ADDRESSING HEALTH INEQUITIES IN PEOPLE WITH INTELLECTUAL DISABILITIES THROUGH COMMUNITY-BASED PARTICIPATORY RESEARCH

by

Elizabeth M. Cardell

A dissertation submitted to the faculty of
The University of Utah
in partial fulfillment of the requirements for the degree of

Doctor of Philosophy

Department of Health Promotion and Education

The University of Utah

August 2012

The University of Utah Graduate School

STATEMENT OF DISSERTATION APPROVAL

The dissertation of **Elizabeth M. Cardell**
has been approved by the following supervisory committee members:

Glenn E. Richardson	, Chair	**6/11/2012** Date Approved
Lauren Clark	, Member	**6/10/2012** Date Approved
Justine J. Reel	, Member	**6/12/2012** Date Approved
Julia Franklin Summerhays	, Member	**5/01/2012** Date Approved
JoAnne Wright	, Member	**6/11/2012** Date Approved

and by **Les Chatelain** , Chair of
the Department of **Health Promotion and Education**

and by Charles A. Wight, Dean of The Graduate School.

ABSTRACT

Many of the health concerns of people with intellectual disabilities do not differ from the nondisabled population; however, it is important to develop interventions that target the unique needs of this population to achieve health equity. Health promotion efforts can meet the needs of this population through collaboration, intervention, and advocacy at multiple levels. This study initiated the process of addressing health inequities by using a qualitative, community-based participatory research method, photovoice, in conjunction with interviews and observations, to identify the health perceptions of 25 adults with intellectual disabilities. The first phase of analysis yielded four themes: defining health, feeling connected, having something to do, and being part of the community. A content analysis, the second analysis phase, explores the use of an occupational perspective of health (doing, being, belonging, and becoming) to address the health needs of this population. Incorporating adults with intellectual disabilities in the initial stages of health promotion planning provides information that can be used to design broad programs that move beyond fitness and nutrition knowledge, areas often well understood by many of this population. A community-based participatory study offers support for this collaboration and suggests additional areas to incorporate into health promotion programs. A more holistic approach to health is proposed, which includes life skills training, self-determination, client-centered interests, and an emphasis on strengths and potential. Experiences and observations are shared to highlight issues of social justice and emphasize the need for a multilevel approach to promoting health. An occupational perspective of health is offered as a method to address the social determinants of health and broaden the practice framework of health promotion.

TABLE OF CONTENTS

ACKNOWLEDGMENTS

Life has a funny way of giving you exactly what you need. Although changes in our lives are often not understood and frequently unwelcomed, they all take us on a journey we could never have foreseen. The path to completing this study was not smooth, but as I look back, I can see life gave me exactly what I needed to get it done.

My gratitude goes to my community research partners who allowed me to be a part of their lives and who were willing to share their insights. I am honored they trusted me to represent their concerns and experiences. Also, this study would not have been possible, in its final form, without the generous financial contribution made by Roadwave, LLC, which allowed me to purchase the cameras. I am grateful for their interest in the topic and their belief in its significance.

Without the support of my open-minded graduate committee, I would not have been able to pursue my passion. Their advice and role modeling offered me visions of the academian I'd like to become. Special thanks goes to Lauren Clark for taking that first phone call, from the student she didn't know, and then for sticking by me throughout the process. Her guidance, patience, humor, and wisdom pushed me to set higher goals and expect great things from everyone involved, including myself. In addition, I thank Glenn Richardson, Justine Reel, Julia Summerhays, and JoAnne Wright, whose encouragement and recommendations enabled me to see myself as a researcher.

Last, but not least, I thank my husband, Tracy Timothy for understanding my desire to have a positive impact on the lives of people with disabilities. Throughout my career, he has never once questioned any of my projects, including my goal to return to school, and he has supported my progress by making significant changes in his life. I don’t know how I could have done this without him.

INTRODUCTION

People with disabilities may experience numerous challenges that can contribute to negative health outcomes. Some of the obstacles are due to environmental barriers, while others are due to insufficient services, lack of education, and underdeveloped skills (Jobling & Cuskelly, 2006; Ravesloot et al., 2007; Rimmer & Rowland, 2008; Temple & Walkley, 2007). An intellectual disability (ID) is “characterized by significant limitations both in intellectual functioning and in adaptive behavior, which covers many everyday social and practical skills. This disability originates before the age of 18” (American Association on Intellectual and Developmental Disabilities [AIDD], 2009). People with ID display cognitive and communication difficulties that impact decision-making and advocacy skills. Health is further complicated by the fact that the lives of people with ID often include many of the factors that have been identified as determinants of negative health, including unemployment, low education levels, decreased income, and limited social networks (O’Hara, 2010). This combination of disability-related and social challenges makes achieving healthy lifestyle goals even more difficult (Rimmer & Rowland, 2008). Altman and Bernstein (2008) stated that only 3.4 % of people without disabilities reported their health to be in the fair to poor range, which was markedly lower than the 37.9 % of the people with disabilities related to mobility, but the disparity is even more apparent when compared to the fair to poor health reported by 63.8 % of the individuals with cognitive difficulties, which includes people with ID.

Many of the health conditions recorded in this population, including obesity, diabetes, dental disease, osteoporosis, and stress, are considered to be preventable, yet health promotion interventions have been slow to address these concerns (Fedele & Scully, 2010; U.S. Department of Health and Human Services [USDHHS], 2000; Wullink, Widdershoven, van Schrojenstien Lantman-de Valk, Metsemakers, & Dinant, 2009). Within the U.S. healthcare system, a lack of accessible health and wellness services, negative healthcare provider attitudes, insufficient professional preparation, and poor awareness of health issues all contribute to the well-documented health disparities and inequities for this group (USDHHS, 2000). These issues are often seen when treatment is based only in a medical model of disability. This method does not effectively address the needs for this population because the focus is generally only on the primary diagnosis and ways to cure the person of the condition (Drum, 2009). The medical model places the healthcare provider as the expert and overlooks the emotional implications of having a disability as well as the impact contextual factors have on the person.

Conversely, a social model of disability emphasizes a broader view of disability and attributes the limitations experienced by people with disabilities to inaccessible environments and the noninclusive attitudes of society (Drum, 2009). This type of model stresses the need to address disability issues from social and policy levels rather than emphasizing the disability itself as the contributing factor to daily challenges. The model's focus is primarily participation and abilities, rather than health.

Health is a multidimensional construct that involves more than having normal blood pressure or being in the correct range for body mass index. According to the World Health Organization (2003), health is "a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity" (para. 1). This definition of health includes the traditional beliefs of the medical model but also includes psychological well-being and participation in society. It is the combination of all of these aspects that allows a person to achieve optimal health. This holistic definition of health calls for health promotion to expand beyond the healthcare system and consider the social determinants of health by engaging multiple levels and including policy change and social action (Drum, 2009).

Authors encourage an ecological approach to health promotion when addressing the health needs of people with ID (Howard, Nieuwenhuijsen, & Saleeby, 2008; Nieuwenhuijsen, Zemper, Miner, & Epstein, 2006). Utilizing an ecological approach addresses barriers through an examination on five levels: intrapersonal, interpersonal, community, public policy, and institutional (McLeroy, Bibeau, Steckler, & Glanz, 1988). This approach addresses health issues through an individual, group, and political focus and includes the unique aspect of considering factors of the physical environment. By establishing effective interventions that can influence multiple levels, health professionals can move beyond the focus of changing individual health behavior to acknowledging the dynamic interaction between environmental factors and individual behaviors (Drum, 2009).

