Doing, Being, and Belonging: A Photo Elicitation on the Meaning of Well-being of Adults with Intellectual Disabilities

A Dissertation
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Abstract

Adults with Intellectual and developmental disabilities disproportionately experience poverty, social isolation, and may have more co-occurring chronic health conditions than the general population. Interventions aimed at improving health outcomes for people with IDD typically focus on physical activity, with few considering other causes of poorer health outcomes. Few interventions address health from a holistic perspective. This study adds a better understanding of what is important to adults with IDD think about wellness. Understanding the day to day experiences of people with IDD can improve interventions and supports. A descriptive qualitative research approach was used to answer the research question “How do adults with IDD describe health and wellness?”

Photo elicitation was used to develop narratives from ten adults with IDD to provide a qualitative description of health and wellness. Three themes emerged from this narrative: Doing, Being, and Belonging. These three themes highlight the importance of meaningful activities, positive self-identity, and social inclusion as key factors contributing to overall well-being.

Recommendations for future research include the use of research techniques such as photography that promote the inclusion of people with IDD in research. Photo narrative proved to be an effective tool for including people with IDD in this project, allowing participants to share their full experience. Further research should consider upstream factors for health disparities and should consider individual and community level investigations on how best to enhance the environments in which people with IDD live and work and how these environments affect their health.

Keywords: intellectual and developmental disabilities, health and wellness, photo elicitation

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Thanks to all the friends and family for the encouragement to keep working. I know some of you thought this day would never come. Finally, thank you to my spouse, Doug, who supports all of my whims and schemes, even the ill-advised ones.

Acronyms

AAIDD – American Association on Intellectual and Developmental Disabilities

ACL – Administration for Community Living

ADL – Activities of daily living

BMI – Body mass index

IADL – Instrumental activities of daily living

ICF – Instrumental classification of functioning, disability, and health

IDD – Intellectual and developmental disabilities

PEOP – Person-environment-occupation-performance model

WHO – World Health Organization

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Chapter 1
Introduction

Background

Individuals with Intellectual and Developmental Disabilities (IDD) are estimated to comprise about 1.5% of the population (Larson et al., 2018). Slightly more than half of individuals with IDD receiving Medicaid funded long-term supports and services live in the home of a family member (Larson et al., 2018). Community living has improved the quality of life for individuals with IDD over those living in institutions (Chowdhury & Benson, 2011). However, health disparities such as increased risk of chronic disease and premature mortality have been identified as a significant problem for people with IDD (Anderson et al., 2013).

Public health entities at both local and national levels have failed to address the needs of individuals with IDD in public health efforts, and in the professional training of health care workers, a clinical focus on the primary diagnoses of IDD at the expense of the prevention and management of secondary conditions, and issues of poverty and other social determinants of health (Draheim, 2006; Krahn, Hammond & Turner, 2006; Anderson et al., 2013). There has been increased attention to research and health interventions aimed at improving the health of people with IDD following the Surgeon General's report (USPHS, 2002) calling for increased attention to this problem.

Statement of the problem

Few studies have explained perceptions of health, health-promoting behaviors, or facilitators and barriers to health from the perspective of individuals with IDD, despite the attention given to addressing the health disparities of individuals with IDD over the past two decades (Temple & Walkley, 2007; van Schijndel-Speet et al., 2014).

Most interventions aimed at reducing health disparities focus on changing physical activity and dietary intake, with mixed success (Scott & Havercamp, 2016). One focus group study asked people with IDD what they saw as barriers to increased physical activity and found that although people with IDD were positive about participating in physical activity, they experienced barriers such as the lack of support in learning how to use gym equipment, lack of staff or family availability to provide support, lack of transportation, or the lack of financial resources (Temple & Walkley, 2007). Parents and staff identified the inability of community resources (such as gyms) to accommodate the needs of people with disabilities and the lack of focus on physical activity as an important part of service support. I was unable to locate any studies that addressed health and wellness from a holistic perspective addressing the multiple facets that lead to improved health outcomes, such as mental health and social connectedness in addition to nutrition and physical activity.

Anderson and colleagues (2013), noted in a summary of the current state of research about health and people with IDD that future research needed to improve understanding and interventions of health promotion for people with IDD. In addition, it is critical to include the voice of people with IDD in research.

Purpose

This study used a descriptive qualitative research approach to understand how adults with intellectual and other developmental disabilities describe what is important to their overall health and wellness.

Research question

To better understand the experiences of adults with IDD related to their health and wellness, this study asked the following question: How do adults with IDD describe health and wellness?

Significance of the study

This study contributes to the knowledge of health and wellness for people with IDD by providing a better understanding of what is important to adults with IDD as it regarding wellness. Given the numerous health disparities and health inequities identified for this population (Anderson et al., 2013), understanding the day-to-day experiences of people with IDD may inform better interventions and supports.

Individuals with IDD disproportionately experience poverty, social isolation, and may have a higher number of co-occurring conditions such as mobility limitations, chronic health conditions, medication usage, or reliance on others for opportunities to participate in activities such as exercise that may pose barriers to participating in health-promoting activities (Krahn, Hammond & Turner, 2006; Emerson, 2011; Anderson et al., 2013; Stancliffe & Anderson, 2017). In addition, systemic barriers such as the failure of public health entities to consider the needs of individuals with IDD in public health efforts contribute to these disparities (Krahn & Drum, 2007).

Theoretical Framework

Research involving participants with intellectual disabilities poses a particular challenge for researchers due to the unique cognitive and communication differences presented by this group. Because of this, the inclusion of the perspective of individual's with IDD in health research is a significant gap in the literature. I was unable to find any general population health initiatives that included people with IDD. Any efforts at providing interventions to this population were conducted at local levels. While there is some evidence that physical activity and nutrition interventions have positive outcomes, this is based on only a few interventions (Heller, McCubbin, Drum, & Peterson, 2011). Implementing and sustaining interventions overtime has been problematic (Heller, McCubbin, Drum, & Peterson, 2011). In order to improve the health outcomes for people with IDD, we need to understand their circumstances from their perspective (U.S. Public Health Service, 2001).

User-led research is an important tool that may lead to a better understanding of the individual's perspective. It has the ability to add relevance to the research in question (Faulkner & Thomas, 2002). I used a photo-elicitation narrative process to provide a qualitative description of the social and environmental factors of health and wellness that are identified as important by adults with IDD. This information can then inform interventions that address wellness holistically and may provide clearer directions in addressing barriers to better health.

Dissertation Overview

I introduced the study and presented an overview of the background and problem statement, outlined the purpose of the study, stated the research question and study significance, presented a theoretical perspective, and defined conceptual definitions used during the course of this dissertation research in this chapter. In chapter 2, I will review the models of disability, provide an overview of the health disparity and health intervention research done related to individuals with IDD and introduce the concepts related to the selection of qualitative research for this study. In chapter 3, I will define the philosophical underpinnings for this descriptive qualitative study, as well as the research design, participant recruitment and information, data collection and analysis methods, researcher positionality, and study limitations. I present the findings for this study in chapter 4. I discuss the findings in relation to the literature in chapter 5 and discuss the implications of this study's findings and recommends directions for future research.

Chapter 2

Review of the Literature

Introduction

This chapter provides an overview of the models of disability and the conceptual framework informing the work done in this dissertation. An overview of the health disparity and health intervention research done related to individuals with IDD is provided. Finally, the chapter introduces the concepts related to the selection of qualitative research for this study. Chapter three describes qualitative research in greater detail.

Individuals with Intellectual and Developmental Disabilities (IDD) are estimated to comprise about 1.5% of the population (Larson et al., 2001). About 1.2 million adults and children receive long-term supports and services. More than half of all individuals with IDD receiving Medicaid funded long-term supports and services live in the home of a family member; the rest live in an out of home setting such as congregate care settings, their own homes, or in host or family foster homes (Larson et al., 2018). The move from institutional care to community living has improved the quality of life for individuals with IDD (Chowdhury & Benson, 2011), however, health disparities such as increased risk of chronic disease and premature mortality is a significant problem for people with IDD (Anderson et al., 2013).

Health inequities, or differences in determinants of health that lead to health disparities, experienced by people with IDD include failure of public health entities at both local and national levels to address the needs of individuals with IDD in public health efforts, lack of appropriate health care professional training, a clinical focus on the primary diagnoses of IDD at the expense of the prevention and management of secondary conditions, and issues of poverty and other social determinants of health (Draheim, 2006; Krahn et al., 2006; Anderson et al, 2013). There has been increased attention to research and health interventions aimed at improving the health of people with IDD following the Surgeon General's report (USPHS, 2002) calling for increased attention to this problem.

Few studies have explained perceptions of health, health-promoting behaviors, or facilitators and barriers to health from the perspective of individuals with IDD, despite the research and interventions aimed at addressing the health disparities of individuals with IDD over the past two decades (Temple & Walkley, 2007; van Schijndel-Speet et al., 2014). Anderson et al. (2013), noted in a summary of the current state of research about health and people with IDD that future research needed to improve understanding and interventions for people with IDD. Interventions need to better address the social determinants that increase the risk of health disparities in this population. This literature review will describe the literature related to health disparities and adults with IDD, an overview of models of disability, theories of health behavior change, and the current status of health and wellness interventions for adults with IDD.

Intellectual and Developmental Disabilities

The American Association of Intellectual and Developmental Disabilities (AAIDD) (2010), defines Intellectual Disability as "significant limitations in both intellectual functioning and in adaptive behavior, which covers many everyday social and practical skills. This disability originates before the age of 18 (AAIDD definition of intellectual disabilities section, para. One)." Generally, significant limits in intellectual functioning is defined as an IQ test score of 70 or below (although IQ scores up to 75 may be included). Adaptive behavior are skills that are used in everyday life (e.g., understanding social rules, cooking meals or managing money (AAIDD, 2010). Developmental disabilities are related conditions defined as severe and chronic disabilities that occur before age 22, are expected to continue indefinitely, and that restrict functioning in major life activities. Major life activities include areas such as self-care, language, learning, mobility self-direction, independent living, or economic self-sufficiency (ACL, 2000).

Developmental disabilities may include diagnoses such as autism, cerebral palsy or Down syndrome, for example. People with developmental disabilities may or may not also have an intellectual disability. However, people in both groups may require long-term services and supports to successfully live and work in their communities and are typically served in the same support systems.

Data from the National Health Interview Survey provide prevalence estimates of IDD in the noninstitutionalized population of the United States to be to be 14.9 per thousand (1.49%) (Larson et al., 2001). Although this data is from the 94-95 Disability Supplement of the National Health Interview survey, there are no national survey data sets that reliably allow for the identification of individuals with IDD in the sample, making prevalence estimates difficult with more recent data sources (Anderson et al., 2013).

Individuals with intellectual and developmental disabilities are the focus of this research project. People with intellectual and other developmental disabilities have unique challenges stemming from their support needs to achieve their idea of optimal health and wellness that will be detailed in this literature review.

Conceptual or Theoretical Framework

Wellness. Wellness has varied definitions. Wellness is a “multidimensional, positive health, possessed by the individual” (Corbin & Pangrazi, 2001). Greenberg (1985) describes health in five dimensions – physical health, social health, mental health, emotional health, and spiritual health. The National Institute on Wellness (2018) describes six dimensions – emotional, occupational, spiritual, physical, social and intellectual. Wellness comes from the integration of all of these dimensions (Greenberg, 1985). A person experiencing physical illness may also be experiencing wellness if they have strong social support, meaningful spiritual practices, and are able to manage their stress, for example. The concepts of wellness, or a holistic understanding of health, are important in understanding health disparities because of the interconnection between social health determinants and physical and mental health.

Disability Models. Models of disability describe prevailing attitudes about disability, its causes, society’s behavior towards people with disabilities, and healthcare professionals’ treatment of people with disabilities. These models have changed over time from the moral model of antiquity to the civil rights models of today.

The moral model of disability dating to antiquity sees disability as the result of personal failures/behavior or due to a moral failing in the case of parents of disabled children. Barnes and Mercer (1997) quote Paul Hunt as saying that people with disabilities were viewed as ‘unfortunate, useless, different, oppressed and sick.’ The moral model of disability continues to be a common belief particularly about people with mental health challenges. People with mental health challenges are often viewed as weak or flawed because they do not have the ability to control their illness (Corrigan, 2000).

With the advent of the modern era and the development of the scientific method and modern medicine, the medical model was applied to disability. The medical model does not directly lay blame for disability on the person with the disability but sees the deficit or inability to function as a problem inherent in the individual (Brandt & Pope, 1997). Social factors such as occupation and personal characteristics such as gender were disregarded when determining disability and the lived experience of people with disabilities is medicalized (Brandt & Pope, 1997; Scallion, 2010). These models were prevalent through the 1950s and 60s. The primary focus was to find a cure for the condition causing the impairment. The medical model continues to be a dominant model of disability. One common experience of people with disabilities that typifies the medical model is the experience of diagnostic overshadowing. People with disabilities often report that despite their intended reason for a healthcare visit, their disability becomes the focus of the appointment, even when it has nothing to do with their reason for seeing their healthcare provider. This diagnostic overshadowing an identified factor that leads to health disparities (Anderson et al., 2013).

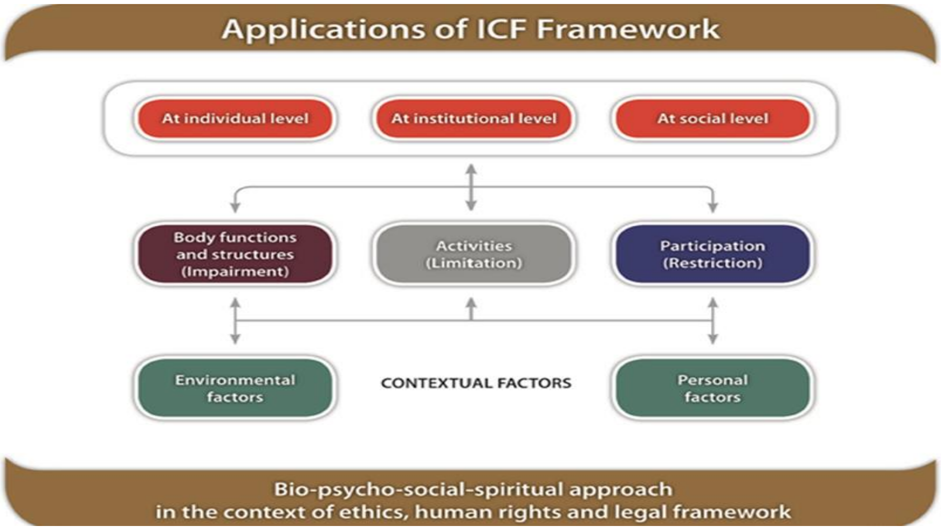
The forces of the Civil Rights movement in the United States encouraged people with disabilities to assert their rights causing models of disability to change. Disability moved away from solely focusing on individual impairment or deficit and began considering the role environment plays in people's ability to perform roles and tasks.

In 1976, Nagi first introduced the idea of the environment into understanding disability (Brandt & Pope, 1997; Putnam, 2002). Nagi's model started with pathology, which could then lead to impairment. Impairment led to the loss of function, resulting in disability if the person was unable to function in a given environment. Nagi saw disability as the inability to perform defined social roles and tasks within an appropriate social context (Putnam, 2002).

