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Wellness Programming For Adults With Disabilities: A Qualitative Inquiry Of Stakeholders' Perspectives

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WELLNESS PROGRAMMING FOR ADULTS WITH DISABILITIES: A QUALITATIVE
INQUIRY OF STAKEHOLDERS' PERSPECTIVES

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ABSTRACT

There is a well-established need for a wellness program for adults with disabilities in the regional community. In alignment with best practice guidelines, and as a first step in the development of a program in the regional community, qualitative methodology was utilized to explore the views of key community stakeholders to gain an in-depth understanding of their perceptions of wellness programming needs for adults with disabilities in the regional community. Data were collected through semi-structured interviews which specifically explored barriers and facilitators to wellness programming for this population in the regional community to inform future steps of program development. Three main themes emerged for barriers: accessibility, community factors, and political factors while two main themes emerged for facilitators: accessibility and community factors during the data analysis. These themes were further viewed through the lens of the Social Ecological Model (SEM) to determine the specific implications of the findings on subsequent stages of program development. Upon completion of this step, it was recognized that all five layers of influence were represented in the study's findings. Therefore, moving forward, it will be prudent to incorporate these results and consider the multiple layers of influence of the SEM as future planning commences in order to build a program with lasting results (Drum et al., 2009, LaMorte, 2019; DHHS, 2020).

Keywords: adults with disabilities, wellness programming, barriers, facilitators

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CHAPTER ONE

INTRODUCTION

According to recent estimates from the Center for Disease Control and Prevention ([CDC], 2019), one in four adults in the United States is living with a disability. This equates to approximately 61 million total disabled adults nationwide (CDC, 2019). Of that number, 42,604 of these individuals reside within the local community of interest for this study (Erie County Department of Health, 2018). Further, the prevalence of disability, both nationally and regionally, is expected to significantly rise in the upcoming years as a result of the aging baby boomer population (Erie County Department of Health, 2018; United States Census Bureau, 2014).

The health status of adults with disabilities and the costs associated with their health care compounds the concerns regarding the expected rise of disabled adults in the future (CDC, 2019; United States Census Bureau, 2014). For example, adults with disabilities are reported to have lower rates of physical activity and higher rates of preventable, non-communicable health conditions such as obesity and cardiovascular disease (CDC, 2019; Krahn et al., 2015; United States Census Bureau, 2014). Additional reports indicated that adults with disabilities also have a general lack of access to preventative services, which in turn, contributes to further health complications for these individuals (CDC, 2019; Krahn et al., 2015; United States Census Bureau, 2014). Further, from a financial perspective, estimates of disability-associated health care expenditures indicated that healthcare costs for this population approached $400 billion dollars per year in recent years (Anderson, Armour, Finkelstein, & Wiener, 2010).

The combined impact of these factors led to the formal recognition of the health status of adults with disabilities as a major health disparity within the nation's health care community

(CDC, 2019; Krahn et al., 2015). As a result, many public health initiatives focused on the development of wellness programs for adults with disabilities as a top priority (CDC, 2019; Department of Health and Human Services [DHHS], 2008; National Council for Disability [NCD], 2009; NCD 2012). Further, the effectiveness of these wellness programs is well established as indicated by the results of high quality empirical research (Heller, McCubbin, Drum, & Peterson, 2011; Stuifbergen, Becker, Blozis, Timmerman, & Kullberg, 2003; Stuifbergen, Morris, Jung, Peirini, & Morgan, 2010; Young, Erickson, Johnson & Johnson, 2015).

Statement of the Problem

The World Health Organization (WHO) is well recognized for its role in leading health and wellness initiatives for many populations including adults with disabilities, both at the international and national level (WHO, 2006). To focus their efforts, the WHO (2006) established the following definition of wellness:

> The optimal state of health of individuals and groups…with two focal concerns: the realization of the fullest potential of an individual physically, psychologically, socially, spiritually, and economically, and the fulfillment of one's expectation in the family, community, place of worship, workplace and other settings. (p. 5)

It is important to recognize that this definition, which remains current today, supported an individualized and holistic approach to wellness and is inclusive of not only physical well-being, but emotional, spiritual, and social well-being as well.

As wellness programs for adults with disabilities developed, many effective programs incorporated a similar holistic approach to wellness in their program design. The most compelling evidence in this regard stemmed from an extensive systematic review completed by

Stuifbergen et al. (2010). One hundred ninety articles investigating wellness programs for adults with disabilities were included in the study. Nearly all the programs studied incorporated aspects of nutrition and psychological well-being in addition to physical exercise as part of a comprehensive wellness program. The collective results of these programs demonstrated large treatment effects for program participants on multiple health domains, providing clear evidence for the benefits of participation in such programs (Stuifbergen et al., 2010).

However, despite the proven effectiveness of wellness programs for adults with disabilities, utilization is limited (Blonski et al., 2014; Durstine et al., 2000; Heller et al., 2003; LaMorte, 2019; McPhail, et al., 2014; NCD, 2012; Rimmer et al., 2008; Rimmer et al., 2014; DHHS, 2005). Further, no wellness programs for adults with disabilities exist in the regional community (Erie County, 2018). Therefore, the overall goal of this research is to guide the creation of such a program in the local community.

Purpose of the Study

To build a program with lasting effects, consideration of factors limiting utilization of existing programs throughout the planning process is critical (Drum et al., 2009; Stuifbergen et al., 2010). It is well recognized that factors associated with accessibility such as a lack of transportation, physical features of the program environment, and costs associated with program participation serve as significant deterrents to program use (Rimmer, Wang, & Smith, 2008). Stuifbergen et al. (2010) also found that limitations in the design of the wellness program itself, including a lack of long term follow through and a lack of accountability for contextual factors associated with long term program participation (i.e. personal preferences, social resources) were additional elements associated with program utilization.

Stuifbergen et al. (2010) further acknowledged the negative impact of a lack of adherence to best practice guidelines during the development and implementation of wellness programming for adults with disabilities on program utilization. Best practice guidelines as established by Drum et al. (2009) emphasized the importance of incorporating a well-defined conceptual or theoretical framework into program design, ensuring participants' ongoing needs are met through routine process evaluation, and collecting outcome data to determine program effectiveness. These guidelines further outlined the importance of involving key stakeholders at the onset of planning and incorporating their perspectives throughout the implementation process to enhance the program's overall success (Drum et al., 2009).

In alignment with these recommendations regarding initial steps of program development, the purpose of this study involved an in-depth exploration of the views and perceptions of key stakeholders in the regional community as it relates to wellness programming needs for adults with disabilities. Specific focus was placed on exploring key stakeholders' perceptions of positive and negative factors which impacted the utilization of wellness related services by adults with disabilities; and, the impact of their perspectives on program design. The information gleaned from this exploratory study was used to outline subsequent steps of program development and implementation.

Research Questions

To gain insight into key stakeholders' perceptions of wellness programming needs for adults with disabilities in the regional community, the following questions were used as a guide:

- RQ 1: How do key stakeholders within the regional community characterize barriers and facilitators to wellness programming access for adults with disabilities?

- RQ 2: How do key stakeholders' perspectives of barriers and facilitators to wellness programming access impact wellness program design for adults with disabilities?

Conceptual Framework

Ravitch & Riggan (2016) defined conceptual frameworks in research as the "overarching arguments for the work-both why it is worth doing and how it should be done" (p. 8). The authors further described that this element is shaped by the combined influence of the researcher's personal interests, topical research, and underlying theoretical framework (Ravitch & Riggan, 2016). When considering the application of these concepts to this research, it was important to first return to the study's overarching goal, which involves the development of a wellness program for adults with disabilities in the regional community. Ultimately, the effects of the program will be widespread and will positively influence the community's overall state of health and wellness (Golden & Earp, 2012; Shogren, 2013, Stuifbergen et al., 2010). This end result aligns with the researcher's personal and professional goals as a health care professional and educator and as such, served as a driving force of this inquiry.

The literature further substantiated the importance of the development and implementation of a wellness program for adults with disabilities. There is a well-established need for such services in the regional community as a result of the disproportionate rates of preventable health conditions which affect this population, the effectiveness of wellness programs on reversing these preventable health conditions, and the lack of such programming in the regional community for this population (Erie County, 2018; Krahn et al., 2015; Stuifbergen, et al., 2010). Further evidence also outlined best practice guidelines for how such a program should be built (Drum et al., 2009). In alignment with these guidelines, this study involved the exploration of key community stakeholders' perspectives regarding wellness program needs as a

first step in the process of the development and implementation of a program for adults with

disabilities in the regional community.

From a theoretical framework perspective and in order to fully understand the nature and

context of key stakeholders' shared perspectives, it was also essential to consider theories related

to health behavior change and factors that are associated with the adoption of positive, self-

determined health behaviors. As described by LaMorte (2019), theories of health behavior

change began to develop in the 1950s in order to better understand the processes and the

elements that impact processes associated with the sustained and autonomous adoption of

positive health behaviors. Founded by Brofenbrenner (1977) and expanded upon by McLeroy,

Bibeau, Steckler, & Glanz (1988), the social ecological model (SEM) is one such widely

accepted theory of health behavior change. Unlike other models of health behavior change, SEM

recognizes the "multifaceted and interactive effects of personal and environmental factors"

(CDC, 2009, p. 1) involved in self-determined human behavior. Specifically, the following five

layers of influence on such behavior are recognized within SEM: intrapersonal factors,

interpersonal factors, community and social factors, organizational factors, and political factors

(Brofrenbrenner, 1977; McLeroy et al., 1988).

Utilizing SEM and its related constructs as a lens by which to view the data during the

data analysis phase offered critical insight into adults with disabilities' unique needs related to

wellness programming in the regional community. In alignment with the foundational work of

Brofenbrenner (1977) which was expanded upon by McLeroy et al. (1988), particular focus was

placed on understanding the nature of stakeholders' voiced perspectives and the relationship of

these perspectives with factors associated with SEM. Thematic elements related to these factors,

their interrelationships, and underlying implications on program design were specifically utilized

to outline the next phases in the development and implementation process in order to maximize the program's success.

Assumptions

Key stakeholders in the community with a vested interest in the health and wellness status of adults with disabilities in the regional community served as the primary study participants. Confirmation of their vested interest in this topic was self-verified during the enrollment process. To ensure recruited participants functioned as information rich sources of data, details regarding their level of experience in this specific field were additionally self-verified at the time of study enrollment. It was assumed that participants' responses during these self-verification processes were honest and true. It was further assumed that a high level of honesty was reflected in participants' shared perspectives throughout the remainder of the data collection process. Intentional efforts to minimize the impact of researcher bias, ensure participants' rights were maintained and highlighting the confidential nature of shared responses served to foster the participants' comfort level and ease with providing honest and true responses (Walters, 2001).

Limitations and Scope

Because participants in the study were limited to stakeholders within the regional community who had a vested interest in the health and wellness status of adults with disabilities, the transferability of the results is limited (Yin, 2018). To minimize the impact of this limitation and to maximize the ability to gain a holistic view encompassing a wide variety of key stakeholders' perspectives within the scope of the study, non-random, purposeful maximum sampling was utilized (Creswell, 2017; Yin, 2018). This process specifically involved the recruitment of specific stakeholder groups with a vested interest in the health and wellness of

adults with disabilities who had distinct and diverse experience in the field. The utilization of this sampling method, which maximized diversity within primary study participants, will additionally serve to enhance the program's overall success (Drum et al., 2009).

Rationale and Significance

An in-depth understanding of wellness programming needs for adults with disabilities from the perspectives of key stakeholders offered important insight toward the development of a successful and sustainable program in the regional community (Drum et al, 2009, Golden & Earp, 2012; LaMorte, 2019; Shogren, 2013). The results indicated that considering the influence of multiple layers of contextual factors as outlined with the SEM model will be essential for programmatic success and sustainability. Given the growing need for such services, assurance of long term viability is key (CDC, 2019; Drum et al., 2009; Krahn et al., 2015). With access to effective preventative programs focused on health and wellness, current evidence suggests that not only will those directly participating in the program experience improvements in quality of life, global improvements in the overall state of the community's health and well-being will be seen as well (Golden & Earp, 2012; Shogren, 2013, Stuifbergen et al., 2010).

Definitions of Terms

To provide a point of reference for terminology related to this research, definitions of key terms are provided below.

Disability. "A condition that results from the interactions of health conditions (that contribute to impairments of body functions, activity, and/or participation) and contextual factors (such as physical and social elements) which in turn, interfere with life experiences" (WHO, 2002).

Health disparity. "The avoidable and unjust differentials, and health differences, which refer to avoidable and unavoidable causes" (Krahn et al., 2015, p. S198).

Non communicable disease. A chronic disease of long duration that results from a combination of genetic, physiological, environmental and behavior factors (WHO, 2018, para 1.)

Stakeholder. An individual "who is involved in or affected by a course of action" (Merriam-Webster, n.d).

Wellness. "The optimal state of health of individuals and groups…with two focal concerns: the realization of the fullest potential of an individual physically, psychologically, socially, spiritually, and economically, and the fulfillment of one's expectation in the family, community, place of worship, workplace and other settings" (WHO, 2006, p. 5)

Conclusion

In recent years, the poor health status of adults with disabilities gained increased attention (CDC, 2019; United States Census Bureau, 2014). A combined impact of a lack of access to preventative health care in the setting of high rates of preventable, non-communicable disease in this population raised the level of urgency for the development and implementation of sustainable and effective comprehensive health and wellness programs for these individuals (CDC, 2019; Krahn et al., 2015; United States Census Bureau, 2014). However, no such programs exist in the regional community of interest in this research (Erie County, 2018). To develop a successful program in the regional community, a foundational in-depth knowledge of key stakeholders' perceptions of wellness programming needs that are unique to this population within the community is essential for programmatic success (Drum et al., 2009). The information gained from this study added to the growing body of knowledge related to the delivery of

wellness services for adults with disabilities and assisted with efforts in the regional community to inform next steps of program development and build a program with lasting results.

In subsequent chapters, further details related to the study are provided. Specifically, Chapter 2 provides a more detailed review of the literature to substantiate the need for the development and implementation of a wellness program for adults with disabilities in the regional community. Chapter 3 reviews the methodology and outlines the specific steps that were utilized during this research process. Results are reviewed in Chapter 4 while main points of discussion related to the implications of the results on further phases of program development are presented in Chapter 5.

CHAPTER 2

LITERATURE REVIEW

Nearly 61 million adults in the United States live with a disability (CDC, 2019; U.S. Census Bureau, 2014). The health status of these individuals is of growing concern due to the increasing prevalence of non-communicable, preventable health conditions, such as obesity and diabetes, and avoidable social determinants of health, such as low income and below average education levels that are common in this population (Krahn et al., 2015). Poor health status, in combination with a lack of access to effective preventative health care services resulted in the formal recognition of the health status of adults with disabilities as a health disparity (Krahn et al., 2015). In turn, many national public health initiatives focused on the development of wellness programming designed specifically for this population. The effectiveness of these programs, particularly those incorporating a comprehensive approach to wellness, on the achievement of a variety of positive health indicators for adults with disabilities is well established with high-quality empirical evidence (Heller et al., 2011; Stuifbergen et al., 2003; Stuifbergen et al., 2010; Young et al., 2015).

However, despite the proven effectiveness of these programs, utilization is limited (Blonski et al., 2014; LaMorte, 2019; McPhail, et al., 2014; NCD, 2019; Rimmer et al., 2014). Further, no wellness programs for adults with disabilities exist in the regional community of interest for this research (Erie County, 2018). Therefore, the overall end goal of this research is to guide the creation of such a program in this local community.

In order to develop a sustainable and effective program, consideration of factors limiting utilization of existing programs throughout the planning process is critical (Drum et al., 2009). Barriers impacting use are largely recognized to be related to factors associated with the

environment, both from an accessibility and interpersonal perspective (Blonski et al., 2014; LaMorte, 2019; McPhail, et al., 2014; NCD, 2019; Rimmer et al., 2014). Further recognized as barriers are items associated with the design of the program itself, such as a failure to account for contextual factors impacting long term program participation and a lack of adherence to best practice guidelines for program development and implementation (Drum et al., 2009; Stuifbergen et al., 2010).

Best practice guidelines for community-based wellness programs for adults with disabilities were established by Drum et al. (2009). These guidelines provided a specific framework for the following three general domains deemed essential for program success: operations, participation, and accessibility (Drum et al., 2009). Additionally, as a key first step, the guidelines outlined the importance of stakeholder involvement at the onset of program planning (Drum et al., 2009). Expanding on the work of social ecological health behavior change theorists (McLeroy et al., 1988), who first described this concept in models for community-level health promotion efforts, the authors stated that the inclusion of the perspectives of key stakeholders in the community during the initial stages of development is of utmost importance for participants' achievement of self-determined, autonomous adoption of positive health behaviors and lasting changes in health (Drum et al., 2009).

Study Purpose

The overarching end goal of this research involves the development of a wellness program for adults with disabilities in the regional community. According to best guidelines for this type of program, engaging key stakeholders within the community at the onset of planning is an essential first step (Drum et al., 2009). In alignment with these recommendations, the purpose of this study was to explore the perspectives of key stakeholders in the community who were

vested in the health and wellness of adults with disabilities to gain insight into wellness programming needs for this population. This information was used to inform subsequent steps of program development and implementation to foster its overall success in the regional community (Drum et al., 2009).