In order to develop useful health promotion programs and influence health-related policy, health educators must understand the perceptions of the priority population (Woodgate & Leach, 2010). Most programs lack the personal perspective of the community, leading to the development of inadequate interventions (Hergenrather, Rhodes, Cowan, Bardhoshi, & Pula, 2009) that do not address the reasons for health disparities (Lichtman, 2006). By exploring the experiences of people with intellectual disabilities, professionals can better understand their health concerns and related determinants.

The first manuscript is a commentary on current research practices that relate to addressing health inequities in people with intellectual disabilities. Support for the need to reframe how researchers and health professionals approach this topic is offered through a review of the literature and related government documents. Considerations related to study design, data collection methods, and collaborations with people with intellectual disabilities are described along with examples of promising alternatives.

The second manuscript is a qualitative descriptive study that demonstrates successful research collaboration with individuals with intellectual disabilities. A community-based participatory research method was used to gathered perceptions of health directly from adults with intellectual disabilities. The data include four themes that illustrate multiple aspects of health: defining health, feeling connected, having something to do, and being part of the community. Results reveal that even though people with intellectual disabilities have a working knowledge of health and healthy lifestyle behaviors, there are factors related to context, skill development, and social stigma that impact the ability to successfully apply the knowledge. A multilevel approach to addressing these issues is proposed. A second outcome of the report demonstrates that including adults with ID in research study procedures can be successful when an accessible method is used and the proper level of support is offered.

The final manuscript is a content analysis of the collected qualitative data. An occupational perspective of health is utilized to describe ways in which health promotion interventions can expand to address social justice for people with intellectual disabilities. The examples provided offer insights into the daily experiences that impact health and healthy lifestyle behavior in this population and describe how incorporating occupation, meaning, capabilities, and opportunities can benefit overall health and well-being. Recommendations for the development of meaningful health promotion curricula are discussed.

Health promotion programs for people with intellectual disabilities are an emerging field for health promotion professionals. As the paradigm shifts, every effort should be taken to avoid marginalization of this vulnerable population (Reel & Bucciere, 2010). One way to ensure this is to gather information directly from this priority population regarding perspectives of health and the factors that influence well-being. This population has valuable information to offer in the development of health programs (Coulter, 2005; Drum et al., 2009; Moore & Huerena, 2005; Powers, Dinerstein, & Holmes, 2005; Rimmer & Rowland, 2008). By including members of this population in the planning stages, healthcare providers encourage a partnership that facilitates empowerment and eliminates the attitude of being the expert on someone else's experience (Drum et al., 2009; Kannenberg, Amini, & Hartmann, 2007).

References

Altman, B., & Bernstein, A. (2008). *Disability and health in the United States, 2001–2005*. Hyattsville, MD: National Center for Health Statistics.

American Association on Intellectual and Development Disabilities. (2009). Retrieved September 5, 2009 from http://www.aamr.org /content_100.cfm?navID=21

Coulter, D. L. (2005). Comprehensive health supports and health promotion. In K. C. Lakin, & A. Turnbull (Eds.), *National goals & research for people with intellectual & developmental disabilities* (pp. 109-124). Washington, DC: American Association on Mental Retardation.

Drum, C. E. (2009). Models and approaches to disability. In C. E. Drum, G. L. Krahn, & H. Bersani (Eds.), *Disability and public health* (pp. 145-162). Washington, DC: American Association on Intellectual and Developmental Disabilities.

Drum, C. E., Peterson, J. J., Culley, C., Krahn, G., Heller, T., Kimpton, T.,… White, F. W. (2009). Guidelines and criteria for the implementation of community-based health promotion programs for individuals with disabilities. *American Journal of Health Promotion, 24*(2), 93-101. doi:10.4278/ajhp.090303-CIT-94.

Fedele, S., & Scully, C. (2010). Dentition and oral health. In J. O'Hara, J. McCarthy, & N. Bouras (Eds.), *Intellectual disability and ill health: A review of the evidence* (pp.156-161). New York, NY: Cambridge University.

Hergenrather, K. C., Rhodes, S. D., Cowan, C. A., Bardhoshi, G., & Pula, S. (2009). Photovoice as community-based participatory research: A qualitative review. *American Journal of Health Behavior, 33*, 686-698.

Howard, D., Nieuwenhuijsen, E. R., & Saleeby, P. (2008). Health promotion and education: Application of the ICF in the US and Canada using an ecological perspective. *Disability and Rehabilitation, 30*(12-13), 942-954.

Jobling, A., & Cuskelly, M. (2006). Young people with Down syndrome: A preliminary investigation of health knowledge and associated behaviors. *Journal of Intellectual and Developmental Disability*, *31*(4), 210-218.

Kannenberg, K., Amini, D., & Hartmann, K. (2007). *Occupational therapy services in the promotion of psychological and social aspects of mental health*. Retrieved from American Occupational Therapy Association, Position Papers: http://www.aota.org/ Practitioners/Official/Position/40878.aspx.

Lichtman, M. (2006). *Qualitative research in education: A user's guide*. Thousand Oaks, CA: Sage.

McLeroy, K. R., Bibeau, D., Steckler, A., & Glanz, K. (1988). An ecological perspective on health promotion programs. *Health Education & Behavior, 15*(4), 351-377.

Moore, T. & Huerena, J. (2005). Can you really be healthy as a person with a disability? In W. N. Nehring (Ed.), *Health promotion for persons with intellectual and developmental disabilities* (pp. 343-346). Washington DC: American Association on Mental Retardation.

Nieuwenhuijsen, E. R., Zemper, E., Miner, K. R., & Epstein, M. (2006). Health behavior change models and theories: Contributions to rehabilitation. *Disability and Rehabilitation, 28*(5), 25-256. doi: 10.1080/09638280500197743

O'Hara, J. (2010). Health care and intellectual disability. In J. O'Hara, J. McCarthy, & N. Bouras (Eds.), *Intellectual disability and ill health: A review of the evidence* (pp.156-161). New York, NY: Cambridge University.

Powers, L., Dinerstein, R., & Holmes, S. (2005). Self-advocacy, self-determination and social freedom and opportunity. In K. C. Lakin, & A. Turnbull (Eds.), *National goals & research for people with intellectual & developmental disabilities* (pp. 257-287). Washington DC: American Association on Mental Retardation.

Ravesloot, C. H., Seekins, T., Cahill, T., Lindgren, S., Nary, D. E., & White, G. (2007). Health promotion for people with disabilities: Development and evaluation of the Living Well with a Disability program. *Health Education Research, 22*, 522-531.

Reel, J. J., & Bucciere, R. A. (2010). "Not so different from you": Body image and eating disorders among individuals with disabilities. In J. J. Reel, & K. A. Beals (Eds.), *The hidden faces of eating disorders and body image* (pp. 145-158). Sewickley, PA: AAHPERD.

Rimmer, J. & Rowland, J. L. (2008). Health promotion for people with disabilities: Implications for empowering the person and promoting disability-friendly environments. *American Journal of Lifestyle Medicine, 2*, 409-420. doi: 10.1177/1559827608317397

Temple, V. A., & Walkley, J. W. (2007). Perspectives of constraining and enabling factors for health-promoting physical activity by adults with intellectual disabilities. *Journal of Intellectual and Developmental Disability, 32*(1), 28-38.

U.S. Department of Health and Human Services. (2000). *Healthy people 2010: Understanding and improving health*. Washington, DC: U.S. Government Printing Office.

Woodgate, R. L. & Leach, J. (2010). Youth's perspectives on the determinants of health. *Qualitative Health Research, 20*, 644-653. doi: 10.1177/1049732310370213

World Health Organization (2003). Constitution of the World Health Organization. Retrieved November 17, 2011 from http://www.who.int/about/definition/en/print.html.

