HEALTH AND WELLNESS: WHAT ADULTS WITH INTELLECTUAL AND DEVELOPMENTAL DISABILITIES PERCEIVE AS FACILITATORS AND BARRIERS

By

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Author Note

Since the completion of this study but prior to publication, the New York State Office of Mental Retardation and Developmental Disabilities (OMRDD) officially changed its name to the New York State Office for People with Disabilities (OPWD).
Acknowledgment

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Abstract

National health initiatives directed towards promoting the health and wellbeing of people with intellectual and developmental disabilities (I/DDs), across their life span, are reflective of the larger evolving process of social inclusive policy and normalization for people with I/DDs. Despite these initiatives, a gap in the literature exists when examining health promotion from the perspective of the person with the disability.

This study explored perceptions of facilitators and barriers to health and wellness shared by adults with I/DDs through photographs and corresponding narratives. A critical social theory lens supported the approach and analysis of this study. Participants, 11 adults with I/DDs, were given cameras in order to take pictures of situations, experiences, people, and things that affect their health. Through one-on-one interviews, the participants were able to share the meaning of the photo in relation to facilitators and barriers to their health. This technique of taking photos followed by describing photos is known as Photovoice. It has been an especially useful technique to gather data with vulnerable or marginalized populations who often times are not able to find voice or are represented by proxy voice. In addition, nine people who support the participants living an independent life, also known as direct support professionals (DSPs) participated in a focus group meeting. The purpose of that meeting was to share their perceptions around health and wellness for the individuals they support.

Overall, themes generated around facilitators and barriers to health and wellness were similar to those of the general population. However, a more crucial observation was that people with disabilities were able to generate the study data, thus changing how one comes to know about
health and wellness for people with disabilities, through an authentic voice. Implications for policy, research, education, and practice are discussed.
Chapter 1: Phenomenon of Interest

National health initiatives, set forth in *Healthy People 2010* (U. S. Department of Health and Human Services [USDHHS], 2000) contain objectives that aim to promote the health and wellbeing of children and adults with disabilities across their life span. It is well documented that these individuals are faced with poor nutritional choices, decreased fitness levels, higher rates of obesity, heart disease, and increased risk of secondary conditions (Heller, 2008; Draheim, 2006; Rimmer & Yamaki, 2006; Krahn, Hammond, & Turner, 2006; Rimmer, Braddock, & Fujiura, 1994; Rimmer, Braddock, & Fujiura, 1993) Additionally data shows these individuals are living longer, creating a complex cluster of health care needs and increased service utilization (Janicki, et al., 2002). A modest number of studies have evaluated programs designed to provide health promotion interventions for this population (Allen, Dodd, Taylor, McBurney, & Larkin, 2004; Stanish, Temple, & Frey, 2006; Ewing, McDermott, Thomas-Koger, Whitner, & Pierce, 2004; Marshall, McConkey, & Moore, 2003; Taylor, Dodd, & Larkin, 2004). These programs are based on a medical model of care with a disease prevention focus.

The working assumption is that knowledge of health and wellness is a nexus situated within the sole possession of the health care provider to be shared with the participant. Direct support professionals (DSPs), people who work closely with adults with I/DDs to support them in an interdependent lifestyle influence the conversation around health and wellness. However, there appears to be a gap in the literature when inquiring what individuals with I/DDs, living in the community, perceive as facilitators and barriers to health. This paucity of research in the area of health and wellness for community dwelling adults with I/DDs generates the phenomenon of interest for this study. Specifically, what are facilitators and barriers to a sustainable, holistic wellness approach for individuals with I/DDs living in the community?
Background

State mental hospitals and institutions are vestigial reminders of a bygone era. The last 40 years have witnessed a marked shift in where and how society supports individuals with I/DDs. Politicians, experts in the field, advocacy groups, and family have pioneered policy directed toward an inclusive society. The visible result is a movement from large institutions to smaller, community-based locations, epitomizing the community health philosophy focus of organization located within the family, community, and close to employment (Talbott, 2004). Presently, it is estimated that 2–4 million Americans have an intellectual or developmental disability (Humphries, Traci, & Seekins, 2008) and less than 37,000 live in institutions (Scott, Lakin, & Larson, 2008).

In addition to more adults with I/DDs living a fully supported life in a community setting are data that show that their life expectancy is increasing (Bittles, et al., 2002). Individuals with mild I/DDs show little difference in aging patterns than the general population (Fisher & Kettl, 2005; Patja, Iivananinen, Vesala, Oksanen, & Ruoppila, 2000). Increased length of life is associated with a corresponding increase in chronic conditions. The sustained and successful management of chronic conditions impacts quality of life and also drains economic resources. Increased prevalence of chronic conditions typifies a society with a decreasing level of overall health and contributes to more serious illness, further disability and eventual death. Despite increased life expectancy, chronic conditions are more prevalent for adults with I/DDs than the general populations. This creates a health disparity of great magnitude; they are living longer but with a higher incidence of preventable risk factors and added co-morbidities (Krahn, Hammond, & Turner, 2006).
Emphasis on health and wellness at a national level has encouraged formal dialogue on shifting from curative health to a preventive approach. This is evident in *Healthy People 2010* (USDHHS, 2000), the nation’s goal directed health objectives, which speak specifically to addressing the increase quality and years of life for *all* citizens, regardless of ability or disability. More specifically, people with disabilities are represented in 207 of the 467 of the Healthy People objectives. Preventive health practices among individuals with I/DDs present a challenge as minimal research has been conducted in the area and these individuals present a complex amalgamation of lower fitness levels, poorer nutrition, higher rates of obesity, sedentary life styles and overall higher risk than the general population for developing secondary chronic conditions (Heller, 2008).

Deinstitutionalization of individuals with I/DDs over the past 40 years has mirrored the civil rights movement in America. Prejudice, stigma, and segregation were noted to impede social participation of people with disability to a greater degree than the disability itself (Braddock, 2002). The process of deinstitutionalization decreased the number of persons with I/DDs living in institutions in the United States, from 194,650 in 1967 to 36,650 in 2007 (Scott, Lakin, & Larson, 2008). Progressive attitudes prevalent at the time contributed to the deinstitutionalization movement. An international focus on human rights was significant following the atrocities of World War II, nationally civil rights was a pervasive and paramount focus, and alternative approaches such as a few service models of a small scale community care for people with I/DDs in Scandinavian countries had drawn interest (Emerson & Hatton, 2005).

Two national initiatives have established a focus on promoting healthy aging and preventing further impairment and disability among this population. *Closing the Gap: A National Blueprint to Improve the Health of Persons with Mental Retardation* (USDHHS, 2002) and the
Surgeon General’s Call to Action to Improve the Health and Wellness of Persons with Disabilities (USDHHS, 2005) inform ways to improve health of those with intellectual disability, increase understanding, knowledge and awareness among people with disability, and the health care professionals involved in providing their care. Long and Kavarian (2008) proposed that a paradigm shift from medical model to social model has occurred in the arena of disability. Disability is no longer viewed as impairment or abnormality that necessitates treatment, management, and cure by society, rather, disability viewed through a social model conceptualizes it within the context of psychological, social, and environmental constraints which may interfere with functioning (Long & Kavarian, 2008, p. 3). This analysis presumes that disability is not an illness but a state, and therefore, supports for wellness, throughout the life continuum, must be a part of community based support.

Nursing, Health and Wellness

Internationally, nurses are inspiring a grass roots effort directed at prioritizing health and empowering nurses and citizens to unite for a healthy world. The Nightingale Initiative of Global Health (NIGH) is composed of more than 18,000 people from 89 nations who believe “the achievement of a healthy world to be the priority objective for action by ordinary citizens, by civil society organizations and by all governments, local and national” (The Nightingale Initiative, n.d.). Nurses are in a key position to facilitate health among the citizenry of their country. The grass root to global reach begins with one person or small group.

This proposal seeks to hear the voice of the small group of citizens otherwise marginalized by society in an effort to identify their vision of health and thus inform society at large of this priority. Listening to the voice of the individuals with I/DDs and their DSPs, may provide a grounded understanding of the perceptions of these groups of people. This may
generate new and expanded knowledge around the topic, potentiate sustainability of change, and decrease chance for bias when creating interventions and wellness programs.

**Critical Social Theory**

A postmodern approach of inquiry emphasizes the creation of reality as being unique to the individuals joined in a relationship. The relationship and the meaningfulness are socially constructed (Denzin & Lincoln, 2008). Non-static in nature, the relationship is heavily influenced through language, power, interests, and motivation of each person. Critical social theory is a philosophical perspective that applies theoretical ideas to social problems of poverty, intolerance, contradictions, and disparities in relationships for the purpose of creating change (Polit & Beck, 2008, Bohman, 2010). At its core, critical social theory questions types of dominance, seeks to liberate people from enslaving circumstances, and strives for a more egalitarian society (Kincheloe & McLaren, 2000).

The use of critical social theory in research focused on adults with I/DDs and their DSPs may help to develop a lens that allows providers, policy makers and when possible the individuals themselves to examine their knowledge base and address issues of power, interests, and consequences. Critical social theory is sensible in that it desires to improve the lives of people and envision change. To that end, critical social theory moves beyond discovery for the sake of discovery, but rather seeks the construction of a new, more just, reality. The authentic nature of critical social theory places expertise in the possession of the participants, the adults with I/DDs and the DSPs. A qualitative study that conveys the voice and view of adults with I/DDs and their DSPs may help discover meaning around the social concerns of health, wellness, and health disparities.
The underpinning for this review is a theoretical construct of critical social theory. This path of inquiry attempts to reveal as well as confront injustices situated contextually within a segment of society. A critical social theory lens is used when reading this literature, to question dominant cultural beliefs, raise consciousness towards oppression, and question contradictions. Redressing previous ideology around I/DD can promote emancipation for this population. This is a foundational step for directing research in developing a sustainable approach to health and wellness for this population.

Objectives of the Study

The primary objective of this study is to explore facilitators and barriers to health and wellness from the perspective of adults with I/DD. A secondary objective is to explore the perception of direct support professionals about health and wellness for adults with I/DD. This combined information will be used to inform program development of a sustainable approach to health and wellness for individuals with I/DD who are living in the community.

Research Questions

This study will explore the following research questions and results may inform the leadership in the field of developmental disabilities, of recommendations for developing a sustainable, intentional approach to wellness.

1. What do adults with I/DDs, living in the community, perceive as facilitators and barriers to health and wellness?

2. What are the direct support professionals’ perceptions about facilitators and barriers to health and wellness for adults with I/DDs?
Limitations

Limitations to this study are as follows. This study will focus specifically on health promotion for adults with I/DD who live in a residential home, supported by a community agency. Individuals who live in the community with family will not be part of this study. This study will not examine the physiologic nature of chronic conditions, temporary disability as the result of acute illness, accident, trauma, or rehabilitation efforts for individuals who are in need of those services. This study will focus on participants who are adults and capable of communicating perceptions around the issues of health and wellness. Therefore, the ability to generalize these results to all people with I/DD will be limited.

Assumptions and Biases

Assumptions of this study are as follows. Socially inclusive policy of people with disabilities in the community has created a change in public perceptions and attitudes. Due to the fact that they rely on others for services, these services can be limiting or liberating to the individual, literally they can define their world. This level of responsibility and accountability of services has historically been implemented from a paternalistic perspective, inconsistently incorporating the person with developmental disability into the dialogue (Rothman & Rothman, 2005). Self-determination by people with I/DD has been slowly evolving. Emerging assumptions around people with developmental disability are that they are capable of making choices, contribute to decisions, and establish rewarding relationships. Their capacities and needs are best understood within the framework of a trusting relationship (O’Brien & O’Brien, 1994, p.6). Adults with I/DD living in supportive community residences, do so interdependently with their direct support professionals, constructing better lives when supported by helpful resources, meaningful personal relationships, and opportunities for participation and problem solving (O’Brien, 1989).
Continually raising consciousness towards any forms of oppression may promote a more full emancipation for this population. Increasing knowledge around common ground or ways that people are similar rather than different may build a stronger community for adults with I/DD and give voice to ways of sustaining health for all community members.

Our knowledge, resources, and capacity to support people with disabilities have improved over time and are evidenced in the increased life span. However, compared with the general population, individuals with disabilities are experiencing poorer health and the development of chronic negative health conditions (U. S. Public Health Service [USPHS], 2001). Emancipation of people with disabilities, particularly in the area of health and wellness, has been only partially fulfilled. Assimilating people with I/DD into the dialogue on health will allow the chance to collect their perspective and self-author their concerns. The first goal of the Surgeon General’s Report, *Closing the Gap: report of the Surgeon General’s Conference on Health Disparities and Mental Retardation*, calls for integrative health promotion in community environments (USPHS, 2001, p.3).

**Operational Definitions**

Operational definitions relevant to this study include barrier, developmental disability, direct support professional, disability, health, intellectual disability, and wellness.

*Barrier*: Barrier is defined in the Encarta Dictionary (2009) as “a structure . . . that intends to prevent access or keep one place separate from another, something that obstructs or separates, often by emphasizing differences”.

*Developmental disability*: For the purposes of this study, definitions for developmental disability are taken from the Surgeon General’s Call to Action to Improve the Health and
Wellness of Persons with Disabilities (2005). Developmental disabilities are defined in the same document as

a severe, chronic disability of an individual attributable to a mental or physical impairment or combination of impairments that (a) manifests before the individual attains 22 years of age; (b) is likely to continue indefinitely; and (c) results in substantial functional limitations in three or more of the following areas of major life activity: self-care, receptive and expressive language, learning, mobility, self-direction, capacity for independent living and economic self-sufficiency, and the continuous need for individually planned and coordinated services (p.37).

Direct support professionals: The New York State Office of Mental Retardation and Developmental Disability (OMRDD) defines direct support professionals as employees who provide the ‘grass-roots’, hands on, person-to-person care of the individual with intellectual or developmental disabilities (NYS Office of Mental Retardation and Developmental Disability [OMRDD], n.d). Direct support professionals may assist with skills of daily living, cooking, making appointments, or with larger scale needs such as increasing life skills and social skills. For the purposes of this study, community living consists of a certified home setting, operated by OMRDD or a not-for-profit agency. This setting may include supervised groups with 24 hour staffing or semi-independent or supported group living which has less than 24 hour staffing and supervision (OMRDD).

Disability: The term ‘disability’ is a broad term that can mean many different things. It may be defined by time, in that disability may be temporary or permanent. It may also be defined by the extent or effect, meaning it may have an isolated or single discreet effect or it may affect
many aspects of the person’s life and ability. In general disabilities are characteristics of the body, mind, or senses that, to a greater or lesser extent, affect a person’s ability to engage in some or all aspects of day-to-day life (USDHHS, 2005, p. 1). This is considered a biopsychosocial approach to disability, which lies in sharp contrast to the illness model from an institutional era of bygones years.

**Facilitator:** Facilitator is defined by the Encarta Dictionary (2009) as “somebody who enables a process to happen, especially somebody who encourages people to find their own solutions to problems or tasks”.

**Health:** The World Health Organization’s definition of health has remained unchanged for more than 60 years, “health is the state of complete physical, mental and social wellbeing and not merely the absence of disease or infirmity” (World Health Organization, 1948).

**Intellectual disability:** For the purposes of this study, definitions for intellectual disability will be taken from the Surgeon General’s Call to Action to Improve the Health and Wellness of Persons with Disabilities (2005). Intellectual disability is defined in the following way “Once referred to as ‘mental retardation’, an impairment of thinking abilities that generally results in an intelligence quotient (IQ) equivalent that is two or more standard deviations below the average, or 70 or lower when the mean is 100. Intellectual disability often is a component of a developmental disability arising in an individual “before he or she is 22 years of age” (p.38).

**Wellness:** The World Health Organization (Smith, Tang, & Nutbeam, 2006) has a newly created definition for wellness which states “wellness is the optimal state of health of individuals and groups. There are two focal concerns: the realization of the fullest potential of an individual physically, psychologically, socially, spiritually and economically, and the fulfillment of one’s
role expectations in the family, community, place of worship, workplace and other settings” (p.344).

Summary

Deinstitutionalization has been a powerful force for change in the lives of individuals with intellectual and developmental disabilities (Braddock, 2002). Negative societal attitudes are slowly moving towards disability as a characteristic rather than a label. No longer is disability viewed as an illness that requires treatment, oppressive management or control, segregation or cure. Disability is a state of interaction between environment, the physical being, and the emotional being. This shift in conceptualization literally moves persons with I/DD from the margins of life to the center of the community.

The general increased health of our nation has resulted in a corresponding increased life expectancy for all individuals (Bittles, et al., 2002). The paradigm shift from medical model to preventive care has also benefited people with intellectual and developmental disabilities. For the first time, the nation’s health initiatives directly address health promotion and wellness throughout the life span for individuals with intellectual and developmental disabilities.

Socially inclusive policies deem that health promotion is essential for this population, yet efforts have lagged in assessment and implementation of a sustained approach for wellness (USPHS, 2001). Poor nutrition, obesity, inactivity, and a plethora of secondary chronic conditions are abundant among persons with I/DD (Heller, 2008; Draheim, 2006; Rimmer & Yamaki, 2006; Krahn, Hammond, & Turner, 2006; Rimmer, Braddock, & Fujiura, 1994; Rimmer, Braddock, & Fujiura, 1993). To date, few studies have examined health from the perspective of the person with the disability.
The majority of individuals with intellectual and developmental disabilities live in the community in an interdependent relationship with direct support professionals. The power and influence of this relationship must not be overlooked. In the best circumstances meaningful goals are set by the individual and respected through a valued relationship. Inclusion of direct support professionals in health and wellness activities can serve to strengthen the resiliency and sustainability of the actions (O’Brien & O’Brien, 1994).

Identification of facilitators and barriers to health and wellness among individuals with intellectual and developmental disabilities, living in the community is the first step towards creating a shared knowledge to further health promotion in a holistic, sustainable fashion. The nation’s health initiatives have established an expectation in this area and society at large can no longer be tolerant of health disparities. Nurses are empowered to prioritize health and include self-determination by people with I/DD in the design of a healthier state of being.
Chapter 2: Review of the Literature

Historical Context

Disabilities (mental, physical, sensory, and developmental) and mental illness have shared a long, interwoven history. Both have been poorly understood and ill-defined or differentiated. The interpretation has changed through time from punishment distributed by an angry God, to demonological possession, to that of a symbiotic relationship with the wealthy to satisfy almsgiving, assuring benevolence of the wealthy (Osborn, 2009).

The Enlightenment period brought with it a widespread change in perceptions and methods of understanding. An emphasis on reason, rationality, tolerance, and human understanding replaced traditional institutions, customs, and morals (Branham, 1998). More importantly, changes in the attitudes of citizens were stimulated by the belief that social and environmental modifications could create change in individuals. John Locke, philosopher and physician of the 17th century, is credited with the first, formal distinction between mental retardation and mental illness. Locke identified mental retardation by the term ‘idiocy’ and mental illness with the terms ‘lunatic’, ‘mad men’ or ‘madness’ (Braddock, 2002; Wickham, 2006). The writings of John Locke describe the difference as follows:

... the defect in [idiots] seems to proceed from want of quickness, activity, and motion in the intellectual faculties, whereby they are deprived of reason; whereas mad men seem to suffer by the other extreme. For they do not appear to me to have lost the faculty of reasoning: but having joined together some ideas very wrongly... they argue right from wrong principles... In short, herein seems to lie the difference between idiots and mad men, that mad men put wrong ideas together, and so make wrong propositions, but argue
and reason right from them: but idiots make very few or no propositions, but argue and reason scarce at all. (Locke, p. 236 as cited in Braddock, p.15)

The significance of the distinction between disability and mental illness was essential for determining privileges of ownership of land and certain additional freedoms. ‘Idiots’ were denied the ability to own land and any ownership that may have existed was transferred to the English government in order to pay for a lifetime of care. ‘Lunatics’ on the other hand, were allowed ownership of property and additional rights and freedoms, as it was felt they may recover from a condition and have need for meaningful sources of income (Wickham, 2006).

Disability in America

The first documentation of disability in America can be traced back to Benoni Buck, born in 1616 in Jamestown, Virginia to an Anglican clergyman (Braddock, 2002, Wickham, 2006). At age six, Benomi was an orphan. His father, anticipating his own death, designated two guardians for Benomi, one for taking care of Benomi and one for managing the farm and cattle which would provide the financial resources to continue physical care for the child. The English court attempted to retain the monies secured from the cattle, deeming Benomi an ‘idiot’ and therefore not entitled to the privileges from ownership. The court’s decision was eventually in favor of Benomi and his guardians. Benomi lived to 23 years of age.

A steady flow of immigration into the United States brought an increased societal awareness and visibility of mental illness and disability. Treatment of mental illness, which involved an aggressive manipulation of the physical body and the senses, was best suited for hospitals and institutions (Osborn, 2009). The disabled, initially represented in small numbers within the hospital, rapidly increased as disability became more differentiated from mental illness. Benjamin Franklin and physician Thomas Bond established the first general hospital in
Philadelphia, in 1752 (Braddock, 2002), intended for treatment of mental illness. Within four years, an entire wing was added onto the hospital and by 1836 a separate building for those with disabilities was constructed.

Civil liberties for those with disability began to evolve through a few different events. In 1776, the Continental Congress approved the Declaration of which granted freedom from the rule of Great Britain. A less well known gain was the first disabled veteran pension compensation. Disabled veterans from the Revolutionary War were now entitled to receive a pension (Braddock, 2002). At the same time, schools for the deaf and blind began to flourish in Europe and expand to the United States. This created a beginning of a systematized differentiation between categories of disabilities, and also a differentiation from mental illness (Osborn, 2009).

Despite distinction between certain types of disabilities and differentiation between disability and mental illness in the professional arena, the mainstream of society held a bias of disabilities and mental illness as analogous, that of being a deviant behavior in need of control. As a result, mental hospitals, residential schools, asylums, and almshouses proliferated in the United States during the 19th century. The emphasis on treatment and intervention created an emergence of new roles, such as specialized physicians, educators and caretakers (Osborn, 2009; Braddock, 2002). Society perceived institutions as the treatment of choice and success was measured in relation to rate of cure.

The increased rate of immigration to the United States created a rapidly growing general population, including the number of people with disabilities and mental illness. As a result, overcrowding in institutions was common. Despite calls for a moral approach to treatment, championed by social reformers such as Dorothea Dix and physician Philippe Pineal, admissions
from prisons seeking to re-direct inmates with mental illness to the new facilities ultimately created overcrowding. Custodial care, confinement, and management mode replaced treatment and cure. Pessimism replaced optimism about cure for residents in institutions (Osborn, 2009).

The census of 1830 was the first time people with disability were enumerated, listing ‘deaf’, ‘blind’, ‘idiotic’, and ‘insane’ (Braddock, 2002). The authenticity of enumeration is questionable as financial compensation to the enumerator was based on the number of disabled reported and pervasive racism was evidenced by the high percentage of blacks listed. Despite the less than ethical methods of gathering the census data, the number of disabled was taken at face value. Alarmed by the increasing numbers, a move through the country to control the disabled population gave rise to a eugenics movement. Strategies such as marriage restrictions and sterilization were implemented.

Distinction of blindness and deafness as separate disabilities coupled with the ability to diagnosis different disabilities within the population with I/DD stimulated thinking among medical professionals of the mid to late 1800’s to realize that people with disability should have care different and separate from people with mental illness. Educational and interventional approaches could be targeted to type of disability. In 1848, the first school for children with mental retardation was opened and followed later that year by the first residential institution for people with disabilities (Braddock, Hemp, Parish, & Westrich, 1998). Schools for the deaf and the blind were also expanding. Over the next 20 years many residential schools and institutions for people with disabilities opened with an emphasis on training, educating, and reforming children for the ultimate return to community, family, and as a productive worker in some simple capacity.
The brief nascent success of the residential schools was circumvented by the events of the Civil War, World War I, and the Great Depression. These events redirected energy, efforts, personnel and monies away from support of residential schools and institutions. There was a realization that training children for jobs within the institution brought selfish benefits of cheap labor, leading to misuse of the children. Overshadowing this period was the general held public belief of negative attitudes towards people with mental retardation as evidenced by the growing enforcement of marriage restrictions and eugenics (Braddock, 2002).

From the late 19th century through the early 20th century, the eugenics movement was gaining momentum. A cluster of events aided this movement. First, Freak shows prevalent during this time period were a common place to see people with disabilities on display for entertainment and curiosity purposes. Thomson (as cited in Braddock, 2002) states that Freak shows served to reaffirm the normalcy of the paying patron and further solidify the public perception and belief of the individual with disability as deviant. A second key event was the 1927; the U.S. Supreme Court *Buck v. Bell* established the right for states to sterilize people with intellectual disabilities (Braddock, 2002). Lastly, newly developed intelligence tests served as a way to distinguish and segregate children and individuals with intellectual disability. This created a clearly identifiable, well defined, category of people with disabilities.