Significance

Health care expenditures related to disability were most recently estimated to approach $400 billion dollars per year (Anderson et al., 2010). This level of cost, in combination with the projected disproportionate growth of the number of adults living with a disability, both nationally and regionally as a result of the aging baby boomer population, draws attention to the urgent nature for the need to develop sustainable and effective wellness programs for this population (NCD, 2012; WHO, 2018). With access to effective wellness services, data suggest that in addition to direct impacts on program participants' measures of quality of life and physical performance, global improvements in the overall state of the community's health and well-being will be seen as well (Stuifbergen et al., 2010).

Conceptual Framework

As defined by Ravitch & Riggan (2016), conceptual frameworks in research are the "overarching arguments for the work-both why it is worth doing and how it should be done" (p. 8). The authors stated that the beginnings of its formation are a function of the researcher's personal interests, which serve as key motivating factors in prompting the inquiry (Ravitch & Riggan, 2016). The authors further suggested that topical research supplements this element as it involves an exhaustive search and critical analysis of the literature to identify what is known and what remains unknown about the topic, which together identify areas that warrant further formal investigation (Ravitch & Riggan, 2016). The authors defined the last element as the theoretical

framework, which serves to additionally inform the conceptual framework by providing foundational information related to the interrelationships of the key variables of interest and a lens by which to analyze these variables (Ravitch & Riggan, 2016).

Upon applying these concepts to this research, it was first important to consider the overarching goal of this research: to develop a community-based wellness program for adults with disabilities. The program is posited to have global impacts on the regional community at large by shifting the overall status of the community's health towards a more positive state of wellbeing (Stuifbergen et al., 2010). This end result directly aligns with personal and professional goals of the researcher. As a physical therapist, the researcher is personally charged with the task of "transforming society by optimizing movement to improve the human experience" (APTA, 2019, para. 1). The researcher is similarly challenged at a professional level as an educator in a physical therapy program for a small, faith based service oriented and community focused institution whose strategic plans include a desire to facilitate transformative change in the local community.

In addition to the researcher's vetted personal interest in the development of a wellness program for adults with disabilities in the regional community and as previously discussed, there is a well-established need for this type of program as a result of the disproportionate rates of preventable health conditions affecting this population, the effectiveness of wellness programs on reversing these preventable health conditions, and the lack of such programming in the regional community for this population (Erie County, 2018; Krahn et al., 2015; Stuifbergen, et al., 2010). Further evidence also defined best practice guidelines providing guidance for how such a program should be built (Drum et al., 2009). In alignment with these guidelines, this study involved the exploration of key community stakeholders' perspectives regarding wellness

programming needs as a first step in the process of the development of a wellness program for adults with disabilities in the regional community.

Theoretical Framework

From a theoretical framework perspective, in order to fully understand the nature and context of the information gleaned from this exploratory study, it was essential to understand theories related to health behavior change and factors that are correlated with the adoption of self-determined behavior. As described by LaMorte (2019), theories of health behavior change began to develop in the 1950s in order to better understand the processes and the elements that impact processes associated with the sustained and autonomous adoption of positive health behaviors. Founded by Brofenbrenner (1977) and expanded upon by McLeroy et al. (1988), the social ecological model (SEM) is one such widely accepted theory of health behavior change. Unlike other models of health behavior change, SEM recognizes the "multifaceted and interactive effects of personal and environmental factors" (CDC, 2009, p. 1) involved in the self - determination of human behavior.

Specifically, SEM theorists recognized that self-determined individual health behaviors were a function of five layers of influence (Brofrenbrenner, 1977; McLeroy et al., 1988). The first level of influence recognized in SEM is the microsystem. This level is described to include intrapersonal factors, such as personal beliefs and values. The second level of influence, known as the mesosystem, is comprised of elements surrounding interpersonal factors, such as the impacts of social networks and support systems on health behavior. Community factors are recognized within the third level, which consists of items related to intra and inter community relationships and coordination. The fourth level, the macrosystem, is made up of elements related to organizational items on a larger scale such as overarching societal and cultural principles.

Policy and regulatory boards are examples of items included in the fifth level of health behavior influence, known as the chronosystem (Brofrenbrenner, 1977; McLeroy et al., 1988).

Utilizing SEM and these related constructs as a lens by which to view the data during the data analysis phase offered critical insight into adults with disabilities' unique wellness programming needs in order to create a successful program in the regional community. In alignment with the work of Brofenbrenner (1977) and McLeroy et al. (1988), particular focus was placed on understanding the nature of stakeholders' voiced perspectives and the relationship of these perspectives within the five levels of influence of SEM. Upon considering the implications of shared perspectives and inter relationships with SEM constructs, it became apparent that it will be prudent to consider the influence of multiple layers of contextual factors in subsequent stages of program development and implementation to maximize the program's overall success and sustainability.

Adults with Disabilities: Definition

In order to fully understand the target population of the program, it is important to consider the way in which disability is defined. In 2002, the World Health Organization (WHO) introduced a model for the categorization of health and health conditions in a landmark document known as the International Classification of Functioning, Disability, and Health (ICF) framework. This model, which remains in place today, described disability as the result of interactions of health conditions (that contribute to impairments in body functions, activity, and/or participation) and contextual factors (such as physical and social elements) which in turn, interfere with life experiences (WHO, 2002).

The legal definition of disability as defined by the latest version of the Americans with Disabilities Act and summarized by the Department of Justice (DOJ, 2009) expanded on this

perspective and formally recognized an individual with a disability "as a person who has a physical or mental impairment that substantially limits one or more major life activities, a person who has a history or record of such an impairment, or a person who is perceived by others as having such an impairment" (para. 1). Similarities drawn from these definitions supported the importance of contemporary views of disability, which extend beyond the direct impacts of underlying medical conditions, and include the recognition of quality of life elements as defining factors (WHO, 2002; DOJ, 2009).

Adults with Disabilities: Health Status

In order to build a successful wellness program for adults with disabilities in the regional community, it is also important to fully understand the current and overall state of health of these individuals and the unique challenges faced by this population from a health and wellness perspective. In recent years, the health status of adults with disabilities became a grave concern (CDC, 2015; Krahn et al., 2015; WHO, 2018). Findings from both self-reported research and formal scientific inquiries documented that when compared to non-disabled peers, adults with disabilities have increased rates of co-morbidities, increased rates of risky health behaviors and reduced levels of physical activity (CDC, 2015; Krahn et al., 2015; WHO, 2018).

For example, compilations of data from national population based surveys including the Behavior Risk Factor Surveillance System, National Health and Examination Survey, and National Organization on Disabilities Survey of Americans with Disabilities as summarized by Krahn et al. (2015) indicated that adults with disabilities were four times more likely to report their health to be fair to poor compared to adults without disability. Additional results revealed that 28.8% of respondents with disabilities were smokers while only 18.0% of those without disabilities were smokers (Krahn et al., 2015). Rates of co-morbidities including cardiovascular

disease and diabetes were also found to be higher among disabled adults, reported at 27.7% and 19.1% compared to non-disabled adults, reported at 9.7% and 6.8%, respectively (Krahn et al., 2015).

Similarly, data related to rates of obesity indicated that rates for adults with disabilities were 11% higher compared to non-disabled adults (Krahn et al., 2015). Rates of physical inactivity below the thresholds as established by the CDC (2018), which include 150 minutes of moderate intensity or 75 minutes vigorous aerobic and strengthening of all major muscle groups two to three days per week, were also found to be significantly less (20%) among disabled adults compared to non-disabled adults (Krahn et al., 2015). Further data summarized by the WHO (2018) also indicated that rates of poor diet and premature death are higher among disabled adults compared to their non-disabled peers.

In addition to the increased prevalence of these conditions, which are related to direct measures of health, findings summarized in the report by Krahn et al. (2015) also indicated that indirect, or social determinants of health, such as those related to economic and social status, shared a similar discrepancy when comparing adults with disabilities to those without disabilities. For example, 13% of adults with a disability had less than a high school education compared to only 9.5% of those without a disability (Krahn et al., 2015). Furthermore, nearly half of adults with a disability lacked access to the internet while only 15% of non-disabled adults lacked such access (Krahn et al., 2015).

Rates of employment were also disproportionally lower among disabled adults as the majority (79%) reported unemployment while only 29% of non-disabled adults reported unemployment (Krahn et al., 2015). Additional results indicated income was significantly less among disabled adults compared to non-disabled adults (Krahn et al., 2015). Specifically, the

rate of those with a household income of less than $15,000 was reported to be 34% for disabled adults compared to 15 % for non-disabled adults (Krahn et al., 2015). Further, adults with disabilities were reported to be 11% more likely to be a victim of a violent crime, 13% less likely to have satisfactory levels of emotional and social support and 18% less likely to have adequate transportation (Krahn et al., 2015).

Adults with Disabilities: Recognition as a Formal Health Disparity

The combined impact of the increased prevalence of both negative direct and indirect factors impacting the health outcomes of adults with disabilities contributed to the recognition of the health status of these individuals as a formal health disparity (Krahn et al., 2015). According to Krahn et al. (2015), a health disparity is defined as a "difference in health outcomes at the population level" (p. S198), which results from preventable and avoidable social, economic, and/or environmental disadvantages (Krahn et al., 2015). Of further significance, epidemiological evidence predicted an alarming disproportionate increase in the magnitude of the health disparity among disabled adults in the upcoming years as a result of the aging baby boomer population (NCD, 2009; WHO, 2009; Mather et al., 2015). These data strengthened the urgency for the development and implementation of sustainable and effective solutions to decrease the discrepancies in health care outcomes for adults with disabilities. These specific strategies are outlined below.

Wellness and Adults with Disabilities: Public Health Initiatives

As a result of the recognition of health related discrepancies among adults with disabilities, improving the health status of these individuals became a major focus of many public health initiatives. Most notably of these was the nationwide initiative launched in 2000 by the Office of Disease Prevention and Health Promotion under the Department of Health and

Human Services known as Healthy People 2010 (DHHS, 2005). This plan outlined goals for health providers to become more knowledgeable about persons with disabilities in order to provide a more holistic and comprehensive approach to their medical care (DHHS, 2005). Additional emphasis was centered on improving the accessibility of health care services for individuals with disabilities; and, for persons with disabilities to promote their own health by maintaining a healthy lifestyle (DHHS, 2005).

This initiative was formally continued into the next decade as Healthy People 2020 (DHHS, 2008). This updated initiative included extensive collaboration with disabled persons to expand the focus on the health and wellness for these individuals (DHHS, 2008). Specifically, new objectives called for the elimination of preventable disease, injury, premature death, and disparities; and, the creation and promotion of healthy environments and behaviors for all individuals, including those with disabilities (DHHS, 2008).

Wellness and Adults with Disabilities: Wellness Defined

In order to better understand the increased emphasis of wellness among disabled adults in these public health initiatives and their application in resulting programming, it was essential to consider how wellness is defined. The World Health Organization (WHO, 2006) proposed the following definition: "the optimal state of health of individuals and groups…with two focal concerns: the realization of the fullest potential of an individual physically, psychologically, socially, spiritually, and economically, and the fulfillment of one's expectation in the family, community, place of worship, workplace and other settings" (p. 5). The American Physical Therapy Association (2009) echoed a similar definition of wellness and stated that wellness is "a state of being that incorporates all facets and dimensions of human existence, including physical health, emotional health, spirituality, and social connectivity" (para. 1). It is important to

recognize that while both of these definitions were formally established a few years apart, both shared a holistic view of wellness, beyond that associated with more traditional physical measures of wellness, such as weight, cholesterol, and resting blood glucose and were inclusive of factors associated with broad measures of quality of life. Of further importance, these holistic definitions served as the foundational basis for many programs which were developed for adults with disabilities. The specific application of the adoption of this holistic view in these programs and the subsequent impact on the health outcomes for this population is expanded upon below.

Effectiveness of Wellness Programs for Adults with Disabilities

As a result of the inclusion of the concept of wellness for adults with disabilities in national public initiatives, many wellness programs were developed specifically for this population. Further, many of the developers and implementers of these programs included a comprehensive approach in program designs as a result of the expanded holistic definition of wellness (Heller et al., 2011; Stuifbergen et al., 2003; Stuifbergen et al., 2010; Young et al., 2015). The effectiveness of these programs is well-established with high quality empirical evidence (Heller et al., 2011; Stuifbergen et al., 2003; Stuifbergen et al., 2010; Young et al., 2015).

Specific study surrounding the effectiveness of comprehensive wellness programming for adults with disabilities began in the early 2000s. One such study was conducted by Stuifbergen et al. (2003). Specifically, these authors conducted a randomized control trial to investigate the effectiveness of a comprehensive wellness program for adults with multiple sclerosis. Participants randomly assigned to participate in the wellness program completed one, 90 minute educational wellness session per week for eight weeks. The educational session topics focused on various aspects of wellness such as stress management, nutrition, exercise, physical activity,

and sexuality. Upon completion of the educational sessions, participants additionally received bimonthly follow up phone calls over a three month period to facilitate the adoption of healthy behaviors into their lifestyle. Compared to participants in the control group (who received no intervention), participants in the wellness program group demonstrated statistically significant improvements in self-efficacy, health-promoting behaviors, and mental health quality of life indicators as well as decreased pain (Stuifbergen et al., 2003).

The effectiveness of comprehensive wellness programs for adults with disabilities is also supported by synthesized forms of evidence. For example, in a review of wellness programs for adults with disabilities conducted by Stuifbergen et al. (2010), 190 studies were included. The focus of the review was to gain a broad perspective of the benefits of wellness programs for a variety of chronic, disabling conditions including arthritis, cancer, heart failure, stroke, HIV and other cardiovascular conditions among others. Of the 42 studies that included a comprehensive approach, all reported positive treatment effects as measured by participants' improvements on self-report, physical, and/or biologic measures whereas those that included a single mode approach demonstrated inconsistent effects on similar measures (Stuifbergen et al., 2010).

Heller et al. (2011) also completed a review of the literature related to the effectiveness of wellness programming for adults with disabilities; however, the scope of the study was limited to those with intellectual disabilities. The specific purpose of the study was to investigate the effects of comprehensive wellness programs focused on exercise and nutrition compared to programs focused on exercise alone for adults with intellectual disabilities. Consistent with previous research, the results, which included the synthesis of data from 11 articles, indicated that participants who completed programs offering a more comprehensive approach to wellness

demonstrated statistically significant improvements on wellness measures compared to those who participated in exercise only programs (Heller et al., 2011).

More recently, a study conducted by Young et al. (2015) investigated the effects of an individualized wellness program incorporating a comprehensive and holistic approach including aspects of both exercise and nutrition for 15 adults with disabilities. Conditions among participants varied and included those with cerebral palsy, intellectual disability, Down syndrome, stroke, knee replacement, spinal cord injury and peripheral arterial disease. Participants of the program, which consisted of 60 - minute sessions delivered three times per week for three months, demonstrated positive treatment effects with reductions in body mass index and improvements on a variety of individualized fitness measures (Young et al., 2015). These results supported previously completed research indicating the superiority of a comprehensive approach to wellness for adults with disabilities as compared to single modality programs focused on exercise and its impact on physical measures alone.

Overall, the compilation of this evidence strengthened the support for the need of the development and implementation of a wellness program for adults with disabilities in the regional community. Specifically, the results of this evidence overwhelmingly suggest that to be effective, the program should utilize a comprehensive, holistic approach. Incorporating the results of this evidence with this study's findings, which was focused on gaining an in-depth understanding of key community stakeholders' perspectives regarding wellness programming needs for adults with disabilities in the regional community, will be key for the program's overall success.

Limitations of Wellness Programs for Adults with Disabilities

Despite the well-defined need for wellness programming for adults with disabilities and the established efficacy of such programs, specifically those that focus on a comprehensive approach, wellness programs for this population are largely underutilized (Blonski et al., 2014; Drum et al., 2009; Heller et al., 2003; LaMorte, 2019; McPhail et al., 2014; NCD, 2019; Rimmer et al., 2014). Further, wellness programs for this population are non-existent in the regional community of interest of this study (Erie County, 2018). In order to develop a sustainable program, factors that have impacted utilization of existing programs must be considered (Stuifbergen, et al., 2010). These factors have primarily involved elements associated with the environment, both from an accessibility and interpersonal perspective, limitations with program design, and a lack of adherence to best practice guidelines throughout the development and implementation process (Blonski et al., 2014; Drum et al., 2009; Heller et al., 2003; LaMorte, 2019; McPhail et al., 2014; NCD, 2019; Rimmer et al., 2014).

Environment

Specific environmental barriers cited by adults with disabilities that impact participation in wellness programs have included items related to accessibility, both from a physical and financial perspective, as well as an interpersonal perspective. For example, in a study completed by Heller et al. (2003), 44 individuals with Down syndrome and their caregivers were surveyed to identify barriers to community based exercise participation. The results revealed that environmental barriers related to the external environment of community based exercise facilities were a primary factor impacting respondents' participation in an exercise program.

Similar findings were demonstrated in an investigation completed by the NCD (2009). In the report, data were synthesized from literature reviews and interviews from 23 subject matter

experts and 20 key informants which included but were not limited to health and fitness professionals as well as adults with disabilities. Results indicated that specific environmental barriers of community based exercise programs for women with disabilities and adults with vision impairments included inaccessibility, both from an internal and external physical environment perspective.

