may also be poorly designed or may have obstructions on them that can limit their usefulness, which is consistent with findings from previous studies (Hammel et al., 2015; Harris et al., 2015; Rimmerman, 2013). In addition, similar to findings presented by Trembath and colleagues

(2010) and Barclay et al., (2016) participants in this study also discussed how negative attitudes and assumptions about people with disabilities can make it more difficult for people with disabilities to participate in their communities and in volunteer activities.

Participants' discussions about micro level factors, such as the accessibility of their home environment, is also consistent with findings from research on home modifications for older adults and people with disabilities (Imrie, 2004; Wahl, Fänge, Oswald, Gitlin, Iwarsson, 2009). For example several participants in this study discussed modifying their environment to avoid falls. In addition, like findings presented by Imrie (2004), participants in this study discussed how their connections with others can be reduced because of inaccessibility of other homes in the community. Moreover, participants' discussions of the energy required to navigate their home environments is similar to findings reported by Imrie (2004) and highlights how important it is to consider modifications to the home environment for people with disabilities across the life course. At the same time, this study also adds nuance to these discussions, as participants' discussions of the different types of modifications that they made to their homes or decisions to avoid areas of their homes in order to save energy and avoid falls adds important information to our understanding of how older adults with mobility-limiting disabilities make tradeoffs and take steps to conserve their resources.

Participants also provided a complex discussion of how social attitudes can facilitate or impede participation. Unique to this study, participants discussed experiencing both stigma due to disability and ageist attitudes. Yet, while participants noted that many people with disabilities may face an uphill battle to convince organizations that they can be valuable volunteers, they also shared positive experiences, and many reported that they did not encounter or perceive many barriers to their participation. Interestingly, many participants discussed reframing

negative experiences or using them as an opportunity to educate others. This helps to illustrate the complex transactions that can occur between a person and their environment and highlights the need to include a strengths-based approach when using an ecological perspective or the ICF to measure environmental factors that influence participation. Indeed, a strengths-based approach can be useful for exploring how individuals with disabilities develop resiliency even in oppressive environments.

Discussion of Individual Facilitators and Barriers

This section reviews study findings related to secondary conditions and personal characteristics and how they fit with results from previous studies. Findings from this study are similar to other studies in terms of participants' discussion of secondary conditions and also provide important insights on how they manage these issues so that they can continue to volunteer. In addition, this section highlights study findings relevant to ongoing work to expand the ICF's classification system for personal factors.

Declines in health. Similar to research on participation in volunteer activities by older adults (Ahn et al., 2011; McNamara & Gonzales, 2011; Tang, Morrow-Howell, & Choi, 2010), participants in this study noted that declines in their physical or mental health would be the main reason why they stopped volunteering. Importantly, with the exception of one person, participants in this study rated their health as moderate to very good. As research suggests that people with disabilities may evaluate their health differently than people without disabilities (Drum, Horner-Johnson, & Krahn, 2008), there is a need to explore how older adults with mobility-limiting disabilities define and discuss their health. Social constructionism could provide a useful framework for helping to understand how people with disabilities both define and discuss their health and how their perceptions influence their desire and ability to participate

in volunteer or community activities. In addition, it could be useful to explore interactions between disabilities and self-reports of health in order to better understand connections between views of health, disability, and volunteerism.

Secondary conditions. Similar to previous research, participants in this study discussed how secondary conditions can make it more difficult to participate (Barf et al., 2009; Benka et al., 2016; Cardol et al., 2002; Silva et al., 2016). Participants' reports that self-care takes more time for people with disabilities is also consistent with recent findings from a study comparing time spent on self-care between those with mobility impairments and those without (Greiman, Fleming, Ward, Myers, & Ravesloot, 2018). Unique to this study, participants discussed both how these secondary conditions can specifically impact volunteerism and the approaches they use to manage secondary conditions so that they can participate. This information could be particularly useful for working with older adults and people with disabilities who are interested in increasing their community engagement or becoming volunteers.

Findings from this study also suggest important information that should be assessed when looking at personal characteristics using the ICF. While the ICF provides useful information on how to assess the body, ADL/IADLS, and the environment, it does not provide guidance on what to measure in terms of personal factors, such as individual goals or strengths (WHO, 2001). As noted by Álvarez (2012), this limits the usefulness of the ICF. Recent work by Geyh and colleagues (2018) has focused on developing a classification system for personal characteristics. Findings from this study are consistent with suggestions put forth by these authors and lend further support to the argument that motivations for participation, strengths, coping skills, and making adjustments over time should be considered when using the ICF's classification system for personal characteristics.

Beyond Functional Limitations and Health

This section reviews study findings related to factors beyond functional limitations and health that could impact participation and how they expand on the current literature on volunteerism among older adults. Previous research suggests that having a functional limitation, poorer health, or depression can reduce the likelihood that an older adult will start or continue volunteering (McNamara & Gonzales, 2011; Tang, Morrow-Howell, & Choi, 2010; Burr et al., 2007; Butrica et al., 2009). This study expands on these findings and suggests a need for further research by showing additional aspects of the person and their environment that may help to explain lower participation rates.