Wullink, M., Widdershoven, G., van Schrojenstien Lantman-de Valk, H., Metsemakers, J., & Dinant, G. J. (2009). Autonomy in relation to health among people with intellectual disability: A literature review. *Journal of Intellectual Disability Research, 53*(9), 816-826.

REFRAMING RESEARCH ON THE HEALTH INEQUITIES OF PEOPLE WITH INTELLECTUAL DISABILITIES

Abstract

People with intellectual disabilities (ID) have been identified as being more sedentary and having more health concerns than people without intellectual disabilities. Although the health conditions recorded in this population are largely preventable, health promotion interventions have been slow to meet these needs. It is disturbing how rarely the literature represents perspectives collected directly from this group, considering the marked health inequities they experience. Until researchers utilize criteria identified by this priority population, they may be representing the concerns of only academia and caregivers, thereby contributing to the daily experience of health inequities rather than decreasing them. Are the limited abilities of people with intellectual disabilities a legitimate reason to exclude them from research? Or do the limitations in abilities really belong to the researchers? Designing programs without the priority population's perspectives, utilizing measures that are neither accessible nor developed for this group, and perpetuating entrenched research methods that limit accessibility reflects poorly on health promotion researchers and beckons for a change. Transformation needs to focus on the development of accessible instruments, innovative methods that will assist in defining health concerns and in turn appropriate solutions, and include collaborations with the "experts" in the lived experiences of people with intellectual disabilities.

Background

Approximately seven million Americans have a diagnosis of intellectual disability, formerly referred to as mental retardation. This condition is “characterized by significant limitations both in intellectual functioning and in adaptive behavior, which covers many everyday social and practical skills. This disability originates before the age of 18” (American Association on Intellectual and Developmental Disabilities [AIDD], 2009). Individuals with ID are likely to be more sedentary and to have more health concerns related to inactivity than people without intellectual disabilities (Temple, Frey, & Stanish, 2006). Among these health concerns are increased prevalence of diabetes, osteoporosis, stress, and high blood pressure, along with higher rates of obesity, which have been increasing steadily over that last 20 years (Rimmer & Yamaki, 2006).

Although the health conditions recorded in this population are largely preventable, health promotion information and interventions have been slow to meet these needs (U.S. Department of Health and Human Services [USDHHS], 2000b; Wullink, Widdershoven, van Schrojenstien Lantman-de Valk, Metsemakers, & Dinant, 2009). Until recently, many health providers held the belief that reduced health was an inevitable consequence of any disability (Smeltzer, 2007) and utilized a symptom management approach to treatment rather than focusing on health promotion or preventative medicine (Frey, Temple, & Stanish, 2006). Healthcare providers are generally undereducated on how to manage the health needs of people with disabilities, beyond addressing their primary diagnosis (Kielhofner, 2009; Rimmer & Rowland, 2008). This predominant medical model has encouraged negative attitudes toward people with disabilities by promoting the “expert” role of healthcare providers and curative methods of interventions (Kielhofner).

The lack of accessible health and wellness services, healthcare provider attitudes, and poor awareness of issues have all contributed to well-documented health disparities and inequities for this group (USDHHS, 2000a). Health disparities are defined by the National Institutes of Health (2000) as “differences in the incidence, prevalence, mortality, and burden of disease and other adverse health conditions that exist among specific population groups in the United States” (p. 11). Whitehead (1990) has defined health inequities as differences in health that are not only “unnecessary and avoidable but, in addition, are considered unfair and unjust” (p.5).

Although preventive health practice is a frequent topic in literature for the general population, most research involving people with intellectual disabilities is descriptive and very few studies actually focus on the remediation of secondary conditions, health risks, or barriers to healthy lifestyles (Frey et al., 2006). Current health and wellness literature is changing the way interventions are provided by redirecting the focus toward the health disparities and inequities experienced by people with disabilities. As these trends adjust, it is a prime time for health promotion professionals to expand services to meet these needs.

Expanding Services

Several well-known publications have addressed the future of health promotion by making suggestions and setting goals to expand preventative and promotional programs for people with disabilities. This has become an emerging area of practice for health promotion professionals since *Healthy People 2010* increased awareness of the health disparities of this group and identified specific goals and action steps to address the needs of people with disabilities (USDHHS, 2000b). The proposed document, *Healthy People 2020*, continues this call with similar goals and directly recognizes the need to extend health promotion and wellness services to this population (USDHHS, 2009).

Although this charge has been noteworthy, only a fraction of the over 100 health promotion programs and educational campaigns developed to address the needs of people with disabilities have any empirical evidence to support their use and even fewer address the needs of people with intellectual disabilities (Drum et al., 2009). People with disabilities cannot be treated as a homogenous group because each diagnosis and condition involves different health challenges and risks for secondary health complications. The paucity of health promotion materials and interventions developed to address the specific need of people with intellectual disabilities could certainly be considered a health inequity and has led researchers to urge the profession to develop and evaluate health promotion and wellness services specifically for this subgroup (Wullink et al., 2009). This appeal demands that we proceed by considering the unique characteristics, assets, and limitations of individuals with intellectual disabilities.

The Surgeon General's conference report, *Closing the Gap,* identifies several goals and vital steps aimed at decreasing health disparities in individuals with intellectual disabilities. The first goal explicitly identifies the need for additional health promotion programs that include opportunities for empowerment, community settings, and peer involvement (USDHHS, Public Health Service, 2002). This tenet is echoed in the *National Goals & Research for People with Intellectual & Developmental Disabilities,* which suggests providers, researchers, and policymakers address the needs specific to this group by incorporating a sense of empowerment in all agendas related to individuals with intellectual disabilities (Lakin & Turnbull, 2005). Including people with intellectual disabilities in both the development and evaluation of curricula will not only enhance empowerment but will also assist in expanding health promotion services and ensure programs and educational materials are meaningful and useful to the participants. The future of health promotion is moving toward the inclusion of people with intellectual disabilities.

Development of Health Promotion Programs

Regardless of the intended community, a needs assessment with stakeholders has traditionally been the preliminary step in developing effective health promotion curricula (Drum et al., 2009; Rew, Hoke, Horner, & Walker, 2009). The *Jakarta Declaration on Leading Health Promotion into the 21st Century* states, “people have to be at the center of health promotion action and decision making for them to be effective” (World Health Organization, 1997, p. 4). Inclusion in the needs assessment empowers them by offering them ownership of the project, thereby increasing support for and participation in the program (Rew et al.).

Many health programs have used statistical data that reflect health behavior trends or the consequences of those behaviors, the “what” of health behavior, to develop services (Lorenz & Kolb, 2009). This approach to intervention development relies on a positivist’s approach, the belief that reality has one true source. A constant, static world that offers an objective truth becomes the source of knowledge. Programs created utilizing this process lack the personal perspective of the community, leading to the development of inadequate interventions (Hergenrather, Rhodes, Cowan, Bardhoshi, & Pula, 2009) that never address the “how” or “why” questions around health disparities.

This paradigm of objectivity limits the use of alternative research approaches that might benefit marginalized groups and runs the risk of misrepresenting the participants' experiences while encouraging a problem-based approach (Zarb, 1992).

Abma, Nierse, and Widdershoven (2009) suggest that the values and experiences of stakeholders can be represented when a program is inclusive of the group that has the least amount of influence. However, it is alarming that researchers often neglect to represent the perspectives of individuals with intellectual disabilities (Parish, Moss, Richman, & Taylor, 2008). This omission certainly falls into the "unnecessary and avoidable" along with the "unfair and unjust" differences in health used by Whitehead (1990, p. 5) to define health inequities.