The previous economic down turn of the Depression era was reversed by World War II. Now attention financially, socially, and from a research perspective could be redirected toward those with needs. In 1954 the New York State Community Mental Health Services Act was passed mandating financial support of outpatient clinics. As a result outpatient clinics rose in numbers, by 1959 there were 1,400 outpatient clinics serving more than 502,000 patients (Grob, 1995).
The period of time from 1900-1950 has been labeled the Progressive era in American reform (Rothman & Rothman, 2005). Psychiatrist, psychologist, and social workers believed in the ability to reform individuals with disability. Appealing to legislatures for funding and regulations, the care providers were confident in their ability to define client’s needs and make them better. This approach encouraged bureaucratic control over institutions. Rothman and Rothman (2005, p.4) define this as a paternalistic influence over the individual with disability.

It was during this time period that the New York State Legislature authorized the construction of another state facility to assist with accommodations for people labeled as mentally retarded. The existing facility at Letchworth Village was already overcrowded. Willowbrook State School, in Staten Island, opened in 1942 (Bronston, 1979). The segregation of people with disabilities in institutions, most of whom were severely or profoundly retarded, created a convenient population for medical experiments (Grob, 1995; Rothman & Rothman, 2005; Bronston, 1979). For almost 30 years residents at the Wrentham and Fernald facility in Massachusetts were subjected to food injected with radioactive elements. Dr. Saul Krugman used children with severe mental retardation at Willowbrook State School to investigate hepatitis-B infections. All of these studies were conducted without the consent of the individual or knowledge of the family (Rutz, 2003; Rothman & Rothman, 2005).

The last 50 years have witnessed profound changes in where and how, care and support are provided to people with I/DD. The process of deinstitutionalization decreased the number of persons with I/DD living in institutions in the United States, from 194,650 in 1967 to 36,650 in 2007 (Scott, Lakin, & Larson, 2008). A significant point is that deinstitutionalization was not an event, but a step along the long journey in a process. A process of emancipation that is strongly
influenced by the public perception, financial and policy considerations, and how successful the support and care is at achieving positive outcomes.

Public perceptions worldwide shifted to human rights following the atrocities of World War II, and nationally civil rights was a pervasive and paramount focus. Outpatient clinics continued to grow treating people with mental illness. Reminiscent of the Enlightenment period, in which those with mental illness were permitted ownership of property and allowed greater privileges, the individual with mental illness was now becoming empowered to live in a community and no longer be perceived as deviant, a goal not yet realized for individuals with disability.

Social advocacy groups were developing. In 1940, the National Federation of the Blind was created. Writings by people who were blind were instrumental in creating a paradigm shift in the perceptions around disability (Braddock, 2002). Authors from within the blind community were able to describe the most difficult aspect of their lives. It wasn’t the fact that they were blind; it was the attitude of those with sight towards the blind. This shifting paradigm provided foundational work to Saad Nagi’s definition of disability as a social construct (Krahn, 2003). The National Association for Retarded Children (currently The Arc) was also formed during this period by concerned parents and families. Significant for these organizations was the desire for leadership of the organizations to be by people with disabilities. This was the first departure from leadership by able bodied people over people with disabilities (Roberts, as cited in Braddock, 2002).

Changes in treatment for mental illness and commitment from social advocacy groups to support those with disabilities in a community venue resulted in a decreasing number of institutionalized residents. Nevertheless, navigating the advocacy system was challenging and
near impossible for those who were in most need, people with severe and profound mental retardation and those individuals with multiple handicaps (Rothman & Rothman, 2005). Abandoned by a system that provided no solutions, state schools such as Willowbrook housed the children that could no longer be cared for by family and were not deemed fit for community housing.

Deplorable conditions at Willowbrook were exposed to the public through a series of photojournalism stories. A physician and a social worker, who had been terminated by the facility, made contact with a local news agency and arranged to film, unannounced, the squalid conditions. The parents of residents now knew what they had suspected all along, and the public, politicians, and legislators were now aware of the intolerable conditions (Rothman & Rothman, 2005; Medicine, 1972). A class action suit followed leading to the Willowbrook Consent Decree, which called for New York State to improve conditions in the school, relocate residents into community housing and decrease the number of residents to 250 over the next 6 years. In 1987 Willowbrook officially closed its doors (Rothman & Rothman, 2005).

By the late 1980’s deinstitutionalization had moved people with I/DD into communities. Visibility in the community helped to remove the perception that disability was equated with depravity, deficits, and limitations. The concept of person centered planning evolved, through works of John O’Brien, Beth Mount, and others. This approach focused on ability and positive attributes of individuals rather than the deficits and limitations. The shift from service demand designed to fill deficits and treat disabilities was increasingly replaced with a collaborative approach between family, the individual with I/DD, and those supporting them. The objective was collaborative definition of goals and dreams (Mount & Zwernik, 1989, O’Brien, 1989).
Emerson and Hatton (2005) state that deinstitutionalization has been associated with benefits such as increased satisfaction, social inclusion, and engagement in the community.

Increasing numbers of adults with I/DD are living in a community-based setting, participating in community activities, enjoying more freedoms, experiencing choices, and are included as neighbors (Hewitt & Larson, 2007). Relocating adults with I/DD into the community has not been a trouble free, smooth process. Unanticipated problems developed and continue through today. For example, creating and sustaining a work force to provide support in agencies is challenging. Direct support professionals, those individuals who supply support to individuals with I/DD, are necessary to complete a genuine approach to support for adults with I/DD. This creates a need for recruiting, retaining, and training. Direct support professionals no longer work within institutions fulfilling the identified needs or deficits for individuals. Instead they are spread out throughout the community, working where the adult with I/DD is living or working. Responsibilities of direct support professionals have expanded beyond basic health, safety, and care needs and now include assisting individuals to develop and achieve personal goals, make safe choices, identify risks, secure and maintain employment and become engaged citizens in their communities (Hewitt & Larson, 2007). The shift from a deficit model of providing services to a model of assisting in the realization of goals requires that the direct support professional listen carefully, explore potential,1 and anticipate needs. Bottom line, direct support professionals are called on to provide a deep level of support and wide range of roles, on a consistent basis. This expectation creates a relationship that is fundamental to the safety, security, and ultimately autonomy of the individual with I/DD.

Deinstitutionalization of adults with I/DD established a visibility of this population in the community which was only the beginning of establishing an identity. The past 10 years have
witnessed government and global actions that seek to include adults with I/DD in the overall design of securing health and wellness across the life span. *Healthy People 2010, Closing the Gap: A National Blueprint to Improve the Health of Persons with Mental Retardation, The Surgeon General’s Call to Action to Improve the Health and Wellness of Persons with Disabilities* (USDHHS, 2000; USDHHS, 2002; USDHHS, 2005) and *Healthy Aging-Adults with Intellectual Disabilities* (WHO, 2000) have focused preventive health measures on individuals with I/DD. As a society, we have begun to unravel disability from health. What is less clear is a perspective on health promotion articulated by the voice of the adult with I/DD.

The relocation of individuals with I/DD from institutional settings to community based living arrangements in least restrictive environments, supported by prevalent beliefs of the time, began a process of emancipation. Community participation, inclusion, personal autonomy, and self-determination are some of the benefits of community based housing. However the concept of least restrictive environment is not directed solely at the physicality of housing arrangements and living situations, this concept is meant to permeate the life course of the individuals with I/DD. As a nation, our growth towards inclusion and efforts to eliminate disparities has recently begun to include individuals with I/DD. This is especially true in the area of health promotion and wellness.

**Current State of Health Disparities among Adults with I/DD**

Despite the recognized importance of health promotion, increased health disparities exist among adults with I/DD. It is evident that lower fitness levels, poor nutrition, and a general sedentary lifestyle (Draheim, Williams, & McCubbin, 2002; Long & Kavarian, 2008; Yamaki, 2005) have increased risks for chronic conditions such as heart disease, vascular disease,
diabetes, dental disease, vision problems, and thyroid malfunction (Draheim, 2006; Owens, Kerker, Zigler & Horwitz, 2006; Rimmer & Yamaki, 2006) among this population.

**Cardiovascular Disease**

Cardiovascular disease is a prominent health concern for all people, but especially among adults with I/DD. Cardiovascular disease is one of the most common causes of death in adults with I/DD and is strongly associated with lifestyle choices of inactivity and poor nutrition (Heller, 2009). Draheim’s (2006) conducted a literature review on cardiovascular disease (CVD) prevalence, CVD-related mortality, physiological CVD risk factors, and behavioral CVD risk factors. This review also examined literature on potential influences of modifiable behavioral and physiological CVD risk factors. Three key findings were revealed: adults with mental retardation have a greater incidence of CVD, it presents earlier in life, and specifically in those with mild to moderate mental retardation living in community settings. Individuals with mild to moderate mental retardation living in the community appear to have elevated disease prevalence, increased CVD related mortality, increased physiological and behavioral risk factors. Draheim’s review supports the benefits of participating in physical activity and consuming a nutritionally sound diet directed at reducing CVD risk. Noting a lack of research in the area of longitudinal studies, Draheim encourages primary prevention programs, strategies aimed at lowering the CVD risk factors, educating the individual with mental retardation, along with direct support professionals and family members.

**Obesity**

Obesity is a national public health concern. Rimmer and Yamaki (2006) reviewed prevalence data gathered from nine studies on obesity among adults with I/DD and discussed environmental factors that may be linked to obesity in this population. Four studies were
conducted in the United States and five studies were conducted in other industrialized countries, England, Germany, Ireland and Australia. The review of studies spanned from 1985–2000 and found that the prevalence of obesity among adults with I/DD was higher as well as steadily increasing among this population.

In the United States, obesity was more prevalent. Obesity and extreme obesity in the general population was noted at 30.5% and 4.7% respectively. Adults with Down syndrome and mental retardation show a sharp increase in the percentages; 70.7%, 60.6% obese and 19% and 12.1% extremely obese respectively. Data analyzed from a residential setting perspective revealed that obesity increased with decreasing environmental restrictions. Males and females living in institutions had obesity prevalence of 30.3% and 12.1% respectively. Obesity prevalence among males and females living with family were 64% and 57% respectively. In other industrialized countries obesity was found in a higher rate of prevalence and demonstrated gender differences when compared to the native population. Females generally reported a higher rate of obesity than males throughout the studies regardless of age. Rimmer and Yamaki (2006) acknowledge the intellectual disability service conceptually supports providing the least restrictive environment, however there exists a struggle at the service and provider level between honoring self-directed goals and positive health outcomes.

Rimmer and Yamaki (2006) stated it is unclear how environment impacts health, freedom of choice, and decreased emphasis on physical activity. A gap in the literature exists on factors associated with obesity in adults with I/DD and the relationship with environment to determine potential areas for change. Rimmer and Yamaki believe further study of obesity should receive one of the highest research priorities because of the strong association between obesity and other health complications.
Bhaumik, Watson, Thorp, Tyrer and McGrother (2008), conducted a large scale prevalence based study in the United Kingdom, on obesity among adults with intellectual disability (ID) to identify weight inequalities with the typical population and investigate factors associated with obesity and underweight for adults with ID. Data was gathered from the Leicestershire Learning Disability Register on 1119 adults with ID who had a health check within a year defined period of data collection and had a home interview follow up. Only complete records with no missing data were included in the study. Body mass index was calculated for each individual. Prevalence data revealed that 15% of men with ID were obese compared with 19% of the general population. For females the prevalence was 32% and 23% respectively. When analyzing the data for underweight, 19% of men with ID were underweight compared to 2% of the general population and 12% of females compared with 5% respectively. In a univariate analysis the following were associated with obesity: relatively mild ID, female gender, those who could feed and drink unassisted as well as those with Down syndrome, and hypertension. Underweight was associated with males more than females, younger age, absence of Down syndrome and not taking medications. Bhaumik et al. (2008) also note that extremes in weight are more common among adults with I/DD, either towards obesity or underweight. The authors state that reducing obesity as well as managing underweight is essential to reducing chronic disease and disability, to increase quality of life and reduce health inequities within this population. However, the current evidence base for managing these conditions has been developed from and relates to the general population. Information sensitive to the unique needs and presentation of adults with I/DD is necessary.
**Dental and Vision**

Dental and vision problems are another area of concern. *Healthy People 2010* does not direct objectives regarding vision and oral health towards people with I/DD. Research in this area is scarce for this population. Woodhouse, Adler and Duignan (2004) report vision screening of athletes at the Special Olympics United Kingdom National Summer Games. As part of a “Healthy Athletes” program, athletes were invited to attend a vision screening when they registered for the Games. Coaches were also informed about the opportunity. On completion of the screening, the results were analyzed by an optometrist and any athlete failing to reach an acceptable standard of vision received a full refraction examination by an optometrist. Overall 518 athletes participated and data on 504 athletes was analyzed. The screening success rate was 95.4%, ages ranging from 9-69 years, median age of 27, 191 females and 313 males, 107 athletes underwent full refraction examination. The authors acknowledged a male bias in the sampling and believe this is reflective of the strong male bias associated with prevalence of Down syndrome and Fragile X. The outcome of the screening obtained from Special Olympics initiatives revealed that 40% of participants were found to have ocular problems and almost 20% reported never having had an eye examination. The significance of low vision and no or inconsistent eye examinations is huge, impacting quality of life, safety, mobility and even creating a potential barrier to independence. The authors conclude that optometrists are perfectly positioned to fulfill the needs for quality eye care and should engage in specialized training to service these adults with I/DD. Additionally, educators and careers should be informed of the visual abilities and problems of adults with IDD, advising the best way to maximize function and potential.
Owens et al. (2006), replicated and updated a literature review, originally reported by the Special Olympics, Inc entitled *The Health Status and Needs of Individuals with Mental Retardation*. Five hundred articles were considered for review and 170 were deemed directly related and included in the review. The findings supported original data that vision problems present in patterns similar to the general population, but are more common among individuals with I/DD than those without. These problems included refractive errors (hyperopia, myopia and astigmatism), strabismus, cataracts, and keratoconus. The literature reveals that refractive errors have a prevalence rate of 4 to 25% in the general population and 27 to 52% among individuals with I/DD. Similar findings exist for strabismus and cataracts. Strabismus has a 2 to 3 times increased prevalence among individuals with I/DD. Down syndrome in particular is associated with higher prevalence of visual needs, as high as 70% compared to 30% of the general population with I/DD.

Dental health issues were present but the pattern of presentation was more irregular. Studies reviewed that included children with severe ID living in institutions revealed fewer dental caries, missing teeth, and filled teeth. Studies examining community based living arrangements found dental caries to present in a pattern similar to the general population. Individuals with Down syndrome were more likely to have poorly treated dental caries and increased gingivitis than the general population of individuals with I/DD (Pueschel, 1995; Saenz, 1999).

Owens et al. (2006) states the individuals with I/DD have greater oral and dental needs in three areas; etiology, health behaviors, and treatment access. Increased life expectancy may contribute to the increased reporting of vision and dental problems as a natural occurrence of the aging process. However, differences in ocular growth and physiologic changes in subgingival
conditions contribute to certain visual and oral conditions unique to this population (Owens et al.). Self-care skills or shared care skills, such as regularly brushing teeth are found to be more consistently implemented among adults with moderate or severe I/DD. The increased incidence of vision and dental problems is multi-factorial. Increasing life expectancy brings with it associated age related changes in vision and dental health. Practitioners must be educated to screen for these changes and follow up. The lack of timely detection, adequacy of vision and dental services, and consistency of follow up all contribute to increasing incidence of vision and oral problems (Owens et al.; Waldman, Perlman, & Roesch, 2008).

**Physical Activity**

The recommendation of moderate physical activity, 30 minutes on most days, can significantly promote health and ameliorate modifiable health risk factors (USDHHS, 2000; WHO, 2003). Studies on physical activity infrequently include a representative sample of adults with I/DD. Stanish, Temple and Frey (2006) conducted a literature review for the purpose of describing what is known about adults with mental retardation and physical activity behavior in relationship to established standards, and to describe findings about physical and social environments and their impact on healthy behaviors. Findings revealed that demographics and biologic factors played a role with respect to activity. Increasing age was negatively associated with activity and individuals with Down syndrome walked fewer steps per day then other individuals with mental retardation from another cause. Individuals with fewer behavior and health problems were more active. Psychosocial factors such as personal beliefs, motivation, self-determination, expected benefits, played a role in activity but were more challenging to assess for these individuals. The study authors encouraged the use of qualitative approaches to examine these psychosocial constructs from the participant’s perspective.
To date, only two studies are published that examine physical activity from the perspective of the individual with I/DD (Frey et al., 2005; Messent, Cooke, & Long. 1999). Social and cultural factors also influence the physical environment in relation to physical activity. The studies examining physical activity in relation to restrictive or less restrictive environments revealed inconsistent findings. The authors believe the discrepancies in physical activity in relation to living arrangement may be due to the influence of care giver staff, which is difficult to control. A constraint consistently reported was lack of staff motivation to promote physical activity. Individuals with mental retardation expressed the negative message regarding physical activity that they received from staff, teachers, coaches, even medical personnel. The well-meaning, but persistent message was to avoid over exertion, despite the fact that the individual was motivated to participate. In summary, the major form of physical activity were walking or cycling for transportation or performing chores, usually activities that take less than the recommended 30 minutes (Stanish, Temple, & Frey).

**Health Disparities in Context**

Cardiovascular disease, obesity, vision, and oral problems create barriers to health and wellness and continue to undermine health for a lifetime. These chronic conditions increase health disparities for the individual and initiate a downward health spiral. Krahn, Hammond and Turner (2006) conducted a literature review on the health profile of individuals with I/DD spanning 1999-2005. The authors placed an emphasis on the role of health care access and the corresponding impact on health outcomes. The purpose of the review was to highlight the negative health bias that is sustained through the impact of health disparities among individuals with I/DD. Similar chronic conditions were noted in the literature review, increased cardiovascular disease, sensory impairments of hearing and vision, respiratory, intestinal, and
dermatologic problems. The authors note an underreporting of problems, specifically vision and dental problems, when proxy reporting was used. Despite the fact that researchers have encouraged soliciting input of people with I/DD, few studies have applied this technique.

Krahn, Hammond and Turner reiterate the congruence between disability advocates philosophy and the position of The International Classification of Functioning, Disability, and Health (ICF), that physical and social environments contribute to many of the disabilities present in the life of a person with I/DD. Numerous recommendations by the authors of this literature review included early identification of health care issues, inclusion and self-determination for individuals with I/DD, reducing the impact of secondary conditions, and empowering direct support and family care providers to meet the health needs and promote healthy behaviors among individuals with I/DD.

Health Promotion Programs

Health promotion programs for adults with I/DD fall into two general categories. Those directed towards disease prevention with a singular focus, for example obesity reduction, cardiovascular health promotion, nutrition education, or oral health (Marshall, McConkey, & Moore, 2003; Humphries, Traci, & Seekins, 2008; Ewing, McDermott, Thomas-Koger, Whitner, & Pierce, 2004; Doyle & Dalton, 2008). Other programs are holistic in nature and include combinations of health education, nutrition, and exercise or slight variations of combinations (Temple & Walkley, 2007; Hahn & Aronow, 2005). Many outcomes are similar showing modest to measureable initial positive effects for the adult with I/DD in relation to health improvement. A significant recurring theme is evident in many of the studies: educating and involving the caregiver, be it a family care provider or direct care professional, is necessary alongside education for the adult with I/DD to improve outcomes and create sustainable change.
Marshall, McConkey and Moore (2003) report on two studies conducted in Northern Ireland. One study examines health screening for obesity among adults with I/DD and the second study examines the impact of health promotion classes on weight loss among the same population. The first study included 503 people with I/DD age 10 and up, with a median age of 31, and 75% of the sample size greater than 19 years of age. Overall, 79% lived with family care providers, while 21% lived in a form of residential assisted homes. A health screening was conducted which consisted of a questionnaire designed to gather information about health history and a physical examination. The questionnaire was completed in conjunction with the person with I/DD and their care provider. The resulting information was forwarded to the individual’s health care provider. The results identified half of 20 year olds as obese, but the number rose dramatically with increasing age to two thirds the population. All total 122 people were classified as obese and 110 as overweight. A follow up questionnaire 3 months later yielded a 57% response rate of which 24% indicated no action had been taken to improve their health status. Only 2% of the people referred for weight reduction mentioned weight loss in the three month follow up questionnaire.

The second study addressed outcomes from health promotion classes (including diet and exercise) designed for people with I/DD. Three locations were selected to conduct the teaching sessions, two at day centers and a third location at a resident facility. All total 25 participants volunteered for the classes with one subsequently dropping out. Sessions were either 6 weeks or 8 weeks and lasted about 2 hours. One participant was under 20, otherwise participants were 30 – 60 plus years old. Body mass index (BMI) scores revealed 36% were overweight, 12% obese, and 32% very obese. Weights were obtained at each session along with BMI scores. Significant drops in weight and BMI were noted over the 6 week period. BMI scores dropped from an
average 33.5 kg/m² at the initiation of the program to an average of 31.9 kg/m² by the 6 week mark. Two participants classified as overweight were now classified as normal, and one person moved from the category of obese to overweight (Marshall, McConkey, & Moore, 2003).

The first study documented the prevalence of obesity among the population of people with I/DD. Despite identifying a need for action, on follow up, only three individuals reported losing weight. The second study demonstrated the impact of linking identification of obesity to a health promotion option, which associated a measurement of success in the 6 weeks of the program plan. The authors called for partnership with the participant and family or staff to facilitate the success of weight reduction programs (Marshall, McConkey, & Moore, 2003).

A cardiovascular health promotion program implemented by Ewing et al. (2004) revealed similar results with marginal weight reduction results. This study consisted of a group health intervention program designed to promote healthy behaviors. The 8 week educational program consisted of two groups of people categorized and labeled by the study author as “typical” learners (n= 97) and the second group “mental retardation” (MR) (n=92). Both groups had a baseline BMI over 27kg/m². Weekly meetings were held at a clinic or convenient community setting. Programs were tailored and delivered separately for the typical learners or for those with mild to moderate mental retardation. The basic content of the programs were similar, but presented in a more concrete and simple manner for those in the MR groups. All participants were offered two to four home visits to focus on individual exercise, eating plans and making healthy eating choices while shopping. The mean BMI decreased .89 kg/m² for typical learners, no change was evident for those with MR. A decrease of .75 kg/m² in BMI was noted in 18.5 % of individuals in the MR group. Follow up phone calls revealed what the author described as a ‘gestalt’ perception among the research team that the MR groups did indeed receive more value
than a lowering of BMI. Post health intervention program, individuals with MR reported sustained exercise and healthier eating. The authors identified the fact that meals, prepared by family members or direct support professionals, were a barrier to the program success and suggested including these ancillary, yet influential people in any future programs designed for the adult with I/DD.

Doyle and Dalton (2008) implemented an action research project targeting oral health among adults with I/DD in southern Ireland. At the dental health services provider, an oral health examination was conducted on 68 people with learning disabilities. Eighteen of these individuals lived in homes run by public services; the remaining 50 lived with their families. A total of 38 needed some form of dental treatment, two requiring general anesthesia. The high incidence of need for treatment informed the need for the development of oral health promotion guidelines. Further inquiry also revealed that nurses, staff and caregivers desired education in the area of oral health for adults with I/DD. A direct result of this research was the development and implementation of clinical guidelines for oral health and dental services. Evaluation of this newly implemented program is pending.

Humphries et al. (2008), noting that adults with I/DD have little choice over food purchases or meals prepared, implemented a 16 week nutrition education program that included direct support professionals, managers, and health specialists along with adults with I/DD. Four residential group homes in Montana, operated by two service providers, were randomly selected to participate in the study. There were 32 adults (16 male, 16 female) with I/DD, 20 direct service staff, 4 managers of group homes and 2 health specialist included in the program. The methodology consisted of a comprehensive nutrition program consisting of a flexible daily menu planner, informational material about food groups, a shopping organizer, recipe book and a
poster to hold and display the information was created. Health specialists were trained in using the material and in turn, educated the house managers and staff. Assessments on nutritional food intake were conducted at the initiation of the program, at 8 weeks and at 16 weeks. Results showed that more healthy meals were planned, prepared, and served to the adults with I/DD after participating in the educational program. The menus provided a prompt for healthy eating, and individuals with I/DD were supported in choices of healthy food selections through the using the programs materials. The program material made it possible for the adults with I/DD to be included in a meaningful way in menu planning, shopping, meal selection, and preparation.

Holistic programs have had modest positive outcomes, similar to disease prevention programs. Physical activity is essential to reducing chronic conditions. It has a large impact on individual and community health, the larger question is how to include individuals with I/DD in physical activity. Temple and Walkley (2007), examined the facilitators and barriers to physical activity. Focus groups composed of adults with I/DD, direct support workers, group home supervisors, managers, and parents participated in the study. Participants were asked to provide their perspective on facilitators or barriers to health promoting physical activity. Parents and staff believed adults with I/DD were not predisposed to physical activity, nor motivated to remain engaged and persist in an activity. Conversely, adults with I/DD expressed a positive feeling towards physical activity, an appreciation for team membership, awards, and a sense of affiliation. Barriers for adults with I/DD were not being supported to engage in physical activity, lack of knowledge around performing the activity, and changes in access to activities.