Consistent with previous studies of volunteerism among older adults (Tang et al., 2010; Thoits & Hewitt, 2001), findings from this study suggest that volunteering can increase self-esteem. In addition, in a study exploring the relationship between social participation and mental health, Mikula and colleagues (2017) found that self-esteem fully mediated the relationship for individuals with MS. Hence, there appears to be a complex relationship between volunteerism and self-esteem, with some level of self-esteem needed to participate and the potential to increase self-esteem from participation. Similarly, participants in this study suggested that self-esteem could play an important role in whether an older adult with a mobility-limiting disability volunteered, with lower self-esteem and self-confidence as a barrier to participation. This is also consistent with research by Benka and colleagues (2016) which suggests that people with RA who had lower social participation rates also had lower self-efficacy. Hence there may be a potential interaction between having a disability and self-esteem, with people with disabilities with lower self-esteem being less likely to volunteer, that could help to further explain why older adult with disabilities are less likely to volunteer than their non-disabled peers.

Similar to previous studies on volunteerism and community participation by adults with disabilities (Kirchner et al., 2008; Lynch et al., 2008; Silverman et al., 2017), findings from this study suggest that participants employ a variety of coping strategies to work around challenges to volunteering. Uniquely, this study provides examples of coping skills used to help manage their health and secondary conditions as well as approaches taken to mitigate barriers in participants' physical and social environments. This information is particularly relevant as work continues on the ICF as it demonstrates the need to take a more holistic look at how people with disabilities manage multiple barriers to participation.

As discussed earlier, findings from this study also suggest that inaccessible environments can potentially make it more difficult for older adults with mobility-limiting disabilities to volunteer as they must expend most of their energy navigating and working around barriers. Therefore, as suggested by Gitterman and Germain (2008) in order to develop a more holisitic understanding of the person and their experiences we need to better understand how their immediate physical environment (e.g. home) and the built and social environments can influence a person's energy levels and ability to engage in volunteerism. In particular, we need to expand on current research that only looks at whether an individual has a functional limitation by including variables related physical accessibility, as this will help us more fully understand why some older adults do not participate.

Discussion of Costs of Participation

Participants' discussions of the costs of participating in volunteer activities are similar to previous studies of volunteerism among older adults in the United States (Martinez et al., 2011; Tang, Morrow-Howell, & Choi, 2010) and older adults with disabilities in Australia (Balandin et al., 2006; Trembath et al., 2010). In particular, there appear to be several drawbacks to

volunteerism including the costs associate with participation, not having enough time to do other valued activities, and the potential to exacerbate secondary conditions. Similar to previous research on employment and accommodations for people with disabilities (Schur et al., 2014), participants in this study also noted that, while there are costs of including people with disabilities, they are often less than organizations expect. Interestingly, participants also discussed how religious and non-profit organizations have a responsibility to include people with disabilities and that the accommodations that are made often benefit everyone.

Discussion of Organizational Facilitation

Participants' discussions of how organizations can recruit and support older adults with disabilities shares some similarities with previous research on organizational facilitation for older adult volunteers but also expands on this work. Similar to previous work, flexibility, support and training, and stipends were all discussed as important ways for organizations to support volunteers (Morrow-Howell et al., 2009; Mui et al., 2013; Tang, Morrw-Howell, & Choi, 2010; Pillemer, et al., 2017). While previous research suggests that a personal invitation serves as the primary way to involve people in volunteer work (Martinez et al., 2006; Tang & Morrow-Howell, 2008), participants in this study had several interesting suggestions for how requests and communications about opportunities could be made more inclusive for people with disabilities. These include stating explicitly that the organization would work with people with disabilities and detailing the types of tasks that would be required of volunteers.

Participants' discussions of organizational facilitation included several important insights that can help expand our knowledge of how to support older adults with mobility-limiting disabilities. First, participants discussed the need for organizational staff to increase their knowledge about people with disabilities and to ask the person about how to best support them.

Second, beyond flexibility in terms of schedule and choosing activities, participants' stressed that organizations also may need to make accommodations for older adults with mobility-limiting disabilities. These accommodations could range from purchasing equipment, to changing the layout of an area, to being willing to do things a little bit differently, to finding creative ways to include older adults with disabilities. Echoing research on work place accommodations (Schur et al., 2014), participants' also stressed that often the accommodations needed are not as expensive as organizations think. Finally, participants suggested that an important way for organizations to include older adults with mobility-limiting disabilities and people with disabilities in general is to focus on their strengths and abilities and to match them with tasks.

<div align="center">**Implications for Social Work**</div>

As one of the few studies that explores volunteerism among older adults with mobility-limiting disabilities, this study's findings provide important insights that can guide future research. In addition, this study helps to expand our understanding of the needs of and how to work with older adults with mobility-limiting disabilities. This section reviews the implications of these findings for social work theory, research, practice and policy.

Theory

This study has several implications for theory. First, while the ICF provides a bio-psychosocial approach to understanding the intersection between impairments and contextual factors that create disabling environments, use of additional theoretical perspectives could help to expand on findings in many studies of people with disabilities. For example, a more explicit use of social constructionism could provide a more holistic discussion of the role of the social and physical environment in shaping opportunities for people with disabilities to be engaged with their communities. In addition, it could help to highlight both how the social construction of

disability limits opportunities for people with disabilities to participate and how members of this population help to challenge negative stereotypes.

Second, while the life course approach and the ICF provide important frameworks for studies exploring the experiences of older adults with disabilities, the strengths perspective can provide an important expansion for both. Researchers have used a life course approach to look at cumulative disadvantages (Dannefer, 2003) and experiences of adults aging with disabilities (Grassman et al., 2012). Use of the strengths perspective could help to expand on this work by exploring the goals that people with disabilities set and the resilience that they develop over time. In addition, as work continues around the development of the "personal factors" section of the ICF (see Geyh, Schwegler, Peter, Müller, 2018), key ideas from a strengths based approach, such as the goals of an individual and the internal and external resources that a person with a disability uses to overcome obstacles to participation, could add insightful information.