Results from a study conducted by Rimmer et al. (2008) additionally found that cost was also a significant barrier impacting disabled adults' accessibility and participation in community wellness programs. The study specifically surveyed 83 individuals' status post stroke. The results indicated that 61% of respondents reported that cost was the most significant barrier to accessing and participating in available wellness programming. These concerns were further confirmed in investigations by McPhail et al. (2014) and Blonski et al. (2014) for adults with musculoskeletal related disability and post stroke aphasia, respectively.

McPhail et al. (2014) offered further insight into barriers prohibiting adults with disabilities from participating in wellness programming as it relates to accessibility. The authors surveyed a total of 112 adults with a disability stemming from a variety of musculoskeletal conditions primarily involving low back and shoulder conditions. Two specific, open-ended survey questions inquired about barriers and facilitators of participation in wellness programs. Data analyses from these questions revealed that, in addition to cost, the majority of participants agreed that travel time to get to and from available wellness programs was perceived as a significant barrier (McPhail et al., 2014).

Similar results, defining transportation related elements as a barrier, were also found in a study completed by Blonski et al. (2014). Like Rimmer et al. (2008), Blonski et al.'s (2014) investigation also explored barriers for participation in wellness programs for adults' status post

stroke. However, unlike Rimmer et al. (2008), Blonski et al. (2014) specifically included

participants with post stroke aphasia. Data analyses confirmed that for this population, like other

populations of adults with disabilities, a common theme among participants related to barriers for

participation in wellness programs were related to transportation. Many participants reported that

long travel times associated with inefficient and unreliable public transportation were of

particular concern (Blonski et al., 2014).

     In addition to these internal and external environmental related barriers, factors

associated with the intrapersonal and interpersonal aspects of the environment of wellness

programs were also demonstrated to impact program utilization among adults with disabilities.

For example, results of the study conducted by McPhail et al. (2014) indicated that in addition to

cost and transportation, a lack of motivation was also a common barrier impacting wellness

program participation among those with musculoskeletal related disabilities. Similar reports of a

lack of motivation as a primary barrier to wellness program participation were also found in the

aforementioned study by Rimmer et al. (2008). Of further importance, additional findings of this

study indicated that 25% of the survey respondents felt uncomfortable in a fitness facility while

others (36%) stated they did not feel exercise would help them (Rimmer et al., 2008). Concerns

related to communication were also cited as a barrier among those with post stroke aphasia and

hearing impairments (Blonski et al., 2014; NCD, 2009). Specifically, reports of exercise

instructors talking too quickly or being impatient were found to be the most significant primary

barrier for participation in wellness programs by those with post stroke aphasia (Blonski et al.

2014).

Program Design

Other factors limiting program utilization and recognized to be a barrier to participation involved elements within program design. One such limitation cited by Stuifbergen et al. (2010) and Heller et al. (2011) related to a lack of inclusion of a theoretical framework. Historic models of health behavioral change theory clearly recognized the importance of long term tracking in order to determine that an actual change in behavior had occurred as a result of participation in a wellness program (LaMorte, 2019). However, Stuifbergen's et al. (2010) review of 190 articles investigating the effectiveness of wellness programs utilized by a wide range of disabled adult populations indicated that 76% of program designs were not informed by theory. The results further indicated that the majority of the programs included in the review did not track outcomes past the intervention period. Heller et al. (2011) echoed similar limitations in a review of 11 wellness programs specifically for adults with intellectual disabilities. Due to the lack of inclusion of long term tracking, long term adherence and sustained health effects from short term participation remain unknown and as such, is recognized as a significant limitation for long program utilization (LaMorte, 2019).

Other limitations reported by Stuifbergen et al. (2010) and Heller et al. (2011) related to program design included a lack of consideration for contextual factors associated with program participation. As noted by Shogren (2013), many of the factors recognized in the SEM ultimately impact self-determined and autonomous, sustained adoption of positive health behaviors. However, of the combined 190 wellness programs reviewed by Stuifbergen et al. (2010) and Heller et al. (2011), no programs accounted for these factors in the program design.

Lack of Adherence to Best Practice Guidelines

Another major limitation related to existing wellness programs for adults with disabilities as cited by Stuifbergen et al. (2010) was a lack of adherence to best practice guidelines throughout the development and implementation processes associated with such programs. A systematic approach for the development and implementation of community-based wellness programs outlining best practice guidelines for the general population was developed by Shediac-Riskallah & Bone (1998) and subsequently expanded upon by Drum et al. (2009) to include adults with disabilities. While the results of Stuifbergen et al.'s (2010) investigation indicated that a few of the 190 programs included in the study did incorporate these best practice guidelines in part, none of them fully adhered to the recommendations.

As first outlined by Shediac-Riskallah (1998), when developing and implementing a community based wellness program, participation of key stakeholders is essential to maximize sustainability. The authors specifically stated that "change is more likely to occur when the people it affects are involved in the change process" (p. 95). In 2009, Drum et al. utilized an expert panel to expand on these guidelines and develop a model to create sustainable community-based health programs specifically for adults with disabilities. In alignment with Shediac-Riskalllah & Bone (1998), the updated guidelines emphasized the importance of the use of an underlying evidence based theoretical model for behavioral change and the inclusion of key stakeholders at the onset of program planning and throughout the implementation process to assist in maximizing its overall success (Drum et al., 2009).

Rimmer et al. (2014) reinforced these concepts as part of best practice guidelines for adapting existing programs for adults with disabilities. The framework became known as known as Guidelines, Recommendations, Adaptations Including Disability or GRAIDs (Rimmer et al.,

2014). GRAIDS specifically recommended the use of focus groups with key stakeholders, such as working professionals with expertise in disability and health and other content experts as well as adults with disabilities, as part of an ongoing process for the development and implementation of wellness programs for this population.

In addition to incorporating evidence-based recommendations for the inclusion of a comprehensive approach to wellness in the regional program's design, it will also be essential to consider these recognized barriers throughout the process of program development and implementation. Specifically, incorporating the implications of these known barriers with the results of this study (which provided insight into key stakeholders' perspectives of wellness programming needs for adults with disabilities in the regional community) at the onset of planning will maximize the overall utilization of the program and facilitate long term programmatic success.

Conclusion

In summary, there is a well-established need for a wellness program for adults with disabilities in the regional community (Erie County, 2018; Krahn et al., 2015; Stuifbergen et al., 2010). As highlighted in the framework embedded in the best practice guidelines for the development and implementation of such a program, it is essential to involve key stakeholders at the onset of program planning to maximize programmatic success (Drum et al., 2009; Rimmer et al., 2014). In alignment with these recommendations, as a first step in the development of a wellness program for adults with disabilities in the regional community, the purpose of this research was to gain an in-depth understanding of the wellness programming needs from the perspectives of key stakeholders vested in the health and wellness of this population within the local community. Chapter 3 will detail the specific methodology which guided this process.

Chapter 4 and Chapter 5 will present the themes which were identified related to these

perspectives, and further discuss the implications of these perspectives on subsequent stages of

program development and implementation to build a program with lasting effects, respectively

(Drum et al., 2009; LaMorte, 2019).

CHAPTER 3

METHODOLOGY

The overarching goal of this research is to guide the development of a wellness program for adults with disabilities in the regional community. According to best practice guidelines for this type of program, engaging key stakeholders in the community at the onset of planning to gain insight into wellness programming needs for this population is an essential first step (Drum et al., 2009). By first understanding these perspectives, and subsequently incorporating these elements into the foundational underpinnings of the program's future design, the program's sustainability and success will be maximized (Drum et al., 2009).

In alignment with these recommendations, the purpose of this study was to explore the views of key community stakeholders to gain an in-depth understanding of their perceptions of wellness programming needs for adults with disabilities in the regional community. Specifically, this research sought to answer the following central questions:

- RQ 1: How do key stakeholders within the regional community characterize barriers and facilitators to wellness programming access for adults with disabilities?

- RQ 2: How do key stakeholders' perspectives of barriers and facilitators to wellness programming access impact wellness program design for adults with disabilities?

The findings of this study informed next steps in the process toward the development of a successful wellness program for adults with disabilities in the regional community.

Due to the exploratory design of this research, a qualitative methodology was employed (Creswell, 2017). To gain a holistic and comprehensive view of key stakeholders' perceptions of wellness program needs, diverse groups of key stakeholders within the regional community were recruited for inclusion. As cited by Creswell (2017), acquiring diverse and varied perspectives

served to enhance the overall quality of this research. Additionally, gaining a diverse, holistic view of key stakeholders' perceptions related to needed program elements and subsequently, applying these varied views into the program's design, will enhance its overall success (Drum et al., 2009).

Setting

The regional community of interest in the study is a small, urban community in Northwestern Pennsylvania. According to the most recent census data, the total population of this community was 97,639 (Onboard Informatics, 2020). Collective data reports also indicated that the rates of direct health measures among individuals in this community, such as obesity, diabetes, high cholesterol, and high blood pressure, as well as rates of indirect health measures, such as low income, poor nutrition, and low education levels, were below both state and national averages (Onboard Informatics, 2020). Further reports indicated that nearly 40,000 of those living in this community also have a disability (Onboard Informatics, 2020; University of New Hampshire, 2020). Therefore, this specific region was chosen not only due to its accessibility to the researcher, but also due to these demographic characteristics, which support the need for a wellness program for adults with disabilities within its regional limits.

Participants/Sampling

Key stakeholders within the regional community served as the primary study participants. For the purposes of this research, key stakeholders were defined as working professionals in the regional community who had a vested interest in the health and wellness of adults with disabilities and whose professional role involved direct interactions with adults with disabilities within the realm of health and wellness. Specifically, this included rehabilitation personnel (i.e. physical therapists [PTs], occupational therapists [OTs]), social workers, fitness professionals,

and members of community organizations/groups who were involved with health and wellness services specifically for adults with disabilities. These specific types of key stakeholders were utilized due to their diverse and well-established roles in maximizing adults with disabilities capacities for health (International Federation of Social Workers [IFSW], 2012; Super, Kaschak, & Blair, 2018; WHO, 2018).

Ultimately, the final sample size was comprised of eight participants (two social workers, one fitness professional, three community organization members, and two occupational therapists). To recruit these individuals, a variety of sampling strategies were employed. First, non-random, maximum purposeful sampling was initially utilized to specifically recruit primary study participants within each stakeholder group. Due to the researcher's role as a physical therapist, relationships with key individuals who work in these varied capacities are well-established and were utilized to purposefully locate participants positioned to provide information-rich data for the study. Therefore, recruitment began with these individuals. Snowballing was used next. This specifically involved asking initial study participants to refer other potential study participants who "exemplified the characteristics of interest in the study" (Merriam, 2015, p. 79). As suggested by Merriam (2015), this technique fostered the acquisition of additional information rich sources of data, and assisted with the overall methodological quality of the study (Creswell, 2017).

To maximize the alignment of each working professional's experience and role with the study's purpose, the following served as inclusion criteria: 1) self-verification that current role involved direct interactions with adults with disabilities related to the status of their overall health and wellness, and 2) self-verification of at least three years of experience in respective role. The working professional was also asked to explain his/her specific role in further detail to

ensure that maximum sampling was employed and no more than three participants functioned in the same capacity within the realm of health and wellness for adults with disabilities. For transparency, and due to the potential for pre-existing professional relationships with some of the study participants and the researcher, the study participants were also asked to fully disclose the nature of any such pre-existing professional relationship during the interview.

Data Collection

To obtain in-depth insight into key community stakeholders' perspectives related to wellness programming needs for adults with disabilities in the regional community, interviews served as the primary data source. With consent, semi-structured interviews were completed with working professionals in the regional community who had direct interactions with adults with disabilities within the realm of health and wellness. Specifically, rehabilitation personnel, social workers, fitness professionals, and members of community organizations/groups who cater to adults with disabilities were recruited by the researcher. The semi-structured interview protocol is outlined in Appendix A.

Consistent with recommendations by Creswell (2017), the interview was completed in each interviewee's natural setting, at a location of his/her choosing. Each interview lasted roughly one hour and with permission, was recorded with an audio recorder. In alignment with Merriam's (2009) recommendation, part one of the interview included a demographic survey regarding questions related to the interviewees' age, occupation, and self-verification of inclusion criteria. Once inclusion criteria were verified, part two was completed. This part of the interview contained open-ended questions to explore study participants' perspectives on wellness programming needs for adults with disabilities in the regional community.

Data Analysis: Interviews

Interviews with key stakeholders in the regional community who had direct roles associated with the health and wellness sector for adults with disabilities served as the primary data source for this research. In order to adequately prepare the data for analysis, each interview was first transcribed into an easy to read format (Creswell, 2017). Next, the process of member checking was completed. As described by Creswell (2017), this involved sending each interviewee their respective transcription to provide verification and seal of approval for use in the study. Upon receipt of approval for use, the researcher read each transcription repeatedly in order to "get a sense of the interview as a whole" (p. 183). As this step was completed, memos were utilized to represent short phrases or concepts to assist the researcher in clearly "seeing what the interviewees said" (p. 184). For ease of reference, these memos were written in the margins of each transcription.

After these initial verification and organizational steps were completed, the next phase of data analysis commenced. This involved examining the data and reducing it into smaller categories of information (Creswell, 2017). First, each transcription was specifically coded in order to tentatively group the data based on their categorical similarities. In alignment with Creswell's (2017) recommendation, no more than 25-30 initial codes for each transcription were identified. Each code was labeled by the researcher to assist with the overall organization of the data at this stage in the process. Labels were formed by the researcher to purposefully represent and describe the associated information for each code (Creswell, 2017).

The codes for each transcription were further analyzed for patterns and ultimately condensed into five to six themes (Creswell, 2017). To assist with the organizational process at this stage, themes were represented in a table format. Subsequent cross transcription analysis was

completed to triangulate the data and determine the level of "replicative relationships" within stakeholder groups (Yin, 2018, p. 196). Emerging patterns and relationships across stakeholder groups were additionally identified, coded, triangulated, and inserted into the table.

Lastly, and as described by Yin (2018), to further reduce the data, the codes were thoroughly examined to identify themes with broad applicability on higher conceptual planes. To aid in the identification of these broad themes, the data were viewed through the lens of the constructs associated with Social Ecological Model (SEM). This model, when applied to the concept of health and wellness, as described in Chapter 2, posits that multiple contextual factors across a variety of sociocultural levels influence health behaviors (McLeroy et al., 1988). Utilizing this model as a framework during this stage fostered a richer analytical process. Specifically, it assisted the researcher in gaining an in-depth understanding into the foundational elements which underlie key stakeholders' shared perspectives as they relate to wellness programming needs for adults with disabilities. Ultimately, this information was utilized to determine the implications of the findings on subsequent steps of program development and implementation to maximize the program's overall success (Drum et al., 2009).

Data Analysis: Demographics

Demographic information collected during part one of the interview protocol was represented numerically. Specifically, as described by Yin (2018), tabular formats were utilized to present these data. Professional role was represented with nominal data while age and years of experience was represented with ratio level data. Narrative descriptions accompanied these tabular numerical summaries to further illustrate the characteristics of primary study participants and enhance the overall context of the study.

Potential Limitations

Limitations are an inherent part of any research study (Creswell, 1994). As succinctly described by Creswell (1994), a limitation is a "potential weakness of the study" (p. 110). Limitations, or weaknesses, related to this specific study from a methodology perspective are summarized in this section. Subsequent strategies which were used to minimize the impact of these issues are also addressed.

Sample Number Selection

Creswell (2017) cites that a challenge innate to qualitative design lies within the researcher's determination of the number of participants for inclusion in the study. To assist with sample size determination, the researcher used the literature to identify the specific types of key stakeholders which would provide the most information rich data for the purposes of this study. The resultant search revealed that rehabilitation therapists, social workers, fitness professionals and community organization/group members, would yield the best data for the purposes of the study based on their respective vested interests in the health and wellness of adults with disabilities (International Federation of Social Workers [IFSW], 2012; Super, Kaschak, & Blair, 2018; World Health Organization [WHO], 2018). Therefore, these specific groups of stakeholders were chosen for inclusion in the study. This ultimately resulted in a total sample size of eight participants, which is further consistent with Creswell's (2017) recommendation.

Credibility

More generally, Creswell (2017) and Yin (2018) further assert that credibility, also known as the degree of truthfulness, is often questioned with qualitative research. In accordance with best practice guidelines and to enhance the study's overall credibility, the proposed semi-

structured interview protocol was field-tested prior to formal use (Dikko, 2016; Yin, 2018). This process specifically involved testing the interview protocol with two participants who shared similar characteristics to those who were recruited for the main study (Yin, 2018). Minor revisions to enhance the organizational flow were identified during this process and subsequently integrated into the final interview protocol in advance of the formal research process to maximize its overall quality (Dikko, 2016; Kvale, 2007).

Transferability

Creswell (2017) further describes that an additional inherent limitation of a qualitative design is its overall transferability. Transferability refers to the ability of research findings to be relatable to a broad set of applications external to the primary elements of interest in the study (Domholdt, 2005). However, Yin (2018) and Merriam (2015) cite that when using a diverse sample, as was the case in this research, the study's transferability was enhanced.

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Ethical Issues

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Ethical issues are an inherent part of any research process (Creswell, 2017; Yin, 2018). To ensure maximal adherence of research guidelines, identification of ethical issues by the researcher specific to the study of interest is of utmost importance (Creswell, 2017). Additionally, a description of strategies to minimize the impact of these ethical concerns is required (Creswell, 2017, Yin, 2018). In alignment with these recommendations, this section outlines the major ethical concerns involved in this research and describes strategies that were employed to maintain the utmost compliance with ethical standards.

