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SOCIAL CONNECTEDNESS, COMMUNITY PARTICIPATION, AND HEALTH

By

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Dissertation

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Social Connectedness, Community Participation, and Health

Chairperson: Dr. Jennifer Waltz

Persons with disabilities (PWD) experience social, economic, and environmental disadvantages which have contributed to marginalization, health disparities, and challenges with community participation. Various forms of social closeness appear to serve as protective factors against physical and mental health for the non-disabled population, but it is unclear whether social connectedness is associated with community participation and health for PWD. This within-subjects, correlational design study used survey and Ecological Momentary Assessment (EMA) data from a sample of persons with mobility impairments (MI) to determine the direct and indirect effect of social connectedness and participation on health, the barriers and facilitators to participation that contribute to social connectedness, and whether social connectedness explains well-being during socializing experiences. Results indicated that social connectedness predicted health related outcomes and mediated the relationship between measures of community participation and mental health. Social connectedness can be best predicted by examining one's sense of community integration and the severity of personal and environmental barriers. Finally, the effect of socializing on in-the-moment and later-day well-being does not seem to be significantly affected by social connectedness. Limitations and future directions are discussed.

*Keywords:* persons with disabilities (PWD), social connectedness, community participation, mental health, physical health, barriers to participation, socializing, community integration

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## Introduction

PWD constitute a large percentage of the U.S. population, with estimates of the prevalence ranging from 12% (Kraus, Lauer, Coleman, & Houtenville, 2018) to 26% (Courtney-Long et al., 2015). These rates are even higher for females, African Americans, older adults, as well as within disadvantaged populations, including individuals who are unemployed, who have lower levels of income, and who have less education (Courtney-Long et al., 2015). Mobility or ambulatory impairments are the most prevalent type of disability, followed by impairments in cognition and independent living (Brault, 2012). These limitations in functioning can result in challenges with community participation and integration (Law, 2002). Historically, this marginalization from communities, along with mass institutionalization, has led to a narrative of social, economic, and environmental disadvantages for this population (Krahn et al., 2015).

Compared to individuals without disabilities, persons with disabilities (PWD) report higher rates of physical and mental health symptoms, and have been characterized as a health disparity population (e.g. Krahn, Walker, & Correa-De-Araujo, 2015; Jones & Sinclair, 2008). The health disparity status of PWD indicates a need for public health interventions that address the unique needs of PWD (Reichard, Stolze, & Fox, 2011), which should be based in scientific investigation that leads to public policy (Lollar & Crews, 2003). PWD tend to face logistical challenges in obtaining and maintaining employment, engaging in their local communities, and accessing healthcare services (Jezzoni, 2011). The consensus of PWD is often that the lack of opportunity and ability to participate fully in their communities is the most significant barrier to well-being (e.g. Dijkers, 2010), and this hurdle may result in experiences of social isolation and social marginalization. This study aims to examine the important components of community participation that hinder PWD' degree of social connectedness, and whether social connectedness is related to mental and physical health for PWD.

Social connectedness is defined as an individual's enduring, internal sense of belonging within relationships (Lee & Robbins, 1998). These types of intimate interpersonal relationships serve a basic

human need, and have been considered a fundamental human motive (e.g. Baumeister & Leary, 1995). Feeling connected to others is so central to humans' vitality, that it serves as a predictor of physical and mental health (e.g. Courtin & Knapp, 2017) and even mortality (e.g. Holt-Lunstad, Smith, & Layton, 2010).

Importantly, PWD may be predisposed to experiencing inadequate social closeness with others (Hawkey & Cacioppo, 2007). This susceptibility to social isolation is likely influenced in part by well-known barriers to community participation faced by many PWD. These barriers include environmental misattunements within the home and community, personal factors such as motivation and self-efficacy, current physical and mental health, and excessive exertion required to complete Activities of Daily Living (ADLs). Although these barriers to community participation likely coincide with a diminished capacity to connect socially with others, the relationship between participation barriers and social connection are not well understood. Few studies have examined the predictive value of barriers and facilitators to community participation on social connection, and the effect social connection may have on physical and mental health for PWD.

## **Disability**

### **Defining Disability**

The definition of disability has evolved in line with the evolving zeitgeist of the time. Disability has been viewed through a moral lens and considered the result of a sin, through a medical lens as a defect or sickness cured through medical intervention, through a rehabilitation lens as cured only by a rehabilitation professional, and finally through a disability lens as a normal aspect of life caused primarily by shortcomings in the physical environment and society (Kaplan, 2000). The legal definition of disability stems from the 1990 Americans with Disabilities Act (ADA), which defined a PWD as “a person who has a physical or mental impairment that substantially limits one or more major life activity.”



Following the ADA, the U.S. Department of Health and Human Services (DHHS) implemented guidelines for data collection on disability in an effort to create uniform data collection standards. Institutional recommendations were incorporated into economic, public health and public policy research (e.g., The Bureau of Labor Statistics, American Community Survey, Current Population Survey), which expanded upon the legal definition of disability in the ADA. U.S. DHHS (2011) bases disability status on a set of six questions which screen for the most common impairments in functioning. The questions are verbatim as follows: *1) Are you deaf or do you have serious difficulty hearing? 2) Are you blind or do you have serious difficulty seeing, even when wearing glasses? 3) Because of a physical, mental, or emotional condition, do you have serious difficulty concentrating, remembering, or making decisions? 4) Do you have serious difficulty walking or climbing stairs? 5) Do you have difficulty dressing or bathing? 6) Because of a physical, mental, or emotional condition, do you have difficulty doing errands alone such as visiting a doctor's office or shopping?* (U.S. DHHS, 2011). These domains assess for the most common types of functional limitations, and because of their effectiveness at detecting a large percentage of PWD, are considered the national standard. For these reasons, these six questions are often used to determine disability status in other areas of research, or as general screening questions in case management or clinical practice (Kelly, 2017).

Although these domains attempt to detect common challenges in functioning, useful for research or general screening purposes, they do not capture the true complexity of disability nor the individualized experience of it. Beyond their capacity for functioning, PWD constitute a diverse group of individuals with a wide array of disabilities and experiences of those disabilities. Two individuals with the same category of disability, such as deafness or serious difficulty hearing, may experience their impairments uniquely, and may exhibit disparate related symptoms, such as their ability to communicate verbally. Similarly, individuals with numerous types of diseases or disorders may experience similar impairments. For example, individuals with cerebral palsy, ALS, Parkinson's disease, paraplegia, spina bifida, or who

have experienced a stroke, loss of limb, injury to their inner ear, or orthopedic injury may all experience MI.

Along with potential variations or overlap in the experience of disability, PWD vary in the manner in which they develop, maintain, and/or overcome their disability. For example, individuals can inherit some type of disability through genes or traits, such as being born with a disabling condition like cerebral palsy or Down syndrome, or can be diagnosed or develop a condition in childhood or early adulthood, such as autism or schizophrenia. Some disabilities are acquired through accident or injury, such as damage to the spinal cord, or as the result of a chronic condition, such as limb loss due to diabetes. Some individuals develop a disability later in life, such as Alzheimer's or mobility impairment due to physical deterioration in old age. Finally, some are able to grow out of their disabilities with further development and adaptation, as is sometimes the case in individuals with hearing impairment who receive cochlear implants. Thus, certain PWD report a consistent pattern of disability, while others vary in their interpretation and experience of their disability, moving in and out of self-labeling as having a disability (Ward, Myers, Wong, & Ravesloot, 2017). This indicates that one's subjective appraisal of disability is not necessarily a constant, and instead can reflect a transitory pattern (Myers, Ward, Wong, & Ravesloot, 2020). Therefore, disability is a multifaceted and multilayered experience that is unique to each individual and that can evolve over time.

This unique and dynamic experience of disability has caused a headache for researchers when attempting to sort PWD into different categories, and has resulted in a trend towards impairment-specific research within the field. A significant proportion of the research examines groups of individuals with a specific type of injury or disease, such as those with a spinal cord injury or with Parkinson's disease, or a specific category of impairment, such as a visual or cognitive impairment. Although impairment or disorder-specific studies tend to demonstrate good internal validity, they do so at the expense of external validity. Few studies, with the exception of larger, population-based samples, such as studies conducted

by the Bureau of Labor Statistics, make a more generalized distinction between PWD and persons without disabilities.

The current study focuses on persons with MI, but the literature review covers all types of disabilities and manners of defining disability for several reasons. First, we were interested in the broadest questions related to disability, community participation, physical and mental health, and social connectedness. Because of the relative dearth of research combining these topic areas, focusing on MI alone would have significantly limited the scope of our review. Second, we recognize the immense diversity in the experience of disability and were hoping to examine the full spectrum of this experience by not limiting our review to specific disability categories. By integrating disability research across various types of injuries, diseases, and functional impairments, we believe our literature review provides a more thorough picture of the current literature on disability as it relates to our areas of interest.

### **Disability & the ICF**

To address the immense variability within disability and the complexity of each individual's experience, the World Health Organization (WHO) developed the International Classification of Functioning, Disability and Health (ICF, 2001) to provide a common language and an organizational scaffolding for understanding various components of disability. The WHO recognizes disability as “the umbrella term for impairments, activity limitations and participation restrictions, referring to the negative aspects of the interaction between an individual (with a health condition) and that individual's contextual factors (environmental and personal factors)” (2011, p. 4). This definition encapsulates the multifaceted and interactional nature of the components of disability, and attempts to incorporate a socio-ecological approach. Within this framework, health and related domains of disability are separated into two main categories: 1) functioning and disability, and 2) contextual factors. A graphical representation of these categories can be seen in Figure 1.

Figure 1

An overview of the ICF (ICF, 2001)

	Part 1: Functioning and Disability		Part 2: Contextual Factors	
Components	Body Functions and Structures	Activities and Participation	Environmental Factors	Personal Factors
Domains	Body functions Body structures	Life areas (tasks, actions)	External influences on functioning and disability	Internal influences on functioning and disability
Constructs	Change in body functions (physiological) Change in body structures (anatomical)	Capacity Executing tasks in a standard environment  Performance Executing tasks in the current environment	Facilitating or hindering impact of features of the physical, social, and attitudinal world	Impact of attributes of the person
Positive aspect	Functional and structural integrity	Activities Participation	Facilitators	not applicable
	Functioning			
Negative aspect	Impairment	Activity limitation Participation restriction	Barriers / hindrances	not applicable
	Disability			

The functioning and disability category is further separated into two subcategories: body functions and structure, and activities and participation. According to the WHO, impairment to a person's *body structure* refers to significant deviation or loss of an anatomical component of the body, such as damage to the structures involved in voice or speech, structures of the nervous system, or the loss of a limb. *Body functions* include both physiological and psychological functioning, and impairments in functioning include disabilities such as vision or memory loss. *Activity limitations* refer to difficulty in executing tasks, such as difficulty seeing well enough to drive, hearing well enough to understand others'

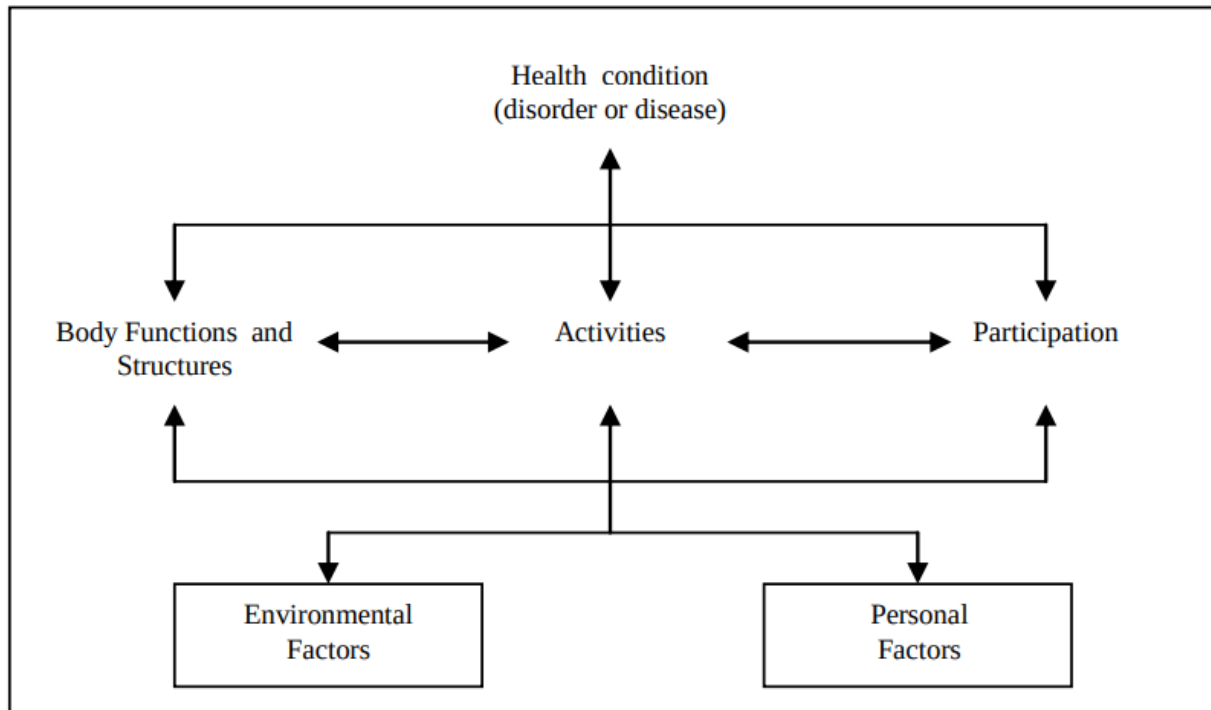
speech, having the musculoskeletal structure and strength to walk independently or having the mental capacity to problem-solve. *Participation* refers to involvement in a life situation, and participation restrictions occur in normal daily activities such as working, engaging in social and recreational activities, and obtaining health care and preventive services (ICF, 2001).

Contextual factors, the second major ICF category of disability, is separated into two subcategories as well, and includes environmental factors and personal factors. According to the ICF, environmental factors refer to the external influences, such as the physical, social and attitudinal habitats in which individuals live and operate, whereas personal factors include the internal factors (e.g., gender, race, age, lifestyle, past and current life experience, psychological strengths or challenges, etc.) which influence functioning and disability.

In addition to providing unique contributions to the overall experience of disability, the four components (i.e., body functions and structures, activities and participation, environmental factors, and personal factors) create both an interactional and evolutionary process of disability. An individual's health condition, combined with personal factors and environmental contexts constitutes a variable and dynamic experience of disability. For example, a mobility impairment (body function) caused by a loss of limb (body structure) can cause challenges in activities (e.g., climbing stairs), which leads to difficulties in participation (e.g., attending church) due to environmental factors (inaccessible entrance with stairs), and exacerbated by personal factors (e.g., frustration). These components may change over time, as any one of the above factors may evolve, such as the creation of an accessible entrance or improved capacity to climb stairs with assistance. Altering any component of the system has the potential to influence one or more components of the system. A graphical representation of the interactional nature of these components can be seen in Figure 2.

Figure 2

*Interactions between the components of the ICF (ICF, 2001)*



### **Disability and Physical Health**

It is important to acknowledge that disability is related to, but separate from, physical health. Disability is not a cause of poor health, but rather a physical and or medical deviation that is exacerbated by social and environmental influences (Reichard, Nary, & Simpson, 2014). Individuals with a disability have been found to experience disproportionately poorer physical health outcomes than those without a disability (Drum, Krahn, Culley, & Hammond, 2005; Havercamp, Scandlin, & Roth, 2004). This discrepancy in risk for adverse health outcomes suggests that PWD should be characterized as a health disparity population (Krahn et al., 2015). Health disparities are evident in PWD access and utilization of preventative health services, health behaviors, prevalence of chronic conditions, and are exacerbated by several social determinants of health.

In terms of preventative services, PWD are less likely to receive important preventative screenings compared to the general population, despite maintaining a regular source of care (Reichard et al., 2011). Similarly, PWD are more likely to experience difficulties or delays in accessing the health services they need (Office of Disease Prevention and Health Promotion [ODPHP], 2010). PWD also tend to experience barriers to engaging in health promoting activities, such as gaining access to fitness facilities and using health information technology (ODPHP, 2010). Additionally, PWD tend to receive fewer preventative screens, are less likely to have received a recent mammogram or Pap test and other types of annual cancer screenings, and are less likely to participate in routine checkups including visits to the dentist (Pharr & Bungum, 2012).

In regards to appraisals of their own health, PWD often report worse perceived health status (Reichard et al., 2011; Froehlich-Grobe, Jones, Businelle, Kendzor, & Balasubramanian, 2016). Additionally, compared to persons without disabilities, PWD note significantly more unhealthy days in the past month in which they perceived their physical or mental health as not good (Froehlich-Grobe et al., 2016; Havercamp, Scandlin, & Roth, 2004). PWD also tend to demonstrate poorer health behaviors. PWD are less likely to engage in physical activity, and are more likely to live sedentary lifestyles, smoke or have a history of smoking, and develop diabetes (Froehlich-Grobe et al., 2016; Pharr & Bungum, 2012; Krahn et al., 2015).

Chronic conditions are more common among PWD, although many of these conditions are preventable for this population (Courtney-Long et al., 2015). Additional documented chronic health conditions for PWD include higher prevalence rates of high blood pressure, high cholesterol, stroke, arthritis, asthma, obesity (Reichard, Stolzle, & Fox, 2011), hypertension, falls-related injuries (ODPHP, 2010), diabetes, and chronic pain (Havercamp, Scandlin, & Roth, 2004). Chronic conditions tend to increase the number of self-reported unhealthy days for PWD compared to those without disabilities (Froehlich-Grobe et al., 2016). Furthermore, obesity and chronic health conditions can exacerbate functional limitations and place individuals at greater risk for developing additional adverse health

conditions or premature death (Reichard et al., 2011). Even PWD without chronic conditions tend to demonstrate poorer self-rated health status and health behaviors, including likelihood of being a current smoker and not engaging in regular physical activity (Froehlich-Grobe et al., 2016).

Thus, the relationship between chronic conditions and disability appears to be bidirectional. PWD are more likely to develop chronic conditions compared to individuals without disabilities (Dixon-Ibarra & Horner-Johnson, 2014), and several of the most common causes of disability are chronic conditions, such as arthritis, cardiac disease, and diabetes (Krahn, Reyes, & Fox, 2014). However, it is important to differentiate between disability and chronic conditions, as many PWD continue to live with chronic conditions because of the fallacy of conflation that people with disabilities are inherently unhealthy (Reichard, Nary, & Simpson, 2014). Yes, PWD tend to demonstrate higher rates of chronic conditions compared to the population of individuals without disabilities, but these chronic conditions are exacerbated by the immense disparity in social determinants of health faced by PWD.

Social determinants of health play a significant role in disability. Compared to individuals without disabilities, PWD are twice as likely to live in poverty, have less than a high school education, and experience unemployment even when actively seeking employment (Stevens et al., 2016). Individuals without disabilities are more than twice as likely to have a college degree than individuals with activity limitations (Altman & Bernstein, 2008), while PWD are more likely to experience challenges with inclusion in educational settings and attending university (USDHHS, 2010). PWD also experience substantial disparities in amount of earned income, access to the internet, access to transportation, and secure housing (Peacock, Iezzoni, & Harkin, 2015). Indicators of lower socioeconomic status (SES) appear to have a dose-response relationship with the number of disabilities experienced by an individual, such that the lower the SES, the greater the probability of additional disabilities (Stevens et al., 2016). Interestingly, the opposite end of the economic spectrum appears to follow a similar pattern, with previous research demonstrating a social-class gradient up to the age of 85, indicating that individuals



with higher incomes have lower levels of functional limitation (Minkler, Fuller-Thomson, & Guralnik, 2006).

In addition to experiencing disproportionately poorer social determinants of health, a number of environmental, societal, and personal barriers contribute to physical health disparities for PWD. Peacock, Iezzoni, and Harkin (2015) provided a review of these barriers in a recent article. In terms of physical barriers to receiving health care, the authors note that inaccessible medical equipment such as examination tables or imaging technologies often prevent routine screenings or exams, as providers are unable to perform these procedures in an accessible manner. The experience of othering, or experiencing judgment, marginalization or inequality based on identity, can be so significant for PWD that they avoid medical appointments altogether. Additionally, non-inclusive health and wellness programs can prevent engagement for PWD, such as group materials or online platforms that are not accessible for individuals with a visual impairment. Likewise, communication errors or shortcomings, such as failure to accommodate someone who communicates using sign language, contribute to ineffective and othering medical care. Finally, the authors argue that misattribution or stigmatizing attitudes of medical providers unfamiliar with disabling conditions continue to be a problem, and invalidating experiences are likely to contribute to feelings of subordination and alienation, or of avoidance of medical providers altogether. These differences highlight the unmet healthcare needs, unfavorable health behaviors, and social determinants of poor health for PWD (Krahn et al., 2015).

### **Disability and Mental Health**

Globally, mental health issues contribute to disability on a massive scale. According to the World Health Organization, depression ranks as one of the leading causes of disability worldwide (Murray & Lopez, 1996). Prevalence rates of mental health diagnoses within the population of persons with non-mental health related disabilities appear to be higher than the general population. One study demonstrated that close to half of participants with a lifetime disability meet criteria for a psychiatric disorder unrelated to their disability (within the year preceding the study) (Turner et al., 2006). The same study found that

lifetime prevalence of psychiatric and/or substance use disorders for individuals with a physical disability was substantially higher (37%) than the rate for individuals without a disability (22.3%). Suicide attempts appear to be higher among PWD as well (e.g. Lyons, 1993).

Rates of depression and suicide attempts seem to increase with more severe functional limitations. For example, physical impairments in a person's body structure or function are associated with increased rates of depression, and serious impairment can double or quadruple the frequency of depression (Mirowsky & Ross, 1999). Another study found that both the number of ADL limitations measured at baseline (current disability status) and the extent to which individuals declined in ADL functioning over the course of a year (functioning deterioration) predicted the likelihood of developing depression (Weinberger, Raue, Meyers, & Bruce, 2009). Specifically, research has demonstrated that individuals who experience difficulty in ADLs and IADLs experience a fourfold increase in the likelihood of a suicide attempt in the past year, while the chances of suicide attempt by those who have difficulty in 3 or more ADLs increases by eightfold (Meltzer et al., 2012). In other words, the greater the functional limitation, the greater the likelihood of a suicide attempt.

Mental health issues are so central to disability that they have been demonstrated to have more of an effect on functional disability than common physical disorders. For example, Ormel and colleagues (2008) used a within-person comparison of individuals from 15 countries who had common physical disorders (e.g., asthma, cancer, ulcer, cardiovascular disease, diabetes, musculoskeletal disorders, and chronic pain disorders) and/or common mental health disorders (e.g., anxiety mood, and impulse-control disorders) within the past year to determine the most disabling conditions. Results indicated that major depressive disorder and bipolar disorder were rated by participants as significantly more disabling than any of the physical conditions. This finding is notable given that some of the participants who were depressed were also suffering from cancer, heart disease, or other physical conditions, such as arthritis, that are often viewed as disabling. Likewise, depression has been shown to increase the risk of developing MI and challenges in completing ADLs longitudinally (12 years), even when controlling for socio-

economic status variables (Covinsky et al., 2010). Moussavi et al., (2007) summarized the role of depression in disability noting that “depression is a disease at least on a par with physical chronic diseases in damaging health” (p. 857).

The disabling nature of psychiatric illnesses makes disentangling mental health from disability a daunting task. Disability is related to but separate from mental health, just as it is from physical health. This distinction can be confusing, as one of the common determinants of disability is having serious difficulty concentrating, remembering, or making decisions because of a mental or emotional condition. In other words, disabilities can be cognitive or psychological in nature, as is the case with individuals with a learning disability, intellectual disability, or disabling mental disorder like depression or post-traumatic stress disorder (PTSD). Researchers have attempted to separate the constructs of disability from mental health, but due to the extent of comorbidity, the driving force of mental health issues within disability, and the complex and dynamic definition of disability, the majority of the research has focused on separating mental health from chronic conditions, not disability as a whole.

For example, the World Mental Health Survey Initiative, a project of the Assessment, Classification, and Epidemiology (ACE) group at the WHO, analyzes epidemiologic surveys of mental, substance use, and behavioral disorders around the world. Findings from the World Mental Health Survey highlight the substantial comorbidity of mental disorders with physical ailments (e.g. Chatterji et al., 2013). Although focusing on chronic physical conditions instead of the WHO’s disability dimensions, the survey found that among the 17 countries surveyed, depression and anxiety were significantly linked to a variety of chronic, potentially disabling, physical conditions including arthritis, ulcers, heart disease, back/neck problems, chronic headaches, and multiple pains (Scott et al., 2007). This work demonstrated the significant comorbidity between mental and physical health, but did not differentiate the unique effect of each on overall functioning.

To better understand the relationship between chronic conditions and mental health (experienced disproportionately by PWD), Scott et al., (2009) later conducted surveys in 17 countries in order to

differentiate between the effects of common mental health disorders (depressive disorders such as dysthymia and major depressive disorder, and anxiety disorders including generalized anxiety disorder, panic disorder and/or agoraphobia, post-traumatic stress disorder, and social phobia) on functional disability. Results from this study indicate three key findings in relation to mental health, chronic conditions, and disability. First, individuals with mental disorders are more likely to experience more severe functional disability than individuals with chronic physical conditions. This indicates that mental health may be responsible for a greater proportion of functionality than physical health.

Second, individuals with comorbid mental and physical conditions are the most likely to experience severe functional disability than individuals with either condition alone. Third, for individuals with both a mental disorder and physical condition, the combination of these two characteristics is significantly more disabling than the additive nature of each of these characteristics, suggesting an exponential additive effect. These findings demonstrate that individuals who experience chronic conditions and poor mental health have the most significant challenges in functioning.

Other research has confirmed the prevalence and detrimental additive effect of mental health to individuals with chronic disease. Twelve-month prevalence rates of depression for individuals with one or more chronic physical diseases fall between 9.3% and 23%, while the rate for individuals without comorbid diseases is only 3.2%, indicating that those with chronic physical diseases are significantly more likely to experience depression (Moussavi et al., 2007). Additionally, psychopathology has been associated with increased disability, even when controlling for physical disease severity (Ormel et al., 1994). Likewise, mental disorders have been shown to predict functional disability in several domains of functioning, including life activities, communication and understanding, getting around and transportation, self-care, social activities, and community participation; with the exception of getting around, mental disorders predict functionality in these domains better than arthritis and heart disease (Buist-Bouwman et al., 2006). Similarly, individuals with comorbid chronic disease and depression demonstrated significantly worse overall health compared to individuals with multiple chronic diseases

(Moussavi et al., 2007). Furthermore, severity of mental illness and disability appears to be related in a dose-response manner, such that the greater the number of psychiatric diagnoses, the greater likelihood of functional impairment (Andrews, Henderson, & Hall, 2001). This finding holds true even when controlling for physical health (Ormel et al., 1994).