Although the practice of including people with intellectual disabilities in a collaborative research process is gaining acceptability, many researchers may be dissuaded by literature that describes the complexities of this venture. Decreased literacy, impaired physical abilities, and limits in the comprehension needed to complete questionnaires or rating forms complicate the data collection process (Andresen & Meyers, 2000; Finlay & Lyons, 2001). Even when questions are administered orally, difficulties understanding the purpose behind scales, the passage of time, and complex, often-foreign concepts led to incomplete or inconsistent responses (Andresen & Meyers). A variety of types of questions are also impacted by the tendencies for acquiescence and recency, the tendency to state the last option as the answer (Rodgers, 1999). These issues are compounded by the fact that very few measurement tools have been developed specifically for this population, resulting in the inappropriate utilization of instruments that have been developed for the general public (Finlay & Lyons, 2001).

People with intellectual disabilities are often excluded because of assumptions about the population. Many researchers believe that people with intellectual disabilities are incapable of expressing opinions, attitudes, and/or needs regarding health concerns (Catalani & Minkler, 2009). This group is assumed to be too immature to properly analyze life situations (Bogdan & Taylor, 1976; Goodley, 1996) and unable to access the new learning it takes to carry through with health promotion strategies (Catalani & Minkler).

The challenges identified have frequently led researchers to exclude direct elicitation from people with intellectual disabilities and instead collect data from other sources, including physician examinations, record reviews, observations, and proxies (Temple et al., 2006). Caregivers often serve as a proxy voice on the behalf of people with intellectual disabilities through questionnaires, interviews, and journals, even though research has shown these results frequently misrepresent the needs of those they are meant to represent. Under reporting of symptoms, inconsistent answers, approximation of unknown data, offering an overly positive representation of the situation, and highlighting areas of concerns to receive additional services are among the issues identified with proxy reports for people with intellectual disabilities (Rodgers, 1999; Temple et al.).

Developing health and wellness interventions from information that is not directly acquired from the priority population leads to materials that do not reflect the needs and concerns of those they are meant to address. This process creates an imbalance of power and marginalizes the group by denying the existence of the priority population’s concerns and opinions (Goodley, 1996), offering a biased representation of health concerns

(Bogdan & Taylor, 1976), and ultimately undermining the success of the intervention (Rew et al., 2009).

Cruz (2008) speaks of the power inequity of research with vulnerable groups and those who have been historically marginalized by stating:

> We don't trust the nonacademics to have enough insight, enough reflexivity, depth enough, to be able to see past the traps of ideological discourse, speak beyond their own immediate experience. We can theorize about their lives and circumstances better because we are formally trained to do so. Our discourse, however, is not less entangled in the workings of power; that power capable of silencing, of denying…. (p. 656)

Until health promotion specialists utilize criteria identified by people with intellectual disabilities, the profession might be representing the concerns of only the researchers and caregivers (Finlay & Lyons, 2001), thereby contributing to the daily experience of health inequities rather than decreasing them.

In order for health promotion programs to be successful with people with intellectual disabilities, the values and beliefs of this group must be incorporated (Kielhofner, 2009; Rimmer & Rowland, 2008). Taylor (1996) stated "the perspective and experiences of people labeled mentally retarded must provide a starting point for all research and inquiries in the study of mental retardation" (p. 7). Although not without its challenges, the benefits of directly including this population in the development stage of health promotion research and curricula are not different from the standards of health program development. In addition, there are researchers who have produced successful research results that dispel these misperceptions, offering encouragement for future studies.

Rodgers (1999) studied people with intellectual disabilities to develop a perception of health that reflected the experiential knowledge of living with a disability and suggested the need to alter the medical model definition of health widely used by practitioners. The ability to construct these insights surprised the supporters involved in the study, supporting the notion that even familiar caregivers were not fully aware of the participants' skill level. Matysiak (2001) collected rich data through group and individual interviews that revealed an understanding of many of the complexities experienced in adult interactions and ultimately contributed to the development of a theory. These examples offer evidence that researcher and/or caregiver assumptions should not dictate the level of inclusion or exclusion of people with intellectual disabilities when planning research studies.

New Directions

Allowing people with intellectual disabilities to fully participate in all stages of research requires the exploration of nontraditional, creative research approaches (Andresen & Meyers, 2000; USDHHS, 2000a; Wullink et al., 2009). Professionals can develop a deeper understanding of disability and health concerns through the exploration of experiences and the meaning our patients assign to those experiences (Lorenz & Kolb, 2009). This simple gesture offers an opportunity for empowerment by recognizing people as experts on their own experiences and acknowledging the insights they can offer that "outsiders" often lack (Hergenrather et al., 2009).

Those authors who have been successful collaborating with individuals with intellectual disabilities have generally adopted a constructivist approach. Through the use of qualitative methods, these researchers were able to access an "insiders" perspective to topics that were previously unexplored. A constructivist framework is holistic and is based on the ontology that there is not a single interpretive truth but that reality is constructed through multiple sources, including interactions, experiences, and social context (Hergenrather et al., 2009). This type of inquiry can access participants' strengths by transforming the "insider" into the "expert," someone capable of educating the researchers (Knox, Mok, & Parmenter, 2000).

Participatory research has recently become evident in the literature across disciplines as a way to promote partnerships between academics and communities, especially communities that have been historically marginalized. This joint venture distributes the power by including the participants in the research development and process and by incorporating the insights and lived experiences of the participants, thereby co-creating knowledge (Hergenrather et al., 2009; Lorenz & Kolb, 2009).

This alliance ends up benefiting both parties. The "insiders" perspective offers the profession relevant information based on experiential knowledge. This viewpoint contributes to the validity of results and the production of quality services, thereby strengthening study designs and proposals for future research and funding opportunities. This collaborative approach also assists the profession in reflecting the attitude that people with intellectual disabilities have valuable information to offer in the development of health programs and eliminates the attitude of being the "expert" on someone else's experience (Rimmer & Rowland, 2008).

Through the promotion of shared decision-making and autonomy, people with intellectual disabilities can become contributors and take active roles in health-related choices. The involved community is exposed to effective strategies for social change, educated in self-advocacy, and encouraged to develop problem solving skills rather than dependency (Rimmer & Rowland, 2008). In addition, facilitation of participant control and ownership of knowledge production and utilization results in opportunities for empowerment (Friere, 2003). Offering the community a voice in the research process through incorporation of community concerns, values, strengths, and experiences ensures that the project will have meaning to the participants and increases the potential to produce useful results (Hergenrather et al., 2009; Rew et al., 2009).

People with ID are considered to be a vulnerable population and every effort should be taken to avoid marginalization (Reel & Bucciere, 2010). Providing opportunities to respond to questions thoroughly and allow data collection and analysis without risk of misrepresentation should be the goal when designing studies with this population. Utilizing qualitative approaches and community-based participatory research will foster inclusion, but even these techniques might require creative alterations to maximize the abilities and recognize the assets of this population (Rew et al., 2009). Previous studies have shown innovative methods to be viable options with marginalized groups. Alternatives to consider include the use of storytelling (Bogdan & Taylor, 1976), focus groups (Abdullah et al., 2004), group interviews (Matysiak, 2001), drawings (Rodgers, 1999), and photovoice (Jurkowski, 2008).