Participant Rights

Ethical issues common to the research process involve participants' rights (Creswell, 2017; Yin, 2018). The researcher's due diligence to ensure participants remain protected

throughout all stages was an integral part of the research process (Yin, 2018). In an effort to ensure participants' rights are upheld, all study participants were provided with an informed consent form (see Appendix C) in writing commensurate to their role. This document clearly conveyed to participants that their participation was on a voluntary and confidential basis. It also explained the purpose of the study and provided further context for what was expected in their role as a study participant. This document also explicitly communicated to participants that they were able to discontinue their participation in the study at any time at their discretion.

Participant Privacy and Confidentiality

Maintaining participant privacy and confidentiality is an additional essential component of the research process (Creswell, 2017; Yin, 2018). To protect primary study participants' confidentiality and privacy, each primary participant was assigned an identification number. Until participant assignments were finalized, the participant assignment key was secured in the researcher's office, contained within a locked file cabinet. Once participant assignments were completed, the assignment key was shredded for an additional layer of confidentiality protection.

Researcher Bias

Because the researcher assumes the role of the research instrument in qualitative inquiries, insertion of researcher bias is a major ethical concern (Creswell, 2017). More specific to this research project is the researcher's role as a physical therapist who is well versed and personally vested in the health and wellness sector for adults with disabilities. It was therefore essential for the researcher to make every effort to minimize the impact of researcher bias throughout all stages of the research process.

One such strategy that was utilized to minimize the impact of researcher bias occurred during the data collection process. As specifically suggested by Creswell (2017), the researcher

avoided the use of leading questions and withheld personal impressions. Another strategy, known as member checking, was used during the data analysis phase of the research. During this specific phase, Yin (2018) notes that researcher bias can be inserted into the process due to the researcher's potential to "disregard some of the interviewee's words in an interview…because they did not fit…preconceptions" (p. 86). To limit the potential impact of researcher bias in this way, upon transcription, the process of member checking was employed. This specifically involved interviewees' verification of transcription accuracy and seal of approval for inclusion in the study (Creswell, 2017). Additionally, the use of triangulation involving the verification of results within and among stakeholder groups, external audit through peer review, and the representation of data with thick, rich description collectively further served to enhance objectivity and minimize bias.

Conclusion

The overall end goal of this research is to guide the development a wellness program for adults with disabilities in the regional community with lasting results. As a recommended first step in this process, this research specifically involved the exploration of key community stakeholders' perspectives to gain an in-depth understanding of elements deemed essential for inclusion in the program design. In alignment with this purpose, this chapter outlined the steps for the study's methodology. As illustrated, an evidence-based systematic approach was utilized to ensure the utmost adherence to quality measures and ethical guidelines. The findings of the study and the implications of the results are reported in subsequent chapters.

CHAPTER FOUR

RESULTS

The purpose of this qualitative study was to explore the views of key community stakeholders to gain an in-depth understanding of their perceptions of wellness programming needs for adults with disabilities in the regional community. Specifically, this research sought to answer the following central questions:

- RQ 1: How do key stakeholders within the regional community characterize barriers and facilitators to wellness programming access for adults with disabilities?

- RQ 2: How do key stakeholders' perspectives of barriers and facilitators to wellness programming access impact wellness program design for adults with disabilities?

This chapter provides a detailed description of the participant sample, briefly reviews the methodology, and summarizes the thematic results.

Study Participants/Sampling

The study participants were comprised of working professionals in the regional community who had a vested interest in the health and wellness of adults with disabilities and whose professional role involved direct interactions with adults with disabilities within the realm of health and wellness. Specifically, the participants represented rehabilitation personnel (i.e. physical therapists [PTs], occupational therapists [OTs]), social workers, fitness professionals, and members of community organizations/groups who were involved with health and wellness services specifically for adults with disabilities. These specific types of key stakeholder groups were selected a priori due to their diverse and well established roles in maximizing adults with disabilities capacities for health (International Federation of Social Workers [IFSW], 2012; Super, Kaschak, & Blair, 2018; WHO, 2018).

Initial participant recruitment involved non-random, maximum purposeful sampling of working professionals who were representative of the above stakeholder groups. Snowball sampling was subsequently utilized to locate additional information-rich sources of data. The final sample included eight working professionals: two social workers, one fitness professional, three members of community organizations, and two occupational therapists (OTs). The study participant demographic data are summarized in Table 1.

Table 1

Participant Demographics

Participant	Professional Role	Code	Age	Years of Experience
#1	Social worker	SW1	42	10
#2	Fitness professional	FP	32	2.5
#3	Community organization member	COM1	49	11
#4	Social worker	SW2	50	11
#5	Occupational therapist	OT1	35	3.5
#6	Community organization member	COM2	45	15
#7	Occupational therapist	OT2	47	11
#8	Community organization member	COM3	37	6

Methodology: A Brief Review

Upon receipt of informed consent, semi–structured interviews were completed with study participants to obtain in-depth insight into their perspectives related to wellness programming needs for adults with disabilities in the regional community. In order to maximize the credibility of the overall study, the semi-structured interview protocol was field tested prior to formal use. Specifically, two participants who shared similar characteristics of those included in the main study were recruited to provide feedback on the protocol. Minor revisions of the demographic section were recommended to enhance the overall flow of the protocol. These revisions were incorporated into the final semi-structured interview protocol, which is outlined in Appendix A.

The interviews were recorded and lasted about an hour each. The interviews were subsequently transcribed in order to prepare the data for analysis. To ensure transcription accuracy and minimize the potential of researcher bias, the process of member checking was utilized. This involved sending copies of the transcriptions to study participants for review and to provide a seal of approval for formal use in the data analysis process. No revisions were requested and each transcription was approved for the data analysis phase by each study participant.

As recommended by Creswell (2017), the first phase of data analysis involved multiple reads of each transcript and the creation of memos written in the margins in order to create meaning and context around the responses as they related to the research questions. The second phase involved completion of the open coding process for each transcription. During this phase, data were grouped based on categorical similarities and alignment to barriers or facilitators to wellness programming for adults with disabilities. Triangulation through cross-transcription analysis was subsequently completed to determine emerging patterns and subthemes, first from within stakeholder groups and across stakeholder groups. Sub-themes were further analyzed and reduced into main themes, with broader applicability on a higher conceptual plane as suggested by Yin (2018). The Social Ecological Model (SEM) was utilized at this stage as a framework to foster a richer, deeper analysis. The details of the results are presented in the next section.

Data Analysis: Results

No differences emerged within or between stakeholder groups throughout the stages of the data analysis process. Ultimately, three main themes were identified for barriers to wellness programming for adults with disabilities while two main themes were identified for facilitators. These results are further explained and expanded upon in the following subsections. Of note, the

application of the Social Ecological Model (SEM) and verification strategies which were utilized
are first presented to provide further context for this discussion.

Application of Social Ecological Model (SEM)

The results were viewed through the lens of the social ecological model (SEM), a health
behavior change theory, developed in the 1950's. It was founded by Brofenbrenner (1977) and
expanded upon by McLeroy et al. (1988) to better understand the processes and the elements that
impact processes associated with the sustained and autonomous adoption of positive health
behaviors. It remains one of the widely accepted theories of health behavior change today.
Unlike other models of health behavior change, SEM recognized the "multifaceted and
interactive effects of personal and environmental factors" (CDC, 2009, p. 1) involved in the self
determination of human behavior. Specifically, SEM theorists recognized self-determined
individual health behaviors were a function of five layers of influence associated with
intrapersonal, interpersonal, community, societal, and political factors, respectively.

Upon considering the main themes and subthemes related to barriers and facilitators of
wellness programming for adults with disabilities with the SEM, it is important to recognize that
there is clear alignment across all five layers of influence. The details of the results, which
include information rich textual data to illustrate this alignment, are presented below.

Verification Strategies

It is also important to recognize that as the discussion outlining the details of these results
proceeds, many strategies, in addition to member checking, were utilized for verification.
Triangulating the data within and across stakeholder groups throughout the data analysis process
served this purpose through the use of confirmation via multiple data sources. The use of
information rich textual data and detailed descriptions of the data for each theme and subtheme

further functioned to maximize the confirmability of the results. External auditing involving

extensive peer review was also utilized throughout all stages of the research to further enhance

confirmability.

Wellness Programming Barriers

This section presents the results for barriers to wellness programming for adults with

disabilities in the regional community. As demonstrated in Table 2: Data Analysis Coding

Overview – Barriers, eleven codes were identified, from which six subthemes emerged. Upon

further analysis, three main themes were identified: accessibility, community factors, and

political factors. Appendix C: Tabular Representation of Barriers to Wellness Programming

Access provides an overview of the textual data to support each of these areas. This section

details each main theme and corresponding subthemes.

Table 2

Data Analysis Coding Overview – Barriers

Codes	Subthemes	Main Themes
Weather Transportation – Inconvenient	External Environment Factors	Accessibility
Inaccessible Facility – Layout Limited Adaptability of Program/Equipment	Internal Environment Factors	
Lack of Motivation Lack of Financial Resources - Transportation	Intrapersonal Factors	
Unknowledgeable staff Interpersonal Environment	Interpersonal Factors	
Lack of Community Support Lack of Community awareness	Limited Community Network	Community Factors
Lack of Policy Support	Limited Political Support	Political Factors

Accessibility

Accessibility emerged as a main theme from barriers related to wellness programming for

adults with disabilities. Four subthemes were further identified within this category and included

factors related to the external and internal environment as well as elements associated with intra- and interpersonal factors. Each of these are discussed in the subsections below.

External Environment Factors. External environment factors impacting accessibility emerged as a subtheme for barriers to wellness programming. Three participants (FP, SW2, OT2) specifically detailed the impact of inclement weather as a barrier within this subtheme. All three of these participants agreed that living in an area known for its extended and harsh winter season is of particular significance in this regard. For example, SW2 noted, "Getting people here, especially when you in live in [community name]. You're looking at weather. So when you talk about November through March, getting the amount of people here to do some of the activities…is quite difficult." FP further stated, "Of course, because we provide our class throughout the year, the winter months are a barrier." Issues surrounding safety during periods of inclement weather was also deemed to be an associated factor for this subtheme.

Factors associated with the public accessible transportation system were additionally identified as a significant barrier to wellness programming access within this subtheme. Five participants (SW1, FP, SW2, OT1, COM3) described high levels of frustration and dissatisfaction with the reliability and efficiency of the specific public transportation system available to adults with disabilities in the regional community. SW1 specifically stated "Time-wise, there can be delays with [public accessible transportation] and there's inconvenient windows, you have to be ready in this window and we can come get you in this other 45 minute window." COM3 further commented on the issues with the accessible public transportation system as illustrated in the following statement:

> I will say the individuals I work with that have visual impairment; they ride the [public accessible transportation]. And it's a mixed bag of comments. I mean, I'll just give you an

example. I have a 70-year-old woman who comes here, completely without vision, comes on the [public accessible transportation]. Her class starts at 4:00, but a window of time could be an hour. So, sometimes she's waiting an hour to start class and then sometimes she's waiting an hour after class. So, that in itself is a huge inconvenience for someone just trying to take care of their health. So, what should only take them an hour, it's taking up three hours of their day due to the transportation system.

The remaining three participants (FP, SW2, OT1) shared similar dissatisfaction with the inefficiencies of the public accessible transportation system and felt strongly that it alone serves as a significant barrier to wellness programming access for this population.

Internal Environment Factors. A subtheme was also discovered related to accessibility barriers to wellness programming in the form of internal environment factors. Items such as an inaccessible facility layout (described by SW1, FP, COM1, SW2, OT1) and limited equipment adaptability (described by SW1 and COM3) specifically emerged in this area. COM1 described significant frustration in this regard in a great amount of detail upon attempting to locate an accessible facility in the regional community for a wellness program for adults with disabilities:

We toured a lot of places in [community] and many places were offered to us saying that they were ADA compliant and they were absolutely either not or they must have been really, really loose with their interpretation. A perfect example would be we went to a facility where the handicap parking was at one end of the parking lot. The ramp access was at the other end of that parking lot, so the people had to get out of there if they wanted to use the handicapped accessible parking. They would then have to walk a decent distance to get into the building if they chose to use the ramp and not use the couple of steps. Those weren't huge steps, but again, for someone with a walker, that

would have been a big challenge. Then once they got into the building, if they wanted to

access the elevator to get to the room that they were showing us, which was in the

basement, they would've had to go, you guessed it to the other end of the building from

where they entered to get to the elevator and then take the elevator down one floor and

go, you guessed it, it back to the other end of the building.

SW1 further shared that in her experience, "People don't have adaptable equipment at their

gyms," and COM3 stated, "The curriculum being adaptable is very troublesome…So, I think

program adaptability can be a big setback." The remaining participants' (FP, SW2, OT1)

perceptions reflected similar findings, supporting the subtheme of inaccessibility from an internal

environment perspective as a barrier to wellness programming access for adults with disabilities.

Intrapersonal Factors. Factors associated with intrapersonal elements also emerged as a

subtheme related to accessibility barriers for wellness programming for this population.

Specifically, four participants (SW1, COM1, SW2, COM3) reported that intrinsic motivation is a

significant barrier for adults with disabilities. This is best illustrated by SW1 who stated, "It's

already hard enough to motivate yourself to go to the gym without any barriers…When you're

talking about a whole population with all these limitations, fitness, it's an even bigger struggle

than the average person." COM3 also provided further insight in this regard, sharing that

personal circumstances of adults with disabilities often result in these individuals being in

"survival mode." This participant further described that because most are barely able to make

ends meet, their motivation for prioritizing their health is subsequently and frequently, negatively

impacted.

A lack of financial resources, specifically for transportation, also emerged as an element

for this subtheme. SW1 shared that the majority of their program participants are on fixed

incomes and as a result, paying "for transportation is not in the cards for them." COM3 further described that although the cost for public accessible transportation is low, "something like $2 per trip," it can be a huge burden for some individuals. OT2 went on to state that in attempt to offset the cost of transportation, often individuals attempt to rideshare if they have the means; however, this participant further elaborated that the majority of individuals are unable to do so and end up having to use public transportation or personally hire transportation to attend their class. When viewed collectively, these issues, surrounding intrapersonal factors, and their emergence as a subtheme for barriers limiting overall program accessibility, is clearly illustrated.

Interpersonal Factors. Interpersonal factors were also found to be a significant barrier to wellness programming access for adults with disabilities. Items within this subtheme were largely related to unknowledgeable program staff and the nature of the interpersonal environment of the program. Specifically, five participants (SW1, FP, COM1, OT1, COM2) stated that the knowledge of the staff was a significant barrier to wellness programming. This was described as a lack of willingness to work with adults with disabilities as well as a lack of understanding and inability to relate to an adult with disability as a "human being" as noted by FP. COM2 went on to acknowledge that it takes a "certain type of person" to work with this population and that finding staff proves, at times, to be a difficult task.

From an interpersonal environment perspective, three participants (SW1, COM1, OT1) described that often adults with disabilities lack a sense of belonging in traditional wellness settings, which further serves as a barrier. For example, SW1 shared that she has seen nondisabled adults interrupting the workout of disabled persons to tell them, "You're such an inspiration…but you don't go up to anybody else at the gym who's running super-fast on the treadmill and be like, oh, excuse me, let me interrupt your workout, you are an inspiration. It's

silly, but those things affect people from going out." SW2 further explicitly described the impact

of the interpersonal environment as being associated with society's stigma of a person in a

wheelchair at a gym with this statement, "You don't want to go to [Name] gym where you've got

the muscle heads working out there and staring at you." These data provide clear support that

interpersonal factors are perceived to negatively impact the accessibility of wellness

programming for those with disabilities.

Community Factors

Community factors emerged as the second main theme from barriers related to wellness

programming for adults with disabilities. One main subtheme emerged, which consisted of

elements associated with a limited community network. This is further discussed in the

subsection below.

Limited Community Network. Within this subtheme, two main factors emerged and

included a lack of community support and a lack of community awareness. A lack of community

support was specifically reported by three participants (FP, OT1, COM2). For example, FP and

OT1 both shared a desire to collaborate with other organizations in the community but found that

others within these community organizations were resistant to do so. COM2 further perceived

this lack of community support and resistance to collaborate to be a result of a sense of

competition among community partners. The following scenario was specifically described by

COM2 in this regard:

> Because this particular program is more closely aligned with one of the hospital systems,
>
> we believe that at times that alignment has made it more challenging for other physicians,
>
> other entities that are aligned with other hospital systems to be more receptive to what

we're doing. I don't have any hard proof of that, that's just my belief. But I think that it's

always a challenge if you're reaching across the aisle, essentially, to invite someone.

Three participants (COM3, FP, OT2) went on to describe that a limited community

network seemed to result from a lack of awareness. COM3 specifically stated that "Everyone is

own their satellite" when referring to overall community awareness of programming availability.

Participants FP and OT2 further stated that this lack of community awareness was most

troublesome in those associated with the organizations involved in overseeing medical care of

adults with disabilities in the regional community. Collectively, these data indicate that both a

lack of collaboration and support as well as a lack of awareness are factors at the community

level which serve as barriers to wellness programming for adults with disabilities.

Political Factors

Political factors were identified as the third main theme associated with barriers related to

wellness programming for adults with disabilities. One main subtheme further emerged and

consisted of elements associated with limited political support. This is further discussed in the

subsection below.