These findings together indicate several important conclusions. First, disability is often driven by mental health. Second, the disabling effects of mental health problems are often worse than the disabling effects of physical health. Third, combining poor physical health and mental health increases the likelihood for more extreme disablement. Fourth, the interconnected nature of mental and physical ailments with disability suggest a bidirectional relationship, as individuals with comorbid physical and mental disorders are more likely to have a disability (Scott et al., 2009). Although the focus of our study is on persons with MI, it is essential to keep in mind the interrelated nature of mental health, chronic conditions, and disability.

### **Person-Environment Fit**

In order to understand the multidimensional nature of disability, it is important to examine the multitude of contributing factors. Historically, research and treatment for PWD has overemphasized personal factors, such as the particular impairment, disease, or disability, which has led to alienation and stigmatization for this population (e.g. Braddock & Parish, 2001). This ‘fix the individual’ approach stems historically from the medical model of illness (e.g. van de Ven, Post, de Witte, & van den Heuvel, 2005), and places the onus of responsibility for disability on the individual person. This perspective defines disability as a problem of functioning at the individual level, emphasizing that impairment is a result of a disease or health condition, and that alleviating malfunction requires treating the individual (Lutz & Bowers, 2005). Unfortunately, treating the PWD meant displacing them from their original community and into an institution (Braddock & Parish, 2001). In doing so, the medical model approach neglected to ensure that the social and physical environments be conducive to a diversity of functioning requirements (e.g. Noreau & Boschen, 2010).

In contrast to the medical models, person-environment (PE) fit models embody a socio-ecological perspective, and provide a more comprehensive synthesis of the multiple factors that contribute to disability. PE fit is defined broadly as the match between the person and the environment (Edwards, Cable, Williamson, Lambert, & Shipp, 2006). The person refers to the biological, psychological, and social components of a given individual, and the environment includes both physical and social elements (Magasi et al., 2015). Proper facilitation between person and environment must occur in order to allow for effective functioning (Baum & Christiansen, 2005). By highlighting the extent to which physical and social environments are able to cater to individual differences and disparate personal needs, PE fit models interpret the environment as enabling or constraining functioning (e.g. Iwarsson & Ståhl, 2003). By placing equal emphasis on environmental factors, PE fit models embody a person-centered philosophy, and have become prominent within disabilities studies.

PE fit is key to enabling (or restricting) independent living, and often dictates disability status (Steinfeld & Danford, 1999). Thus, PE fit models provide a complementary framework to the Independent Living (IL) movement. The IL movement, often referred to as the Civil Rights Movement for PWD, strives to address independence and equality issues faced by many PWD. The IL movement advocates for a paradigm shift in disability theory and management, echoing PE fit models to highlight the role that environmental barriers play in community participation. In addition to shifting the responsibility of PE fit away from the individual, the IL movement strives to foster additional autonomy and self-determination. The IL movement aims to fundamentally alter the identity of PWD from a medicalized population of patients whose impairments are treated by professionals claiming to know what is best for them, to the independent role of consumer, who experiences ownership in determining how to overcome physical and psychological barriers that are the result of the environment, not the individual (Dejong, 1979).

Peer support serves as a pillar of the IL movement, and aids PWDs' transition from the role of patient to the role of consumer. Born out of the recovery movement popularized by Alcoholics

Anonymous, peer support is based on the premise that individuals living under certain conditions (e.g. similar disabilities or experiences of living with a disability) will be able to understand and help others adjust to and cope with similar circumstances (Ravesloot & Liston, 2011). Specifically, fellow consumers who have personal experience accessing resources within the community are in a unique position to provide creative, nontraditional, and individualized approaches to treatment, which may differ from the more antiquated top-down, professional-directed care (Mowbray & Moxley, 1997). This non-professional vantage point is essential in helping individuals re-engage in the community following a disconnecting event or experience, as those who have endured similar experiences can provide poignant empathy and validation (Mead & MacNeil, 2006). Furthermore, peer support opportunities such as groups and individual conversations help humanize the experience of living with disability and diminish self-stigma associated with it, while simultaneously providing voluntary assistance from peers (Campbell, 2005).

At the core of peer support are positive, voluntary, and trusting relationships that help individuals believe in themselves and become more independent in their daily lives (Ahern & Fisher, 2001). Peer support relationships are based on the idea of mutual empowerment, that through equal respect, a sense of egalitarianism, and reciprocity among peers, peer support relationships are mutually beneficial (Mead, Hilton, & Curtis 2001). These symbiotic relationships allow the support-recipient to receive help without becoming dependent on the supporter and recreating the dependency features of the professional-client relationship (Scott & Doughty, 2012).

A second key element of peer support is that it empowers PWD to take control of their own hopes, needs, and choices both in treatment and in their everyday lives (Campbell, 2005). Peer support helps PWD embody the independent role of the consumer, encouraging increased self-determination and personal agency. Self-Determination Theory (Ryan & Deci, 2000) argues that competence in the context of independence is essential to well-being, positing that the need for autonomy must be satisfied for individuals to experience an ongoing sense of integrity. Likewise, causal agency, the belief that it is the individual who makes or causes things to happen in their life, contributes to experiences of autonomy and

self-efficacy for PWD (Wehmeyer & Abery, 2013). PWD who lack the capacity to exercise additional control over their lives are often overshadowed in their ability to do so by others in decision-making roles (Stancliffe, Abery, Springborg, & Elkin, 2000). Therefore, fostering additional competence, autonomy, and causal agency are commensurate with the IL movement, allowing PWD to have more of “a voice in their own future” and “a new sense of dignity and pride that for too long has been denied them” (Dejong, 1979, p. 446).

The transition to having more ownership over one’s life, and entitlement to make one’s own decisions, has resulted in consumer driven interventions to improve community participation. Fortunately, PE fit frameworks have helped PWD highlight common environmental barriers, rather than personal factors, that prevent equal opportunities for participation. Not surprisingly, this process of recognizing environmental barriers to participation has changed significantly over the years, and has mimicked the transition from “experts” identifying barriers for PWD to consumers identifying their own experienced barriers that inhibit participation.

The Person-Environment-Occupation (PEO) model (Law et al., 1996) and the Person Environment-Occupation-Performance (PEOP) model (Christiansen & Baum, 1991) provide useful examples of how PE fit models of disability differ from more traditional medical models. The PEO model posits that components of the person, environment, and particular occupation or task overlap in a cohesive manner, and that other parts of each of these domains are in contrast, working against one another. Law’s (1996) PEO model acknowledges that each person is dynamic, motivated, and evolving, continually influencing their environment. Similarly, the PEOP model outlines an interaction of personal factors and environmental factors that either support, enable, or restrict the activities, tasks, and roles of individuals, groups, or organizations (Baum & Christiansen, 2005).



## Participation

### Overview

The publication of the ICF in 2001 was an attempt to synthesize the medical model and the socio-ecological perspectives of PE fit to better classify and treat disability (Hurst, 2000). The ICF (2001) used the term participation as a means of describing individual engagement, and defined it as “involvement in a life situation.” Participation was intended to highlight the social consequences of disability, shifting the focus of disability from a disadvantage caused by accident or disease toward an issue of engagement, with a focus on physical and social environmental influences that contribute to or hinder engagement (Noreau & Boschen, 2010). The term participation was also an improvement in terminology, replacing the previously used pejorative term, “handicap” (Whiteneck & Dijkers, 2009). In the years since the ICF, participation has come to represent “a shift toward a dynamic view of disability” (Seekins et al., 2012, p. 231), and has become a central goal for rehabilitation, medical, and social service programs for PWD (Dijkers, 2010).

Although improving participation is a common goal for both providers and consumers, participation means different things to different people. Varying interpretations of participation overlap with quality of life (QOL) or community integration (Heinemann et al., 2010). These different perspectives contribute to a lack of consensus about a shared definition of participation (Dijkers, 2010). Despite varying interpretations of the concept of participation, one ubiquitous aspect is the individualized experience of what it means to participate. For consumers, participation often has a richer meaning than merely “involvement in a life situation.” Themes central to participation for PWD include experiences of self-determination, a sense of social identity or being known, reciprocity and valued contribution, expectations of equal participation, and psychological safety in the form of having a voice and being respected (Milner & Kelly, 2009).

Likewise, consumers have felt that inconsistent experiences of being physically present in settings such as social events or community gatherings do not suffice for an experience of participation.

Instead, these experiences can contribute to feelings of being inconsequential and to social othering. Consumers note that sustained presence within a social setting is often needed in order to “help others see beyond impairment and for them to become assimilated with the social history of mainstream community settings” (Milner & Kelly, 2009, p. 58). By providing their own definition of participation, PWD embody the role of consumers and dictate for themselves what it means to participate.

Experiences of participation for consumers have been framed as “being a part of” and “being a respected, valued member of” the community, more so than just being present or exhibiting independent “physical or cognitive performance” (Hammel, Jones, Gossett, & Morgan, 2006, p. 55). These more individualized, subjective appraisals of participation differ from objective or observable components of participation (e.g. trips to the store, gym, or park), and are sometimes labeled as community integration. Community integration consists of four domains, including “assimilation (conformity, orientation, acceptance); social support (close and diffuse relationships), occupation (leisure, productivity); and independent living (personal independence, satisfaction with living arrangement);” but the construct as a whole is fundamentally an experience of community belonging and participation (McColl, Davies, Carlson, Johnston, & Minnes, 2001, p. 429). Community integration falls under the larger umbrella term of participation, and provides a unique lens to magnify the personalized experiences of community participation.

PWD experience barriers to participation in unique and nuanced ways as well. The relationship between barriers to participation and lack of participation is not organized in a dose-response relationship. Oftentimes, individuals who are more active in their professional and social lives experience more frequent and severe environmental barriers, an effect deemed “the paradox of barriers” (Whiteneck & Dijkers, 2009). Within this paradox, individuals with the most engagement tend to report more barriers to participation compared to those who participate less. Conversely, minimally participating individuals, who experience limited capacity for participation due to minor barriers, are largely unaware of additional

barriers beyond the most basic (e.g. leaving their home), and therefore report fewer roadblocks to participation.

Another important consideration regarding the concept of participation is that it overlaps with the concept of activity. The ICF attempts to theoretically differentiate between activity, or “the execution of a task or action” and participation, or “involvement in a life situation,” but distinct separation of these variables remains challenging (Whiteneck & Dijkers, 2009). One method for differentiating between activity and participation is to designate activities as actions that occur alone and at the individual level, while participation can be considered to occur with others at the societal level (Whiteneck, 2006). With this distinction, it is possible to presume that activity limitations may be caused more by impairments in body structure or function, while participation may be more limited by social or physical environmental factors (Whiteneck & Dijkers, 2009). However, this delineation remains messy, as many activities are often required for participation, such as leaving the home (activity) to attend a community meeting (participation).

Engagement in activities and participation are technically determined by ability and execution, but other important individual factors and experiences also contribute to or hinder activity and participation. The ICF explains that evaluation of a person’s activity/participation occurs through rating the degree of difficulty the person has in engaging in the activity/participation and the person’s capacity to perform that activity/participation (Brown, 2010). The ICF (2001) thus distinguishes between capacity (ability to execute a task or an action), and performance (what an individual does in his or her environment). Although an individual may be *able* to complete a task, and may even complete that task regularly, presuming that activity/participation consists of capacity (ability) and performance (execution) alone neglects the individual’s subjective experience of activity/participation (Hemmingsson & Jonsson, 2005). For example, although a person has the capacity to host friends for dinner, and may perform this activity quite regularly, doing so may require substantial effort or exertion, and may result in unique

consequences. Activity/participation therefore includes more than just a combination of capacity and performance.

### **Personal Factors & Participation**

Importantly, participation entails the personalized experience of executing the task and being involved in a particular life situation. Each individual may experience unique personal barriers or facilitators to activity/participation that can be physical or psychological in nature (e.g., physical exertion, fatigue, pain, frustration, excitement, joy). For example, for adolescents with disabilities, motivation appears to serve as the most prevalent barrier to participation (Boudos & Mukherjee, 2008). Each individual may also experience unique physical or psychological outcomes of participation (e.g., fatigue, pain, happiness, sadness, frustration). Oftentimes, these unique psychological experiences are the impetus of participation in the first place (Lysack, Komanecky, Kabel, Cross & Neufeld, 2007), such as experiencing a sense of happiness and accomplishment after hosting others for dinner. These examples demonstrate that participation encompasses both the actual engagement and the personal meaning and fulfillment stemming from that engagement (Hammel et al., 2008). Sometimes, participation can result in a sense of personal growth or personal agency, and these experiences contribute to a person's conceptualization of what it means to participate (e.g. van de Ven, et al., 2005). Individualized physical and psychological experiences therefore serve as important barriers or facilitators to participation and can help shape what participation means for each individual.

In addition to the unique physical and psychological experiences that contribute to or hinder activity/participation, more pervasive characterological traits or personal factors influence participation as well. Personal factors are individual characteristics or past formative experiences such as lifestyle, habits, upbringing, coping styles, social background, behavioral patterns, personality traits, psychological assets, and any other characteristics that contribute to PWD' participation (ICF, 2001). Two personal factors which appear to commonly contribute to participation are mental and physical health. Mental health issues have been shown to negatively impact community participation for PWD (e.g. Barclay, McDonald,

Lentin, & Bourke-Taylor, 2016). Likewise, poor physical health conditions, such as medical complications, feeling ill, bladder and bowel incontinence, pain, and becoming easily fatigued, significantly predicted community participation (Carpenter, Forwell, Jongbloed, & Backman, 2007).

Just as personal factors influence participation, experiences of participation have the capacity to influence personal factors as well. For example, minimal community participation likely manifests in experiences of loneliness and isolation (Owens, 2009). Furthermore, PWD who were more active, engaged, and integrated into their communities described their health status as better than those who were less involved (Crawford, Hollingsworth, Morgan, & Gray, 2008). Oftentimes, this bidirectionality between participation and personal factors is mediated through environmental barriers and facilitators. Experiences of participation interact with elements of the environment to either facilitate or complicate social engagement (Lysack, 2007). For example, an individual may enjoy attending church services but may find that the new building occupied by the church is inaccessible to wheelchair users, limiting their ability to participate. This may result in the individual feeling socially isolated or socially othered from their community. Conversely, a church that builds an accessible entrance may allow a wheelchair user who was previously limited to watching church services on television to attend services in person, increasing their sense of community participation.

### **Environmental Factors & Participation**

Both physical and social environmental factors contribute to participation. Two important environmental constructs related to community participation for PWD are accessibility and usability. Iwarsson and Ståhl (2003) defined accessibility as “the encounter between the person's or group's functional capacity and the design and demands of the physical environment” (p. 61). In this definition, functional capacity refers to what the individual is capable of doing physically (e.g., being able to climb stairs or open doors) while the demands of the environment refer to the physical requirements needed to use the space (a building that requires climbing stairs and opening doors for entrance). By this, the authors hoped that accessibility would be understood as compliance or noncompliance with standards for

construction, and could be used objectively to differentiate between accessible or inaccessible environments. For example, a doorway that is not 32” wide is not accessible for most wheelchair users because most standard wheelchairs cannot easily fit within the confines of the doorway. Although this particular environment may be inaccessible for chair users, it may be accessible for other groups of individuals with MI who use other assistive walking devices (e.g., a walker). This example demonstrates the need to consider both the functional capacity of users and the physical environment of the space when determining accessibility.

The term usability is similar to accessibility, except that it incorporates the physical environmental characteristics as experienced subjectively by the user, as opposed to objectively in relation to standards (Iwarsson & Ståhl, 2003). For example, although a given shower may have been created in an accessible manner (e.g., chair accessible), without grab bars, lever water controls (instead of knobs), and a bathing seat, the shower may not be very usable for individuals with a mobility impairment. Importantly, usability also emphasizes the specific activities performed by individuals or groups within any physical environment (e.g., in the home, the neighborhood, the city), and the extent to which the physical environment facilitates or inhibits engagement in those activities. For these reasons, usable environments tend to facilitate community participation for PWD, while environments that are experienced as unusable or inaccessible are likely to hinder community participation. Even though a space may be designated as accessible, it may not be usable.

PWD have historically faced innumerable environmental barriers to community participation, many of which have been related to accessibility. Several common environmental barriers include constructed barriers in the form of building accessibility, land development and transitions (e.g., sidewalks, roadways), situational barriers such as noise, crowds, and air quality, and components of community livability (e.g., access to transportation and other resources, safety/security) (Hammel et al., 2015). These environmental barriers may vary by region or specific location, and may be different for individuals living in rural versus urban areas (Maart, Eide, Jelsma, Loeb, & Ka Toni, 2007). Without

mitigation, accessibility shortcomings create substantial barriers to participation for PWD. For example, because of a lack of accessible design, a PWD may be unable to use the sidewalk to access the subway station. Even if they were able to arrive at the subway station, a lack of an elevator (or a broken one) may prevent them from entering the station. If they were able to access the subway platform and board the subway, they still may be unable to enter their destination building because of a lack of an accessible entrance.

Interestingly, many accessibility issues within the community environment, like the ones raised in the previous example, occur at the societal level. Examining the effects of societal accessibility changes (meso) at the individual/personal (micro) level often proves difficult. Some researchers argue that participation should be examined hierarchically within each level (e.g., micro, meso, macro level), because barriers may differ depending on the level of the environmental setting (Heinemann et al., 2010). This may explain why a significant proportion of the research in this field has examined the effect of person-level modifications in accessibility and usability. For example, substantial research has examined the association between usable home environments and personal and psychological factors.

In general, usable home environments seem to reduce common environmental barriers associated with disability, which often result in increased community participation. For example, usable home environments enable more optimal performance within the home (Petersson, Kottorp, Bergström, & Lilja, 2009), allowing for less difficulty in task completion, increased feelings of safety during those tasks (Petersson, Lilja, Hammel, and Kottorp, 2008), and fewer falls and accidents overall (Wahl, Fänge, Oswald, Gitlin, & Iwarsson, 2009). Greater home usability is also associated with greater health outcomes, well-being, as well as positive psychological effects including decreased feelings of depression (Cho, MacLachlan, Clarke, & Mannan, 2016). The positive effects of improved home usability are linked to increased participation within the community (Petersson et al., 2008; Stark, 2004). Usable home environments therefore allow for improved task performance outside the home, including greater engagement in activities (Stineman, Ross, Maislin & Gray, 2007), increased involvement in hobbies and

leisure activities, and improved social contacts (Fänge & Iwarsson, 2005). Home usability is also associated with improvement in occupational performance and overall life satisfaction (Stark, 2004).

Homes that are more usable also seem to decrease the level of exertion needed to execute tasks, making it easier for PWD to complete both ADLs and Independent Activities of Daily Living (IADLs) (Cho et al., 2016). This finding is significant given that PWD report higher levels of exertion in ADLs, such as bathing, which is associated with a lower likelihood of engagement in social and recreational activities outside of the home (Greiman, Fleming, Ward, Myers, & Ravesloot, 2018). This relationship suggests that there is a causal link between home environment and community participation for PWD (Greiman et al., 2018). In other words, tasks of everyday living that require immense exertion are often a result of a poor PE fit, and engagement in strenuous activities within the home are unlikely to lead to community participation.

Similarly, unusable home environments can physically prevent PWD from leaving their homes and getting out into the community (Cho et al., 2016). For example, one study demonstrated that over 50% of homes rented by persons with MI had steps present at the entry to the home, making leaving and returning to their home virtually impossible without significant help (Greiman & Ravesloot, 2016). Environmental barriers that prevent entering and exiting the home therefore represent a significant barrier to community participation (Greiman, & Ravesloot, 2016). Importantly, identifying environmental barriers to participation needs to occur through the eyes of the consumer, as consumers dictate for themselves what it means to participate as well as what gets in the way.

### **Participation Legislation and the Administration for Community Living**

The impetus for promoting participation for PWD has roots in the legal system as well. The 1999 U.S. Supreme Court ruling in *Olmstead v L.C.* played a major role in acknowledging community participation as a right, and that it should be the rule, not the exception. In this case, the Supreme Court ruled that several common practices were in violation of the 1990 ADA that prohibited discrimination against PWD. Specifically, the *Olmstead* ruling required public entities to provide community-based



services for PWD whenever appropriate, allowing this population to seek services in their communities as opposed to institutions. The Court also ruled that unnecessary confinement to institutions was a form of segregation, and diminished PWD' capacity to engage in everyday life activities including family and social relationships, employment, education and cultural enrichment. The ruling deemed that PWD capable of living in community-based settings often benefit from this integration within the community, and are legally entitled to live and participate fully in these settings.

In 2012, the DHHS established the Administration for Community Living (ACL) for the purpose of helping PWD and older adults increase community participation through personal choice of where they live, with whom they live, and how they engage in their community. ACL's vision is that "all people, regardless of age and disability, live with dignity, make their own choices, and participate fully in society" (ACL Strategic Plan, 2013, p. 4). The ACL posits that there are countless benefits to community living for both PWD and the communities in which they live (ACL, 2019). First, PWD prefer to live in their communities, not institutions. Remaining within a community allows PWD to maintain a connection to place, including the physical environment itself (e.g., houses, streets, parks, businesses) and the memories associated with that place. Residing in their community also allows PWD to maintain their social connectedness with family members, friends, and neighbors. Living in the community enriches the diversity of that community, which benefits other members. Finally, the ACL notes that community living is less expensive than institutional living. Community living therefore provides a foundation for participation.

## **Social Connection**

### **Social Support, Social Capital & Loneliness**

Feeling connected to others through warm, trusting, and supportive interpersonal relationships is so essential to well-being that it has been categorized as a basic human need, or a fundamental motive (Baumeister & Leary, 1995). Research has attempted to codify this sense of relational connection (or lack

thereof) through various constructs including social support (e.g. Cobb, 1976), social capital (Coleman, 1988), loneliness (e.g. Peplau & Perlman, 1982; Ernst, & Cacioppo, 1999), and social closeness (e.g. Kok & Fredrickson, 2014).

Early research on the beneficial effects of supportive relationships was pioneered by Cobb (1976). Cobb used the term social support to denote any “information leading the subject to believe that he is cared for and loved, esteemed, and a member of a network of mutual obligations” (p. 300). For Cobb, care and love referred to experiences of reciprocal nurturing and mutual trust, otherwise deemed emotional support. Information concerning whether or not one is valued and esteemed was considered esteem support, and stemmed from public affirmations of one’s worth. Finally, serving as a member of a network of mutual obligations was determined by several factors: 1) the acknowledgment of a shared relationship with others; 2) the understanding of how those relationships formed; 3) a common agreement about shared services (e.g., technical help, favors), protection, or defense provided by all members of the group. Cobb’s central idea was that one or more of the above three elements (care/love, esteem, member of a group) was needed to be present for an individual to experience social support. His review of the literature demonstrated that social support generally served as a protective factor in moments of crisis and against physical and mental health challenges including arthritis, tuberculosis, medication adherence, mortality, depression, alcoholism, and other psychiatric illness.

Another perspective on the beneficial effects of supportive relationships was studied using an economic lens. Social capital (Coleman, 1988) refers to the advantages in personal interests gained through trustworthy relationships with others. The function of social capital is that it helps members of the social group with the resources needed to achieve individual interests, and this in turn helps the group as a whole. Social capital may involve enlisting a neighbor to help with a home improvement project, borrowing money from a friend, or getting a ride to a job interview from an in-law. A group high in social capital, in which each member is trustworthy and there is trust among all members, is able to accomplish more than a group that lacks these relational bonds (Coleman, 1988). In these groups, individuals rich in

resources share those resources with others within the group with the expectation that the favor will be returned when the others in the group are themselves rich in resources. Thus, social capital exists in the relationships between people, but is often used as a means to achieve something greater, just as economic capital (money) by itself does little, but helps individuals to achieve other outcomes.

Researchers have also examined the social disconnection construct of loneliness for many years. Loneliness is unique from the previously described constructs of social support and social capital because it highlights the opposite end of the spectrum of connection, examining the effect of social relationship deficits (e.g. Heinrich & Gullone, 2006). Whereas social support and social capital index the positive effects of social relationships, loneliness examines the negative effects of inadequate social relationships, which is unique from merely the absence of positive effects. Early definitions of the construct of loneliness described it as an absolute void of social connection. For instance, Ferreira (1962) defined loneliness as “the feeling of no-relationship, the feeling that there is no other, not a significant human being in the world with whom one relates at all” (p. 201). Peplau and Perlman (1982) later described loneliness as the discrepancy between an individual’s preferred and actual social relations. Peplau and Perlman’s definition of loneliness has been used by many researchers, and is reflected in the current most widely accepted definition of loneliness: “the aversive state experienced when a discrepancy exists between the interpersonal relationships one wishes to have, and those that one perceives they currently have” (Heinrich & Gullone, 2006, p. 698). The discrepancy named in both definitions is caused by individuals feeling disconnected from those around them or perceiving a lack of social closeness with others (Hawkley & Cacioppo, 2013). Thus, loneliness tends to be more dependent on the quality, rather than the quantity, of relationships (Hawkley et al., 2008).

Loneliness can occur in multiple settings, can be long term or short lived, and can be experienced within any relationship. Importantly, loneliness reflects how an individual feels about their relationships, and therefore feeling alone does not mean being physically alone (not around others), and being alone physically does not mean feeling alone (Cacioppo, Grippo, London, Goossens, & Cacioppo, 2015). Thus,

individuals can feel lonely in crowds of other people or in the presence of a friend or partner, and can feel not lonely when physically isolated. Loneliness can occur within multiple relationships and can manifest in various situations, such as when intimate, romantic partners fail to satisfy the need for connectedness, when sincere, confiding friendships leave individuals wanting additional relational connectedness, or when social groups that one values leave the individual feeling out of place (Hawkley & Cacioppo, 2013). In order to prevent loneliness, researchers have argued that one needs to feel relationally connected to significant others (Cacioppo, et al., 2015).

Some researchers have argued that loneliness is the perception that one is lacking in social closeness. Social closeness has been defined as “a belief or perception about a person’s degree of embeddedness in a social network or networks. In this formulation, social closeness may or may not be related to actual behaviors from relationship partners: what matters is the individual’s perception of their relationships with others” (Kok & Fredrickson, 2014, p. 1). This definition echoes the definition of loneliness, that current discrepancy between an individual’s preferred and actual social relationships determines one’s social closeness. Although we could not find empirical evidence corroborating the relationship between social closeness and loneliness, social closeness appears to be operationally defined as the inverse of loneliness.