Finally, similar to suggestions put forth by Velez-Agosto and colleagues (2017), this study highlights the importance of exploring the influence of macro level events (e.g. passage of the ADA) on both the meso and micro levels. For example, several of the participants discussed how, when they encountered barriers in the physical environment that violated the ADA, they would educate others about the law and file complaints to try to force change. Hence, without this macro level policy, participants would not have a legal avenue available to support their efforts to change their communities.

Research

Given the benefits of participation and the limited number of studies on volunteerism among older adults with mobility-limiting disabilities, particularly in the United States, more research is needed on the experiences of members of this group as they engage in volunteer

activities. In particular, there is a need to further understand how to recruit and support members of this population, the benefits of participation, and why older adults with mobility-limiting disabilities stop volunteering.

In order to better recruit and support older adults with mobility-limiting disabilities, more information is needed on how aspects of urban or rural environments specifically impact volunteerism. In addition, as participants with different types of impairments discussed different needs in terms of accommodations or accessible environments, future studies could look at similarities and differences in experiences and needs within (e.g. those with post-polio) and across different types of disabilities. Finally, it would be important to explore online volunteering and how different types of assistive technology can facilitate participation for older adults with mobility-limiting disabilities.

As participants in this study described a number of benefits for their health and well-being, it will be important to explore whether these findings are consistent across different groups of older adults with mobility-limiting disabilities. In addition, given participants' differing discussions of how volunteerism helped them cope with pain (e.g. pushing through vs. taking mind off of pain) it will be important to explore how much and what types of volunteer activities are helpful for coping with pain and whether there are personal characteristics that influence this process. Finally, as one participant who acquired a disability in midlife talked about how volunteerism helped her regain strength and functioning beyond her OT/PT services, it could be important to explore whether volunteerism could be similarly beneficial for other older adults who acquire a disability in midlife.

Participants' discussions of how they overcame barriers to participation and the potential impact of low-self-esteem on the willingness to volunteer suggests that there may be more

complex reasons why older adults stop volunteering than just having a functional impairment or poorer health. Going forward, it could be informative for studies on volunteerism to explore interaction effects between having a disability and a number of other factors such as self-esteem, assistive device use, accessibility of the home environment, and accessibility of the community. In addition, it could also be informative to explore whether older adults who have aged with a disability are more likely to be volunteers than those who have aged into disability. Unfortunately, many of the publicly-available data sets do not include measures of age of onset of disability (see Putnam et al., 2016) and many tend to include questions about neighborhood safety but not community accessibility (e.g. MIDUS).

Practice

Similar to discussion by Kim and Canda (2006), findings from this study suggest that it is important for social workers to practice from a social model but to also take into account the impact that health conditions and impairments can have on clients. Social workers need to have a dual focus, helping the individual find appropriate ways to manage their health condition and secondary conditions but also working to help the person remove barriers in their immediate environment and the community when possible. The ICF provides a useful framework for social workers to understand medical terminology and develop interventions that facilitate the health and well-being of people with disabilities (Saleeby, 2007). Findings from this study suggest that it is important for social workers to explore how the person shapes their environment (e.g. coping strategies and strengths) and how the home and community can affect how much energy a person spends as they navigate barriers.

In order to work with older adults with disabilities, social workers may need to become more knowledgeable about different types of disabilities and the experiences and needs of people

who age with disabilities. While social workers have long worked with people who develop disabilities in older age, they may not have experience or knowledge about working with individuals who have aged with a disability (Putnam & Wladkowski, 2016). Based on participants' conversations, two ways for social workers to increase their knowledge are to explore online resources and to connect with their local independent living center.

Also critical to working with people with disabilities is recognizing our own limitations and biases and being willing to be taught by people with disabilities. This will likely require social workers to take on a stance of cultural humility. According to Fisher-Borne and colleagues (2015), cultural humility "seeks to cultivate self-awareness on the part of providers and acknowledges the ways in which cultural values and structural forces shape client experiences and opportunities" (p. 172). Key aspects of this approach are self-reflection, being aware of your own limitations and biases, and being open to learning new things (Foronda, Baptiste, Reinholdt, & Ousman, 2016). Hence, social workers working with people with disabilities will need to be open to reflection on their own biases and be willing to learn from people with disabilities.

Finally, as noted by participants in this study, non-profit and other community-focused organizations have a responsibility to include people with disabilities as volunteers. Given our Code of Ethics (NASW, 2017) and the fact that many social workers operate in non-profit settings, it is important for social workers to take a leading role in advocating for and including people with disabilities as volunteers in our organizations. This may be challenging, given limited budgets or staff time available, but the rewards are likely to be worth the effort, as including people with disabilities can help organizations network with the disability community and may allow them to access new grants and revenue streams that are aimed at increasing the inclusion of people with disabilities in volunteer and employment activities.

Policy

Findings from this study have implications for policy and advocacy work at the local and national level. In this study, participants discussed a number of factors that were important for participation, such as transportation and accessible environments, but they also noted limitations that could make it more difficult for an older adult with a mobility-limiting disability to volunteer. For example, participants discussed how important transportation was to facilitating participation but also noted limitations with services. As the baby boomers continue to retire, having public transportation systems that meet their needs will be an important way for communities to keep their aging population active and engaged. Social workers working with and advocating for older adults and people with disabilities could help communities and the federal government recognize the importance of investing in public transportation systems.