The enabling-disabling process model as described by Brandt and Pope (1997) identifies the interaction between the individual and their environment as the pivotal point in defining disability. A person's disability is a function of the amount of support the individual receives from his/her environment (Brandt & Pope, 1997). Disability can be context dependent and can vary across environments (Putnam, 2002). For example, environment and its role in creating disability can be seen in differing modes of public transportation, as an example. Older buses had inaccessible stairs for people with mobility challenges. Eventually, buses had lifts enabling people using mobility aids to use buses as a form of public transportation. However, this required the bus driver to leave the bus to operate the lift for the person needing assistance. Now, many new buses have flat curb level entries that enable a person using mobility aids to board the bus much like other users, eliminating a disabling barrier to the use of public transportation. In this model, disability is caused by a lack of access rather than by physical impairment.

The World Health Organization's (WHO) *International Classification of Functioning, Disability and Health* (ICF) is a revision of an earlier WHO model of disability (*International Classification of Impairments, Disabilities, and Handicaps*, ICIDH) (Jette, 2006). The ICF Model (see Figure 1) is a framework developed to provide a standard language and basis for understanding health and disability.

Figure 1: ICF Framework



http://www.who.int/hrh/news/2014/hrh_icf_framework/en/

The components of the ICF model include two component parts (WHO, 2013). The first, functioning and disability, includes body functions and body structures, and activities and participation. Body functions are the physiological and psychological functions of body systems. Body structures are the anatomical parts of the body. Activities include those day-to-day tasks whereas individuals participate in identified roles in their community. Functioning is the result of the interaction between the functioning and disability and the second component part, context. Context includes environmental factors that facilitate or inhibit participation including physical, social, or attitudinal factors. The second context factor is personal factors such as an individual's beliefs or motivation.

The ICF model of disability attends to both environmental and personal factors that contribute to the disablement process. The ICF also addresses concerns beyond physical impairment, function, and disability and includes a focus on participation in society and subsequently the quality of life (Jette, 2006). According to Jette and Latham

(2011), the ICF has played an important role in the further understanding of disability and that this greater understanding of the scope of disability has increased both the focus on participation for people with disabilities as well as the means to achieve it.

Nordenfelt (2003), criticized the ICF model and how it influenced the measurement of disability. For example, there is the underlying assumption that the activities and tasks are those that people do in their daily lives, yet this may not be the case. However, Nordenfelt (2003) posits that this may not, in fact, be true. There is no way of measuring whether or not someone wants to do a particular activity. Further, there is not enough explication of the role of environment and there is a supposition that people's environments are "standard" which is, of course, not true. And finally, the boundaries between activity and participation aren't always clear which can make both assessing disablement and research that measures disablement muddied.

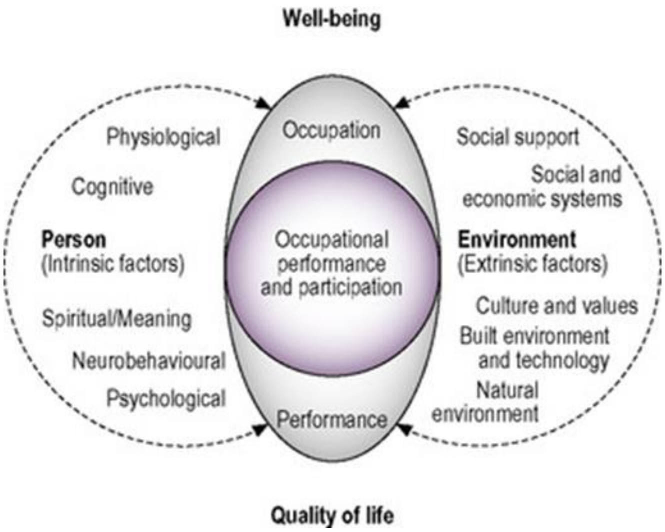
Despite models such as the ICF that focus on impairments, activities and participation, in practice, many researchers and practitioners continue to focus on a person's limitation or impairment without considering the societal role that is of value to the individual and the tasks and activities associated with those roles (Nordenfelt, 2003). Consideration of what individuals with disabilities consider to be important isn't part of the equation when developing interventions.

The social model of disability addressed the criticisms of other disability models in which the focus continues to be on the individual, despite attempts to incorporate the environment into the model. The social model of disability holds that people with disabilities are a minority group and that there are "social, cultural and political" aspects to disability (Shakespeare, 2002). In the social model, the focus is not on individual impairment, but rather on removing the barriers in society. The shift of blame moved from the individual to society (Shakespeare, 2002).

Understanding disability models is important because describe how perceptions regarding people with disabilities form. People with IDD and other disabilities face these perceptions on a daily basis in their interactions with service providers, healthcare professionals, and the general public. These perceptions may be that someone can be as strong as possible in the body they inhabit or that because someone has a disability, one has lowered expectations about what they might be interested in or able to achieve. Messages people receive about their bodies, minds, abilities, and acceptable activities can shape their beliefs about themselves. While one's personal beliefs and ideas of self-efficacy are important factors in choosing health-promoting behaviors, the extent to which others include or exclude people with disabilities from full participation may be even bigger barriers to achieving health and wellness.

PEOP model. PEOP (Person-Environment-Occupation-Performance) is an ecological-transactional systems model that focuses on the characteristics of the person and environment (Baum and Christiansen, 2015). It was originally developed in 1985 by Baum and Christiansen as a more person-centered model for occupational therapists to identify and address the barriers people with disabilities have in performing tasks or occupations that fulfill valued and meaningful social roles. The underlying principles of PEOP include human agency, or the belief that people are motivated to engage with the world around them and by the belief that experiencing success in mastering occupations builds confidence leading to the development of a strong self-identity and fulfillment (Baum & Christiansen, 2005). The PEOP model focuses on an individual's goals and outcomes that are based on supporting people to live satisfying lives, rather than on how to perform a particular task (Baum & Christiansen, 2005).

Figure 2: PEOP Model



Christiansen, C.H., Baum, C.M., Bass, J., 2005. Occupational Therapy: Performance, Participation and Well-being, third ed. Slack Inc. Thorofare, NJ. , p. 3

According to the American Occupational Therapy Association (2014), occupational therapy "emphasizes the occupational nature of humans and the importance of occupational identity to healthful, productive, and satisfying living (p. S3)." Occupations are the activities of humans and include self-care activities such as grooming (ADLS), activities of daily life such as shopping (IADLS), rest and sleep, education, work, play, leisure, and social participation (AOTA, 2014). These occupations are essential for human growth and well-being (Harper & Wood, 2014). Occupations have been defined as everyday activities chosen by individuals that are goal-directed, have meaning and purpose, and have value to the individual (Hinjosa, Kramer, Royeen & Luebben, 2003; Christiansen, Baum & Bass-Haugen, 2005; Boyt Schell, Gillen & Scaffa, 2014).

Wilcox (2005) identifies occupation as an agent of health and that occupational needs are essential to human functioning. Participation and engagement not only predict life satisfaction, but engagement in occupations influence health (Yerxa et al, 1989). Supporting occupations in areas that support health-promoting behaviors such as physical activity or self-care activities are obvious interventions. However, the focus on participation, meaningful activities and social connections are just as critical, perhaps more so to over-all health and well-being.

The ICF framework and the importance of participation are underlying principles for this research on two levels. The first is the underlying belief that the inclusion of people with IDD in research about their lives is ethically important, and therefore, the methods used in this project were chosen to encourage people to be active participants in the creation of knowledge. The second is the belief that participation is fundamental to overall health. In order to flourish, humans need to have the opportunity to participate in valued social roles and to have meaningful activities. The PEOP model is a tool that can be used to develop interventions that support the ICF framework. For a crosswalk of the ICF Framework and PEOP model see Appendix F.

Review of Research

Health disparities

Healthy People 2020 outlines the nation’s health goals for the coming decade. One of the overarching goals is to eliminate health disparities. The website of the Office of Disease Prevention and Health Promotion (ODPHP) (2014) defines health disparitiesa as a particular type of health difference that is closely linked with social, economic, and/or environmental disadvantage. Health disparities adversely affect groups of people who have systematically experienced greater obstacles to health based on their racial or ethnic group; religion; socioeconomic status; gender; age; mental health; cognitive, sensory, or physical disability; sexual orientation or gender identity; geographic location; or other characteristics historically linked to discrimination or exclusion.

Social determinants of health play a powerful role in understanding health disparities. They include individual behavior and genetics, but also environmental factors such as socioeconomic status, literacy, poverty, discrimination, and public policy (ODPHP, 2014). While people with disabilities experience many of the social determinants that are associated with health disparities such as poverty or discrimination, Krahn & Fox (2014) identify disability as a risk factor for health disparities in and of itself. Health disparities may result from an accumulation of experiences that lead to poor health (Krahn & Fox, 2014).

People with disabilities are more likely to report unmet needs in health, dental, and mental health than the general population (Anderson, Larson, Lakin& Kwak, 2003; Krahn et al., 2006). Identified health care access challenges include physical accessibility challenges, communication barriers, negative physician attitudes regarding providing care to people with IDD, and inappropriate referrals (both under- and over-referring problems were noted) (Reichard & Turnbull, 2004). Other studies report that persons with IDD did not receive thorough physical examinations, providers directed communication at the caregiver rather than the individual with IDD, insensitive office staff made appointments difficult, reports of misdiagnoses were common, and people with challenging behavior received worse quality of care (or no care) (Ward, Nichols, & Freedman, 2010).

Physicians themselves reported challenges to providing effective health care such as their own lack of training on how to effectively treat people with IDD, inadequate reimbursement from Medicaid, inadequate exposure to and discomfort around people with IDD, and lack of time to adequately deliver health care services to people with intellectual limitations (Reichard & Turnbull, 2004). Brown and colleagues (2010) found that medical students exhibited poorer performance caring for patients with IDD compared to others in tasks varying from taking a medical history, conducting physical exams, and ordering laboratory tests, perhaps reflecting the lack of disability training in most medical school training programs.

Most adults with IDD rely on Medicaid-funded insurance programs that have notoriously poor provider reimbursement further decreasing access to care. Often medical and dental providers may be reluctant to provide services to patients for whom they believe they will not be adequately reimbursed (particularly for a group of patients who may require more time for office visits) (Birenbaum, 2009; Martin, 1997).

The lack of experience with and an understanding of people with disabilities is reflected at a policy level related to clinical guidelines and the care given to people with disabilities. Mizen, Maclie, Cooper, and Melville (2012) found that most clinical guidelines failed to address people with IDD as being at high risk for particular conditions when appropriate. They also noted that guideline development groups do not include people with IDD experience on the committees developing guidelines (Mizen, Maclie, Cooper, & Melville, 2012). Guidance that could be available for health care providers in terms of appropriate screening and treatment for individuals with IDD is, therefore, missing.

The results of these health inequities include high rates of chronic conditions, decreased life expectancy and greater rates of co-occurring conditions as compared to the general populations (Scepters et al., 2005). As many as 87% of people with a disability (defined as having any activity limitation in this research) report having at least one chronic condition when compared to 49% of people without a disability (Kinne, Patrick & Doyle, 2004). Other studies show that people with disabilities are 14 to 16 times more likely than the general population to report at least one chronic condition and nearly a quarter (21%) of people with disabilities report more than one chronic condition (Kinne et al., 2004; Vogel et al., 2007). These chronic health conditions include high cholesterol, hypertension, and cardiovascular disease; and are more likely to experience multiple chronic conditions. (Bodde & Seo, 2009; Draheim, 2006; Krahn, et al., 2006; Reichard & Stolze, 2011; Reichard, Stolze, & Fox, 2011; Tyler, Schramm, Karafa, Tang, & Jain, 2010).

Despite changes in long-term supports and services that have enabled people with IDD to live in the communities of their choice, rather than in institutional settings, there are still significant challenges in terms of overall health and well-being that need to be addressed. The inability of the healthcare system to meet the health needs of people with IDD paired with societal structures that undermine health has meant that people with IDD experience poorer health outcomes at a greater rate than does the general population.

Health and Wellness Interventions. The significance of the problem related to health disparities and calls to action were noted by the U.S Surgeon General (2002) in the report Closing the Gap: A National Blueprint to Improve the Health of People with Mental Retardation. Similarly, the American Dietetic Association and the US Department of Health & Human Services have both called attention to the need to address the nutritional status and related health problems among people with IDD (US Dept. of Health & Human Services, 2013; Van Riper & Wallace, 2010). This has led to an increased focus on the health and wellness of people with IDD in the past decade. Attention to the health of people with IDD has expanded from a focus on primary causes of the disability to include health-promoting interventions such as wellness programs, nutritional supports provided to people with IDD by support staff, interventions to increase physical fitness, and educational interventions to improve health self-advocacy and health behavior (Abdullah et al., 2004; Rimmer et al, 2004: Holburn, Cea, & Cordon, 2008; Humphries, Traci, Pepper, & Seekins, 2009; Humphries et al, 2009; Marks, Sisirak, Medien, & Magallanes, 2012).

Evaluations of these interventions have shown that, similar to health-promotion programs aimed at the general population, outcomes for people with IDD are modest and evaluations have rarely measured change longer than one year following program completion. In addition, few health and wellness interventions include the training of support staff and the creation of health-promoting environments in residential and vocational settings. This is likely to be a critical component of any successful health-promotion intervention given the need for on-going support required by many people with IDD.

Temple and Walkley (2007) conducted focus groups regarding barriers to physical activity, with one group comprised solely of adults with IDD. These researchers found that barriers to physical activity included external factors, such as lack of staff support or lack of transportation. Schijndel-Speet and colleagues (2014) conducted 14 indepth interviews and focus groups with 40 participants with IDD about physical activity. Participants identified external barriers to participation in physical activity (i.e., social support, transportation) as well as intrinsic or personal factors (i.e., self-confidence, or skills). No studies directly asked participants with IDD about their perceptions related to any aspects of health other than physical activity.

Information regarding nutritional status and dietary intake or the success of nutritional interventions for health promotion (as opposed to nutritional interventions for clinical conditions that require special diets such as genetic disorders) among individuals with IDD is limited. Most of the available literature is available for people living in 24-hour care settings, such as group homes, in which support staff typically control the purchase and preparation of food. Information for those living in the community, such as in their family home or their own home, is scant, primarily due to the lack of validated methods to gather dietary intake information from people with IDD in less restrictive residential settings (American Dietetic Association, 2010; Humphries et al, 2009). Despite these methodological difficulties, concerns about nutrition and diet remain because limited evidence suggests that the diets of people with IDD living in the community setting are nutritionally poor (Bertoli et al, 2005; Humphries et al., 2009).

The lack of effective health interventions given the health disparities experienced by this population is an area that needs further attention. Most studies have focused on physical activity, which is an important component of health, however, other aspects of health and wellness such as access to nutritious foods, poverty, stigma or social isolation are gaps in the health intervention research. Interventions that have been tried have had mixed results. Understanding what adults with IDD identify as important to their health and wellness can be one means of creating interventions that incorporate the full range of needs and desires of individuals with IDD.

Limitations in health and wellness research

A significant limitation of current health research for people with IDD is the focus on individual behavior, particularly on increasing physical activity. Little attention is paid to other social determinants that play a role in health disparities. Oullette-Kuntz and colleagues (2005) note that many individuals with IDD have limited to no literacy skills, yet population-based public health efforts often require literacy and abstract thinking levels that are challenging for people with IDD. Further, limited literacy increases risks for medication errors, misunderstanding health care orders, and increase safety risks for people with limited literacy (National Literacy and Health Program, 1989). The lack of recent literature highlights the lack of research in this area for people with IDD.