Hahn and Aronow (2005) present a descriptive study on an in-home preventive intervention for adults with I/DD entitled “Stay Well and Healthy”. The purpose of this study was to develop, and test a person centered advance practice nurse intervention designed to
promote healthy aging and prevent functional decline among adults residing in the community. This program unfolded over a 12 month period. Participants lived either in private residences or in group homes. At an initial home visit, a comprehensive geriatric assessment was completed and analyzed for the purpose of identifying health risks, establishing health goals, and making recommendations around presenting problems. The final summary was provided to a case manager supporting the study participant through the study. The majority of recommendations (42%) were clinical prevention such as vision and oral examinations, increasing dietary calcium, maintaining up to date immunizations, colorectal, pap, and breast screenings. The second most common recommendation (37%) was directed toward self-care such as increasing physical activity, proper taking of medication, following a low fat/low cholesterol diet, and increasing dietary fiber. Up to three, quarterly, in home follow ups were conducted to assess adherence to recommendations. Assessments were performed by an advanced practice nurse and questionnaires were formulated at the fourth-grade reading level. At the conclusion, it is noted that slightly more than 50% of participants had adhered to or partially adhered to the recommendations of the program. The authors believed due to the fact this program was conducted in home, adequate time was allowed with each participant and in home caregivers were included in the conversation (Hahn and Aronow). Although not a focus of this study, Hahn and Aronow (2005) believed investigating the impact of direct support professionals on adults with I/DD and choices around health promotion behaviors should be a next area of focus.

Health promotion programs were targeted towards specific disease prevention or holistic in nature. Regardless of the focus, similar themes appeared to emerge. Including the direct support staff and family caregivers in health promotion education programs was beneficial to overall success of the program. Fewer studies were noted in the area of dental health; however it
was found that education was beneficial to the professional health providers as well as direct support staff, family, and individual with I/DD. Adults with I/DD valued the ability to have a voice and make a choice. A fundamental difference in perception around physical activity existed between care providers and those with I/DD. Issues of motivation, persistence, and structural barriers were evident.

**Health from the Perspective of Adults with Intellectual and Developmental Disability**

Assessing health and wellness has for the most part, been a measuring of the deficit that the disability creates for the individual, and then compensating with services or missing needs. In addition, health disparities have been measured through the lens of the typical population. Little emphasis has been placed on health from the perspective of the adult with I/DD. Literature reveals five studies to date that include the perspective adults with I/DD, in their own voice, in examining physical activity, assessing health promotion, aging and health issues (Messent, Cooke, & Long, 1999; Frey, Buchanan, & Rosser Sandt, 2005; Canrinus & Lunsky, 2003; Thompson, 2002; Jurkowski, Rivera, & Hammel, 2009).

Messant, Cooke, and Long (1999) were the first to publish research that examined perspectives and attitudes of health held by individuals with I/DD. Looking specifically at facilitators and barriers to physical activity, the study methodology triangulated data collected from the participants with schedules of direct support professionals involved in the lives of participants. The authors acknowledge methodological difficulties with interviewing participants using detailed item by item questionnaires. However, success was noted using informal, semi-structured interviews in which participants were able to verbally communicate a perspective of enjoyable activities. Three themes were conveyed by the individuals with I/DD; they felt little control over their environment, few opportunities for structured physical activity, and frustration
with the lack of choices for physical activity during free time. The study authors noted that participants in this study identified barriers to physical activities that were also implicitly acknowledged by the staff.

Frey, Buchanan and Rosser Sandt (2005) employed interpretive ethnography to examine perceptions of physical activity behaviors among adults with I/DD. Twelve participants were purposefully selected for the study, based on verbal and expressive ability. Multiple sources of data provided information on their daily routine. An understanding of physical activity behaviors emerged as a result of 5 themes revealed from the study: perceived barriers; lack of guidance; negative supports; leisure-time choices, and perceived benefits. Things such as jobs, money, weather, and time got in the way of physical activity for the participant much as it does for the general population. Lack of guidance and negative supports were the most significant themes and most troublesome as these are directly related to the support people present in the lives of the individual with I/DD. This study was able to convey the reality of participants, experienced in their daily lives, reflective of their choices and expressed in their words.

Jurkowski, Rivera and Hammel’s (2009) conducted a pilot study in Chicago with a small group (n=15) of purposively recruited Latinos with intellectual disabilities. The purpose was to explore health perceptions and beliefs among the participants. A total of four, 90 minute focus groups were conducted. To allow for any gender specific sensitive issues to surface, some focus groups were all male or all female. An additional member check focus group was conducted with five original participants to validate accuracy of data and interpretation. Focus groups were audio recorded. The data was analyzed using a content analysis approach of coding statements based on the main concept. Codes were then grouped into themes. In addition, the authors also used a software program of “Atlas ti” to conduct a content analysis. The analysis revealed the following
themes: social relationships, emotional states, energy, interconnection between work and health, beliefs about healthy behavior and cultural beliefs about health. Social and emotional aspects of health and relationships were highlighted by participants in regards to broad concepts of health. Physical health appeared to be eclipsed by an emphasis on relationships instead. Positive and negative interactions with family or other important people influenced health in a similar direction. The study authors state that developing literature around health and wellness from the perspective of the person is necessary to assure the ultimate success of health promotion programs.

Canrinus and Lunsky (2003), and Thompson (2002), have examined aging and health issues among adults with I/DD. Canrinus and Lunsky recruited female participants through the social services agencies of Toronto using a snowball technique. Criteria for participation was being in the “late forties or beyond” and having an intellectual disability. Nine women with I/DD ranging in age from 47-65 with an average age of 57 were participants in the study. A structured interview protocol used in a previous study was conducted in an unhurried atmosphere, taking typically between 1 and 2 hours to complete and at a location convenient for the participant. Living arrangements varied from group home to completely independent settings. The interview consisted of 103 questions divided into five sections, personal demographics, economic and personal safety net, health, social roles, and wellbeing. In general, it was noted that these women appreciated the opportunity to share their experiences. They faced challenges such as the loss of loved ones and also worried about things such as finances and health, but overall, they reported being relatively happy and content. Support was seen as a key element in their lives, essential for navigating and coping with difficult situations as well as for involvement in recreational
activities. Canrinus and Lunsky acknowledged the small sample size and encouraged future research on larger populations.

Thompson’s (2002) study on aging addressed not only health, but quality of life in a broad sense. A convenience sampling of adults, age 40 and older, and their care providers, was gathered from a variety of service providers in the United Kingdom with the assistance of snowball technique sampling. Participants lived either in the family home with family care providers, or in a community care setting. The sample of 161 adults was composed of 82 men and 78 women (gender was not identified for one participant), average age of 62.9 years. Two questionnaires were used to gather information from the study participants. The first questionnaire was designed to elicit subjective perceptions of age situations and challenges from the adult with I/DD. Adults of high ability levels could complete this questionnaire independently; those of lesser ability levels were assisted in responding. The second questionnaire collected data from the care givers about how well the individual’s age related needs were being met. Using these questionnaires subjective perceptions on quality of life for adults with I/DD were elicited. The study showed that adults with I/DD deal with many changes during the aging process, changes in services and support received, and loss of family and friends. Choice and control rated high in relation to quality of life for these participants. The author stated that understanding what people with I/DD value, provided information for policy and service improvements.

Chronic conditions are more numerous, which magnifies the increased state of health disparities among individuals with I/DD. This contributes to a progressive decline in overall health and taxes the health care system. More importantly health disparities also present a barrier to fully participating in life as a citizen with freedom of choice and opportunity. The accurate
analysis of the state of health requires a willingness to broaden perspectives around adults with I/DD and disentangling of health from disability. Although infrequently reflected in the literature, this process has revealed that adults with I/DD value the opportunity to speak about health, are engaged in the conversation, and frequently share perceptions similar to people without disabilities. Quality of life is important to these individuals, and facilitated through a supportive environment and the ability for choice and control.

**Photovoice and Adults with Intellectual and Developmental Disability**

To date, a handful of research studies have used a qualitative approach to capture the voice of individuals with I/DD, empowering them share perspectives and attitudes around health and health promotion (Messent, Cooke, & Long, 1999; Frey, Buchanan, & Rosser Sandt, 2005; Canrinus & Lunsky, 2003; Thompson, 2002; Jurkowski, Rivera, & Hammel, 2009). An additional study has used Photovoice to assist in the expression of facilitators and barriers to health by the adult with I/DD (Jurkowski & Paul-Ward, 2007).

Jurkowski & Paul-Ward (2007) conducted a pilot study using participatory action research methods of Photovoice, as part of a larger pilot study (Jurkowski, Rivera, & Hammel, 2009). A purposive sampling of 15 Latino adults, age 30 and older, with mild to moderate ID composed the original study participants. During this 1 year study, four of the original 15 participants were recruited to share their reality related to health using Photovoice technique. Two men and two women, ages 32-68, lived with their family or in a group home with other adults with I/DD. After completing training how to use a camera and how to use a camera safely, the participants were asked to take pictures that answered the question of ‘what makes me feel healthy or sick’. Once the cameras were returned, interviews with these participants were
one on one, providing an opportunity for the participant to explain why they took a specific photo and how it related to their health.

Information collected from Photovoice interviews and focus groups were transcribed verbatim and analyzed together. Each statement was coded in light of the main concept conveyed in the statement. Codes were then grouped into themes and a content analysis conducted. The content analysis included a systematic coding based on themes relevant to the study. Additionally, the “Atlas ti” software program was employed. Jurkowski and Paul-Ward state that allowing for the voice of adults with I/DD in the process of collecting health promotion information, through techniques such as Photovoice, is a useful strategy. Unique themes were identified such as the impact of weather and pollution on one participant’s asthma. Other participants took photos that emphasized the importance of social and community activities on their health, such as dancing or playing games. Another participant photographed accommodations that enabled him to remain connected with the outside world, such as a wheelchair lift in a van. This was described as a facilitator to his health. Adults with I/DD participating in the study were engaged, reflective, and able to record their health beliefs and identify priorities.

The participants in this study demonstrated knowledge of health and healthy behaviors but a lack of translation of this information into everyday choices. This finding is diametrically opposed to the belief of staff and caregivers, shared with the study author as part of the larger study, that individuals with I/DD do not know how to make healthy choices. The participants also placed an emphasis on health as a result of positive social and emotional relationships. “Consequently, the view of a healthy person had more to do with day-to-day social experiences,
emotional states, and having energy than with physical symptoms of chronic conditions” (Jurkowski, Rivera, & Hammel, 2009, p. 152).

Jurkowski et al. stated this study was successful in contributing to the overall growing body of knowledge describing the reality of health from the perspective of the adult with I/DD. This knowledge can contribute directly to informing future health promotion program development. “. . . health needs of people with intellectual disability (PWID) have often been determined by caregivers or medical professionals, the participatory aspect of this health promotion research project is an important contribution to the advancement of research and practice with PWID” (Jurkowski, et al., 2009, p. 153).

**Influence of Direct Support Professionals**

Despite an increased emphasis on health and wellness at a national level, for individuals with I/DD it is evident that increased risk factors and health disparities are present. The literature reveals that beliefs about health have not been fully separated from disability, even among support professionals. Kerr et al. (2003) report on a study conducted in the United Kingdom involving 589 adults with I/DD who were anticipating community placement. Adequate health care in the community relies on well informed care providers; therefore this study gathered data to identify a wide range of medical needs, including information on vision and hearing. Nurses assessed vision and hearing as ‘perfectly normal’ in 49% and 74% of their clients respectively. Formal assessment revealed that less than 1% had normal vision and 11% had normal hearing (Kerr, et al., 2003). The authors’ emphasized that lack of awareness of health problems can have a negative consequence for treatment, particularly in the early stages of detection when many conditions are amenable to intervention.
Janicki, et al. (2002), conducted a large scale convenience sampling (n = 1371) of adults with I/DD living in small group or community based residences in New York State and found similar results. Data was collected on the health of adults with I/DD through the use of survey instruments completed by nursing staff or individuals working closely with the individuals. Staff completing the survey used medical records to validate all form entries. General health was subjectively characterized by the person completing the survey, as ‘good’ to ‘excellent’ in 81% of the cohort, despite the fact that more than 50% of the cohort engaged in no exercise, 8% smoked, 10% lived with smokers and over half the cohort were classified as obese based on body mass index (BMI) (Janicki, et al., 2002). Janicki et al. suggests that lack of recognition of poor health noted among adults with I/DD could be related to lifestyle, diet and direct support professionals’ lack of information regarding exercise, diet and nutrition. Attention placed on obesity, through education of the direct support professional, may assist in alleviating some of the obesity prevalence. Attitude and knowledge of the direct support professionals as well as family caregivers regarding the benefit of exercise was a powerful influence on adults with I/DD. The author noted the discrepancies in perception and factual information warrant further investigation.

Heller, Ying, Rimmer, and Marks (2002) studied the impact of environmental factors and caregiver attitudes on the participation of adults with cerebral palsy (CP) in exercise. The study included 83 adults with CP, 47% males and 53% females and was drawn from two ongoing studies with attention to achieve a variety of residential settings and levels of functioning. Research staff gathered data through interviews with caregivers. Hierarchical regression analysis used exercise as a dependent variable and independent variables of type of residence, exercise facility access, caregiver perceived benefits and participant’s characteristics. The outcome
revealed that adults with cerebral palsy were more likely to exercise if direct support professionals perceived a benefit in the exercise, are active and interested in fitness (Heller, Ying, Rimmer, & Marks, 2002). The study emphasized the attitude of caregivers was directly related to the outcome of exercise for the adult with I/DD. Additionally, a lack of interest on the part of the direct support professionals yielded a decrease interest in exercise for the adult with I/DD.

Lunsky, Emery, and Benson (2002) found slightly improved results when comparing self reports of health, somatic complaints, and medication usage among 77 adults with mild I/DD against reports from designated direct support professionals. In areas of existing medical conditions (epilepsy, diabetes, high blood pressure), agreement between the two groups was strong. Agreement about somatic conditions (chest pain, headaches, and shortness of breath) was not well correlated and was reported in significantly lower frequency by the direct support professional. Interestingly, Lunsky (2002) notes that many of the study participants possessed a high degree of ability in reporting the correct timing and reasons for their medication regime, suggesting these participants hold a reliable perspective about their health care routine. It is unusual for a study to use self-reporting for adults with I/DD in the data collection, the general sense that more reliable data can be obtained from a support personal rather than the individual. Lunsky notes the disadvantage of this approach was the limited amount of knowledge that was gathered about how people with I/DD understand health, health promotion, and health risks. Understanding this perspective can provide information which the care giver is not privy to, opens a door to further educating the individual on health and healthy behaviors, and empowers the individual to become knowledgeable about their health status. It should be emphasized that
this study included only adults with mild I/DD, and generalizations to a larger population of adults with I/DD or with lower cognitive abilities was not advised.

There is a scarcity of studies that examine the direct support professional’s perception of health for adults with I/DD. Those studies that have addressed this perception revealed that poor health and disability continue to remain woven together and accepted by direct support professionals. Assumptions and perceptions of acceptable level of health were set at a lower level, which tolerated conditions such as obesity or poor vision, as an acceptable normative state if the individual presents with an I/DD.

**Social and Health Policy Implications**

Advances in medicine and improved diagnostics have increased the life span of adults with I/DD. The increased longevity is not associated with increased health; in fact, it correlates with increased health disparities, increased risk factors, and co-morbidities. As this population ages, with increased co-morbidities and chronic conditions there are social and health policy implications. Specifically, the issues develop around securing and maintain adequate services with a shifting population, managing health through the life span continuum, and planning and securing public financing (Fujiura & Parish, 2007).

According to census bureau data (U. S. Census Bureau, 2009) the number of persons age 65 and older will triple over the next 40 years. Correspondingly will be an increase need for services for adults with I/DD who reside with family caregivers (Braddock, 2002). It is estimated that there are currently 600,000 to 1.6 million adults with I/DDs over age 60 (American Association on Intellectual and Developmental Disabilities [AAIDD], 2009). In 2004, 2.8 million adults with I/DD received residential support from family caregivers with 25% of the
caregivers older than 65 years of age (Braddock, p. 2). Fisher (2004), states that a public healthcare crisis may ensue if planning and prevention are not addressed now.

Adults with I/DD are living longer than their aging parents and family caregivers potentially create a situation of placement in community settings, larger group homes, or assisted living arrangements (Fisher, 2004). This concept is directly opposed to current legislative agenda adopted by NYSARC which calls for a downsizing of older, larger group homes to smaller state of the art residences (NYSARC, 2009). Community living arrangement would be unable to handle a dramatic increase in population in a way that meets the needs and service requirements. Community care requires active engagement, consistent, solid resources, and adequate, well-educated staff. Adults with increased health needs entering into and overtaxing a system would not be well served.

Providing health care for these adults is also a policy issue. Most health care professionals have minimal experience assessing, diagnosing, and providing care for these individuals. The tendency remains to treat the disability rather than the person with the disability. Fisher (2004) conducted a literature review spanning 10 years of literature to identify health care needs, accessibility, and availability of services for adults with mental retardation. The review identified barriers to accessing services exist, which includes a lack of resources in some areas and less than adequately trained health care professionals.

The economic relief proposed through President Obama’s American Recovery and Reinvestment Act touches everyone’s life in some way or another. In the area of health reform the goal is to modify and strengthen the existing health care system. Focus is directed to the Medicare and Medicaid programs which presently account for more than $700 billion in federal spending annually, with one third of this spending directed towards long-term services (National
Leadership Consortium on Developmental Disabilities [NLCDD] 2009). Adults with I/DDs comprise 14% of the Medicaid recipients while utilizing 42% of the Medicaid spending (NLCDD). It is yet to be determined as to how the health care reform will address the needs of adults with I/DD and the direct support professionals. With details of President Obama’s plan yet to be established we are left with more questions than answers.
Chapter 3: The Method of Inquiry

Overview

This qualitative research study was informed by a postmodern perspective that holds reality as a social construction negotiated within communities and relationships (Denzin & Lincoln, 2008). Critical social theory philosophy was applied to the narratives of participants to ascertain meaning and accentuate participants’ expertise. The primary objective of this study was to explore facilitators and barriers to health and wellness from the perspective of adults with I/DD. A secondary objective was to explore the perception of direct support professionals (DSPs) about health and wellness for adults with I/DD. This combined information may be used to inform strategic planning and program development of a sustainable approach to health and wellness for individuals with I/DD who are living in the community.

Critical social theory is defined as ‘an approach to viewing the world that involves a critique of society, with the goal of envisioning new possibilities and effecting social change” (Polit & Beck, 2008, p. 751). Closely aligned with other research designs that emanate from an ideological perspective, such as feminist research and participatory action research (PAR), this approach was the most appropriate selection.

Feminist research concerns itself with gender domination and gender discrimination (Denzin & Lincoln, 2008). This study with a focus on health disparities among a diverse group of individuals does not meet the intent of a feminist research approach. The father of PAR, Kurt Lewin, recognized that action research is a combination of practice and theory for the ultimate goal of producing social change (Bargal, 2008). Through iterative processes, a helix of the social problem studied, as well as endeavors to solve it, is generated. Outcomes of PAR are usually specific or meaningful predominately to the group that was involved in the study. The results are
not generalizable (Speziale & Carpenter, 2003). For this reason, PAR has been particularly useful in organizational cultures and climates (Bargal; Cassell & Johnson, 2006). Critical social theory grew from German philosophers and social scientist from the Frankfurt School of Critical Social Theory, in the late 1920’s and further developed by sociologist and philosophers Adorno, Horkheimer, and Marcuse. Critical social theory, at its core, applies philosophic ideas to social problems of poverty, intolerance, contradictions, and disparities in relationships for the purpose of envisioning and creating change (Polit & Beck).

In this essence, all three approaches share the common underpinnings of addressing social problems and seeking liberation. Critical social theory was applicable to this study due to the fact that the change envisioned was broad in scope and generalizable to large segment of society. The ultimate purpose was for creating epistemological and ontological changes that support a greater degree of emancipation among adults with I/DDs. This change in knowing and being will then inform strategic policy development and social programs. This deep level of change, which is larger than raising consciousness within an organization or a single gender, has desired to truly erode and ignorance and create a transformation.

**Situated Perspective**

The American Nurses Association defines nursing as “Nursing is the protection, promotion, and optimization of health and abilities, prevention of illness and injury, alleviation of suffering through the diagnosis and treatment of human response, and advocacy in the care of individuals, families, communities, and populations” (American Nurses Association, 2003, p. 6). This definition provided a fundamental perspective for approaching this study. From a nursing perspective the study intended to promote and optimize health and abilities among people. As a nurse researcher, this study intended to situate the researcher with people in the world, and to
make visible, representations of their reality, and to interpret these in terms of the meaning people bring to them. This is accomplished with the personal belief that authentic advocacy begins with the people and their self-authored reality which will in turn direct future change. As an advocate, the personal perspective is not to impose but rather to expose and advance change.

Methodological approaches used in this study reflect the role of the researcher as nurse advocate. In this study Photovoice (photographs taken by the research participants) and photo elicitation (photographs selected and provided by the researcher) were used to assist the adults with I/DDs to share their experiences around facilitators and barriers to health and wellness. Using two approaches allowed for possible stories to emerge from different vantage points. A focus group meeting was convened with the direct support professionals. This meeting facilitated interest in understanding their descriptions of practical experiences with the participants around health and wellness. The rationale for gathering information through these techniques was to emphasize and broaden the understanding of experiences, behaviors, attitudes, and relationships that support health and wellness for adults with I/DDs. These strategies supported the situated activity of the researcher.

**Critical Theory**

Critical social theory pursues a social inquiry directed at decreasing oppression, increasing freedom, and promoting human emancipation (Bohman, 2010). It is particularly applicable when exploring circumstances of hegemony that perpetuate a persistent oppression. A predominantly unique feature of critical social theory is the reliance on the participant as expert in the generating of study data. Learning to recognize uncritically accepted and unjust dominant ideologies in everyday situations is an awareness benefitted through a critical social theory lens. Assuming the perspective of critical researcher was a logical approach this study, for a number
of reasons. The literature review for this study revealed that adults with I/DDs remain oppressed through the persistent entanglement of health and disability. This entanglement has repercussion socially, politically, and culturally. As a critical researcher, personal biases and assumptions were explored involving the entanglement of disability and health and the professional role of nurse as advocate. This theoretical perspective supported the exploration of health and wellness as experienced by adults with I/DD. Interpreting findings from the meanings contributed by the individuals is the first step, further examining apparent and even subtle power dynamics, differences in perceptions and opportunities to advocate and direct change contribute to the criticality of thinking.

This study used multiple methodological practices, consistent with critical social theory, to approach the research questions. The use of a range of inquiries allows for a better understanding of the reality in question and adds strength, depth, and trustworthiness to the study (Denzin & Lincoln, 2008). The methodology included the application of Photovoice, photo elicitation, and focus groups. These methodologies involved the participation of adults with I/DDs and the direct support professionals who provide support to the participants.

Photovoice methodology by design empowers individuals who are frequently underrepresented by society and in discussions around policy. Rather than entrusting a representative for this population, such as policy makers, professionals and even advocates, the individual themselves, in this case the participant, is entrusted to take photographs of situations and share the meaning of the photo. Using this methodology with the participants provides a concrete method to communicate reality and share their voice. Photovoice positions the participant as the expert author of the study data, a fundamental concept of critical social theory. The three main goals of Photovoice are to provide the opportunity for reflection on reality for an
individual or community; to stimulate dialogue about this reality as shared through the photos, and to inform policy makers of the experiential process (Wang & Burris, 1994; Wang & Burris, 1997; Wang, Yi, Tao, & Carovano, 1998). In this study, by using cameras, the participants were able to share visual images representing their reality. Through one-on-one interviews with each participant a rich description of the meaning associated with the photograph with regards to health and wellness was created.

A photo elicitation interview is a technique of introducing photographs into the interview context. The photographs serve to encourage conversation and sharing between the researcher and the study participants (Clark-Ibáñez, 2004). The photos are not the reality of the participant, but provide a method of expanding the dimension of communication around the participant’s life. The use of photo elicitation also allowed for the researcher to provide photographs of places that the participant may not have easily accessed for the purpose of taking photos and yet may still have had significance in the life of the participant.

This study also included a focus group meeting with direct support professionals and house managers. These are the individuals who support the participants’ quest to live a life at the highest level of independence. Focus groups involve the gathering and interviewing of four or more participants, using specific questions to guide the group discussion. Polit and Beck (2008) state that focus groups “have been used by researchers in many qualitative research traditions, and can play a particularly important role in feminist, critical theory and participatory action research” (p. 395). The focus group meeting addressed health and wellness from the perspective of the supporting staff.

Evaluation of critical research centers on the degree of participant participation, exposure of bias and assumptions, analysis and synthesis of the data revealed, and stimulation of change.
The goal of creating change within a system is realized through the challenging of inequalities, oppression, or marginalization of people (Munhall, 2007). Unexpected positive events or outcomes are also noted as part of the evaluation. For this study the aim was to provide the opportunity for adults with I/DDs to self-identify what helps them, and what impedes them being healthy, provide a chance for participants to identify and discuss their reality, to engage direct support professionals and managers in a conversation about their perceptions of facilitators and barriers to health and wellness for the individuals they support, and to share the information gathered with the Rensselaer County ARC in an effort to inform future change and contribute to strategic planning for the agency.