### **Social Connectedness**

Social connectedness is a uniquely important construct of connection within relationships. Social connectedness (Lee & Robbins, 1995) has been defined as one’s cognitive appraisal of oneself in relation to other people, and encapsulates “the emotional distance or connectedness between the self and other people, both friends and society” (p. 239). Put succinctly, it is the “enduring interpersonal closeness with the social world in toto” (Lee, Draper, & Lee, 2001, p. 310). Unique to social connectedness is the idea that the extent of connectedness is based upon appraisal of oneself, not on other individuals or the greater social network. Social connectedness therefore serves as a sense of belongingness within relationships (Lee & Robbins, 1995).

Social connectedness tends to be enduring and is based on the idea that its development continues throughout the lifetime. Individuals begin to develop their sense of belongingness in childhood, testing their sense of connection within larger social groups. Over time, these social experiences are aggregated into cognitive representations of self in relation to others (Lee & Robbins, 1998). For example, the combined experiences of having few friendships, not participating in larger social groups, experiencing difficulty relating with others, and feeling disconnection from society at large accumulate over time resulting in a generalized dissatisfaction with social relationships (Lee & Robbins, 2000). Additionally, both past and recent relationship experiences with friends, family, acquaintances, relatives, neighbors, and strangers all amalgamate in one's cognitive appraisal of social connectedness. Thus, one's sense of social connectedness begins to develop early on, but is dynamic and influenced by on-going relationship experiences throughout life.

Social connectedness and socially connecting experiences are organized in a positive feedback loop. Unfortunately, people who demonstrate poor social connectedness tend to sustain their social disconnectedness over time. For example, individuals who experience minimal social connectedness typically do not exhibit interpersonal behaviors that attract and maintain connection, such as sociability, intimacy, and reciprocity (Lee, Draper, & Lee, 2001). Without engaging in these types of interpersonally connecting behaviors, individuals often experience enduring feelings of detachment from society, and may even reject opportunities of interpersonal closeness because they lack the ability to be interpersonally vulnerable (Lee & Robbins, 2000). Without displaying socially connecting behaviors, socially disconnected individuals continue to feel misconstrued by others, like social outsiders who are ill-equipped to relate socially. Conversely, social connectedness influences the appraisal of social experiences, resulting in engagement in relationship-improving behaviors (Lee, Dean, & Jung, 2008). Thus, individuals who experience social connectedness tend to engage in socially connecting behaviors, strengthening their experience of social connectedness over time.

The construct of social connectedness was originally created to fill a gap in clinicians' capacity to describe a common experience of relational distress in their clients. Specifically, individuals who attend therapy often lack a sense of belongingness within their relationships (Lee & Robbins, 2000). Although these belongingness shortcomings within relationships could be considered symptoms of loneliness, and were designated as such for many years, this cluster of symptoms is more representative of a perceived interpersonal deficit rather than a temporary cognitive or affective state. Lee and Robbins (1998) noted the pervasiveness of social connectedness on one's social functioning and overarching interpretation of relationships, noting that "the enduring sense of connectedness provides people with a social lens with which to perceive the world in which they live (p. 338). Thus, using the construct of loneliness to codify these overarching relational shortcomings was a misattribution, and did not provide an accurate depiction of the embedded nature of these challenges. The construct of social connectedness was established to make up for these shortcomings.

Social connectedness shares several similarities with the aforementioned concepts of social support, social capital, and loneliness, but provides a unique lens through which to understand interpersonal connectedness. For example, previous research has demonstrated that social connectedness is positively correlated with social support (e.g. Williams & Galliher, 2006), and negatively correlated with loneliness (Lee, Draper, & Lee, 2001; Satici, Uysal, & Deniz, 2016). Like social support, loneliness, and social closeness, social connectedness also depends on an individual's appraisal of their connection to their social sphere. Uniquely, social connectedness refers to one's experience of social closeness within any relationship, or to anyone in society for that matter, not just within more intimate relationships. Thus, social connectedness represents a reflection of self as interpreted through one's ability to connect with anyone else, reflecting global beliefs and appraisals of relationships and the "general other" (Lee, Draper, & Lee, 2001). This generalization of belongingness within relationships is unique from social support, loneliness, and social closeness, which interpret discrepancy in specific, current relationships and social interactions as the primary cause of inadequate social closeness.

Whereas social support seems to be temporary and group specific, social connectedness tends to be long lasting, and can occur with specific others, a group, or society as a whole. Social connectedness is differentiated from social closeness, or the opposite of loneliness, in that social connectedness resembles a cumulative sense of belonging within relationships rather than a momentary reaction to the status of current fluid relationships. Loneliness and social closeness are determined by whether one feels their current relationships with others are sufficient or are meeting their relational needs, while social connectedness is determined by one's global sense of interpersonal closeness, or whether one feels capable (or has been capable) of cultivating intimate connections with others. Thus, shortcomings in social connectedness are more than just current feelings of isolation or negative emotional reactions in the response to the loss or inadequacy of relationships (Lee, Draper, & Lee, 2001). Social connectedness is more of a pervasive sense of self security within relationships.

Importantly, the process of developing a sense of social connectedness may be unique for PWD compared to individuals without disabilities. PWD typically do not have equal opportunities to engage in social activities or to take part in sports, clubs, events, and other leisure activities where socializing is common. PWD may also face significant challenges leaving their homes to get together with friends, attend social gatherings, and generally participate in community activities. Overall, PWD participate less in social activities, even when compared to individuals with a chronic disease (e.g. Jang, Mortimer, Haley, & Graves, 2004). This lack of equal opportunity for participation may explain why PWD often report having few friends and experience a sense of marginalization from the world of interpersonal intimacy (Milner & Kelly, 2009).

Even though PWD may be able to occasionally participate, intermittent presence within a community social setting may not allow PWD to feel like they are assimilated into that community (Milner & Kelly, 2009). It has been proposed that over time, these exact types of physical and social environmental factors, such as availability of, accessibility to, and acceptance or rejection by mainstream communities, may affect development of social connectedness (Yoon, Jung, Lee, & Felix-Mora, 2012).

For example, if a PWD were to try to participate in their local community, but equal and meaningful participation was not possible due to physical environmental barriers (e.g. inaccessible home entrance, lack of transportation), or social environmental barriers (e.g. alienation or social othering), they may begin to develop a poor sense of social connectedness. Thus, social connectedness for PWD may be disproportionately linked to the numerous experiences which have prevented full participation in the community. If barriers to full participation were mitigated or removed, PWD' experience of social connectedness may begin to shift, and over time look entirely different.

### **Social Connection and Health**

Research on social connectedness has primarily examined its association with personality characteristics, feelings about oneself, or how it serves as a mediator or moderator within models of various forms of psychopathology. For example, lacking social connectedness has been linked to anxiety, low self-esteem, lack of personal trust, and stress (Lee & Robbins, 1998). Poor social connectedness serves as a predictor of depression (Williams & Galliher, 2006). Social connectedness also seems to serve a function in preventing individuals with eating disorders from feeling the need to conform to societal standards of body image (Vartanian & Hopkinson, 2010). Social connectedness is related to experiences of guilt and shame, although these are mediated through other variables such as hope and differentiation of self (Williamson, Sandage, & Lee, 2007). The link between lacking social connectedness and increased psychological distress appears to be mediated through dysfunctional interpersonal behaviors, such as poor assertiveness, sociableness, intimacy, and submissiveness (Lee, Draper, & Lee, 2001). Social connectedness therefore appears to serve as a protective factor against various psychological disorders, enhance psychological distress tolerance and improve individuals' overall sense of self.

The majority of studies examining the relationship between variations of social connection and health use the construct of loneliness or other measures of social closeness. Therefore, the remainder of this review is a combination of several of the constructs used to measure social closeness (e.g., social support, loneliness, and social closeness). Although these terms represent unique constructs from social



connectedness, we believe that combining all of these constructs in a broad and inclusive manner provides the best approximation of related research in the field.

Extensive research demonstrates a simple finding: individuals' mental and physical health appears to benefit from feeling connected to one another and seems to deteriorate when faced with inadequate connection. Social support in general helps to buffer against the deleterious effects of stressful life events (Cohen & Wills, 1985), while loneliness has numerous psychosocial, physiological, and psychological consequences across the lifetime.

Loneliness can both stem from and serve as a driving cause of social isolation, and serves to weaken the relational bonds that create a cohesive community (Williams & Braun, 2019). A recent scoping review of the literature on older adults who lack social closeness revealed that almost every study examined in the review found evidence that social isolation and loneliness have detrimental effects on mental and physical health (Courtin & Knapp, 2017). In terms of mental health, loneliness has been directly linked to depression (e.g. Cacioppo, Hughes, Waite, Hawkley, & Thisted, 2006), anxiety (e.g. Lasgaard et al., 2011), suicidal behavior (e.g. Schinka et al., 2013), and behavioral withdrawal, lack of active coping, and failure to seek emotional support (Hawkley & Cacioppo, 2007).

In regard to physical health, loneliness is associated with cardiovascular functioning and heart disease (Caspi, Harrington, Moffitt, Milne, & Poulton, 2006), and increased blood pressure over several years (Hawkley & Cacioppo, 2010). Vice Admiral Vivek H. Murthy, former Surgeon General of the U.S. from 2014-2017, labeled loneliness as a national epidemic. Murthy (2017) noted how, for many individuals from diverse backgrounds, loneliness is often related to clinical illness, contributing to disease and impeding patients' ability to cope and heal. In terms of health care behavior, loneliness predicts physician visits and inpatient hospitalizations, and combined with the other pervasive influences it has on health and well-being, should be viewed as a fundamental determinant of health (Beutel et al., 2017).

Loneliness has even been tied to mortality (Shiovitz-Ezra & Ayalon, 2010; Luo et al., 2012; Holt-Lunstad et al., 2010). One meta-analysis of the effect of social relationships on mortality examined

research that followed over 300,000 individuals for an average of 7.5 years, and revealed that individuals with poor or insufficient social relationships had a 50% greater likelihood of an early death compared to those with adequate relationships (Holt-Lunstad, Smith, & Layton, 2010). The significant influence of loneliness on mortality is comparable to excessive cigarette smoking, and exceeds other common risk factors for mortality such as obesity, lack of physical activity, and excessive consumption of alcohol. Holt-Lunstad, Robles, and Sbarra (2017) characterize the gravity of the effect of lacking social closeness on health by stating that “there are perhaps no other factors that can have such a large impact on both length and quality of life—from the cradle to the grave” (p. 13).

PWD may be particularly vulnerable to loneliness (e.g. Hawkey & Cacioppo, 2007). Compared to individuals without a disability, PWD have been found to experience significantly higher rates of feelings of social inadequacy and alienation from others (Rokach, Lehcier-Kimel & Safarov, 2006). Likewise, for individuals with a degenerative disease, more significant disability was associated with less social closeness (Soleimani, Negarandeh, Bastani, & Greysen, 2014). Also, one study found that PWD rarely experienced loneliness as an opportunity for personal growth and development as is sometimes the case with non-disabled individuals (Rokach et al., 2006). In addition, physical disabilities or illness can make it difficult to travel to group or individual therapy sessions, further alienating these individuals from potential mental health services (Kok & Fredrickson, 2014). Furthermore, for individuals with a major mental disorder, having strong social relationships was one of the best predictors of quality of life, suggesting that a positive appraisal of one’s social network likely inhibits feelings of loneliness (Vatne & Bjørkly, 2008). Finally, social support seems to predict global ratings of mental health for PWD, but may not effectively predict symptoms specific to anxiety, depression, and well-being (Tough, Siegrist, & Fekete, 2017). Thus, numerous studies demonstrate that experiences of poor social connection seem to serve as a risk factor for PWD.

## **Social Connection & Participation**

Relationships are a crucial facet of participation. Chapter 7 of the ICF (2001) is entitled *Interpersonal interactions and relationships*, and describes “the actions and tasks required for basic and complex interactions with people (strangers, friends, relatives, family members and lovers) in a contextually and socially appropriate manner” (p. 165). In this chapter, the ICF designates various criteria for coding relational issues as they relate to activity and participation (e.g., appreciation, tolerance, and criticism in relationships). Although previous research has demonstrated that relationships with others can serve either as catalysts or barriers to participation, what seems to matter most within these relationships is the experience of interpersonal connection (Hammel et al., 2008). Cummins and Lau (2004) proposed that community participation is dependent upon a sense of belonging within relationships, which include reciprocal care, emotional sharing, and perceived support. The authors further argue that these types of relationships provide life purpose, foster a sense of responsibility, and enhance esteem (Cummins & Lau, 2004). Thus, perhaps more important than the classification of relational issues is the subjective experience of social connection as a facet of participation.

Overall, experiences of social closeness seem to be linked to improved community participation, while experiences of loneliness appear to be associated with poorer outcomes. For example, prior research has demonstrated that social support is central to community participation and is necessary for a satisfactory PE fit (Baum & Christiansen, 2005). Likewise, social isolation and loneliness have been associated with decreased motor functioning, and loneliness has been associated with increased difficulty in completion of ADLs in older adults (Shankar, McMunn, Demakakos, Hamer, & Steptoe, 2017). In addition, PWD who are socially connected to their communities experience a sense of belongingness and personal independence (Cummins & Lau, 2003). In focus groups with PWD, social closeness was seen as central to community participation, and included experiences that were both highly intimate and personal as well as ones that were more public and socially appropriate for the situation (Hammel et al., 2008). When PWD feel supported by their family and by others within the community, they tend to participate

more in their communities (Verdonschot, de Witte, Reichrath, Buntin, & Curfs, 2009). The relationship between social support and participation appears to be bidirectional as well, as some would argue that community participation is necessary for social closeness (e.g. Owens, 2009). Similarly, social engagement provides PWD the ability to support others within their community, resulting in experiences of belongingness and mutuality (Hammel et al., 2008).

When PWD do not participate in their communities, they tend to experience a lack of social closeness. For example, for individuals with Parkinson's disease, participation in fewer social activities because of their disability was associated with disrupted social closeness (Soleimani, et al., 2014). These types of challenges with participation often lead PWD to report having few friends and experiencing a sense of marginalization from the world of interpersonal intimacy, which contributes to feelings of poor quality of life (Milner & Kelly, 2009). If PWD are isolated within their communities, they may receive the majority of their social support through vocational centers or Centers for Independent Living (CILs). Although PWD may feel more socially connected to staff and other consumers at CILs, this sense of connection is often tied to the particular place. Many PWD report spending long hours alone at home and often feel bored and vulnerable to feelings of isolation and loneliness (Milner & Kelly, 2009).

Environmental barriers may also be linked to social closeness. For example, despite notable improvements in accessibility in the eight years after the establishment of ADA, levels of social participation did not increase proportionally, which caused many PWD to continue to live in relative social isolation (Kaye, 1998). According to the 2010 Survey of Americans with Disabilities (Kessler Foundation/National Organization on Disability), compared to persons without disabilities, PWD report less socializing with friends, relatives, and neighbors, likely resulting from participation barriers. The report found that the gap in socializing between PWD and persons without disabilities has remained constant since 2000.

It is important to keep in mind, however, that although many individuals with disabilities may share a similar feeling of marginalization, and often experience barriers to participation, this experience is

not held by all. Instead, the association between disability and participation depends on the individual's self-definition, view of the world, and appraisal of their disability. Thus, objective evaluations of disability by others must include the specific individual's subjective interpretation of impairment in order to accurately understand the unique impact of the disability (Power, Green, & The WHOQOL-Dis Group, 2010). The research of Albrecht and Devlieger (1999) highlights the dimensional nature of the experience of living with a disability, noting that regardless of potential limitations in daily living, difficulties fulfilling social roles, and discriminatory challenges, many PWD report an excellent or good quality of life. Albrecht and Devlieger (1999) labeled this phenomenon the "Disability Paradox."

### **Current Study**

Persons with disabilities (PWD) constitute one fifth of the U.S. population and tend to experience both mental health and physical health disparities when compared to the general populace. Although the relative marginalization of this group of individuals has been evident for many years, there has been a recent shift in how to best serve this population. With the emergence of the Disability Rights and Independent Living (IL) Movements (e.g. DeJong, 1979), the enactment of ADA in 1990, and more recently, the creation of the Administration for Community Living (ACL) in 2012, improving the lives of PWD shifted from a top-down medical model of "experts" (e.g., doctors, researchers, and other specialty providers) helping "the disabled," to a grassroots movement of consumer driven, bottom-up autonomous growth. PWD are now understood as the experts within their own lives, and as consumers, dictate the what, how, when, and where, various adjustments to their lives can be made to improve functioning and self-determination. This transition to consumer driven change is born of the Disability Movement ethos of "nothing about us without us" (e.g. Charlton, 2000), and has shifted the course of intervention and treatment within this field.

One of the most common beliefs embedded within consumer driven care is the notion that PWD should be able to participate in their lives and within their communities to the same extent as individuals without disabilities. Thus, consumers have argued that facilitating opportunities for community

participation is the primary mechanism for instilling change within their lives and therefore improving overall well-being and quality of life.

As a result of this shift in focus towards community participation, much of the recent research in this field has examined methods for improving participation for PWD. This is a challenging task, as community participation is a multifaceted and individualized construct that consists of both objective and subjective appraisals, as well as environmental, personal, situational, and social factors. One element of community participation that requires additional inquiry is the social component, and more specifically, one's experience of social connectedness within one's community.

As previously mentioned, peer support is a hallmark of IL philosophy and is a fundamental service provided by CILs to promote community participation. The fact that peer support has been a pillar of the grassroots disability movement since its emergence speaks to the movement's innate understanding of the benefit of these types of reciprocal relationships. Although peer support is intended to provide PWD with empathic and validating experiences that encourage self-determination and personal agency, it is unclear whether peer support experiences generalize to a more global sense of belonging within relationships. Since peer support appears to be fundamental to the disability experience, it is necessary to further unpack the correlates of the more global experience of social connectedness for this population.

Previous research has demonstrated that intimate interpersonal relationships that provide a sense of belonging are considered a fundamental need for well-being (e.g. Baumeister and Leary, 1995). Although previous research has examined social interaction or social support as they relate to community participation for PWD, few studies have investigated the deeper, underlying experience of a sense of intimate connection with others. To the best of our knowledge, the specific construct of "social connectedness" (Lee & Robbins, 1995), or an internal sense of belonging within interpersonal relationships, has yet to be examined in a sample of PWD. This dearth of evidence is noteworthy given that participation for PWD is based predominantly on a sense of social identity or being known, having a voice and being respected, and being a valued and contributing member of the community (Milner &

Kelly, 2009). Since participation depends on a sense of belonging and reciprocity within the greater community, it makes sense that a sense of belongingness within relationships would be inexorably tied to community participation. Although various interventions aim to help PWD engage in their community independently, independent participation is more than just involvement in a life situation. True community participation includes experiences of reciprocal care, emotional sharing, and perceived support—experiences that often provide life purpose, foster a sense of responsibility, and enhance esteem. Better understanding of the experience of social connectedness for PWD may provide helpful insight into the complex nature of community participation.

Importantly, experiences of social connectedness may be dependent upon other important facilitators and barriers to community participation. Despite this likely link, there is a gap in the research concerning whether known barriers and facilitators to physical community participation (e.g., leaving home and engaging in one's community) and socializing are associated with experiences of social connectedness. In other words, are the factors that contribute to or hinder one's capacity to participate in their community linked to a more global sense of belonging within relationships? Understanding potential associations between known barriers and facilitators and social connectedness would help elucidate whether various intervention strategies aimed at improving community participation and well-being also predict social connectedness for PWD. This information would also shed light on whether experiences are similar or unique for PWD in urban and rural areas. Addressing several specific research questions would help fill the current gaps in the literature.

First, although some aspects of interpersonal relationships (e.g., loneliness, social support) have been found to be related to health in PWD, the role of social connectedness has yet to be explored. Social connectedness may play an important role in aspects of physical and mental health for PWD, and may alter their experience or appraisal of limiting conditions.

Second, since the related construct of peer support is a tenet of the IL movement, and a fundamental resource for many living with a disability, PWDs' mental health and well-being may depend

not only on their community participation, but also on these types of bonding relationships. Social connectedness may therefore help explain the link between community participation and mental well-being for PWD.

Third, community participation may be linked to one's experience of social connectedness. Community participation involves both the lived, subjective experience of participation, sometimes referred to as integration (e.g., assimilation, social support, occupation, and independent living), and the objective level of community participation (e.g., number and duration of trips out of the home and into the community). These two components of community participation may be associated separately with social connectedness. Individuals who remain at home and do not make trips into the community may not experience adequate social connectedness. Similarly, although there may be some overlap between social connectedness and community integration (e.g., experiencing a sense of belonging in one's relationships versus in one's community environment), these concepts are theoretically different. Determining whether these two constructs are related would shed light on the potential relational outcomes of subjective experiences of community participation. For example, if individuals who felt an attachment to their physical community also felt that their capacity to connect with others was greater, this could help inform strategies for increasing community participation.

Relatedly, poor PE fit within the home and the community serves as a major barrier to community participation. Barriers can be environmental in nature, such as difficulty entering and leaving the house, experiencing poor air quality, or lacking reliable access to transportation. Barriers can also be more personal in nature, such as concentration difficulties, fatigue, chronic pain, poor physical fitness/conditioning, sleep disturbances, negative side effects from medication, and feeling unsafe. The effect of experiencing barriers to participation has not been examined in relation to social connectedness. Barriers at home and in the community may therefore prevent individuals from experiencing social connectedness with others.



However, although one would expect a dose-response relationship between barriers and participation, such that additional perceived barriers would lead to less participation, previous research has demonstrated otherwise. According to “the paradox of barriers” (Whiteneck & Dijkers, 2009), individuals with the highest degree of community participation tend to report the most barriers to participation. If associations between barriers and social connectedness resemble the paradox of barriers, those who report the greatest barriers to participation may also report the most social connectedness. Importantly, because of the enduring nature of social connectedness, and the variability with several personal and environmental barriers to participation, a relationship resembling the paradox of barriers may not exist between these constructs.

Along with environmental and personal barriers within the home, extent of exertion is associated with community participation. Previous research has demonstrated that higher levels of exertion in ADLs at home is associated with a lower likelihood of engagement in social and recreational activities outside of the home (Greiman, et al., 2018). Little is known about the extent to which increased exertion at home may also be linked to social connectedness. If exertion at home is associated with less engagement in social and recreational activities outside the home, it may be related to experiencing a lack of social connectedness.

Although PWD constitute a diverse group of individuals with a wide array of disabilities and experiences of those disabilities, the most common assessment method for determining disability is through the examination of functional limitations using the guidelines set forth by DHHS (2011). These functional limitations appear to be associated with community participation for PWD. Previous research has found that functional ability has a significant effect on participation restriction such that greater functional ability is associated with greater participation (Chau, Thompson, Twinn, Chang, & Woo, 2009). It is unclear whether functional difficulties are associated with social connectedness.

Fourth, it is unclear whether social connectedness has an impact on socializing experiences for PWD. Although socializing is an indicator of interacting with others, and often includes being in the

presence of others, it does not necessarily equate to feeling connected to others. It is entirely possible to be in the midst of acquaintances and continue to experience minimal social connection. Conversely, some people can feel very socially connected to others, even when actual contact is not frequent. One important factor that may be associated with social connectedness is one's experience of well-being and satisfaction while socializing. Previous research has demonstrated that being in the presence of friends and family members (not necessarily socializing) is associated with greater well-being for PWD (Silverman, 2018). Despite this link, it is unclear whether socializing is associated with greater well-being when compared to other types of activities or when individuals are alone. Likewise, the relationship between socializing and well-being may look unique for individuals who experience more social connectedness versus those who feel less socially connected. Thus, it would be useful to determine whether PWD' experience of social connectedness is related to their well-being while socializing.

Another important factor is the temporal association between experiences of socializing and well-being. If socializing is associated with greater well-being compared to other types of activities, it would be useful to know if well-being during these social events is sustained over the course of the day. EMA allows for these types of "in the moment" and within-day temporal experiences of well-being to be examined.

We are curious to examine the aforementioned research questions both in a more global, overarching manner, and also in a more momentary, lived-experience manner. We plan on using a combination of survey and EMA data to achieve this goal. EMA exhibits several advantages over other types of measurement that rely on recall, and provides a unique window into the lived experience of day-to-day life. Cognitive science indicates that when asked to recall autobiographical information, respondents tend not to retrieve actual memories, count, and aggregate those experiences, but instead rely on inexact inferences made from fragmented details encoded into memory (Bradburn, Rips, & Shevell, 1987). Although unintentional, this process of relying on cognitive heuristics to essentially "fill in the

gap” in memory is unreliable, and accounts for much of the bias in recall data (Shiffman, Stone, & Hufford, 2008).

Conversely, EMA uses real-time sampling to measure participants' report of their experience “in the moment.” To achieve this momentary sampling, EMA employs the use of smart devices or smart phones that remain with participants throughout the course of the day. These devices notify participants randomly or at pre-programmed hours to answer questions in “real-time,” allowing participants to respond in various ecologically representative environments. Participants often respond to such prompts as their whereabouts, what they are doing, who they are with, and their current well-being. This type of real-time data collection is resistant to many of the cognitive heuristics common in recall data (Shiffman et al., 2008). Real-time data collection also provides additional temporal resolution, and is amenable to measuring variables that may change throughout the course of the day, such as activities one participates in, where one goes, or one’s affective state (Stone & Shiffman, 1994). Another advantage of EMA is that it allows for data to be collected in real-world environments, as individuals go about their daily lives (Shiffman et al., 2008). EMA therefore provides a unique sampling opportunity, as the measurement device literally “lives” with the participant for a set period of time, which may include experiences and life events that are more public and those that are more private in nature. This type of ecological assessment allows for a more in-depth look at individuals' experiences both at home and in the community. A third strength of EMA is that it can incorporate random sampling, increasing the likelihood that an accurate representation of participants' experiences over the measurement period will be captured. Thus, EMA allows for a unique snapshot into the lives of participants, and is a current strength of this study.

This project utilizes data collected as part of a larger study examining home usability and community participation. The larger study is intended to promote community participation for adults with MI using a PE fit model. Our project will examine the variables that were assessed at the time of the pre-test, before any intervention was implemented.