Poverty is often an overlooked risk factor for health disparities in this population. People with IDD are more likely to experience poverty and poverty-related health disparities (Emerson, 2007, Emerson & Hatton, 2007). Emerson & Hatton (2007) found that self-reported health status was in large part explained by social indicators such as hardship, defined as having to do without needed items due to lack of money. Poverty is associated with multiple poor health outcomes for people with IDD (Larson et al., 2001). Because it is not possible to identify people with IDD in large national data sets, such as the National Health Interview Survey, more recent information about the poverty status and health outcomes for people with IDD is not available.

A third overlooked social determinant that has not been addressed in the literature related to health and IDD is the relationship between social isolation and health in this population. Individuals with IDD are much more likely to have limited social networks outside of family and paid caregivers (Lippold & Burns, 2009; Amado, Stancliffe, McCarron & McCallion, 2013). The role of social networks and social support and their relationship to health outcomes has been well-studied in the general population. Strong social support is predictive of both better physical and mental health across the lifespan (Seeman, 2009; Resnick, 2000; Berkman, Glass, Brisette, & Seeman, 2000; Uchino, 2006). Full understanding of how the lack of strong social networks on health affects people with IDD needs further research.

Stigma, another social determinant for health disparities is not well studied in the IDD population. Hatzenbuehler, Phelan & Link (2013) argue that stigma is an important social determinant for health. They define stigma as “the co-occurrence of labeling, stereotyping, separation, status loss, and discrimination in a context in which power is exercised (p. 813).” Stigma is a significant stressor for many marginalized populations and conveys social disadvantages. According to Hatzenbuehler and colleagues (2013) stigma negatively affects things such as the availability of resources, social relationships, psychological and behavioral responses, and stress that have been shown to lead to adverse health outcomes. In a review of the literature, Werner and colleagues (2012) identify a number of forms of stigma frequently experienced by people with IDD. These include things such as being exposed to teasing and stares and being avoided by others to the lack of services and overly restrictive environments, such as segregated services that limit choice making opportunities. Stigma may also lead to devalued roles within society and lack of acceptance by members of the community (Werner, et al, 2012). Often people with IDD are aware of the stigma associated with their disability and reported that this is a painful experience (Werner, Corrigan, Ditchman & Sokol, 2012).

Health literacy, poverty, social isolation, and stigma have all been demonstrated to be powerful predictors of health outcomes in other populations. Developing a better understanding of the upstream effects of the social determinants of health on outcomes for people with IDD is an area that requires more research.

Qualitative research and IDD

Disability and rehabilitation research reflects society's attitudes towards disability. The dominant research paradigm of the "scientific method" and the medical model is positivist (Oliver, 1992). Positivist research takes a mechanistic view and reflects the belief that the social world can be studied in the same way as the natural world (Oliver, 1992). Models of disability from the medical model to the social model of disability influence the way researchers think, develop questions, and interact with people with disabilities. The early medical models focus solely on pathology to the exclusion of the personal characteristics of the individual and his or her social context. These models reduced people to their disease. The social model reflects the idea that disability is a social construction, and this is also reflected in a research paradigm that holds that knowledge is a social construct as well leading to an interpretive research philosophy (Oliver, 1992). Interpretive research stems from this idea that we learn through our experiences and through our interactions with others and recognizes the connection between the researcher and the research participant in creating new knowledge.

Rehabilitation Science covers the spectrum from bench research about the physiology and functioning of the human body to societal structures, including governmental policy, which promotes disablement. The challenge for Rehabilitation Science is to gain a deeper understanding of the experiences of people with disabilities. Research involving participants with intellectual disabilities poses a particular challenge to active research participation due to the cognitive and communication differences prevalent in this group. The inclusion of the perspective of individuals with IDD in health research is a significant gap in the literature. The Surgeon General noted in a report about the health disparities experienced by people with IDD:

> We have been too likely to expect others, without mental retardation, to speak to their needs. We have found it too easy to ignore even their most obvious and common health conditions. Just as important, we have not found ways to empower them to improve and protect their own health. No one who cares would suggest that this is acceptable. Nothing, however, will flow from this effort unless we help our society better understand and appreciate that these persons are an integral part of the American people, with much to give if they, too, enjoy proper health (U.S. Public Health Service, 2002, p. v).

Ultimately asking end-users what matters to them will lead to better research questions and better research (Faulkner & Thomas, 2002). Qualitative research offers a meaningful way for adults with IDD to participate in research in order to better understand the experiences of health and wellness of people with disabilities from their perspective. Understanding the lived experiences of people with IDD can potentially lead to better interventions needed to address health and other disparities.

This research project addresses two of the gaps in the research related to health and wellness for people with disabilities. The first is to fill the gap of limited research about people with IDD in areas of health and wellness other than through nutrition and physical activity. This project also includes the voice of individuals with IDD and their experiences of well-being and what is important to them. This research project seeks to add to the body of literature by addressing this using a qualitative approach.

Chapter 3

Methodology

Overview

This project is a qualitative descriptive research design that used photo-elicitation and interviews as data collection methods. Descriptions of the participants, data collection methods, and the process used to analyze the data are presented in this chapter.

Qualitative Research

All research has an underlying paradigm. Positivist research is most closely associated with quantitative research and "reflects a deterministic philosophy in which causes probably determine effects or outcomes" (Creswell, 2009, p.7). The goal of positivist research is prediction and control (Guba & Lincoln, 1994). The positivist researcher is seen to be objective or unbiased.

The constructivist or interpretive research paradigm that is most often associated with qualitative research posits that knowledge creation occurs in the interaction between the researcher and the research participant (Guba and Lincoln, 1994). In qualitative research, the subjective understanding and world-view of the researcher are acknowledged (Cresswell, 2013). That is all of our experiences, beliefs, assumptions, and motives influence our behavior and helps us make sense of our experiences. Because researchers in this paradigm recognize that previous experiences influence their research, they work to set aside or bracket their knowledge and experiences and approach the research with an open stance (Dahlberg, 2008). The application of this process to this research is described in greater detail in chapter 4.

In qualitative research, the text is constructed by continually looking for meaningful words and phrases in relation to the whole of the data (van Manen, 1990).

The researcher seeks to understand what the research participant is really saying. The individual's story or text is compared and contrasted to that of other participants' stories to find differences and commonalities in their experiences (van Manen, 1990). This continual reflection between the parts of the text and the whole text is always done in the context of the research question.

Research Design

This project has a qualitative descriptive design. The purpose of descriptive research is to describe a phenomenon or events in everyday language (Lambert & Lambert, 2012). Sandelowksi (2000) describes qualitative descriptive research as staying "close to the data and words" without excessive interpretation. This makes qualitative descriptive research data-driven with coding coming from the data itself rather than from pre-ordained rules stemming from theory or philosophical stances (Lambert & Lambert, 2012; Sandelowski, 2000). This project uses a qualitative descriptive method to learn how adults with intellectual or other developmental disabilities experience wellness. In qualitative descriptive research, the researcher collects enough data so that the description of the events under question would be recognized and thought of as accurate to most people, including other researchers and participants (Maxwell, 2002). Qualitative description includes a variety of data collection methods and materials including, but not limited to, photographs and interviews in order to illustrate and provide evidence for the validity of the final description (Bogdan & Biklen, 1998). Qualitative descriptive provides an explanation of the experiences from a group of individuals about an event (Sandelowski, 2000).

A photo elicitation process in which participants took photographs that were the basis for creating a narrative to answer the research question "How do adults with IDD describe health and wellness?"

Photo Elicitation. Visual imagery has been used throughout human history to represent shared human experiences (Hodges, Keeley, & Grier, 2001) and are a form of story-telling (Harrison, 2002). In this project, participants used photography to create visual images of their experiences. By having the camera, the data collected was directed by the participants rather than the researcher and reflected that which is interesting and important to the participant rather than to the researcher (Harrison, 2002). Because photographs became the focus of the research interview, the researcher and participant become collaborators in the production of knowledge (Carlsson, 2001: Harper, 2002). The participant was viewed as the expert on the content of the photographs and their meaning.

The photo-elicitation process includes researcher-generated prompts and participant-generated photographs that are then used as prompts for descriptions of the events of interest within the interviews (Mitchell, et al, 2016). As in traditional qualitative research, text from the transcribed interviews provided the data for analysis. However, photographs also served as a source of data. As Carlsson notes (2001), the photographs are not just *of* something; they are also *about* something and represent a choice about what the participant wants to communicate.

While no studies of photo elicitation with adults with IDD were found, there have been several studies using a similar method called Photovoice. One of the primary differences is that photovoice includes a group process to analyze the photographs (Wang

& Burris, 1997). Photovoice has been used successfully with marginalized populations; including individuals with IDD demonstrating that using photography as a means of empowering individuals with IDD to participate in research can be an effective tool with this population (Booth & Booth, 2003; Jurkowski & Paul-Ward, 2007; Jurkowski, Hammel, & Rivera, 2009).

Photo-elicitation rather than photovoice was chosen for this project because this is a descriptive study with the purpose of describing the wellness experiences of the participants, while photovoice is a method of participatory action research with the end-goal of changing some aspect of the systems or policies (Wang & Burris, 1997). The purpose of this research was to gain a deeper understanding of what people with IDD identify as important to their well-being, thereby photo-elicitation best aligned as a methodology for this research.

Ethical Considerations

Ethical approval was obtained from the University of Minnesota’s Institutional Review Board (Appendix A). The researcher completed training on obtaining informed consent from vulnerable populations. The process to obtain consent varied based upon the legal autonomy of each participant, because individuals with guardians have already been legally determined by a court to be incompetent to make their own decisions or to give consent. For participants with legally appointed guardians, consent was obtained from the guardian before individuals participated in the project. Individual assent was obtained for those participants under guardianship. Consent from individuals not under guardianship and assent for those who had legally appointed guardians was obtained when meeting directly with the researcher to explain the project. The researcher used plain language principles to develop the consent/assent process and language. Information provided during the consent/assent process included the purpose of the project; expectations of their role if they would participate; risks and benefits of participation; and privacy and protection of their information. Individuals were asked to explain to the researcher what their understanding of the purpose of the project was, what they would be doing if they participated in the project and the risks and benefits of participating. Individuals were also instructed about the various ways they could withdraw from the study if they chose to do so. These options included informing the researcher; informing their guardian, if appropriate; or, telling some other person such as a staff person.

Participants took photographs as part of the data collection for this project and were able to keep the photographs they took. They received a $20 Target gift card as compensation for their time. Consent and assent were recorded through written consent via the consent and assent forms (Appendix A).

Recruitment

Adults with IDD were primarily recruited through two provider agencies known to the researcher. The first was a large urban residential service provider. Two of the ten participants recruited through this provider lived in independent apartment buildings operated by this provider in two suburban locations. These individuals had participated in a prior training project related to the development of a health and wellness curriculum that I led prior to the start of this project. The second provider agency was an arts organization located in a large metropolitan area in which participants were performing artists. I knew five of these individuals through volunteer work at a community farm.

One participant was recruited through her personal outreach. Other recruitment efforts included recruitment information sent to area advocacy agencies, word of mouth, and postings on the Research and Training Center for Community Living's website. Two additional individuals were recruited through these methods (See table 1).

Inclusion/Exclusion Criteria

Participants were included if they were aged 18 or older, had an intellectual disability or related diagnosis as identified by agency staff, could manipulate a camera and take photographs, and could explain the photographs by speaking or using an alternative mode of communication, and had the capacity to respond for one's self without the need for proxy respondents. It was important for this project that each person be able to speak for themselves because the research purpose was to describe each person's experience from their point of view.

Exclusion criteria included being under the age of 18, not having guardian consent to participate, being unable to understand and communicate in English, and or lacking skills to use a camera. At the initial interview, participants were shown how to use the camera and were asked to demonstrate their ability to take photographs with the camera by taking a picture. As part of the recruitment process, information about the study and inclusion criteria for participation was provided the staff of each agency who informed eligible individuals and/or their guardians about the study.

Participants

Thirteen individuals agreed to participate in the project. Five were not under guardianship and provided their own consent. The remaining eight had guardian consent to participate and also completed an assent process. Ten of the individuals completed all phases of the project.

Three individuals did not complete the project. All three met with the researcher and completed the consent (one individual) or assent process (two individuals). In one instance, the guardian informed the researcher that the individual could not decide what he wanted to photograph, and therefore, would not be participating in the project. One individual told the researcher that he was too busy to participate after consent, and the third person rescheduled a meeting with the researcher twice indicating that she did not feel well. She asked the researcher if she "had to do this." The researcher informed her that it was voluntary and treated this as a withdrawal of consent to participate and did not contact her further about the project. Table 1 provides basic information about each of the participants that completed the project.

Half (50%) of the participants lived in their own apartments. Four participants (40%) lived with parent(s) and one lived with a sibling (10%). Fifty percent of the participants identified as female and 50% as male. The average age of the participants was 39.1 years, with ages ranging from 24 to 56 years of age. Most of the participants self-identified as white (80%). Two self-identified as black (20%). While the sample did not include people who lived in congregate settings, such as group homes, the sample reflected the majority of the population of people with IDD. Seventy percent of people with IDD receive services under the auspices of their state's developmental disabilities agency live in their own homes or with their families (Larson et al, 2018). This study excluded people with more severe cognitive and communication limitations due to the study’s objective that participants needed to be able to independently describe the pictures they took.

Each participant is described in table 1 and in a brief description of each individual following the table. These descriptions provide context to the reader when interpreting their narratives about how they described health and wellness. Participant names are pseudonyms.

Table 1: Participant table

Participant	**Gender**	**Age**	**Living Arrangement**	**Place of Interview**
Cici	F	45	Own apartment	Home
Meryl	F	54	Own apartment	Home
John	M	36	Own apartment	Library
Trudy	F	47	Own apartment	Restaurant
Evan	M	24	With Family	Home
Will	M	27	With Family	Coffee shop
Donna	F	56	Own apartment	Home
Hannah	F	23	With Family	Work
Todd	M	39	With Family	Work
Tom	M	41	With Family	Home

Participant Descriptions

Cici was a 45-year old woman who lived in a suburban apartment building specifically designated for adults with IDD. She was unemployed at the time of the study and tried to stay busy while she looked for work. She received employment supports that involved looking for new employment and supports for tasks such as money management and other independent living skills. She lived in a community that allowed her to walk to do many of the things that are important to her, such as walking to the local coffee shop.

Meryl was a 54-year old woman living in an apartment within a complex that had a mixture of people with and without disabilities. A support provider agency maintains an apartment in the complex from which staff provides support to a number of people with IDD.

She has been an actor for a number of years and considered herself a “diva.” Family is very important to her. Her mother has passed away and her father has retired to a warmer climate. She talked about her parents and looked forward to her father’s visits back to Minnesota.

John is a 36-year old man who lived in an apartment with a roommate who also has IDD. He described himself as being very close to his family and had a cat to whom he is quite attached. He was an avid cook and enjoyed cooking meals to share with his roommate. He was also a talented musician according to the direct support worker who brought this participant to the interview. He was working on developing a career in music.

Trudy was a 47-year old woman living in an inner ring suburb. She lives independently in an apartment while receiving a few hours a week of support services for assistance with tasks such as shopping, money management, doctor appointments, and reading mail and paying bills. She had a mobility limitation for which she wears orthotics and uses a crutch. She was an active member of her community, volunteering on a number of boards and committees related to disability agencies and issues.

Evan was a 24-year old man who lived with his mother in a city neighborhood. His parents were divorced, so he also spent time at his father's house. He was a new actor, having joined a theater company in the previous two years. He enjoyed music and was proud of his music collection. He was also active and enjoys things such as riding his bike and gardening.