Limited Political Support. A lack of support at the policy level was identified as the

major factor within this subtheme. Two participants (SW1, OT1) shared their dissatisfaction with

the lack of support in this regard and specifically cited limitations associated with current

insurance and third party payer reimbursement models as a significant and undue barrier to

wellness programming access for adults with disabilities. SW1 went as far as to say that the

"insurance system is failing people….people are falling through the cracks." This was

specifically shared in the context of adults with disabilities' desire to not necessarily improve,

but rather, maintain their current fitness ability; and, a lack of funding as a result of insurance

regulations to do so. OT1 shared similar remarks in this regard and stated that, "We're just succumbed by insurance and bureaucracy and policies…what happened to just doing meaningful stuff with clients, and get them to do things that they want to do that's healthy?" Both of these perspectives provide insight into limitations in the political arena that are impacting adults with disabilities access to wellness programming.

Summary

In summary, there is ample information rich textual data to support the identification of accessibility, community factors, and political factors as main thematic elements regarding key stakeholders' perspectives of barriers to wellness programming for adults with disabilities in the regional community. The textual data associated with the subthemes, which further emerged from the data analysis for each main theme, provided further insight into the nature of barriers of wellness programming in the regional community. The implications of these results on future stages of program development are discussed in Chapter 5.

Wellness Programming: Facilitators

This section presents the results for facilitators to wellness programming for adults with disabilities in the regional community. As demonstrated in Table 3: Data Analysis Coding Overview - Facilitators, eleven codes were identified, from which four subthemes emerged. Upon further analysis, two main themes were identified: accessibility and community factors. Appendix D: Tabular Representation of Facilitators to Wellness Programming Access provides an overview of the textual data to support each of these areas. This section details each main theme and corresponding subthemes.

Table 3

Data Analysis Coding Overview - Facilitators

Codes	Subthemes	Main Themes
Use of Adaptable Equipment Accessible Facility Design Program Timing	Internal Environment Factors	Accessibility
Extrinsic Motivation Intrinsic Motivation	Intrapersonal Factors	
Participant Centered Activities/Empowerment Interpersonal relationships – Staff Interpersonal Relationships – Peers	Interpersonal Factors	
Funding Support Established/Coordinated Community Partnerships Community Awareness	Established Community Network	Community Factors

Accessibility

A main theme which emerged from facilitators related to wellness programming for adults with disabilities were factors surrounding accessibility. Three subthemes were further identified within this category and included factors related to the internal environment as well as elements associated with intra and interpersonal factors. Each of these are discussed in the subsections below.

Internal Environment Factors. Internal environment factors impacting accessibility emerged as a subtheme for facilitators to wellness programming. Two participants (SW1, OT1) specifically detailed the positive impact of having access to adaptable equipment, including adaptations such adjustable heights, seats, and variable hand gripping mechanisms, as a significant contributor to wellness program access within this subtheme. Two additional participants (COM1, SW2) further described the positive influence of an accessible facility design on program accessibility. For example, COM1 noted, "You can see by being at the [facility], why we love it. You literally drive into the parking lot, the door is right there, everything is flat, you're going into a gym that's wide open, there are several different accessible

bathrooms nearby." SW2 went on to note that their facility layout design was designed very purposefully to "foster connection and accessibility."

Factors associated with program timing was further shared as an important element of positively influencing accessibility within this subtheme. Three participants (SW1, COM1, SW2) specifically described the importance of timing programming around adults with disabilities' schedules and needs on the facilitation of program participation. SW1 shared:

> There's only a key time that a lot of people can be seen, although we can be here any time of day. We'll run a staff class at 7:30 AM. But because of people with disabilities, probably the process of getting up takes longer, the general estimated time, we don't really plan anything before 9:00 AM or 10:00 AM."

Together, the common undertones and details of these statements support the internal environment as a facilitating subtheme of program accessibility.

Intrapersonal Factors. Factors associated with intrapersonal elements also emerged as a subtheme related to accessibility facilitators for wellness programming for this population. Items within this area were noted to be primarily related to factors associated with intrinsic and extrinsic motivation. Two participants (FP, COM3) cited that implementing the use of extrinsic motivators in the form of incentives for program attendance and participation positively influenced overall program accessibility and success. Both specifically described reimbursing program attendees for the cost of transportation to and from their respective classes as a way to keep their participants motivated.

Two participants (OT2, COM3) further described that the level of intrinsic motivation of their program attendees seemed to serve as a facilitator of program accessibility. OT2 specifically shared:

Certainly, the people that we serve are facilitators. I mean, that's why we're doing what

we're doing…the far majority of the participants that we have are positive and they're

saying, "Okay, I have Parkinson's disease. What can I do about it? What is it that I need

to do to keep myself healthy and keep doing things I want to do?" That has been by far

the profound sentiment that I have received in my interactions with the participants, and

that does keep a program going. We have some really dedicated participants.

COM3 went on to note that intrinsic motivation was fostered by program attendees being able to

see and feel the direct benefits of program participation in regards to their overall state of health

and functional status. These examples provide evidence to support the identification of

intrapersonal factors as a subtheme associated with accessibility as a facilitator.

Interpersonal Factors. Interpersonal factors were also found to be significant

accessibility facilitators to wellness programming access for adults with disabilities. Three main

categories emerged specifically in this regard and included: participant centered

activities/empowerment and interpersonal relationships, from both a staff and peer perspective.

Five participants (FP, COM1, SW2, OT1, OT2) specifically identified that the utilization of

participant centered activities was an important element to incorporate in order to positively

influence accessibility. All of these participants (FP, COM1, SW2, OT1, OT2) shared detailed

descriptions of intentional strategies and purposeful efforts to promote ongoing engagement and

self-empowerment with their program attendees as essential facilitatory components of the

process. For example, FP shared, "So in the gym, I'll do whatever is comfortable for them and

most people are willing to try anything…," while COM1 noted:

Our patients, first of all, we tell them up front. We don't know it all. We're creating this

program and we want you to be a part of what we're creating. This is for you. If this is not

meeting your needs, we need to know that and we are always responsive to that… I really

do believe that because they feel they're a part of that program and a part of that growth

that that has been the biggest difference.

Seven participants (FP, COM1, SW2, OT1, COM2, OT2, COM3) additionally

highlighted the importance of positive and genuine interpersonal interactions with staff and peers

alike as other key facilitators related to accessibility. COM1 specifically noted that in addition to

ensuring attendees have positive interpersonal interactions with staff, they also strive to take it a

step further, and "maintain some fun and some levity to what we're doing." SW2 and COM2

shed even more light on the nature of the interpersonal environment among staff when they

compared their relationships with attendees to a "family" and a "community in itself,"

respectively. From a peer perspective, SW1 referenced its importance and stated, "It is the peer

relationships that are built that brings a lot of the folks back." Attendees building a peer social

network outside of the class to hold each other accountable, forming friendships, and generally

becoming involved with one another on a personal level were also noted to be positive

facilitators in this regard. These data provide clear support that interpersonal factors are

perceived to positively impact the accessibility of wellness programming for those with

disabilities.

Community Factors

Community factors emerged as the second main theme from facilitators for wellness

programming for adults with disabilities. One main subtheme emerged and was associated with

the importance of a community network. The elements within this area are further identified and

detailed in the subsection below.

Established Community Network. Securing funding support was identified as a major factor within this subtheme. A variety of funding sources, including monies from grants, donations, and fundraisers were collectively described as essential program facilitators by seven of the participants (FP, COM1, SW2, OT1, COM2, OT2, COM3). Being active in the community, gaining community support, and subsequently coordinating like efforts, particularly with other organizations functioning in similar capacities, were additionally highlighted as important elements by three participants (COM1, COM2, OT2) related to facilitation. OT2 specifically stated the following in this regard, "Obviously our partnership between a nonprofit, a hospital system, a community agency, and as well as [organization]… they're all involved in missions that are designed to serve other people and to help other people, which is a benefit to our community."

Three participants (COM1, COM2, COM3) further shared that increasing community awareness was yet another component at the community level associated with programmatic success. COM2 shared, "So in a great way, our success and the people that have benefited from that success have been great facilitators sharing this information and getting it out there in the public." Specific efforts "to cover as much of the area as we can and increase referrals," were further described by COM3 from this perspective. These examples demonstrate clear support for the identification of the critical and facilitatory role of community factors, both from a funding and awareness perspective, for wellness programming for adults with disabilities.

Summary

In summary, there is ample information rich textual data to support the identification of accessibility and community factors as main thematic elements regarding key stakeholders'

perspectives of facilitators to wellness programming for adults with disabilities in the regional community. The textual data associated with the subthemes, which further emerged from the data analysis for each main theme, provided further insight into the nature of facilitators of wellness programming in the regional community. The implications of these results on future stages of program development are discussed in the Chapter 5.

Conclusion

The purpose of this research was to explore the views of key community stakeholders to gain an in-depth understanding of their perceptions of wellness programming needs for adults with disabilities in the regional community. Maximum purposeful sampling was utilized to recruit key community stakeholders who represented a variety of working professionals with a vested interest in the health and wellness of adults with disabilities. Specifically, information was sought from these study participants related to barriers and facilitators of wellness programming access for this population.

Related to this purpose, this chapter reviewed the results of the data analysis. Three main themes were identified as barriers to wellness programming access for adults with disabilities while two main themes emerged as facilitators. Thematic elements associated with barriers included accessibility, community factors, and political factors. Accessibility barriers included factors related to the external and internal environment as well as intra and interpersonal factors. Also represented were items associated with a lack of support, both from a community and political perspective, respectively.

Two parallel main themes, namely accessibility and community factors, were identified as facilitators to wellness programming for adults with disabilities in the regional community. From an accessibility perspective, factors associated with the internal environment as well as

those associated with intra and interpersonal factors emerged as subthemes. At the community level, an established community network which supported funding and promoted awareness was identified as facilitator.

When viewed collectively, it is important to recognize the representation of these results within the SEM. The SEM, a theory of health behavior change, suggests that in order for prolonged changes in health to be realized, self-determined behavior is key. The SEM further recognizes the multiple layers of influence, such as those associated with interpersonal and community factors, which impact self- determined behaviors. It will therefore be essential to consider the alignment of these results with the layers of influence within the SEM in subsequent stages of program development to enhance the overall success of the program in the regional community. A more detailed discussion of these implications as well as interpretations of the findings, recommendations for future areas of action and study, and summative remarks will be presented in Chapter 5.

CHAPTER FIVE

DISCUSSION AND CONCLUSIONS

In recent years, the poor health status of adults with disabilities gained increased attention (CDC, 2019; United States Census Bureau, 2014). A combined impact of a lack of access to preventative health care in the setting of high rates of preventable, non-communicable disease in this population raised the level of urgency for the development and implementation of sustainable and effective comprehensive health and wellness programs for these individuals (CDC, 2019; Krahn et al., 2015; United States Census Bureau, 2014). However, no such programs exist in the regional community of interest in this research (Erie County, 2018).

The purpose of this study was to explore the perspectives of key stakeholders in the regional community to gain insight into wellness programming needs for this population as a first step in the process of the development of such a program in the regional community. Qualitative methodology was utilized and included the completion of semi-structured interviews with key stakeholders in the regional community. Specifically, for the purposes of this study, key stakeholders consisted of working professionals whose professional role involved working directly with adults with disabilities within the capacity of health and wellness. The following research questions served as a guide throughout this process:

- RQ 1: How do key stakeholders within the regional community characterize barriers and facilitators to wellness programming access for adults with disabilities?

- RQ 2: How do key stakeholders' perspectives of barriers and facilitators to wellness programming access impact wellness program design for adults with disabilities?

This chapter briefly summarizes the results of this research, interprets the findings, discusses implications, and provides recommendations for action and areas of further study.

Results: Brief Review

Three main themes emerged related to barriers to wellness programming for adults with disabilities: accessibility, community factors, and political factors. Six subthemes were further identified and included: external environment factors, internal environment factors, intra and interpersonal factors, limited community network, and limited political support. Two main themes emerged related to facilitators: accessibility and community factors. Four subthemes within these themes were further identified and included: internal environment factors, intra and interpersonal factors, and an established community network. The interpretation of these findings is summarized in the section below.

Interpretation of Findings

The results of this research defined key stakeholders' perspectives of barriers and facilitators to wellness programming for adults with disabilities in the regional community. The main themes of this research align with findings of other scholarly works. A detailed discussion of the relationship between the findings of other literature and the main thematic findings of the present study is presented in the sections below.

Barriers to Wellness Programming

The results of this study revealed that barriers to wellness programming for adults with disabilities in the regional community were associated with accessibility, community factors, and political factors. Table 1: Barriers – Study Results and Literature Support identifies the relationship between these findings, the corresponding sub themes and those found in previously conducted research. The specific literature support for each of these areas is further described in the sections below.

Table 4

Barriers – Study Results and Literature Support

Main Themes	Subthemes (Codes)	Literature Support
Accessibility	External Environment Factors (weather, transportation – inconvenient)	Blonski, et al. (2014), McPhail et al. (2014), DHHS (2020)
	Internal Environment Factors (inaccessible facility – layout, limited adaptability of program/equipment)	Heller et al. (2003), NCD (2009, 2019), DHHS (2020)
	Intrapersonal Factors (lack of motivation, lack of financial resources – transportation)	Blonski et al. (2014), McPhail et al. (2014)
	Interpersonal Factors (unknowledgeable staff, interpersonal environment)	Blonski et al. (2014), NCD (2009, 2019), DHHS (2020)
Community Factors	Limited Community Network (lack of community support, lack of community awareness)	NCD (2009, 2019), DHHS (2020)
Political Factors	Limited Political Support (lack of policy support)	NCD (2009, 2019), DHHS (2020)

Accessibility

The present study revealed that barriers related to accessibility for adults with disabilities in the regional community were associated with the environment, both from an external and internal perspective. The impact of weather and inconvenient transportation was specifically described as external environment factors. Internal factors which emerged included items related to the physical layout of the facility and limited adaptability of program/equipment.

These environmental accessibility barriers are also well defined in the literature. Heller et al. (2003), completed a study with 44 individuals with Down syndrome and their caregivers to identify barriers to wellness programming. The results revealed that environmental barriers

related to the external environment of community based exercise facilities, such as transportation issues and physical features of the external environment, as well as factors in the internal environment, such as inaccessible equipment and physical layout of the facility, served as barriers to respondents' participation in wellness programs. Similar findings were demonstrated in a subsequent investigation conducted by the National Council on Disability (NCD) in 2009. McPhail et al. (2014) and Blonski et al. (2014) additionally confirmed these findings in their investigation of wellness programming for adults with disabilities resulting from musculoskeletal conditions and post stroke aphasia, respectively. More recent reports from the NCD (2019) and Department of Health and Human Services (DHHS, 2020) indicated that these barriers remain on ongoing concern on a global scale across all disability types.

Factors related to intrapersonal and interpersonal factors also emerged as barriers related to accessibility to wellness programming for adults with disabilities in the present study. A lack of motivation and personal financial circumstances were specific areas that emerged related to intrapersonal factors while unknowledgeable staff and the nature of the interpersonal environment emerged as interpersonal factors. Similar accessibility barriers associated with intra and interpersonal factors were also reported in the investigations by Blonksi et al. (2014), McPhail et al. (2014), and NCD (2009, 2019). McPhail et al. (2014) specifically found that a lack of motivation was a common intrapersonal barrier to wellness programming among their study participants. The results of the study conducted by the Blonksi et al. (2014) and NCD reports (2009) echoed similar findings, and further, revealed that interpersonal factors, such as a lack of knowledge of staff and an overall lack of general disability awareness among persons in the wellness program environment served as additional barriers to wellness programming for adults with disabilities. Of even more significance, current reports by the NCD (2019) and

DHHS (2020) acknowledged the persistent nature of these factors serving as barriers, which highlights the continued impact of these areas on wellness programming for adults with disabilities.

Community Factors

Another shared finding of this study and previous research regarding wellness programming for adults with disabilities was associated with factors in the community. In the present study, a lack of community awareness and a lack of community support were specifically found in this regard. The NCD (2009) found similar results. Specifically, the results indicated that there are issues with collaboration and coordination of support services within and across community organizations who provide services for individuals with disabilities. Further described by more recent reports is that in many cases, this lack of community support is coupled with a lack of awareness of available wellness services for this population which results in the magnification of an ongoing disconnect among community organizations providing these services (NCD, 2019; DHHS, 2020).

Political Factors

Political factors, such as a lack of support at the policy level, were also identified as a common barrier to wellness programming for adults with disabilities in this study as well as previous research. The NCD report (2009) extensively identified the negative impact of political factors on wellness programming for adults with disabilities. Current reports further acknowledge that although health care coverage has improved for those with disabilities, overly restrictive eligibility guidelines in the setting of a highly complex and siloed system, is resulting in continued limitations on benefits for coverage of wellness services (NCD, 2019; DHHS, 2020). Frustrations with these "loop holes" and gaps in coverage was also evident in the present

study participants' responses in their identification of political factors as a barrier to wellness programming for adults with disabilities.

Summary

In regards to barriers of wellness programming for adults with disabilities in the regional community, the findings of the present study are comparable to those previously established in the literature (Blonski et al., 2014; Heller et al., 2003; McPhail et al., 2014; NCD, 2009). These findings further confirm that the barriers to wellness programming found in the present study are not unique to the regional community and further, seem to not only be common, but also persistent areas of concern which are continuing to impact wellness programming for adults with disabilities on a more global scale. Collectively, this data strengthens the critical nature of considering these barriers in subsequent stages of program development in order to maximize overall program utilization as well as programmatic success.