Discussion

Results of the *Healthy People 2010* Midcourse Review offer an eye-opening illustration of the challenges health promotion professionals face. Utilizing data available in 2005, results illustrate that progress toward reducing health disparities has been minimal among education levels, income levels, and disability status. Additionally, obesity rates across the United States have increased demonstrated by the percentage of adults reporting a health weight decreasing from 42% to 33%. Outcomes specific to people with disabilities reflect an increase in the level of depression that interferes with being active and most relevant to our discussion, the number of states that offer health promotion programs for people with disabilities only increased by three, from 14 to 17 (target goal of 50) with the number of programs available to caregivers remaining at zero (USDHHS, Office of Disease Prevention and Health Promotion, 2005).

The obstacles to improving health and wellness in individuals with intellectual disabilities are many but the needs are greater. In order to overcome these challenges, the profession needs to consider the following questions: Where do these obstacles lie? Are the limited abilities of people with intellectual disabilities a legitimate reason to exclude this population from research and program development? Or do the limitations in abilities really belong to the researchers (Booth & Booth, 1996)? Are we letting our attitudes, assumptions, and traditions dictate the future of health promotion? Designing studies and curricula without the priority population's perspectives, utilizing measures that are neither accessible nor developed for use with this group, and perpetuating entrenched research methods that limit accessibility reflects poorly on health promotion researchers and beckons for a change in the customary research process. According to the social theory of disability, changes to improve accessibility need to take place within the non-disabled mind-set and established processes, not those of the disabled (Matysiak, 2001). Research transformation needs to focus on the development and testing of accessible instruments, innovative methods that will assist in defining existing health and wellness concerns and in turn appropriate solutions, and collaborations between researchers and the "experts" in the lived experiences of people with intellectual disabilities.

References

Abdullah, N., Horner-Johnson, W., Drum, C. E., Krahn, G., Staples, E., Weisser, J., & Hammond, L. (2004). Healthy lifestyles for people with disabilities. *California Journal of Health Promotion, 2*(Special Issue: Oregon), 42-54.

Abma, T. A., Nierse, C. J., & Widdershoven, G. (2009). Patients as partners in responsive research: Methodological notions for collaborations in mixed research teams. *Qualitative Health Research, 19*(3), 401-415. doi: 10/1177/1049732309331869

American Association on Intellectual and Development Disabilities, (2009). Definition of Intellectual Disability. Retrieved September 5, 2009 from http://www.aamr.org/ content_100.cfm?navID=21

Andresen, E. M., & Meyers, A. R. (2000). Health-related quality of life outcomes measures. *Archives of Physical Medicine and Rehabilitation, 81*(12, Part 2), S30-S45. doi: 10.1053 /apmr.2000.20621

Bogdan, R., & Taylor, S. (1976). The judged, not the judges: An insider's view of mental retardation. *American Psychologist, January*, 47-52.

Booth, T., & Booth, W. (1996). Sounds of silence: Narrative research with inarticulate subjects. *Disability & Society, 11*(1), 55-70.

Catalani, C., & Minkler, M. (2009). Photovoice: A review of the literature in health and public health. *Health Education & Behavior, 37*, 424-451. doi: 10.1177/1090198109342084

Cruz, M. R. (2008). What if I just cite Graciela? Working toward decolonizing knowledge through a critical ethnography. *Qualitative Inquiry, 14*, 651-658. doi:10.1177 /1077800408314346

Drum, C. E., Peterson, J. J., Culley, C., Krahn, G., Heller, T., Kimpton, T.,… White, F. W. (2009). Guidelines and criteria for the implementation of community-based health promotion programs for individuals with disabilities. *American Journal of Health Promotion, 24*(2), 93-101. doi:10.4278/ajhp.090303-CIT-94

Finlay, W. M., & Lyons, E. (2001). Methodological issues in interviewing and using self-report questionnaires with people with mental retardation. *Psychological Assessment, 13*, 319-335. doi: 10.1037//1040-3590.13.3.319

Frey, G., Temple, V. A., & Stanish, H. I. (2006). Introduction: Preventive health and individuals with mental retardation. *Mental Retardation and Developmental Disabilities Research Reviews, 12*, 1-2. doi:10.1002/mrdd.20094

Friere, P. (2003). *Pedagogy of the oppressed: 30th anniversary edition*. New York, NY: Continuum.

Goodley, D. (1996). Tales of hidden lives: A critical examination of life history research with people who have learning difficulties. *Disability & Society, 11*, 333-348.

Hergenrather, K. C., Rhodes, S. D., Cowan, C. A., Bardhoshi, G., & Pula, S. (2009). Photovoice as community-based participatory research: A qualitative review. *American Journal of Health Behavior 33*, 686-698.

Jurkowski, J. M. (2008). Photovoice as participatory action research tool for engaging people with intellectual disabilities in research and program development. *Intellectual and Developmental Disabilities, 46*(1), 1-11.

Kielhofner, G. (2009). *Conceptual foundations of occupational therapy practice* (4th ed.). Philadelphia, PA: F. A. Davis.

Knox, M., Mok, M., & Parmenter, T. R. (2000). Working with the experts: Collaborative research with people with an intellectual disability. *Disability & Society, 15*(1), 49-61.

Lakin, K. C., & Turnbull, A., (2005). *National goals & research for people with intellectual & developmental disabilities*. Washington DC: American Association on Mental Retardation.

Lorenz, L. S., & Kolb, B. (2009). Involving the public through participatory visual research methods. *Health Expectations, 12*, 262-274. doi:10.1111/j.1369-7625.2009.00560.x

Matysiak, B. (2001). Interpretive research and people with intellectual disabilities: Politics and practicalities. *Research in Social Science and Disability, 2*, 185-207.

Parish, S. L., Moss, K., Richman, E. L., & Taylor, S. J. (2008). Perspectives on health care of adults with developmental disabilities. *Intellectual and Developmental Disabilities, 46*(6), 411-426.

Reel, J. J., & Bucciere, R. A. (2010). "Not so different from you": Body image and eating disorders among individuals with disabilities. In J. J. Reel, & K. A. Beals (Eds.), *The hidden faces of eating disorders and body image* (pp. 145-158). Sewickley, PA: AAHPERD.

Rew, L., Hoke, M. M., Horner, S. D., & Walker, L. (2009). Development of a dynamic model to guide health disparities research. *Nursing Outlook, 57*(3), 132-142. doi: 10.1016/j.outlook.2008.07.008

Rimmer, J., & Rowland, J. L. (2008). Health promotion for people with disabilities: Implications for empowering the person and promoting disability-friendly environments. *American Journal of Lifestyle Medicine, 2*, 409-420. doi:10.1177/1559827608317397

Rimmer, J., & Yamaki, K. (2006). Obesity and intellectual disability. *Mental Retardation and Developmental Disabilities, 12*, 22-27. doi:10.1002/mrdd.20091

Rodgers, J. (1999). Trying to get it right: Undertaking research involving people with learning difficulties. *Disability & Society, 14*(4), 421-433.

Smeltzer, S. (2007). Improving the health and wellness of person with disabilities: A call to action too important for nursing to ignore. *Nursing Outlook, 55*, 198-195. doi: 10.1016/j. outlook.2007.04.001

Taylor, S., (1996). Disability studies and mental retardation. *Disability Studies Quarterly*, *16*(3), 4-13.

Temple, V. A., Frey, G. C., & Stanish, H. I. (2006). Physical activity of adults with mental retardation: Review and research needs. *American Journal of Health Promotion, 21*(1), 2-12.

U.S. Department of Health and Human Services, National Institutes of Health, (2000a). NIH Health Disparities Strategic Plan, Fiscal Years 2004-2008, vol. 1. Retrieved from http://www.nimhd.nih.gov/about_ncmhd/Strategic%20Plan%20FY% 202004-2008% 20vol%201.pdf

U.S. Department of Health and Human Services, Office of Disease Prevention and Health Promotion. (2000b). *Healthy people 2010.* Retrieved from http://www.healthypeople.gov /About/goals.htm.