Participants also discussed many aspects of the physical environment that could limit the ability of people with disabilities to participate in their communities, such as uneven or broken sidewalks and inaccessible buildings. Several of the participants discussed advocating for change when they encountered barriers in their physical environment. They engaged in advocacy efforts both in terms of educating people in their community and at the state and national level through their volunteer work, such as the participant who was involved with AARP. Participants in this study demonstrated that they have valuable knowledge and skills that they can bring to the table in advocating for change. As many communities work towards becoming "age friendly", a strategy proposed and supported by the World Health Organization to help older adults stay engaged in their communities, it will be important to ensure that the voices and needs of people with disabilities are included in these discussions. Social workers can play a key role in advocating with and for the inclusion of people with disabilities in community discussions in order to help ensure that decisions are not made without the thoughtful input from people with disabilities.

Participants also discussed how support from various programs, such as Meals on Wheels, allowed them to volunteer. The Older Americans Act, re-authorized in 2016, provides funding for Meals on Wheels and other programs that help older adults live as independently as possible in their community (Administration for Community Living, 2018). Social workers can work with older adults and people with disabilities to advocate for the continued funding of these programs. In particular, social workers can educate themselves, older adults, and people with disabilities of all ages about the 1999 U.S. Supreme Court Decision in Olmstead vs. L.C. and other protections afforded by the ADA. Often referred to as the Olmstead decision, this ruling argues that people with disabilities have the right to supports and services that will allow them to live in their communities instead of in institutions (*Olmstead* v. L.C., 1999; Schur et al., 2013). Social workers, older adults, and people with disabilities can educate others about the right of people with disabilities to live in and be engaged with their communities.

Finally, volunteerism appears to provide many health benefits for the participants in this study that help them to maintain their health and independence. As such, it is important for social workers to continue to identify opportunities for interested older adults with disabilities to participate in volunteer activities. At the federal level, the Administration on Community Living (ACL) serves as a single agency responsible for increasing the supports and services people with disabilities and older adults need to remain healthy and to live independently in their communities (ACL, n.d.). The ACL brings together the Administration on Aging, the Administration on Intellectual and Developmental Disabilities, and the Health and Human Services Office on Disability. Social workers can work with the ACL to identify opportunities to increase funding and develop volunteer programs that are inclusive of older adults with disabilities, as this may help to meet the ACL's goal of ensuring that people with disabilities and older adults have full access to their communities (ACL, n.d.).

Limitations

This study uses a social constructionist approach and methods from naturalistic inquiry to take an in-depth look at the experiences of older adults with mobility-limiting disabilities who engage in volunteer work. While this study provides important insights and suggestions for future research, there are some limitations. First, while prolonged engagement can aid the researcher in conducting a study using naturalistic inquiry methods (Lincoln & Guba, 1985), this was not possible in this study due to funding and time constraints. However, the face-to-face, in-depth interviews with participants at locations of their choice, field notes, and member checks did help to provide greater trustworthiness of findings and more context for understanding participants' experiences.

Second, the average age of participants in this study was 66. While it is possible that volunteerism mostly occurs among younger-older adults with mobility-limiting disabilities, it will be important to explore the experiences of individuals who are older (e.g. 75+) as they may have different experiences and challenges to participation.

Third, while this study originally set out to explore volunteerism among older adults with mobility-limiting disabilities overall and to compare experiences between those who have aged with a disability to those who aged into disability, a third group was identified, those who acquired a disability in midlife. Due to time and funding limits and the fact that additional participants who would fit within this third group were not identified, this group only contained three members. While the information they provided was valuable and informative, future research with a larger sample of people who acquired a disability in midlife will likely yield additional insights. Finally, this study was conducted in three Midwest cities, one of which is politically and socially progressive, and one smaller town. Further research is needed, using the

ICF, the strengths perspective, and the ecological perspective, to understand how different community contexts, such as more conservative or less affluent environments, shape participation for older adults with mobility-limiting disabilities.

Conclusion

This dissertation is an exploratory, qualitative study drawing on social constructionism and naturalistic inquiry to investigate the experiences of twenty older adults with mobility-limiting disabilities who engaged in volunteer activities. Participants in this study want to be engaged in meaningful activities and have many strengths and abilities that they can bring to volunteer programs. While there are a number of barriers to their participation at the individual level and in their physical and social environments, participants appear to have developed a wide array of coping skills to navigate these barriers. They also provided many valuable recommendations for how organizations could better recruit and support people with disabilities. Importantly, there are benefits to the individual, volunteer organizations, and the community to including older adults with mobility-limiting disabilities, and social workers can and should play an active and important role in helping interested older adults with mobility-limiting disabilities become volunteers.

This study also adds information to our current understanding of volunteerism among older adults in the United States. In particular, these findings demonstrate that older adults with mobility-limiting disabilities want to be involved in volunteer activities and can be involved. While they face a number of barriers to participation, participants described using a variety of coping skills so that they could participate. While these findings are dependent on the context and experiences of participants, the use of thick description, purposive sampling, and an audit trail in this study allows for transferability and can help other researchers compare these findings

with their own ideas and research (Lincoln & Guba, 1985). In particular, findings from this study suggest that volunteerism can help reduce perceptions of pain for some individuals and that it can increase physical and health functioning. Given these benefits, future research is needed to explore how much involvement and what types of volunteer activities can help older adults with mobility-limiting disabilities. In addition, findings from this study suggest that there is a need to look more closely at the impact of self-esteem on volunteerism among older adults with disabilities. Moreover, there is a need to include more disability-related variables in nationally representative data sets, such as questions about age of onset and home and community accessibility.