Facilitators of Wellness Programming

The results of the present study also revealed categories of facilitators to wellness programming for adults with disabilities. These were associated with accessibility and community factors. Table 2: Facilitators – Study Results and Literature Support identifies the relationship between these findings, the corresponding sub themes and those found in previously conducted research. The specific literature support for each of these areas is further described in the sections below.

Table 5

Facilitators – Study Results and Literature Support

Main Themes	Subthemes (Codes)	Literature Support
Accessibility	Internal Environment Factors (use of adaptable equipment, accessible facility design, program timing)	Blonski et al. (2014), Drum et al. (2009), McPhail et al. (2014), NCD (2019), DHHS (2020)
	Intrapersonal Factors (extrinsic motivation, intrinsic motivation)	McPhail et al. (2014), NCD (2019)
	Interpersonal Factors (participant centered activities/empowerment, interpersonal relationships – staff, interpersonal relationships – peers)	Blonksi et al. (2014), Drum et al. (2009), McPhail et al. (2014), NCD (2019), DHHS (2020)
Community Factors	Established Community Network (funding support, established/coordinated community partnerships, community awareness)	CDC (2009), NCD (2009, 2019), DHHS (2020)

Accessibility

Accessibility emerged as a barrier to wellness programming for adults with disabilities. However, the results further revealed that this factor also served as a main facilitator in this regard. As a facilitator, accessibility factors associated with the internal environment were identified as a subtheme and included items such as availability of adaptable equipment, accessible facility design, and program timing. Similar findings regarding these facilitators of the internal environment were found in the literature. In the studies by Blonski et al. (2014) and McPhail et al. (2014), specifically referenced were items associated with the consistency and convenience of program timing as well as the accessibility of the facility itself and equipment, respectively. Best practice guidelines developed by Drum et al. (2009) for wellness programs for adults with disabilities, which remain supported in current reports by the NCD (2019) and DHHS (2020), further echoed these findings in their recommendation that emphasized the importance of

assuring programmatic accessibility in these areas as a vital element for the facilitation of program participation.

Similar to accessibility, the findings of the present study also dually recognized intrapersonal and interpersonal factors as both barriers and facilitators to wellness programming for adults with disabilities. As it relates to facilitation, extrinsic and intrinsic motivation factors were the primary areas associated with intrapersonal factors while participant centered activities/empowerment and interpersonal relationships with peers and staff emerged among interpersonal factors. These findings are also representative of the findings of previous research conducted by Blonski et al. (2014) and McPhail et al. (2014). Both studies cite factors associated with extrinsic and intrinsic motivation as facilitators. Extrinsic motivation was most evident in this research through program participants' reports of the degree of encouragement and emotional support received by family/friends while intrinsic motivation as a facilitator to wellness programming was supported by program participants' remarks regarding improved health and overall functional status as a result of participation in wellness programming (Blonski et al, 2014; McPhail et al., 2014).

Interpersonal factors as a facilitator to wellness programming for adults with disabilities, including knowledgeable staff and a supportive peer network, were also significant findings in the studies by Blonski et al. (2014) and McPhail et al. (2014). Additionally, interpersonal factors in the form of participant centered activities/empowerment were also found to be essential elements in the best practice guidelines established by Drum et al. (2009) and the current recommendations by the NCD (2019). These guidelines collectively and explicitly stated that participants should be actively involved in all stages of wellness program planning and implementation in order to maximize programmatic success. Similar sediments were shared by

participants in the present study, who collectively described the importance of fostering a patient centered environment on programmatic success.

Community Factors

Community factors also served as facilitators to wellness programming for adults with disabilities in the present study. Specific subthemes emerged and were related to funding support, established/coordinated community partnerships, and community awareness. Similar results were also reported in the findings of previous research. Initial calls to action in these areas were outlined to facilitate wellness programming for adults with disabilities by the NCD (2009). These initiatives, which remain in place in their current report (NCD, 2019), included specific recommendations for community organizations to coordinate efforts when providing services to adults with disabilities and increase societal awareness of disability more broadly through the implementation of educational training programs. The CDC (2009) further emphasized the importance of coordinated community efforts in its framework established to "promote positive and measurable behavioral and social change" (p. 1) for a variety of public health issues, including those associated with health and wellness for disabled persons. More recently, the DHHS (2020) highlighted the ongoing need for the inclusion of disability training to enhance cultural competence and overall community awareness of persistent issues surrounding disability.

Summary

As seen with barriers to wellness programming in the regional community for adults with disabilities, the findings related to facilitators of the present study were also comparable to those previously established in the literature. These findings further confirm that, like barriers, facilitators to wellness programming for this population are not unique to the regional

community and further, align with ongoing recommendations to enhance wellness programming for adults with disabilities on a more global scale. Collectively, this data strengthens the critical nature of considering these facilitators in subsequent stages of program development in order to maximize overall program utilization as well as programmatic success.

Implications

The implications of this study are further viewed through the lens of health behavior change theory. Health behavior change theories began to develop in the 1950s in order to better understand the processes and the elements that impact processes associated with the sustained and autonomous adoption of positive health behaviors. Founded by Brofenbrenner (1977) and expanded upon by McLeroy et al. (1988), the social ecological model (SEM) is one such widely accepted theory of health behavior change. Unlike other models of health behavior change, SEM recognizes the "multifaceted and interactive effects of personal and environmental factors" (CDC, 2009, p. 1) involved in the self determination of human behavior.

Specifically, SEM theorists recognized that self-determined individual health behaviors were a function of five layers of influence (Brofrenbrenner, 1977; McLeroy et al., 1988). The first level of influence recognized in SEM is the microsystem. This level is described to include intrapersonal factors, such as personal beliefs and values. The second level of influence, known as the mesosystem, is comprised of elements surrounding interpersonal factors, such as the impacts of social networks and support systems on health behavior. Community factors are recognized within the third level, which consists of items related to intra and inter community relationships and coordination. The fourth level, the macrosystem, is made up of elements related to organizational items on a larger scale such as overarching societal and cultural principles.

Policy and regulatory boards are examples of items included in the fifth level of health behavior

influence, known as the chronosystem (Brofrenbrenner, 1977; McLeroy et al., 1988).

Upon viewing the results through this lens, and as summarized in Table 3: Results and

Implications Viewed through the Social Ecological Framework (SEM), clear indicators

surrounding factors associated with barriers and facilitators to wellness programming for adults

with disabilities were represented across all five layers within the SEM. A detailed discussion of

the results as it pertains to each layer of influence follows. Further outlined are the subsequent

implications of the results, as framed through the SEM, on future stages of program planning.

Table 6

Results and Implications Viewed through the Social Ecological Framework (SEM)

Social Ecological Model (SEM) Layer of Influence	Results	Implications
Microsystem (intrapersonal factors)	Intrinsic/extrinsic motivation Financial resources	Include intrinsic/extrinsic motivational components Facilitate accessibility
Mesosystem (interpersonal factors)	Participant centered activities/empowerment Interpersonal: environment, relationships	Engage participants in decision-making Foster a positive environment
Exosystem (community factors)	Collaborative community effort	Develop coordinated community partnerships
Macrosystem (cultural, societal factors)	Interpersonal environment, societal awareness	Provide education about disability, remove "stigma"
Chronosystem (political factors)	Political support limitations	Facilitate policy change

Microsystem

The results of the present study identified intrapersonal factors as a subtheme which

impacts wellness programming for adults with disabilities. Specifically, intrinsic and extrinsic

motivation as well financial circumstances emerged as key elements within this area. These

factors align with the microsystem of the SEM. The implications of this alignment suggest that it will be prudent to maximize program participants' motivation through both intrinsic and extrinsic means as well to foster the overall accessibility of the program from a financial perspective in order to promote long term participation in wellness programming. From an intrinsic motivation perspective, this may be achieved through helping the participants consistently recognize their own improvements in personal health as a result of program participation while extrinsic strategies may include providing incentives which promote participation. The implications of the findings at this level further suggest that it will be important to minimize costs of program participation throughout the stages of implementation.

Mesosystem

The second layer of influence, the mesosystem, involves interpersonal factors. Results from the present study which align with this layer of influence are best summarized by the terms relationships and empowerment. The results of the study revealed that the inclusion of participant empowerment as well as the nature of the interpersonal environment and relationships with staff and peers alike, are critical to programmatic success. To this end, attention to strategies which facilitate participant engagement and foster positive interpersonal connections will also be important considerations in subsequent stages of program development.

Exosystem

Intra and inter community factors are recognized as primary elements of the third layer of the SEM, known as the exosystem. Findings from the present study which align with this layer involve the importance of the development of collaborative and coordinated networks of community partnerships. This was found to not only be important for funding, but also to increase community awareness of ongoing efforts related to wellness programming for adults

with disabilities as well as the benefits of wellness programming for these individuals in the community as whole. Moving forward and in order to build a successful program in the regional community, these findings suggest that it will be important to seek out community partners and opportunities for collaboration throughout the development and implementation phases of the program.

Macrosystem

The macrosystem, the fourth layer of influence with the SEM, consists of organizational elements on a larger scale such as those associated with cultural and societal views. This layer is best represented in the findings of the present study related to interpersonal factors and community awareness. Specifically described is the "stigma" of societal views of disability and persons in wheelchairs, even among trained professionals in health care. The implications of these results, when viewed through the SEM, suggest that proper education and training regarding the concept of disability will be an additional important component to consider in subsequent stages of program development.

Chronosystem

The fifth and final layer of influence within the SEM, comprised of regulatory and political factors, is the chronosystem. Findings from the present study which align with these elements surround factors related to the current model of health care. Specifically described were frustrations with the lack of insurance coverage and reimbursement for preventative and maintenance wellness programs for adults with disabilities. The implications of these findings suggest that it will be important to track programmatic outcomes to establish efficacy and further, engage in advocacy efforts to drive policy change as data is gathered to support program effectiveness.

Summary

In order for a wellness program for adults with disabilities in the regional community to be successful and sustainable, it will be essential for program participants to adopt self-determined, positive changes in health. The SEM recognizes the many layers of influence which impact this process (Brofrenbrenner, 1977; McLeroy et al., 1988). Viewing the results of the present study through the lens of the SEM and considering the subsequent implications offer key insight in order to build a program with lasting effects. It will be prudent to be intentional with efforts which maintain focus on these implications as future phases of program development commence.

<div align="center">Recommendation for Action</div>

The overarching goal of this research involves the development of a wellness program for adults with disabilities in the regional community. As a first step in this process and in alignment with best practice guidelines established by Drum et al. (2009), the purpose of this study was to explore key stakeholders' perspectives of wellness programming needs for this population in the regional community. The results of the study have clear implications for future phases of program development. As a next step, it will be important to share these findings with others in the community who are vested in the health and wellness of adults with disabilities in order to collaborate and outline a definitive plan. As further supported by U.S Department of Health and Human Services (DHHS, 2020), explicit attention and incorporation of these findings, which encompass a wide variety of contextual factors to maximize programmatic success, in the plan will be of utmost importance in subsequent stages of program development and implementation.

Recommendations for Further Study

Outlined in the best practice guidelines established by Drum et al. (2009) for the development and implementation of a community-based wellness program for adults with disabilities is the engagement of key stakeholders at the onset of planning. The present study involved the perspectives of working professionals in this regard. However, as further emphasized by Drum et al. (2009) and echoed in current recommendations by the U.S Department of Health and Human Services (DHHS, 2020), it will also be prudent to engage potential program participants themselves in the process. Therefore, a key area of further study which is needed involves the exploration of adults with disabilities' perspectives of their needs related to wellness programming within the regional community. This information, when combined with the information gleaned from this study, will provide a strong foundation for the development of a successful program in the regional community.

Limitations

As with any scholarly work, there are inherent limitations to recognize related to this study. First, because participants in the study were limited to stakeholders within the regional community who had a vested interest in the health and wellness status of adults with disabilities, the transferability of the results is limited (Yin, 2018). To minimize the impact of this limitation and to maximize the ability to gain a holistic view encompassing a wide variety of key stakeholders' perspectives within the scope of the study, non-random, purposeful maximum sampling was utilized (Creswell, 2017; Yin, 2018). This process specifically involved the recruitment of specific stakeholder groups with a vested interest in the health and wellness of adults with disabilities who had distinct and diverse experience in the field.

Second, due to the qualitative nature of this inquiry, researcher bias was also of concern. As noted by Creswell (2017), this is largely due to the fact that the researcher assumes the role of the research instrument in qualitative inquires. Further, and more specific to this research project, given the researcher's role as a physical therapist who is well versed and personally vested in the health and wellness sector for adults with disabilities, the potential impact of researcher bias was magnified. It was therefore essential for the researcher to make every effort to minimize the impact of researcher bias throughout all stages of the research process.

One such strategy that was utilized to minimize the impact of researcher bias occurred during the data collection process. As specifically suggested by Creswell (2017), the researcher avoided the use of leading questions and withheld personal impressions. Another strategy, known as member checking, was used during the data analysis phase of the research. This specifically involved interviewees' verification of transcription accuracy and seal of approval for inclusion in the study (Creswell, 2017). Additionally, the use of triangulation involving the verification of results within and among stakeholder groups, external audit through peer review, and the representation of data with thick, rich description collectively further served to enhance objectivity and minimize bias.

Conclusion

According to the recent estimates from the Center for Disease Control and Prevention ([CDC], 2019), one in four adults in the United States is living with a disability. This equates to approximately 61 million total disabled adults nationwide (CDC, 2019). Of that number, 42,604 of these individuals reside within the local community of interest for this study (Erie County Department of Health, 2018). Further, the prevalence of disability, both nationally and regionally, is expected to significantly rise in the upcoming years as a result of the aging baby

boomer population (Erie County Department of Health, 2018; United States Census Bureau, 2014).

The health status of adults with disabilities and the costs associated with their health care compounds the concerns regarding the expected rise of disabled adults in the future (CDC, 2019; United States Census Bureau, 2014). Adults with disabilities are reported to have lower rates of physical activity and higher rates of preventable, non-communicable health conditions such as obesity and cardiovascular disease (CDC, 2019; Krahn et al., 2015; United States Census Bureau, 2014). Additional reports indicated that adults with disabilities also have a general lack of access to preventative services, which in turn, further contributes to health complications for these individuals (CDC, 2019; Krahn et al., 2015; United States Census Bureau, 2014). From a financial perspective, the most recent estimates of disability-associated health care expenditures, which indicated that healthcare costs for this population approached $400 billion dollars per year, draws further attention to the growing concerns surrounding the rise of the number of disabled persons in upcoming years (Anderson, Armour, Finkelstein, & Wiener, 2010).

The combined impact of these factors led to the formal recognition of the health status of adults with disabilities as a major health disparity within the nation's health care community (CDC, 2019; Krahn et al., 2015). As a result, many public health initiatives focused on the development of wellness programs for adults with disabilities as a top priority (CDC, 2019; Department of Health and Human Services [DHHS], 2008; NCD, 2009; NCD, 2012). Further, the effectiveness of these wellness programs is well established as indicated by the results of high quality empirical research (Heller, McCubbin, Drum, & Peterson, 2011; Stuifbergen, Becker, Blozis, Timmerman, & Kullberg, 2003; Stuifbergen, Morris, Jung, Peirini, & Morgan, 2010; Young, Erickson, Johnson & Johnson, 2015).

However, despite the proven effectiveness of wellness programs for adults with disabilities, utilization is limited (Blonski et al., 2014; Durstine et al., 2000; Heller et al., 2003; LaMorte, 2019; McPhail, et al., 2014; NCD, 2009; Rimmer et al., 2008; Rimmer et al., 2014; DHHS, 2005). Further, no wellness programs for adults with disabilities exist in the regional community (Erie County, 2018). Therefore, the overall goal of this research is to guide the creation of such a program in the local community.

As highlighted in the framework embedded in the best practice guidelines for the development and implementation of wellness program for adults with disabilities, it is essential to involve key stakeholders at the onset of program planning to maximize programmatic success (Drum et al., 2009; Rimmer et al., 2014). In alignment with these recommendations, and as a first step in the development of such a program in the regional community, the purpose of this research was to gain an in-depth understanding of the wellness programming needs of this population from the perspectives of key stakeholders within the local community. Specific information was sought to answer questions regarding barriers and facilitators of wellness programming for this population and the implications of these perspectives on future program design.

Study participants consisted of working professionals in the regional community with a vested interest in health and wellness of adults with disabilities. Data were collected through semi-structured interviews and subsequently analyzed for themes. As the data were analyzed, three main themes emerged for barriers: accessibility, community factors, and political factors while two main themes emerged for facilitators: accessibility and community factors.

Upon considering the interpretation of these findings, these themes were found to align with elements identified in past and current literature, which provides insight into the ongoing

and persistent nature of the continued impact of these areas on wellness programming for adults with disabilities on a broad scale. To foster a richer analysis and determine the implications of these results on subsequent stages of program development, the data were viewed through the lens of the SEM. It was recognized that all layers influence within the SEM were represented in the study's findings. The resultant implications suggest that it will be prudent to incorporate these results and consider the multiple layers of influence which impact health behaviors and wellness program participation for adults with disabilities as future planning commences in order to build a program with lasting results (Drum et al., 2009; LaMorte, 2019; DHHS, 2020).