Methods of Data Collection

The Setting

This study was conducted through the assistance of Rensselaer County Chapter of NYSARC, Inc. Rensselaer (Arc). Arc is an association of people with disabilities, parents, professionals, and community members committed to a fully inclusive community (The ARC of Rensselaer County, 2007). Philosophically embracing a person-centered approach, the goal of Arc is to explore individual preferences for participating and integrating in the community. Arc provides services to more than 700 children and adults with intellectual disabilities and their families. Approval for this study was provided by Dr. Hanns Meissner, Chief Executive Officer (see Appendix A). Dr.Meissner’s letter served to inform mid-level managers employed by the Arc of the study.

Participant Selection

After approval was secured, the researcher met with the Associate Executive Director (AED) of Family and Community Supports for Arc. The purpose was to describe in detail the
The nature of the study, with an emphasis on the criteria for participation and to clarify any questions. The selection process was purposive. Polit and Beck (2008) define purposive sampling as “a nonprobability sampling method in which the researcher selects participants based on personal judgment about which ones will be most informative” (p.763). This study involved a level of physical dexterity and interactive communication among the adults with I/DDs. Since some members of the Arc community would not have met these criteria, a purposive sampling was in the best interest of study design. The AED was the designated person for providing the names and contact information for potential participants. The AED was informed of the criteria and expressed a clear understanding. Seeking a target of 10-12 participants, the AED provided the names of 14 adults with I/DDs, hereafter referred to as ‘participants’, and 11 direct support professionals. This sample size was appropriate for this study. Polit and Beck (2008) state that an adequate sample size should help the researcher achieve data saturation. This was evident by the redundancy in data that was generated through Photovoice and the focus group meeting.

**Phases of the Study**

From that point, there were five phases of the study, listed in Table 1 below. The phases overlapped, and participants moved through the phases in a linear and self-directed pace. The phases, associated activities, and approximate length of time for each are outlined in detail next.

<table>
<thead>
<tr>
<th>Phase of the study process</th>
<th>Activities of the phase</th>
</tr>
</thead>
<tbody>
<tr>
<td>Phase 1- Invitation to participate, consents, and orientation</td>
<td>Phone call to set up meeting with participant and support staff. Meet with participant/DSP, provide explanation, secure consents, and orient to roles and camera. (2 weeks in length).</td>
</tr>
<tr>
<td>Phase 2 – Maintaining forward progression</td>
<td>Weekly phone follow up with DSP. Ongoing until the cameras are completed or interest has</td>
</tr>
</tbody>
</table>
ceased in the activity. Pick up camera from participants. Pictures developed. (9 weeks in length)

Phase 3 – Participants share their story
Set up one-on-one meeting with participant to share photos and learn about the meaning of the photo. (9 weeks)

Phase 4 – Direct support professional share their perceptions
Schedule focus group meeting with DSP. (1 day)

Phase 5 – Final touches
Re-interview participants – as needed – to seek clarification and better understanding of descriptions and information provided. (7 days)

Table 1 – Outline: Study phases

Phase 1
This phase began with a phone call to the residence, to arrange a meeting with the participant and the DSP. The initial meeting at the participant’s residence, allowed the opportunity for introductions between the researcher and the DSP and participant. Information was shared in more detail about the purpose of the study, and questions either person may have had were answered. The timing of this group meeting, with the DSP and the participant was determined by the participant's schedule of daily obligations, seeking a time when they were home and unhurried, and avoiding meal time. Due to the fact that the DSP was previously informed of the study through leadership at ARC, each meeting commenced by speaking with the participant first.

Over the course of 2 weeks, 14 participants and 11 DSPs were visited. At these one-on-one meetings, the nature of the study was explained to the participant and details on using the camera were provided. The participant and researcher talked about health, wellness, ‘helpful things’ and things that are ‘not helpful’ with respect to health, and the concept of taking pictures
about these topics. If the participant expressed an interest in participating, written consent was obtained. The process of reading the consent was audio recorded. Next, a camera was given to the participant and together a few pictures were taken to experience the use of the camera. These trial photos assured that the participant could look through the camera at a subject matter, physically depress the shutter and then advance the film. These meetings took approximately 45 minutes. Eleven of the 14 participants and nine DSPs consented to participate at the initial meeting. One participant expressed he felt the project would be “too frustrating”, a second participant refused to meet with the researcher and a third participant requested the chance to ‘think about it for a few days’. For this last participant, a follow up meeting was scheduled at which point he declined to participate.

The eleven participants represented nine community residences. All participants expressed a desire to join the study, they stated they understood the purpose for taking photos, were able to follow directions for using the camera, were physically able to operate the camera, were able to communicate, and able to assent to participate in the study. As compensation for participating, each participant was made aware that they would receive a small photo album which would include all their photos. See Table 2 for limited participant demographic information. After meeting with each participant, the researcher assigned a pseudonym that was used to organize the photos and data collected.
<table>
<thead>
<tr>
<th>Pseudonym</th>
<th>Age</th>
<th>Acute/chronic illnesses</th>
<th>Time with camera</th>
<th># of photos taken</th>
</tr>
</thead>
<tbody>
<tr>
<td>Manny</td>
<td>54</td>
<td>Mild hearing loss, corrective glasses, seasonal allergies, toenail fungus</td>
<td>10 days</td>
<td>15</td>
</tr>
<tr>
<td>Marilyn</td>
<td>29</td>
<td>High blood pressure controlled with medication, exercise induced asthma, obesity</td>
<td>8 days</td>
<td>23</td>
</tr>
<tr>
<td>Victoria</td>
<td>69</td>
<td>Epilepsy, controlled a-fib, arthritis, osteoporosis</td>
<td>8 days</td>
<td>22</td>
</tr>
<tr>
<td>Derek</td>
<td>50</td>
<td>Diabetes X 38 years, dialysis for kidney failure, high blood pressure, blind in left eye</td>
<td>7 weeks</td>
<td>15</td>
</tr>
<tr>
<td>Julia</td>
<td>45</td>
<td>Arthritis, obesity</td>
<td>33 days</td>
<td>11</td>
</tr>
<tr>
<td>Elizabeth</td>
<td>62</td>
<td>Seasonal allergies, obesity</td>
<td>33 days</td>
<td>3</td>
</tr>
<tr>
<td>Rachel</td>
<td>49</td>
<td>Over weight</td>
<td>33 days</td>
<td>27</td>
</tr>
<tr>
<td>Billy</td>
<td>40</td>
<td>n/a</td>
<td>8 weeks</td>
<td>13</td>
</tr>
<tr>
<td>Thomas</td>
<td>49</td>
<td>H/O DVT, depression, elevated cholesterol</td>
<td>9 weeks</td>
<td>25</td>
</tr>
<tr>
<td>Name</td>
<td>Age</td>
<td>Diagnosis</td>
<td>Duration</td>
<td>Age Group</td>
</tr>
<tr>
<td>---------------</td>
<td>-----</td>
<td>---------------------------------------------------------------------------</td>
<td>----------</td>
<td>-----------</td>
</tr>
<tr>
<td>Martha Stewart</td>
<td>27</td>
<td>Heart failure, pacemaker, diabetes, seasonal allergies, obesity</td>
<td>27 days</td>
<td>11</td>
</tr>
<tr>
<td>Richard</td>
<td>57</td>
<td>Seizures, colostomy</td>
<td>6 weeks</td>
<td>23</td>
</tr>
</tbody>
</table>
At this same meeting, once participant participation was established, the DSP was then approached for participation. The DSP was asked to participate in the entire study, but had two distinct roles. The first role was to be a neutral companion (not suggestive of pictures to take) for any participant who needed assistance or supervision with the taking of photographs. The second role was to participate in a focus group meeting after all the cameras were returned to share their experience in the study as well as their perceptions of health and wellness for the participants they support. The criterion for inclusion for DSPs was a minimum of one year experience in their role. Participation in all aspects of this study was voluntary. Nine DSPs, affiliated with the 11 participants, agreed to participate in both aspects of the study. None of the DSPs opted out of any aspect of the study.

There were three consent forms used in this study, one for the participant and two for the DSPs; one for each of the two roles they assumed in the study. All consents forms received approval from the Sage Colleges Institutional Review Board (IRB). The consent form that participants signed was developed at a basic level for ease of understanding and read to participants (see Appendix B). Direct support professionals were asked to provide dual consent. All DSPs voluntarily consented to both aspects of the study. These consent forms are presented in appendices C and D.

The DSPs supplied limited demographic data about the participant, specifically, the participant’s age, and presence of acute illness and chronic illness. Limited demographic data was collected to review trends that may have been present among the group of participants. A confidential log that also assigned the participant an alphabetical letter was developed. This letter was used to code any further data generated by this participant. This log was kept in a locked file cabinet and separate from any data for analysis in this study. The pseudonyms assigned by the
researcher, after meeting each participant are used for presentation purposes in this discussion, since names have more meaning than an alphabetical letter.

Phase 2

The second phase of this research involved weekly phone contact with the DSPs. This assured that the study remained current in their minds and also allowed the chance to answer any questions, process any technical problems with the cameras, and keep track of how involved each participant was in the project. Interaction on the part of the participant varied from extremely active (4 participants) to needing reassurance around self-efficacy (1 participant), the remainder of the participant fell in the middle of the two extremes. There were no problems experienced with the function or performance of the camera.

The cameras were collected when the film was completed, or the participant expressed that they felt there was nothing else they needed to photograph and they were ‘done’ with the camera. This point in time was determined during the weekly phone call. The camera was picked up at each participant’s home. The film was developed at a local store that provided on site, same day developing services, making duplicate copies of all photos and archiving the photos on a disc.

Data was collected during phases 3 and 4, through one-on-one interviews and a focus group meeting. The aim of these methods was to allow the participants to be the experts at generating their personal description around health and wellness. In addition to these methods, field notes were kept during the entire process as well as close contact with the committee chair to monitor the overall experience.

Phase 3
Once the film was developed, an appointment was made to meet with each participant to learn more about the meaning of the picture. These appointments were driven by the participant’s schedule. Specifically searching for times when the participant would be home, in an unhurried atmosphere, and avoided meal times. These meetings lasted approximately one hour and the entire conversation about each photo was audio recorded.

During this one hour interview, each photograph was discussed with the participant. The participant explained why they took the photo and how it was meaningful in their life. Sometimes, the participant could not recall taking the photo or the photo was too dark or of a poor quality, making it unusable. However, for the most part, the photos were clear, usable, and the participant was able to provide a description of the meaning. With these photos, the concentration was on the relationships and situations or the events in the photo, in an effort to collect their meaning. A selection of small, colorful photo albums was provided from which the participants chose a favorite album. As the participant shared the meaning of each photo, we assembled the photo album together as their keepsake.

Completed interviews were then transcribed with attention to words, pauses, and tones of voice. Upon completion of the transcription process, the audio tapes were reviewed for a second time, to assure accuracy and completeness of the transcription. Words that were difficult to hear, or any responses that were confusing, were noted. Follow up appointments were made with those participants in an effort to clarify the part of the transcript that was unclear. The follow up meeting was phase 5 of the process.

Phase 4

In phase 4, the focus group meeting was held. The meeting was facilitated through assistance of the AED, who arranged for a meeting on a day and time that was convenient for the
majority of DSPs who participated in the study. The meeting was held in a small room at Rensselaer Arc. The researcher arrived early to the room, assuring enough seating around the table and adequate personal space between chairs so all participants would feel more comfortable. Healthy snacks of nuts, oranges, and water were provided for all the DSP participants. Five of the 9 DSPs were present for the meeting. The meeting was audio recorded. Video was not a feasible due to the shape and lay out of the room. The meeting lasted for one hour with one support DSP, who had arrived late, remaining an additional half hour after the original group had left.

As a follow up, outreach to the remaining DSPs that expressed an interest in the focus group meeting, but were unable to attend, were offered the opportunity to respond to the focus group questions over the phone. One of the DSPs accepted and this interview was conducted via the telephone and audio recorded.

The focus group meeting was transcribed in a similar fashion as the one-on-one interviews, attention to words, pauses and tones of voice. The audio was played through twice to assure accuracy. Any unclear words, or confusing comments were noted and follow up phone calls were placed to that staff member. This was part of phase 5 of the study process.

**Phase 5**

As previously mentioned, in phase 5, selected participants and DSPs were interviewed again, as necessary. The decision to re-interview was based on the following: inaudible words on the audio tape; lack of clarity around meaning of the words used, or to pose a follow up question. Two participants and two DSPs were re-interviewed. The participants were re-interviewed in a face-to-face meeting at their home. This meeting was audio recorded. The DSPs were re-interviewed through a phone call conversation that was audio recorded.
Data Coding and Analysis

Interviews with Participants

Interviews with participants were audio recorded. The audio recorded interviews were transcribed word for word by the researcher. All transcriptions were checked twice against the audio tape and adjusted as necessary. The methodological approach of content analysis was then applied to the data.

Polit and Beck (2008) define content analysis as “. . . analysis of content of narrative data to identify prominent themes and patterns among the themes” (p.517). Fraenkel and Wallen (2000) describe the process of content analysis as “. . . a technique that enables researchers to study human behavior in an indirect way, through an analysis of their communications” (p. 469). The process of reviewing and distilling data down into smaller units, which are then coded allows for collection and analysis of information represented. This involves six phases (Marshall & Rossman, 1999), organizing the data, generating themes and patterns, coding the data, testing emergent understanding, searching for alternative explanations, and writing a final report.

A thorough review of the audio transcription was conducted to organize the data collected. This process also provided a preliminary sifting through, noting the general nature of data collected. Next the transcribed audio text was analyzed for themes, categories, or patterns of responses. The researcher was aware that many different meanings may be expressed as the reality is generated on an individual basis. Next, themes were clustered in an analysis of patterns for meaning, examining how they related to each other and what they revealed about the overall research questions. In addition, the overall success of participant engagement was analyzed as well as any serendipitous findings revealed through the interview process. A member check to look at the interpretation of the data was conducted with the research committee chairperson,
who is experienced in this field of research methodology. At the point that the researcher was certain that the audio recordings were accurately transcribed, the audio recordings were destroyed.

**Focus Group with Direct Support Professionals**

The focus group meeting was audio recorded. Due to the physical layout of the room, video recording was impossible. The audio was transcribed in a process identical to that described for the Photovoice interview process. Once the audio recordings were transcribed the content was analyzed as a group unit of analysis. Morrison-Beedy, Coté-Arsenault, and Feinstein (2001) state that group analysis of themes, interactions, and sequences within and between groups is an appropriate level for focus group analysis. Due to the fact that responding as part of a group may influence the content of the response, the researcher made key notations during interviews, to supplement and triangulate data from transcription and audio recording. Completion of the data analysis from the focus group was gathered in an aggregate format based on themes.

**Trustworthiness**

Research integrity is an overriding concept throughout any study, from question design to dissemination of findings. The terms rigor and validity are most often associate with positivist paradigm and a quantitative research design. In the qualitative field of research, terminology for integrity criteria, are abundant. For this study, this researcher has chosen to use criteria held in high regard among qualitative researchers. Lincoln and Guba (Speziale & Carpenter, 2003) are credited with setting the benchmark equivalent to rigor and validity for qualitative research through the application of trustworthiness. Trustworthiness is developed through five criteria: credibility, dependability, confirmability, transferability, and authenticity.
Credibility refers to the likelihood that findings will be truthful as well as accurate interpretations of data (Polit & Beck, 2008; Speziale & Carpenter, 2003). Credibility in this study was assured through a multiple approaches. First the researcher had prolonged interaction with participants; 2 weeks of orientation, followed up with phone contact on a weekly basis through the DSPs, for up to a 9 week period or until the participant was completed with the photos. A second approach involved validating the interpretation of the data through a summary of the one-on-one interview with the participant at the conclusion of interviews and with the DSPs at the conclusion of the focus group. This allowed the participants to member check the data gathered. Speziale and Carpenter describe member check as “. . . to have those people who have lived the describe experiences validate the reported findings represent their experiences” (p. 38). Credibility was also assured through the use of field notes by the researcher which allowed for self-reflection and growth. Denzin and Lincoln (2008) state “All research is interpretive; it is guided by the researcher’s set of beliefs and feelings about the world and how it should be understood and studied” (p.31). Field notes combined with face-to-face meetings and phone contact with the committee chair also allowed for a peer examination and reflexive critique of the overall process. Changes to interview technique or improvements were processed in real time and implemented by the next interview. Re-interviews with selected participants and DSPs further enhanced the credibility of the study by providing clarification and elaboration of the data.

Dependability flows from credible data. Dependability is defined as stability of results over time and conditions (Polit & Beck, 2008). Dependability was assured in a stepwise process that was consistently applied throughout the study. All participants were approached in a similar manner, with a priority placed on participant understanding and comfort with study participation.
Likewise the DSP was approached in a similar fashion. An orderly outline was used by the researcher to provide consistency in the approach and thoroughness of explanations. Peer examination by the committee chair allowed for any adjustments in the moment to be made. The use of multiple methodologies to collect data provided for triangulation of methods. Photovoice allowed participants to select and self-author the meaning of objects, people, and situations in their life; photo elicitation allowed the participant to comment on objects, people, and places that would by nature be challenging to capture in picture on their own, and focus groups allowed DSPs to share their perceptions of health and wellness for the people they support on a daily basis.

Confirmability refers to the objectivity of the data that can be confirmed by two or more people (Polit & Beck, 2008). For this study, confirmability was assured through the use of audio recordings that were reviewed a minimum of two times and validated through a random review by the committee chair. The use of two people in the review and confirmation removes the opportunity for bias in the data recording and interpretation. Additionally, the use of multiple methods, Photovoice and photo elicitation add a dimension of triangulation which serves to confirm data. Self-critical examination and continual conversation with the research chair helped to reduce any distortions in thinking or interpretations.

Transferability falls on the responsibility of those who will use the findings and refers to the likelihood that results may be generalized to other people in other settings (Polit & Beck, 2008). It must be recognized that this study employed a purposive sampling of participants and not a random sampling. The use of a thick, rich description around the setting, processes and data assists in transferability.
Rather than focusing on a methodological approach, authenticity moves toward an ontological approach for researcher and participants (Polit & Beck (2008). This criterion describes authenticity as the faithfulness of researchers to show a range of different realities (p. 540). From a position of reflexive conversation, with the research chair, the researcher was able examine personal experiences, address, and control bias. Authenticity was also assured through audio recording all interviews, verbatim transcripts with self-checking of all work, and frequent checks with committee chair throughout the process.

**Limitations**

Generalizability and transferability to other adults with I/DDs is limited for the following reasons: (a) each participant’s experience with health and wellness is a personal experience, (b) although data saturation was achieved with the sample size of 11, the sampling technique was purposive, therefore limiting the ability to extrapolate, and (c) all participants are part of the same community of Arc.
Chapter 4

Presentation of the Data

This qualitative study used a critical social theory perspective to examine facilitators and barriers to health among adults with I/DDs and perceptions around health and wellness among the DSPs who work with them daily. Authentic in the nature of data collection, critical social theory locates expertise in the possession of the oppressed, in this study the participants. In order to facilitate this process, multiple techniques were employed. The primary methods of data collection were with Photovoice, photo elicitation, and one-on-one interviews of adults with I/DDs, hereinafter referred to as participants. A secondary source of information was gathered through a focus group meeting with DSPs. In total, study participants included 11 participants and nine DSPs, all part of the Rensselaer County Chapter of NYSARC, Inc. Rensselaer community.

Demographics

Demographics of participants included the following. The 11 participants ranged in age from 27 – 69 years, six females and five males. Living arrangements varied based on individual need and ability. One participant lived in his own apartment. The living arrangement for this participant was truly independent in that his apartment was not considered under the regulatory guidelines of the NYSARC community. Supportive services were provided according to his needs. A second participant lived alone in a Supportive Individualized Residential Alternative (IRA), and the nine remaining participants lived in, geographically disbursed throughout the county, Supervised IRA’s of various sizes from 2 – 8 persons. The difference between a Supervised IRA and Supportive IRA is related to how relationships with DSPs are experienced. In a Supportive IRA, the DSP is accessible, but does not live in the home. The individual with
I/DD is fully capable of triaging issues around safety and independent in multiple areas of their life, such as finances, medication administration, and transportation. A Supervised IRA is configured to provide onsite support on a 24 hour, daily basis. The level of support is based on unique and specific needs of each individual living in the home.

In addition to age, gender, and living arrangement the presence of acute and chronic illnesses was also identified. Obesity and cardiac disease were the most prevalent co-morbidities, affecting six of the eleven participants and five of the eleven participants respectively. Diabetes and epilepsy followed, each affecting two of the eleven participants. Additional chronic health problems included exercise induced asthma, allergies, arthritis, osteoporosis, and kidney failure. Nine of the 11 participants had multiple combinations of the chronic conditions noted above.

The nine DSPs participating included six females and three males. All had been employed for a minimum of one year. One of the DSPs provided services to three of the female participants. Therefore, a DSPs associated with every participant participated in the study.

Data analysis

Data analysis centered on two research questions which were generated from literature on the historical perspective of disability, health disparities, health promotion, influence of DSPs, and social and health policy. The two research questions addressed in this study were:

1. What do adults with I/DDs, living in the community, perceive as facilitators and barriers to health and wellness?

2. What are Direct Support Professionals’ perceptions about facilitators and barriers to health and wellness for adults with I/DDs?

In total, 189 photographs were taken by the participants and one participant added his own personal photograph to his collection, yielding a total of 190 photographs. Twenty
photographs were eliminated from review due to the fact that the photo was of poor quality (extremely dark or blurry), or the photo was a repetitive photograph (the exact picture taken twice). This left 170 photographs that were reviewed during the one-on-one interview with participants. The participants generated several similar themes of facilitators and a lesser amount of themes around barriers to health and wellness. The DSPs shared common themes that supported health or created barriers to health and had a large degree of agreement amongst the group on most issues.

Data analysis was consistent with a process that reflected the emic perspective, an essential component of the theoretical construct of critical social theory. Verbatim transcripts were reviewed multiple times, distilled into smaller units and then coded for emergent thematic meaning. Regular meetings with the dissertation chairperson provided opportunity to discuss and monitor the process, progress, and emerging themes.

Critical social theory furthers human emancipation through the examination of hegemony, sustained by uncritically accepted normative states. Central to critical social theory is an assumption that normative states are experienced through rules, convictions, and habits of a society (Brookfield, 2005). Emancipation stems from time devoted to self-reflection that leads to the development of self-awareness and self-knowledge. Development of self and self-identity gives voice. Voice is power to those who are oppressed. In light of this theoretical approach to this study and a protracted history of societal oppression, data must be viewed within a context of empowerment. Each participant will be presented as an individual, authentic voice of a person with disabilities experiencing positive and negative opportunities for health and wellness. The participant’s words are presented with their photographs, to the extent that the uniqueness of each person becomes evident to the reader. Pseudonyms have been used for the participant’s
names and all likenesses of people in the photographs. Permission to use these photographs in presentation or publication has been obtained from anyone whose likeness appears in the photograph. Aggregated data relative to the first research question is presented after the individual stories from participants. Data from the focus group is subsequently presented and examined in relation to the second research question.

**Participant Participants Share Their Individual Experiences with Health and Wellness**

**Billy**

Billy was a 40 year gentleman; he lived alone in his own apartment. This apartment was not under the auspices of NYSARC community. His services were self-directed. Billy had no pre-existing acute or chronic health problems. He had recently lost a large amount of weight and to accomplish this, he faithfully went to the YMCA 4-5 days a week. He shared that his recent weight loss had made mobility easier and he spoke with pride of being able to keep the weight off for ‘some time now’. Billy took a total of 13 photos on a wide variety of topics; exercise equipment, food, important places in his life, technology, and his major means of transportation. Through his photos, Billy shared a number of facilitators and barriers for health. Facilitators included a sound knowledge base of health coupled with an intentionality of decisions towards health (healthy eating, exercise, and self-care), support of health promotion behaviors, and self-acceptance. Barriers included a lack of balance in life, lack of support, and fear of lacking advocacy and acceptance. Photographs and quotes around the themes are discussed next.

Billy’s life was largely self-managed and appeared centered around an organized structure guided by rules. This was supported by an intense depth of discipline and self-motivation in his quest for health and wellness.
Yeah, it is the exercise bike. It is a helpful thing as far as if I can’t get to the “Y”, it is there as a quick workout. And then if you connect it with stretches and with sit ups that alone is quite a bit and it is easy, gets the job done. And that is pretty much it, and it gets the job done.