In order to examine potential associations between facets of community participation and social connectedness, individuals' self-reports of various components of community participation will be assessed and compared to self-rated experiences of social connectedness. These self-report survey measures will be augmented with several EMA questions. Within-person ratings of perceived and experienced personal and environmental barriers and facilitators to participation, including exertion, physical and mental health, disability and limiting conditions will be compared to social connectedness in a sample of PWD. Components of community participation will be measured in a multifaceted manner, which includes both objective and subjective measures of participation and integration. Furthermore, this sample will provide a snapshot of the typical experience of social connectedness for PWD accessing a CIL, a finding that is not well documented in the literature.

We will also use EMA data to answer questions related to socializing, social connectedness, and well-being. In order to examine any interaction between socializing experiences and well-being based on one's extent of social connectedness, we will compare well-being experienced during socializing events to well-being experienced during other types of activities. We will also examine the interaction of one's extent of social connectedness with their well-being following socializing experiences. This will inform us as to whether there is a temporal effect of well-being following experiences of socializing, and whether social connectedness mediates this effect.

The study will add to the research literature, which currently focuses almost exclusively on community participation and mental and physical health as they relate to objective measures of social interaction. To the best of our knowledge, the role social connectedness plays within the framework of participation is not well understood. Investigating the relationship between common facilitators and barriers to community participation, mental and physical health, and experiences of socializing as they relate to social connection may help enrich our understanding of these complicated constructs.

## **Method**

### **Participants & Recruitment**

Study recruitment and procedures were approved by the Institutional Review Board at the University of Montana. The bulk of participants in this study were recruited through CILs in Missoula, Montana, and Kansas City, Missouri. Some participants were also recruited through home health agencies in these two geographic locations. A number of individuals who had participated in previous Rural Institute for Inclusive Communities disability research projects were also recruited for this study.

Participants consisted primarily of consumers who were already in the process of accessing services at their local CIL, although some were new to this process. CILs typically provide a number of core services including information and referral, peer support and advocacy, personal care assistance, skills training, and transition. The majority of participants for this study were recruited from those seeking information and referral services and those participating in skills-training classes. Information and referral services provide guidance to consumers about independent living services and programs available within the CILs, as well as other supports, groups, and agencies both in the local community or available nationally. Independent skills classes provide training in various domains of independent living, including employment, life skills, assertiveness, communication, self/disability awareness, management of personal care services, and adapting to common bodily impairments (e.g., deaf/hard of hearing, blindness/low vision). In addition, a third but smaller group of participants recruited through the CILs were invited to participate in the study because they contacted the CIL requesting a housing need or modification, or were receiving some sort of personal home assistance through the CIL. A total of 238 participants completed the paper and pencil or electronic survey at their CIL. Following the survey, 194 of the participants also completed the EMA portion of the study.

## **Procedure**

CILs in each location served as the nexus for the project. A specialist at each of the CILs was trained on how to guide participants through each step of the research project. To streamline this process, individuals who were recruited through home health services or through involvement in previous disability research were opened as consumers at their local CIL. This allowed the study to be conducted through the specialist at each CIL, as all participants were members.

Participants were provided with an informed consent and asked to take part in a survey examining how people participate in daily life activities, both inside the home and out in the community. After providing consent, participants were given a paper and pencil or an electronic version (tablet) of a survey entitled Home and Community Survey. As an incentive, participants were provided \$10 for completing the paper and pencil/electronic survey.

In addition to completing the paper and pencil/electronic survey, a number of participants also agreed to participate in a separate phase of the study, which involved Ecological Momentary Assessment (EMA) (Stone & Shiffman, 1994). These participants were instructed by the CIL specialist on how to use an application on a handheld smart device (smart phone). Once trained, participants were asked to carry this device with them at all times for seven days. During this timeframe, the device would randomly prompt participants to answer a short, on-screen survey throughout the course of the day. The smart device would notify participants to complete the short survey eight times per day following a preprogrammed, randomized pattern, with each notification occurring randomly within a two-hour interval between 7:00 AM and 11:00 PM. Prompts included an audible tone that repeated until participants either completed the survey or selected to “snooze” the audible tone for 10 minutes. If electing this option, the device would repeat the audible tone 10 minutes later, giving participants another opportunity to complete the survey or silence the prompt again. If participants elected to silence the device twice in a row, the response was recorded as missing. Participants were provided \$40 as incentive for completing the EMA portion of the study.

## Measures

*Demographic Information.* Demographic information collected included age, sex, race, ethnicity, relationship status, education, income, employment status, benefits received, health care coverage, disability status, medical conditions, use of adaptive equipment, and access to transportation.

*Social Connectedness.* To measure social connectedness, participants completed the Social Connectedness Scale-Revised (SCS-R) (Lee, Draper, & Lee, 2001). The SCS-R measures one's belief about their interpersonal closeness with the social world. The scale consists of 20 statements (10 positive, 10 negative) about one's experience of social connectedness with responses options graded on a 6-point likert scale (1= "strongly disagree," 6 = "strongly agree"). The measure demonstrates good internal reliability, and good convergent validity, correlating positively with measures of self-construal and collective self-esteem, and negatively with measures of loneliness, social distress, social discomfort, dysfunctional interpersonal behaviors. The SCS-R also demonstrates good discriminant validity with interdependent self-construal and collective identity among other measures (Lee, Draper, & Lee, 2001) (see Appendix A).

*Subjective Community Participation (Integration).* To measure subjective experiences of community participation, the survey used the Community Integration Measure (CIM) (McColl et al., 2001). The CIM provides a measure for assessing perceived experience of community participation. Responses to questions about feelings of social adjustment are coded on a 1-5 likert scale (1 = "Always Disagree", 5 = "Always Agree"). Statements include feelings such as assimilation (e.g., "I know the rules in this community and I can fit in with them"), support (e.g. "I know a number of people in this community well enough to say hello and have them say hello back"), independence (e.g., "I can be independent in this community"), or sense of place within the community (e.g., "I feel like part of this community, like I belong here"). Although no single metric can capture the diverse experience of community participation, the CIM is based on an empirically derived, theoretical model of integration and

demonstrates suitable psychometric properties for samples of PWD (McColl et al., 2001) (see Appendix B).

*Exertion.* To examine the extent of exertion during various tasks, the survey used a variation of the Rating of Perceived Exertion (RPE) Scale (Borg, 1998). The RPE is a subjective measure for estimating exertion during various activities. The scale provides a self-rated experience of exertion that allows for comparison across activities and individuals. For the purpose of this study, the level of physical exertion experienced when using various areas of the home was rated on a 1-10 likert scale (1 = “Nothing at All”; 10 = “Very, Very Hard”). Home areas examined included “getting into and out of your home,” “using your kitchen,” “using your toilet,” “using your tub/shower,” “using your living area,” “using your storage places like closets and cupboards,” “using your bedroom for dressing and going to bed,” and “cleaning and tidying up” (see Appendix C). To examine the extent of exertion during various activities, the EMA questions prompted participants to rate their level of physical exertion for their current activity. Participants had the option to select the same exertion answer choices from the RPE (1 = “Nothing at All”; 10 = “Very, Very Hard”).

*Personal and Environmental Factors.* The survey used an adapted version of the Disability and Health Perceived Barriers (DHPB) scale (Murphy-Southwick & Seekins, 2000) to examine common environmental and personal barriers to community participation. Although this was not an exhaustive list of potential barriers, as the possibilities are infinite, the DHPB questions provided insight into some of the more common potential personal and environmental barriers. Experiencing personal and environmental barriers over the past 7 days was rated on a 1-4 likert scale (1 = “Never”; 4 = “Routinely”). Environmental barriers included issues such as entering and leaving the house, poor air quality, and reliable access to transportation. Personal factors included such barriers as trouble concentrating, experiencing fatigue, and feeling safe. Frustration with barriers over the past 7 days was also examined on a 1-10 scale (see Appendix D).



*Physical and Mental Health.* To address physical and mental health, the survey used the Behavioral Risk Factor Surveillance System (BRFSS), which includes nine Health Related Quality of Life (HRQOL) items used by the Centers for Disease Control (CDC, 2000) to monitor the health status of the nation (Horner-Johnson, Krahn, Andresen, & Hall, 2009). The 9-item HRQOL included both the Health Related Quality of Life-4 (HRQOL-4) core module, the Healthy Days Symptoms Module. The HRQOL-4 assesses self-rated general health as well as the number of days a person has felt physically unhealthy, mentally unhealthy or felt limited in their capacity to engage in their typical daily activities, and encapsulates the key concepts of health outlined by the WHO (Moriarty, Zack, & Kobau, 2003). The Healthy Days Symptoms Module (CDC) includes five items that assess recent days of pain, depression, anxiety, sleeplessness, and vitality. The survey also included several additional general health questions that assessed participants' ability to independently engage in activities, recent visits to an emergency room or urgent care provider, number of prescribed medications, number of medications prescribed for pain, a 0-10 Numerical Rating Scale (NRS) for pain, and a checklist of current conditions or medical problems (see Appendix E). The EMA prompt also addressed several questions related to health and well-being. The EMA questions prompted participants to respond to how fatigued, stressed, depressed, and happy they currently felt, as well as how much pain they were currently experiencing. Responses were coded on a 1-4 likert scale (1 = "Not at all"; 2 = "Somewhat"; 3 = "Quite a bit"; 4 = "Very much") (see Appendix F).

*Limiting Conditions.* Several questions were used to assess large-scale categories of perceived barriers to participation. These included barriers related to fatigue, chronic pain, physical fitness/conditioning, sleep disturbances, depression, anxiety, and side effects from medication. Questions were assessed using a 4-point likert scale that differentiated level of limitation based on the number of hours of activity limited per week, with options listed as rarely/never limits participation, mild or infrequent (1-5 hours/week), moderate/occasional problem (6-10 hours/week) or significant/chronic limitation (11+ hours/week) (see Appendix G).

*Disability & Functional Impairment.* The Six-Question Disability Sequence (6QS) was originally developed by the U.S. Census Bureau for use in the American Community Survey. These questions are currently used to assess disability status in numerous large-scale population surveys including the Current Population Survey conducted by the Bureau of Labor Statistics. The 6QS measure consists of 6 statements that describe functional difficulties common to 6 disability types, including hearing difficulty, vision difficulty, cognitive difficulty, ambulatory/mobility difficulty, self-care/bathing difficulty, and independent living difficulty.

Additionally, the study used a measure of difficult conditions to obtain a numerical rating of functional limitations. To determine perceived difficulty in executing the same types of tasks outlined in the 6QS, responses are recorded on a 11-point likert scale (0 = “no difficulty, 10 = “extreme difficulty) (see Appendix H).

*Participation Behavior.* To examine objective participation behavior, the survey included the Brief Community Engagement Questionnaire (BCEQ) (Livingston et al., 2015). This scale selected the most frequently endorsed survey items from two other participation scales, the Survey of Participation and Receptivity in Communities (SPARC) (Gray, Morgan, Dashner, Garret, & Hollingsworth, 2012), and the Participation Survey/General (PARTS/G) (Gray et al., 2006). These items assess the number of trips out of the home and into the community, number of activities (e.g., active recreation, religious activity), and hours spent engaging in work/volunteer engagements (e.g., employment, school/education, volunteering) over the past 7 days. Each item also includes a place to indicate whether the frequency of engagement or time spent engaging in a particular trip or activity was “less,” “same,” or “more” than what is typical for a 7-day period (see Appendix I).

*Socializing.* To measure the number of times participants reported socializing, one of the daily EMA questions prompted “Please describe what type of activity you are engaged in.” One of the choices that was provided in the answer options was “socializing.”

## Hypotheses

The following hypotheses correspond to the numbered questions in the current study section.

1) It was hypothesized that social connectedness would predict self-ratings of mental and physical health, and limiting conditions in a sample of PWD, such that greater social connectedness would be associated with greater mental and physical health and less severe limiting conditions. Limiting conditions included barriers related to fatigue, chronic pain, physical fitness/conditioning, sleep disturbances, depression, anxiety, and side effects from medication. We anticipated that the more social connectedness one experienced, the less limiting one would perceive these conditions.

2) We hypothesized that social connectedness would mediate the relationship between both objective and subjective participation and mental health.

3) It was hypothesized that numerous participation factors (objective and subjective participation, barriers, exertion, and functional limitations) would predict social connectedness for PWD. First, we anticipated that both objective and subjective measures of community participation would predict social connection in a positive direction. Objective measures included the number of trips to various locations within the community, the number of various activities in which one participated within the community, and the number of hours spent participating in employment/education/volunteer activities. Subjective measures of community participation included the personalized experience of participation (e.g., feelings of assimilation, social support, occupation, and independent living). Second, we anticipated that the significance of barriers to community participation would predict social connectedness in a negative direction, such that those who denoted having more limiting barriers to community participation would also report the least social connectedness. Although the paradox of barriers may suggest an opposite hypothesis, we believed that the nature of social connectedness was associated with an overall experience of interpreting community participation and integration as far from reach. In other words, we believed that one's subjective awareness of interpersonal closeness with others would be associated with their perceived ability to participate in their community (predicting participation barriers in a negative

direction). Third, we anticipated that increased exertion in completing ADLs and using other spaces within the home would predict social connectedness in a negative direction. Fourth, we anticipated that functional limitations (quantity and severity) would predict social connectedness in a negative direction, such that those who experienced more significant functional limitations would experience less social connectedness.

4) It was hypothesized that social connectedness would moderate the relationship between socializing and in-the-moment well-being and satisfaction. Furthermore, we hypothesized that social connectedness would moderate the relationship between socializing and happiness experienced for the remainder of the day following a socializing event. In other words, greater social connectedness would result in greater happiness following socializing events compared to days without socializing or periods of time prior to socializing.

### **Data Management**

Survey data were transcribed into an Excel spreadsheet and analyses were conducted using IBM SPSS Statistics 25. EMA data were recorded through the smart devices, aggregated into text files and analyzed using Stata.

Scores on several of the measures were recalculated so that higher scores would represent more positive outcomes (e.g. greater social connectedness, greater community engagement, less exertion, fewer perceived barriers, fewer unhealthy days, less severe limiting conditions, and less severe difficult conditions). For the SCS-R and DHPB, this required reverse scoring the negatively worded items, and computing an average social connectedness or average perceived environmental and personal barrier score for each participant. For the CIM the average community integration score was computed. For the BCEQ, the average community engagement score within each category was calculated. Categories included number of trips into the community, number of social activities, and hours spent participating in work/volunteer engagements, such as employment, education, or volunteer service. For the RPE scale in

Home Experiences, Limiting Conditions measure, and Difficult Conditions Questionnaire, the entire measure was reverse scored, and average scores were computed for each participant.

To obtain physical health and mental health scores from the HRQOL and Healthy Days Symptom Module, 8 of the 9 questions were divided into a mental health variable (4 questions) and a physical health variable (4 questions). This method provides “more complete information about physical and mental HRQOL than is available from single items, while limiting the number of individual variables required for a given analysis” (Horner-Johnson, Krahn, Andresen, & Hall, 2009, p. 109). To combine the four mental health items and physical health items into single-scale scores, raw responses to the items were converted to standard (z) scores. The mean z-scores for the items in each scale (physical and mental) were calculated. The resulting means were then converted to T-scores to create distributions with a mean of 50 and standard deviation of 10.

## Results

Descriptive statistics and sample distributions were analyzed for demographic variables, including age, sex, ethnicity, marital status, education level, annual household income, and employment status (See Table 1). The participants reported an average age of 53.8; most were female (61.2%); the majority were white (69.8%), and had never been married (31.6%). With regard to education, about half of the sample consisted of high school graduates (25.8%) and those who had completed some college or technical training (24.0%). A substantial proportion of the sample reported earning less than \$10,000 dollars income per year (42.4%), or \$10,001 - \$20,000 dollars per year (28.4%). Overall, the vast majority of participants reported having a household income of less than \$50,000 dollars per year (91.3%), and not being employed at the time of the survey (79.9%).

Table 1

*Demographic Characteristics of the Survey and Ecological Momentary Assessment (EMA) Samples*

Demographic Variable	Survey (n=238)	EMA (n=194)
Age, mean +/- SD	53.8 +/- 13.8	53.5 +/- 13.9
Sex		
Male	37.9 %	38.1 %

Ethnicity	Female	62.1 %	61.9 %
	American Indian/Alaska Native	8.1 %	9.3 %
	Asian	0.4 %	0.5 %
	Black/African American	20.9 %	18.6 %
	White	69.8 %	71.6 %
	Other	4.7 %	5.2 %
	Hispanic Latino Identified	4.3 %	4.7 %
Marital Status			
	Married	19.2 %	20.2 %
	Separated	5.6 %	6.7 %
	Divorced	29.5 %	26.9 %
	Widowed	9.0 %	8.8 %
	Never been married	31.6 %	31.6 %
	Member of an unmarried couple	5.1 %	5.7 %
Education			
	Less than 8th grade	0.9 %	1.0 %
	Grades 9-11	10.7 %	9.8 %
	Grade 12 or GED	25.8 %	24.7 %
	Some college or technical training	24.0 %	24.7 %
	Associate or technical degree	12.9 %	12.4 %
	Bachelor's degree	16.7 %	17.5 %
	Master's degree or higher	9.0 %	9.8 %
Annual household income			
	10,000 or less	42.4 %	42.6 %
	10,001 - 20,000	28.4 %	28.7 %
	20,001 - 30,000	7.4 %	6.4 %
	30,001 - 40,000	6.6 %	5.9 %
	40,001 - 50,000	6.6 %	6.4 %
	50,001 and above	8.7 %	10.1 %
Employment status			
	Full time with pay (30+ hours)	5.6 %	6.7 %
	Part Time with pay (29 hours or less)	14.5 %	15.0 %
	Not employed	79.9 %	78.2 %

All participants completed the first round of survey data collection. The EMA sample is a subset of the survey participants. From the initial group of 238 survey participants, 194 participated in 7 days of EMA data collection. SD = Standard Deviation.

Table 2

*Means and Standard Deviations of Survey Measures*

Measure	Mean	Standard Deviation
Social Connectedness Scale - Revised (SCS-R)	4.069	0.957
Physical Health*	50.057	8.229
Mental Health*	50.041	8.733

Limiting Conditions	1.467	0.789
Community Integration Measure (CIM)	37.101	8.650
Trips (BCEQ Trips)	8.664	7.942
Activities (BCEQ Activities)	5.069	6.074
Work/Volunteer (BCEQ Employment hours)	5.974	11.208
Personal Barriers (DHPB Personal)	2.707	0.722
Environmental Barriers (DHPB Environmental)	2.965	0.550
Disability Functioning	5.834	2.211
Exertion (RPE)	7.397	1.826

*Note:* Physical Health = Health Related Quality of Life (HRQOL) and Healthy Days Symptoms Module physical health items. Mental Health = HRQOL and Healthy Days Symptoms Module mental health items. Trips = Brief Community Engagement Questionnaire (BCEQ) community participation trips. Activities = BCEQ community participation activities. Work/Volunteer = BCEQ participation employment hours. Personal Barriers = Disability and Health Perceived Barriers (DHPB) Scale, personal items. Environmental Barriers = (DHPB) Scale, environmental items. Disability Functioning = Difficult Conditions Questionnaire. Exertion = Rating of Perceived Exertion (RPE) Scale in Home Experiences. \* = Designates standardized score

Table 3

*Pearson Correlations Between Survey Measures*

	SCS-R	PH	MH	LC	CIM	BCEQ-T	BCEQ-A	BCEQ-E	DHPB-P	DHPB-E	DF
PH	.411**										
MH	.550**	.728**									
LC	.487**	.716**	.749**								
CIM	.494**	.385**	.382**	.343**							
BCEQ-T	.011	.081	.011	.034	.098						
BCEQ-A	.134*	.276**	.218**	.293**	.118	.597**					
BCEQ-E	.140*	.245**	.106	.164*	.228**	.218**	.139*				
DHPB-P	.419**	.567**	.549**	.537**	.261**	.095	.235**	.143*			
DHPB-E	.455**	.520**	.448**	.461**	.566**	-.006	.207**	.167*	.416**		
DF	.295**	.441**	.374**	.417**	.392**	.090	.128	.254**	.297**	.429**	
RPE	.272**	.341**	.256**	.294**	.399**	.157*	.189**	.212**	.245**	.399**	.514**

SCS-R = Social Connectedness Scale - Revised. PH = Health Related Quality of Life (HRQOL) and Healthy Days Symptoms Module physical health items. MH = HRQOL and Healthy Days Symptoms Module mental health items. LC = Limiting Conditions. CIM = Community Integration Measure. BCEQ-T = Brief Community Engagement Questionnaire (BCEQ) community participation trips. BCEQ-A = BCEQ community participation activities. BCEQ-E = BCEQ participation employment. DHPB-P = Disability and Health Perceived Barriers (DHPB) Scale personal items. DHPB-E = DHPB Scale environmental items. DF = Difficult Conditions Questionnaire. RPE = Rating of Perceived Exertion (RPE) Scale in Home Experiences.

## Hypothesis 1

To test hypothesis one, that social connectedness predicts self-ratings of mental health, physical health, and limiting conditions, social connectedness was regressed on each of the three outcome variables (HRQOL mental, HRQOL physical, and Limiting Conditions). Social connectedness significantly predicted HRQOL mental ( $F[1, 233] = 101.051, p < .001, R^2 = .303$ ) and HRQOL physical ( $F[1,234] = 47.553, p < .001; R^2 = .169$ ) indicating that there was a positive effect between participants' degree of social connectedness and the number of days they were unaffected by poor mental or physical health. Social connectedness also significantly predicted limiting conditions ( $F[1,231]=71.969 p < .001; R^2 = .238$ ), indicating that social connectedness predicts less severe (fewer hours throughout the week) of limiting conditions. Full results can be seen in Table 4. These effect sizes reflect that between 16% to 30% of the variance in mental health, physical health, and the experience of limiting conditions can be accounted for by an individual's social connectedness.

Table 4

*Separate Linear Regression Analyses for Social Connectedness Predicting Mental Health, Physical Health, and Limiting Conditions*

Outcome Variable	B	SE	$\beta$	t	R <sup>2</sup>	F
Mental Health	5.016	0.499	0.550	10.052	0.303	$F(1, 233)=101.051^*$
Physical Health	3.53	0.512	0.411	6.896	0.169	$F(1,234)=47.553^*$
Limiting Conditions	.400	0.047	0.487	8.483	0.238	$F(1,231)=71.969^*$

*Note.* Mental Health = Health Related Quality of Life (HRQOL) and Healthy Days Symptoms Module mental health items. Physical Health = HRQOL and Healthy Days Symptoms Module physical health items. Higher scores for Limiting Conditions denote less severe limitations (fewer affected hours).

\*  $p < .001$

As a post-hoc analysis, we computed bivariate correlations between social connectedness and each of the limiting conditions questions to determine which individual conditions were significantly associated with social connectedness. Results indicated that each limiting condition question was significantly correlated with social connectedness, such that greater social connectedness was associated with less severe limiting conditions. Feeling depressed ( $r=.532$ ) and anxious ( $r=.490$ ) had the highest



correlations, followed by fatigue ( $r=.378$ ), sleep disturbance ( $r=.297$ ), chronic pain ( $r=.288$ ), physical fitness ( $r=.268$ ) and side effects from medications ( $r=.197$ ).

Although these results demonstrate the most straightforward associations between social connectedness and health for our first hypothesis, we were interested in examining these same relationships with a more stringent lens. Specifically, we wanted to see the effect of social connectedness while controlling for the most common physical health conditions/problems. The average number of health problems/conditions per participant was 6.78 ( $SD = +/- 3.35$ ). Table 5 shows the rate of each of these conditions/problems in our sample.

Table 5

<i>Number and Percentage of Participants Reporting the 10 Most Common Health Problems/Conditions</i>	
<i>Problem/Condition</i>	<i>Number (%) (n=234)</i>
Eye or vision problems	152 (65.2%)
Arthritis or rheumatism	125 (53.6%)
Back or neck problem	141 (60.5%)
Fracture, bone, or joint injury	66 (28.3%)
Weight problem	119 (51.3%)
Lung or breathing problem	72 (30.9%)
Gastro-intestinal problem	70 (30.2%)
Hypertension or high blood pressure	103 (44.2%)
Circulation problems	64 (27.5%)
Migraine headaches	62 (26.6%)
Any health problem/condition	233 (99.6%)

*Note:* responses are from the survey data.

We next conducted regression analyses with social connectedness as the independent variable, and mental health, physical health, and limiting conditions as the dependent variables, but this time we used a hierarchical regression to control for the 10 most common physical health conditions/problems within our sample. We entered these 10 conditions into step 1 of the analysis, and social connectedness into step 2. These analyses revealed that common health conditions/problems explained a significant proportion of variance in our model. Social connectedness still significantly predicted mental health,

physical health, and limiting conditions, but explained less of the variance (7% - 19%), compared to when we used no controls. Results of these analyses can be seen in Table 6.