Will was a 27-year old man who lived with his parents in a city neighborhood. He owned a French bulldog and enjoys sharing pictures of him. Will was a musician and likes to create electronica music. He also liked to take photographs and experiment with a variety of filters to make them look interesting.

Donna was a 56-year old woman who lived in an apartment in a building specifically for adults with IDD in the suburbs. She worked at the airport for the TSA directing airport passengers to the appropriate security line. She had a long-term relationship with a man she has known for 20 years. They live separately. She had a son and grandson from a previous marriage, with whom she desires more contact.

Hannah lived with her family in an outer-ring suburb. She recently started working as an actor. She liked children and helped at her church's Sunday school. She also volunteered at a church camp every summer to work with the younger children.

Todd lives with his mother in a suburb. He had his own space in the basement of his mother's house that he calls his "man cave." He is close to his sister who lives in a nearby town. He is an actor, belonging to a local theater troupe. When he is not acting, he enjoys going to a local coffee shop and writing poetry. He participates in a writing group.

Tom is a 41-year old man who lived with his parents in an outer ring suburb. His family recently moved and he misses his old community where he was closer to his friend and could walk to places he enjoyed, such as a coffee shop. He stated that he wanted to move from his family home into his own apartment. He was a close friend with Todd, sharing a love of poetry and acting. They often spend time together, including “guy trips” with Todd’s brother.

Data Sources

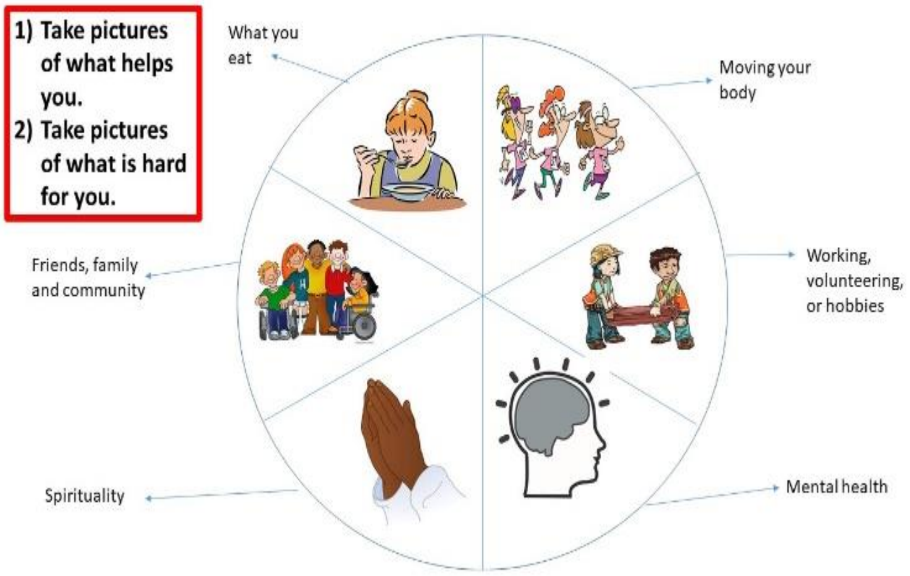
This study uses interviews as the primary data source. These were open-ended interviews that lasted from 25-55 minutes. The interviews were transcribed into text that was used for the data analysis. Photographs taken by the participants were a second source of data, however, their primary purpose was to elicit narratives from each of the participants about their experiences.

Data Collection

In order to answer the research question “*How do adults with IDD describe their health and wellness?”* participants were asked to take pictures of situations in their lives that related to health and wellness. Participants were given a 24-exposure Kodak™ disposable camera and were invited to use all of the exposures to take their pictures. Participants were shown how to activate the built-in flash and where the button to push to take a picture was located. Participants were then asked to take a picture to demonstrate they could take pictures with the camera. Two participants chose to take photographs with their cell phones. These pictures were provided to the researcher on a USB drive that was returned to the participants during the meeting in which the interview was conducted.

Instructions to participants changed during the study to simplify the process for study participants. In the initial interviews, participants were given a one-page instruction sheet that included a wellness wheel containing six categories (food, physical activity, social connections, spirituality, mental/emotional health, and work/meaningful activities) often associated with wellness. This was simplified from a much more complicated wellness wheel developed by The National Wellness Institute (https://www.nationalwellness.org). The adaptations were informed by work done by the researcher to develop and deliver a health and wellness curriculum for adults with IDD called "Partnerships in Wellness." The wellness wheel included pictures and simple descriptions of each category (Anderson, et al, 2016).

Figure 3: Wellness Wheel Handout



Participants were asked to take pictures of things that helped them in each of these areas and of things that made each of these areas hard. Within the first three participants, I realized that this task was too complicated despite explaining it in simple vocabulary, giving examples, and using pictures to illustrate each of the ideas. Two main challenges stemmed from this approach. First, individuals got "stuck" on each of the categories, and when they couldn't think of pictures to take that they thought fit into a category, they ended up not taking many (or any) pictures. Second, participants had difficulty thinking of both supports and challenges. Participants particularly had a hard time thinking about what kind of pictures that depicted something that was not working or was a challenge. One of the people who did not complete the project was an early participant with the original directions. By the third participant, it was apparent that this approach was not working. Instructions were changed to encourage participants to take pictures of things that made them feel "happy and healthy." Following this change in instructions, the remaining participants generally took more pictures than the original three, leading me to believe that this was a more appropriate set of instructions for taking pictures.

The underlying principles of wellness include the integration of social, mental, emotional, spiritual, and physical aspects (Greenberg, 1985). Recent meta-analyses of the effects of positive psychology on both mental health demonstrate improvement when interventions based on positive psychology are used (Bolier et al, 2016). Having positive emotions directly effects biological markers linked with disease (Steller et al, 2015). Based on this literature, I used the phrase "happy and healthy" to elicit photographs and interviews that would answer the research question in a manner that was understandable by the participants in this project. When participants had taken their pictures, they contacted me to collect the camera and develop the pictures. The length of time required for participants to complete their photos ranged from two weeks to three months. This did not appear to change the quality of the pictures or the interviews.

I then met with the participants to discuss the pictures at locations of their choosing. I tried to meet with participants within two weeks of receiving the cameras.

However, due to scheduling difficulties or participant illness, the range was two weeks to five months, most were within a month of receiving the cameras. Participants chose to meet in their homes (three participants), in a community room or other public location at their apartment complex (two participants), a coffee shop (one participant), in a study room at a public library (one participant), and their work location (two participants). The interviews ranged in length depending on the number of photographs taken by the individual and the extent to which the individual expressed him/herself verbally. Each interview ranged from 25 to 55 minutes. When I met with the participants, they were given a chance to look through the pictures before starting the interview. Participants were told they could exclude any pictures that did not want to share with me. In all cases, if participants chose to exclude pictures, it was because they were unhappy with the quality of the picture, rather than the subject matter. Three participants chose to exclude pictures. Generally, these pictures were taken indoors and were too dark to see the subject matter. However, they did tell the researcher what they had tried to photograph. These explanations are included in the transcripts.

All of the interviews were audio-recorded to ensure the entire interview was accurately captured. In addition, audio recording allowed the researcher to focus on the participant and the photographs rather than taking notes. The interviews followed a set format. First, the participants were asked to describe their usual day. Once they finished telling me about their typical day, I gave them their photos to review. The envelopes were sealed by the developer, so participants saw the photos before I did. If participants took the entire roll of film, they were asked to choose their top ten favorite pictures but were encouraged to talk about all of their pictures if they chose to do so. Interviews about the pictures were informal. I asked participants to “Tell me about this picture.” If participants offered little information, I would follow up with questions such as “Why was this important to you?”

In qualitative research, the interviewer needs to maintain an open stance when the researcher seeks to “listen, see, and understand” with respect and humility (Dahlberg, et al, 2008). The study participant is viewed as the content expert and the researcher as a curious questioner about that individual’s experience. Because the researcher’s own experiences and perceptions can influence what a researcher might hear, see or understand, part of having an open stance is maintaining a critical eye towards the researcher’s own perceptions and how they may influence the researcher’s understanding of the event under question (Dahlberg, et al, 2008). To remain open to the participant’s experience, I intentionally focused on being present and listening deeply to the participant. This meant that I sat in proximity to the participant (also necessary to view the photos), did not take notes and focused my attention on what the individual was saying and to the participant’s body language. This allowed the direction of the conversation to be flexible and to redirect the conversation back to the interview topic as needed. For example, Evan had pictures of a class that he was talking about his disability that was of interest to me, however, he moved that picture to the bottom of the pile when I questioned him about the photo. At this point, I redirected his attention to a different photo to describe, as it was clear he did not want to talk about the class photo with me. Evan chose not to discuss this photo during the interview.

Data Analysis

All interviews were transcribed into written text (See Appendix B for example). Interview transcripts and photos were entered in the qualitative analysis program Atlast.ti (Friese, 2018) for coding and further analysis. Examples of photographs are included in Chapter 4.

Data were analyzed based descriptive phenomenological method of analyzing data (Giorgi, 2009). Descriptive phenomenology is an attempt to explicate the meanings we make of our lived experiences in our everyday lives (Van Manen, 1990). The purpose of data is not to provide interpretation of the intent of the study participant, but to describe the experience from the data that is given by the participant's description (Giorgi, 2009).

In this method, the researcher must first adopt a 'phenomenological attitude.' The researcher sets aside or brackets their prior knowledge and experiences. Researchers question what they experience (Giorgi, 2007). Assuming this phenomenological stance is called a reduction. "Data reduction refers to the process of selecting, focusing, simplifying, abstracting, and transforming the data that appear in written up field notes or transcriptions (Miles & Huberman, 1994)." Data reduction includes transforming data and means that the researcher must make choices about which data is used or set aside in order to answer the research question. The phenomenological attitude is maintained through all phases of the data analysis. I did this by being listening and being curious and interested in the photographs taken by the participants and their accompanying narrative without interjecting her own experiences.

Following the process of the transcribing, organizing and entering the data into the Atlas.ti software program (Friese, 2018); my initial step was to read the interview transcripts in order to achieve an overall understanding of the general content and meaning of the data. Once all of the transcripts were read as a whole description, I wrote a summary of my initial impressions of the experience of “happy and healthy.” I then read each individual transcript a second time and wrote a summary of each participant’s description (See Appendix C for example).

The second step in Giorgi’s method is to determine meaning units (2009). The process of creating meaning units is straightforward, in that, the researcher reads the text and notes when the participant’s description changes in the context of the experience under examination. For example, meaning units identified from these interviews included feelings of belonging and having meaningful activities (See Appendix D).

The third step of the process is to convert the participants’ everyday expressions into the essence of the experience. In Giorgi’s method, one does this from a disciplinary perspective. That is, one considers the meaning units from the perspective of a researcher analyzing data with a particular knowledge base and context. In this reduction of data, the researcher looks for similarities and differences as the new meanings are grouped together to describe the essence of the experience (Dahlberg, et al, 2007). The description of the experience changes according to the meanings that appear from the data (See Appendix D).

In the final step of this process, the researcher synthesizes the meaning units into a description of the experience being described. If the structure of the description does not account for all of the data, then the researcher must describe variations of the structure of the experience. This is described in more detail in Chapter 4.

Once all of the meaning units synthesized, a description of the experience was written into a description of the experience of health and wellness of adults with IDD described in Chapter 5.

Research Quality

Transparency in qualitative research is as important as in quantitative research. Qualitative research has a number of strategies to ensure rigorous research practices (See Table 2).

Table 2: Quantitative and Qualitative Criteria for Assessing Research Quality and Rigor

Quantitative Term	**Qualitative Term**	**Strategy**
Internal validity	Credibility	• Prolonged engagement in the field • Use of peer debriefing • Triangulation • Member checks • Time sampling
External validity	Transferability	• Thick description • Purposive sampling
Reliability	Dependability	• Create an audit trail • Code-recode strategy • Triangulation • Peer examination
Objectivity	Confirmability	• Triangulation • Practice reflexivity

Anfara, et al, 2002.

Credibility, when conducting this study, was sought through conducting enough interviews that the researcher felt certain that there were no additional things to be learned. That is the interviews reached saturation. Glaser and Strauss (1967, p. 61) define saturation as "... no additional data are being found whereby the sociologist can develop properties of the category. As he sees similar instances over and over again, the researcher becomes empirically confident that a category is saturated." The study sample was purposely chosen in order to understand the experience of wellness from a particular population (adults with IDD). Data analysis itself was made transparent (See Appendix D) by using tables to explicate each step of the data reduction and transformation of meaning units. Another experienced qualitative researcher further reviewed this process. Finally, an audit trail in which the researcher created memos about impressions of the data during the data analysis process (see Appendix E). These memos were part of the analyses done in the Atlas.ti program (Friese, 2018).

Methodological limitations

The first limitation stemmed from the participants themselves. Some participants were able to talk extensively about their pictures allowing for a rich description. These individuals also provided a richer description of their daily lives. Other participants only provided concrete descriptions of their pictures and, therefore, the verbal descriptions were less rich, increasing the importance of the images captured on film.

The second limitation was with the cameras themselves. Seven of the participants used disposable cameras. The picture quality of indoor shots was poor making it difficult to see some of the images. Digital cameras with automatic flash may have eliminated this challenge.

Chapter 4

The Findings

Introduction

This chapter presents the findings of a photo narrative project conducted with adults who have IDD about their understanding of health and wellness. Participants were asked to take photographs of things that made them feel "happy and healthy." These photographs were the basis of narrative interviews. The data gathered from these interviews were analyzed with the aim of answering the research question "What do adults with IDD identify as important factors in their lives related to health and wellness?"

This chapter describes the role of the researcher in qualitative research, data analysis procedures, and the resulting themes that emerged from the analyses.

Role of the Researcher

Because of my experiences, training, and personal interest in this topic, I had to be mindful to not project personal biases into analyses of the data. This was accomplished through a process called ‘bracketing.’ Bracketing is when the researcher acknowledges and then “sets aside” their knowledge and beliefs in order to be open to the experiences of the person being interviewed (Dahlberg, 2008; Fischer, 2009). The goal is to be open to the other person’s experience without preconceived notions of what is right or wrong. Bracketing is an on-going process that occurs throughout the analysis process so that the researcher continually checks emerging themes not only with the original data but also against any biases the researcher may themselves have.

In order to do this, I participated in an interview with an experienced qualitative researcher about my personal and professional experiences and training which might influence my beliefs about health and wellness for people with IDD. The following is a summary of those experiences. Other forms of bracketing included memos (appendix E) about the research interviews after they occurred and during the data analyses process to record my reflections on emerging themes and the process itself.

I chose this research area because it intersects with my academic career as well as with my professional experience. Professionally, I have worked as direct support staff, a live-in "house parent," and a program director for individuals with IDD living in group home settings. I have also been a county case manager for individuals with disabilities who use Medicaid-funded long-term supports and services. In my work at the Research and Training Center on Community Living (RTC/CL) housed within the Institute on Community Integration at the University of Minnesota (ICI), I was the primary investigator for a project in which we developed and delivered a health and wellness program for adults with IDD. I have had the opportunity to work on other projects related to health such as a longitudinal study examining the effects on health care coordination for people with physical disabilities. And I have had the opportunity to work on both qualitative and quantitative research projects at the RTC/CL.

I am the guardian of a woman with IDD. I have seen how the lack of access to health-promoting activities such as exercise as well as lack of access to primary health care can be challenging. I believe that intentional focus to essential aspects of well-being such as physical activity, stress management, and high-quality nutrition can improve physical and mental health. My personal and professional background provided a deep understanding of the need for research about health and wellness for people with IDD, but is also solidified beliefs and assumptions that required bracketing during this project.