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Appendix A: Semi Structured Interview Protocol

Interviewee ID number (*for researcher's use only*):_____

Introduction: Thank you for volunteering to participate in this interview. As you know from reading the consent, the overall goal of this project is to develop a wellness program for adults with disabilities. As a first step, it is necessary to understand the nature of wellness programming needs for adults with disabilities in the regional community. You were intentionally chosen to be interviewed due to your vast firsthand knowledge within the health and wellness realm specific to adults with disabilities. Given your experience, the goal of this interview is to gain insight into your views related to what you perceive as barriers and facilitators to wellness programming for the population in the regional community. The information obtained from the interview will inform subsequent steps of program development and implementation to maximize the program's overall success.

To ensure accuracy, our conversation will be recorded. Please understand that all information collected during this interview will be confidential and will be utilized for the sole purpose of the research project. To respect your time, this interview is scheduled for approximately 60 minutes and time will be monitored throughout the interview to ensure all the questions are completed. The interview can be discontinued at any time at your discretion.

Part One:

Interviewee Background: We are going to start with an introduction. Can you tell me a little more about yourself by answering the following questions?

How old are you? _____

What is your occupation?
      Social worker
      Community organization/group member
      Rehabilitation professional
      Other (specify):_____

Does your current position involve working directly with adults with disabilities within the realm of health and wellness?

      Yes
      No

If, yes can you describe what your professional role entails, and how your professional role involves the health and wellness of adults with disabilities? How many years have you served in this role? _____

Follow up: Can you describe what your professional role entails, and how your professional role involves the health and wellness of adults with disabilities?

Have you worked in other capacities, settings, or regions? If yes, please describe:

Lastly, for full transparency, can you describe the nature of any pre-existing professional relationship with myself?

Part Two:

Transitions: Thank you for telling me a little more about yourself and what you do. We are now going to transition to questions focused more specifically on health and wellness programming for adults with disabilities.

Question 1: In your experience, what barriers in the regional community impact adults with disabilities' participation in wellness services?

Question 2: Reflecting on these barriers, what are key program elements that will be necessary to incorporate into a wellness program for adults with disabilities in the regional community?

Question 3: In your experience and in contrast, what elements in the regional community serve as facilitators of adults with disabilities' participation in wellness services?

Question 4: Reflecting on these facilitators, what are key program elements that will be necessary to incorporate into a wellness program for adults with disabilities in the regional community?

Question 5: Is there anything else you would like to share at this time?

Closing Statement: This concludes our interview. Thank you very kindly for your time. The level of thoughtfulness in your responses allowed me to gain insight into your perspectives regarding wellness programming needs for adults with disabilities in the regional community. This information will be useful in the future to design a successful program in the community for this population.

Appendix B: Informed Consent

UNIVERSITY OF NEW ENGLAND

CONSENT FOR PARTCIPATION IN RESEARCH

Project Title: Wellness Programming for Adults with Disabilities: A Qualitative Inquiry of Stakeholders' Perspectives

Principal Investigator(s): Courtney Roca PT, DPT

<u>Introduction:</u>

- Please read this form. You may also request that the form is read to you. The purpose of this form is to give you information about this research study, and if you choose to participate, document that choice.

- You are encouraged to ask any questions that you may have about this study, now, during or after the project is complete. You can take as much time as you need to decide whether or not you want to participate. Your participation is voluntary.

<u>Why is this research study being done?</u>

The goal of this research is to develop a comprehensive wellness program for adults with disabilities in the regional community. The first step in the process involves obtaining information about key stakeholders' perspectives regarding wellness programming needs for adults with disabilities residing in the regional community.

<u>Who will be in this study?</u>

Key stakeholders with a vested interest in health and wellness programming for adults with disabilities will be included as study participants.

<u>What will I be asked to do?</u>

You will be asked to complete a one hour interview with the researcher. This interview will be completed in a setting of your choosing and will involve answering questions and sharing your perspectives related to wellness programming needs for adults with disabilities in the regional community. To ensure accuracy, the interview will be recorded. Next, the interview will be transcribed. Lastly, the interview will be sent to you to ensure accuracy and obtain final approval for inclusion in the study.

<u>What are the possible risks of taking part in this study?</u>

There are minimal risks as a result of participation in the study. The degree of risk in the study will be no greater than those associated with functions of daily living.

What are the possible benefits of taking part in this study?

There are no direct benefits as a result of participation in the study. Generally, the information you provide will be used to inform subsequent steps of program development.

What will it cost me?

There is no cost as a result of participation in the study.

How will my privacy be protected?

Your participation will not be disclosed to anyone other than the researcher.

How will my data be kept confidential?

All data obtained from the interviews will be stored on password protected electronic devices and locked in the researcher's office. Further, no personal identifying information will be kept on these records.

What are my rights as a research participant?

- Your participation is voluntary. Your decision to participate will have no impact on your current or future relations with the University.
- Your decision to participate will not affect your relationship with the researcher or other parties.
- You may skip or refuse to answer any question for any reason.
- If you choose not to participate there is no penalty to you and you will not lose any benefits that you are otherwise entitled to receive.
- You are free to withdraw from this research study at any time, for any reason.
  - If you choose to withdraw from the research there will be no penalty to you and you will not lose any benefits that you are otherwise entitled to receive.
- You will be informed of any significant findings developed during the course of the research that may affect your willingness to participate in the research.
- If you sustain an injury while participating in this study, your participation may be ended.

What other options do I have?

- You may choose not to participate.

Whom may I contact with questions?

- The researchers conducting this study are Courtney Roca.
  - For more information regarding this study, please contact Courtney Roca at 814-871-5710 or email: roca001@gannon.edu.
- If you choose to participate in this research study and believe you may have suffered a research related injury, please contact Dr. Michelle Collay, 207-602-2010.

- If you have any questions or concerns about your rights as a research subject, you may call Mary Bachman DeSilva, Sc.D., Chair of the UNE Institutional Review Board at (207) 221-4567 or irb@une.edu.

Will I receive a copy of this consent form?

- You will be given a copy of this consent form.

Participant's Statement

I understand the above description of this research and the risks and benefits associated

with my participation as a research subject. I agree to take part in the research and do so

voluntarily.

_____   _____

Participant's signature or   Date

Legally authorized representative

_____

Printed name

Researcher's Statement

The participant named above had sufficient time to consider the information, had an

opportunity to ask questions, and voluntarily agreed to be in this study.

_____   _____

Researcher's signature   Date

_____

Printed name

Appendix C

Tabular Representation: Barriers to Wellness Programming Access

Main Theme	Subtheme	Textual Data Support: Direct Quotes
Accessibility	External Environment Factors	*Weather* **FP** There's only limited choices in [community], especially when the weather's poor for most of the year so they can't do much. **SW2** The biggest barrier, I would say, is the fact that we're working with people with disabilities, is the transportation. Getting people here, especially when you live in [community name] You're looking at weather. So when you talk about November through March, getting the amount of people here to do some of the activities that we do is quite difficult. Because they don't want to go out of their house, because it's cold. **OT2** Of course, because we provide our class throughout the year, the winter months are a barrier. Having a class in the middle of winter and you're in [community] is a barrier because we just have times where the snow is just so bad that they don't feel safe coming to class. They don't feel safe going anywhere, especially if they have to drive themselves. *Transportation – Inconvenient* **SW1** Time-wise, there can be delays with [public accessible transportation] and there's inconvenient windows, you have to be ready in this window and we can come get you in this other 45 minute window. **FP** They might live 15, 10 minutes away, but it'll take them like an hour or two sometimes to get home. So the inconvenience of that. They don't want to take the [public accessible transportation]. **SW2** And one of the reasons people don't like the [public accessible transportation] is because they have to go places and wait. So they're going places, they're waiting. If they miss their window for pick up, the [public accessible transportation] leaves them for two hours to get their other rides, and then they come back and circle back to get them. So, not very good for business. But it's very difficult. Especially when you think about somebody who has a routine. An

		independent living routine. That they might have to be home for bladder care or bowel management or whatever it might be. If you're going early someplace, you're left after a doctor's appointment or a wellness activity like this, so you're gone for say 7 hours straight, that's when accidents happen, that's when frustration sets in, and that's when a person says, 'I'm not going back.' So that's another barrier. **OT1** Transportation, that's the other one. We use the [accessible public transportation] and that is awful… the window is like half hour, 45 minutes. We kind of just hangout and stay until the [accessible public transportation] shows up. So that's really inconvenient. **COM3** I will say the individuals I work with that have visual impairment, they ride the [public accessible transportation]. And it's a mixed bag of comments. I mean, I'll just give you an example. I have a 70-year-old woman who comes here, completely without vision, comes on the [public accessible transportation]. Her class starts at 4:00, but a window of time could be an hour. So, sometimes she's waiting an hour to start class and then sometimes she's waiting an hour after class. So, that in itself is a huge inconvenience for someone just trying to take care of their health. So, what should only take them an hour, it's taking up three hours of their day due to the transportation system.
	Internal Environment Factors	*Inaccessible Facility - Layout* **SW1** For instance….it wasn't very accessible…I had to take a freight elevator to get downstairs to where the weights and machines were and you had to ask somebody at the front desk to help you but they wouldn't ride with you because they were too freaked out…it was a really sketchy elevator… all their cardio equipment was up one step…there was a step to get up to the steppers and whatever….all of their free weights were in the back corner, which was fine, but they had their equipment so close together, it was really hard to navigate around in a wheelchair. **FP** So it's limited access, or it's mostly like getting access to the equipment and space-wise because sometimes other gyms are a really tight fit. **COM1** Well, I think the big one is we initially were looking for a facility to house the program. We toured a lot of places in [community] and

		many places were offered to us saying that they were ADA compliant and they were absolutely either not or they must have been really, really loose with their interpretation. A perfect example would be we went to a facility where the handicap parking was at one end of the parking lot. The ramp access was at the other end of that parking lot, so the people had to get out of there if they wanted to use the handicapped accessible parking. They would then have to walk a decent distance to get into the building if they chose to use the ramp and not use the couple of steps. Those weren't huge steps, but again, for someone with a walker, that would have been a big challenge. Then once they got into the building, if they wanted to access the elevator to get to the room that they were showing us, which was in the basement, they would've had to go, you guessed it to the other end of the building from where they entered to get to the elevator and then take the elevator down one floor and go, you guessed it, it back to the other end of the building. **SW2** Because a lot is that even if there's accessible facilities from even a restroom perspective for bowel and bladder, it doesn't mean that you can manage how you have to do that. **OT1** Our problem is that our building is not accessible. So we've been working on getting a ramp. Let me rewind. We wanted to grow, we wanted to get more athletes involved, but our building entrance wasn't accessible and our back door wasn't accessible. They're accessible for manual chairs, but not power. *Limited Adaptability of Program/Equipment* **SW1** …people don't have adaptable equipment at their gyms…their seats on the weight machines were not removable. **COM3** The curriculum being adaptable is very troublesome. Part of my program is journaling. You need to journal your food intake. Well, with someone without vision, we have to get very creative on how they do that. So, is it you record everything that you eat? Which is even more troublesome. You can't just discreetly write it down; now, you're at work talking into this recording. So, I think program adaptability can be a big setback.
	Intrapersonal Factors	*Lack of Motivation* **SW1** It's already hard enough to motivate yourself to go to the gym without any barriers…When you're talking about a whole

population with all these limitations, fitness, it's an even bigger struggle than the average person. It's a hard market to sell. That's where we struggle always, getting the people, for sure.

COM1
Well initially it's just that it was something new. So there's a lot of fear of the unknown. 'What will this be like? I don't want to be embarrassed. Do I really need this?' You needed the buy in.

SW2
And I want to open it up to more. It's just getting the people here is the issue. Because there's so many people I've worked with over the last 11 years that would benefit so much from coming in and doing this. And you talk to them and they're like, 'No, I'm not interested.' So I might have to push that a little harder and say, 'Come on, just give it a try. One time. See if you like it. If you come and you don't like it, fine.' But don't sit at home and say, 'I don't like it.' If you've never tried it. It's like a little kid with vegetables.

COM3
A lot of the individuals we work with are in survival mode. So, 'is it save this $2 so that I can buy something I need, a necessity for my home? Or do I go to this program and take care of myself? And a lot of the times, they're choosing to save their money or to take that hour of time and look for jobs. So, when you're in survival mode, I think your health goes on the back burner, and what needs done right in front of your nose needs to get done. So, that I think is my biggest barrier. It is their biggest barrier to wellness, is 'I have a million other things that I need to get done…then my health will come last. So, that's my job, is I'm always trying to talk to people about the improvement in their quality of life… But switching that mindset is very difficult.

Lack of Financial Resources – Transportation
SW1
But for so many people in this community, I'd say 99% of the people we serve, are not employed or on fixed incomes. They're living on their social security so that's not in the cards for them, to pay for transportation. That's a luxury.

With cost, it's hard for them to get here with a [public accessible transportation] because it is $3.30 each way. $3.30 to get here, $3.30 to go back. And then, if they need to go get groceries, they only get so much money with disabilities and they have to portion that out.

		OT2 Another barrier that the participants have conveyed to us is that, they often experience challenges with transportation. There's a cost involved. A lot of them are ride sharing, but some of them are not able to ride share, and they have to seek other forms of public transportation or hire transportation to get to class. **COM3** For the [public accessible transportation], the cost is not high. I believe it's something like $2 per trip. But for some people, that's a huge burden.
	Interpersonal Factors	*Unknowledgeable staff* **SW1** No fault of the gyms but in their education and through their training to become a personal trainer, they don't really cover working with people with disabilities… he just didn't have the knowledge on adaptive movement if you're seated. **FP** They may not even realize how much effort it takes sometimes for these folks to get dressed, get breakfast or lunch, take whatever medications just to get out of the house. Then it's getting into the vehicle, getting to the facility to exercise. We were just stunned. We just couldn't believe it. So we just found that sometimes it's just that basic understanding of what the challenge of even getting folks to come to the class. And even finding trainers that are willing to work with them. A lot of people are uncomfortable because they don't want to hurt them or it's a liability. Even gym owners, it's a liability for them. The relationship really affects, because you might have a personal trainer that knows his backs, but if you can't relate to somebody... Especially with disabilities, I feel like people are so cautious of what they say and do with them and they don't realize that they're just a human being. **COM1** It's because of who was providing the resources, information, that's what surprised us because prior to this [name] had done some surveying with patients themselves because he had a gentleman that he knew I'm not even sure how, all he wanted to do and with Parkinson's, is get on the treadmill. And no gym would help him get on the treadmill. He's like, 'I'm fine once I'm on there, but I just need some assistance to get it started. And then when I'm done, can I wave to somebody and just help me get off? But I'm good when I'm there, I'm very steady.' [name] went with him and then he started going around surveying gyms and all of them were terrified to talk or deal with people who needed that slight little bit of help.

OT1

Their biggest barrier is the help, finding coaches that are willing to do that… to work with that population, yeah, because it's like there's a huge gap, in my eyes, just from being in it. Personal trainers are great, but this is a little bit I think outside of their wheelhouse, for most of them. I know there's a special certification that some can get, but most are not comfortable with somebody that's in a power chair, cerebral palsy, severe tone in four extremities. Like working with somebody like that.

COM2

But the challenge with that is once you don't have the person who has either the gifts, the talents, or the education to work with them, because then after she left, I had another... We hired a staff member who had some education to be able to work with the special needs, and then, when she was gone, it just takes a certain type of person and if they've got that education level, that's even better. So that's challenging.

Interpersonal Environment

SW1

...people assume, it's just societal views and they just don't know…that if you're in a wheelchair, you're stuck in a wheelchair, you can't get out.
Somebody with disability has that on top of it, whether its people staring or coming over telling them you're such an inspiration. I understand from both sides. I know a lot of people with disabilities will be like, oh, my gosh, it's so annoying. But I understand they mean well… I see where they mean well, but you don't go up to anybody else at the gym who's running super fast on the treadmill and be like, oh, excuse me, let me interrupt your workout, you are an inspiration. It's silly, but those things affect people from going out.

SW2

But for somebody who is now using a wheelchair for the first time, they don't want to come to a group where there's people they've never seen before, they don't know how they're going to be treated.. So I think that's one of the barriers, is getting new people to join, because they're not certain what to expect.

And part of the stigma about being in a wheelchair with a disability is you don't want to go to [Name] Gym where you've got the muscle heads working out there and staring at you saying, 'What's this guy doing? He's lifting 5 pound weights,' I'm over here doing this.