Table 6

*Hierarchical Regression Analyses Comparing the 10 Most Common Health Conditions/Problems Alone, and 10 Most Common Health Conditions/Problems with Social Connectedness Predicting Mental Health, Physical Health, And Limiting Conditions*

Outcome Variable	Step	Variables Entered	B	SE B	$\beta$	t	sig.	$\Delta R^2$	F
Mental Health	1						< .001	.217*	6.030*
		Vision	-2.190	1.158	-.119	-1.891	.060		
		Arthritis	.358	1.270	.020	.282	.778		
		Back/neck	-4.267	1.224	-.238	-3.485	.001		
		Fracture	-2.074	1.239	-.107	-1.675	.095		
		Weight	-2.347	1.075	-.134	-2.183	.030		
		Lung	-.211	1.245	-.011	-.169	.866		
		GI	.066	1.190	.003	.056	.956		
		Blood Pressure	-1.669	1.149	-.095	-1.452	.148		
		Circulation	1.190	1.221	.061	.975	.331		
		Migraine	-4.308	1.227	-.219	-3.510	.001		
		2					< .001	.192*	.13.661*
		Vision	-1.034	1.018	-.056	-1.016	.311		
		Arthritis	.496	1.106	.028	.448	.655		
	Back/neck	-3.885	1.067	-.216	-3.642	< .001			
	Fracture	-1.711	1.079	-.088	-1.585	.114			
	Weight	-1.836	.938	-.105	-1.957	.052			
	Lung	.993	1.093	.053	.908	.365			
	GI	-.269	1.037	-.014	-.259	.796			
	Blood Pressure	-1.482	1.001	-.084	-1.481	.140			
	Circulation	1.064	1.063	.055	1.002	.318			
	Migraine	-2.155	1.098	-.109	-1.962	.051			
	SC	4.307	.512	.472	8.408	< .001			
Physical Health	1						< .001	.309*	9.749*
		Vision	-1.883	1.012	-.110	-1.861	.064		
		Arthritis	-1.283	1.111	-.078	-1.155	.249		
		Back/neck	-4.178	1.071	-.250	-3.901	< .001		
		Fracture	-1.366	1.084	-.076	-1.260	.209		
		Weight	-.925	.940	-.057	-.984	.326		
		Lung	-1.793	1.090	-.102	-1.646	.101		
		GI	-1.946	1.042	-.110	-1.868	.063		
		Blood Pressure	-1.312	1.001	-.080	-1.311	.191		
		Circulation	-1.761	1.069	-.097	-1.648	.101		
		Migraine	-2.715	1.075	-.148	-2.526	.012		
		2					< .001	.070*	12.095*
		Vision	-1.240	.970	-.072	-1.278	.203		
		Arthritis	-1.198	1.056	-.073	-1.135	.258		
	Back/neck	-3.957	1.019	-.236	-3.884	< .001			

		Fracture	-1.158	1.031	-.064	-1.123	.263		
		Weight	-.629	.895	-.039	-.703	.483		
		Lung	-1.111	1.045	-.063	-1.064	.289		
		GI	-2.131	.991	-.120	-2.151	.033		
		Blood Pressure	-1.220	.951	-.074	-1.283	.201		
		Circulation	-1.830	1.016	-.100	-1.802	.073		
		Migraine	-1.499	1.050	-.081	-1.428	.155		
		SC	2.426	.490	.285	4.957	< .001		
	1						< .001	.349*	11.737*
		Vision	-.250	.094	-.151	-2.644	.009		
		Arthritis	-.165	.104	-.105	-1.593	.113		
		Back/neck	-.526	.100	-.327	-5.262	< .001		
		Fracture	-.196	.101	-.113	-1.942	.053		
		Weight	-.168	.088	-.107	-1.913	.057		
		Lung	.186	.102	.110	1.826	.069		
		GI	-.150	.097	-.088	-1.545	.124		
		Blood Pressure	-.081	.093	-.051	-.866	.388		
		Circulation	-.010	.100	-.006	-.101	.920		
		Migraine	-.399	.100	-.226	-3.983	< .001		
Limiting Conditions	2						< .001	.123*	17.682*
		Vision	-.168	.086	-.102	-1.951	.052		
		Arthritis	-.154	.094	-.098	-1.649	.101		
		Back/neck	-.498	.090	-.310	-5.510	< .001		
		Fracture	-.170	.091	-.098	-1.859	.064		
		Weight	-.130	.079	-.083	-1.639	.103		
		Lung	.272	.093	.161	2.942	.004		
		GI	-.174	.088	-.102	-1.977	.049		
		Blood Pressure	-.069	.084	-.044	-.820	.413		
		Circulation	-.019	.090	-.011	-.209	.835		
		Migraine	-.245	.093	-.138	-2.628	.009		
		SC	.309	.043	.377	7.111	< .001		

*Note:* Responses are from survey data. Vision = Eye or vision problems, Arthritis = Arthritis or rheumatism, Back/neck = Back or neck problem, Fracture = Fracture, bone, or joint injury, Weight = Weight problem, Lung = Lung or breathing problem, GI = Gastro-intestinal problem, Blood Pressure = Hypertension or high blood pressure, Circulation = Circulation problems, Migraine = Migraine headaches, SC = Social connectedness. Mental Health = Health Related Quality of Life (HRQOL) and Healthy Days Symptoms Module mental health items. Physical Health = HRQOL and Healthy Days Symptoms Module physical health items. Higher scores for Limiting Conditions denote less severe limitations (fewer affected hours).

\*  $p < .001$

## Hypothesis 2

Hypothesis two predicted that social connectedness would mediate the relationship between measures of community participation (community integration, trips into the community, activities, and work/volunteer engagements) and mental health. Pearson correlations between these measures indicated

that social connectedness was significantly correlated with community integration, activities, and work/volunteer engagements (employment, education, volunteering), but not with trips into the community (Table 3). Because of the lack of statistical association between social connectedness and trips into the community, we decided not to perform mediation analysis with trips into the community.

Next, three simple mediation analyses were calculated using PROCESS macro for SPSS (version 3.5) (Hayes, 2018). In all three mediation analyses, the outcome variable was the HRQOL mental health variable, and the mediating variable was social connectedness.

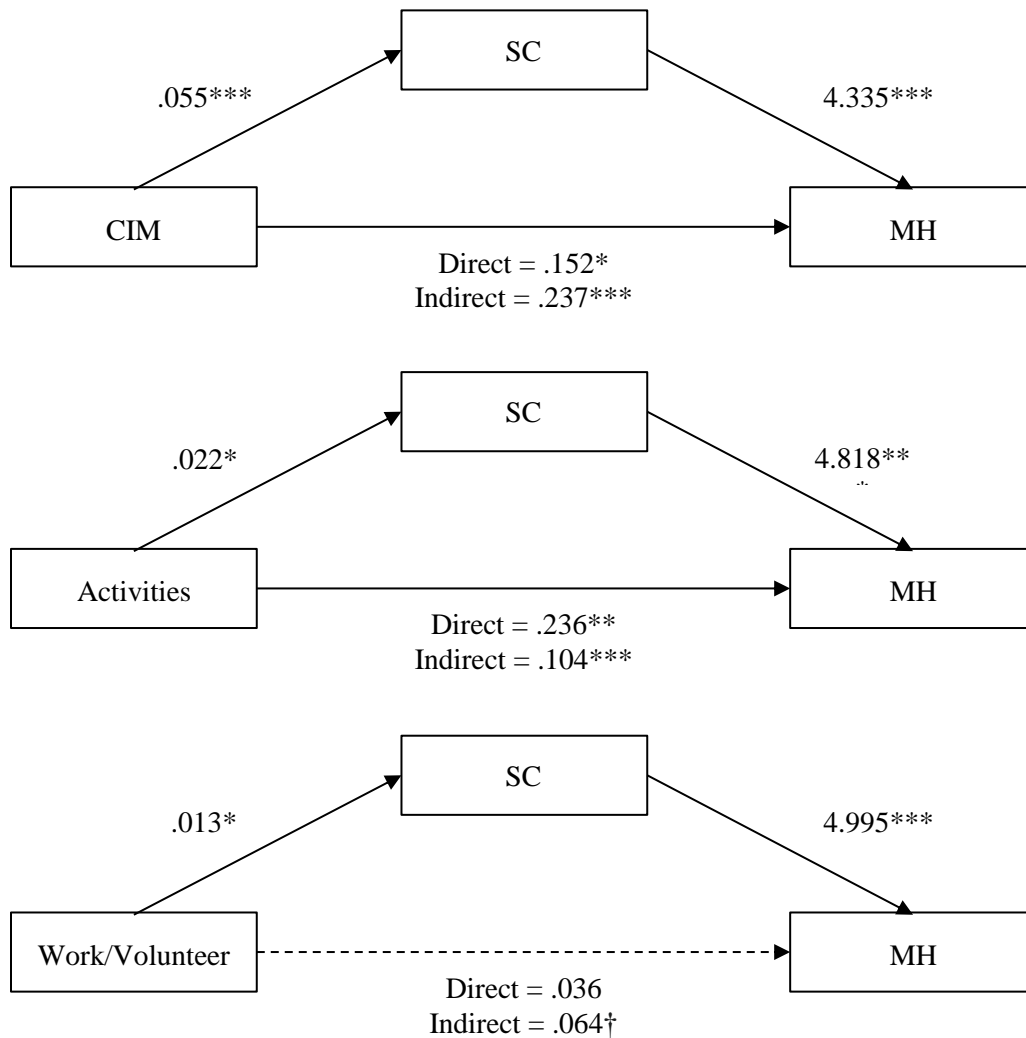
For the first mediation model, community integration (CIM) served as the independent variable. There was a significant mediation effect found in the prediction of mental health,  $\beta = 0.390$ ,  $SE = 0.061$ ,  $p < 0.001$ , 95% CI [0.269, 0.511], whereby community integration was positively associated with social connectedness, which in turn was positively associated with mental health (See Figure 3). Unstandardized indirect effects were computed for each of 5,000 bootstrapped samples, and the 95% confidence interval was computed by determining the indirect effects at the 2.5th and 97.5th percentiles (Figure 3).

Similarly, a significant mediation effect was found when activities (BCEQ activities) were used in the prediction of mental health,  $\beta = 0.340$ ,  $SE = 0.095$ ,  $p < 0.001$ , 95% CI [0.153, 0.527], whereby activities were positively related to social connectedness, which in turn was positively associated with mental health.

Additionally, there was a trend found when work/volunteer engagements were used to predict mental health,  $\beta = 0.101$ ,  $SE = 0.055$ ,  $p < 0.10$ , 95% CI [-0.008, 0.209], whereby work/volunteer engagements were positively associated with social connectedness, which in turn was positively associated with mental health. Trips into the community were not significantly correlated with social connectedness nor mental health, and therefore we did not complete a mediation analysis for this independent variable.

Figure 3

*Mediation Analysis of Social Connectedness in the Relationship Between Components of Community Participation and Mental Health*



Path diagram of unstandardized coefficients depicting mediation of social connectedness in the relation between community participation and mental health.

*Note.* CIM = Community Integration Measure. Activities = Brief Community Engagement Questionnaire (BCEQ) community participation activities. Work/Volunteer = BCEQ participation employment. SC = social connectedness. MH = Health Related Quality of Life (HRQOL) and Healthy Days Symptoms Module mental health items. Dashed lines represent non-significant paths.

† $p < .10$ . \*  $p < .05$ . \*\*  $p < .01$ . \*\*\*  $p < .001$

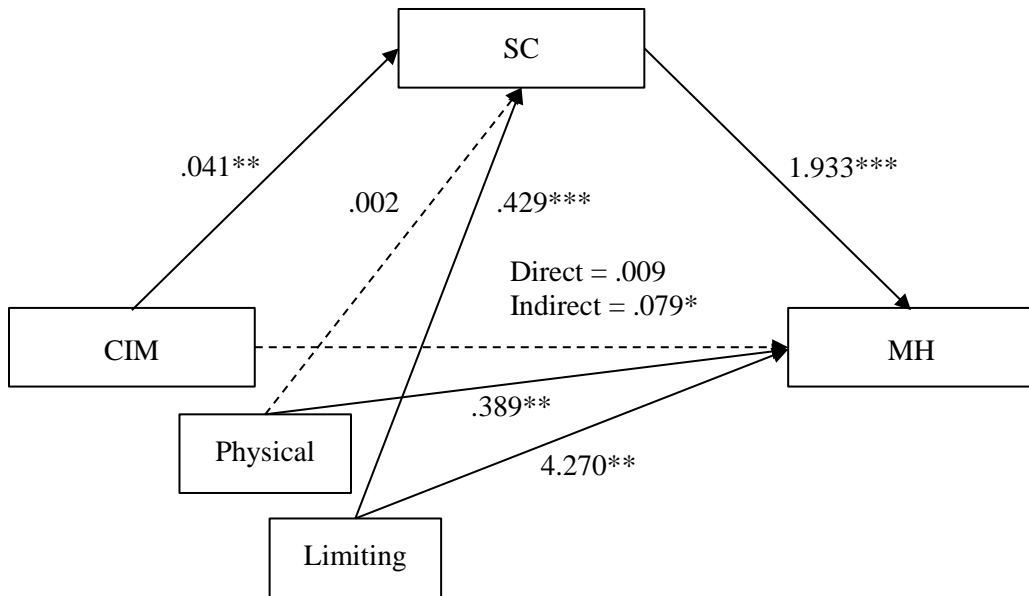
To further examine the mediating role of social connectedness between participation variables (community integration, activities, work/volunteer engagements) and mental health, two control variables (physical health and limiting conditions) were added to the model (See Figure 4). Social connectedness continued to have a significant mediation effect between community integration and mental health,  $\beta = 0.088$ ,  $SE = 0.043$ ,  $p < 0.05$ , 95% CI [0.003, 0.173], even when controlling for physical health and

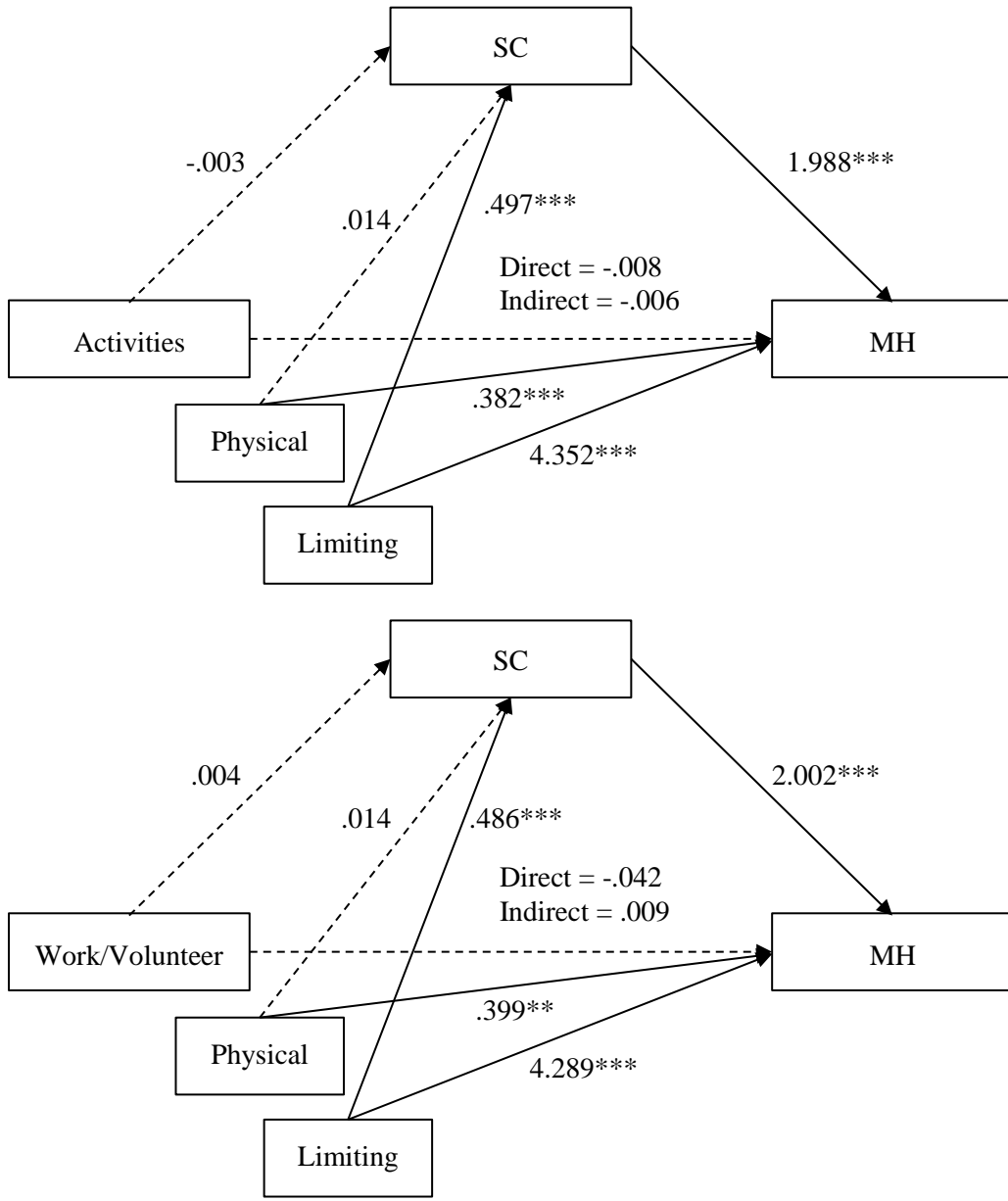
limiting conditions; however, community integration no longer had a significant direct effect on mental health when controlling for physical health and limiting conditions (Figure 4).

In the second of these analyses, social connectedness no longer had a significant mediation effect in the relationship between activities and mental health,  $\beta = -0.013$ ,  $SE = 0.062$ ,  $p > 0.05$ , 95% CI [-0.135, 0.109], when controlling for physical health and limiting conditions. Likewise, social connectedness no longer significantly mediated the relationship between work/volunteer engagements and mental health,  $\beta = -0.033$ ,  $SE = 0.035$ ,  $p > 0.05$ , 95% CI [-0.102, 0.035], when controlling for physical health and limiting conditions.

Figure 4

*Mediation Analysis of Social Connectedness in the Relationship Between Measures of Community Participation and Mental Health, Controlling for Physical Health & Limiting Conditions*





Path diagram of unstandardized coefficients depicting mediation of social connectedness in the relationship between measures of community participation and mental health while controlling for physical health and limiting conditions.

*Note.* CIM = Community Integration Measure. Activities = Brief Community Engagement Questionnaire (BCEQ) community participation activities. Work/Volunteer = BCEQ participation employment. SC = Social Connectedness. MH = Health Related Quality of Life (HRQOL) and Healthy Days Symptoms Module mental health items. Physical Health = HRQOL and Healthy Days Symptoms Module physical health items. Dashed lines represent non-significant paths.

\*  $p < .05$ . \*\*  $p < .01$ . \*\*\*  $p < .001$

### Hypothesis 3

To test which barriers to community participation best predicted social connectedness, zero order correlations between variables were first calculated (Table 3). Due to the significant intercorrelation between many of the variables, all of the predictor variables were kept in the model when completing the initial multiple regression analysis (Model 1). Results of the multiple linear regression indicated that there was a collective significant effect between the predictor variables and social connectedness, ( $F(8, 212) = 13.973, p < .001, R^2 = .345$ ) (See Table 8). The individual predictors were examined further and indicated that community integration ( $t = 4.697, p < .001$ ) and personal barriers ( $t = 3.950, p < .001$ ) were significant predictors in the model. Environmental barriers approached significance ( $t = 1.720, p < .10$ ). Next, the multiple regression was re-computed including only these three independent variables (Model 2). Results indicated that the collective significant effect remained ( $F(3, 228) = 40.330, p < .001, R^2 = .338$ ), and environmental barriers became a significant predictor in the model.

Table 7

*Multiple Linear Regression Analyses for Measures of Community Participation Predicting Social Connectedness*

Model	Variables Entered	B	SE B	$\beta$	t	sig.	R <sup>2</sup>	F
Model 1							0.345	F(8, 220)=13.97*
	CIM	.037	.008	.327	4.697	< .001		
	Trips	-.007	.009	-.055	-.792	.429		
	Activities	.006	.012	.036	.504	.614		
	Work/Vol.	.000	.005	-.003	-.056	.956		
	Per. Barriers	.338	.086	.252	3.950	< .001		
	Env. Barriers	.229	.133	.132	1.720	.087		
	Exertion	-.003	.037	-.006	-.090	.929		
	Fun. Limit.	.022	.031	.050	.711	.478		
Model 2							0.347	F(3, 228)=40.33*
	CIM	.037	0.007	0.337	5.149	< .001		
	Per. Barriers	.356	0.078	0.269	4.550	< .001		
	Env. Barriers	.262	0.122	0.149	2.146	< .05		

*Note.* CIM = Community Integration Measure, Trips = Brief Community Engagement Questionnaire (BCEQ) community participation trips. Activities = BCEQ community participation activities. Work/Vol. = BCEQ participation employment. Per. Barriers = Disability and Health Perceived Barriers (DHPB) Scale personal items. Env. barriers = DHPB Scale environmental items. Exertion = Rating of Perceived Exertion (RPE) Scale in Home Experiences. Fun. Limit = Difficult Conditions Questionnaire. SC = Social Connectedness.



\* p <.001

To better understand if the model would continue to predict social connectedness when controlling for demographics (e.g., age, sex, education, income, employment status), a hierarchical multiple regression analysis was calculated. Age, sex education, income, and employment status were entered into the first bloc as controls. The predictor variables of community integration, personal barriers, and environmental barriers were added into the second bloc with the previous variables from the first bloc to determine the effect of the overall model. Results indicated that the demographic variables alone explained 10% of the variance in social connectedness, while the combination of all the variables explained around 40% of the variance. Full results are in Table 8.

Table 8

*Hierarchical Regression Analyses Comparing Demographics Alone, and Demographics Combined with Community Integration, Personal Barriers, and Environmental Barriers Predicting Social Connectedness*

Step	Variables Entered	B	SE B	$\beta$	t	sig.	R <sup>2</sup>	F
Step 1							0.099	F(5, 217)=4.777*
	Age	.013	.005	.184	2.677	p < .01		
	Sex	-.062	.130	-.031	-.487	.633		
	Education	.093	.046	.147	2.021	p < .05		
	Income	.020	.031	.049	.654	.514		
	Employment	.334	.122	.190	2.736	p < .01		
Step 2							.400	F(8, 214)=17.821*
	Age	.012	.004	.168	2.955	p < .01		
	Sex	.085	.108	.043	.782	.435		
	Education	.090	.038	.143	2.355	p < .05		
	Income	-.037	.027	-.089	-1.390	.166		
	Employment	.164	.103	.093	1.595	.112		
	CIM	.037	.007	.327	4.916	p < .001		
	Per. Barriers	.398	.078	.301	5.123	p < .001		
	Env. Barriers	.224	.131	.127	1.717	.087		

Note. Com Int. = Community Integration Measure. Per. Barriers = Disability and Health Perceived Barriers (DHPB) Scale personal items. Env. Barriers = DHPB Scale environmental items.

\* p <.001

#### Hypothesis 4

A combination of survey and EMA data was utilized to test whether the relationship between socializing and subjective well-being was moderated by social connectedness. Moderation, also known as

interaction, is used to test “when, or under what circumstances, or for what types of people” an effect exists (or does not exist), as well as the magnitude of the potential effect (Hayes & Rockwood, 2017, p. 47). To run these analyses, computed separate within-person, fixed-effects regressions with social connectedness as our predictor variable and the EMA well-being items (pain, fatigue, stress, depression, exertion, happiness, satisfaction) as our outcome variables. A dummy variable was used to differentiate socializing activities from all other types of activities. The analysis controlled for the time of day, the day of the week (weekdays versus weekends), and how well each participant slept the night before. These controls are common in EMA analyses examining this type of data (e.g. Ravestloot et al., 2016). Results indicated that there were no significant interactions between socializing and social connectedness with the negative well-being items (pain, fatigue, stress, depression), signifying that one’s level of social connectedness did not have a significant effect on the negative well-being experienced while socializing (full results in Table 9). Likewise, social connectedness did not have a significant effect on satisfaction or happiness during experiences of socializing. Interestingly, there was a significant negative effect for social connectedness on exertion during socializing experiences, such that being more socially connected was associated with a decrease in ratings of exertion during socializing activities.

To examine experiences of socializing that were not captured by the “socializing or visiting” activity option available to participants at each EMA prompt, we expanded our definition of socializing to include a number of other connection-oriented activities with socially close others. As an example, having dinner with friends would not have been considered “socializing or visiting” in our first analysis if the participant had selected “eating” as the primary activity. In expanding our definition of socializing, we hoped to capture these types of socializing experiences that originally may have been coded as non-socializing activities. We considered the following activities as connection-oriented activities and included them in our analyses: watching TV or a movie, eating, food and drink prep, resting, reading, recreation or leisure, transportation or mobility, community or volunteer activity, and religious activities. We included the aforementioned activities only when participants indicated that one of the following was

present: friends, coworkers, other non-household family members, or entries in the "other" text box that captured these types of relationships (e.g. boyfriends, girlfriends, grandchildren, co-workers, neighbors, church members, and other friends). Results from our expanded definition of socializing were similar to our original analyses, indicating that even with the expansion to additional socializing activities there was not a significant interaction between social connectedness and the majority of well-being items. Social connectedness did contribute to a small but significant positive effect on depression (e.g. more depressed), and a small but significant negative effect on happiness (e.g. less happy). Full results can be seen in Table 9.

Table 9

*Interaction between Social Connectedness and Ecological Momentary Assessment (EMA) Well-Being During Experiences of Socializing and Expanded Socializing*

Well-being Outcome	N	Socializing		Socializing x SC		R <sup>2</sup>
		$\beta$	SE B	$\beta$	SE B	
Pain	7151	-0.08	0.07	0.00	0.08	0.01
Fatigue	7292	-0.17**	0.04	-0.03	0.05	0.03
Stressed	7206	-0.12**	0.04	-0.01	0.05	0.01
Depressed	7262	-0.11**	0.04	0.03	0.04	0.01
Exertion	7134	0.00	0.08	-0.26**	0.09	0.02
Happy	7253	0.40**	0.05	-0.07	0.06	0.02
Satisfied	7312	0.51**	0.06	-0.03	0.06	0.02

Well-being Outcome	N	Expanded Socializing		Expanded Socializing x SC		R <sup>2</sup>
		$\beta$	SE B	$\beta$	SE B	
Pain	7151	-0.01	0.04	0.05	0.04	0.01
Fatigue	7292	-0.06	0.03	0.00	0.03	0.03
Stressed	7206	-0.09**	0.03	0.05	0.03	0.01
Depressed	7262	-0.08**	0.02	0.05*	0.02	0.01
Exertion	7134	0.02	0.06	-0.06	0.05	0.02
Happy	7253	0.29**	0.04	-0.09*	0.04	0.03
Satisfied	7312	0.31**	0.04	0.01	0.04	0.02

Individual, within-person, fixed effects analyses of socializing and “expanded socializing” by social connectedness on well-being. SC = Social Connectedness.

\*p <.05, \*\* p <.01

We also predicted that there would be an interaction between social connectedness and well-being later in the day following socializing events, such that those who were more socially connected would experience greater happiness following socializing events. We again used within-person, fixed-

effects regressions to examine well-being, but this time we examined the well-being recorded at EMA prompts that followed “socializing and visiting” activities. We also ran these analyses using our previously explained “expanded socializing” activities. We continued to control for the time of day, the day of the week, how well each participant slept the night before, but also controlled for type of current activity. Results for these analyses demonstrated that there was not a significant interaction between social connectedness and well-being during the next consecutive prompt following a socializing event. Specifically, after socializing activities, social connectedness did not significantly predict happiness. Full results can be seen in Table 10.