My academic career includes a Master of Public Health degree focusing on community health education. In my Rehabilitation Science Doctoral program, I have taken courses related to health and wellness such as the Biology of Aging. My primary research interests are to better understand health disparities experienced by people with intellectual and other disabilities and to improve individual and systemic processes to address them. I believe that people with disabilities should be included in the knowledge production process, and it is this belief that drove me to select a photo narrative method to study this problem.

Data Analysis Procedure

Interview data were first transcribed into text (see Appendix B). Once all of the interviews were transcribed into text, I then read each interview and wrote a summary of my initial understanding of the content of the interview. Once all ten interviews were summarized, I wrote an overall summary of my perceptions of the interviews (see Appendix C). The next step of the process as outlined by Giorgi (1997) was identifying the meaning units from each person's transcript (See Appendix D). I then reread all of the transcripts, researcher summaries, and meaning units to review how all of the pieces related to each other in order to identify and create codes for each of the meaning units. A meaning unit can vary in size from a word to a phrase. Meaning units should be large enough to be a complete concept, but not so large that they lose relevance (Elo et al, 2014). For example, Cici talked about her frequent trips to a coffee shop noting that "*It is like Cheers for me where everybody knows my name. I go there like three or four times a day…I go there to meet everybody, try to get boys.*" I identified the meaning unit as "*everybody knows my name*." Reading through Cici's narrative, this meaning unit was coded as belonging.

Once I identified and coded meaning units, I then combined them into groups of meanings or categories. For example, I combined all of the meaning units related to the friendship into a category about friendships and social networks. Once I created categories of meaning units, my analysis then moved to a higher level of abstraction and I identified the themes that described the participants' experience and that answered the research question of identifying important factors that people with IDD identified as important for health and wellness.

Findings

Themes. Three themes emerged from the participants' narratives – Doing, Being, and Belonging. Table 3 shows the themes and their categories. The theme *Doing* encompasses all of the meaning units related to activities that are important to the participants and the supports they need to participate in them. Activities included paid jobs, volunteering, civic activities such as voting or serving on committees, and hobbies or leisure pursuits such as exercising or writing poetry.

Being are categories related to self. These included things that made people feel happy or that made them feel good such as being in nature or doing things to take care of themselves. It also included having valued social roles and identities. Social roles included being an actress, a poet, or friend. People's self-identities included being a diva, being strong, or being the one who cheers other people up. Finally, *Being* included the pride or self-worth people identified when they had worked to accomplished something such as being a good cook or musician.

The last theme was *Belonging*. Belonging included important relationships in people's lives, families and friends. The category, a sense of belonging, was broader than having relationships with friends or family. Friends and family were different categories because the participants talked about their experiences with friends and family differently. For many people, the narratives about friends were more frequent and more detailed than were their narratives about their families. Sense of belonging implies a sense of being part of a community that is greater than personal relationships – of going places where people know you or of being accepted or recognized in the community. Each theme will be described in more detail.

Table 3: Themes and Their Categories

Doing	**Being**	**Belonging**
Meaningful activities	Nature	Family
Participation support	Taking care of self	Community
	Self-identity	Friends
	Pride in mastery of skills	

Theme 1: Doing. The theme Doing includes having activities that are meaningful such as employment or hobbies, but it also includes the things that people do as parts of ordinary life, such as going to the coffee shop or the store. Because people with IDD often need supports to be able to participate in the activities they want to do, supports that make

participation possible, such as support from family or staff and transportation are included in this theme.

Meaningful activities. The participants had a wide range of activities that included a variety of hobbies, volunteering, and employment. All of the participants took pictures of and talked about participating in activities that were vocationally or personally important to them. Many of the activities people described were discussed with passion. Donna has a job at the airport assisting with the security lines. Her photos reflected the values she places on this job, as many of them were of airplanes. *"I work as a line cue by security. If you are going on a plane, I tell you what line to go to. Priority would be first class. Standard and then pre-check. So the pre-check, standard and first class. I tell people which line to go – pre-check or not pre-check. I point to whatever line they have to go to. I love the job I have been there a year already."*

Meryl has had a long career as a performing artist. She appeared to have pride in work in which she had a wide range of strengths. "*I am an actor, but I am a singer by training. I like to sing, that's my strength. Singing and acting are my strengths. Singing before acting. Singing and acting are my strengths. But I do singing, acting…I do – improvise, um, I help write songs. I move. I do a little bit of everything. Sometimes it takes a performing artist to do two or three things to survive out in the real world. I've been doing this for 20 years."* Meryl

The importance of employment was also apparent in its loss. Cici had recently been laid off from her job and spoke of the challenges in the transition to a life in which she did not have some place to go every day. *"I am off of work I thought I would change the routine…just trying to get back into a routine of life…that's the new normal for me. I am still trying to navigate all of that. I am also looking for a new job…my boss is moving on...it's hard to figure out what the new normal is. Everything is a new routine. Everything is new."*

Both Cici and Trudy were avid volunteers. For Cici, the purpose of volunteering is to give back to her community and is a practice that stems back to her childhood. *"I volunteer at the food shelf. I volunteer twice a week. I love it. I love the people. I love working there. I love helping people. They are so nice to me. I tell people that I do that. I figure how lucky I am I can afford everything and had great schooling and health and I can live here. There are a lot of these kids needing school supplies and I just like giving back to the community. I've done that since I was a little kid. I volunteered with the homeless, and I knew that was a path I wanted to follow. So, I followed it. I followed where my heart went."*

Trudy volunteers for various advocacy organizations and has sat on government committees. She is passionate about rights for people with disabilities. This activity seems to be an integral part of her identity. "*…we advocate for changing the system and making it better for people with intellectual and developmental disabilities and for other disabilities that falls under it, so you could be intellectual and developmental disability and all the way up. So you know because some of the issues we fight for overlap. So* *that's really cool, and that's the same with [organizations], and, um, my transportation or metro mobility I am on the [committee].”*

Perhaps due in part to one of the agencies from which participants were recruited (an arts organization), and perhaps, due to the nature of the project itself, seven of the ten participants reported having an interest in artistic endeavors – music, photography, acting, singing, and writing poetry. Tom talked about his poetry writing and describes how he enjoys sitting on the patio to write *“Outside my house on my deck. One time I was home alone, beer, book of poetry. I am writing…”* Tom is also passionate about acting. *“The play is to me – life.”*

Participants had a sense of pride in their mastery in their areas of interest. John, for example, had learned to play keyboards and composed music. He was also proud of his cooking abilities and had several pictures of the meals he made. He enjoyed sharing his skills with his roommate. *"This is a picture of one of the meals I made. I really like to cook, and I make meals for me and my roommate."*

Some activities are meaningful just because they bring pleasure. *"This a picture of my music because I like to dance. It keeps me moving. When I find the music – I scroll down and pick the music and I click on it and then I dance. Dancing makes me feel good. I am a natural dancer. I just dance."* Evan

Participation includes the activities of daily life. Many people's photographs included the things that people do every day as part of living life, including hanging out at coffee shops, going to the grocery store, or going out to eat.

Participation support. Having access to transportation such as Metromobility or receiving financial assistance to access public transit was essential to participants' ability to participate in preferred activities. *"And that's my limited mobility go card because it gives me freedom. I get it through my waiver services which is my CADI waiver, and it also has my Metromobility on it. It helps me get where I need to go, and I take the city bus to go down to the [organization] to do certain projects. Yes, I know human* *services kinds of owns it, and I have to show them that I am using it. If I use it correctly and don't overuse it, it gives me freedom for the month."* Trudy

Hannah also took pictures of the Metromobility bus that takes her to the art program where she is an actress.

Walking was another vital source of transportation. Several people lived in communities in which they could walk to locations that they enjoyed visiting. Being able to walk places affords more independence. *" I walk three or four times a day. I can walk to all these places. It's convenient. I try to do things that are close to home."* Cici

Tom also talked about living in communities that he could walk to places he enjoyed by himself. *"An apartment – I want to move out. Close to movies. Starbucks. Easy to walk. And a gas station, too, so I can get junk food. By myself."*

Staff and families provided another source of support that enabled people to participate. Trudy talks about going places with staff. "*I am probably saying that wrong, but ILS worker through the county you know. Through Human Services. And from 9 to 11:30 we go out and do different things."*

Other participants have family support to participate in activities in their communities. "*Costco because my Mom has a membership card and we go grocery shopping and stuff. We get everything like snacks and food. It's cool." Todd*

All of the participants talked about doing things that were important to them. Their participation in activities ranged from the mundane tasks of everyday life like shopping to activities that brought them pleasure such as dancing or poetry. The supports that people received were part of their narratives about participation. Supports ranged from assistance from staff or family to the importance of transportation to be able to go and do the activities they wanted to do.

Theme 2: Being. The theme *Being* encompasses those things that refer to the self and how the participants related to the world. It includes valued social roles and identities – how the participants perceived and described themselves. It also includes care of self by doing things that make them feel mentally or physically good. The activities that are described in *Being* are different than the ones in *Doing* in that these activities are really focused on the self while *Doing* activities generally directed outward towards other people or objects.

Valued roles and identities. The first category under *Being* was valued social roles and identities. Many of the roles were implied; employee, sibling, romantic partner, or friend. However, more than half of the participants expressed a strong role or personal identities. “I am an actor.” “I am a musician.” “I am an expert gardener.” These identities were earned through hard work, training, and mastering skills.

Taking care of self. Six of the people talked about specific things that they do for their health and wellness. One participant, Evan, was particular conscientious about his health and talked about the importance of personal hygiene, drinking water, eating fruits and vegetables, and getting physical activity. However, Evan’s comments reflect the reliance people with disabilities often have on others to be able to participate in activities.

“Southdale YMCA and and….I get some exercise and….My mom has a key or whatever it is. I usually go, but I don’t anymore. My Mom doesn't have a pass. We

usually don't go. When I do go, I like to swim or work out. I like getting exercise." Evan

Some participants also talked about working on building behaviors that support health and wellness. For example, Cici spoke about needing to change her eating and drinking habits. *"This is a water bottle, and I felt that and I thought about hydration and how you can take better care of yourself. That's why I took the water bottle. I do need to drink more water. I drink a lot of Gatorade, but I need to drink more water. My dentist would approve. After two more cavities, my dentist really would approve if I drank more water."*

Donna also expressed the need to change some of her habits related to her health and had recently purchased a Fitbit for motivation to be more active and to adopt healthier lifestyle practices. *"I've got a Fitbit. I spent 169 bucks on this. I can even do this on my phone. It's from Shavorksies - the jewelry store. It's fancy. I got it because I work a lot and I walk a lot. It shows me how many steps I've taken and how many calories I've eaten and how I sleep. I've been sleeping better. I walk all over the airport."*

For the other five, participating in activities that promote health and wellness were implied such as for walks or about participating in self-care practices that made them feel good, such as pedicures, spending time in the sun, or taking time to relax. Trudy has a spot outside of her apartment where she likes to sit. "*I like the sun because it makes me feel good and I like the lights and darks. I really like the sun - not because you get a tan but because it really makes you feel good. You can soak it and just relax. I've always liked that since I was little."*

Cici said *"It makes you feel better about yourself, like when I go get my nails done at Mystic Nails I get a massage and I get a pedicure and Oh my god, it feels like heaven. I babied myself – even if I am a little broke at times – I wanted to get a pedicure and I got a pedicure and it felt so good."*

Nature. Seven people took pictures of things in the natural world, such as flowers, trees, the changing seasons, or the sun and clouds. The narration accompanying these pictures spoke of the beauty of nature and aspects of nature that made people feel happy or inspired. Todd said of a photograph of a wooded area - *"And I took this picture of the woods and trees and stuff like that. I feel like open my heart."*

Donna expressed a particular interest in outdoor activities, such as hiking. *"... and I was hugging a tree. I went on a nature hike once, and they said if you find a tree, and you like it hug it, so I hugged that tree…I like to do nature hikes and camping and fishing and being outside in summer."*

Will's photos were of a Japanese Garden that gave him a sense of spirituality. *"I um I really liked being in that area, and the plants and I liked seeing what almost looked to me like a shrine. It was to me somewhat of a spiritual looking site."*

Being was expressed by self-identities and social roles such as being a poet, a diva, a cook, a volunteer, and an employee. Taking care of one's self both mentally and physically were also expressions of *Being*.

Theme 3: Belonging. The theme *Belonging* included family connections, friendships and a sense of belonging. While all of these seem to overlap, they are separate categories in this analysis. The narratives of the participants about their relationships with others drove these distinctions. The sense of belonging was about the participants' relationship with the community as a whole and the extent to which they felt accepted out in the world. The friendship connections described by the participants in this study were often long-term friendships, going back to childhood. Because so many of the participants lived with their families, the narratives about families were often associated with the activities of life, as their families (mainly parents) provided daily supports for them. For several of the older participants, talking about families came with a sense of loss from parents that had passed away or from siblings who no longer lived in the family home.

Family. Nine of the ten participants talked about their families. Because half of the participants lived with their parents, their families were involved in their day-to-day lives. By default, many of the daily activities such as shopping or leisure activities involved their parents. Parents were a source of support. Hannah stated "*I learn to take care of myself. I always take clothes and (unintelligible), and I change. Sometimes I get assistance from my Mom.*"

Donna's partner was also a source of support for her, taking care of her when she was experiencing ill-health. *"We've been going together for 21 years…And then I had my teeth taken out – all 18 of them at one time. I stayed at his apartment in Dinkytown."*

People talked about being close to their families and spending time with them. *"Somewhere between there, I get to hang out with my mom. Last night we watched a movie together. She wants me off of the computer, and we hang out."* Evan

Three participants talked about loss and their families. Two participants' parents had passed away. They both reminisced about the things they did with their parents. Trudy reminisced about the love for horror movies she shared with her mother. Meryl remembers that her mom used to make jam, and she hoped that she would be able to do it herself. *"My mom made jam. I was going to enter it in the fair this year, but we didn't have some of the stuff. I need to look at it more for the equipment and stuff. I've already got the jars. I just gotta get some of the other stuff. It takes some doing, but no biggie. Not defeated, going to keep on trying. I'll get some of the other equipment, but it is awful spendy. We thought about Crate and Barrel, but they are expensive. Or some other store…I am going to get my stuff, and then I am going to make that jam."*

Tom expressed a different kind of loss. His family had recently moved from his childhood home to one in a different location in order for his parents to be closer to their grandchildren and he missed his old neighborhood. Tom was the only sibling still left at home. "*… It's a house. Like poetry. A house and our family is all together. My brother is gone at the house. I am only at the house. Everybody else has left. I am the only one left."*

Friends. Having friends was a common theme throughout the participants' narratives. Having a companion was an essential aspect of friendship. Many of the activities people described were done with friends. *"Applebee's – it's where I like to eat* *with my family. It's healthy and its good food. My friends Jill and Janey like to hang out there, too. It's where everybody knows you, and you can get good food. Jill is my best friend. Janey is three. Janey is her daughter. She's hilarious."* Cici

Two of the participants, Tom and Todd, were close friends who share many common interests and spent a lot of time together. Both of them included the other in their narratives. For example, Tom and Todd both enjoy writing poetry and going to coffee shops together to write or walking around together *"I was with Tom at his place 'cause there is a park. So, that's a park area… It gets nice and warm there, and we walk around."* Todd

Tom and Todd have an annual trip to the state fair. *"And when we were at the state fair my favorite was corn dogs. We do a lot of stuff. Rides and stuff like that. We have to pay for tickets and stuff."* Todd

Talking about friendships brought back childhood memories of friends. The people who spoke about these past friendships included more description than when talking about current friendships.