U. S. Department of Health and Human Services, Office of Disease Prevention and Health Promotion. (2005). *HP2010 Midcourse Review*. Retrieved from http://www.healthypeople.gov/data/midcourse/html/focusareas/FA06ProgressHP.htm.

U.S. Department of Health and Human Services, Office of Disease Prevention and Health Promotion. (2009). *Healthy people 2020.* Retrieved from http://www.healthypeople.gov /About/goals.htm.

U. S. Department of Health and Human Services, Public Health Service. (2002). *Closing the gap: A national blueprint for improving the health of individuals with mental retardation*. Retrieved from http://www.surgeongeneral.gov/topics/mentalretardation/retardation.pdf.

Whitehead, M. (1990). *The concepts and principles of equity and health*. Copenhagen: World Health Organization.

World Health Organization (1997). *Jakarta declaration on leading health promotion into the 21st century*. Retrieved from http://www.who.int/hpr/NPH/docs/jakarta_declaration _en.pdf.

Wullink, M., Widdershoven, G., van Schrojenstien Lantman-de Valk, H., Metsemakers, J., & Dinant, G. (2009). Autonomy in relation to health among people with intellectual disability: A literature review. *Journal of Intellectual Disability Research, 53*, 816-826.

Zarb, G. (1992). On the road to Damascus: First steps towards changing the relations of disability research production. *Disability, Handicap, & Society, 7*(2), 125-138.

IDENTIFYING PERSPECTIVES OF HEALTH IN ADULTS WITH INTELLECTUAL DISABILITIES THROUGH ENGAGEMENT IN PARTICIPATORY RESEARCH

Abstract

The purpose of this study was to address the health inequities experienced by people with intellectual disabilities (ID) by identify their perceptions of health. Photovoice, a community-based participatory research method, was used to develop collaboration between the researcher and a group of 25 adults with intellectual disabilities. In addition to individual interviews and observations of each adult, the participants completed a photograph assignment aimed at identifying things that are good or bad for their health. Four themes emerged from this study: defining health, feeling connected, having something to do, and being part of the community. Additionally, insight was gleaned on promoting health in this population. This study demonstrates that this group can contribute to research when an accessible method is used. People with intellectual disabilities possess knowledge of health but they report lacking the skills and/or supports to incorporate healthful behaviors. Meaningful health promotion curricula need to include this population's strengths, interests, and context.

Introduction

Health-related literature has drawn attention to the health needs of people with intellectual disabilities (ID) by publishing numerous articles and documents, within the last decade, that encourage the expansion of health promotion programs to meet the health disparities specific needs of this group. *Healthy People 2020* (U.S. Department of Health and Human Services [USDHHS], n. d.) and *Closing the Gap* (U.S. Public Health Services, 2002) identify specific goals and action steps to develop health promotion curricula for this population. Historically, people with disabilities have had little contribution into the interventions developed to address their health-related concerns (Kielhofner, 2009; Rimmer & Rowland, 2008; Wilcock, 2006). Stereotyping and stigma related to cognitive abilities have further excluded people with intellectual disabilities. One of the action steps identified by the Surgeon General in *Closing the Gap* (2002) is to empower people with intellectual disabilities and their caregivers by partnering in the development and implementation of research on specific health issues. This principle of peer-developed research is supported by many authors across a variety of health-related professions who call for the direct inclusion of people with ID during the development, implementation, and data gathering phases of research (Goodley, 1996; Koch, Marks, & Tooke, 2001; Marks & Heller, 2003, Matysiak, 2001; Taylor, 1996).

Traditionally, researchers have assumed that people with ID were unable to independently participate in research secondary to little insight into their situation and a decrease in the cognitive skills required to understand research constructs (Matysiak, 2001; Stanish, Temple & Frey, 2006). This belief has led to the process of gathering information through proxies (i.e., parents or caregivers) or with the assistance of proxies, rather than a firsthand report from the study subjects (Kerr et al., 2003; Krahn, Hammond, & Turner, 2006; Temple, Frey, & Stanish, 2006; Temple & Walkley, 2007).

A critical step in formulating successful health promotion programs is incorporating the priority population into the preliminary steps of planning, unfortunately the opinions and lived experiences of people with ID are often ignored by healthcare providers and researchers, which can negatively impact the participation and motivation of program participants (Hodges & Videto, 2011) and ultimately leads to ineffective programming that contributes to the health inequalities already experienced by the group (Melville, Hamilton, Hankey, Miller, & Boyle, 2007). Literature supports the assertion that people with intellectual disabilities have valuable information to offer in the development of health programs and research (Coulter, 2005; Drum et al., 2009; Kannenberg, Amini, & Hartmann, 2007; Lakin, Gardner, Larson, &Wheeler, 2005; Moore & Huerena, 2005; Powers, Dinerstein, & Holmes, 2005; Rimmer & Rowland, 2008; Wilcock, 2006). Including these individuals in a needs assessment as an initial step in health promotion planning empowers the group by offering them ownership of the project and conveys confidence in what the group has to offer (Drum et al., 2009; Kannenberg et al., 2007). Although the body of literature supporting the call for inclusion is increasing, there is still a dearth of studies that report this process being done in a meaningful way or that reflect the contributions this population can make (Young, 2007). Through shared decision making, people with ID can become contributors to health related choices and interventions.

Purpose of Study

People with ID can be advocates for change and should be encouraged to believe in the value of the information they have to offer; therefore, the primary aim of this descriptive study was to identify the perceptions of health in people with ID, through direct elicitation and observation. The information gathered can be used to develop meaningful health promotion curricula that include the population's strengths, interests, needs, and contextual factors related to health. The specific research questions included:

1. What factors do adults with intellectual disabilities perceive as influencing health behaviors?
2. What contextual factors help explain the health perspective of people with intellectual disabilities?

Answers to these questions are reported from an "insider" perspective. This information reflects the opinions of the participants and represents the data as assembled by the participants, with minimal influence from other sources. This is done in an effort to demonstrate the contributions people with intellectual disabilities can make to a research project (Walmsley, 2004). A co-created perspective, utilizing my observations and analysis along with the participants' data to offer suggestions for practice, policy, and research is reported elsewhere.

Method

A community-based participatory research (CBPR) method, a partnership between researcher and participants, includes the participants in the research development process and incorporates the insights and lived experiences of the participants' to co-create knowledge (Hergenrather, Rhodes, Cowan, Bardhoshi, & Pula, 2009; Lorenz & Kolb, 2009; Marshall & Rossman, 2006). Common health-related data collection techniques such as self-reports, questionnaires, and daily journaling are difficult for many people with ID to accurately complete secondary to the memory and the executive functions skills frequently required. The use of these methods might also contribute to feelings of inadequacy (Wang & Burris, 1997) by highlighting illiteracy, inexperience, and lack of knowledge; therefore, it was crucial for me to choose a data collection method that was both accessible and inclusive.

Photovoice was selected because this method follows the guidelines of CBPR, offers equity of power, and is accessible to people with intellectual disabilities regardless of skill level. Additionally, photovoice does not require the person to be literate and it offers a voice to a community that often goes unheard when more traditional data collection methods are used (Cooper & Yarbrough, 2010; Hergenrather et al., 2009; Lorenz & Kolb, 2009). Photovoice is intended to be highly flexible in order to meet the needs of the intended population, the research question(s), and the targeted outcomes (Wang & Burris, 1997). The overall intent was to honor contributions of the participants, generally vulnerable populations, without the presumption of prior skills.