Table 10

*Interaction between Social Connectedness and Ecological Momentary Assessment (EMA) Well-Being at EMA Prompt Following Experiences of Socializing and Expanded Socializing*

Well-being Outcome	N	Socializing		Socializing x SC		R <sup>2</sup>
		β	SE B	β	SE B	
Pain	5609	0.06	0.07	-0.10	0.07	0.03
Fatigue	5719	0.00	0.05	-0.07	0.05	0.06
Stressed	5648	-0.03	0.05	0.00	0.05	0.02
Depressed	5690	-0.00	0.04	-0.00	0.04	0.01
Exertion	5597	0.08	0.07	-0.02	0.08	0.23
Happy	5685	0.07	0.05	-0.06	0.05	0.04
Satisfied	5731	0.06	0.05	0.05	0.07	0.06

Well-being Outcome	N	Expanded Socializing		Expanded Socializing x SC		R <sup>2</sup>
		β	SE B	β	SE B	
Pain	5609	0.03	0.05	0.06	0.05	0.03
Fatigue	5719	0.02	0.03	0.00	0.03	0.06
Stressed	5648	-0.01	0.03	0.04	0.03	0.02
Depressed	5690	-0.05*	0.02	0.04	0.03	0.01
Exertion	5597	0.02	0.05	-0.04	0.05	0.23
Happy	5685	0.10**	0.04	-0.03	0.04	0.04
Satisfied	5631	0.11**	0.04	0.01	0.04	0.06

Individual, within-person, fixed effects analyses of socializing and “expanded socializing” by social connectedness on well-being during the next EMA prompt. SC = Social Connectedness.

\*p <.05, \*\* p <.01

Following these results, we were curious if there was any relationship between social connectedness and global ratings of well-being as measured by EMA. As a post-hoc analysis, we conducted separate between-person, random effects specification regressions to account for person-level effects. This allowed us to continue to control for variations among potential confounds, such as the types

of activities our participants engaged in throughout the measurement period, and capture person-specific differences in the level of well-being. In these analyses, social connectedness served as our predictor variable and each of the EMA well-being items across the measurement period served as our outcome variables. We also controlled for time of day, day of the week, and sleep quality, as well as demographics (sex, age, education, and income). Results indicated that social connectedness significantly predicted weekly global ratings of satisfaction, pain, fatigue, stress, depression, and happiness. Full results are in Table 11.

Table 11

*Social Connectedness Predicting Ecological Momentary Assessment (EMA) Global Ratings of Well-Being*

Well-being Outcome	N	$\beta$	SE B
Pain	6818	-0.57**	0.20
Fatigue	6960	-0.35**	0.06
Stressed	7881	-0.36**	0.06
Depressed	6931	-0.43**	0.06
Exertion	6800	-0.02	0.11
Happy	6924	0.37**	0.06
Satisfied	6977	0.24**	0.04

Individual, within-person, random effects specification analyses of social connectedness on global ratings of well-being across the measurement period.

\*p <.05, \*\* p <.01

## Discussion

The results of the current study shed light on the complex relationships between community participation, social connectedness and physical and mental health for PWD, specifically people with mobility impairment (MI). Four themes that emerged from the results were: first, social connectedness significantly predicts health related outcomes for persons with MI. Second, social connectedness mediates the relationship between community participation and mental health, signifying that community participation better predicts mental health when social connectedness is also taken into account. Third, social connectedness can be predicted using a combination of one's sense of community integration and the severity of personal and environmental barriers faced in engaging in the community. Other facets of

community participation, including trips into the community, activities, employment, exertion, and functional limitation are not significantly predictive of social connectedness. Finally, the effect of socializing on in-the-moment and later-day well-being does not seem to be significantly affected by social connectedness. In other words, social connectedness does not help predict whether socializing experiences contribute to well-being. However, greater social connectedness is associated with greater in-the-moment well-being on a global scale, across all activities throughout the measurement period. Together, these findings contribute to our understanding of the value of one's social closeness with others, and how this sense of belonging within relationships relates to a variety of facets of community participation and health.

### **Social Connectedness, Physical and Mental Health, and Barriers**

Maintaining intimate relationships is inexorably linked with mental and physical health for persons without disabilities, but research to date looking at this issue in PWD has been limited. Therefore, one central purpose of this study was to examine whether social connectedness could predict mental health, physical health, and limiting conditions in a sample of persons with MI. Broadly speaking, we found several interesting relationships between these variables that we believe contribute to the current understanding of this topic.

#### **Physical Health**

Previous research demonstrates that for persons without disabilities, maintaining intimate connections with others contributes to good physical health, while lacking social closeness tends to be associated with poorer health. Inadequate social closeness and loneliness are associated with markers of poor physical health including illness (e.g., Murthy, 2017), and disease (e.g., Caspi et al., 2006). Individuals who are disconnected from those around them are also more likely to die prematurely (Holt-Lunstad, Smith, & Layton, 2010). Some argue that social relationships are so central to physical health that they should be considered a fundamental determinant of health (Beutel et al., 2017).

The current study adds to previous research linking social support and loneliness to physical health and functional ability by demonstrating that greater social connectedness is associated with fewer days of being negatively affected by poor physical health. Importantly, to the best of our knowledge, this is the first study to highlight the association between social connection and health for a sample of PWD.

Numerous mechanisms may help explain why social connection predicts positive health outcomes for persons with MI, although most of the research examines the constructs of social support or loneliness. First, social connectedness may be associated with physical health due to the various types of functional support gleaned from socially close relationships. For example, social support is multifaceted, and in addition to the acknowledgment of a shared relationship with others, can include support in the form of completing tasks or following through with responsibilities. According to Cobb (1976), one element of social support is a common agreement about shared services (e.g., technical help, favors) provided by all members of the group. Although social support and social connectedness are unique constructs, it is logical to believe that experiencing a sense of belonging within one's relationships (social connectedness) would include an element of instrumental support akin to the agreement about shared services inherent in social support. Instrumental support is the "provision of financial aid, material resources, and needed services" (Cohen & Wills, 1985, p. 313).

Instrumental support experienced through social connectedness is likely to help alleviate stress and improve daily functioning, and may be particularly important for individuals who face significant environmental barriers and manage multiple health complications. Given that 99% of our participants reported health conditions, instrumental support likely plays a key role in helping to manage these conditions. For example, research has suggested that social support in the form of others' preparing meals, picking up medications, or providing transportation contributes to improvement in physical health for individuals with heart conditions (Boutin-Foster, 2005). Likewise, individuals recovering from heart failure have indicated that instrumental support, such as help with daily tasks or responsibilities including transportation, meal preparation, bathing, chores, pet care, and home maintenance, was essential to the

process of healing (Riegel & Carlson, 2002). Given the prevalence of environmental barriers to independent living for many persons with MI, instrumental assistance of this type likely contributes to daily functioning and overall health and well-being. Importantly, some evidence suggests that having sufficient opportunities for companionship and feeling more connected within these relationships serves as a better predictor of health outcomes than instrumental or other forms of social support (Ashida & Heaney, 2008). Thus, instrumental support appears to improve health outcomes directly, and a sense of connection within these instrumentally supportive relationships may be partially responsible for these positive health outcomes.

Second, being socially connected may result in the receipt of positive social influence from others. Social influence is the effect of others' actions and social norms on one's own behavior (Nolan, Schultz, Cialdini, Goldstein, & Griskevicius, 2008). Socially connected participants in our study may have reported better physical health because they were more likely to be involved in health promoting behaviors and activities. For example, health-enhancing social influence may shape attitudes about help seeking behaviors, such as seeking medical attention for medical concerns or receiving an annual physical from a primary care provider. Previous research demonstrates that social influence and encouragement from socially close others helps to motivate individuals to engage in preventive health behaviors, such as intention to receive preventative screenings (Ashida, Wilkinson, & Koehly, 2010). This type of preventative health behavior is likely essential for the individuals in our study, who reported an average of 7 health conditions or problems. Likewise, perceived exercise habits of socially close others have been shown to predict one's own exercise patterns (Darlow & Xu, 2011). Socially connected individuals may have friends who model exercise behavior, or with whom to exercise and hold accountable for maintaining a regular exercise routine. Conversely, individuals who are lonely and lack social closeness are more likely to be overweight or obese, and to smoke (Lauder, Mummery, Jones, & Caperchione, 2006). Thus, social influence, and influence from close relationships in particular, seems to play an



important role in various determinants of health. Positive physical health influence may therefore be one outcome of greater social connectedness for this sample of persons with MI.

Third, social connectedness, like social support, may help persons with MI feel more grounded and capable to manage stress in their daily lives, and more equipped to handle specific negative events or traumas if and when they arise. The vast majority of the sample in the current study likely manages chronic financial stress as a result of low SES, in addition to numerous health conditions and environmental barriers. Although these types of life stressors have a known damaging effect on physical health (e.g., Thoits, 2010), being socially connected to others appears to help ease the burden of these persistent challenges for persons with MI. Cohen and Wills (1985) found evidence for both a main effect model, in which social support is associated with less overall stress, and a buffering model, in which social support buffers against particularly stressful life events. In their review of the social support literature, the authors found evidence indicating that relationships that include esteem support appear particularly useful in staving off everyday stress for the general population (Cohen & Wills, 1985). Esteem support is considered a type of emotional social support provided by others that enhances individuals' self-appraisal of personal attributes, abilities, and accomplishments (Holmstrom, 2012). This type of esteem support may bolster capacity to overcome perceived barriers, paving the way for persons with MI to more effectively manage everyday life stressors.

If socially instrumental relationships help individuals to feel more capable in their daily lives, experiencing a sense of belonging within relationships may elicit similar positive self-appraisals of capacity to manage everyday challenges and mitigate global experiences of stress. Despite the significant number of health conditions and problems faced by our sample, participants who were more socially connected reported that their physical health was less likely to detract from their ability to engage in everyday activities, such as self-care, work, or recreation. This finding echoes previous research for the general population that suggests that lonely individuals, when compared to non-lonely individuals, report greater overall stress and threat in response to the circumstances of daily life, are more likely to appraise

similar circumstances as more threatening, and feel less equipped to manage daily stressors (Hawkley, Burleson, Berntson, & Cacioppo, 2003).

In addition to aiding in daily coping capabilities for persons with MI, social connectedness may shield against specific negative or traumatic events. Evidence for the buffering effect of social support suggests that those who feel supported are able to lean on their support system in times of need, preventing worsening psychological or physical health conditions. For example, Cobb (1976) found that social support generally served as a protective factor in moments of crisis and against physical health challenges including arthritis, tuberculosis, medication adherence, and mortality. Likewise, evidence suggests that lonely individuals are often less able to manage stressful life events, and are more likely to turn to unhealthy coping mechanisms, such as substance misuse, as a result of life stressors (Segrin, McNelis, & Pavlich, 2018). Social connectedness, like social support, may therefore provide both a consistent foundation for persons with MI to manage chronic stress and a safety net for uniquely stressful life events, both of which are closely tied to physical health.

The finding that social connectedness predicts physical health for persons with MI may represent an added element of self-efficacy gained from a sense of belonging within close relationships. For example, someone who experiences close connections with others may feel that they have the capacity to execute the necessary steps or behaviors to form these types of relationships. In essence, they may feel capable in their ability to develop a sense of social connectedness with others across contexts or domains. Although not well documented in the literature, there is some evidence for a significant association between social connectedness and self-efficacy (Brown, Hoyer, & Nicholson, 2012). Social connectedness focuses on one's cognitive appraisal of oneself in relation to other people, and should reflect a degree of ownership within or responsibility for relationships. This potential self-determination gleaned from social connectedness may therefore generalize to greater self-efficacy, which manifests in various domains, such as health behaviors.

Previous research supports the assertion that various types of social support and social integration contribute to greater self-efficacy for persons without disabilities, and that self-efficacy is predictive of health and functional outcomes (e.g., Berkman & Glass, 2000). Social support is also predictive of greater self-efficacy and health control, or one's feeling of responsibility for one's own health, (Schieman & Campbell, 2001). For PWD, peer support empowers a shift into the role of the consumer and the establishment of greater self-efficacy in daily functioning (e.g., Campbell, 2005). If social support predicts self-efficacy and health control for the general population, and peer support contributes to self-efficacy for PWD, social connectedness is likely to have a similar beneficial effect on self-efficacy and health outcomes for PWD.

Thus, self-efficacy may help explain the link between social connection and health. PWD who experience greater overall self-efficacy and specific self-efficacy in regards to health behaviors are more likely to engage in a health-promoting lifestyle (Stuifbergen & Becker, 1994). For this reason, interventions aimed at improving the health of PWD often attempt to harness the influence of self-efficacy across multiple domains in achieving desired outcomes (e.g., Marks & Allegrante, 2005). Social connectedness, which implies a degree of agency within relationships, may therefore contribute to PWDs' sense of self-efficacy and contribute to a physically healthier life.

Fourth, significant evidence points to physiological processes as mediators between social support and physical health, and many of these same mechanisms may explain the link between social connectedness and health. One early meta-analysis demonstrated that social support was associated with better immune functioning, indicating that those with more social support appeared more protected from sickness and disease (Uchino, Cacioppo, & Kiecolt-Glaser, 1996). In a review of the literature on this topic, Berkman and Glass (2000) summarized that several processes were likely central to this link, including an activated Hypothalamic Pituitary Adrenal (HPA) axis response, increased allostatic load, decreased immune system function, poorer cardiopulmonary fitness, easier transmission of infectious disease, and cardiovascular reactivity. Researchers have since empirically tested several of these

processes. For example, one study found that lonely individuals exhibit poorer cardiovascular functioning and poorer quality sleep, which likely prevents nightly restorative processes (Cacioppo et al., 2002). Likewise, more recent literature reviews have concluded that social support is associated with lower blood pressure, better overall cardiovascular functioning, and in some cases, neuroendocrine functioning, such as lower cortisol (Uchino, 2006). Socially connected persons with MI may therefore experience improved direct and indirect physiological benefits as a result of feeling connected, leading to better physical health.

Fifth, feeling socially connected to others may increase social engagement or participation for persons with MI, which can contribute to health for several reasons. Social engagement sometimes includes experiences of relational bonding or feeling in tune with others, which often gives individuals a sense of meaning or purpose in life. Thoits (2011, p. 148) argues that “knowing who we are to others also provides purpose and meaning in life... which in turn should have positive effects on health habits and psychological well-being.” Likewise, belonging to a social network of reciprocity and mutual obligation allows individuals to feel cared for, loved, esteemed, and valued, which has a significant protective effect on health (Wilkinson & Marmot, 2003). The experience of belonging within relationships is therefore closely tied to physical health for persons with MI.

The finding that social connectedness predicts physical health has significant implications given the immense physical health disparities faced by many PWD. Individuals with a disability have been found to experience disproportionately poorer physical health outcomes than those without a disability (Drum, Krahn, Culley, & Hammond, 2005), suggesting that PWD should be characterized as a health disparity population (Krahn et al., 2015). In particular, PWD tend to report significantly more unhealthy days in the past month in which they perceived their physical or mental health as not good (Froehlich-Grobe et al., 2016; Havercamp, Scandlin, & Roth, 2004). Likewise, PWD and those with physical impairments also tend to report worse overall health control compared to persons without disabilities (Schieman & Campbell, 2001). As previously mentioned, the link may be attributable to a combination of

functional and instrumental support, social influence, aptitude at managing chronic and acute stress, physiological pathways, or social engagement and sense of meaning/purpose. The contribution of social connectedness to physical health for persons with MI is an essential finding for this study, indicating that intimate relationships are foundational for physical health within a health disparity population.

Prior research has demonstrated that specific contexts which encourage relationship building can lead to improved health outcomes. For example, peer support has been a pillar of the grassroots disability movement since its emergence and continues to serve as a hallmark of IL philosophy. Research has suggested that peer support groups can cultivate a sense of belonging through reciprocal and intimate bonds with other group members (e.g., Mejias, Gill, & Shpigelman, 2014). The current study indicates that a general sense belonging within relationships contributes to physical health for persons with MI, regardless of whether this belonging occurs within the context of peer support. This sense of belonging within any relationship may be an important link between social connectedness and health. Prior research has demonstrated that for college students, belongingness was the domain of support most predictive of physical health (Hale, Hannum, & Espelage, 2005). Although correlational, our findings suggest that relational opportunities for enhancing social connectedness and a sense of belonging may contribute to improved physical health for persons with MI.

### **Mental Health**

Like physical health, extensive research has examined the association between various types of social closeness and mental health for the general population, although few studies have investigated social connectedness and mental health for PWD. Social connectedness as a specific construct serves as a protective factor against various psychological disorders and psychosocial correlates such as anxiety (Lee & Robbins, 1998), depression (Williams & Galliher, 2006), and guilt and shame (Williamson, Sandage, & Lee, 2007). Other constructs related to social connectedness also contribute to mental health. For example, in a recent broad review of the literature on social isolation, loneliness was often associated with poor mental health (Courtin & Knapp, 2017). Some scholars argue that the research in this area is robust

enough to suggest evidence for some degree of causality in the relationship between social support and mental health, whereby social support has the capacity to improve mental health (Turner & Brown, 2010). Together, this evidence suggests that social connectedness and other forms of intimate interpersonal support are essential to mental health for the general population.

Although there is less research linking social closeness to mental health for PWD, marginalized populations like PWD may be particularly vulnerable to loneliness (e.g. Hawkey & Cacioppo, 2007). Disability status has been associated with experiences of social inadequacy and alienation (Rokach et al., 2006), less social closeness (Soleimani et al., 2014), and additional environmental barriers to mental health treatment (Kok & Fredrickson, 2014). Social connection may be especially important to the well-being of PWD, as strong social relationships predict global ratings of mental health for this population (Tough et al., 2017). Social connection likely inhibits feelings of loneliness for PWD, and predicts quality of life (Vatne & Bjørkly, 2008). Thus, numerous studies suggest that experiences of poor social closeness seem to serve as a mental health risk factor for PWD, while social closeness serves as a protective factor.

The current study expands upon previous research demonstrating the importance of close relationships as a key component of mental health. Maintaining intimate social relationships is so central to mental well-being for the general population that it can help prevent the onset of psychopathology. For example, social group participation predicts depression longitudinally in an inverse direction, protects against the development of depressive symptomatology for individuals who have not been depressed, and predicts fewer depressive symptoms for formerly depressed individuals (Cruwys et al., 2013). If this type of involvement in social relationships has such a significant benefit for the mental health of the general population, it is likely to have a similar if not greater effect for persons with MI, many of whom face social isolation as a result of poor PE fit.

To the best of our knowledge, our study is the first to reveal that social connectedness predicts mental health for PWD. This finding is noteworthy given that persons with non-mental health related disabilities (e.g., MI) tend to experience significantly higher rates of mental health diagnoses compared to

persons without disabilities (Turner et al., 2006). In general, disability is often driven by mental health, and the disabling effects of mental health problems are often worse than the disabling effects of physical health. Importantly, social connectedness played a significant role in mental health within a marginalized and often othered population. In the current study, social connectedness explained between 24% and 30% of the variance in mental health, signifying that it is a major component of mental well-being for persons with MI.

Researchers have posited several mechanisms responsible for the link between social closeness and mental health for the general population, some of which overlap with the link between social closeness and physical health that was previously discussed. For example, functional and instrumental support are likely to help reduce the effects of daily and acute stress, and may be especially important for mitigating these experiences for PWD who tend to face additional environmental barriers and psychosocial stressors. Reduced stress has both physical and psychological benefits (e.g., Thoits, 2013), and may be especially helpful for persons who face both physical and mental health challenges. In addition, social closeness may be associated with health behaviors and substance use, which have repercussions for both physical and mental health. For example, loneliness predicts decreased exercise and physical activity (Hawkley, Thisted, & Cacioppo, 2009), which has significant benefits for mental health (Cooney et al., 2013). Loneliness can also contribute to substance use disorders (e.g., Åkerlind & Hörnquist, 1992). Thus, many of the same mechanisms that may explain why intimate social relationships predict physical health for persons with MI also seem pertinent to the link between this sense of connection and mental health. This type of overlap of mechanisms is not surprising given the inexorable connection between mental and physical health.

One mechanism of particular importance that may help explain the association between social closeness and mental health involves social threat. Hawkley and Cacioppo (2010) propose that the primary link between loneliness and mental health stems from hypervigilance for social threat caused by the experience of perceived isolation. Specifically, individuals who experience inadequate social

closeness interpret their environment as more threatening, come to expect negative social interactions, and more commonly encode negative social information into memory (Hawkley & Cacioppo, 2010). This perception of social threat may be especially salient for PWD who have often faced discrimination, marginalization, and lack of equal access to community participation.

Humans have evolved as social creatures, dependent upon one another for survival, and it follows that without adequate social closeness, one's environment could be construed as unsafe. Persons with MI may be particularly vulnerable to experiencing an environment as unsafe due to prior experiences of social othering. Perpetual perception of one's social environment as unsafe is likely to cause a stress response or increased hypertension, a predictor of physical health and a common symptom of anxiety related disorders. Importantly, social connectedness appears to have the opposite effect on this type of trait anxiety, suggesting that social connectedness is negatively associated with perceptions of daily life as stressful (Lee & Robbins, 1998). Thus, social connectedness may provide the type of social belonging for persons with MI that promotes interpretations of social interactions as safe, preventing the stress response experienced by lonely individuals.

Social connectedness may also contribute to psychological well-being for persons with MI through a slow and steady building of a relational belief system, which is likely to have psychosocial and psychological ramifications. Social connectedness begins to develop in childhood, is tested throughout adolescence and young adulthood, and over time aggregates into an "enduring interpersonal closeness with the social world in toto" (Lee et al, 2001, p. 310). Early relational experiences of persons with MI are therefore likely to influence the development of social connectedness throughout the lifespan, and the social environment during this period of crystallization may have significant downstream consequences. In instances where combined early experiences lead individuals to feel that they are not connected to others, such as having few friendships, not participating in larger social groups, or experiencing difficulty relating with others, these experiences result in a generalized dissatisfaction with social relationships (Lee & Robbins, 2000). Importantly, this generalized dissatisfaction and ensuing lack of social connectedness



is associated with lower self-esteem and greater likelihood of depression (Williams & Galliher, 2006). How one appraises one's belongingness within relationships is therefore associated with one's view of oneself (self-esteem) and a risk factor for psychopathology (depression). Relational disconnectedness from a social group contributes to poor mental health outcomes, corroborating the notion that a sense of belonging is a fundamental need (e.g., Baumeister & Leary, 1995).

It appears that the experience of how socially close relationships are developed (or not developed) may serve as another mechanism linking social closeness to negative affect and mental health for the general population. For example, Newall and colleagues (2009) found that individuals who interpret their loneliness as a result of external and uncontrollable factors (e.g. luck or context), as opposed to controllable factors (e.g. effort), are more likely to experience loneliness. This lack of agency in developing close relationships contributes to a negative feedback loop, whereby individuals feel unable to become more socially connected. Without agency, individuals have little motivation and tend to put in minimal effort into cultivating relationships, which results in loneliness (Newall et al., 2009) and likely in poor mental health. The link between social connectedness and self-efficacy would suggest that PWD who experience social connectedness are likely to interpret this connection as a result of internal factors as opposed to external, environmental factors.

Affect also appears to play a role in the link between social closeness and mental well-being. For example, a greater ratio of negative to positive affect significantly predicts psychopathology (Diehl, Hay, & Berg, 2011). Results from the current study indicated that social connectedness predicts global ratings of well-being for persons with MI. Conversely, loneliness is characterized by global negative affect as well as increased negative affect following social interactions and lasting throughout the day (Hawkley, Preacher, & Cacioppo, 2007). Whereas lonely individuals may experience negative affect and come to expect negative social interactions, socially connected individuals tend to experience greater interpersonal trust and social self-esteem as a result of social interactions (Lee & Robbins, 1998). Thus, a difference in affect between socially connected and disconnected individuals may contribute to mental health for PWD.

The finding that social connectedness predicts mental health is particularly important given the socioeconomic disadvantages faced by our sample. For example, almost 80% of our sample was unemployed, and over 40% had an annual household income of less than \$10,000, which is below the federal poverty threshold (DHHS, 2020). This number is likely an underrepresentation of the actual percentage of our sample living in poverty, as it does not account for households containing more than one person whose aggregate income is less than the poverty threshold for the given number of inhabitants. These demographics indicate that the participants in our study are likely experiencing severe financial stressors associated with low SES. Social inequalities serve as a risk factor for mental health (Allen, Balfour, Bell, & Marmot, 2014; Adler & Ostrove, 1999), and those living in poverty tend to utilize mental health services less often (Patel et al., 2010). Prior evidence suggests a cycle in which living in poverty increases the likelihood of developing a mental illness, and that living with a mental illness increases the likelihood of becoming or remaining impoverished (Lund et al., 2011). Unemployment alone causes discouragement, anger, worry, and frustration (Wanberg, 2012), and has a moderate overall effect on mental health (Paul & Moser, 2009). The combination of multiple factors contributing to low SES are likely to have a cumulative effect on mental health outcomes.

The fact that social connectedness was predictive of mental health for the financially vulnerable sample in the current study likely indicates that there are multifaceted elements of social connectedness that promote mental well-being. Those with high social connectedness may feel more connected in part because they may have access to greater social capital or instrumental support. Such support could help mitigate chronic and acute financial stress that contributes to psychopathology. For example, having a friend who is instrumentally supportive by providing transportation to an appointment may increase feelings of social connectedness, and help mitigate the effects of financial hardship. More generally, these types of supportive relationships may help to distribute the burden of various responsibilities, expectations, or obligations, and attenuate stress associated with low SES and poor physical health. This sense of tangible instrumental social support, where members of a community are available to “lend a

hand” in order to be supportive, is an essential component of coping with financial stressors (Åslund, Larm, Starrin, & Nilsson, 2014).

Second, social influence is likely central to those who are socially connected. In addition to contributing to health behavior patterns (e.g., Lewis & Rook, 1999), social influence may improve mental health coping strategies. For example, experiencing a sense of belonging within relationships is likely a good indicator that socially close others can be turned to for emotional support in times of need. Emotional support is likely essential when coping with significant socioeconomic stressors and physical health conditions. Supportive relationships that serve as coping resources help individuals manage stress through the coping process and have a direct effect on mental health (Taylor & Stanton, 2007). Furthermore, social connectedness is associated with greater social self-esteem (Lee & Robbins, 1998). Therefore, socially connected persons with MI may be less likely to experience social threat commonly experienced by lonely individuals. This strength may be particularly important for bolstering the self-worth of PWD living poverty, who have a longstanding history of experiencing discrimination, alienation, and social othering. Our finding that social connectedness seemed central to the mental health of our sample highlights the protective nature of feeling close to others.