"We like to run around back there and play back there, and it's a pretty big yard. It reminds me of when I was a kid and the pasture, and we used to run down to the pasture. Except we didn't play in the pasture, we had this well, and it had these boards, and we would play walk the plank and see who could try not to fall into the well. We were fine until one of the girls got pretty banged up

and then we had to stop. It was pretty good until that happened. We goof around until somebody gets hurt." Cici

Cici also talked about her role among her childhood friends, some of whom are still friends. *"My friend [friend] - We would laugh about all the things we did as kids. I don't believe we did all that. I get a hold of them when they are down. My role was the cheerer upper one."*

Meryl expressed a conflicted view about friendships. She talked about the importance of her friends, but she also stated that she did not have many friends. *"My friends are good people, and my friends are few and far between. I have very few close friends. My friends are like my second family."*

Pets were another source of companionship. More than half of the participants had pets. Two of the people who did not talk much about friendships did speak about the importance of their pets. *"That's one I took at home of my French bulldog. His name is Charlie. He is important to me…"* Will

Community. While the narratives of all of the participants reflected the importance of "social connections" through family, friends, or pets, the descriptions of two of the participants indicated the deeper need for belonging. For Trudy, the sense of belonging came through a stranger buying her a muffin on her birthday.

"I was at Perkins, and I said it was my birthday and this nice gentleman who has a disability but, he, you know, got it later in life, wished me a happy birthday, and he bought me a muffin. And so that was really cool, and so I took a picture of it to show that

was appreciation of it. About someone caring about me you know that was a total stranger. You know, he was being really nice about it, you know. I mean I didn't even know him, and he came up and said I heard it was your birthday would you like a muffin?"

Cici talks of people knowing her name. She mentions this both when talking about her doctor's office and her favorite coffee shop. Being recognized or being seen reflects that one belongs to a community. *"It's like Cheers for me where everybody knows my name. I go there like three or four times a day... So, um, I go there meet everybody, try to get boys."*

Cici specifically talked about her family's religious practices and how the church was not a welcoming place for her – she felt as if she did not belong. Because of her experiences, she no longer belongs to a religious community.

> "*I was trying to get the cross, but I meant to get the church… I spend a lot of time there for spiritual things when I was a kid. My parents believed in church every single day as children. We must go to church. Dress up you're going to church. My grandparents are Catholic, so we always went to church. Me and my brother both got older, and he didn't get married in a church. I think we were over-churched. Now the times we step foot in a church is zero. (Laughs).   I'd get all emotional and people would start freaking out. So I quit going."*

Belonging was characterized by feeling accepted in the community, and by both having supportive relationships and by loss. Participants had supportive family and friends that were important to them. But participants also talked of parents that had passed away, friends no longer seen, and siblings that had moved out of their family home.

Surprising Findings

Based on the literature I expected, but did not find, data supporting themes in areas of financial security, healthcare, and supports. Therefore, they are not included in the main themes of the participants' narratives. I included a brief description of the participants' stories related to each of these are because they are of interest given the literature related to the health of individual IDD.

Financial security. Two participants mentioned money-related concerns which are less than expected, however, half of the participants lived with their families that may have given them a greater sense of financial stability. Both of these participants lived alone, had parents who had either passed away or had retired, and, possibly didn't have a source of additional family financial support. For Meryl, financial concerns were related to basic needs, such as food. *"Food. Good food. I am not a vegetable person. But, I like it when there is a lot of food in the freezer. I wish I had money to fill it."*

Healthcare. Healthcare was rarely mentioned, perhaps because the group was relatively young, and likely had fewer health concerns. One participant photographed the building that houses his eye doctor. Cici liked her health care provider; but expressed frustration at the lack of communication that sometimes occurred. *"Sometimes there isn't good communication between my doctor, and the nurses and labs get missed, and I have* *to prod them a little bit. Get it right, please. I wish there were better communication between everybody."*

Supports. All of the participants were received at least one government-funded long-term support or service either provided by the agencies who recruited for this study or by some other agency. Few participants mentioned these services. If it mentioned, it was in an off-hand manner about being somewhere with staff. One participant, Trudy talked about working with supports. She classified her days into days in which she was meeting with people who provided supports and those days that were her own. *"My other kind of day is I'll get up and if it's not a workers day…Mondays I have my nurse that comes on Mondays at 8 o'clock and 9 o'clock is my ILS worker – Independent Living Skills – I am probably saying that wrong, but ILS worker through the county you know. Through Human Services. And from 9 to 11:30 we go out and do different things."*

Summary

Three themes related to health and well-being emerged from people's photographs and narrative: *Doing, Being, and Belonging.* These themes reflect the experiences that contribute to overall health and well-being. Humans desire to have a purpose and activities that are meaningful to them to live a life that feels satisfying. However, participants in this project point to some of the unique needs of people with disabilities and their ability to fully participate. For example, people with disabilities may need support from family or paid support staff or access to special transportation to have full access to needed or desired activities.

Social connectedness or belonging is one of the most critical factors in health and well-being, and the participants in this project reflected the importance of connections with family and friends to feel happy and healthy. Health and wellness are also supported by health-supporting behaviors and is reflected in the theme *Being*. Some participants actively participated in activities that made them feel good, such as being in nature. While others participated in health-promoting behaviors such as physical activity or sought to make changes towards actions they perceived as more healthful, such as drinking more water.

The following chapter will discuss the findings in relation to the current literature and models of health promotion.

Chapter 5

Conclusions and Discussion

This chapter will provide a brief overview of the study and a discussion of the results of the data analyses. The findings will be discussed in the context of the ICF and PEOP models, as well as in the context of the current literature. Implications of the study for future research as well as limitations will be discussed.

Discussion of the findings

This descriptive qualitative study used photo-elicitation to better understand activities, events, and objects that made adults with IDD feel “happy and healthy.” The photographs were used as the basis of an interview that aimed to answer the research question “How do adults with IDD describe their lives related to health and wellness?” Three themes emerged from the participants’ narratives Doing, Being, and Belonging. Doing reflects the importance participants placed on meaningful activities, being on self-identity, roles and their place in the world, and belonging on the importance of social connections. Each of these themes is related to factors associated with well-being.

Psychological models

The themes *Doing*, *Being*, and *Belonging* identified in this study are reflected in the literature about human development and flourishing. Deci and Ryan (2008) describe three basic psychological needs as necessary for human development; autonomy, competence, and relatedness. Autonomy is volitional behavior that is congruent with one’s self and relates to the theme *Being*. Competence is feeling effective and having opportunities to use one’s capabilities is reflected in the theme *Doing*. Finally, relatedness, or *Belonging*, is having connections to others. Meeting these psychological needs are essential for well-being and functioning (Deci and Ryan, 2008).

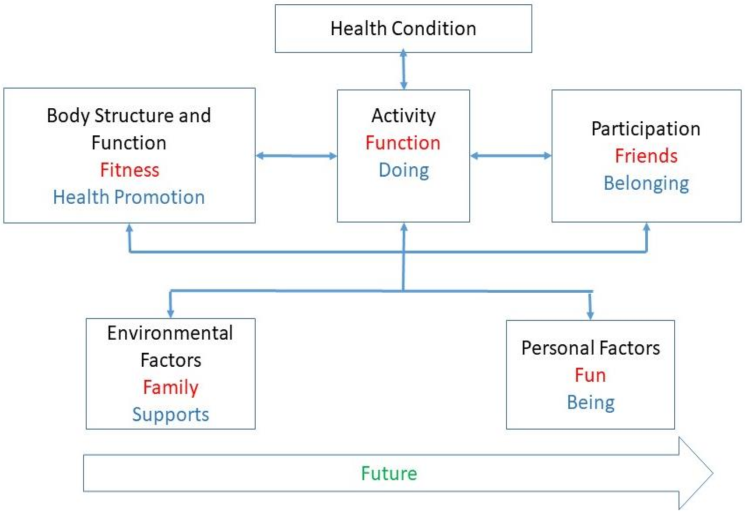
Other aspects of positive psychological functioning such as having a purpose in life, or *Doing*, experiencing personal growth is a key element of the concept of flourishing (Keyes, 2005). Flourishing means “to be filled with positive emotion and to be functioning well psychologically and socially” (Keyes, 2002, p. 210). The second dimension includes feeling social acceptance, contributing to society, and being integrated into society, or *Belonging* (Keyes, 2005). Emotional well-being is the third dimension of flourishing (Keyes, 2005). Meta-analyses link positive psychological functioning have been positively associated with short-term health outcomes such as immune system responses or pain tolerance, long-term health outcomes such as general health, cardiovascular functioning, and general health, with symptom control such as disease progression and longevity, and with lowered mortality (Howell, Kern, & Lyubomirsky, 2007; Chida & Steptoe, 2008).

The psychological needs described by Deci and Ryan (2008) and Keyes’ (2005) concepts related to flourishing are important concepts underlying rehabilitation science. They are fundamentally related to human occupations that are defined as “refer to the everyday activities that people do as individuals, in families and with communities to occupy time and bring meaning and purpose to life. (World Federation of Occupational Therapists, 2010)” Occupations are fundamental to health and one’s state of being (Wilcock, 2000). The themes and sub-themes in this study are all human occupations.

The ICF Model

The ICF Model and the PEOP models provide a framework for understanding the findings related to well-being to the rehabilitation science field. The main principle of the ICF is that activity and participation are a function of the interaction between a person's health and their environment and personal factors. Figure 3 identifies the key components of the ICF framework in black text. As noted earlier, activities are the day-to-day tasks and participation is involvement in life situations. Rosenbaum & Gortner (2012) adapted the ICF for children with disabilities as a means of encouraging a more holistic approach to think about education, treatment, and supports that focuses less on how things are done and more on what is important to child development. Their model (depicted in red in figure 3) includes: 1) function - what people do; 2) family – the primary environment for children with disabilities; 3) fitness -how children stay active; 4) fun –activities children enjoy; and, 5) friends – peer relationships (Rosenbaum & Gortner, 2012). They also include a sixth word, future, referring to child development and expectations and dreams about the future. Rosenbaum and Gortner's holistic conception of the ICF framework to support child development can be adapted across the lifespan when thinking about human development with some adaptations to consider the life stage needs of adults.

Figure 3: A holistic view of the ICF framework



Adapted from Rosenbaum, P., & Gorter, J. W. (2012). The ‘F-words’ in childhood disability: I swear this is how we should think!. *Child: care, health and development*, *38*(4), 457-463.

A revised view of the ICF framework that updates Rosenbaum’s and Gorter’s conceptualization for adults is depicted in Figure 3 in blue. Health promotion encompasses the self-care and disease management activities that adults perform to maintain their individual optimal physical and mental wellness. The theme *Doing* from this study lines up with Rosenbaum & Gortner’s conceptualization of function. *Doing* encompasses all of the activities that define adult social roles and that an individual finds meaningful. While Rosenbaum & Gortner conceptualized participation as having friends, for the adults participating in this project, friends were also important. However, adults are more likely to belong to a broader community that encompasses more than a friendship group, conceptualized in the theme *Belonging*. Families continue to play an important role for adults with disabilities; however, adults with disabilities often get supports to participate in their communities from other sources, such as paid supports and access community resources, such as transportation, to accomplish participation goals.

Rosenbaum & Gortner conceptualized personal factors for children as fun. For the adults in this study, the factors associated with *Being* broadened Rosenbaum's and Gortner's concept of fun for adults. *Being* encompasses how a person views themselves and their place in the world. The final concept of Rosenbaum & Gortner's conceptualization is future. Human development is contingent on having goals and planning for the future and is applicable across the lifespan. Planning for the future was not specifically discussed in the participants' narratives, however, it was implied by examples of activities participants talked about doing such as Tom making plans to move out on his own or John working on achieving a career in music.

The PEOP Model

The PEOP Model incorporates the ICF framework into a model for practice. Meaningful participation builds our self-identity and our place in the world. Having meaningful participation, being engaged in occupation is believed to predict life satisfaction and influences health (Yerxa et al, 1989). The PEOP model can be used as a framework for both individual and community-level interventions. According to Youngstrom and Brown (2005), effective interventions match an individual's interests and abilities with the task demands and environmental supports to promote a balanced lifestyle (Youngstrom & Brown, 2005), which is a core concept of wellness. This study supports the belief that individual interventions promoting self-agency, self-identity, participation in meaningful occupations, and social connectedness may have a positive effect on the health outcomes of people with intellectual disabilities. Findings from this study suggest that when considering designing interventions to support the health and well-being of people with IDD, holistic interventions that address more than physical activity should be considered.

The PEOP model can also be used to address health disparities on a community level. Community-level health promotion activities are aimed at changing cultural, political, and economic risk factors rather than at individual behavior (Scaffa & Brown, 2005). These interventions include opportunities to achieve one's individual potential, social integration, and support and justice while decreasing societal barriers such as occupational imbalances, deprivation and alienation (Wilcock, 1998). The importance of transportation and walkable communities to the participants in this study is an example of community-level intervention. Universally designed community amenities that allow for ease of access for people with disabilities promotes the full participation of all citizens of the community.

Figure 4: The PEOP Model

Christiansen, C.H., Baum, C.M., Bass, J., 2005. Occupational Therapy: Performance, Participation and Well-being, third ed. Slack Inc. Thorofare, NJ. , p. 3

Interpretation of Theme 1: Doing

Health is influenced by the meaning and satisfaction people experience by participating in occupations (Persson et al, 2009). The perception of the value of the occupation to the individual than the activity itself (Eklund & Leufstadius, 2007). Jonsson & Josephsson (2005), noted that people place a number of meanings on their participation such as independence, self-determination, physical and mental well-being and self-identity. Participation is more than merely taking part in an activity; it needs to include a sense of purpose. Findings from this study reflect the literature. Study participants' narratives were often focused on participation in activities they found meaningful. For some work brought meaning and satisfaction whether this work was at the airport, as an actor, or engaged personal interests such as writing poetry or cooking.

Having a purpose has been associated with lower mortality (Boyle, Barnes, Buchman, & Bennett, 2009). For example, in a study of purpose and all-cause mortality in a study of older community-dwelling adults, researchers found that people with the highest scores on a purpose in life measures had 57% of the hazard rate for all-cause mortality than those with the lowest scores (Boyle et al., 2009). The association between mortality and purpose was consistent regardless of age, gender, education, race, incomes, disability, or the presence of other medical conditions (Boyle et al., 2009). Employment has mixed outcomes related to health stemming from the work conditions of workers. Factors such as the type of work, autonomy in the workplace, and the precarious nature of employment can positively or negatively affect health. People with better jobs have long been known to have better health (Clougherty, Souza, & Cullen, 2010). The tenuous nature of employment and health outcomes holds true for people with IDD as well. Employment for people with IDD has been shown to have some positive effects on quality of life and mental health, although a meta-analysis of the employment outcome literature found a weak relationship between employment and health and quality of life outcomes (Dean, Shogren, Hagiwara, & Wehmeyer, 2018). The participants in this study had employment that they valued. Findings suggest that engagement in productive activities such as work has health-promoting attributes.

Studies have shown that overall people with IDD experience lower levels of engagement in activities, including physical activity (Channon, 2014). According to an analysis of the National Core Indicators survey, people with IDD reported low levels of paid employment (15%; Butterworth et al, 2015). Nearly half of those without paid employment (47%) wanted to have a job (Butterworth et al, 2015). Most people with IDD who are employed have jobs that involve cleaning, retail or food service (77%; Butterworth et al, 2015).