Specifically, photovoice utilizes participant-generated photographs to elicit information on the research topic during group conversation. By placing a camera in the hands of the participants, the researcher is instilling a sense of pride while allowing an opportunity to be proactive (Catalani & Minkler, 2009). This method is used to record the strengths and concerns of the group, increase awareness in the general public, and increase individual empowerment through participation with the camera as the chosen vehicle for transformation.

Participants

Once approval was obtained from the University of Utah Institutional Review Board, a flyer was distributed to several community agencies that provide services for people with ID. Adults, 22 years and older, who were diagnosed with an intellectual disability and communicate primarily in English, were invited to participate. Those who were older than 21 were chosen because this is the age school services are discontinued and many people with ID move onto community living without the school-based supports often accessed to achieve or maintain healthy lifestyles. In an attempt to recruit a sample that represented a range of abilities, no specific IQ range was defined.

Because this study utilized a CBPR method and recruited from several community agencies, no medical records were utilized to verify diagnosis. Self-identification as a person with an intellectual disability was all that was required. For this reason, specific diagnoses of the individuals are unknown and unimportant for the purposes of this study. In addition to ID, several interested individuals had limited physical abilities, making operation of a camera difficult (e.g., athetoid cerebral palsy). If it was determined that there was sufficient caregiver involvement, individuals with physical disabilities were enrolled in the study with the understanding that the subject for the photographs would be determined by the individual but the caregiver would operate the camera.

Research Consent Process

Upon identification of guardianship, the consent process was initiated. The majority of the individuals did not have guardianship and could complete the consent process independently. If the individual did have a legal guardian, consent and assent forms were utilized. The consent process included a verbal and written explanation of the study procedures along with possible risks and benefits. All questions posed by the individuals and guardians were answered. I also asked the prospective participant several yes/no questions to ascertain comprehension of the nature of the study and participation. If the participant and guardian (if applicable) remained interested in participating, the consent form was signed to document voluntary agreement to enroll in the study.

Study Procedures

In general, the process for this study followed the traditional steps of photovoice, using several adaptations to adequately address the research questions and match the skills of the participants. At an initial meeting, participants were trained in the use of a camera and how to obtain consent prior to taking photographs. A multifaceted definition of health, adapted from the World Health Organization, was used to guide a discussion about the study topic. General examples (i.e., how we feel, the people we are around) were offered in an effort to expand the representation of health beyond physical aspects. The initial plan was to complete this training phase in small groups, but this proved to be difficult to coordinate during sporadic recruitment, so some of the participants received this training on a one-to-one basis (Figure 1). Original photovoice studies were completed utilizing disposable cameras. After debating cost and required skill level, I chose to complete this study using digital cameras. This seemed to be a better match to the participants' abilities and allowed more freedom of choice, as the number of photographs would not be limited. Each person was given a Kodak Easy Share M550 digital camera. Directions for camera operation were converted into a simplified handout with illustrations of each step (see Appendix A). Participants were encouraged to take practice photographs during this educational session so concerns could be addressed.

The photo assignment was to take pictures that reflect “anything that is either good or bad for your health.” The number of expected photographs was not defined; participants were told they could take as many or few as they wanted. Occasional contact, through visits to a partnering community agency, phone calls, or email, was used to remind the participants to take pictures. The actual timeframe individuals spent on the photo assignment varied and averaged to be 51 days across all participants.

Once participants indicated they were finished taking photographs, individual interviews were conducted. This allowed participants an opportunity to share their experiences and photographs with the researcher. Each individual’s photographs were used during the interview to provide structure and elicit individual opinions on the research topic. This technique is based on the assumption that photographs can encourage reflections beyond those the researcher would be able to elicit utilizing only a verbal interchange (Clark-Ibanez, 2004). I deliberately organized the interviews to increase the participant’s comfort by allowing caregivers to be present, letting the participant choose the location, and controlling the pace by giving them control of the advance button during image review. After the interview was complete, I collaborated with the participant in choosing two images to share during the group analysis discussions. The participant picked the first photograph and I assisted in choosing the second in an effort to have a representative sample of the topics that emerged.

I scheduled group discussions in an attempt to involve the entire study population in further analysis of the photographs. Two different groups were organized, but only 13

(52%) people attended. During these assemblies, the selected pictures were projected and the group was asked to comment on what they saw and how it might relate to health. The overall tone of these exchanges was positive. Many of the participants complimented each other's photographs and a lively conversation ensued with full participation of the attendees. The results of the study, after completion of analysis, were presented during an additional group meeting with a small segment of the study group (*n*=5) to confirm accuracy and verify health priorities.

Both the individual interviews and the analysis group discussions were loosely organized using a semistructured interview format (Table 1). Questions were only used to begin the conversation. The participants shared any information they felt relevant and commented on any themes they saw across the photographs.

This study also included documented observations of the participants in a familiar setting, chosen by the individual. I had the opportunity to observe many of the participants several times as approximately 1/2 of them participated in activities at a common community organization. These observations assisted in analysis by adding the context in which to frame the participants' comments and allowed for a co-created research experience.

The established protocol for photovoice includes an action phase that is meant to educate the public and influence stakeholders. This is generally done through a public exhibit of the photographs displayed with participants' narratives. A photo exhibit for this study is scheduled for July 2012. Several of the participants have assisted in making the plans for this event, including designing an invitation, and deciding who to invite and how the exhibit should be set up.

Analysis

This study included data from multiple sources: groups, individual interviews, observations, and field notes. All interviews and group discussions were audio recorded and personally transcribed verbatim. This totaled approximately 830 pages of text. Photographs (3031) were downloaded into iPhoto and titled using a number representing the participant who took it and the order it was taken.

The concurrent analysis process began during data collection while reviewing the photographs with the participants. This method allowed the participants to be involved in the steps of analysis and the researcher to direct the questions in a way that allowed for richer description and deeper meaning (Creswell, 2007; Woodgate & Leach, 2010). Transcriptions and field notes were entered into ATLAS.ti.6.2. I used the photographs as a way to engage the participants in interviews and critical discussions on the topic, in accordance with the photovoice methodology (Wang, Yi, Tao, & Carovano, 1998). Careful field notes along with detailed memos were recorded during the entire process to record initial insights and document decisions made during the study. This audit trail contributes to the dependability of the study by making decisions regarding procedures and conclusions transparent (Creswell, 2007; Flick, 2006; Portney & Watkins, 2009).

The authors of photovoice give a brief description of the analysis process in their original articles (Wang & Burris, 1997; Wang et al., 1998) but details are not present. Based on the suggestions from these articles, I used an inductive thematic analysis for this study. This process aims to identify and report patterns of information that relate to the original research topic. This is a recursive procedure that requires exploration of the entire data set to discover themes of interest. Each step of the process was completed after each initial interview and again upon completion of the groups. These data were analyzed separately and jointly during the research process, which offered a way to crosscheck the patterns in the data across the entire set of interviews, observations, and groups (Morse & Field, 1995).

Discrete elements of the transcribed data were labeled, utilizing initial coding as the first step. This process allowed me to stay close to the data while examining differences and relationships among factors influencing health (RQ#2). This step was followed by the use of a second-level analysis, using an evaluation coding process to judge how the information impacted health (Saldana, 2009). Data, coded as influencing health, were assessed to determine if the topic was a barrier or facilitator to health (RQ#1). The extensive memos allowed me to compare bits of coded data across documents and identify semantic themes. These themes are based on the superficial meanings of what the individuals said rather than a deeper interpretation (Sandelowski, 2000). This paper represents the analysis process to this point, in an effort to demonstrate the participants' contribution to the study.