### **Limiting Conditions**

In addition to examining the association between social connectedness and mental and physical health, the current study examined the relationship between social connectedness and limiting conditions. These conditions are sometimes referred to as secondary conditions, and in the current study included fatigue, chronic pain, feelings of depression and anxiety, fitness or conditioning concerns, sleep disturbances, and negative side effects from medications. Previous research indicates that various measures of social closeness are associated with limiting conditions, although these findings are less well documented in the disability literature. Loneliness, for example, is a risk factor for developing the secondary symptom cluster of pain, fatigue, and depression (Jaremka et al., 2014), and has been associated with sleep disturbances (Griffin, Williams, Ravyts, Mladen, & Rybarczyk, 2020). Loneliness

can serve as both a precursor to or as a result of sleep disturbances in older adults (Griffin et al., 2019). Similarly, for stroke survivors, fatigue appears to be exacerbated by perceptions of social isolation (Michael et al., 2006). Additionally, less social support is linked to greater functional limitation and lower self-rated health status in women with multiple sclerosis (MS). (Beal & Stuifbergen, 2007).

Limiting conditions appear to be central to health and well-being for persons with MI. For example, chronic pain is common in persons with physical disabilities such as spinal cord injury (SCI), MS, and neuromuscular disease (Müller et al., 2016). For persons with SCI, pain has been associated with lower satisfaction with life, decreased physical and emotional health, and more severe functional limitation (Putzke, Richards, & Dowler, 2000). Likewise, for persons with MS, pain has the potential to interfere with daily functioning, and is associated with poorer general health, worse depressive symptomatology, and increased fatigue (Osborne et al., 2006). Fatigue, like chronic pain, further exacerbates limiting conditions for PWD, and has been associated with decreased motivation and exercise, and poorer physical functioning (Michael, Allen, & Macko, 2006). Furthermore, symptoms of depression and anxiety are by definition associated with significant distress and impairment in daily functioning. These examples demonstrate how limiting conditions have the potential to have an enormous impact on well-being for PWD.

The current study highlighted that social connectedness significantly predicted persons with MIs' experiences of limiting conditions, providing additional evidence that social connectedness is an essential contributor to diverse components of health. This finding echoed previous research which linked various forms of support to specific limiting conditions. For example, social support and global ratings of fatigue are significantly correlated in an inverse direction (Sirois, Millings, & Hirsch, 2016). In terms of chronic pain, there is some evidence that social connectedness may help change the meaning ascribed to chronic pain. Specifically feeling socially connected to another may reduce feelings of alienation, isolation, and hopelessness when individuals are faced with chronic pain, ameliorating the magnitude of the pain

experience (Osborn & Smith, 2008). Thus, social connectedness appears to play a key role in the experience of limiting conditions for persons with MI.

Mental health, physical health, and limiting conditions can all serve as barriers to community participation, falling under the contextual factors category of the ICF (2001). Since social connectedness significantly predicts these three barriers in an inverse direction, enhancing social connectedness for persons with MI may decrease these barriers and allow for additional community participation. Although our study provides preliminary evidence that social connectedness may be associated with greater opportunity for community participation (through greater mental and physical health and less limiting conditions), we also anticipated that this relationship may be bi-directional, and that elements of community participation have the potential to influence one's social connectedness and mental health.

### **Community Participation, Social Connectedness, and Mental Health**

Our second hypothesis was that social connectedness would mediate the relationship between components of community participation and mental health. Mediation variables are behavioral, biological, psychological, or social constructs that transmit the effect of one variable to another variable, and help explain the mechanism of this transmission (MacKinnon, Fairchild, & Fritz, 2007). These types of questions are important because they can help flesh out complicated, indirect relationships between related constructs. Experts in mediation analysis have argued that while examination of cause and effect relationships are important, they provide only part of the story. Understanding the process of how such effects may operate is equally important (e.g., Hayes & Rockwood, 2017). By examining the mediating role of social connectedness in the relationship between community participation and mental health, we were able to shed light on *how* community participation predicts mental health for persons with MI.

Community participation predicts mental health via the indirect pathway of social connectedness. Specifically, community integration and activity participation predict social connectedness, and social connectedness predicts mental health. In other words, community participation affects mental health for persons with MI because the independent variable (community integration or activity participation)

affects the mediator variable (social connectedness), and this effect then transmits community integration's or activity participation's effect to mental health through the effect of social connectedness on mental health (see Figure 3 for a visual representation). Without considering an individual's social connectedness, predicting mental health based on community participation provides an incomplete picture.

Several mechanisms may help explain why social connectedness mediates this relationship. First, engagement in participation activities, which tend to be social, may highlight one's extent of connectedness (or disconnection) and influence emotional affect. Persons with MI who report high levels of social connectedness may feel particularly good about their connection to others during these social experiences, while those who are disconnected may feel particularly sad, guilty, or worthless. Previous research demonstrates that in general, lonely individuals tend to demonstrate more consistent negative affect (e.g., Hawkey et al., 2007), whereas socially connected individuals report more consistent positive affect (Stephens, O'Donnell, Marmot, & Wardle, 2008). As previously mentioned, a greater ratio of negative to positive affect is a predictor of psychopathology (Diehl, Hay, & Berg, 2011). Additionally, participation in activities that shed light on the extent of one's social connection may have a significant influence on affect. For example, an activity that accentuates one's social connectedness, such as providing emotional support and relational advice for a friend, may result in feelings of affection, warmth, and tenderness. Conversely, activities that are less dependent on strong connection (e.g. watching a movie with coworkers), may not influence affect because connection is not central to the experience.

Another simple explanation why social connectedness may play a mediating role is that engagement in participation activities provides fertile ground for improving social connection. Meaningful social and psychological experiences are often the impetus for participation in the first place (Lysack et al., 2007). Individuals who elect to engage in participation activities may become more socially connected through these experiences, and greater social connection promotes greater mental health.

Interestingly, social connectedness mediated the relationship between both subjective and objective measures of community participation and mental health. Subjective participation was measured by examining the experience of community integration (Community Integration Measure [CIM]). Community integration, compared to other measures of participation, demonstrated the largest indirect effect via social connectedness on mental health. There are several explanations for this finding. First, community integration may be particularly salient to social connectedness because community integration entails experiences of assimilation, support, independence, or sense of place, many of which are likely associated with one's closeness in relationships within the community. According to PWD, what typically makes community participation important and meaningful are experiences of self-determination, a sense of social identity, valued contribution, expectations of equal participation, and psychological safety in the form of having a voice and being respected (Milner & Kelly, 2009). This type of valued contribution and sense of belongingness within a community would logically improve one's sense of social connectedness with other members of the community. Social connectedness is determined by one's self-appraisal within relationships, and the experience of feeling like the community is respectful, valuing, and supportive of oneself would naturally lead to stronger feelings of connection and belonging. Berkman and colleagues note that "measures of social integration or 'connectedness'... give meaning to an individual's life by virtue of enabling him or her to participate in it fully, to be obligated (in fact, often to be the provider of support) and to feel attached to one's community" (Berkman, Glass, Brissette, & Seeman, 2000, p. 849). Thus, experiencing a sense of integration within the community is likely to increase relational belonging, which has a significant effect on mental well-being for persons with MI.

When positive elements of integration are lacking from community participation, PWD can experience negative consequences from community engagement. Inconsistent experiences of being physically present but not integrated in settings, such as social events or community gatherings, can contribute to feelings of being inconsequential and to social othering. For example, attending a party without knowing the other attendees, without speaking to them, and without taking part in the gift

exchange would technically be a form of participation (involvement in a life situation), but clearly lacks an experience of community integration. These types of participation experiences are likely to have a negative influence on one's degree of social connectedness. In particular, social environmental factors, such as availability of and acceptance or rejection by mainstream communities may affect development of social connectedness (Yoon et al., 2012). Furthermore, socially othering experiences can be potentially harmful or hurtful, as PWD are particularly vulnerable to experiencing feelings of social inadequacy and alienation from others (Rokach et al., 2006). Community participation without integration or self-determination may exacerbate these experiences.

Other disability researchers have echoed this call for forming stronger relational bonds as a means to establish a greater sense of community integration, and ultimately enhancing community participation and well-being for PWD. Condeluci (1999) argues that IL Movement's goal for independence, which strives for a socio-ecological lens of disability and consumer driven care, could be improved with additional emphasis on relationship building within communities. Condeluci's term for this hybrid model, "interdependence," balances independent living with a drive to strengthen PWDs' social capital through relationships outside of disability circles. Social capital is the propensity to experience advantages in personal interests that are gained through trustworthy relationships with others (Coleman, 1988). Condeluci (1999) believes that by increasing PWDs capacity to establish more intimacy within a wider range of relationships, PWD would be able to bridge the gap between what they themselves can contribute to the community and what they desire out of the community. In essence, connecting with others will help PWD generalize to the larger community the benefits of social capital common in peer support groups. Persons with MIs' forming of close relationships with others within the community is likely a necessary element to experiencing a sense of community integration.

Previous exploratory research examined the relationship between various measures of community integration, social support, and mental health for persons with a disability, and yielded similar results to our study. A validation study of the CIM with individuals who had experienced traumatic brain injuries



showed that the CIM was significantly correlated with the Social Provision Scale, a measure of social support (Griffen, Hanks, & Meachen, 2010). Likewise, Griffen and colleagues' study revealed that the CIM was significantly correlated with a global measure of mental health and significantly negatively correlated with several specific measures of somatic symptoms, depression, anxiety, and a global severity index. Although Griffen and colleagues (2010) linked community integration directly to social support and directly to elements of mental health, the current study is the first to demonstrate that community integration appears to have a greater effect on mental health for persons with MI when mediated by social connectedness. Feeling an attachment or sense of belonging within one's physical community appears central to one's sense of relational connectedness, which in turn predicts mental well-being. This pathway from community integration through social connectedness to mental health provides a novel explanation of *how* community integration affects mental health.

In addition to assessing the relationship between subjective experiences of community participation, social connectedness, and health, the current study examined the role of objective community participation within this triad. Objective community participation was measured by the incidence of trips participants made into the community and the number of participation activities engaged in outside of the home, such as active recreation, socializing, religious activities, community engagement, and entertainment. The study also asked participants about the amount of time spent engaged in work/volunteer engagements, which included employment, school/education, and volunteering. These types of work activities tend to be more consistent and involve significantly more time throughout the course of the week when compared to participation activities.

Results indicated that trips into the community were associated with participation activities and work activities, but were not associated with any of the psychosocial measures. This finding is not surprising given that many of these trips resemble errands (e.g. going to a store, restaurant, or pharmacy) and are unlikely to have a significant effect on one's sense of social connectedness or mental health. Although some studies use trips outside the home as a proxy for measuring social engagement for older

adults (e.g., Cherry et al., 2013), our study suggests that trips into the community seem to have little influence on social connectedness or mental health, and represent different experiences than participation activities.

Social connectedness significantly mediated the relationship between participation activities (e.g., active recreation such as exercise or sports, socializing outside the home, religious activities such as church services, entertainment such as movies or sporting events) and mental health. Engagement in activities such as recreation, socializing, religious events, community experiences, and entertainment predicted greater mental health for those who were more socially connected. The added benefit of social connectedness in predicting mental health for persons with MI is an important contribution to this area of research. Persons with MI tend to leave their homes at half the rate of persons without MI, and are significantly less likely to engage in social and recreational activities (Greiman et al., 2016). Our study demonstrates that these types of participation activities are associated with greater social connectedness and serve as important contributors to mental health.

Interestingly, participation activities also directly predicted mental health without taking into account social connectedness. This is noteworthy, indicating that getting out of the home and participating in activities within the community is a significant predictor of overall mental health for persons with MI. One possible explanation as to why engaging in participation activities appears to benefit mental health regardless of social connection is that these types of social and recreational activities may be inherently pleasurable and provide a sense of accomplishment. For example, Behavioral Activation (BA), a common cognitive behavioral approach to treating depression, helps individuals re-engage in these types of pleasurable or mastery activities, which tend to be enjoyable, provide a sense of accomplishment, and increase positive emotions. Specifically, BA attempts to increase this activation systematically, in a manner which allows individuals to more readily engage in naturally rewarding and fulfilling experiences (Dimidjian, Martell, Herman-Dunn, & Hubley, 2008). If activation is rewarding for individuals who are clinically depressed, it would follow that it may also be rewarding for sub-clinical populations, and result

in improved overall mental health. Some evidence appears to support this hypothesis, as PWD who are more active and engaged in their communities describe their health status as better than those who are less involved (Crawford et al., 2008). Engagement in pleasurable and social activities may therefore help explain the direct effect between participation activities and mental health.

Another potential explanation for the direct association between participation activities and mental health is that those who engage in activities with others absorb some of the mental health benefits of spending time in the presence of socially close others, even if this experience has little impact on their overall experience of social connectedness. This finding is in line with our finding from the EMA data that well-being experienced during socializing experiences is not dependent upon one's level of social connectedness, and in fact, many participants who reported excellent social connectedness indicated that their well-being did not significantly change while socializing.

Although work activities significantly predicted social connectedness, and social connectedness significantly mediated the relationship between work activities and mental health, the overall effect of this model was quite small. Hours spent engaged in work activities was not significantly associated with mental health, so meaningful mediation of this relationship was unlikely. One explanation for these results may be that the vast majority of the sample was unemployed. Only 22% of our sample reported any employment, and participants reported an average of only 6 hours per week spent engaged in these types of work, school, or volunteer activities. Logically, it makes sense that working or volunteering may predict social connectedness, especially if the work or volunteering takes place within a social setting. However, some jobs entail very little social interaction (e.g. long-distance truck driving) and may not be predictive of social connectedness.

As was the case with our first hypothesis, the relationship between community participation and mental health became more complicated when we began adding controls into our models. After controlling for the HRQOL physical health items and limiting conditions, none of the community participation measures had a significant direct effect on mental health. Social connectedness continued to

significantly mediate the relationship between community integration and mental health, but the effect was minimal. Physical health and limiting conditions demonstrate strong collinearity with mental health and appear to dominate models that incorporate them as controls while attempting to examine smaller, more sensitive mediation effects among variables. These findings suggest that physical health and limiting conditions alone serve as better predictors of mental health than community integration alone or community integration mediated via social connectedness. Results from the current study point to the likely utility of interventions that target physical health and limiting conditions as a means to try to improve mental health for persons with MI.

### **Predicting Social Connectedness from Components of Participation**

This study sought to provide a clearer picture of various community participation factors that contribute to social connectedness. By studying which factors are associated with a sense of belonging, we can highlight potentially life-altering relational repercussions of improved PE fit. The most important participation factors predicting social connectedness for persons with MI were 1) the extent to which they felt integrated into their community, 2) the extent to which they faced personal barriers, such as feeling fatigued or having difficulty concentrating, and 3) the extent to which they faced environmental barriers. Barriers were negatively associated with social connectedness, such that the less severe the barriers, the greater the sense of connectedness. In the previous section, the rationale for why community integration and social connectedness are closely related was explored, and it follows that community integration would serve as a useful predictor of social connectedness.

#### **Personal Barriers**

Personal barriers can be physical or psychological in nature (e.g., fatigue, pain, frustration). For the current study, personal barriers included cognitive, psychological, or medical factors such as difficulty thinking and concentrating, feeling tired or fatigued, and feeling like health was limiting engagement. Personal barriers can limit participation, such as when lacking motivation prevents attendance of a

neighborhood gathering or when an upset stomach gets in the way of going to a baseball game. Personal barriers like having a hard time thinking and concentrating, becoming easily fatigued, and feeling limited by one's health are predictive of community participation for PWD (e.g., Carpenter, et al., 2007). Patterns or habits of distorted thinking also seem capable of exacerbating the magnitude of personal barriers. For example, PWD who tend to catastrophize their pain experiences also tend to report more severe personal barriers to participation (Ravesloot, Berendts, & Schiwal, 2017). Additionally, personal barriers can include a wide variety of factors, and certain disabilities tend to be associated with different types of personal barriers. Persons with MI tend to report feeling that their health is a limiting personal factor more frequently than persons with other types of disabilities (Ravesloot et al., 2017). Personal barriers are prevalent amongst PWD, and in some cases are the primary obstacle to community participation. For example, lack of motivation serves as one of the biggest hurdles to participation for adolescents with disabilities (Boudos & Mukherjee, 2008).

In addition to limiting participation, personal barriers can be isolating and may limit engagement in early life experiences that promote social connectedness. For example, a child who suffers from irritable bowel syndrome may feel uncomfortable leaving home to spend time with acquaintances or neighborhood peers who may eventually grow into close friends. Even if this sort of personal barrier were to last only several years, it may have a devastating effect on that child's initial development of social connectedness. Personal barriers experienced early on may therefore shape social connectedness throughout the lifespan. One study found that PWD who lacked intimacy and meaningful relationships in adulthood often highlighted earlier formative experiences of loneliness as the catalyst for feeling ill-equipped to relate socially, withdrawing from emotional closeness, or rejecting it completely (Tarvainen, 2020).

Likewise, the onset of personal barriers as an adult could affect social connectedness later in life. For example, an individual who experiences a first episode of dysthymia or the first year of chronic pain or chronic fatigue may slowly start to feel less socially connected to friends and family. Although this

individual may have previously felt socially connected, these types of personal barriers may cause the individual to stop engaging in behaviors which typically help to maintain social connectedness. Some researchers have referenced these types of limitations as challenges with access. According to Owens (2009, p. 86), “Access is necessary for achievement of social connectedness... and is primarily dependent upon agency. Access involves positive engagement and response at every process point so that equality of opportunity is realized.” Personal barriers may therefore inhibit agency that fosters socially connecting or maintaining experiences.

The personal barriers examined in the present study were cognitive, psychological, or medical in nature, and included such challenges as having difficulty with concentrating, feeling fatigued, or feeling limited by physical health. Although not assessed directly in the study, additional personal barriers that resemble pervasive characterological traits may negatively affect social connectedness as well. For example, an individual who is irritable, dominates social situations, lacks empathy, or is often emotionally dysregulated may have a challenging time becoming socially connected to others. Conversely, individuals who are particularly interpersonally skilled, relationally oriented, or empathic may have an easier time establishing social connection. Personal barriers to participation may therefore generalize to serving as barriers to social connectedness.

### **Environmental Barriers**

PE fit highlights the extent to which physical and social environments are responsive to individual differences and disparate personal needs, serving to enable or constrain functioning (Iwarsson & Ståhl, 2003). Proper facilitation between person and environment allows for effective individual functioning (Baum & Christiansen, 2005). Poor PE fit limits PWD capacity to live independently, and can dictate disability status or degree of functional limitation (Steinfeld & Danford, 1999). Appropriate fit within the social and physical environment is central to independent functioning. Results of the current study suggest that appropriate PE fit also serves as a key ingredient for social connectedness.

The current study revealed that perceived environmental barriers predicted social connectedness in an inverse direction. Environmental barriers can be social or physical in nature (e.g. unsafe neighborhood or inaccessible design), and in our study included factors such as poor air quality, challenges related to accessibility, access to transportation, cost of living, sense of safety, and availability of help. Significant environmental barriers are an indicator of poor PE fit. Our findings echo previous research that examined the association between environmental barriers and loneliness. For example, one study found that perceived environmental barriers to outdoor mobility have been associated with feelings of loneliness in older adults (Rantakokko et al., 2014). Environmental barriers also appear to be prevalent in the lives of PWD who are lonely. Another study found that as many of 74% of PWD who acknowledged feeling lonely and isolated also experienced environmental barriers within their communities (Macdonald et al., 2018). Thus, perceived environmental barriers appear to be commonplace in PWDs' feeling of isolation.

One simple explanation for this finding is that physical environmental barriers can prevent engagement in social activities outside the home. Unusable home environments can physically prevent PWD from leaving their homes and getting out into the community (Cho et al., 2016). If an individual is not able to easily leave home, the availability and practicality of engaging in socially connecting experiences may be limited. Besides communicating electronically or having others come into the home, there would be minimal opportunities for social engagement. Remarkably, one study found that over half of homes rented by persons with MI had steps present at the entry to the home, making leaving and returning to their home virtually impossible without significant help (Greiman & Ravesloot, 2016). If a significant proportion of our sample had difficulty leaving home to participate in socially connecting experiences within the community, environmental barriers would naturally have an impact on social connectedness.

Another possible explanation for this finding is that environmental barriers of the social type limit possibilities for social connectedness. Environmental barriers in the form of societal attitudes can have a

profound impact on community participation for PWD (e.g., Hammel et al., 2015), and are likely to have a similar effect on social connectedness. Historically, medical models of illness have overemphasized the particular impairment, disease, or disability for individuals whose functioning is outside of what is considered “normal,” leading to alienation and stigmatization (Braddock & Parish, 2001). Living in a neighborhood or community environment where alienation and stigmatization are present could easily contribute to difficulty in establishing social connectedness for PWDs. A social hierarchy or environment of strong ingroup/outgroup differences is likely to exacerbate challenges with fitting in socially, feeling close to others, or establishing a sense of belonging. Environments of this nature that neglect to create a space that is conducive to a diversity of functioning negate equal opportunities for participation (e.g. Noreau & Boschen, 2010), and are likely to hinder equal opportunities to establish a sense of belonging within community relationships.

A third explanation for this finding is that the association between perceived environmental barriers and social connectedness may be mediated by a third factor, such as a personal barrier. For example, depression is an example of a potential mediating factor, as those who feel depressed would likely feel less capable of problem solving in order to overcome environmental barriers to socially connecting experiences. Previous research has suggested that for PWD who face environmental barriers, feelings of restricted autonomy may exacerbate the experience of loneliness (Rantakokko et al., 2014). Thus, a personal barrier like lacking motivation could easily deter those who face environmental barriers from overcoming those barriers to engage in socially connecting activities. If meeting a close friend for coffee required assistance in navigating a flight of stairs, obtaining assistance to overcome the environmental barrier would require significant motivation; however, mediating personal variables could also have a positive influence on social connectedness. In some cases, a personal factor may be the primary driver behind an individual’s ability to overcome environmental barriers to achieve social connectedness. For example, a person with MI who has difficulty navigating stairs but descends several flights to leave the apartment to meet up with friends is likely immensely motivated, resourceful and/or



high in self-efficacy. In this case, personal traits mediate environmental barriers, allowing the individual to overcome these barriers and cultivate connection. Prior research indicates that positive psychological attributes like self-efficacy may help ameliorate the relationship between the experience of environmental barriers and loneliness (Rantakokko et al., 2014). Thus, social connectedness may hinge on an environment which is both physically and socially amenable to cultivating relationships, and may also depend on personal factors or attributes that facilitate or hinder social closeness.

### **Participation Factors not Statistically Significant**

Interestingly, the current study demonstrated that social connectedness for persons with MI was not significantly predicted by functional limitations. Previous research has implicated functional limitations as predictors of loneliness. For example, measures of functional decline, including difficulties with ADLs, upper extremity tasks, and climbing stairs, are associated with loneliness in older adults (Perissinotto, Cenzer, & Covinsky, 2012). Our study found that the total degree of limiting conditions, which included challenges with seeing, hearing, concentrating, remembering, climbing stairs, dressing, bathing and running errands, was unlikely to significantly affect social connectedness. One explanation for the difference in these findings is that social connectedness and loneliness are tapping into different constructs. Loneliness, which often demonstrates more temporal variability, is likely more susceptible to change, and may therefore shift with the commensurate deterioration in functional decline throughout the life course. Social connectedness tends to be more of a consistent trait or characteristic, and may be less likely to fluctuate.

The current study revealed that social connectedness was not significantly predicted by the average extent of exertion expended in various areas of the home. It appears that even persons who have to exert themselves to a greater extent within the home, suggesting that going about the day is more physically taxing, are not deterred by this exertion from establishing and maintaining close relationships. Similar to the functional limitation finding, this suggests that social connectedness may be more of a personal characteristic or trait-like attribute, and therefore somewhat resistant to fluctuations in daily

experience. Interestingly, PWD who report higher levels of exertion in ADLs, such as bathing, are less likely to engage in social and recreational activities outside of the home (Greiman et al., 2018). Although exertion may be predictive of engagement in these types of activities in an inverse direction, social connectedness is determined by more than just engagement in social and recreational activities. In other words, it is possible to feel socially connected, even if engagement in social and recreational activities outside the home are a rare occurrence. For example, community integration and personal and environmental barriers to participation are much better predictors of social connectedness than actual social participation activities. Thus, feeling like a contributing member of the community, feeling that one is personally capable of participating, and feeling that the environment is amenable to participation seem to predict social connectedness more so than the average extent of exertion over the course of the week.

Furthermore, close relationships may be powerful enough that one can still feel socially connected to others whether or not one ends up engaging in social or recreational activities outside the home. Individuals who form strong interpersonal relationships early in life may not need these types of activities to maintain social connectedness. A phone call with a close friend, a visit from a relative, or an email from a socially close coworker may be adequate to maintain a sense of connectedness. For individuals who have less opportunity to engage in socializing experiences outside the home, fewer opportunities may mean that the occasions spent with others outside the home are more meaningful. In fact, for someone who has to substantially exert themselves to leave home, experiences of going out into the community to socialize with others may shape social connectedness more so than the everyday social interactions experienced by those for whom leaving the home is a regular occurrence. Thus, persons with MI appear to develop a sense of belonging in their relationships regardless of the functional limitations they experience or the extent to which they have to exert themselves within their homes. Social connectedness appears to be based on a combination of community belongingness, assimilation, support, sense of place, independence, and subjective appraisals of personal and environmental barriers to participation. Although community engagement through participation in activities and work/volunteering

is associated with social connectedness, it appears that the feeling of community integration and perceived ability to participate are the best predictors of social connectedness for persons with MI.

### **Socializing, Social Connectedness, & Well-being**

A final aim of our study was to examine the relationship between socializing, social connectedness and well-being. Specifically, we were curious if social connectedness would help predict in-the-moment experiences of well-being experienced while socializing and later in the day after socializing. Surprisingly, we found that the construct of social connectedness seems minimally related to PWDs' momentary ratings of well-being during and after socializing activities. Even when we expanded our definition of socializing to include activities that tend to be social in nature, social connectedness appeared to provide little additional predictive power into momentary well-being during and after socializing. Interestingly, our post-hoc analysis of the relationship between social connectedness and in-the-moment well-being assessed throughout the week demonstrated that social connectedness significantly predicts global ratings of satisfaction, pain, fatigue, stress, depression, and happiness. Thus, social connectedness appears less predictive of well-being experienced during and after socializing experiences, but is an important factor in more global ratings of well-being.

### **Social Connectedness, Socializing and Well-being**

We previously described how social connectedness resembles a more crystalized attribute as opposed to a flexible state, and why trips, activities, and employment in the community are not strong predictors of social connectedness for persons with MI. In a similar fashion, embodying a consistent trait like social connectedness may have minimal influence on momentary experiences of well-being while socializing. Social connectedness forms over time, as iteration upon iteration of social experiences are coalesced into a sense of enduring interpersonal closeness with the social world (Lee et al., 2001). If social connectedness is slow to crystalize, and relatively consistent once it does solidify, it may be unlikely to have an effect on momentary experiences of socializing. For example, an individual who

easily connects with others may not experience a spike in momentary well-being when socializing, especially if the socializing experience is unremarkable or does not evoke a relationship enhancing interaction. Likewise, an individual who does not easily connect with others may not experience a decrease in momentary well-being when socializing because it would not alter the individuals' preconceived notions about their lack of connectedness.