Billy had a sensible understanding of ways to achieve and maintain health promotion in his personal life. In many situations he relied on self-discipline and adherence to set rules and order to achieve his goals. In addition to regular exercise at the “Y”, he relied on supports in his home, such as his exercise bike, healthy food choices and healthy eating habits. Furthermore, he took photographs of his computer, through which he maintained an electronic nutrition diary. The computer technology was used to support wellness, along with “Y” affiliated nutrition wellness chat groups and tracking tools to monitor and maintain his progress. He photographed and spoke of additional supports, “My work out bag, it basically keeps my clothes together so I have clothes to work out in. Without my clothes I can’t appropriately work out, my water bottle and my clothes”. A solid knowledge of health, healthy choices and ways to maintain health through exercise and healthy eating were represented in six of Billy’s 13 photos.
I go to the “Y” 5 times a week. I know when I took it [this picture], it kind of made me take a step back and say ‘you know, you need to quit working so hard on reaching the next goal in front of you, and appreciate the fact that you are even there’. Rather than trying to search so hard for a connection with other people all the time. You know, its some people what you get is what you get. You need to learn to feel the love that they do have.

An insightful sense of self-acceptance was a reoccurring theme displayed among photos and the interviews with Billy. He continued in his interview regarding the “Y” and losing weight, “you know, being hard on yourself you miss that celebration, because you know, you are use to thinking of celebrating as being with people and you have to learn how to do it with yourself”. Self-acceptance also included accepting diversity and adversity. In a photo he composed of different teddy bears, he stated the following:

Well, the teddy bears tend to be just, they symbolize acceptance, learning to, because if you see the difference with the teddy bears, they are not all teddy bears, there is BonTon bear, but in the picture somewhere there is like a mouse. The mouse is different from all the others, so it is like accepting adversity.
Often Billy referred to a sense of balance as key to maintaining his health. He acknowledged balance was a struggle; he needed to be aware, intentional in his actions, and thoughtful of his approach to life on a daily basis in order to maintain a sense of balance. He spoke of this in reference to many things, drinking too much coffee, drinking too little water, monitoring salt intake. He spoke of a sense of balance with using technology appropriately, using technology for its potential as a helpful tool, and not being distracted into chat rooms that are not helpful or healthy. He shared the following about a picture of a cupcake at a local café.

Okay, I was hoping we got this one. This is interesting. This was the Flavor Café. Again, you know, going back to the coffee, if they’re eaten and it is a planned thing when it is a social event, then it is no worse than having an occasional drink. But it is when you do it, and it is just “yum, yum, yum” – that’s when it is not good.

Planning for social trips, such as the Flavor Café, allowed Billy to address his diet, weight control, and life choices with a sense of intentionality. His emphasis and ability to plan was a facilitator of health and allowed him to maintain a sense of continuity in his life.

During the Photo Elicitation phase of the interview, Billy shared the following astute comments about the photo of the nurse in reference to barriers that health care professionals can
present. The reality of the relationship between himself and a health care professional was identified as being influential in directing him towards or away from health.

They [a nurse] can [be a barrier], if they are not compassionate enough, where they put the problem more on you to survive than recover. But if you do get a nurse that is more compassionate towards what you are going through, it could be a very helpful thing.

In discussing situations that Billy may have wanted to photograph but was unable to find the opportunity or the subject matter, he was quick to mention humor and the importance of humor. He shared his experience of using humor when he was recently a patient in the hospital. Again, he was able to also discern the reality of power in relationships that moved him towards or away from health.

If you have a sense of humor about it – it is helpful. But very few people know how to be humorous when they are injured. Those that do though; tend to grab hearts, so you do get help. I mean if you grab hearts, you are more likely to get better treatment, if you should end up in a situation, because people are going to advocate for you.

The sense of balance was presented again, but from a barrier perspective. Rather than spend time watching mindless TV, Billy would much prefer to be involved with his music or artistic endeavors.
He shared his intuitive understanding about common, ever present temptations in his life.

Yes, the boob tube, I call it. Try to envision a couch potato that sits in their recliner. He’s doing – they are doing nothing, really. A TV just sits there and it doesn’t help you. All it really does, it gives you something to look at. The only way a TV actually is a benefit to you, is if, like for example, if you are watching a television program but you can do a bike at the same time and you can work out at the same time. I suppose it can be a stimulator. But again, that is a very limited thing because what are you going to do after a half hour? It is a distraction from prioritizing your life and it doesn’t help with relationships which make a further barrier towards health.

Self-acceptance and the risk involved with being accepted were viewed as additional barriers. Billy did not take any pictures that included other people in his life. The question posed to him, asked if he preferred to work out alone at the YMCA or with other people. The following was his response.

I wish, actually, I had what I would call pals at the “Y”, but it is really tough to get that kind of thing, you won’t believe, you won’t believe how hard you have to work to get that kind of interaction. You have to be right in with classes, it takes
all kinds of risks, all kinds of knowing that you might be sore the next day – you almost have to drop any kind of fear. Fear on an emotional level, like “am I going to fit in?” you really have to trust the classes. . .

One photograph at a time revealed a story of facilitators and barriers in Billy’s life. When considered in totality, the pictures represented an amplified mosaic of Billy’s life. Billy valued setting goals, a sense of order imposed by knowing how to live within set “rules”, expressed a judicious knowledge for planning and achieving goals, a willingness to work diligently and with intentionality, and openness to working with technology. The interview about the photographs was designed as an assessment that gathered information about Billy’s perception on health and wellness, however through the process; the interview became an intervention and opportunity in which he reflected on his life mosaic. During the interview process, he was transitioned from a position of actively participating in life, to a position of surveyor of his life and his accomplishments. He stated this process gave him the opportunity to value the successes he had attained. Acknowledgement of diversity, adversity and the importance of advocacy were expressed, particularly in relation to the influence of relationships and movement towards or away from health.

Manny

Manny was a 54 years old gentleman. He lived in a home that was designated as a certified Supervised IRA with 4 additional people with I/DD. Direct support professionals were provided on a 24 hour, 7 days a week basis, at the home. Manny had a mild hearing loss that was corrected with the use of bilateral hearing aids. He also wore corrective eye glasses and had seasonal allergies. He worked part time at a local grocery store. He volunteered at a local community hospital, delivering the mail to the patients. Manny took 15 photographs that covered
a variety of subjects; people, food, hobbies, employment, and exercise activities. In general, he depicted many more facilitators than barriers. The facilitator themes included pride, relationships with family and friends, spirituality, health promotion behaviors, emotional health, and knowledge of healthy eating. The prominent barrier was a relationship issue with a house mate.

Manny filled with pride when he spoke of his job. His work provided meaningful context to his day, provided a healthy routine, as well as an organizing focus for day to day living.

See on there where [it says] Price Chopper? There is my shirt. See! I work at Price Chopper. I worked there for 11 years, next year it will be 12 years! I get ready for work, I comb my hair, and I shave, I put on my pants, no. my shirt first and then my pants. I got black shoes that I wear. I got a brand new hat too. You know what it says? Price Chopper #1 – Price Chopper.

His employment also provided a long term relationship with other employees and the company. Manny also took pride in his work skills, he explained “I am good at it [work], I put the toilet paper and the tissues all together. I put the eggs on top. Then I fold the piece of paper and put it in the bag. The paper goes in the bag”.
Relationships were an important facilitator of health in Manny’s life, in and out of work. Manny took pictures of other people who lived at his home, his family and Judge Judy, a TV celebrity who held a special place in his heart. The photographs captured how these various relationships added richness to his life.

“This is Becky and Adam. They help me to feel good. They are my housemates.” Manny was perceptive to different relationships in his life and expressed a high value towards the many different roles. In addition to his friends in the above photograph, he also took a photograph of a family collage. Manny explained that his family is “a part of my life.” When he spoke about Judge Judy, he first identified her as a Grandmother and secondly described her passion for truth and honesty in her role as a Judge. Manny appreciated her adherence to concrete rules. This was evident as he quoted some of Judge Judy’s meaningful comments, “another time she said ‘I don’t believe you, you are full of bologna, I don’t believe you.’ You know why she said that, some boy was lying.” His relationship with Judge Judy was special to him and he considered her to be his best friend. He had painted and sent to her a piece of his art work. In return, a framed 8 by 10 inch autographed picture of Judge Judy hangs next to his family collage. The opportunity to
connect with someone of notoriety, outside of the confines of his daily life, offered a sense of
distinction and recognition. He shared the following:

I made a picture for her [Judge Judy]. I got colors on it, I got paint on it and I
mailed it to her so she can get it. I mailed it to her. I coloring it, I put it like that, I
love brown. And I mailed it so she can get it. Look, it [the autographed photo]
says ‘my friend Manny’, she signed it herself. I am her best friend.

Relationships facilitated Manny’s health through the happiness, and support they
provided. However, Manny also appreciated the reciprocal nature of a meaningful relationship.
This was evidenced by his gift to a television personality, his ability to give to others nurtured his
sincere sense of caring.

Manny’s art work was another source of pride and positive emotional health. He
explained the following about his art work.

“You see these pictures here, this one here, I make the line there. And it looks real good
on it. I am a good artist and I make good pictures. [I do this] everyday, weekends, Saturdays and
Sundays. ”He explained how his hobby began: “A long time ago, one of those pictures, I got it
from Tom. He took me shopping and that is what I got. I gave one to Judge Judy; I made her’s [sic] brown.” When asked about how he felt when he painted, Manny shared, “I feel good, I like it, on the inside, I like it,” as he rubbed his chest with his hand, over his heart. Manny’s choice of words, emotional tone, and physical motions at this point in the conversation conveyed a deep internalizing of his role as artist, and sense of completeness that supported his health.

Spirituality was another facilitator theme shared by Manny. He emphasized the praying hands, which was hung near the pictures of Judge Judy and his family collage, “see this here, the praying hands?” Manny expressed that he relied on reading the bible, his own bible during times of conflict with another housemate. These times of conflict were what Manny had shared as a barrier to health. This was what Manny shared as he reflected on a picture of one of his housemates. “This guy right here, he gets me upset. He calls me names a lot and I don’t like that”. When asked how Manny responded when this happened, he explained the following.

I don’t like it; I go to my room with my pictures [painting]. It helps me to relax and be calm. I got a bible too. I got my own bible. With my bible, I study my bible and it helps too.

Manny took a photograph of the hand held weights he used to exercise his arms and build muscles, a positive health promotion behavior. He described his exercise routine as being a solidarity activity, something he does alone and not with other friends or house mates. He was proud of the strength and definition in his bicep muscles. During the interview, he was eager to show this author the results of his efforts. Manny talked about the weights and shared the following.
Sometimes I work out with the dumbbells like that. That is a picture of my dumbbells. They make this [and he flexed his bicep, encouraging this author to feel his muscles]. I mostly do it alone. I close my door and just do it. I do it by myself.

Manny’s photographs presented a mosaic of themes that he identified as important to his health. He valued his work, the longevity of his relationship with his employer as well as the routine and focus it provided on a daily basis. A sense of pride in his skills was shared through the one on one interview about his daily work. Spirituality and relationships with people and the variety of roles experienced through the relationships were additional important facilitators.

Friends provided social experiences, while family relationships provided a sense of completion. His art work provided a sense of control, independence and release in his life. When asked what he did with his art when he completed the pictures he stated “I give them as gifts, for a birthday, or anniversary, for a wedding. I give them to people I care about”. Negative relationships were a barrier and had potential to affect emotional health.

Rachel

Rachel was 49 years old and lived with a roommate in an apartment identified as a certified Supervised IRA. In the home, DSPs were present on a 24 hour, 7 days per week basis.
Rachel was overweight but had no other acute or chronic health concerns. She completed 27 photographs of which 16 were used for the interview. Rachel was extremely social and this was reflected in her photographs. She had taken pictures predominantly of people, two photos of her church, and two photos of her cat. Common facilitator themes, that she shared, included relationships, spirituality, emotional health, and knowledge around healthy eating and common preventative screenings. Barriers focused on attitudes of health care providers and relationship issues with friends.

Friendship and the dynamics of multiple friendships were both facilitators and barriers for Rachel. The ability to “talk things out”, the use of humor, and emotional support were highly valued, while manipulative behaviors and arguments created unhealthy tensions.

[This is] Jill, [I took it] because she makes me laugh. If I am down, because I have some problems, well I crash. It is like, her [sic] and I got the same level, she understands, her and I have the same levels, so we connect, we talk to certain people. Like right now, I am not really happy or sad. I am supposed to be on one side and I can go down quick. So she makes me laugh. Certain other people here do not.
Rachel was excited to see the picture of her cat, Socks. She took multiple pictures of Socks. A genuine sense of responsibility, caring, and unconditional love for the cat was united with Rachel’s sense of being wanted and needed. The reciprocal nature of the relationship was revealed in her description below.

She likes to play, we have a fan in my room and then we have one in the dining room. She sits there and stares at it, like, when it is going around. And I think that is so cute, how they can sit like this, and hitting you in the face with her tail. She don’t [sic] want Jill or me to leave. She cries a lot. I pick her up and rock her.

Spirituality was another important part of life for Rachel. She had taken four pictures at her church, but could only recall taking two specific photographs. She stated it was possible that someone else used the camera and took a few photos when she was at church.
That is the church we go to. Little Robin, me and Karen, sometimes it is Holly. But now it is like me, Robin and Karen. Before, I never went to church. I went to church when I was born and raised in Troy. They had a church, it wasn’t a Catholic church.

Through the photographs of the church and interview, Rachel reflected back on going to church when she was younger, “I went to church when I was born and raised”. Although going to church now was not a regular weekly event, she indicated that from her perception “it is supposed to be”. Her faith provided a guidepost around acceptable and therefore healthy behaviors. She explained, growing up “there was a lot of drug addicts . . . and we lived right near it, [church] was walking distance”. Rachel described a contrast between the illicit street activity and her spiritual development during her youth. Her return to church based activities was something she valued as a positive influence in her life, sharing that she had recently be baptized in the water.

During the photo elicitation interview, Rachel shared that she needed to go back for another eye examination, she stated “I can’t even see the small lines; I have two sets of glasses. They are strong glasses. My brother and I, our eye sight isn’t like everybody else’s.” Other screenings, such as being weighed or having her blood pressure checked drew different
reactions. Being weighed was a neutral experience for Rachel, she stated “we get weighed on Monday’s and it doesn’t bother me.” Her reaction to having her blood pressure assessed drew a more extreme reaction. She stated the following when she looked at a photograph of a blood pressure cuff, “NO, I know when my blood pressure is up. I can do that in the morning by myself. Monday is the day, if we have an appointment. They do it twice, in both arms and they leave a mark!” The photograph of the hamburger prompted her to respond “I get sick if I eat those, it is not healthy.” She was more hesitant when she spoke about the photograph of the hospital. She stated the following:

Well next week I have to go to the hospital myself. I am not looking forward to it because the lady that sees me [health care provider], she was rude! Not just to me, but to other staff. At the end, she put me on some stronger medication. I am on two medications, I am like a zombie.

Rachel’s photographs created a mosaic heavily reflective of people and relationships. Much of her interview focused on the drama that relationships with friends brought to her life. “Yeah, her [sic] and I had an argument. And I don’t like to have people walk all over me either.” “Sometimes, when things are bad, if one person gets mad the other one jumps in and starts to call me every name in the book.” The powerful influence of these relationships moved her toward or away from emotional health. Her relationship with her cat and her sense of spirituality were helpful in providing a purpose and stability to her life which facilitated health. Adversarial relationships and interactions with people created the most significant frustration for Rachel and were perceived as barriers to her overall health.
Elizabeth

Elizabeth and Rachel were roommates. The living arrangement was as described above. Elizabeth was 62 years old. She had seasonal allergies and was obese. Initially, Elizabeth expressed great interest in participating in the study. She had the camera for 33 days, and took four photographs. When asked why she took only four photographs, Elizabeth’s repeated explanation was “oh, I don’t know”. DSPs that were at Elizabeth’s home during the interview stated Elizabeth was “ambivalent” when it came to taking pictures with the camera. Of the four photos, Elizabeth was only able to speak to three of the photos. The fourth photo she didn’t recall taking. The three photographs she was able to describe were pictures of her treadmill, her bed, and a friend. Unfortunately, the quality of the pictures poorly represented the content. In general, facilitator themes revolved around health promotion behaviors, happiness, and knowledge of healthy eating. No barriers were shared during the one on one interview.

Elizabeth identified her treadmill in one photograph. She shared her knowledge about the importance of exercise as well as avoidance behaviors. “This is a treadmill. I do exercising on the treadmill. Well, I should go on the treadmill, but I don’t know. I don’t do it very often.” Another photo was taken of a friend, about whom she commented “he makes me happy.” When Elizabeth viewed the photo elicitation picture of the hamburger she stated the following “no, I couldn’t eat something like that. I don’t eat like that; I used to eat like that but not anymore.” The question of why she no longer eats like that was asked to which she responded “because I am on a diet. I eat chicken, fish that is pretty much what I have.”

In general, Elizabeth was able to share some of the facilitators that move her towards health. She described with clarity her approach to healthy eating as well as foods to avoid. She was able to discern health promotion behaviors such as using a treadmill, and had a sense of the
temptations that prevented her from using the treadmill more often. She also shared that her bedroom was important because that is where she sleeps, which she valued as essential to health.

**Thomas**

Thomas was 49 years old. He lived in a house that was designated as a certified Supervised IRA with four other housemates. The home had DSPs present on a 24 hour 7 day per week basis. Thomas had a history of deep vein thrombosis, depression, and elevated cholesterol. Thomas took 25 photographs, more than half of them were of the outdoors. The remaining were scattered on the subject of food, people, and his cherished pets. In general, facilitator themes shared by Thomas included relationships, spirituality, a knowledge of healthy eating and self-care, and emotional well-being. Barriers revolved around boredom. The following were photographs and information shared on these themes.

“That is Nancy. I took a picture of her. She is nice. She helps me out when I go out, a lot, outside, I do. I took the picture all by myself.” Thomas valued relationships for the willingness and caring of others to make his life more complete. In the photo above he spoke of a specific DSP, subsequent photos highlighted additional DSPs that helped him achieve independence in his daily living. “Theresa is good stuff. She helps me out, helps me to save my money. Don’t spend it all. I spend it all the time down at Stewarts.” The bond with DSPs was deep. In
particular, he spoke of one DSP who no longer worked at the home where Thomas lived. He had taken a picture of her. When he saw the photograph, he commented the following, “I miss Diane working here. Diane is a sweetheart. She stops at the house and I give her a hug. I miss her a lot.”

The influence of nature on health was a subtle revelation captured through Thomas’ photographs; at times, referring to spirituality and other times referring more directly to the beauty of nature adding to his sense of his well-being as a calming presence.

![Flag on the wall](image)

Thomas referred to his sense of spirituality when he spoke about this photo, above. The conversation went as follows “that is a flag on the, out on the wall out there. I took that. [It means] God. I like the flag and I like helping people. God helps people. . . and I help everybody around here”. Thomas conveyed a sense of connection to a larger than life concept which he experienced as his commitment to help, helping those whom he lived with as well as his pets and animals.
“That’s all the flowers we had outside the house. I took that, I did, it’s helpful.” When asked how it was helpful, he responded “I like being outside, I don’t like being inside. Next year we are going to have a garden; I am going to be doing that.” When the picture of the trees, on the right above, was shown, Thomas immediately spoke to the picture with an emotional tone in his voice. As he referred to the trees he stated ‘The leaves on the trees! The color orange, I like the color of the leaves.” His preference for being outdoors was reflected in the sheer number of outdoor photographs as well as the variety of topics. However, as he described his pictures it was apparent that he was perpetually contemplative of the outdoors and these types of activities, crafting plans for future experiences.

Thomas’ relationships with his animals provided a great sense of emotional well-being for him. They provided a sense of purpose, responsibility, and caring. In addition to two photographs of his cat, he took photos of his birds too.
That is Chico, Chico came into the house. That is my baby. That is my son. I got two birds and I got a cat. I have enough pets. I don’t know what I am going to do with them all.

Thomas spoke about healthy food choices; acknowledging that he had a conceptual understanding of healthy eating although at times was conflicted by daily routines and influences. Relying on DSPs was helpful for him. Woven in his description of healthy eating was also his description of a barrier he struggled with often, boredom.

“I made that, macaroni salad. We have pepperoni and cheese. I cook and the staff helps me. I get bored and I need something to do.” Thomas responded to the photo elicitation of
the hamburger with a large smile. He stated, “I like that!” Then, he was quick mention that this was not a healthy food choice and DSPs encouraged him to select food that was less ‘greasy’.

Thomas did not take pictures that included any exercise or physical activity. As a follow up on this, Thomas shared the following:

Nurse researcher: “I noticed you didn’t take any pictures of any sort of activity, like walking, bowling, or other exercise. Do you exercise?”

Thomas: “A little bit, but not much, I walk to Stewarts and back. And that’s what I do. I take my own self.”

DSP interjected: “Because that is Thomas’ social time, down at Stewarts. He will sit there, he knows everyone. He might want to sit there for an hour, and then he might want to grab something. There is bench between Stewarts and here, by the water. The ducks, or no, actually the Canadian Geese are there, that is where they cross the road. Sometimes he will have a soda or a snack and he will sit there and watch them so he could be gone two hours or maybe gone 15 minutes. And that is just his time, he always goes alone.”

Nurse researcher: “Can you tell me what is about that makes it helpful for you?”

Thomas: “I like being outside a lot. I don’t like being inside the house, it is bored in the house, sitting around. I like being outside.

Nurse researcher: “So what do you do in the winter then, do you still walk to Stewarts?”

Thomas: “yeah, I walk down to Stewarts, I sit inside the Stewarts.”
Thomas’ level of independence and daily routine, coupled with a regular social destination, afforded him a sense of contentment, meaning, and consistency.

In general, Thomas created a mosaic of pictures that represented his emphasis on being out in the community and one with nature, positive and healthy relationships, responsibility for others as well as his pets, and a more limited knowledge of healthy eating. Initially, the importance of being outdoors for Thomas was subtle. This became evident as more pictures were reviewed. His first 10 photographs were taken at an animal rescue farm, and seemingly there was little correlation to any personal health promotion benefit or health barrier. As the interview progressed, the connection of being outdoors coupled with his passion for animals and caring was more evident. The sheer beauty of nature appeared to speak to Thomas’ heart with a sense of fullness and contentment. His passion for experiences outdoors provided a focus and direction for future planning. His genuine caring for animals, pervasive concern for their well-being, and his reference to terms of endearment such as ‘son’ spoke to his strong ties to these relationships. He struggled with boredom. He expressed pride in the photographs that he took, stating on numerous occasions, “I took that photo, all by myself.”

**Martha**

Martha was 27 years old. She lived in a community home that is designated as a certified Supervised IRA. There were five additional house mates and 24 hours a day, 7 days per week, DSPs were provided. Martha had a history of heart failure which necessitated the insertion of a pacemaker. She also had been diagnosed with seasonal allergies, diabetes, and her weight placed her in the category of obese. Martha’s family was an active presence in her life. Martha frequently spent her weekends at home with family. Martha took 11 photographs; nine photos were of food, mostly from a recent trip home, and one photo each of a friend and her
medications. In general, the facilitator themes shared were a solid knowledge of food choices, self-discipline, self-care knowledge, and friendships. Barriers were identified around environmental influences from the community and with her family.

Martha had a grounded concept of healthy and unhealthy food choices. This knowledge empowered her to make appropriate choices despite tempting situations and influences from the environment. This sense of empowerment also supported behavioral choices that reinforced healthy approaches to eating.

Martha: “This is roast beef on a plate. Is it a good choice or a bad choice? And there are little strawberries. Strawberries are good, they are healthy. And – meat, roast beef is, well, fat, fattening”.

Nurse researcher: “Now where was this happening, who was eating this”? Martha: “I was at a party”

Nurse researcher: “So when you are at a party, and there are foods like this, is it harder to make healthy choices or can you look at the table and choose?’

Martha: “yes”

Nurse researcher: “so what do you do?’

Martha: “Yes, I eat only 1 portion, only one plate that is all I have”.
Nurse researcher: “Even when you are at a buffet and you can go back, and back and back?’

Martha: shaking her head in agreement – “only 1 portion”.

Martha shared that choices were difficult, and she worked hard at being disciplined.

Martha: “I took this picture in the snack closet, in the office. Pudding, sometimes I eat this, is healthy, but it has a lot of sugar. Sweets are NOT good. Cranberries, raisins, those are healthy.”

Nurse researcher: “So when you look at this cabinet, what is it like for you?”

Martha: “Actually, see right there [lower left corner of picture], I say ‘hmmmm, which one would I like to pick?’ It is hard. It is hard and I stay here and say ‘which one do I want to pick out?’

Environmental influences were significant and pervasive both where Martha lived and at home with family. Martha spoke about eating pizza when she is home with her family. A choice she identified as very unhealthy. She also spoke of going out to dinner with family and consciously choosing a salad over other less healthy choices.
You know what, think about restaurants. I go out and have fun with my parents. And I make my healthy choices of a salad or another is a burger. But hot dogs are fattening and the buns! So, I think Ted’s Fish Fry – and oh, greasy food is not good for me, and salt, salt intake, watch out [for] what I eat! Sometimes it is fried dough, or fish is fried, it is not good for you.