This study provides an important first step in exploring the experiences of older adults with mobility-limiting disabilities who are engaged in formal volunteer activities. Further qualitative and quantitative research is needed to expand on these findings in order for social workers to both have more knowledge about the needs of this group and to better develop programs and interventions to increase opportunities for participation.

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Appendix A

Phases of Inquiry

Phase I: Refinement of Research Design	1) Proposal Defense 2) IRB Approval 3) Pilot Interview 4) Refine interview Guide 5) Recruitment Flyers Sent out	October 2016 April 2017 May 2017 May 2017 May-June 2017
Phase II: Data Collection	1) Initial audit check and review interview guide 2) Conduct 20 in-depth interviews 3) Transcription of interviews 4) Follow up interviews 5) Intermediate audit check 6) Member checks 7) Review of findings with key informant 8) Peer debriefing	June 2017 May-Aug 2017 Aug-October 2017 Aug 2017-Jan 2018 December 2017 Nov 2017-March 2018 December 2017, March 2018 December 2017, Feb 2018
Phase III: Data Analysis	1) Develop initial coding categories 2) Data analysis and coding 3) Refine coding guide 4) Member checks 5) Intermediate audit check 6) Continue data analysis and preliminary writing 7) Final audit check 8) Review of findings with key informant 9) Peer debriefing	June-Aug 2017 September-November 2017 December 2017 Nov 2017-March 2018 December 2017 December 2017-March 2018 March 2018 March 2018 March 2018
Phase IV: Write up and Defense	1) Write up dissertation 2) Feedback on draft chapters from Chair and Methodologist 3) Submit to committee	Jan-March 2018 Feb-March 2018 April 2018

Appendix B

APPROVAL OF PROTOCOL

April 11, 2017

Alicia Sellon
a714s244@ku.edu

Dear Alicia Sellon:

On 4/11/2017, the IRB reviewed the following submission:

Type of Review:	Initial Study
Title of Study:	Older Adults and Disabilities: Inclusion in Volunteer Activities
Investigator:	Alicia Sellon
IRB ID:	STUDY00140809
Funding:	Name: University of Kansas
Grant ID:	
Documents Reviewed:	• Sellon HRPP_signed_consent_form.docx, • Sellon Study__Demographic cover sheet.docx, • HSCL-Sellon new submission spring 2017.pdf, • Sellon Flyer spring 2017.docx, • Sellon Waiving collection SSN.docx, • Sellon HSCL_Example Interview Questions.docx

The IRB approved the study on 4/11/2017.

1. Notify HSCL about any new investigators not named in original application. Note that new investigators must take the online tutorial at https://rgs.drupal.ku.edu/human_subjects_compliance_training.
2. Any injury to a subject because of the research procedure must be reported immediately.
3. When signed consent documents are required, the primary investigator must retain the signed consent documents for at least three years past completion of the research activity.

Continuing review is not required for this project, however you are required to report any significant changes to the protocol prior to altering the project.

Please note university data security and handling requirements for your project:
https://documents.ku.edu/policies/IT/DataClassificationandHandlingProceduresGuide.htm

You must use the final, watermarked version of the consent form, available under the "Documents" tab in eCompliance.

Sincerely,

Stephanie Dyson Elms, MPA
IRB Administrator, KU Lawrence Campus

Human Research Protection Program
Youngberg Hall | 2385 Irving Hill Rd | Lawrence, KS 66045 | (785) 864-7429 | research.ku.edu/hrpp

Appendix C

Older Adults and Disabilities: Inclusion in Volunteer Activities
Informed Consent Statement

INTRODUCTION

The Department of Social Welfare at the University of Kansas supports the practice of protection for human subjects participating in research. The following information is provided for you to decide whether you wish to participate in the present study. You may refuse to sign this form and not participate in this study. You should be aware that even if you agree to participate, you are free to withdraw at any time. If you do withdraw from this study, it will not affect your relationship with this unit, the services it may provide to you, or the University of Kansas.

PURPOSE OF THE STUDY

The purpose of this study is to develop a more comprehensive understanding of participation in volunteer activities by older adults with mobility limiting disabilities. Mobility limiting disabilities are defined as whether a person has serious difficulty walking or climbing stairs. Knowledge gained from this study will be critical to building a foundation of basic knowledge that may be central to helping organizations recruit and retain older adults with disabilities. In addition, this study will shed light on any disparities in participation between people aging with and without a mobility-limiting disability, which may be essential information for advocacy work and policy changes to address such discrepancies.

PROCEDURES

You will be asked to complete a short demographic survey before the interview. The survey will ask you for information about your age, gender, education level, type of mobility impairment, and length of time you have lived with the impairment. The interview is expected to last 45-60 minutes and will be audio recorded. The interview will include questions about why you volunteer, factors that can facilitate or impede participation, the challenges of volunteering, and the benefits of volunteering.

The audio recordings are required to participate in the study. You may request that the taping stopped be at any time. The researcher and a hired transcriptionist will transcribe the interviews. The transcriptionist will delete the audio recording after completing the transcription. The researcher will store audio recordings on a password protected computer. Audio recordings will be deleted after three years and transcriptions will be kept indefinitely. All materials (demographic survey, audio recordings, and transcription) will be kept on a password protected computer that meets University security standards and in a locked filing cabinet in a locked office.