The participants in this study were reflective of the research related to unemployment and adults with IDD. One of the participants in this study (Cici) did not have paid employment, but was searching for work. Trudy, Will, and John were also unemployed. Five (Hannah, Meryl, Evan, Tom, and Todd) of the participants had work experiences that were different from many individuals with IDD and were employed as actors. Donna was the only participant who had employment that involved regularly scheduled work hours.

Butterworth and colleagues (2015) reported that 30% of adults with IDD participated in unpaid community activities. These activities may also be a source of meaning and satisfaction for adults with IDD. Patterson and Pegg (2009) conducted semi-structured interviews with adults with IDD who participated in serious leisure activities that reflected a life interest that captured the person’s focus and energy. Hobbies and volunteering are examples of serious leisure. For example, Will and John focused on making music. Participants with IDD engaged in serious leisure activities report that increased social networks and positive impacts on role identity (Patterson & Pegg, 2009). Trudy and Cici identified volunteering as important. Adults with IDD report a number of benefits related to volunteering, as well. In a study of adults with IDD in volunteer positions, volunteering provides an opportunity to do something productive with their time, offers social recognition, provides a sense of pride and satisfaction, increases social inclusion, and can provide opportunities for learning new skills which may lead to paid employment (Baldin et al, 2006; Lysaght, et al, 2007)

Interpretation of Theme 2: Being

The themes *Doing* and *Belonging* are conceptualized as being outward focused. *Doing* is focused on activities, *Belonging* other people. In the occupational sciences, being is focused inward on ourselves, our identity, and recognizing what is unique about us in our interactions with others (Wilcock, 2006). The theme *Being* includes how the participants think about themselves and what they do to take care of themselves. Self-identity and taking care of self (other than related to physical activity) are largely missing from the literature related to adults with IDD. Any studies related to self-identity were specific to identification as a person with an intellectual disability (for example, Spassiani & Friedman, 2014). Literature searches related to well-being, self-care, emotional health, and intellectual disabilities yielded search results related to the emotional well-being of parents and other caregivers of individuals with IDD, but not of the individuals themselves. Research about the emotional health of people with IDD was most often about intervening with people who have behavior challenges. The lack of literature related to self-identity, emotional well-being, and self-care is a gap in the literature related to the inner life of adults with intellectual disabilities.

The participants in this study defined themselves by a number of roles and characteristics, none of which were related to their disability. These self-identities included being strong, a poet, an actor, a musician, a cook, an employee, or the friend who cheered everyone up. All of these identities are valued social roles and many involve mastery of skills and competence. Social role valorization is an important theory in disability studies. The underlying premise of this theory is that people who attain valued roles are more likely than those with devalued roles to be "accorded the good things of life (Thomas & Wolfensburger, 1999, p126)." For people, such as those with IDD, who are seen as having less value in society, acquiring valued social roles (such as an actor or an employee) may reduce stigma people with disabilities may experience (Thomas & Wolfensburger, 1999). This study suggests that interventions that support people in developing meaningful social roles may improve the health and wellness of adults with IDD.

The second aspect of the theme *Being* that was present in the participants' narratives was that of caring for themselves. Some of the self-care activities mentioned are those typically associated with wellness, such as getting more physical activity, eating fruits and vegetables, or drinking more water. Interventions that focus on lifestyle changes have had positive effects on health behaviors and health outcomes for people with IDD (Abdullah et al., 2004: Bazzano et al., 2009). No studies were longitudinal, so the long-term effectiveness of programs such as these are unknown. However, research in the general population has shown that lifestyle choices are an important factor in overall health and well-being (for example, Colditz & Hankerson, 2005).

The theme *Being* overlaps with *Doing* and *Belonging*. The participants' narratives of participation included identification of valued roles. *Being* (roles and identities) and *Doing* (participation) are interdependent (Hitch, Pepin, & Stagnatti, 2014). Participating in meaningful activities can enhance *Being* (Hitch et al., 2014). *Being* is also interdependent with *Belonging* in that being is the relationship between a person's occupations and their connections with others (Hitch et al., 2014).

Interpretation of Theme 3: Belonging

Feeling socially connected with *Belonging* emerged as a theme in this study. All ten of the participants talked about family and friends as part of their narratives. Studies have shown that individuals who live in community settings, such as in their own homes, are more likely to have social connections than are people with IDD who live in institutions settings (such as large group homes; Amado et al., 2013). Living in the community, however, does not necessarily mean that one has a sense of belonging to the community. As many as half of adults with ID report feeling lonely (Amado et al., 2013).

Social isolation has been shown to be a risk factor for increased morbidity and mortality for a number of disadvantaged populations, such as the elderly, people living in poverty, and people of color (Cappacio & Cappacio, 2012; Holt-Lundstad, Smith, Baker, Harris & Stephenson, 2015). Adults with IDD are less likely to report contact with family and friends, belong to a group, and receive less financial, emotional and other support and report poorer health than to people without disabilities or people with other kinds of disabilities (Mithen et al., 2014). Regression analyses of these indicators of social capital and self-reported health status showed that factors related to social capital accounted for about 10% of the association between health and disability.

Only one of the participants (Meryl) talked about having few friends, suggesting that this group was unusual in the higher number of people with social networks. Other participants provided rich narratives about spending time with their friends past and present. Half of the participants lived with their families which likey added to the strength of their social connections people. Families provided practical supports such as shopping or teaching new skills, but were companions in activities the participants enjoyed such as biking or going to the theater. The level of social connectedness described by the participants in this study reflects the research that has identified living arrangement as a predictor for social connectedness.

Limitations of the study

There were three primary limitations to this study. The first limitation stemmed from participants' expressive communication styles. Some participants explained their thinking behind their pictures in detail talked allowing for a more robust narrative than those participants who provided a less abstract description of their pictures and reasons for taking a particular photograph.

The second limitation was with the cameras themselves. Despite having flash available, the picture quality of indoor shots was poor making it difficult to see some of the images because they were so dark. Digital cameras with automatic flash would likely have improved picture quality.

The third limitation was the initial set of instructions that some participants found confusing. It led to one participant opting out of the project. A second participant may have taken different and more pictures if she had received the revised instructions earlier in the process.

Recommendations for future research and interventions

1) Photo narrative was an effective tool for including people with IDD in research. Further research should continue to use various tools and methods in research studies to ensure that people with IDD are able to share their full experience. Testing these tools in population-specific research projects in order to test their feasibility may be a means of creating opportunities to use a variety of research tools that can support the full participation of individuals with IDD and other disabilities in larger studies.
2) The challenges facing adults with ADD living in a group residential setting are not explored. Due to the nature of the study, individuals with IDD with greater support needs did not participate in this study. Perceptions of health and wellness may be different among these groups and should be explored further.
3) One of the critiques of participation research related to people with IDD, is that participation is often related to activities, rather than to a broader conceptualization of participation that includes choice, control and individual agency (Dean et al, 2016). Adopting the concepts of occupation from Occupational Therapy, should guide future operational definitions in participation research.

4) Research related to the health of individuals should include a focus on strategies to reduce or minimize health risk factors, including attention to upstream factors, such as social isolation, low levels of participation, and community-level factors such as transportation, that contribute to health disparities (Koh et al, 2010).
5) People with IDD generally have little opportunity to exercise self-determination or autonomy in relation to their health and wellness. This remains an area of need related to research, program development, and translation into practice for both for individuals with IDD and caregivers and support staff. Greater inclusion of people with IDD in leadership roles in developing and leading opportunities for wellness interventions is needed.
6) Self-identity and competence and their relationship to the emotional and physical health of people with IDD need to be better understood.
7) Researchers, service providers, policymakers, and self-advocates need to work together to support integrated models of research that value wellness. Collaborative partnerships should include individuals with IDD, disability service organizations, and community health and wellness agencies in order to address the holistic nature of well-being.
8) Future research needs to address the beliefs about and experiences of health and wellness for people with IDD from linguistically and culturally diverse populations, including those from different race and ethnic backgrounds. Research shows that people from backgrounds other than that of white/European-descent have greater disparities in areas such as health status and determinants, utilization of health resources, health care resources, and health care expenditures

and payers (NCHS, 2016). Understanding the intersection between race and ethnicity and disability is important to addressing health disparities.

Conclusion

This study added understanding of how adults with IDD experienced health and wellness in their everyday lives. Photo elicitation provided a suitable method to obtain participant descriptions of these everyday activities. Themes of *Doing*, *Being*, and *Belonging* emerged as a core structure of this phenomenon. These findings provide guidance for future research and interventions for improving the health and wellness of adult with IDD. The narratives of participants themselves show that having social connectedness, valued social roles, and meaningful activities are important parts of well-being for adults with IDD.

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Appendices

Appendix A IRB

UNIVERSITY OF MINNESOTA

Twin Cities Campus

Human Research Protection Program
Office of the Vice President for Research

D528 Mayo Memorial Building
420 Delaware Street S.E.
MMC 820
Minneapolis, MN 55455

Phone: 612-626-5654
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http://www.research.umn.edu/subjects/

APPROVAL OF NEW STUDY

June 28, 2017

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marti370@umn.edu

Dear Peggy Martin:

On 6/28/2017, the IRB reviewed the following submission:

Type of Review:	Initial Study
Title of Study:	How do adults with IDD understand wellness?
Investigator:	Peggy Martin
IRB ID:	STUDY00000494
Sponsored Funding:	None

Grant ID/Con Number:	None
Internal UMN Funding:	None
Fund Management Outside University:	None
IND, IDE, or HDE:	None
Documents Reviewed with this Submission:	• PIW INDIVIDUAL CONSENT FORM Guardian Survey, Category: Recruitment Materials; • Individual Assent Script survey.pdf, Category: Consent Form; • PIW INDIVIDUAL CONSENT FORM self-advocate survey (1), Category: Consent Form; • PIW INDIVIDUAL CONSENT FORM Self-Advocate Photovoice.pdf, Category: Consent Form; • PIW INDIVIDUAL CONSENT FORM Self-Advocate Photovoice June 6.pdf, Category: Consent Form; • HRP-580 SOCIAL TEMPLATE PROTOCOL 012917-1, Category: IRB Protocol; • INDIVIDUAL ASSENT SCRIPT Photovoice June 6.pdf, Category: Consent Form; • INDIVIDUAL ASSENT SCRIPT Photovoice.pdf, Category: Consent Form; • PIW INDIVIDUAL CONSENT FORM self-advocate survey (1), Category: Recruitment Materials; • Anderson Citi Completion report, Category: Other; • PIW INDIVIDUAL CONSENT FORM Guardian Survey, Category: Consent Form;

The IRB determined that the criteria for approval have been met and that this study involves No greater than minimal risk

This study was approved under Expedited Category(ies):

- (4) Collection of data through noninvasive procedures (not involving general anesthesia or sedation) routinely employed in clinical practice, excluding procedures involving x- rays or microwaves. Where medical devices are employed, they must be cleared/approved for marketing.

- (6) Collection of data from voice, video, digital, or image recordings made for research purposes.

- (5) Research involving materials (data, documents, records, or specimens) that have been collected for any purpose, or will be collected solely for non-research purposes.

- (7) Research on individual or group characteristics or behavior or research employing survey, interview, oral history, focus group, program evaluation, human factors evaluation, or quality assurance methodologies.

The IRB approved the study from 6/5/2017 to 6/4/2018 inclusive. You will be sent a reminder from ETHOS to submit a Continuing Review submission for this study. You must submit your Continuing Review no later than 30 days prior to the last day of approval in order for your study to be reviewed and approved for another Continuing Review period. If Continuing Review approval is not granted before 6/4/2018, approval of this protocol expires immediately after that date.

You must also submit a Modification in ETHOS for review and approval prior to making any changes to this study.

If consent forms or recruitment materials were approved, those are located under the Final column in the Documents tab in the ETHOS study workspace.

In conducting this study, you are required to follow the requirements listed in the Investigator Manual (HRP-103), which can be found by navigating to the HRPP Toolkit Library on the IRB website.

For grant certification purposes, you will need the approval and last day of approval dates listed above and the Assurance of Compliance number which is FWA00000312 (Fairview Health Systems Research FWA00000325, Gillette Children's Specialty Healthcare FWA00004003).

Sincerely,

Jeffery P Perkey,
CIP, MLS IRB
Analyst

INDIVIDUAL CONSENT FORM: Guardian

Health and Wellness Photovoice

The person for whom you are guardian is invited to be part of a participatory project for people with disabilities to share their ideas about health and wellness using photography.

This study is being conducted by Lynda Anderson, MPH, PhD student in the Department of Rehabilitation Science at the University of Minnesota. Her advisor is Dr. Peggy Martin.

Ms. Anderson will ask [NAME] to take pictures about health and wellness. She will also ask [NAME] to talk about the pictures and what they mean to [NAME]. We ask that you read this form and ask any questions you may have before you consent for [NAME] to be in this study.

Background

The purpose of this project is to better understand how people with intellectual and developmental disabilities understand health and wellness and to learn more about barriers to and supports for healthy lifestyles. It is important that a better understanding of how people with IDD view health and wellness in order to better design methods of teaching health and wellness to address the high rates of chronic health conditions experienced by many people with IDD (such as high blood pressure, heart disease, or obesity).

Procedures

Data Collection

As part of the study, Ms. Anderson will meet with each study participant individually and provide them with a digital camera to use to take pictures of things related to health and wellness from the perspective of the person participating in the study. Participants will be asked to take pictures of things that make them feel healthy or experience wellness, things that support health and wellness, and things that are challenges to health and wellness. Ms. Anderson will develop the pictures and give each participant a copy of their photos to keep. Individuals will be able to remove any pictures they don’t want to be included in the project. Any photos of people will be digitally altered so that they are not identifiable. Once the pictures are taken, Ms. Anderson will discuss the photos with the person taking them asking about what the photo means to that person. The interview will include some other basic information such as questions about the person’s typical day. At the end of data collection and analysis, Ms. Anderson will meet with each participant again to share what the main ideas were in order for study participants to have one more opportunity for input.

Risks and Benefits of being in the Study

Risks

Taking part in the project should not have any risks or discomforts for most people. The primary risks are related to the time that will be invested in the project while taking pictures and interviews may be an inconvenience. It is time that could be spent on other activities. Some people may be uncomfortable talking about certain aspects of health and wellness. Individuals have the opportunity to decline to answer any questions.

Benefits

There are no direct benefits.

Compensation

Participants will receive $20 in Target gift card for participating in this project. This gift card will be provided at the second interview when the researcher returns to discuss the pictures with the participant.

Confidentiality:

The records of this study will be kept private and only researchers will have access to the records. The link between information about the participant we gather for the project will be destroyed once the project has ended. Ms. Anderson will write a report about the project to present as part of her PhD program. We will also write about the project to publish in journals and talk about the project at conferences. We will <u>not</u> mention anyone's name or where they live. This means that no one will be identifiable in the reports. However, if researchers learn about situations in which the person might be in danger of harm or exploitation, we will report the situation to the support service agency (if applicable) and to the appropriate authorities.

Voluntary Nature of the Study:

You are free to decide if you want [NAME] to be in this study or not. Your decision will not affect your current or future relations with the University of Minnesota or with any organization from whom the person receives support now or in the future.

Even if you decide that you would like [NAME] to participate, you can still withdraw [NAME] from the project at any time without affecting your relationship with the University of Minnesota or any agency from which [NAME] currently receive services or may receive services in the future.

Contacts and Questions:

If you have questions on the study now or at any time during the study, contact Lynda Anderson at 612-626-7220 or at LLA@umn.edu or Peggy Martin at 612-626-4358 or at marti370@umn.edu.