Relationships were identified as important for health. Martha explained the following regarding a photograph that showed a special friend. “This is my friend, Billy. He comes – [to] his programs - he loves me! He is a good person; he is [a] good choice. He is a good person in that like he can be a friend.” In addition to her friend in the photograph, Martha spoke of her immediate and extended family through some of the photographs.

Astute in her assessment of relationships, Martha values the friendship but acknowledged the potential influence for negative behaviors. The picture of her friend Billy included the fact that he was drinking soda. This was something that Martha stated she avoids, “trust me, I don’t drink soda much, water instead.” She also spoke about the increased challenge to eat healthy when she went home to visit her family, “a big difference [eating healthy at home]. It is hard,
hard choices for them too. Sometimes I get baked chips, they are good for me but regular ones are bad.”

In general the mosaic of Martha’s pictures painted a picture of sound knowledge of healthy choices and a stated commitment to self-discipline. She described healthy foods and unhealthy foods with ease. Although she was able to photograph and describe healthy food choices, obtaining a healthy weight was a struggle for Martha. She also commented on TV reality shows that focused on people who were obese; she stated “I am never going to eat like that again.” Martha valued relationships that supported her health, frequently identified those as with family and DSPs. Martha had one photograph of her medications, which she identified as “this is a good choice, it is important for me to take my meds every day.” Negative influences from the environment were pervasive in Martha’s life, at home with family, in the home where she lived and in the community. She was able to identify these temptations and articulated the need to choose, on a daily basis. Compared to all the participant participants in this study Martha spent the greatest amount of time home with her family. She visited with her family just about every weekend.

Julia

Julia was 45 years old. She lived in an apartment with a roommate and across the hall from Rachel and Elizabeth. Their apartment is designated as a certified Supervised IRA. DSPs were provided 24 hours a day, on a daily basis. Julia had been diagnosed with the chronic condition of arthritis and her weight placed her in the category of obese. Julia took 11 photos on a variety of subjects; people, food, exercise, her home, and her pet fish. Julia identified many facilitators to health, such as happiness, relationships, knowledge of healthy eating, and physical activity. There were no barriers identified.
Julia’s photographs began with a photo of her home, a place that provided her comfort, safety and sense of belonging.

![Home photo](image)

Julia shared her reason for taking this photograph, “because I am lucky to be here. I went to other places; I went to Pauling Ave, and the next one I went to. I have Jill, my roommate and fun with Karen.” Julia was thankful for her home, the companionship and loving, caring relationships.

Exercise was important for Julia to maintain her health. In addition to taking pictures of her bowling ball Julia also took a photograph of her treadmill and a tied dyed t-shirt she made for as a member of the Biggest Losers.
“Yes, well I was standing on my treadmill and I was trying to lose weight and I am very happy.” The question was asked if she had lost weight by using her treadmill. “Yes I did.” Julia was unable to recall how much weight she had lost. In addition to walking on the treadmill, Julia also bowled on a recreational league. She included photographs of her bowling ball and described how she exercises her arms “all week long” to build muscles to improve her bowling game. Julia’s membership in the Biggest Losers was highlighted by the special tied dyed, team T-shirt she wore. She assisted in making the shirt, which also included her name on the back, in large letters. Julia was an individual, yet a part of larger health promotion team, that provided a sense of belonging, support and consistency for reaching goals. Julia was astute to the importance of healthy behaviors in her life.

Julia enjoyed working with the staff to make healthy foods. This positive relationship added to her sense of accomplishment and self-efficacy. Her eyes lit up when she saw the photograph she took of a homemade pizza, a group cooking project at her home.
“Yeah! We made that, I am very proud of my staff, it is healthy too.” Knowledge of healthy eating was revealed during the photo elicitation of the super-sized hamburger. When shown this picture, Julia remarked, “my favorite! Lettuce is okay. Tomatoes are okay. Not the burger, and too many breads.” Julia was asked how she felt when sees saw someone else eating this and she responded “I don’t know.”

Relationships are important to Julia. Photographs included pictures of support staff, her house mate, and one group photograph, shown below. She shared her sense of connection with the variety of people in each photograph. Although Julia used fewer words to express the significance and meaningfulness of relationships, her non-verbal facial expression and warm tone of voice conveyed an additional emphasis to the meaning of her photographs.
Julia: [You have] Karen, Eileen, Sally, Jill, and Katrina.

Nurse researcher: So tell me about this picture, why did you take the picture?
Julia: I like everybody.

Nurse researcher: What is it about them that you like?
Julia: I like anybody, my staff, the best workers to have. I had 2 twin brothers.
Marco and Tim, I forgot his girlfriend’s name. That is Katrina. I like her a lot – she is very kind.

Julia also expressed relationships with support staff are special to her. She conveyed that staff wanted her and helped her to lose weight. “She [support staff] is very special person. I love her, I want her to work here, I am proud of her.” In reference to another support staff, “she is very kind, and she gives me laughs all the time.”

In general, the mosaic Julia created with her photographs and the story she shared revolved around facilitators of her health. She valued relationships in her life, with support staff, family and roommates and was thankful for her home. She described these relationships with a
sense of reverence and most sincere gratitude. When she described her pet fish, Sammie, she was quick to highlight her responsibilities to her pet. She took care of him by “feeding him and talking to him.” This hinted at Julia’s dedication to care for others as has been her experience as well as her sense of accomplishment in being successful in this endeavor. She possessed a sound knowledge around healthy foods. Her physical activity of bowling, using her treadmill and working with weights and membership in the Biggest Losers, supported her recent weight loss and movement towards a healthier state.

Richard

Richard was 57 years old. He lived in a home that is a certified Supervised IRA with seven additional housemates. DSPs were present 24 hours a day on a daily basis. Richard had a diagnosed seizure condition. He had colostomy years ago, but at this point in time, he was healthy. Richard took 23 photographs. He included himself in half of the photos taken. In general, facilitator themes revolved around happiness and friendship, and pride in his accomplishments. Although Richard didn’t identify any barriers, his knowledge of healthy eating was more limited than other participants who participated. With a small number of the photographs, it was more challenging for Richard to speak deeply about the picture. When asked questions such as why he took the photograph or what was the meaning, the response was either silence or “I don’t know”.

Pride was a theme in Richard’s photographs. He spoke of pride in the performance and accomplishment of routine tasks or chores. He used photographs of trash pails, washing and dryer machines, and a clothes basket to illustrate these situations. During the day he was interviewed, he was completing the laundry and sat next to his empty clothes basket waiting for laundry to be completed, “I do [laundry], in fact, I am doing it now. Today is Friday, so I am
doing it”. Success with responsibilities and maintaining an organizing structure in his daily life supported his sense of pride. He also spoke of pride in accomplishments, such as victories achieved during his lifetime. This photograph represents a trophy he won for bowling.

Richard: That’s a statue

Nurse researcher: And what was it for?

Richard: It was for bowling. I bowl on Mondays.

Nurse researcher: And do you enjoy that? Do you go with other people?

Richard: Yep.

Nurse researcher: Do you go with other people?

Richard: Yep, I do.

Friendships were important facilitators of health promotion for Richard. He took a variety of photographs and expressed similar thoughts and beliefs about each photograph. Friends from Riverside Industries, his place of work, DSPs that he held in close regard and this photo below, with his close friend, and housemate, Paul, were included.
Nurse researcher: Here you are again Richard.

Richard: Yep.

Nurse researcher: And why did you take this picture?

Richard: That is Paul, ain’t it? Because he sits by me. He is my friend.

Nurse researcher: What is about your friendship with Paul that (before the statement could be finished, Richard answered). .

Richard: Happy, he is happy.

Nurse researcher: So when you are with friends who are happy, it is good for you?

Richard: Yes.

Richard enjoyed going to Dunkin’Donuts, which was a short walk, across the street from his home. Much of the social context of his daily activities was experienced through trips to Dunkin Donuts.
He described the above picture as follows.

Richard: That’s me!!!

Nurse researcher: That is you. Tell me why you took that picture

Richard: Because I was drinking it.

Nurse researcher: What was it that you were drinking?

Richard: Coffee coolata.

Nurse researcher: And is that good for you, does that make you healthy?

Richard: Yes, healthy.

Nurse researcher: Who do you go to Dunkin Donuts with?

Richard: Anybody.

Other photographs show Richard drinking coffee at different locations or at picnics. It was evident that Richard was content and enjoyed his visits to the coffee shop. During the interview process, Richard frequently used the word ‘happy’ to describe his photograph. This hints to happiness as an essential component of health for Richard.

In general, the photographic mosaic created by Richard and the corresponding description he shared focused on his happiness and friendship, and pride in accomplishments. These were identified by Richard as facilitators to his health. Although he revealed no barriers, he described the super-sized hamburger from photo elicitation initially as “yeah, it’s healthy”, and then adding “well sometimes but not all the time.”

**Derek**

Derek was 50 years old and lived in a home identified as a certified Supervised IRA with two additional housemates. DSPs were present 24 hours a day on a daily basis. Derek lived with more chronic illness than the other participant participants and appeared to have more medical
fragility. He had been diagnosed with diabetes more than 38 years ago. His diabetes was labile and resisted control despite focused attention to the medical condition. He had renal failure that required he undergo dialysis three times a week. He had high blood pressure and was blind in one eye. Derek took 15 photos with his camera, covering the topics of food, people, and the management of his diabetes and kidney failure. Derek was the only participant to add a personal picture to the photographs he took with his camera. This photograph was picture of him connected to the hemodialysis machine. In general, facilitator themes revolved around a firm knowledge of healthy eating choices, relationships and friends, and positive health behaviors. Barriers were identified as negative environmental influences.

Derek had a medical diagnosis of diabetes and kidney failure to the extent of requiring hemodialysis three times a week; therefore diet had a large influence on his overall health. He demonstrated a solid understanding around diet restrictions.

Derek: As you can see, it is mostly all pastries. This is where I have to stay away from. When I go there, I only order coffee. . . The reason why I took this picture is to tell you this is NOT good for me. They do have, I did it once, a sugar free pie or something. And John [support staff] turned around and said ‘what are you doing?’ I said ‘I ordered a sugar free pie.’ And he said ‘oh no, oh no, we can’t have this.’
Nurse researcher: Even though it was sugar free?

DSP: Yeah, the problem was it wasn’t snack time and we had no carb thing, we had no insulin.

Derek: Yeah, I get in trouble for it and I have to watch what I eat. I have to cover for it.

Derek understood diet limitations and restrictions required of his diabetes, and he conveyed a desire for honoring the healthy eating habits and foods that would benefit his overall health. Yet, personally experienced situations provided the opportunity to reflect on the enormity of the situation when it came to competing demands in life, eating healthy and being social.

Nurse researcher: So that is good that you know what is NOT good for you. But what is it like for you when you go to a place like this and you know you can’t eat it?

Derek: It is hard, very hard. You know like, we go out and we get coffee. And I don’t mind that. It is just when they turn around and they, these guys, usually in the morning we go there, and we have, well a breakfast wrap. You know it’s hard, even though they can eat it and I can’t, but what I am trying to do is [talk to] Lisa [nutritionist]. If I could eat it and let her know that I am going to have it, so that way I can substitute my insulin. I am trying really hard not to do what I am doing now, which is really bad. I should not be cheating like this.

In a social context, relationships were equally important to Derek. These social times often happened at places associated with food. He continued in describing his time at the café:

Derek: The Café gets me to meet new people; you know there is a lady that comes in, the little one. . . I can’t think of her name. . . But she comes down and she was
talking to me one day, about one of her people that she works with. Turn around
and she is asking me to talk to one of her staff about diabetes.

Derek’s chronic medical conditions presented him with two choices to approaching life,
to assume a role of victim, or a role of survivor. It appeared that Derek chose the latter and used
his survivor mindset to inform others about diabetes, staff as well as other participants. In
essence, this survivor mode at times was elevated to champion for a cause, and this provided
meaning to his life.

“I will talk to anybody I could to help out. If they are wanting [sic] to give it a try.
I have told people before and they look at me like, how do you do it? Just get out
there every day and do it, I want to live, I don’t want to die. I have to get out there
and do it.

Derek took photographs of and described a number of ways he engaged in social
activities. The relationships he had developed were meaningful to him. In addition to spending
time at the Café, he had a passion for team sports, and following teams. He had attended some
professional level sporting events and spoke of thoroughly enjoying the time he spent with other
people at events such as this. The aspect of ‘being a fan’ was part of Derek’s passion, but this
was equally as important as being part of a social circle that celebrated victories and mourned
losses of teams together. The socially situated relationships created through an affiliation with a
team were as important, and perhaps more important, than the team’s overall winning record.
The reason why I took that one is because I am really a Yankee fan, that’s mostly, I am a sports fan, I love the Yankees and the NY Giants. I would say I [like] to do activities, to go out and go to a game and things, and I go out and meet new people and stuff like that. That is why.

Derek’s chronic health concerns eclipsed many aspects of his life. He took photographs of his daily medications, insulin supplies, blood glucose machine, container for needle disposal, Bi-Pap machine, bottles of hand sanitizer, and a photograph of him receiving dialysis. Below are a series of photographs showing his Bi-pap machine, daily medication containers, and insulin supplies.

Oh wait til you see this one. This is my breathing one, my Bi-pap. If I don’t [use it], I stop breathing. I have done that a couple of times, I haven’t worn it and they come in and shake me - I am really out of it. I bring it with me at dialysis. I have more [energy], I am more alive [when I wear it]. It has really helped me out!
At certain times, I have to take my pills. And if I don’t, I am in trouble. So this is a good thing. This really helps me out with my pills.

This is helpful, this is very helpful. It keeps me alive because that is number 1 in my life. That is the insulin. That really protects me and if I don’t take it, I am in a lot of trouble.

Negative environmental influences were touched on with respect to eating. Derek also shared about risky health behaviors that influenced in a way contrary to health promotion.

Derek: This is a pack of cigarettes.

Nurse researcher: So tell me why you took a picture of this, what does it mean to you?

Derek: Um, well to tell you the truth, I took it because that really relaxes me.

Nurse researcher: It relaxes you? I didn’t know you were a smoker.

Derek: Yes, Yes, I am, I am a very bad person who does that. I have been warned. I have been told by doctors to quit, and I am still going at it. That is one thing that is not healthy.

Nurse researcher: Have you ever had anything else that you can do to relax, has anything else ever worked?
Derek: Yeah, I have a Wii [fitness] game. And that will help me.

Nurse researcher: If you could pick between the two, cigarettes or the Wii, to relax you, which would you pick?

Derek: The Wii.

Nurse researcher: Do other people in the house here smoke?

Derek: Yeah, there is Phil, and there is Rachel, and he [referring to DSP] smokes. Nobody else in the house smokes. Every time he [DSP] goes out, I go out with him, I am like a little puppy dog.

DSP: I try to sneak out when he is not looking but he always finds me.

The conversation regarding the cigarettes highlighted a degree of rationalization that Derek engaged in from time to time. Using an excuse of the relaxation benefit of cigarettes was an acceptable, albeit it knowingly incorrect, action. Derek shared a similar pattern in thinking when he spoke of taking his daily medications. Having already acknowledged the importance of his medications to keep him alive, he also stated that recently he decided to not take his pills. “I thought, I go to dialysis, um, just forget about the pills, and put in my pockets.” On a superficial level, Derek’s decision to rationalize followed patterns set forth by most individuals at various points in life. Beneath the complicit decisions though were implications for engaging in meaningful relationships, a desire to ‘be one of the guys’. Time spent with the DSP, is valued more highly than avoiding cigarette smoking. A life without a reliance on technology and daily pills is more aligned with people close to him in his personal life.

In general, the mosaic of pictures created by Derek included multiple photographs related to his chronic health conditions. He was thankful to be alive and understood that his medications, monitoring and disciplined eating are all essential to maintaining his health. He valued
friendships and opportunities for social engagement. He was articulate in sharing how the behaviors and choices by other people in his life directly impact him, at times, towards a negative health promotion behavior and at times, supported his own rationalization. He supported this with his photographs of cigarettes and sweet foods from a café.

**Victoria**

Victoria was 69 years old. She lived in a home designated as a certified Supervised IRA with four additional housemates. DSPs were present 24 hours a day on a daily basis. Victoria had been diagnosed with epilepsy and atrial fibrillation, both of which were controlled through medication. She also had chronic conditions of arthritis and osteoporosis. Victoria took 22 photographs, 20 photos of food, taken mostly from a trip to the local Farmer’s Market, and two photographs of people. In general, facilitator themes involved substantial knowledge of healthy eating choices and meaningful, caring relationships. Victoria also shared that happiness or emotional health was meaningful to her. She did not identify any barriers to her health.

Victoria shared the following description about this photograph. “Strawberries, yes, this helps [health]. I like eating these things.” Her knowledge of good food choices and bad food
choices was evident through her photographs and descriptions. Additional photographs included items she described as healthy; corn, tomatoes, squash, peppers; as well as photographs of items she described as unhealthy, such as donuts, cakes and cookies.

Relationships were facilitators to Victoria’s health. She photographed the DSPs and related in the one-on-one interview their persistent encouragement for her to eat healthy, make healthy choices and honor her desires for favorite food within moderation. In relation to a photograph of support staff, Victoria shared the following:

Victoria: These are people, here. All the time [they help me]. I come home and get coffee and a cookie and they say ‘Victoria absolutely no’.

DSP: When they come home from program, we encourage them to have a healthy snack before dinner. But Victoria is quick to get coffee and a cookie. Then when dinner comes, she is too full.

Victoria: Oh I so full!!

Relationships filled a social need of adding to Victoria’s self-esteem. During a trip to the mall, to get her hair cut, she intentionally brought her camera and took a picture of her hairdresser, someone who helped to make her feel good. “This is the lady that cuts my hair. Yes, very happy.” Victoria appreciated the overall sense of wellness she experienced by when having her hair colored, cut and styled. She took interest in her appearance, from small things such as her nails being neatly polished to larger concerns such as a flair for fashionable attire.
In general, Victoria’s pictures created a mosaic that revealed an influence of healthy foods, a solid knowledge about unhealthy food choices, and relationships that she valued. The relationships included DSPs from her home, as well as people in the community, such as her hairdresser.

**Marilyn**

Marilyn was 29 years old and lived alone in an apartment. The apartment was designated as a certified Supportive IRA, and DSPs were accessible on 24 hours a day on a daily basis, but not living in the home. Marilyn had high blood pressure that was controlled with medication. She had been diagnosed with exercise induced asthma and her weight placed her in the category of obese. Marilyn completed 23 photographs, of which 15 were used for the one-on-one interview. The unused photographs were either too dark, too blurry or repeat of previous photographs. The photographs covered a variety of topics; people, food, and pets. In general facilitator themes were around a sound knowledge of healthy eating, positive role models, friendships and a high degree of civic responsibility. Barriers focused on negative role models amongst family and friends and financial constraints of eating healthy.
Photographs of friends and DSPs with healthy drinks and unhealthy drinks assisted Marilyn when she described the important role these play in her overall health. She was insightful and demonstrated a depth of understanding, self-awareness and self-discipline.

“Oh she is drinking water; it is healthy water, definitely during the summer. Definitely during the summer days, but it is always good to drink basically 6 – 8 oz [glasses] of water a day.” In discussing unhealthy drinks, Marilyn shared her knowledge and addressed her experience of being influenced by people who are making unhealthy choices.
Marilyn shared this about the photograph above.

It is really hard for you to be healthy because one gets Dunkin Donuts all the time, unless you are getting something that is good for you. But sometimes it is not, Dunkin Donuts is not good for you. She didn’t have nothing [sic] that day, in there that was healthy for you. You could have something better. You know coffee is not good for you either. But at least it could be good to have beside a Dunkin Donuts thing. You could have juice, you could have milk, you could have that, and you could have something not from Dunkin Donuts.

Marilyn understood healthy and unhealthy food choices. Many of her photographs revolved around food or beverages, particularly from popular local coffee chain. Marilyn was capable of considering her preexisting medical conditions as she shopped for foods in the market. In addition to the food, Marilyn also brought forth the high cost of eating healthy and making healthy choices when at the market. She needed to balance the fresh fruit and vegetables she could eat with her existing condition of acid reflux and her relatively small weekly food budget of $45 per week.
Marilyn described the peaches in the photograph above. “No, this is healthy because it is fruit and you should have fruit”. She continued in describing how she approaches her grocery shopping.

Nurse researcher: Tell me more about when you go shopping; do you make your own list?
Marilyn: No, I don’t make a list; I basically get whatever I need for that week.
Nurse researcher: How do you decide what to make or cook?
Marilyn: I decide what I want to make that weekend. I don’t make a list. I only have $45/week for food. That is pretty tight.
Nurse researcher: You took a picture of peaches, how often do you eat fruit?
Marilyn: Not often it depends on what I feel that week. There are things I can’t eat, like apples and oranges because of acid, I have reflex [sic]. I can eat bananas, peaches, pears and carrots, things like that.

Grocery shopping appeared to be done ‘in the moment’, without the benefit of a thought out, organized plan. This spontaneous approach could present a barrier to her overall health. This is in light of the fact that shopping without a plan or thoughtful approach most often results in impulse buying of foods that are appealing to the eye.

Marilyn was insightful about the powerful influence of emotions to steer a person towards or away from health based on their adaptive or maladaptive response to the emotions. Her personal examples were around how she responds, at times, in a maladaptive way to emotions by eating. She stated, “your emotions start rolling. . . and you are going to automatically act on it and pick up whatever is more comfortable to you, chips, ice cream, what else do we have . . .” She continued stating, “I am still having problems with [my emotions], and
I am trying to control [them] which I can’t, now I am trying to say ‘okay, enough is enough’ but it is hard to do. When asked how it was that Marilyn came to be so informed about emotions and her reactions, she stated “I am only 27 and I have been around, I know stuff and I read stuff”. Marilyn’s belief in herself facilitated her behaviors towards health.

A number of Marilyn’s photographs focused on civic responsibilities, for example, picking up litter and depositing it in the trash pail, cigarette smoking and the importance of not smoking among those who are dear in her life. She also touched on animals and the responsibility of walking them regularly which gives both the animal and owner exercise.

Oh that is a cigarette cartoon, um, package that was sitting out there just laying out there... cigarettes are not good for you. And I tell everybody that I see that smokes... basically, it is littering too, and that is not healthy for the earth.

In general, Marilyn’s photographs created a mosaic of her life that focused heavily on healthy food choices, the influence of people in her life who make positive or negative choices,
and her astute sense of self awareness and emotional awareness, balance in the area of health and wellness, and balance with nature. Marilyn spoke of caring for the earth as much as people. She was filled with self-responsibility and spoke openly about her disappointment that a close friend had returned to smoking after having stopped for a long period of time. Barriers were identified through actions of other people who were influential in her life. In addition, the financial cost of eating healthy and her reactions to emotional stressors were also perceived as barriers.

**Aggregate Health and Wellness Themes Shared by Participants**

Multiple themes were repeatedly identified by participants as significant for their overall health and wellness. In general, facilitators were identified more often than barriers. One theme, relationships, was identified as both facilitator and barrier, dependent upon the situated context. There were eight themes identified overall. The six themes identified as facilitators were relationships; knowledge of health promotion; nature as health; positive emotional health; pride; and spirituality. Three themes were identified as barriers; relationships; negative environmental influences; and boredom. The themes, in descending frequency of presentation are discussed below.

**Findings in Relation to the Research Question #1**

Research Question #1: What do adults with I/DDs, living in the community, identify as facilitators and barriers to health and wellness?

This small population of adults with I/DD living in the community, who participated in this research were able to participate in this project as well as identify facilitators and barriers to health and wellness. Each participant’s degree of self-efficacy with the project varied similar to self-efficacy in the general population. Self-efficacy is known to grow and develop through experiences such as social modeling, social persuasion and psychological responses. Therefore
attention must focus on balance in the relationship of DSPs and individuals with I/DDs. A continual focus on this balance can assure human support services remain truly supportive and do not eclipse growing degrees of self-efficacy within the individual with I/DD.

The barriers and facilitators identified were closely aligned with those of the general population. For example, the most frequently identified facilitators for health were relationships. Relationships that were steeped in advocacy, nurturing, and supportive in nature contributed to health and encouraged continued positive health promotion behaviors. The relationships experienced with the DSPs were frequently used as an example of this type of relationship. Participants identified this repeatedly through photographs and dialogue; examples included helping with food choices, cooking healthy meals, assisting with medications, transportation to exercise activities, and in general “helping me out a lot”. The reciprocal nature of relationships was an added dimension; this provided a sense of belonging and caring. The relationships with family, housemates and even celebrities cited as examples were rich and compelling. These relationships were a source of independence when they provide for social mingling and community involvement, especially for individuals who require more support and live in more structured environments. When the relationships were experienced as rich, they contributed to an appreciation and zest for life.