RISKS & Benefits

The researcher anticipates minimal risk in participating in this study. Several benefits are anticipated from participation in this study. First, the research hopes that this interview will provide an important opportunity for you to reflect on and share your experiences and as a volunteer. It is also hoped that this interview will give you a chance to reflect on the contributions your volunteerism makes community. In addition, your experiences and views on volunteering will help to building a foundation of basic knowledge that may be central to helping organizations recruit and retain older adults with disabilities.

PAYMENT TO PARTICIPANTS

You will receive $40 for your time and effort in participating in this study, via debit card. Researchers may ask for your social security number in order to comply with federal and state tax and accounting regulations.

PARTICIPANT CONFIDENTIALITY

Your name will not be associated in any publication or presentation with the information collected about you or with the research findings from this study. Instead, the researcher(s) will use a pseudonym rather than your name. Your identifiable information will not be shared unless (a) it is required by law or university policy, or (b) you give written permission.

Permission granted on this date to use and disclose your information remains in effect indefinitely. By signing this form you give permission for the use and disclosure of your information for purposes of this study at any time in the future.

REFUSAL TO SIGN CONSENT AND AUTHORIZATION

You are not required to sign this Consent and Authorization form and you may refuse to do so without affecting your right to any services you are receiving or may receive from the University of Kansas or to participate in any programs or events of the University of Kansas. However, if you refuse to sign, you cannot participate in this study.

CANCELLING THIS CONSENT AND AUTHORIZATION

You may withdraw your consent to participate in this study at any time. You also have the right to cancel your permission to use and disclose further information collected about you, in writing, at any time, by sending your written request to: Alicia Sellon, 1545 Lilac Ln, Lawrence, KS 66045

If you cancel permission to use your information, the researchers will stop collecting additional information about you. However, the research team may use and disclose information that was gathered before they received your cancellation, as described above.

QUESTIONS ABOUT PARTICIPATION

Questions about procedures should be directed to the researcher(s) listed at the end of this consent form.

PARTICIPANT CERTIFICATION:

I have read this Consent and Authorization form. I have had the opportunity to ask, and I have received answers to, any questions I had regarding the study. I understand that if I have any additional questions about my rights as a research participant, I may call (785) 864-7429 or (785) 864-7385, write the Human Research Protection Program (HRPP), University of Kansas, 2385 Irving Hill Road, Lawrence, Kansas 66045-7568, or email irb@ku.edu.

I agree to take part in this study as a research participant. By my signature I affirm that I am at least 18 years old and that I have received a copy of this Consent and Authorization form.

Page 2 of 3

_____   _____
Type/Print Participant's Name   Date

_____
Participant's Signature

Researcher Contact Information

Alicia Sellon	Dr. Rosemary Chapin
Principal Investigator	Faculty Supervisor
School of Social Welfare	School of Social Welfare
1545 Lilac Ln,	1545 Lilac Ln,
University of Kansas	University of Kansas
Lawrence, KS 66045	Lawrence, KS 66045
785-864-4778	785-864-8941

Appendix D

Research Participants Needed

- Are you and adult age 50+ who has volunteered in the last year?

- Do you have serious difficulty walking or climbing stairs due to a health condition or impairment?

If you answered YES to these questions, you may be eligible to participate in a research study on volunteerism.

The purpose of this study is to develop a more comprehensive understanding of participation in volunteer activities by people with mobility-limiting impairments.

Who can participate?

Adults 50+ who have volunteered in the last year and who have serious difficulty walking or climbing stairs due to a health condition or impairment.

What will you do?

Participate in an interview lasting between 45 and 60 minutes.

Will Compensation be provided?

This study will reimburse participants $40 for their time and effort.

For more information contact Alicia Sellon at
aliciasellon@ku.edu
785-864-4778

Appendix E

Initial Interview Guide
Probe throughout

Thanks for agreeing to talk with me.

<u>I would like to learn about why you volunteer?</u>

1. Can you tell me a little about why you volunteer?
    a. What motivates you to volunteer?
    b. When did you start volunteering?
    c. Are there aspects of being a volunteer that you particularly like?
    d. Can you give me an example of a particularly positive volunteer experience?

2. What tasks or activities do you do as a volunteer?
    a. Are there other tasks that you wish you could do for your organization? (If yes: what types of activities would you like to do? Why would you like to do them? Why aren't you doing them already?)

3. Thinking about your volunteer work and other areas of your life, what are your strengths? Or what do you think you bring to the table?
    a. Do you have s or abilities kills?
    b. Are you particularly good at certain things?
    c. What past experience or skills do you use to help with your volunteer work?

<u>I would like to learn about what factors might prevent/facilitate participation?</u>

4. At a personal or individual level, what factors might help you or a person with a mobility limitation in their volunteer work?
    a. Any health or personality factors?
    b. Family or other supports
    c. Any spiritual factors?
    d. Do you use any assistive technology or other resources?
    e. What kind of help and support might a person with a mobility disability need to volunteer?

5. At a personal or individual level, what factors related to your health or mobility limitation could make it difficult to volunteer?

6. Thinking more broadly, what kinds of barriers in the community can make it difficult to volunteer?
   a. What factors in the natural environment could make it difficult to volunteer?
   b. What factors in the work environment?
   c. What other factors can make volunteering challenging?
   d. Transportation?
   e. What aspects of the community can make it easier or harder to be a volunteer?
   f. Are there organizations that you would like to volunteer for, but don't think that you can?

I would like to understand more the benefits and drawbacks of participating in volunteer activities?

7. Can you tell me a little about some of the benefits of being a volunteer?
   a. Are there benefits for your physical health?
   b. Social benefits?
   c. How about for your emotional or spiritual health?
   d. How does your volunteer work impact other areas of your life?
      i. Do you have enough time to volunteer and do other activities you are interested in?