If you have any questions or concerns regarding this study and would like to talk to someone other than the researcher(s), **you are encouraged** to contact the Research Subjects' Advocate Line, D528 Mayo, 420 Delaware St. Southeast, Minneapolis, Minnesota 55455; (612) 625-1650.

You will be given a copy of this information to keep for your records.

Statement of Consent:

I have read the above information. I have received answers to the questions I have asked about the study. I consent to participate in the study.

Your Name: ____________________________________

Name of the Person for Whom You are a Guardian: __________________________

Your Signature:_______________________________ Date: ______________

Signature of Investigator:____________________________ Date: ______________

INDIVIDUAL ASSENT SCRIPT - PHOTOVOICE

(This script is to be used with individuals who have guardians to obtain assent. The purpose of this process is to ensure that individuals with intellectual disabilities understand the purpose of the study, along with its activities, risks, and benefits. The script will also be used to review the consent form with individuals with IDD who are not under guardianship.)

****

I am a student at the University of Minnesota. I am working on a project to learn more about what people with disabilities think about health and wellness. My advisor is Dr. Peggy Martin

I want to know what helps people live healthier lives. I invite you to help me learn more about how people with disabilities live healthier lives.

I will come to your house or some other place you choose. I will give you a camera to use and will show you how to use it. I will ask you to take 12-24 pictures. The pictures will be about things that make you think of health and wellness. After you are doing taking the pictures, we will talk about them together. You will be able to remove any pictures you don't want me to see before we talk about them. You will get to keep a copy of the pictures you take. You will get a $20 gift card from Target.

(Ask the individual the following questions. If they are unable to answer them, rephrase the above information and ask the questions again.)

Can you tell me what you will take pictures about? What will happen after you take the pictures?

Things you tell me are private. The only people who will see what you tell me are and my advisor. If we talk about the project or write about the project, we will not use your name or where you live.

We will tell someone if we think you are being hurt in any way.

(Ask the individual the following questions. If they are unable to answer them, rephrase the above information and ask the questions again.)

What does it mean when information is private? When would we have to tell someone about you? Will someone pay you to be in the study? What should you do if you are uncomfortable with program activities?

Being in this study means you are a volunteer. Being a volunteer means that you can say yes or no to being in this program. It is your choice. If you say no, it will be ok with the people from the University and with anybody who works with you.

You can also change your mind and decide to quit the study whenever you want. If you want to say no or want to quit the study you can tell your guardian or another person you trust. You can also tell Lynda Anderson that you do not want to be in the study.

(Ask the individual the following questions. If they are unable to answer them, rephrase the above information and ask the questions again.)

What does it mean to be a volunteer?
Who could you tell if you do not want to be in the study?
Who can you tell if you want to quit the program later?

Do you have any questions for me?
Is there anything you don’t understand?
Is there anything you want me to talk to you about again?
Do you want to participate in this project?

INDIVIDUAL CONSENT FORM: Self Advocate

Health and Wellness Photovoice

You are invited to be part of a participatory project for people with disabilities to share their ideas about health and wellness using photography

This study is being conducted by Lynda Anderson, MPH, PhD student in the Department of Rehabilitation Science at the University of Minnesota. Her advisor is Dr. Peggy Martin.

Ms. Anderson will ask you to take pictures about health and wellness. She will also ask you to talk about the pictures and what they mean to you. We ask that you read this form and ask any questions you may have before you agree to be in this study.

Background

The purpose of this project is to better understand how people with intellectual and developmental disabilities understand health and wellness and to learn more about barriers to and supports for healthy lifestyles. It is important that a better understanding of how people with IDD view health and wellness in order to better design methods of teaching health and wellness to address the high rates of chronic health conditions experienced by many people with IDD (such as high blood pressure, heart disease, or obesity).

Procedures

Data Collection

As part of the study, Ms. Anderson will meet with each study participant individually and provide them with a digital camera to use to take pictures of things related to health and wellness from the perspective of the person participating in the study. Participants will be asked to take pictures of things that make them feel healthy or experience wellness, things that support health and wellness, and things that are challenges to health and wellness. Ms. Anderson will develop the pictures and give each participant a copy of their photos to keep. Individuals will be able to remove any pictures they don't want to be included in the project. Any photos of people will be digitally altered so that they are not identifiable. Once the pictures are taken, Ms. Anderson will discuss the photos with the person taking them asking about what the photo means to that person. The interview will include some other basic information such as questions about the person's typical day. At the end of data collection and analysis, Ms. Anderson will meet with each participant again to share what the main ideas were in order for study participants to have one more opportunity for input.

Risks and Benefits of being in the Study

Risks

Taking part in the project should not have any risks or discomforts for most people. The primary risks are related to the time that will be invested in the project while taking pictures and interviews may be an inconvenience. It is time that could be spent on other activities. Some people may be uncomfortable talking about certain aspects of health and wellness. Individuals have the opportunity to decline to answer any questions.

Benefits

There are no direct benefits.

Compensation

Participants will receive $20 in Target gift card for participating in this project. This gift card will be provided at the second interview when the researcher returns to discuss the pictures with the participant.

Confidentiality:

The records of this study will be kept private and only researchers will have access to the records. The link between information about the participant we gather for the project will be destroyed once the project has ended. Ms. Anderson will write a report about the project to present as part of her PhD program. We will also write about the project to publish in journals and talk about the project at conferences. We will not mention anyone's name or where they live. This means that no one will be identifiable in the reports. However, if researchers learn about situations in which the person might be in danger of harm or exploitation, we will report the situation to the support service agency (if applicable) and to the appropriate authorities.

Voluntary Nature of the Study:

You are free to decide if you want to be in this study or not. Your decision will not affect your current or future relations with the University of Minnesota or with any organization from whom the person receives support now or in the future.

Even if you decide that you would like to participate, you can still withdraw from the project at any time without affecting your relationship with the University of Minnesota or any agency from which you currently receive services or may receive services in the future.

Contacts and Questions:

If you have questions on the study now or at any time during the study, contact Lynda Anderson at 612-626-7220 or at LLA@umn.edu or Peggy Martin at 612-626-4358 or at marti370@umn.edu.

If you have any questions or concerns regarding this study and would like to talk to someone other than the researcher(s), **you are encouraged** to contact the Research

Subjects' Advocate Line, D528 Mayo, 420 Delaware St. Southeast, Minneapolis, Minnesota 55455; (612) 625-1650.

You will be given a copy of this information to keep for your records.

Statement of Consent:

I have read the above information. I have received answers to the questions I have asked about the study. I consent to participate in the study.

Your Name: ___________________________________

Your Signature:____________________________________Date: ______________

Signature of Investigator:___________________________ Date: ______________

Appendix B: Transcript example

"…That's being outdoors because I love being outdoors. And I like the sun and I like the shining. I like the sun because it make me feel good and I like the lights and darks. I really like the sun - not because you get a tan but because it really makes you feel good. You can soak it and just relax. I've always liked that since I was little.

Oh, this is in the back of my apartment complex next to the garage. It's a place where I sit – I have another place – but I sit there a lot – you know just watch the cars and relax. West St Paul – I live in an area where it almost looks like a forest you know. And it looks really beautiful so I pick certain spots and that's one of the spots I sit at. So I took a picture to show that I get out and I relax you know if I can't get away… And that's my limited mobility go card because it gives me freedom. I get it through my waiver services which is my CADI waiver and it also has my Metromobility on it. It helps me get where I need to go and I take the city bus to go down to the U to do certain projects. Yes I know human services kinds of owns it and I have to show them that I am using it. If I use it correctly and don't overuse it, it give me Freedom for the month."

Appendix C: Example of interviewer impressions

[Individual] likes to keep busy. A lot of her time is spent volunteering as an advocate on topics related to people with disabilities. She serves on several boards and advisory committees related to things that are important to her- such as accessible transportation. Individual takes a lot of pride in the contribution she makes in this role.

[Individual] divides her description of her days into two different kinds of days - there are the days when her support workers come to assist her and she does her volunteer work. The other days are hers to do with as she pleases - watching movies, listening to music, working on her projects, eating out with friends.

[Individual] talks about her relationship with both of her parents (now deceased). Some of her interests stem from things she did with her family when she was young.

A strong thread that runs through [Individual's] story the importance of being independent. She talks about this in terms of bus card and transportation - but it also underlies some of her other comments and activities. She wants to be able to make decisions for herself.

Appendix D: Examples of Analyses Steps

Photo	Text from Transcript	Meaning Unit: Participant's Voice	Meaning Group: Researcher's Voice	Category
	I've lived here for six years. I like living here. We have a friendly group of people that actually get along. We all get along. We all help each other. If someone gets locked out or leaves their key in the door which happens on occasion. We open the doors for each other. We don't bully each other. We've finally got a group of people that love each other. We have volunteers coming in.	We've finally got a group of people that love each other.	Sense of community is essential - she values the community where she currently lives	Sense of belonging

	And that's my limited mobility go card because it gives me freedom. I get it through my waiver services which is my CADI waiver, and it also has my Metromobility on it. It helps me get where I need to go, and I take the city bus to go down to the U to do certain projects. Yes, I know human services kinds of owns it, and I have to show them that I am using it. If I use it correctly and don't overuse it, it gives me freedom for the month.	It gives me my freedom for the month.	Having access to transportation gives her a sense of freedom	Transportation gives freedom

Appendix E: Examples of Research Memos

Photo coding part 1

Coded the content of photographs. Tried to capture content in a few words. Pictures taken indoors were dark and hard to see. Immediate observations about the photos - they are often taken from a distance - across the street or parking lot. Many people did this. Many are of locations but are related to activities - so rather than showing the activity of shopping, for example, there is a photo of a store. Despite the instructions not to take pictures of people, there were a number of pictures of important people - family, friends, partners. People's pets were also photographed. Almost everyone took pictures of something related to nature - the sun, clouds, trees, flowers, etc.

However, a number of pictures were less concrete and triggered multiple ideas. For example, a picture of the cathedral symbolized a close friendship. The friend used to live in the neighborhood and they would go to a local coffee shop together to hang out.

Transcript coding round 1

Initial impressions from reviewing the transcripts as a whole include:
Needing to belong - "everybody knows my name"
Community, family, friends,
Mastery of activities - "I am a good cook"
Importance of personal identity - "I am a poet." " I am an actor." "I am a singer."
People talked a lot about what they like to do - dancing, music, reading
Importance of employment or other purposeful activities
Self-care - relaxing, nature, getting a pedicure, hanging out in a man cave

Transcript coding round 2

When reviewing the transcripts the extent to which people live and want to live ordinary lives is clear. There a number of pictures of mundane day to day things - going to the grocery store, going to a coffee shop, etc. In relation to this, people often talked about walking or wanting to be somewhere they could walk to the things that they wanted to do on a day to day basis.

Today's analysis brought forth the importance of identity. People expressed strong identities. I am a diva. I am an explorer. I am a poet. I am an actor. The roles people filled were important to them.

Relationships are another strong theme emerging from the data. For some people, there was a sense of wanting to belong. The importance of connections with others - family, friends, even pets was clear. Some of the comments were about loss - siblings that had moved out, HS friends that they didn't see anymore, lost relationships, or moving to a new place and leaving behind friends and neighbors.

When reading through the transcripts there is an undercurrent of wanting to be independent, to make one's own decisions, and to do things and go places for themselves.

A theme is emerging that people do recognize the need to take care of themselves - people are thinking about drinking water, eating healthy, managing mental health, going to physicians, etc.
The idea of mastery or being competent at something is also appearing. People talk about being good at things or wanting to learn new things. This included things such as poetry, acting, photography, and cooking.

A number of people have also talked about appreciation for the natural world - liking to be outside, liking the sun, enjoying outdoor activities. A number of pictures are nature related - landscapes, clouds, the sun, etc.

Doing things that gave people a sense of purpose was important for some people - volunteer work, advocacy work, employment, being creative (music, poetry) were all mentioned by people

Transcript Coding Round 3

I identified 15 themes/main ideas from the meaning units. Four of them were “orphans” in that only one person mentioned them and they did not seem to fit very well under the other theme areas. For each of these theme areas I wrote a description of what kinds of ideas/meaning units are included under each them. I also included the number of people who contributed to the theme and the number of times a constituent part of the theme was mentioned. I created a table in the Analyses 2 excel spreadsheet that includes all of this information.

Once I had all of these themes I drew a quick picture of themes that had been contributed by at least four of the participants. (See the PPT file well-being circle). I placed the themes mentioned by most people closest to the well-being circle. The farther away a theme is, the fewer times it was mentioned by participants. This will need to be revised as I write chapter 4. In addition, I need to consult with graphic design folks at work for ideas that will make it more visually appealing and to better convey the ideas that I want to convey. It’s definitely a rough draft at the moment.

I need to think some more if the themes can be combined any further, because ten is probably still too many, although if I describe these findings based on the OT occupation areas or under the ICF model of participation, then these themes are probably fine.

Appendix F: Crosswalk of ICF Framework and PEOP Model

Adapted from: Christiansen, C. H., Baum, C. M., & Bass-Haugen, J. (2005). Comparing the languages of: the ICF, the PEOP Model, and the AOTA practice framework . In C. H. Christiansen, C. M. Baum, and J. Bass-Haugen (Eds.), Occupational therapy: Performance, participation, and well-being (3rd ed.). Thorofare, NJ: SLACK Incorporate

Key Concept	ICF	PEOP
Occupational Performance		Occupational performance is the doing of occupations resulting from the complex interactions between the person and the environment in which he or she carries out actions, tasks and roles.
Occupation		Occupations are what we do. They provide the basis for feelings about ourselves. They engage us in the world around us, and in so doing, enable us to survive, and maintain ourselves. They develop our abilities and skills, allow us to pursue our interests, related to other people, and express our values.
Role	* see participation	Positions in society with expected responsibilities and privileges.
Task	* see participation	Sets of activities determined as purposeful by the person
Action		A basic unit consisting of behaviors directed toward the performance of a task
Activity	The execution of a task or action by an individual	A productive action required for development, maturation, and use of sensory, motor, psychological, and cognitive function. A valuable vehicle to acquire, maintain, or develop skills.
Participation	Involvement in a life situation	Participation involves active engagement in daily life, in families, in work, and in communities. Participation may be denied because of physical, attitudinal, social or societal barriers limit an individual's ability to engage in the occupations that are necessary and meaningful
Person	An individual as defined by different domains including what a person does do or can do. Creates a profile of an individual, functioning, and health in various domains	An individual' characteristics, including physiological, cognitive, psychological, neurobehavioral, and spiritual that can either support capacities or limit the person's engagement in occupations

Personal Factors	Particular background of an individual's life and living. Comprised of features of the individual that are not a part of a health condition or health status. Factors include gender, race, age, other health conditions, fitness, lifestyle, habits, upbringing, coping styles, social background, profession, past and current experience, behavioral patterns, character style, psychological assets, or any other characteristic which may play a role in disability at any level	Factors include gender, race, age, background, education, profession, and any other factor that indicates genetics or choice that influences the person's occupational performance
Body Functions	The physiological function of body systems (including psychological functions)	*See Person
Body Structures	Anatomical parts of the body such as organs, limbs, and their components	*See Person
Context	Represents the complete background of an individual's life and living. Includes two components: environmental factors and personal factors, which may have an impact on the individual with a health condition and that individual's health and health-related status.	*See Environment
Environment	Physical, social, and attitudinal environment in which people live and conduct their lives	Extrinsic factors that have the potential to enable or create barriers for the occupational performance of individuals, including social support mechanisms, social policies, attitudes, cultural norms and values, built environment/geography