Social connectedness alone may be unlikely to influence momentary well-being during experiences of socializing. Social connectedness reflects a self-evaluation of one's connection with others, and does not include motivations and agentic behaviors to modify this appraisal (Lee et al., 2008). Individuals who experience minimal social connectedness exhibit social behaviors that enhance connection less frequently, such as sociability, intimacy, and reciprocity (Lee et al., 2001). If social connectedness remains relatively stable, individuals who are less socially connected may not experience a change in momentary well-being while socializing because their behavior does not alter the outcome, and the exchange is on par with expectations. Lacking social skills in social exchanges likely results in a self-fulfilling prophecy whereby the interaction fulfills expectations.

Importantly, our study found that socializing activities in general appear to be associated with well-being in the moment and later in the day for persons with MI. The association between socializing and greater subjective well-being is well documented in the literature for persons without disabilities, although both constructs are complicated to operationalize (e.g., Brajša-Žganec, Merkaš, & Šverko, 2011). For PWD, the link between experiences of socializing and greater momentary subjective well-being is less well documented. Daily reconstruction methods have been used to demonstrate that being in the presence of socially close others is associated with greater well-being (e.g., Silverman, 2018), although few studies have yet to corroborate this finding. By using a rigorous EMA approach to address this question, we can more confidently say that persons with MI report significantly greater happiness and satisfaction and less stress and depression while engaged in social activities as compared to activities that

are less social in nature (e.g., household chores/shopping, employment, family caregiving, self-care, education, transportation, healthcare appointments).

In terms of why socializing may be associated with well-being, some have argued that the act of socializing satisfies a basic human social need (e.g., Rodríguez, Látková, & Sun, 2008), and that by interacting with others, we are fulfilling what Baumeister and Leary (1995) depicted as a fundamental motive. Additionally, the relationship between socializing and well-being appears bi-directional, as happy people tend to participate in activities rated as more enjoyable, and are thus more likely to socialize (Robinson & Martin, 2008). Although there appears to be a link between socializing and well-being, it is important to keep in mind that only a very small proportion (1% - 3%) of the variance in well-being was attributable to socializing. This indicates that while socializing is significantly associated with well-being, numerous other factors likely contribute to momentary well-being, some of which may explain a larger proportion of the variance.

### **Social Connectedness and Well-Being**

Results of exploratory analyses found that social connectedness predicts global ratings of well-being throughout the week. Individuals who are more socially connected reported greater happiness and satisfaction and less depression, sadness, fatigue, and pain in momentary assessments over the course of the EMA measurement period. Although social connectedness did not moderate well-being during or following socializing experiences, it did predict overall well-being ratings over the course of the week. One possibility for this finding is that the ratings across the entire measurement period (7 days) provide a more reliable assessment of well-being than assessments measured only during socializing experiences.

This finding provides additional evidence that social connectedness may serve some sort of protective factor against everyday stressors. Much like esteem support, which enhances individuals' self-appraisal of personal attributes and abilities (e.g. Holmstrom, 2012), social connectedness may elicit similar positive self-appraisals of capacity to manage everyday challenges and promote well-being. Conversely, lacking social connectedness may have the opposite effect on assuaging day-to-day stressors,

as lonely individuals tend to report greater overall stress and feel less capable of managing daily stressors (Hawkley et al., 2003).

Another explanation for why social connectedness may be associated with greater well-being measured over 7 days is that social connectedness may alter the experience of personal factors or traits in day to day life. For example, previous research has demonstrated that social connectedness significantly mediates the relationship between more embedded personality traits and subjective well-being. Lee and colleagues (2008) demonstrated that social connectedness significantly mediated the relationship between extraversion and subjective well-being as measured by a combination of cognitive and affective aspects. Specifically, the authors note that extraversion likely contributes to the development of social connectedness through affirming relationships that satisfy the need for belonging and connection, and that forming intimate connections permeates various social situations leading to greater well-being. Thus, although social connectedness is predictive of well-being it could be that the mechanism of this association is due to the influence of social connectedness on personal factors, such as personality or characterological traits.

The current study's use of EMA to measure well-being throughout the course of the week provides a unique contribution to previous research suggesting a link between social connectedness and well-being. Specifically, global measures of well-being typically ask respondents to rate the average experience of well-being over a specified period of time (e.g. days, weeks, months). Recall of these types of experiences is often made using inexact inferences from fragmented details (e.g. Bradburn et al., 1987), is often unreliable, and accounts for much of the bias in recall data (Shiffman et al., 2008). Using EMA to measure dynamic variables like well-being, which may change throughout the course of the day, provides a much more detailed account of the effect on momentary experiences. EMA also allows for data to be collected in real-world environments, as individuals go about their daily lives (Shiffman et al., 2008). By demonstrating that social connectedness predicts in-the-moment well-being across an entire week of EMA prompts, this study suggests that social connectedness is associated with how individuals report

feeling in the moment. In other words, beyond indicating that social connectedness is associated with weekly or monthly ratings of well-being, we can confidently state that social connectedness is related to how individuals feel throughout the day.

### **Limitations & Future Directions**

Measurement issues were one of the main limitations to our study. Concepts like community participation and health are multidimensional and multifaceted. They are best assessed using a combination of subjective and objective metrics, and can be affected by a plethora of personal and environmental factors. In the current study, several constructs were measured using somewhat broad instruments. For example, although the HRQOL questions address the key concepts of health outlined by the WHO (Moriarty et al., 2003), and are commonly utilized by the CDC to assess for overall health, they examine the number of healthy/unhealthy days over the past month based on certain symptoms. This type of public health metric is far different from condition- or disorder-specific measures often used in the medical or mental health fields. For example, asking participants several questions that determine how many days in the past month their mental health affected their well-being provides a general overview of mental well-being, but speaks little to psychopathology.

One alternative method of investigation that may provide additional detail beyond more global assessments of mental and physical health would be to use more stringent measures of the constructs. For example, using measures with stronger psychometric properties to assess for specific mental health diagnoses such as depression (e.g. Patient Health Questionnaire-9) or anxiety (Generalized Anxiety Disorder-7), would increase both sensitivity and specificity for these disorders. These types of construct specific measures would provide more detailed information on mental health compared to the 4 HRQOL questions we used. Additionally, these types of measures may shed light on the types of mental health challenges most closely tied to social connectedness for PWD.

Another measurement issue in our study was that some variables were assessed via single item responses, which can be unreliable. For example, we made several inferences about the effect of social

connectedness on specific limiting conditions (e.g. fatigue, chronic pain, fitness/conditioning, sleep disturbances, and negative side effects from medications) based on single item responses to inquiries about these specific conditions. A limiting condition such as chronic pain is comprised of a combination of physiological, emotional, cognitive, and behavioral experiences, and could never be sufficiently captured by a single question. Likewise, although we found some preliminary data on the specific types of physical health conditions that appear to predict mental health (e.g. back and neck problems, weight problems) for persons with MI, further investigation into these associations would prove useful. For example, if research could determine which physical health problems/conditions have the biggest impact on mental health for persons with MI, consumers may have more insight into which physical challenges to address first in an effort to improve their mental well-being.

A second limitation to our study was that it was correlational in nature, preventing us from making causal inferences. Although some of our independent variables would be near impossible or unethical to manipulate (e.g. functional limitations), the findings from our study could be used to inform future research that incorporates experimental design, randomization, and consumer-driven choice. This type of experiment would be difficult to execute. If possible, it could help determine whether activities and experiences that are specifically designed to increase social connectedness are able to do so, as well as whether there is evidence of a causal influence on mental health, physical health, and limiting conditions. For example, research could examine the effect of randomly assigning participants to one of several activities intended to serve as socially connecting experiences. Control group members could participate in activities in which people are physically together but that may be less likely to be socially connecting. Opportunities for connecting experiences may include attending support or process groups that are intentionally designed to improve social connectedness over the course of several months. Less connecting experiences could include repeated engagement in activities with less likelihood of increasing social connection, such as watching movies together in a group or playing solitaire on computers in the same computer lab. One previous study examined the effect of participation in a one-time socially



connecting experience, and used viewing of a nature video for the control group (Kohlenberg et al., 2015). The study was able to demonstrate that compared to the control group, the socially connecting experience group improved social connectedness directly following the experience. Thus, although it would be difficult to extrapolate this type of experiment to a larger scale (e.g. over weeks or months) experimental design of this nature could provide some evidence for causality.

Our idea that interventions should target social closeness as a means to improve health and well-being is not a new one, even within disabilities studies, as peer support groups were one of the earliest hallmarks of the IL Movement. Since that time, various closeness generating paradigms have been used in laboratory settings and other experimental design studies with generally positive results for persons without disabilities (e.g., Aron, Melinat, Aron, Vallone, & Bator, 1997; Sedikides, Campbell, Reader, & Elliot, 1999). Importantly, social closeness or intimacy within these interactions seems dependent upon both self-disclosure and partner disclosure, and appears to be mediated by partner responsiveness (Laurenceau, Barrett, & Pietromonaco, 1998). This finding indicates that forming stronger connections requires effort on behalf of both parties.

More recent research on the mechanisms of what helps people form stronger social closeness highlights the importance of responding to moments of self-disclosure. Specifically, responsiveness to self-disclosure increases feelings of connectedness and reinforcement of these disclosures may serve as a mechanism of social connectedness (Haworth et al., 2015). This premise has been tested within group settings as well. Using a randomized controlled trial, Kanter, Kuczynski, Tsai, and Kohlenberg (2018) found that 4 session groups aimed at increasing closeness in romantic and non-romantic dyads helped to decrease fears of intimacy and increase social connectedness for individuals who were particularly fearful of relational intimacy, although the overall effect on social connectedness was not significant.

The findings from Kanter and colleagues (2018) suggest that a one-size-fits-all approach to improving social connectedness may not be the best. Specifically, the 4 session groups employed by Kanter and colleagues (2018) improved social connectedness only for those who expressed significant

fear of relational intimacy. Thus, individuals who experience an average or above average level of social connectedness may require a different type of intervention to enhance connectedness. Although Haworth and colleagues (2015) highlighted several key ingredients, including vested interest from both parties, a willingness to self-disclose, and recognition and reinforcement of the emotionally vulnerable moments, it is still unclear whether similar intervention strategies could have the same effect on individuals with varying levels of social connectedness.

Instead, it may make sense to titrate experiences intended to enhance social connectedness, matching one's degree of connectedness with the particular intervention. For example, self-disclosures can range in intimacy, from sharing a personal detail about oneself to sharing an intimate secret or traumatizing life experience. Finding the right level of self-disclosure, if responded to appropriately, may help more or less socially connected individuals push the envelope on how vulnerable they are with others, which may influence social connectedness. Likewise, reinforcement of these emotional risks appears equally important. Validating and reinforcing vulnerability, especially as individuals are first stepping outside of their comfort zones, could be essential to building momentum in developing social connectedness. Interventions that tailor the appropriate level of guidance may have a more significant influence on increasing these relational capabilities over time.

Unfortunately, PWD may face additional barriers to experiencing these types of connecting experiences. PWD were historically limited in their ability to form intimate, reciprocal relationships with others outside of their direct environment because they lacked access due to poor PE fit. Living and operating within disproportionately constricted environments resulted in PWD forming relationships primarily with medical providers, caregivers, or paid aids, who were in their direct proximity. One can surmise that these types of relationships, which were professional in nature for one party and the primary means for emotional intimacy for the other, may not have frequently entailed equal disclosure nor responsiveness to these disclosures. This potential lack of investment on behalf of both parties may help explain why PWD have struggled with a sense of marginalization from the world of interpersonal

intimacy (Milner & Kelly, 2009). To counteract this, Condeluci (1999) highlighted the importance of opportunities for PWD to form intimate relationships with persons without disabilities outside the immediate environment as essential to enhancing interdependence, well-being, and community participation.

In addition to challenges in response to the physical environment, poor social environmental barriers can also cause poor PE fit and prevent PWD from experiencing consistent intimate interactions with others. For example, extreme acts of hostility or social shunning directed at PWD can contribute to the stigma of being separate or “othered,” and often result in long-lasting feelings of alienation, poor self-worth, depression, and social isolation (Green, Davis, Karshmer, Marsh, & Straight, 2005). As a result, these types of interactions may shape PWD into feeling that few situations provide the emotional safety to allow for social intimacy. Thus, discriminatory and hierarchical societal views can interfere with emotionally intimate interactions for PWD.

For the purposes of our study, we were interested in examining the construct of social connectedness. Although we focused on this specific interpersonal construct, it would be helpful for future research in this area to include additional measures of social closeness, peer support, or experiences of loneliness. These related but distinct constructs would provide a more complete picture of potential relationships between various forms of social closeness, health, and community participation, and allow researchers to extrapolate the findings from our study. Additionally, since social connectedness is more of a pervasive attribute, and demonstrates minimal variability over shorter periods of time, more temporally sensitive measures of social closeness may provide unique information. For example, it would be interesting to assess more finite experiences of social closeness when comparing this sense of connection to mental or physical health in the past 30 days, trips and activities in the past week, and EMA responses. Although most measures of social closeness assess more global experiences of relational closeness or connectedness (e.g. UCLA Loneliness Scale), examining participants’ social closeness over the past week or month may help uncover more temporally nuanced differences.

The current study highlights the importance of social connectedness in the health, well-being and opportunities for community participation for persons with MI. At the same time, it is important to recognize that higher-level components of well-being are also at play. On a more global level, social determinants of health and mental health, such as income inequality and lack of education, often speak to larger environmental or systemic barriers faced by marginalized populations. Our sample represents a group of individuals who are largely burdened with challenging life circumstances, and we do not want to lose track of these socioeconomic challenges as additional areas for intervention. As Compton and Shim (2015, p. 419) describe,

“The social determinants of mental health... are understood as being underpinned by unequal distribution of opportunity and, more deeply, by public policies (e.g., legislation that may not specifically pertain to health but ultimately has far-reaching effects on health) and social norms (e.g., cultural opinions and biases that set the stage for poorer health among disadvantaged groups).”

Thus, addressing these societal issues through consumer-driven advocacy and policy revision, a continued effort of the IL Movement, should remain complementary to studies like ours, which examine and argue for more individualized improvements in well-being for PWD. Both are important for continued improvement in health and well-being for marginalized and underserved populations.

### **Conclusion**

The findings from our study help to fill the current gap in the literature by expanding our understanding of the fundamental links between social connectedness, community participation, and health for persons with MI. First, social connectedness is an essential component of mental health, physical health, and global ratings of well-being, and should become a central focus for improving health and quality of life. Second, PWD should be able to participate in their lives and experience a sense of valued contribution and respect within their communities to the same extent as individuals without disabilities. Facilitating opportunities for community participation is the primary mechanism for instilling change within the lives of PWD and therefore improving overall well-being and quality of life. Improving community integration and mitigation of personal and environmental barriers will not only increase

community participation, but likely increase persons with MIs' social connectedness. Third, social connectedness is a significant mediator between community participation and mental health for this population. Experiencing a sense of integration within the community and participating in activities is likely to increase relational belonging, which has a significant effect on mental well-being for persons with MI. And finally, experiences of socializing or visiting are associated with momentary experiences of well-being for persons with MI, regardless of their social connectedness. Spending time socializing with friends, family, or loved ones remains central to everyone's well-being.

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## Appendices

### Appendix A

#### Social Connectedness Scale - Revised (SCS-R)

Following are a number of statements that reflect various ways in which we view ourselves. Rate the degree to which you agree or disagree with each statement. There is no right or wrong answer. Do not spend too much time with any statement and do not leave any unanswered.

Strongly Disagree (1), Disagree (2), Mildly Disagree (3), Mildly Agree (4), Agree (5), Strongly Agree (6)

1. I feel comfortable in the presence of strangers
2. I am in tune with the world
3. Even among my friends, there is no sense of brother/sisterhood
4. I fit in well in new situations
5. I feel close to people
6. I feel disconnected from the world around me
7. Even around people I know, I don't feel that I really belong
8. I see people as friendly and approachable
9. I feel like an outsider
10. I feel understood by the people I know
11. I feel distant from people
12. I am able to relate to my peers
13. I have little sense of togetherness with my peers
14. I find myself actively involved in people's lives
15. I catch myself losing a sense of connectedness with society
16. I am able to connect with other people
17. I see myself as a loner
18. I don't feel related to most people
19. My friends feel like family
20. I don't feel I participate with anyone or any group.

## Appendix B

### Community Integration Measure (CIM)

For each of the following statements, please indicate whether you agree or disagree.

Always Disagree (1), Sometimes Disagree (2), Neutral (3), Sometimes Agree (4), Always Agree (5)

1. I feel like part of this community, like I belong here
2. I know my way around this community
3. I know the rules in this community and I can fit in with them
4. I feel that I am accepted in this community
5. I can be independent in this community
6. I like where I am living now
7. There are people I feel close to in this community
8. I know a number of people in this community well enough to say hello and have them say hello back
9. There are things that I can do in this community for fun in my free time
10. I have something to do in this community during the main part of my day that is useful and productive



## Appendix C

### Rating of Perceived Exertion (RPE) Scale in Home Experiences

Please rate your exertion level when you use each area of your home.

Nothing at All (0), Very Light (1), Fairly Light (2), Moderate (3), Somewhat Hard (4), Hard (5), Very Hard (7), Very, Very Hard (10)

1. Getting into and out of your home
2. Using your kitchen
3. Using your toilet
4. Using your tub/shower
5. Using your living area
6. Using your storage places like closets and cupboards
7. Using your bedroom for dressing and going to bed
8. Cleaning and tidying up

## Appendix D

### Disability and Health Perceived Barriers (DHPB) Scale

In the past 7 seven days, what were your experiences getting out into the community? Getting out last week....

Never (1), Sometimes (2), Often (3), Routinely (4)

1. It was easy to get in and out of my house
2. Poor air quality or other pollutants bothered me
3. I had a hard time thinking and concentrating
4. I had the help I needed
5. I was too tired
6. My health was limiting me too much
7. Buildings were accessible to me
8. I had reliable access to transportation to get where I needed to go (such as personal vehicle, public transportation, family or friends)
9. I had enough money to do things I wanted to do
10. I did not have enough money to pay my (or my family's) medical bills
11. I had enough money to buy the food that my family or I needed
12. I felt safe when leaving my home
13. People's attitudes toward me were positive
14. I had the assistive equipment I needed

## Appendix E

### Health Related Measures

#### Health Related Quality of Life-4 (HRQOL-4)

1. In general, would you say your health is: Excellent, Very Good, Good, Fair, Poor
2. Think about your physical health, which includes physical illness and injury. How many days during the past 30 days was your physical health not good? (check one) 0 2 4 6 8 10 12 14 16 18 20 22 24 26 28 30
3. Think about your mental health, which includes stress, depression, and problems with emotions. How many days during the past 30 days was your mental health not good? (check one) 0 2 4 6 8 10 12 14 16 18 20 22 24 26 28 30
4. During the past 30 days, for about how many days did poor physical or mental health keep you from doing your usual activities, such as self-care, work, or recreation? (check one) 0 2 4 6 8 10 12 14 16 18 20 22 24 26 28 30

#### Healthy Days Symptoms Module

1. During the past 30 days, for about how many days did pain make it hard for you to do your usual activities, such as self-care, work, or recreation? (check one) 0 2 4 6 8 10 12 14 16 18 20 22 24 26 28 30
2. During the past 30 days, for about how many days have you felt sad, blue, or depressed? (check one) 0 2 4 6 8 10 12 14 16 18 20 22 24 26 28 30
3. During the past 30 days, for how many days have you felt worried, tense, or anxious? (check one) 0 2 4 6 8 10 12 14 16 18 20 22 24 26 28 30
4. During the past 30 days how many days have you felt that you did not get enough rest or sleep? (check one) 0 2 4 6 8 10 12 14 16 18 20 22 24 26 28 30
5. During the past 30 days how many days have you felt very healthy and full of energy? (check one) 0 2 4 6 8 10 12 14 16 18 20 22 24 26 28 30

#### Additional health questions

1. Overall, would you say that your ability to independently engage in desired activities such as recreation or daily living over the past 12 months was: Excellent, Very good, Good, Fair, Poor
2. In the past 3 months, have you visited an emergency room/urgent care provider? Yes No
3. In the past 6 months, how many nights have you spent in a hospital?
4. How many medications prescribed by a doctor do you take?
5. How many of these medications help you manage your pain?
6. How would you rate your average pain intensity over the past week on a 0 to 10 scale? (check one) No Pain (1), Pain as Bad as you can imagine (10)

## Appendix F

### EMA Prompts and Response Options

1. What type of activity are you engaged in?  
Optional Responses: Watching TV or a movie, Eating, Food and drink prep, Resting, Household chores/shopping, Employment, Reading, Recreation or leisure, Socializing or visiting, Family caregiving, Self-care, Education, Transportation or mobility, Community or volunteer activity, Healthcare appointments, Religious activities, Other
2. Rate your level of physical exertion for this activity?  
Nothing at All (0), Very Light (1), Fairly Light (2), Moderate (3), Somewhat Hard (4), Hard (5), Very Hard (7), Very, Very Hard (10)
3. How much pain are you experiencing right now?  
No Pain (1), Pain as Bad as you can imagine (10)
4. How fatigued are you?  
Not at all, A little, Somewhat, Quite a bit, Very much
5. How stressed are you?  
Not at all, A little, Somewhat, Quite a bit, Very much
6. How depressed are you?  
Not at all, A little, Somewhat, Quite a bit, Very much
7. How happy are you?  
Not at all, A little, Somewhat, Quite a bit, Very much

## Appendix G

### Limiting Conditions

Please rate how much each of the following conditions have affected your activity and independence in the past 30 days. If you have not experienced the condition in the past 30 days, or if it is a small problem for you, check '0'. Refer to the rating scale when making your ratings.

#### Rating Scale

0 = Not experienced during the past month/insignificant problem (rarely or never limits activity or independence)

1 = Mild or infrequent problem (limits activity 1-5 hours per week)

2 = Moderate/occasional problem (limits activity 6 -10 hours per week)

3 = Significant /chronic problem (limits activity 11 or more hours per week)

1. Fatigue: A tired, though not necessarily sleepy feeling, after minimal exertion.
2. Chronic Pain: Usually experienced as chronic tingling, burning or dull aches. It may occur in an area that normally has little or no feeling.
3. Physical Fitness/Conditioning Problems: Not being able to do normal activities, being out of shape.
4. Sleep Disturbance: Difficulty falling asleep or staying asleep, difficulty staying awake during the day, or waking up early.
5. Depression: Depression is more than feeling blue. Symptoms include: extreme, long-term sadness, loss of pleasure in favorite things and activities, difficulty sleeping, weight loss or gain, thoughts of suicide and frequent and/or unexplained crying.
6. Anxiety: Feeling worried or fearful about the future. Symptoms include: rapid heartbeat, shortness of breath, sweating, and stressful feelings.
7. Side Effects from Medications: Any unwanted conditions caused by a medication.

## Appendix H

### Disability and Difficult Conditions

#### Six-Question Disability Sequence (6QS)

1. Are you deaf, or do you have a serious difficulty hearing? Yes No
2. Are you blind, or do you have serious difficulty seeing even when wearing glasses? Yes No
3. Because of a physical, mental or emotional condition, do you have a serious difficulty concentrating, remembering, or making decisions? Yes No
4. Do you have a serious difficulty walking or climbing stairs? Yes No
5. Do you have difficulty dressing or bathing? Yes No
6. Because of a physical, mental or emotional condition, do you have difficulty doing errands alone such as visiting a doctor's office or shopping? Yes No

#### Difficult Conditions Questionnaire

We'd like to know how difficult these conditions have been for you in the past 30 days. Check your answers (0 = No Difficulty, 10 = Extreme Difficulty)

1. Had difficulty hearing
2. Had difficulty seeing even when wearing glasses
3. Had difficulty concentrating, remembering or making decisions
4. Had difficulty walking or climbing stairs
5. Had difficulty dressing or bathing
6. Had difficulty doing errands alone such as visiting a doctor's office or shopping

## Appendix I

### Brief Community Engagement Questionnaire (BCEQ)

Please circle the number of times you visited each of these places in the past 7 days.  
Compared to what you usually do circle if this was less often, about the same, or more often than usual.

#### I) Community Participation - Trips

Trips last week / Circle number of visits in the past 7 days / Circle if this was less, the same or more than usual.

1. Grocery stores / 0 1 2 3 4 5 6 7 8 9 10+ / Less Same More
2. Doctors or other healthcare providers / 0 1 2 3 4 5 6 7 8 9 10+ / Less Same More
3. Pharmacies / 0 1 2 3 4 5 6 7 8 9 10+ / Less Same More
4. Restaurants / 0 1 2 3 4 5 6 7 8 9 10+ / Less Same More
5. Large box-stores such as Walmart and Home Depot / 0 1 2 3 4 5 6 7 8 9 10+ / Less Same More
6. Public parks or recreation areas / 0 1 2 3 4 5 6 7 8 9 10+ / Less Same More
7. Exercise facilities / 0 1 2 3 4 5 6 7 8 9 10+ / Less Same More
8. Shopping malls / 0 1 2 3 4 5 6 7 8 9 10+ / Less Same More

#### II) Community Participation - Activities and Employment

Activities last week / Circle number of times in the past 7 days / Circle if this was less, the same or more than usual.

1. Active recreation such as exercise, sports or fishing / 0 1 2 3 4 5 6 7 8 9 10+ / Less Same More
2. Socializing outside the home / 0 1 2 3 4 5 6 7 8 9 10+ / Less Same More
3. Religious activities such as church services / 0 1 2 3 4 5 6 7 8 9 10+ / Less Same More
4. Community activities such as voting, meetings / 0 1 2 3 4 5 6 7 8 9 10+ / Less Same More
5. Entertainment such as movies or sporting events / 0 1 2 3 4 5 6 7 8 9 10+ / Less Same More

Employment last week / Circle number of hours spent in the past 7 days / Circle if this was less, the same or more than usual.

1. Employment / 0 5 10 15 20 25 30 35 40+ / Less Same More
2. School or Education / 0 5 10 15 20 25 30 35 40+ / Less Same More
3. Volunteering / 0 5 10 15 20 25 30 35 40+ / Less Same More