8. Can you tell me a little about some of the drawbacks of being a volunteer?
   a. Are there drawbacks for your physical health?
   b. How about spiritual or emotional health?
   c. If you were to stop volunteering, what do you think would be the main reason?

Finally I would like to know about any recommendations you might have for increasing participation of older adults with mobility limitations in volunteer activities.

9. What advice would you give to other older adults with mobility limitations who might want to volunteer?
10. What advice would you give to organizations who are interested in recruiting adults and older adults with mobility disabilities?
11. Do you have any other thoughts or ideas on this topic that you would like to add?

Appendix F

Date

Dear _____,

Thank you for agreeing to participate in my study. The date and time we have for our interview

is: _____at _____. If something comes up and you need to reschedule,

please contact me at 785-864-4778 or at email address aliciasellon@ku.edu. As soon as we

finish the interview, I will be sending you the $40 gift card in appreciation of your sharing your

experiences with me.

I am sending this information to you so that you will have a better idea of the kinds of questions I

will ask. I don't expect you to go out and gather any information, I just want to give you a little

time to think about these things in advance.

Here are some of the topics I would like you to think about:

1. I would like to know a little bit about why you volunteer. What motivates you to volunteer? When did you start volunteering?
2. I also would like to hear about what types of tasks or activities you do as a volunteer.
3. Then I would like to know about some of your strengths as a volunteer, or what skills and abilities you bring to a volunteer experience.

Following this, I will ask some questions about the things that facilitate or act as barriers to

volunteerism for you personally and for people with mobility impairments in general. I would

like to explore these factors at a personal and community level:

1. At a personal or individual level, what factors might help or hinder you or a person with a mobility limitation in their volunteer work? Are there health factors or emotional/spiritual factors that play an important role? How important is your home environment to allowing you to participate? Do you need assistance or use devices to help you volunteer?
2. Can you tell me, briefly, what community level factors help or hinder your volunteer work? Are there aspects of the natural environment or work environment that can help or act as a barrier to participation?
3. If you encounter barriers do you have any suggestions on how to overcome them? Do you advocate for changes or educate others on why changes are needed? On a

personal an emotional level, are there additional ways that you deal with barriers or problems in your volunteer work. Some examples of this might include having a sense of humor, focusing on the positives, or trying to see the problem in a different light.

Next, I would like to know about some of the benefits and drawbacks of being a volunteer.

1. Can you tell me a little about some of the benefits of being a volunteer? Are there physical, social, psychological benefits? How does volunteering impact other areas of your life (do you have enough time to do other activities of interest)?
2. Can you tell me a little about some of the drawbacks of being a volunteer? Are there physical, social, or psychological drawbacks? If you were to stop volunteering, what do you think the main reason would be?

Changing the focus a little bit, I would like to hear your ideas on how volunteerism could be

used as a pathway to employment for people with mobility limitations

1. How could volunteerism be used as a pathway to employment for people with disabilities?
2. What supports are needed to enable this pathway?
3. What programmatic changes would enable this pathway?
4. In your opinion, can volunteerism complement state and community vocational rehabilitation programs?

Finally I would like to know about any recommendations you might have for increasing

participation of older adults with mobility limitations in volunteer activities.

12. What advice would you give to other older adults with mobility limitations who might want to volunteer?
13. What advice would you give to organizations who are interested in recruiting older adults with mobility disabilities?
14. Do you have any other thoughts or ideas on this topic that you would like to add?

If you have any questions, please let me know.

Sincerely,

Alicia Sellon

Appendix G

Final Interview Guide
Probe throughout

 Thanks for agreeing to talk with me.

<u>I would like to learn about why you volunteer.</u>

1. Can you tell me a little about why you volunteer?
    a. What motivates you to volunteer?
    b. When did you start volunteering?
    c. Are there aspects of being a volunteer that you particularly like?
    d. Can you give me an example of a particularly positive volunteer experience?
2. What tasks or activities do you do as a volunteer?
    a. Are there other tasks that you wish you could do for your organization? (If yes: what types of activities would you like to do? Why would you like to do them? Why aren't you doing them already?)
3. Thinking about your volunteer work and other areas of your life, what are your strengths? Or what do you think you bring to the table?
    a. What kind of abilities or skills do you have?
    b. Are you particularly good at certain things?
    c. What past experience or skills do you use to help with your volunteer work?

<u>I would like to learn about what factors might prevent/facilitate participation.</u>

4. At a personal or individual level, what factors might help you or a person with a mobility limitation in their volunteer work?
    a. Personality and outlook on life?
    b. Family or other supports?
    c. Any spiritual factors?
    d. What factors in your home environment?
    e. Do you use any assistive technology or other resources?
    f. What kind of help and support might a person with a mobility disability need to volunteer?
5. How important is your social network to your participation?
    a. how much to you rely on your network of friends and family to learn about opportunities and to participate in volunteer activities?
6. At a personal or individual level, what factors related to your health or mobility limitation could make it difficult to volunteer?
    a. Are there health related factors that limit your ability to volunteer?
    b. Other factors?

      c.   What challenges in your volunteer work are due to age and which are due to impairments?