Relationships were not limited to people, relationships with pets and animals were frequently photographed facilitators of health and wellness. Companionship facilitated a sense of responsibility toward caring for the pets. The responsibility provided meaning and purpose. In speaking about her pet fish, one participant commented, “I talk to him!” Another participant referred to his cat as “my son”. The bond in this situation was a familial bond of unconditional love and a reciprocal relationship.
Relationships were the one theme that was identified as both facilitator and barrier. As a barrier, relationships that were steeped in drama were identified as not supportive of health. One female participant addressed this during the one-on-one interviews, “her [sic] and I had an argument, now she has an attitude”, “I don’t think that is fair that that person can treat me like that . . . be mean and then be nice”. She was able to identify that negative communication, hurtful words spoken between friends was hurtful to her overall sense of wellbeing.

Negative role models were identified as barrier themes. Participants identified the internal conflict they faced when DSPs smoked cigarettes and indulged in foods that the participant was not able to enjoy. “My manager went back to smoking. I knew she was going to do that if she went on a camping trip”, one participant commented in reference to the DSP. Situations such as these created difficult choices and internal conflict. In another situation in which the DSP smoked cigarettes, the participant also chose to smoke. Both parties were complicit in their behaviors. They fully acknowledged this as negative choice of behavior. The participant however, valued the opportunity for camaraderie and a sense of belonging with the DSP over the hazards to his health from smoking.

Another participant spoke to negative role models in relation to health care providers and situations of advocacy. This participant self-managed most aspects of his life. He shared his personal experience with a recent emergency room visit,

You are wondering whether you are going to get admitted, you feel totally alone, like you have nobody in your corner. You don’t know what they are going to do, or what is going to happen to you. Yeah, they will treat you but are you going to feel like they are beside you in the process, because you aren’t a kid any more.
Every participant identified relationships as a facilitator of health and wellness. Five participants identified relationships as barriers but also included facilitator aspects of relationships.

The second most common facilitator theme identified was a solid knowledge of aspects of health promotion that were significant to the individual. Each participant photographed and described health promotion behaviors. These consisted of healthy eating, regular exercise, and outdoor activities. While most of the participants demonstrated a sound knowledge in this area, it was apparent that knowledge of health promotion was individualized and reflective of personal health status. This was most evident in the photographs taken of food, which was the most common thematic presentation. Fresh fruit, vegetables, and farmers markets were common photographs. Participants with diagnosed cardiac conditions, diabetes or obesity were quick to demonstrate a discriminating eye in this regard. For example, these participants identified the photo elicitation picture of the double layer hamburger as a bad choice. While participants with few or no serious chronic health conditions identified the same photograph as “not necessarily bad, depending on the quality of the meat and depending on how . . . and when you plan to eat them.”

Some participants, despite solid knowledge in this area, admitted to being conflicted at times when having to choose. One participant commented on her photograph of the pantry at her home, “hmmm, which one [snack] would I like to pick, it is hard.” Another participant with diabetes commented about his photograph of pastries and experiences of going to the local café with friends, “it is hard, very hard.”

Two participants spoke with an increased resolve that generated from the experience of seeing other people making poor choices. For example, one participant shared her feelings when
observing DSPs drinking super-sized, sweet drinks from a local coffee chain, “I’m like can’t you like do [get] something else when you go [there], because they have juice, water, tea, you don’t have to get a big thing like [that].” The second participant described the conflict she and her family faced when she visited them at home, “It is hard, hard choices for them too. They watch what I eat. Sometimes I like the baked chips, they are good for me but the regular ones are bad.”

Health promotion behavior, as exemplified by engaging in exercise and related activities, was a repetitive photographic theme amongst six of the 11 participants. This included photographs of treadmills, bowling balls, free weights, and the local gym. Participants who photographed these activities demonstrated knowledge, a desire to engage and a fairly consistent commitment. Those participants who did not photograph any physical activity had a more tenuous relationship with exercise, “I [exercise] a little bit, but not much. I walk to Stewarts and back, and that’s what I do.” This relationship, unlike healthy food, appeared more random in nature, and independent of chronic health status. The extent ran the gamut from no exercise to exercise on a regular basis four or five days a week. For example, the participant with the most medical fragility was asked about health promotion behaviors aside from healthy eating, the DSP answered “well the other picture he wanted to take was the track.” The participant responded “I don’t do that at all”, to which the DSP responded “well, occasionally, not a lot”. The participant with the overall highest level of health and no chronic conditions exercised faithfully four to five days a week. Between these two extremes, exercise activities were intermittent, unpredictable, and unique to each participant.

The third common facilitator theme was an astute awareness of self and positive emotional health. Much like relationships and knowledge of health promotion, all the participants identified this theme as a facilitator. Work, hobbies and caring for the self, such as
trips to the hairdresser were all supporting examples. What was apparent was a sense of intentionality and insightfulness when these photographs were discussed. Decisions and actions, what they did and the emotional health with which they approached a behavior or action were described in a thoughtful manner on the part of the participant. These actions contributed directly to an overall sense of well-being and appreciation for life. From an opposing perspective, one participant spoke to a sense of awareness around negative emotions and the rapidly declining spiral that occurs when actions are taken based on negative emotions. The exemplar she spoke about related to unhealthy eating in response to labile emotional states.

Hobbies and health promotion activities also appeared unique, and relative to the participant’s need and perceived benefit. One participant found a health promotion in painting; another participant found a healthy outlet in taking long walks to a local coffee shop, with stops along the river to watch the geese. The participant with the most medical fragility described health benefits of “meeting new people” at sporting events. These were conceptually more challenging to photograph and were more likely to be expressed in conversation about a photograph, specifically in relation to how the participant felt, or what the experience was like, or how the participant was empowered through partaking in the activity. The general, overarching themes from these activities were a sense of happiness, completeness and a meaningful relationship with life. For example, one participant spoke about his photograph of his paintings. He stated “I give these as gifts to people I care about.” In this case the hobby became the vehicle for deepening of relationships with others and adding to personal independence and overall creating a sense of meaning and completeness.

A sense of pride in responsibilities and accomplishments was another theme expressed among five of the participants. This ranged from welcomed acknowledgement and pride in the
daily chores of taking out trash, completing laundry to the winning of trophies. “I take the
garbage out when it is my turn, I put the garbage in there and the garbage man takes it with his
truck” one participant commented about his weekly chores. One participant also spoke with pride
of his work at his place of employment and his volunteer commitment at a local hospital. A spirit
of pride was viewed as helpful to an overall better state of health, level of happiness and zest for
life. One participant commented about his work in taking the photographs for the study and how
even this sense of accomplishment impacted him,

I think since this whole incident [taking photographs] I think I might even think
twice before I say ‘no’ to certain things, social events because I had. . . a hard
shell. Where I was always like, ‘no – no – no’, instead of thinking what I was
saying ‘no’ to socially, when saying ‘yes’ might benefit me.”

The fifth facilitator theme was an active engagement with nature as a health promotion
behavior. Research has shown that appreciating natural beauty and Mother Nature, through direct
engagement with nature or through viewing of scenery, has a positive impact on health (St.
Leger, 2003). Photographs of trees, gardens, flowers, and photographs of people caring for
nature were a theme among four of the participants. One participant commented “I like being
outside a lot, I don’t like being inside the house, it is bored [sic] in the house, sitting around.”
Another participant commented on photographs that he did not have the opportunity to capture
“well, I didn’t get to take a picture of the Farmer’s Market. That symbolizes a community, a
people, you have to go out and get it.” Caring for the environment was important as well,
“basically, littering too, which is not healthy for the earth. I have this thing with the earth being
clean.”
Spirituality was a health facilitator for three participants. It ranged from a concrete activity such as attending church to a more inward spiritual belief in God and belief is a power larger than self. Spirituality created a space and place for health to be cultivated in a way that was less obvious, more personal and unique to individual needs and understanding. One participant described reading the Bible as a coping mechanism during times of stress.

Negative environmental influences, that were present throughout the community, were identified by four participants as a barrier. A particular emphasis was placed on fast food chains. One participant commented about time she spends with her aunt and cousins, “If we go by a McDonalds they [cousins] are like ‘let’s go to McDonald’s’ and I am like ‘oh my gosh . . . okay, what can I have?’” She went on to explain, “Unless you have a salad, it is not very healthy, but do you really want to have a salad every time you go?” Two participants spoke about a local café which provided opportunities for socializing, but also temptations that were challenging on a daily basis, “as you can see, it is mostly pastries. This where I have to stay away from. When I go there, I only order coffee . . . but the café gets me to meet new people.”

The last theme shared was a theme of boredom. In certain situations, boredom may be related to a lack of motivation. For this participant however, it was not an apparent lack of motivation, it appeared more reflective of discordance between desire and opportunity. This difference did not appear to be discerned by the DSPs. This was supported through the fact that DSPs informed the nurse researcher that “don’t expect many photos, Thomas will say ‘yes’ but do nothing”. In the end, Thomas had taken more photographs than most other participants in this study. His photographs reflected a passion for being outside and throughout his conversation he wove together his passion for nature, his commitment to caring for others and frustration with boredom of being inside.
Focus Group Meeting with Direct Support Professionals

Following the participants’ completion of their part of the study, one focus group meeting was held with the DSPs. In total, six of the nine DSPs participated. Five were present at the focus group meeting; three females and two males. One additional female DSP was interviewed over the telephone the day after the focus group. The six DSPs represented eight of the 11 participant participants in the study.

The focus group commenced with a general question around personal health for the DSPs. The question posed to the focus group asked the DSPs about what they did, personally, to maintain health and wellness. The responses varied, from ball room dancing, hiking, meditative moments of spiritual journeys, and jogging late at night when the evening air is filled with solitude. A recurring theme mentioned was the term holistic which was further defined by the group to mean “activities that benefit me physically, emotionally, and mentally.” The fundamental quality desired was the totality of a holistic benefit gained from the activity.

Findings in Relation to Research Question #2

Research question #2: What are the direct support professionals’ perceptions about facilitators and barriers to health and wellness for adults with I/DDs?

In general the perceptions of DSPs around health and wellness for adults with I/DD appeared to fall into four themes. These themes included contextually-situated choices for health, food as a complicated issue for health, organizational barriers to health, and being a role model for healthy living for others.

Focus group participants appeared to share similar perceptions when the topic of ‘choice’ was raised in relation to the participants’ wishes. All the DSPs believed that participants appreciated choices and the agency was “innovative and creative in ways” of engaging
participants around choices. How the DSPs approached incorporating participant choice was varied and fell into one of the three following approaches. One support staff stated “give them the option but also try to steer them toward the healthier choice is very important. I mean they want to have choices.” Another DSP explained choices in this way, “. . . knowing what the things are that the individual really cares about. You can use [these] as a guide post to help them make good healthy choices” basically a carrot and stick conundrum. This DSP used the example of a person who takes pride in appearance and might be encouraged toward certain healthy behaviors through reminders of how they will look better if they do something healthy or don’t do something unhealthy. Another DSP described choices from yet a third perspective. This DSP stated “we are informed resources that help remove the clutter from the decision making process, so it is easier for them [participant], but they are still making their own choices.” This DSP illustrated the contextually-situated importance of choice for a participant who has special dietary restrictions. In an effort to uphold those restrictions, yet not create barriers around social activities, the DSP had researched what food was within the dietary guidelines at a few popular fast food restaurants. Now, when that participant goes out to any of these popular locations, she can order a healthy meal for herself without having to even look at the menu and be confused or tempted by other choices. She is empowered to make her own healthy choice, but more importantly, she is empowered to socialize. The contextually-situated nature was appreciated in varying degrees by the DSPs.

The DSPs provided many examples of their perceptions of how health and wellness was supported for the participants. There were dedicated programs, such as “Biggest Loser” which was a takeoff of a reality TV show that tracks weight loss among contestants. Wii fitness programs were popular in the homes, exercise videos, going for walks, going to parks,
community involvement with the local animal shelter, and playing bingo were other examples. Small behavior changes, such as extra water bottles in the house rather than soda, increased monitoring of salt intake and even pursuing relationships outside of the house to help create meaningful social time were additional examples shared by the group. Other community involvement consisted of volunteering within the community and activities such as going to the hair salon on a regular basis. One staff stated:

. . . as you get to know your clients, then you get to know what their interests are. So because they have communicated their interests to you, we are able to go out and do some more searching. And they [agency] have really encouraged us to search with them [participants]. That way you could really see what their interest are, rather than say, ‘oh I found this today – can we do this’.

One perceived barrier theme that was shared was recognizing that food and eating is extremely complicated. The DSPs voiced the importance of being social, but questioned how to be social and also be healthy when so often being social involved eating. Acknowledging the fact that many participants enjoyed going out in the community, for example to the café, but couldn’t always be sure to be eating healthy when at the café, one DSP stated the following:

She loves to sit in the café down stairs, she loves to be social and that is part of our society, socializing when we eat. It has been a big barrier trying to explain to her, we need to be social in a different way.

Suggested methods to address the need for being social yet supporting health were to incorporate healthy snacks and avoid unhealthy snacks.

Comfort through food; eating to kill pain or depression or boredom was another perceived barrier related to food and eating. Food was also identified by the DSP to be a source
of power struggle between the DSP and the participant. Most DSPs agreed that sometimes participants wanted things just because they were told they could not have it. One DSP described it this way

> Oh yeah, there are times, when individuals would because of their diagnosis and they are in a very fragile state in their health, for instance diabetes – and staff is encouraged to tell them ‘please make good choices, please make good choices – juice and so forth’ and at times, they might feel like- ‘okay, this is my actual option to make good choices and I am choosing to drink the orange juice even though I know the consequence.’ And it is up to us, sometimes, we have to be creative in keeping them away from that food. So it does become, at times, a power struggle

The ‘power struggle’ over food was felt to also extend to other behaviors. An example was given that related an obsession with shopping. The more the person was told ‘no’ they can’t shop, the more the person needed to shop.

The importance of social activity for healthy living coupled with the cultural connection to food was perceived by DSPs to be sources of conflict for the participants’ overall health. The DSPs perceived this as ‘tough choices’ for the participant. This appeared to be all-encompassing in the lives of the participants. Immersion in the community meant experiencing an environment that reinforced unhealthy choices. DSPs were quick to point out the high density of fast food restaurants in the immediate area around the homes. It had gotten to a point, where the fast food services were now available within some of the larger “box” stores. A trip to purchase socks at a Walmart or Target would lead the participant past a Dunkin Donuts or Subway. The magnitude
of this constant intrusion of fast food eateries was shared in the following description of how one DSP was assisted by a participant with directions.

I was trying to find the church one time, to take one of the ladies. And I am new to the area, so I didn’t know [how to get there]. They [participants] are like, ‘listen just find the Pizza Hut and you will find it [church].’ And I am like ‘but is there a name of a road or anything else you guys know?’ ‘No, there is a Pizza Hut right there, and you are going to pass a Chinese food store and then the Pizza Hut.’

Another perceived obstacle to the health was organizational barriers to meeting needs and supporting spontaneity with the participants. It was cited that staffing limitations and resource allocation created a situation of having to take turns on “who is going to get to go on a certain fun activity”. The staff member stated “that can put a hindrance on doing what you want to do, when you are in the mood”. Staffing availability, the day and time, and prior engagements were also noted as influential in the choice of viable activities for the participant. One staff person shared “you know, we can get up in the morning and say ‘it looks like a beautiful day, I think I will take a hike in Grafton’, but the participant is more limited, and can’t always make a choice such as that.”

During the focus group, the DSPs were asked what they perceived their role to be around health and wellness for the participants they support. The simultaneous response was ‘role model’. Role model was interpreted as being a ‘voice of reason’ and ‘chef’. Both of these were linked to eating, healthy eating and decisions around what food to eat. One DSP provided the example of not eating fast food in front of the participant. A second example of role modeling was described as being a positive voice in the life of the participant. In a sense, it was described as “you come in [to work] with enthusiasm and the excitement.” One DSP that was more aligned
in the managerial role shared that she perceives herself as a mentor to her staff, specifically showing them how to be the provider of choices for the participant. She stated “anything they [participant] voice, within reason, we try to make happen.” Acknowledging that at times, participants may make poor choices, she stated “If they choose something not healthy, I try to explain the rational why . . . and sometimes, experiences are the teacher.”

Agreement among DSPs was unanimous when considering ways to making health and wellness more attainable. The general consensus was that eating healthy was expensive, too expensive on a limited budget, and healthy foods cost more than unhealthy foods. DSPs stated they felt the burden of cost to eat healthy, and often times they also ate unhealthy due to this financial burden. The DSPs believed the agency had prioritized health and wellness which was evident by the strong support they sensed in being well educated by the agency around sensitive issues, such as chronic medical conditions. In addition DSPs felt supported as lifelong learners.

In general, comments from the DSPs revealed a consistent good mastery of knowledge on a practical level about the acute and chronic health conditions present among the participants. Statements such as “we are doing a lot of preventative services, because they are aging”, “some people might have GERD, they can’t have certain things”, “diabetes runs [is more prevalent] a little bit more and the meds they are on can cause some obesity” provided evidence of this observation.

**Discussion of Findings**

**Context of the Study**

An analysis of health and wellness facilitators and barriers, as described by participants and perceptions of their DSPs must be viewed within the context that reality is a unique creation between individuals joined in a relationship. Critical social theory holds that a relationship is
non-static in nature; the relationship is heavily influenced through multiple factors; language, power, interests, knowledge, and motivation of each persons. Through the confluence of multiple influences, empowerment, interests and consequences are assembled and sustained.

The setting for this study was multiple participant homes in the community. The specific type of home was defined according to a number of variances; supervised or supportive, and the number of individuals living in the home. The least restrictive home was an independent living arrangement with support provided according the need of the individual. This type of home setting did not fall under any regulatory guidelines of the agency through which this study was conducted. The second least restrictive home was a supervised home. In this setting, the apartment was regulated by the agency; it met specific regulatory guidelines for people with disabilities. In addition, support for the individual was available, though not necessarily on site. The participant in this setting lived alone. The third type of living arrangement was a supervised environment. In this situation, supervision was on site 24 hours a day on a daily basis. The participants received support based on personal needs. So, some of the participants may have required more support than others.

There were two types of staff in the supervised homes, managers and DSPs. The managers were present primarily during the day and responsible for the administrative functioning of the home as well as the provision and allocation of services for participants living in the home. The DSPs were continually present and provided support that ranged from help with activities of daily living, administration of medication, to more global help such as life coaching, transportation, and assistance with job skills.

The sense of “home” was apparent at each home visited during this study. The homes represented a variety of styles from an old Farmhouse style dating back to the Civil War era,
historic Victorian closer to town to more modern buildings and apartments on the outskirts of town. All homes met the physical needs of those participants who lived there. Those participants that required maximum physical support lived in homes with least physical barriers, such as ramps in the entry, one level dwelling, and barrier free environment.

**Critical Social Theory**

This qualitative study used a critical social theory perspective to examine facilitators and barriers to health and disparities in perceptions around health and wellness among people with I/DD and their DSPs. It was essential when using a critical social theory lens, to examine the creation of reality as being unique to the individuals joined in a relationship. Authentic in nature, critical social theory places expertise in the possession of the study participants. Critical social theory concerns itself with uncritically accepted and unjust dominant ideologies in everyday situations. It is through this critical social theory lens that the discussion of the findings was presented.

The focus of the data analysis was directed by critical social theory in examining differences in ideologies, power, and the conceptual integration of health as separate than disability. In general, there were areas that suggested similarity of DSPs’ perceptions with the reality of the participant, and yet other areas that suggested discordance between their perceptions and reality as described by participants.

Areas of similarity included an appreciation for the healthy, positive aspects of social integration within the community coupled with an acknowledgment of the cultural context of food associated with socializing. Participants frequently identified these situations as ‘hard choices’. They verbalized the challenge of watching other people eat food they cannot eat due to medical conditions or should not eat due to the unhealthy nature of the food. DSPs similarly,
acknowledged the value placed on ‘being social’ by the participants, yet the choices that confront the participant can be overwhelming. One staff commented “Going home all weekend, they [family] don’t get to see her [participant] all week. So they are like ‘yeah, let’s order this, let’s go eat this’, so it is difficult.”

Both participant and DSP acknowledged powerful environmental influences and the constant infusion of ‘fast food’ in the surrounding neighborhood, as a barrier to participants’ overall health. Participants described fast food from a perspective of constantly having to make a difficult decision about what is healthy. DSPs related that fast food chains were so prevalent and ubiquitous that participants use fast food restaurants as focal points when describing locations. During the focus group, the DSPs reflected on the immediate environment and described it as this, “I’m thinking about it now, there is Dunkin’ Donuts, Burger King, Mc Donald’s, Mr. Subb, all right there, a straight shot, not even 2 miles, this is within a half mile!”

Organizational obstacles and a lack of spontaneity were a general theme shared by DSPs and identified by one participant. The participant identified this through his numerous photographs that placed him outside of his home and basically at one with nature. DSPs shared a broad view of the reality of using resources in the most efficacious manner, which by nature eclipsed the ability to simply ‘get up and go’ with a participant if the desire presented itself, “I have a limited number of staff and if he [participant] went out yesterday, it is now somebody else’s turn today.”

Discordance of perception among the DSPs were more subtle, intricate, and in the end ultimately contributed to untapped empowerment amid the participants. These areas were associated with how the DSPs understood and experienced health for themselves and how they supported health and wellness for the participants. For example, DSPs personally experienced
health and wellness through a ‘holistic’ lens, describing exercise activities as stimulation ‘physically, emotionally and mentally’. One DSP commented “I actually need to take an hour a day for me, literally, shut off the phone, away from everything, because if you are not mentally feeling well, you are not physically going to be feeling well.” Another DSP stated “I like to go running. You know, really, really late at night, when I know there is no one outside, it’s just me outside by myself. I like the quiet and the solitude.” The perception held by the DSPs of health and wellness for the participant though, was more corporeal in nature and activity specific; bowling, walking on a treadmill, exercise videos. One DSP mentioned volunteer community involvement at the local animal shelter. In general though, the holistic nature of health and wellness was not an obvious perception presented by DSPs in relation to health and wellness for the participants. In reference to the Biggest Loser weight loss program, the DSP stated ‘we kinda get everyone up and active and moving’ but stopped short of explaining how this wellness was integrated holistically into the life of the participant.

A second area of discordance was found in the concept of choice for the sake of choice. Realizing that participants had to make choices between healthy and unhealthy options was understood. Awareness that choices were situated within a multifaceted context was less often appreciated by the DSPs. The focus group participants relied on providing options and steering the participant to the correct choice or the ‘carrot and stick’ method of supporting and rewarding the good choice. During the one on one interview with a separate DSP, she described the larger context that existed around the concept of choice. In that situation, the DSP appreciated the value for the participant to go out in the community, socialize, and enjoy a dinner out with friends. In order to support the participant the DSP researched the nutritional content of the meals at the
local favorite dining locations for this participant to eat. In the end, the participant was empowered to make a healthy choice as part of a larger social activity.

In general, a tremendous sense of support and genuine caring was evident amongst all the DSPs, however, at times; a paternalistic bias in language was evident. For example DSP explained part of health and wellness for participants was more than just healthy eating, she stated ‘why don’t we try showing you what it is like to be part of your community’, ‘definitely showing them different things than just eating all the time or that cup of coffee’. Another DSP explained the following about healthy behaviors in relation to the participants she supports,

If I choose to spend at day at home, and I have pajamas on, that is fine. One day out of 7 days a week, that is okay, but doing it 2 or 3 days a week – that is not healthy. There is something more, there is not really much going on in life – that could mean depression. And with our individuals they are prone to things like that, but we try to keep them as busy as possible.

In other instances, language in the form of labels had the potential to create a difference in power. One staff referred to the participant as “she is a 28 year old woman who is obese”. Another described to the participant as ‘neurotic’ when it came to taking photographs.

**Summary**

The purpose of this qualitative study was to explore facilitators and barriers to health and wellness for adults with I/DD. The primary methods of data collection were with Photovoice, photo elicitation, and one-on-one interviews of participants. A secondary source of information was gathered through a focus group meeting with DSPs. This methodology was congruent with the critical social theory analytical perspective assumed for the study.
Overall, the participants participating in this study were aptly able to identify facilitators and barriers to health and wellness. In this study, the Photovoice experience was able to show how health and wellness for the participants had little to do with their disability. The themes generated were markedly similar to those of the general population. This indicated a capacity to change not only what is known, but how one comes to know about health and wellness for adults with I/DD. By giving voice to participants, the opportunity was created to contribute to a growing knowledge base that supports health throughout their life continuum. Additionally, the authentic participant voice provided expert indications to inform a sustainable approach to wellness.

Exploring perceptions of the DSPs provided opportunity for examining shared values and knowledge of health and wellness. Consistent with a critical social theory approach, this provided opportunities for communication to bring forward cogency of reason. This aspect of the study provided the opportunity to contribute this information to the growing knowledge base and further inform sustainable approaches to wellness for participants.

**Conclusion**

The qualitative techniques used in this study, Photovoice, photo elicitation, and one-on-one interviews provided data regarding facilitators and barriers to health and wellness for the participant participants. The focus group meeting with the DSPs provided information about perceptions held by the DSPs around health and wellness for the participants. Together, this information created rich information that contributed to the growing knowledge base that supports health and wellness for participants throughout their life continuum.
Chapter 5

Summary and Discussion

This chapter provides a summary and discussion of study findings in relation to the literature, limitations and strengths of the study, and implications and recommendations for policy, practice, education, and research. This qualitative study focused on identifying facilitators and barriers to health and wellness as described by the adults with intellectual and developmental disabilities (I/DD), herein after referred to as program participants. A secondary intention of this study was to learn more about the direct support professionals’ (DSPs’) perceptions of health and wellness for the individuals with I/DD they support.