		OT1 I don't think he really felt like he fitted in anywhere, because he's an amputee. So I think that's part of it too.
Community Factors	Limited Community Network	*Lack of Community Support* **FP** Especially if it's on different days. It'd be nice if they coordinated [organization name] and [organization name] and [organization name] and coordinate different days. So it's not here the same day as theirs. **OT1** But I'm like, hey, I know we're doing the same thing but let's collaborate in this community… I find a lot of resistance in people serving people with disabilities in this community wanting to collaborate, like other agencies. **COM2** Because this particular program is more closely aligned with one of the hospital systems, we believe that at times that alignment has made it more challenging for other physicians, other entities that are aligned with other hospital systems to be more receptive to what we're doing. I don't have any hard proof of that, that's just my belief. But I think that it's always a challenge if you're reaching across the aisle, essentially, to invite someone. *Lack of Community Awareness* **FP** Like the doctors or PT or OT, they go by the book and be like, "Oh, you shouldn't do this. Don't do that." And so then, in their mind, they're engraved like, "Well, I shouldn't do this," or, "I shouldn't work out," or, "I shouldn't walk." In reality, most of them could or could benefit from moving. But, because the professional said that they can't or shouldn't, then they don't and they don't push themselves to that limit to where they could improve. So I've seen that a lot too. **OT2** …because our particular program is referral-based, we have had some challenges in terms of communicating our program to the physicians and having them receive that communication in a way that's going to benefit the participants. We've had a difficult time actually just even getting face time with a physician or their nurses to help discuss this program as a resource in the local community. We've made conscientious physical efforts, to even drive to physicians' offices to provide literature, provide information, and

		even to extend an invitation for a brief sit down meeting and we've been met with no response. That is definitely a barrier that we believe has potentially impacted the awareness of this as a resource to people with Parkinson's in our community. It's just really the lack of awareness or the lack of reception and willingness to hear us out as people who are providing a resource to the community in the hopes that perhaps some of the patients of these different physician entities would perhaps benefit from it. That's a barrier for sure. **COM3** Everyone is in their own satellite. Some people become very territorial and are not willing to collaborate.
Political Factors	Limited Political Support	*Lack of Policy Support* **SW1** The recognition of being able to be proactive instead of reactive, that's how our medical system is set up. We'll treat you if something happens, but here's some education about how to be preventative. But there really isn't a strong robust way to make that happen and then having the transition. Also, just maintaining your current level of fitness ability is really important to a lot of people. But then that's where the insurance system is failing people too because the only place they have to go is PT. They only have like what, I don't know what it is sometimes, like 12 visits a month… I feel a lot of people are falling through the cracks that way. **OT1** It's kind of like our profession. I feel like we've gone way too far in that traditional role that we kind of almost lost sight of what we're doing. It's like we're just succumbed by insurance and bureaucracy and policies, and you're just like 'What happened to just doing meaningful stuff with clients, and get them to do things that they want to do that's healthy?'

Appendix D

Tabular Representation: Facilitators to Wellness Programming Access

Main Theme	Subtheme	Textual Data Support: Direct Quotes
Accessibility	Internal Environment Factors	*Use of Adaptable Equipment* **SW1** But then I would find pieces of equipment like they have something called a functional tower. It's a really tall cable machine that has sliders on the side where you can move them up and down, you can attach different bars or different grips to them …you can do it all the way to the ground so you can do leg lifts on the cable. That was the most wonderful machine there because I could pull my wheelchair up to it, I can adjust the height, I can do my full upper body workout that I wanted to do…also, have things that are versatile, have your free weights, your cardio, you can get hand cycles, instead of just having bicycles, have some hand cycles in the gym. **OT1** There's always special equipment. We try and use barbells, we use bands, not TheraBands, but exercise bands a lot. Cowbells. I have bought [name] some hand ... because she doesn't have a functional grasp, because her hands are ... So we've gone to Velcro, like Velcro, and some carabiners and hooks. We've been hooking her to a rower so she can row without her hands, clipping them to barbells so she can kind of do some high pulls. *Accessible Facility Design* **COM1** I mean you can see by being at the [facility], why we love it. You literally drive into the parking lot, the door is right there, everything is flat, you're going into a gym that's wide open, there are several different accessible bathrooms nearby. **COM2** … I mean the way that the [organization] is designed is to be... You'll see round tables, you see benches, we set it up in a way that it fosters connection and accessibility. *Program Timing* **SW1** There's only a key time that a lot of people can be seen, although we can be here anytime of day. We'll run a staff class at 7:30 AM. But because of people with disabilities, probably the process of getting up takes longer, the general estimated time, we don't really plan anything before 9:00 AM or 10:00 AM.

		COM1 We were very cognizant of the timing of the class. The class has been on Fridays at 1:00 for a very long time, but in the beginning it was not, it had moved around. We realized one of the barriers for folks was they absolutely could not do a morning class. A lot of people with Parkinson's really take a long time to start to moving in the morning and for meds to kick in. But too late in the afternoon and they're exhausted and they need a nap. So trying to get that sweet spot, when things are kind of working great. **SW2** That's why we kind of keep our events to the 12:30-3 range, so that people get their routines done mornings, have lunch, we usually have some type of lunch or snack while they're here, and then they catch the bus, get the [accessible public transportation], have our van driver bring them home or whatever right at 3 o'clock. Now you're home, you can get back into whatever routine you have.	
	Intrapersonal Factors	*Extrinsic Motivation* **FP** Because we do a punch card thing right now for a fit class, so they get a prize after 10 sessions that they come to. So we might incorporate getting a [public accessible transportation] ticket or a couple of tickets so they can use that to come here or if they want to go for groceries or whatever else. But, at least they can work towards something. A lot of people with disabilities are more likely to do things if they have a goal in mind, whether it be their strength and mobility, but even if it's like something's free or food or... They'll work more towards that than not anything. **COM3** Luckily, my program, I was able to work with the [public accessible transportation]. And since it is a medicalized program, my participants are able to come without being charged. It's an incentive for sure. *Intrinsic Motivation* **OT2** Certainly, the people that we serve are facilitators. I mean, that's why we're doing what we're doing…the far majority of the participants that we have are positive and they're saying, "Okay, I have Parkinson's disease. What can I do about it? What is it that I need to do to keep myself healthy and keep doing things I want to do?" That has been by far the profound sentiment that I have received in my interactions with the participants, and that does keep a program going. We have some really dedicated participants.	

		COM3
		Oh yeah, mental health. So [name] has shared with all of us and my class that she suffers from depression and generalized anxiety and the adaptive class helps significantly with those types of things. So just like stress management. And some of them have lost weight… Like [name], she couldn't lean over. She's a spinal cord, incomplete, which is a little sensation below her injury. She's a T12. So she could never lean forward and be able to come back. So that was something that she gained, and eventually she was able to pick up her granddaughter and put her on her lap. So, those kinds of things. The strength has carried over into independence.
	Interpersonal Factors	*Participant Centered Activities/Empowerment* **FP** We focus on what they want, their goals, whether it be keeping mobility, getting strength, working on walking…So in the gym, I'll do whatever is comfortable for them and most people are willing to try anything…I've also learned that people get bored of it really fast, so that's why the high function, high intensity workouts work really well with them because the next exercise is something different…they'll get bored if they're on a station too long. So if I keep it short but more high intensity, then they seem to enjoy that a lot more rather than have a long tedious hour workout…And my language is important. Like, so everyone has their own unique burpee, but because I say the word burpee or use the word burpee, they feel like they're accomplishing something rather than I say, 'Okay, come, go down the ground and then come back up.' But if I say, 'Let's do a burpee,' then it's like... It clicks something different in their mind. They're like, 'Oh cool, I can do a burpee.' **COM1** Our patients, first of all, we tell them up front. We don't know it all. We're creating this program and we want you to be a part of what we're creating. This is for you. If this is not meeting your needs, we need to know that and we are always responsive to that… I really do believe that because they feel they're a part of that program and a part of that growth that that has been the biggest difference. **SW2** The girl who's the case manager who kind of runs most of the wellness stuff has such great ideas, and she's always coming up with something, and she communicates with the consumers, 'Hey, what do you want to do?' January, we'll have a meeting, and she'll say, 'What do you guys want to do this year? I don't want to tell you what we're going to do. This should come from you. It's about you guys getting out, you guys doing something. We're going to be here to facilitate it, but don't let us plan every step of the way for you.'

Because you lose independence when that happens. If we're just doing, doing, doing, doing. We listen to the consumers, we make the consumers heard.

OT1

I think it's also empowering, the type of exercise that we do, because there is no 'Oh, I'm sorry you're in a wheelchair. We're going to take it easy on you.' It's 'Suck it up and do it.' It's acknowledged at the door. Yeah, we leave it at the door. It is what it is. 'Okay, I get you can't stand up, but we will find a way to make you sweat.' So I think it's challenging, but I think it also empowers them, because they feel like they're just like a regular member, which they are there. That's the thing. It's quite totally inclusive. And that they are a part of the decision making process, and they're actively involved in directing and expressing their needs and wants. We have to be like 'Okay. What do you want to workout and what do you need to do?'

OT2

It's similar to what I already spoke about in terms of the people we serve is that as advocacy is a facilitator of any program. We have participants... when I said they're go getters, they advocate and I think that they tell us when they like and don't like something and that is advocacy and that makes the program better. That is a facilitator. There's no question about that...We always welcome it. I think that we always try to be conscientious of what we're hearing from them, and what we're seeing from them, and what we're observing when we're doing the class…We hope and we believe that it's lending a comfort level to the class that allows people to feel like they can tell us what they think constructively about the program, about what's happening, and what they like and what we could do differently in the future.

Interpersonal relationships – Staff
FP

So we built that relationship, but they were honest with what they needed or what they didn't need help with. And like me and other people, you want to be helpful even though you don't realize that to them, you're kind of like inhibiting them from doing their daily tasks. Even though they appreciate your help, but they want to open their own door or stuff like that. So I had to learn that part.

COM1

I think all of that flexibility really makes a difference in sort of bringing down a lot of the anxiety that comes from anybody who's starting something new. But when you add in all of the additional challenges when you have some physical disability and maybe some

emotional or psychological barriers that are maybe affecting how you have that impetus to jump into something. I think we do a really good job in trying to bring that down. I think we have a stellar reputation because we do put the participants first. The other thing I think would be huge about us is we always try to maintain some fun and some levity to what we're doing.

SW2

The biggest thing that helps is the staff that we have here at [organization]. Everybody gets involved. It's great…you see my whole staff, they go out there ...they're all talking... We don't just say, 'Come on in,' and go back to our desk and work. You're hanging out with the consumers everyday.

OT1

…that social interaction, they feel like its part of the family. I think me and [name] our relationships with them, because it's almost like we established a community. We all text each other. Like an accountability community kind of. Like if somebody's not showing up, like 'Where have you been?'

COM2

Yeah. And so, our members are great. And so, we do have a lot of people who interact and engage and they get the [public accessible transportation] and get dropped off and somebody'll makes sure they get to the Silver Sneakers class and it's just a community in itself.

OT2

I think that, fundamentally what makes the program successful is certainly the people that are planning it and implementing are committed to it. I think having a strong commitment from your staff, from your resources, that they really believe in the program, they're really invested in it, and they're willing to give their time to make sure it's quality program is key. I mean, if they're just doing it to do it, that's one thing. But if people are really investing their time and really thinking about what they're doing and why they're doing it, then you get a quality program. That is a positive. I think we do have people who are committed and willing to invest their time to make sure that we're doing the best we can to make sure the program output is as best as it can be for the sake of the participants. That is a positive.

COM3

The personal touch. So, they have full access to their lifestyle coaches. And I believe if someone forms a relationship, so to speak, with someone that is trying to help them in the wellness realm, it

makes them more accountable to you. So, they have full access through email, phone calls, and text. If they're having any issues or troubles, they can reach out, and their lifestyle coach will respond. That relationship-building has really helped with the retention also.

Interpersonal Relationships – Peers

FP

Just like the overall environment too. People feel more comfortable being around others with disability, they're not being judged as much as if they went to another gym. We make it feel like a family. So the people that you meet today, most of them always work out together every week. So then, they always celebrate birthdays and always hang out and that type of thing. It's building social skills, building the friendships, and... because I had one girl when she first started, she was very shy, meek. She'd always slouch, never make eye contact. And now, because she's working out and meeting people and becoming stronger and losing weight and liking herself more, now she's making friends, staying more upright, being more social. Completely different person, now she's talking and joking. So it makes a difference.

COM1

We have realized pretty early on that this class probably has a much bigger psychosocial benefit than even it does physically. Which of course that's psychosocial benefit, can certainly benefit the person physically as well. So it all plays into each other. But for some of these folks, this has become an extended support group. It's become, their fun, they're not getting out and being as engaged in community, but this is a part of their now greater community and they're finding that comfort. I don't know how you can really quantify that.

SW2

If you come, they're all going to accept you. Because we're all in the same... Everybody here's in the same boat. We have a disability, we want to get out of our houses, we want to go make a craft or have a luncheon or do whatever it is that we're doing… like I said, the peer relationships that are built brings a lot of the folks back. One people come for the first time and they realize that they're accepted, and they realize that it's fun, they want to come back.

OT1

Yeah, and it's really cute. [Name], she has cerebral palsy and epilepsy and some developmental delays. She's like in her 20s. Super sweet. Cognitively probably about eight maybe, but I caught her saying 'Go, [name]! Go, [name]!' in the middle of the workout.

		I was like 'Are you cheering? You're cheering for [name].' That's cute. **COM2** ... It started off with kind of youth, but then the youth, they've all stayed together. So now, they're probably 24, 25 and the families have gotten to know each other and the... So it's really neat. And they go out and they've done performances and they'll have... So they do dances and the [community organization] and all kinds of things and it's really nice. They have birthday parties and they just really connect…it's that building relationships in the classes. So, not only are they comfortable to be here, but then there's something more in the classes. It's not about what's on the schedule, it's the people. And so that's... Yeah. **OT2** We do see that certain participants form close friendships with each other and they do then, in that regard, may ask each other and keep them going and co-motivate each other. When you use that example, 'You weren't here last week, is everything all right?' We see that happen, but we definitely see it happen more in those individual friendships, those smaller friendships that are occurring… participants that have formed friendships that have taken on a life outside of the class. That were formed in the class and actually have taken on a friendship outside class. They met each other at the wellness program and they actually are doing things outside the class together, so that's awesome. That's also true of our spouses and family members and significant others is that they have actually formed friendships and they do things outside the class as well too, or at least they stay in contact. That's another layer of a psychosocial benefit that we feel that the program has brought, and that's that sense of community for sure. **COM3** But it's the network of support that they get from the class. I can't tell you how many people have came into this class, 15 people, say, and they're quiet and they're not speaking. And by the end of the year, they've exchanged numbers. They're meeting out for healthy outings. I mean, to me that really is a huge piece of why I'm so passionate about the program.
Community Factors	Established Community Network	*Funding Support* **SW1** The way our agency works, we receive some State funding because we provide other services. Our fitness and activities is not a required service by the State… we offer it through a grant.

COM1

I then applied for stipend funding from the [community organization] and this was a number of years after we were established. I felt it was appropriate at that point. We want to help support all the additional hours that [staff] were providing for the program. Not only had [staff] given a lot of their time to the program, but I felt that we were established enough.

SW2

We get donations from the community. We have a big Chinese auction. And so I have to actually get donations from all the different clubs and VFW's and Legion and all that stuff. And [organization] gives us a little bit of money usually, so we pay for everything based on donations. Which is great, because that allows us to do the things that we do.

OT1

…we reached out to local organizations and we received 10000 dollars from [organization]. We received 3000 dollars from the [organization], a couple thousand dollars from the city. Yeah, we're getting funding, people believe in what we're doing.

COM2

We have been fortunate that we have had the ability to have supplies purchased through a variety of different partnerships and things.

OT2

We have a funding partner, a hospital system that provides the staff stipends. That's really essential. That certainly is an important component of it.

COM3

We started... We wrote a grant, we received $100,000. And we ran the program for three years... sorry. Three years with great success. So, it was grant-funded, all grant-funded.

Established/Coordinated Community Partnerships
COM1

[Organization] has been beyond fabulous and we don't see any changes coming in that relationship… that community support from [organization] community partners has helped.

COM2

And I think too, because we are active in the community and have relationships with organizations that provide services, that then they're comfortable here.

OT2

Obviously our partnership between a nonprofit, a hospital system, a community agency, and as well as [organization]… those are all our resources… All of these different entities are already involved in... they're involved in missions that are designed to serve other people and to help other people. I think that is a huge positive of this program. It's a huge benefit that we have is that we just have a bunch of people or organizations that have come together that are sharing a common mission, which is to benefit our community so that's a huge one.

COM3

So, we've set up sites at [organization], at local churches, in schools. We try to get all over the city. That's very helpful. And, like [organization] and [organization]. Yep. So, they do marketing for the program, they'll enroll the participants…which is a blessing.

Community Awareness

COM1

[Organization] has completely bought into this and they've come and they've seen the class and I think that makes a difference. Years ago, years ago, I don't know, seven years ago, six years ago, we made videos and we sent them to every [organization] office in the region. We wanted them to know what it was that we were doing. We had invited every [organization] to come. We're like, you can stop in anytime. We have nothing to hide. So show up please. This is a service that we can offer your patients. And no one took us up on that. Even our own medical director who we consulted and told him what we were doing, no one ever came. But since then, [doctor] has seen the program in person. He asks his patients about it. He knows they're in it. He asks them, are they going back? What do you think? We get feedback from him. There's a practitioner in their office has come and seen the class. So we've gotten suggestions from them on things that they're seeing in the office that maybe we want to address in class. So that relationship has been just fabulous and it has become our…largest referral source. I think that's huge…So in a great way, our success and the people that have benefited from that success have been great facilitators sharing this information and getting it out there in the public.

COM2

So as we have relationships out in the community too and they've got needs and things that they want to... They know that the [organization] is a place that we are open to working with them and

		helping them to achieve their goals as an organization too, and so I think that's helpful. **COM3** I mean, we want to cover as much of the area as we can and increase referrals. So, that awareness piece, we're going into doctor's offices and we're just letting them know, 'Hey, there's a non-medication option to preventing disease and this is what it is.' So, we're at about a 50% referral rate for our enrollees, which I'm really happy with.