7.   Thinking more broadly, what kinds of barriers in the community can make it difficult to volunteer?

      a.   are there features of your neighborhood that facilitate or prevent participation (neighborhood safety or accessibility)?

      b.   What factors in the natural environment (climate, paths are clear, terrain flat) could make it difficult to volunteer?

      c.   What factors in the built environment or where you do your volunteer work environment?

      d.   Are there social barriers to volunteering?

      e.   Transportation?

      f.   Other aspects of the community can make it easier to be a volunteer?

      g.   Are there organizations that you would like to volunteer for, but don't think that you can?

      h.   Can you tell me about a time when you experienced barriers to participating in volunteer activities?

8.   Are there social factors can make volunteering challenging?

         i.   Do people/staff assume you cannot volunteer?

       ii.   Do other volunteers treat you as an equal?

9.   What things can make it more difficult for older adults with mobility-limiting disabilities to volunteer?

10. What can organizations do to better include older adults with mobility-limiting impairments?

      a.   Role or time Flexibility and other accommodations?

      b.   technologies

      c.   innovative methods

I would like to understand more the benefits and drawbacks of participating in volunteer activities.

11. Can you tell me a little about some of the benefits of being a volunteer?

      a.   Are there benefits for your physical health?

      b.   Social benefits?

      c.   How about for your emotional or spiritual health?

      d.   How does your volunteer work impact other areas of your life?

         i.   Do you have enough time to volunteer and do other activities you are interested in?

12. How does your volunteerism benefit the communities that you belong to?
    a. Neighborhood
    b. Disability
    c. Aging
    d. Other communities
13. Can you tell me a little about some of the drawbacks of being a volunteer?
    a. Are there drawbacks for your physical health?
    b. How about spiritual or emotional health?
14. If you were to stop volunteering, what do you think would be the main reason?

Finally I would like to know about any recommendations you might have for increasing

participation of older adults with mobility limitations in volunteer activities.

15. Do you think, if given the chance, older adults with mobility impairments can and would volunteer at the same rates as older adults without mobility impairments?
16. What advice would you give to other older adults with mobility limitations who might want to volunteer?
    a. If you knew another older adult with a mobility-limiting impairment was interested in volunteering, how would you support or mentor them?
17. What advice would you give to organizations who are interested in recruiting adults and older adults with mobility disabilities?
18. Do you have any other thoughts or ideas on this topic that you would like to add?

Appendix H

Older Adults and Disabilities: Inclusion in Volunteer Activities

DEMOGRAPHIC QUESTIONS

1. **Name:**_____
   _____

2. **Preferred
   Pseudonym:**_____

3. **Gender:**
   o Male
   o Female
   o Other
   o Prefer not to answer

4. **Age (please fill in the blank with your
   age):**_____

5. **Race (please circle all that apply):**
   o White
   o White African American
   o Asian
   o Native American or Alaska Native
   o Native Hawaiian or Other Pacific Islander
   o More than one race
   o Other:_____

6. **Ethnicity:**
   o Hispanic or Latino
   o Not Hispanic or Latino

7. **Highest Level of Education (please fill in the blank with your highest level of
   education)**_____

8. **Marital Status (please circle one)**
   - Married/domestic partnership
   - Separated
   - Widowed
   - Divorced
   - Single/never married

9. **Employment Status (please circle one):**
   - Employed full-time
   - Employed part-time
   - Unemployed
   - Retired
   - Other_____

10. **Annual Household Income**_____

VOLUNTEER QUESTIONS

1. **Have you volunteered in the last year:**

   - Yes

   - No

2. **How many organizations do you volunteer for:**_____

3. **Estimated annual hours you volunteer for all**

   organizations:_____

4. **What type of organization(s) do you volunteer for?**_____

5. **How did you become involved with the main organization you volunteer for (please**

   circle all that apply):

   - Approached the organization
   - Was asked
   - Some other way
   - Do not know

DISABILITY/IMPAIRMENT QUESTIONS

1. **How would you rate your health? (please circle the statement that most accurately reflects your current health)**
    - o Very Good
    - o Good
    - o Moderate
    - o Bad
    - o Very Bad

2. **Health condition(s) that causes mobility impairment (please circle all that apply):**
    - o Post-polio
    - o Spina bifida
    - o Spinal cord injury
    - o Multiple Sclerosis
    - o Muscular Dystrophy
    - o Cerebral Palsy
    - o Rheumatoid arthritis
    - o More than one impairment (please specify)_____
    - o Other_____

3. **Length of time with impairment (indicate years or months):_____**

4. **Type of assistive devices used (circle all that apply):**
    - o Manual wheelchair
    - o Powered wheelchair
    - o Walker
    - o Cane
    - o Braces
    - o Other_____

Appendix I

Audit Trail Contents

Classification	File Type	Evidence
Research Proposal	Dissertation proposal (submitted and presented to dissertation committee) Human subjects committee proposal: Applications Consent forms Preliminary interview guide Recruitment flyer	Electronic files
Instrument Development	Interview guide draft and final version	Electronic files
Raw Data Files	Demographic questionnaire Audio-recordings Transcripts Follow up emails Field notes	Electronic files and paper files
Data Reduction and Analysis	Brainstorming file and emerging patterns notes Methodological log	Electronic and paper files

Data Reconstruction and Synthesis	Emerging patterns notes Creation of groups Findings and Conclusions	Electronic files and paper files Drafts of report Electronic files (Atlas.ti)
Analysis Files	Coded transcripts Preliminary and Final Versions of Coding guide Emerging patters notes	Electronic files (Atlas.ti and Word)
Process Notes	Methodology Log including: Date of activities Description of Activities Analysis, procedures, and rationale Field notes Process notes from meetings with methodologist, key informant, and peer debriefer	Electronic and paper files