Eleven program participants (six females and five males) were provided with disposable cameras with which to take topical photographs on things that facilitated health or things that made health more challenging for them. Afterwards, the 11 participants were independently interviewed about the significance and meaning of their photographs. The sampling was purposive and limited to participants who were able to understand the steps of picture taking, able to communicate information about the photographs, physically able to operate the camera and understood the safety and ethics involved in the use of the camera. The DSPs were recruited through their affiliation with the participants, in that they were in a paid positioned to provide support to the participant. Nine DSPs participated in a focus group meeting that explored their perceptions around health and wellness for the participants they support. This study was conducted through the assistance of the Rensselaer County Chapter of NYSARC, Inc, Rensselaer community.

The following research questions were explored in this study. What do adults with I/DDs, living in the community, perceive as facilitators and barriers to health and wellness? What are
the direct support professionals’ perceptions about facilitators and barriers to health and wellness for adults with I/DDs?

In general, facilitators to health and wellness were identified more often than barriers. One theme, relationships, was identified as both facilitator and barrier, dependent upon the situated context. There were eight themes identified overall. The six themes identified as facilitators were relationships; knowledge of health promotion; nature as health; positive emotional health; pride; and spirituality. Three themes were identified as barriers; relationships; negative environmental influences; and boredom. The themes identified are similar in nature to those identified in the general population. This finding was supported in the literature by Thompson (2002), who posited that adults with I/DD value the opportunity to speak about health and frequently share perceptions similar to people without disabilities.

Overall, the perceptions of DSPs around health and wellness for participants appeared to fall into four themes. These themes included contextually-situated choices for health, food as a complicated issue for health, organizational barriers to health and role model for health.

Review of the literature on the historical perspective of disability, health disparities, health promotion, influence of DSPs, and social and health policy provided insight and foundational grounding for this study. People with disabilities (mental, physical, sensory, and developmental) have shared a protracted struggle for empowerment. A review of the literature on disability, from a historical perspective revealed that disability was socially constructed (Krahn, 2003). Particularly, in the area of health, disability has been interwoven with and poorly differentiated from health and wellness. The entanglement of disability with health, coupled with an increased length of life, particularly for individuals with mild I/DD, has contributed to a higher rate of health disparities among people with I/DD (Fisher & Kettl, 2005; Patja,
Iivananinen, Vesala, Oksanen, & Ruoppla, 2000; Krahn, Hammond, & Turner, 2006). To understand the concept of health and wellness for participants it was important to examine the current state of health disparities for this population within a context of all essential components that sustain contradictions and disparities in relationships. To enable such an inquiry, critical social theory was the selected method of philosophic approach.

Critical social theory, defined by Polit and Beck (2008, p.751) as “an approach to viewing the world that involves a critique of society, with the goal of envisioning new possibilities and effecting social change”, is appropriate for studying situations of hegemony, where broad change is envisioned and generalizable to a large segment of humanity. A postmodern approach of inquiry emphasizes the creation of reality as being unique to individuals joined in a relationship. Denzin and Lincoln (2008) posited that relationships and the meaningfulness are socially constructed. Non-static in nature, the relationship is heavily influenced through language, power, interests and motivation of each person. Critical social theory was an appropriate theoretical lens for the unit of analysis which in this study was the words used to describe topical photographs, and the conversations shared during a focus group meeting.

**Findings in Relation to Literature**

Themes in relation to the literature are discussed next.

**Relationships**

Relationships are the fundamental unit for the creation of a sense of being outside of and beyond oneself. Reality is constructed within relationships. Construction of reality without a point of definition or end point is impossible, therefore, relationships are vital to creating an external reality, or sense of being in the world. All participants in this study described the power
of relationships and their ability to move a person towards health as well as away from health. Similar to the general population, everyone has need of relationships and is able to benefit from or be hurt through relationships. O’Brien (2006) described the interdependent relationships between individuals with I/DD and DSPs as powerful and influential. Particularly in the area of health and wellness promotion, relationships that are built on the capacity of the person with I/DD coordinated with opportunities in the community, can serve to strengthen the resiliency and sustainability of the actions.

Noted to be missing from the photographs that described relationships are photos depicting social activities with people who do not have a disability. The world of people relationships for the participants revolved around DSPs, other people with disabilities, and family. This finding suggests a question around the extent of social integration that is experienced by people with disabilities. The full extent of liberation includes valued and voluntary relationships with people in typical community settings. This is reflected in the literature on social role valorization that supports mutually chosen relationships between people, disabled or not (O’Brien, 2006; Lemay, 2006).

Participants in this study spoke of the benefit of support from DSPs, the warmth, love and caring of family, and the social benefits gained through friendship and unconditional love experienced with pets. Relationships that engendered anger, hostility, or unkindness were perceived as barriers to health. Essentially, health was influenced by relationships, in either a positive or negative direction. Relationships were powerful in that they set a context of how the participant experienced health and quality of life. This was consistent with the literature, which revealed that positive emotional and social relationships influenced the perspective of health for the person with disability, more significantly than did the presence of chronic conditions.
Knowledge of health promotion

Knowledge of health promotion, or knowing what to do to stay or become healthy, in the form of healthy eating and healthy activities, was expressed by all participants with a varying depth of knowledge. On a more limited end of the spectrum, some participants spoke of healthy food choices at a more fundamental level. These participants appeared to have a working knowledge around healthy eating or the importance of exercise, but struggled on an almost daily basis to implement action on this knowledge. On the opposite end of the spectrum, other participants were able to articulate more detailed knowledge about healthy eating and in fact leaned into this knowledge on an almost daily basis to navigate potentially negative environmental influences. DSPs attributed the learning in this area to efforts on behalf of the agency to educate participants in the area of health promotion. The value of this type of education for individuals with I/DD was supported by the literature review which revealed educational efforts with people with I/DD can result in positive health behavior changes. The literature also supported educational efforts that involved the caregiver, be it a family member or DSP, in union with the education of the individual with I/DD to improve outcomes and create sustainable change (Ewing, McDermott, Thomas-Koger, Whitner, & Pierce, 2004; Humphries, Traci, & Seekins, 2008; Temple & Walkley, 2007).

Although all participants had sound knowledge around healthy eating and healthy activities, the difference in levels of application in their daily lives nevertheless supports a continued emphasis towards building on capacities of individuals over a focus on remediation of deficits. Personal Futures Planning, developed by Mount and Zwernik, drawing on earlier work
by O’Brien and Lyle (Mount & Zwernik, 1989) emphasized opportunities for people with I/DD that increase their control, choice, and development of individual skills and abilities. Knowledge is always associated with empowerment. Building capabilities around knowledge achieves much more than education for the sake of knowing. It actually empowers the person with disabilities to interact in society. It gives the person with I/DD the tools to connect with a world that is larger than their family or DSPs. The literature on disability supports social integration through a learning approach that truly empowers the person with I/DD (O’Brien, 2006).

Participants experienced life through social relationships that often times involved social eating. This situation was a source of conflict for the participants. In fact, situations such as this are a source of conflict for the general population in relation to health and wellness. It was apparent that some participants were able to discern the advantages and disadvantages of choices during these social situations. This study finding supports the role of DSPs to be ever vigilant as lifelong teachers in the lives of the participants. This responsibility must be balanced in light of the interdependent relationship between people with I/DD and the DSPs. People with I/DDs rely on services for many essential aspects of their life. Therefore, services become life defining. Sensitivity must be paramount to collaboratively design services that promote and sustain the best possible life for the person with I/DD. Developing rules and regulations to guide health actually obfuscates personal desires and preferences on behalf of people with I/DDs, as suggested by the group that participated in this study. Assisting people with I/DDs to learn how to make healthy choices empowers them, capitalizes their skills, and may alleviate the DSP from supervising over the rules and regulations and move the DSP into a role of companion on the journey of health and wellness.

**Nature, spirituality, and pride**
The concepts of nature, pride, and spirituality as sources of health for the participant were significant findings in this study. Appreciating natural beauty and Mother Nature through direct engagement with nature or through viewing of scenery, has been noted to have a positive impact on health (St.Leger, 2003). Human contact with nature has been identified to have positive health promotion effects on people and populations (Maller, Townsend, Pryor, Brown, & St. Leger, 2006). Previous review of studies in the literature, which relied on proxy voice on behalf of people with disability, did not include these concepts as influential to health and wellness. Historically, unconscious patterns of thinking that did not fully value the voice of people with I/DD have made it difficult to accurately assess what is important and most significant in their lives. These findings support the method of inquiry, critical social theory, which relies on authentic voice to generate study data. In this study, three facilitators of health were newly identified by the participants as influential towards their health. The developing knowledge base of information to support health should reflect the concerns, needs, and personal preferences, whenever possible, of the people with disabilities. This developing knowledge base should in turn be used to drive educational programs for the DSPs, therefore creating a meaningful change in the culture of the disability community.

**Positive emotional health**

Emotions were identified by participants as powerful in their lives. Many participants identified happiness as closely aligned with their overall healthy state. Some participants spoke of their reaction to disturbing emotions, which included a downward spiral of unhealthy behaviors. Much as with the general population, when one is frustrated, sad or bored, the temptation for comfort foods is magnified. This was consistent with the literature review which revealed that emotional wellbeing was a significant concern and the use of adaptive or
maladaptive coping mechanisms varied among people with disabilities (Jurkowski, Rivera, & Hammel, 2009). This finding supports educating DSPs and participants around the use of coping mechanisms to navigate the lower points in life within a framework that respects health.

**Photovoice and photo elicitation methodology**

The intent of using a critical social theory lens was in part to frame a method of inquiry that honored the voice of the participant and empowered participants to share their voice. Overall, Photovoice and photo elicitation were effective with most of the participants to achieve the aim of critical social theory. Ten of the 11 participants actively engaged in the picture taking. Elizabeth, the participant who took only four photographs appeared more ambivalent with regards to using the camera. Her pictures were also not well centered on the topic of interest. This finding suggests that using this methodology may not be a perfect match with all study participants. In contrast to this finding, when Thomas consented to participate in this study, the DSP cautioned the nurse researcher that he probably ‘wouldn’t take any photographs at all, he says ‘yes’ to everything, but doesn’t follow through’. In the end, Thomas took 25 photographs and shared a rich description of Nature as essential to his health. He shared his passion for the outdoors, helping other people, and caring for animals.

In light of these two extremes, it reinforces the need for decisions to participate to be made by the participants and not through proxy, whenever possible and appropriate. This position stands in contrast to the traditional approach to people with I/DD that has emphasized deficiencies, sought to find ‘fixes’ for deficits, and has been based on an assumption that DSPs possess the knowledge of what is best for the person with I/DD. Alternatively, building on the capacity of the person with I/DD contributes to effective interdependence. More importantly, informed choices circumvent the tendency towards supporting a narrow range of predetermined
services and approaches. John O’Brien stated “Human service organizations can’t manufacture better lives. People weave better lives from the resources afforded by individual effort, personal relationships, available opportunities, and help from services” (1989, p.5). This was supported in the literature which deemphasized human service systems in support of social integration through social role valorization. The concept of social role valorization purports an approach to social change that anticipates the best possible life for people with I/DD (O’Brien, 2006). Social role valorization prioritizes the self-direction and voluntary choices among people with I/DD towards achieving their personal goals of social integration.

**Perceptions of Direct Support Professionals**

In general the perceptions of DSPs’ around health and wellness for adults with I/DD appeared to fall into four themes. These themes included contextually-situated choices for health, food as a complicated issue for health, organizational barriers to health and being a role model for healthy living for others. These themes must be considered in light of the critical social theory lens which sought to identify assumptions or biases that might exist which would prevent the full liberation for the participant in the area of health and wellness. This philosophic approach is applicable for exposing constraints that interfere with balance in social interactions and relationships. At its core, critical social theory questions types of dominance, seeks to liberate people from enslaving circumstances, and strives for a more egalitarian society (Kincheloe & McLaren, 2000).

Direct support professionals demonstrated a sound factual knowledge around healthy foods and healthy activities. This factual knowledge was an intermittent barrier when supporting participants’ daily lives perhaps because there was a risk of a very concrete application of this knowledge to the lives of the individuals supported. DSPs may have limited ability to see health
and wellness within a larger situated context in the life of the participant. The charge to promote health and wellness may be interpreted as the need to be directive. The compulsion to be directive results in a ‘one size fits all’ concept of choice. When the concept of choice is examined on a continuum, one end of the continuum are individuals who indeed have few choices and on the other end are individuals with few limits, the ‘one size fits all’ concept of choice is troublesome. This supports the crucial nature for DSPs to be able to see the larger context of situations that honor and respect individual life plans and personal preferences. Educational opportunities may include a more intentional emphasis on the DSP’s judicious assessment of the full gamut of the situation.

Organizational barriers to supporting health of the participants were presented as a challenge. The field of disabilities services is charged with providing a great deal of time and attention to supporting people who are assumed by virtue of the fact that they receive services, to be unable to do so themselves. Therefore, the field is heavily regulated by multiple governmental agencies with multiple layers of regulations and statutes. Organizational barriers do indeed exist. The perception on the part of the DSPs supports findings in the literature that indicate the need for redesigning the approach to service development for people with I/DD. John O’Brien has called for a reassessment of human services from the perspective of the service recipient in an effort to negate the power of social devaluation (O’Brien, 2006). This study suggests that DSPs view their role as supporting to a degree, a larger bureaucratic function and to a lesser degree spontaneity in the area of health and wellness for the participants. This study contributes to this information around health and wellness as experienced by the participant and perceived by the DSP.
Although DSPs identified themselves as role models for health and wellness, a conflicting perspective was shared by the participants. Participants were more sensitive to unhealthy behaviors on the part of DSPs than perhaps the DSP was aware. The unhealthy behaviors were perceived as undesirable and left a lasting impression on the participants. When this study began, one participant shared how proud she was that her DSP had stopped smoking. By the conclusion of the study, the participant shared her disappointment that the DSP returned to smoking over the few month period of time. This area of discordance is significant. The power of a role model can be essential to making a difference in the life of a participant. This finding suggests that a difference in perception of what it means to be a “role model” exists between participant and DSPs. As a result of this finding, further exploration into the area is encouraged.

Limitations of the Study

There were several limitations to this study. This study was conducted with participants and DSPs within one agency. This agency embraces a program philosophy with emphasis on a person first approach rather than a systems approach. Therefore, results of this study must be analyzed cautiously before generalizing to a wider disability community, multiple agencies, or programs with differing philosophies.

Purposive sampling generated data that is by nature limited in its application to the general population of people with disabilities. The participants were individuals whom had fewer needs and requirements for attention, in relation to other individuals with disabilities. In addition, the sample of participants was Caucasian and included no apparent ethnic diversity. Each participant shared personal experiences with health and wellness and data saturation was achieved. However, extrapolating from this data should be approached with caution, as it is based on personal experiences of selected participants.
One challenge faced with the methodology of data collection through Photovoice that should be noted. This challenge is accounting for the influence of the DSP during the use of the camera. All DSPs were educated on the concept of positive neutrality, providing support for the participant to use the camera without suggesting or guiding of potential photographs. DSPs are in a helping, supportive role in relation to the participants. This was evident by their responses during the focus meeting. Therefore, it cannot be ruled out that at times, DSPs may have coached the taking of some photographs.

The last limitation was noted during the Photovoice interviews with individual participants. Some participants were more limited in their description and reflection on the photographs they had taken. Despite a parsimonious response to the photograph, the participant was able to communicate facilitators and barriers to health, but may not have been able to explain why. This was consistent with Messant, Cooke and Long’s findings (1999), in which participants with I/DD were able to identify physical activities they enjoyed, but not able to describe why they liked a particular activity. A few participants, in relation to a single, specific photo, stated they didn’t recall why they had taken the photograph. It is reasonable to believe that in these instances, another person had used the camera and taken a photograph.

**Strengths of the Study**

The most significant strength of this study is that the qualitative design, theoretical perspective, and methodology of using Photovoice honors a sense of inclusion for participants. Historically, people with disabilities have been faced with a constant struggle to be seen and heard as members of society. This study trusted participants’ capacity to be expert authors of a life experience, rather than accepting a proxy voice for assessment of facilitators to health and
wellness. The findings from this study contribute to the overall small but growing body of knowledge that describes the reality of health from the perspective of the person with disability.

Identification of this knowledge is a powerful force for change in the lives of people with disability. It holds the potential to inform the design of human systems from the recipient perspective and support a life designed on capacity, rather than deficit, and directed toward a personally preferred future. This information in turn, may be used to inform services around the life of the individual rather than the needs of the staff and a narrow range of predetermined services and approaches.

**Implication and Recommendations for Policy, Practice, Education and Research**

Literature reviewed in preparation for this study supported a pervasive concept of disability as entangled with health. In general studies focused on isolated health problems, cardiac concerns, obesity, vision, and dental problems. In accordance, wellness programs focused on targeted health issues. One study (Jurkowski & Paul-Ward, 2007) included the voice of people with disability in support of self-determination around health and wellness. Findings from this study support findings from Jurkowski and Paul, people with disabilities demonstrated knowledge of health and healthy behaviors and this was associated with the day to day behaviors, experiences and social activities. This study adds to the collective knowledge of self-determination with implications for policy, practice, education and research.

**Policy Implications**

Building a collective body of knowledge is significant in that it provides a focus or point of attention. Attention to this knowledge stimulates the beginning of transformative thinking and consideration of changes in care and methodological approaches to situations. This in turn yields a powerful force to create change in culture. Therefore, building of a body of knowledge around
the authentic voice of people with disability is a deliberate window of opportunity for a change in the culture.

Socially inclusive policy and national health initiatives have established goals that promote improved health, healthy aging, and a decrease in health disparities among people with disabilities. The focus of Healthy People 2020, builds upon decreasing of health disparities as cited in Healthy People 2010, and further expands to include the concept of health equity, the striving for maximum health status for all individuals (USDHHS, 2010). Participants in this study have suggested that the overall experience of health and wellness is similar to that of the general population and had little to do with their disability. Information such as this supports policy directed toward health equity and provides guidance towards achieving these goals.

Health care policy and the American health care system are in a process of moving towards universal access, improved cost effectiveness, and more efficient system wide financing (Gettings, 2009). Debate continues at the federal level with a finalized plan not yet available for review. What are apparent are two competing forces, Medicaid is indispensable for people with disabilities and budget gaps must be closed. In New York State, Governor Cuomo has committed to closing a 10 billion dollar budget gap, which will include cuts to health care spending (Reisman, 2011). Information from this study may contribute to new ideas helpful in creating system change to meet the evolving health promotion needs of the people with disabilities. Supporting health and wellness, in a meaningful way, may reduce costs directed at restoring health and negate the potential downward health spiral that commences when chronic conditions develop.

Along with policy concerns about health and wellness are ethical considerations about supporting health not just among people with disabilities, but all vulnerable populations. The
participants in this study were able to consistently demonstrate a sound knowledge around healthy eating and healthy choices in food. The DSPs’ echoed the same supportive knowledge. Both groups of participants were resolute in identifying the negative influence of fast food stores in the community coupled with the high price of ‘eating healthy’. This information is a valuable contribution to considerations on health and wellness. It substantiates a genuine knowledge and sincere desire to eat in a healthier manner, yet it concedes the sheer magnitude of the environmental influences and incredible financial challenge. This suggests a larger ethical question about our priorities as a nation, and how we support the health of our communities.

**Practice and Education Implications**

Nursing education and practice is fundamentally steeped in the concept of advocacy. However, nursing exists within a system of a medical model of care that heavily emphasizes physical and biological aspects of diseases or illnesses. People with disabilities in this study demonstrated a consistent knowledge of health promotion behaviors, and identified facilitators and barriers to health that were similar to the general population. Therefore, nurses must be proactive in their support of health and wellness for all patients regardless of disability.

Implications fall into two levels. At a systems level, nurses will need to negotiate within a medical model to advocate for prioritizing health promotion and inclusion of people with disabilities in conversations on personal approaches toward health promotion. On a more granular level, nursing education and practice should emphasis proficiency in a variety of methods to assess health needs and health promotion goals for people with disabilities. Subtle cues, non-verbal communication, significance and implications of common age related changes and the fact that facilitator and barriers themes, in this study, were similar among people with disabilities as for the general population should serve as a beginning guide for nurses.
This developing knowledge around health and wellness for people with disabilities is critical for nurses to embrace. Changes in health care delivery have prioritized nursing’s role as part of a larger health care team. A nurse’s ability to navigate a clinical system is more important than knowing how to perform tasks. Therefore the nurse needs a panoramic view that includes concepts uniquely valued within a population and clinical competence to critically think towards problem solving for the population.

The DSPs shared perceptions around health and wellness for the participants. This sharing of information, at times hinted of an incomplete disentangling of disability from health. It is imperative that the assumptions and beliefs of the DSPs are aligned with the authentic voice of the participant. Therefore, educational programs for DSPs need to illuminate the multifaceted considerations around health and wellness for people with disabilities and highlight the importance of role models in the lives of the participant. Knowledge about health and wellness cannot exist purely for the sake of knowledge sake; it must be a transformative and lived experience between the DSPs and the participants. Information from this study may begin to contribute information to such programs.

Education of families around health and wellness is critical to the extent that a person with disabilities spends time at home with family. This study suggested that those person with disabilities that do go home for visits have a more difficult time with things such as eating healthy and joining in family social activities while still attending to their overall health. Education of the family that includes the person with disability may hold hope to be effective for all the parties that are involved and identify each person involved as equal partner in the goal of health.

**Research Implications**
Disability communities across the state and the country vary in philosophical approaches affecting how systems are operated and structured. This study was conducted at a progressive agency with contemporary perspectives, with 11 participants with minimal ethnic diversity. Merit could be found in repeating studies, such as this, in a variety of locations to elaborate, validate and refine initial findings and add strength to the dissemination of results to stakeholders and substantiate policy positions.

In addition, this research suggested that DSPs are influential in the daily lives of people with disabilities. As a group, they present a culture of influence that has been scarcely researched. Further exploration of this culture may help to increase understanding and maximize the positive aspects of the relationship between the DSP and the person with disability. One specific consideration would be examining levels of education between DSP’s in relation to understanding of disability and how life is experienced.

The provision of human support and services to people with I/DDs is under constant review and analysis at all levels for a variety of reasons, from agency through federal government. The specific balance of providing support without impeding growth, independence, and achievement of personal goals is continually scrutinized to assure healthy balance between individual goals and service provided. The observation that the majority of photos taken by participants in this study represented other people with I/DDs or DSP is notable. As community life is experienced in a more fully integrated manner, individuals with I/DDs will correspondingly interact with the general population with increasing frequency. Understanding that self-efficacy is enhanced and supported through social modeling, social persuasion, and psychological feedback, dictates that constant scrutiny will be needed to assess and assure that
self-efficacy is being developed and supported. Further research in this area may provide critical information to enlighten and guide this area of concern.

Individuals with disability who live in the community spend time with family in small, brief amounts of time, perhaps a weekend visit or day trip. Participants in this study shared that time spent at home with family presented challenges around eating healthy. Further exploration into the families’ understanding of health for the person with disability may provide helpful information to support a sustainable wellness program. Tangentially related to this is the concept that full integration into society implicates that people from the general population as role models for individuals with I/DDs. Addressing levels of complicit behaviors will be an essential assessment area to validate movement towards health and wellness.

The body of knowledge self-generated by people with disabilities has been minimal. Although represented on the Nation’s health agenda in Healthy People 2020, little research in the area of health and wellness exists with regards to people with I/DD. In part, this reflects governmental regulations for protection of people with disabilities. However, one must also consider the fact that this may represent an assumption on the part of researchers that people with disabilities are not capable of contributing to research in a meaningful and personal way. The findings from this study suggest that people with disabilities are aptly capable of participating and contributing in a meaningful way to a research study. This suggests that further exploration of methods to access the voice of people with disabilities is imperative. Photovoice was successful in this study but does not preclude the exploration of other nontraditional methods of data collection.
Conclusion

Each participant in this study stands as an exemplar of the journey to health and wellness for a person with disability. The findings from this study suggest that a struggle for empowerment still exists in aspects of the lives of people with disabilities. This is evident in the fact that facilitators and barriers to health and wellness for people with disabilities show little difference than those of the general population. When examined in light of the perception of DSPs, discordance is evident in understanding health as experienced by the person with I/DD. This study sheds light on this situation and contributes to the growing knowledge of opinions, values, and beliefs of people with disability.

Nursing’s strength lies in the ability to present the voice of ordinary, in this case people with disability, while addressing policy. Health and wellness is a continual process and will call for continuing questions to refine and move emancipation of people with disabilities to a more fully realized state.
References


Thompson, D. (2002). “Well, we’ve all got to get old haven’t we?” Reflections of older people