By utilizing multiple methods (interviews and group discussions) and several analysts of the data (the researcher and participants), the data were triangulated to increase the credibility and dependability of the results (Creswell, 2007; Flick, 2006; Hergenrather et al., 2009; Portney & Watkins, 2009). Member checking, a more traditional way of confirming results with the participants, was accomplished through the partnership in the research process and the use of the final groups. Although the participants were involved in several steps of the research project, I developed the final written products.

Through the use of a qualitative approach, which emphasized community-based participatory research, I developed a partnership with the research participants, allowing equity of power, respect of skills and experience, and co-creation of knowledge (Guajardo & Guajardo, 2002). Participants' contribution of the data (the photographs), participation in the analysis of their photographs, and presentation of study outcomes at the public exhibit acknowledges their combined ownership of this study, thereby reinforcing the importance of their involvement in health promotion initiatives (Hergenrather et al., 2009). This collaboration enriched the findings and assisted in formulating recommendations and future directions.

Results

This study recruited a total of 25 participants, all of whom lived in the community, with varying levels of support. The majority of individuals lived with someone: 10 with parents, 2 with a spouse, and 11 with roommates (and assistance of staff). The 2 individuals who lived alone received support from paid staff members. Participants were age 23-64 (M=33) with 12 (48%) being men. The majority of individuals (16) were involved in some type of formal programming during the day, 6 were employed at least part time in the community, and 3 had no employment or formal programming.

Upon reviewing the photographs and transcriptions, the participants and I co-generated four themes to represent their perspective on health: Defining Health, Feeling Connected, Having Something to Do, and Being Part of the Community. The themes are presented here in more detail. Pseudonyms are used throughout to protect the identities of the participants.

Defining Health

All of the participants provided several photographs that depicted knowledge of healthy lifestyle behaviors. In addition to fundamental components of health, photographs and discussions represented healthy behaviors that extended beyond the basics of drinking water and healthy food choices. The images represented an overall understanding of the main concepts of good nutrition and healthy options, along with knowledge about choices that do not support healthy lifestyle behaviors. For example, participants were able to successfully identify foods as healthy or unhealthy and the majority of participants could specify which component made a food unhealthy (e.g., sugar, salt, grease, artificial sweetener, fat, and cholesterol). Healthy items included fruit, vegetables, milk, chicken, and water. Daily water intake was easily defined by the majority of the participants as eight cups a day.

The participants were not able to easily label certain foods (e.g., pizza, dairy products, pasta, and bread), but these nutritional uncertainties are also often seen in nondisabled adults. Ice cream and fast food menus were frequently mentioned in the interviews as difficult to categorize. While discussing a photograph of a milkshake, Kevin states:

> Kevin: A milkshake can be good and it can be bad.
> Beth: Yeah? What can be good about it?
> Kevin: Has milk in it, has calcium.
> Beth: You are right. Why could it be bad?
> Kevin: Sometimes it has too much sugar in it.

Some of the individuals were able to identify items on fast food menus they considered healthy, like salads, but when asked what they usually ate at these restaurants the consensus was "burgers and fries."

> Nancy: I love [fast food restaurant] burgers and fries!
> Beth: How does that contribute to your health?
> Nancy: Not very good.
> Beth: Not very good? How come?
> Nancy: Because burgers are fattening and so are fries!

While looking at a photograph of a fast food restaurant during the group discussion, Sharla commented, ". . . if you eat a lot you will get bigger and bigger and bigger." Despite the fact that most of the participants identified fast food as being unhealthy and having "too much fat," many stated they still ate it often, stating taste and convenience.

Information related to healthy lifestyle knowledge extended beyond the concrete topic of nutrition. Individuals expressed an understanding of additional behaviors that contribute to health both positively and negatively. Many of the participants could identify portion concerns when viewed in a photograph, but admitted to having difficulty controlling portions, especially when it came to eating out in the community or faced with favorite foods. Moderation was mentioned often in conjunction with the identification of foods that were not healthy. Permission to consume these foods was usually associated with special events. Kevin discussed his choice to eat s'mores during a camping trip with friends: "S'mores are usually junk food but you, but you can have it on occasion. For me, I believe in moderation. You don't eat, I mean you can still eat the same food, just not all the time."

Substituting a healthy alternative was a way of dealing with the temptation of unhealthy food options. Tactics mentioned included opting for wheat bread instead of a croissant and making french fries in the oven instead for having them fried. Alternatives were also employed to encourage consumption of healthy, but less preferred items, like water and vegetables. The majority of participants stated they had to work hard to drink enough water during the day. Many were seen with water bottles that had an added low calorie fruit drink mix to encourage intake. A less supportive strategy was observed while visiting a community organization during snack time; 2 participants added approximately 3/4 cup of salad dressing to a small plate of carrots.

Stress, often related to relationships or money, was identified as a factor that negatively impacts health, but only a handful of individuals identified utilizing successful stress management techniques that were healthy. Watching television and food consumption were noted as ways of forgetting about stress, but were also recognized as not promoting health. The only healthy and successful practice mentioned had to do with listening to or producing music. When shown a photograph of someone playing an instrument, the group related this to relaxation:

> Marilyn: Music is healthy.
> Beth: How come?
> Jana: It helps you breathe.
> Beth: Oh?
> Staff: Like relax.
> Beth: Oh! Okay.
> Sharla: . . . music helps you relax.

Robert communicated his ability to manage stress through the physical activity of playing the drums. This offered him a release and a way to control his frustrations:

> So when I felt bad I got behind my drums and just—You know, just had a release. And it wasn't like BANG, CRASH. I wasn't getting mad and—it was just like that sense of calmness, I had the drums. It is just what it was.

Another factor that contributed to poor health was smoking. Only one of the participants identified themselves as a smoker, yet photographs involving smoking or products associated with smoking were frequent. This behavior was unanimously linked to unhealthy choices. When an image of a pack of cigarettes was shown during one of the group discussions, an emotional response came from the entire group:

> Group: Boo!
> Beth: Not healthy?
> Marilyn: Smoking!
> Brady: Your lungs! Cigarettes aren't very healthy because the smoke goes in your lungs.
> Jana: Bad news!

The participants also mentioned health risks by associating the effect of excessive weight and being overweight with medical conditions, life expectancy, and having an impacted on the ability to participate in meaningful activities. Several of the individuals contributed their health status to being overweight. Medical conditions included diabetes, high blood pressure, arthritis, and joint pain. Josh comments on his life expectancy while describing a photograph of his 93 year old grandmother, stating:

> Josh: She is healthy and not fat, like I am.
> Beth: No, she's skinny.
> Josh: Skinny as this [holding up his finger].
> Beth: She's keeping active.
> Josh: Yeah, too bad that wasn't me. [Because], I'm going to die [before] that age
> Beth: Do you think you will live to be 93?
> Josh: No!

Jana became teary-eyed when reviewing an image she took of a horse. She grew up around horses at her family's home, but stated excessive weight restricts her ability to participate in this meaningful activity:

> Jana: I wish I could ride one of them.
> Beth: How come you can't?
> Jana: 'Cause I'm too overweight. I'm trying to lose weight so I can.
> Beth: Oh yeah?
> Jana: Right now I can't get on the horse.
> Beth: How does that make you feel?
> Jana: Sad.

The information in this section demonstrates that the participants knew a fair amount about healthy lifestyle behaviors and understood some of the consequences of not incorporating them. A number of the members of the group stated they were currently participating in weight loss activities while others wished they could lose weight.

Feeling Connected

Overall, a sense of connection and belonging was identified as being supportive of emotional and social health. Connections were described through interactions with people and animals, by spending time in nature, or were achieved through religion. Regardless of the method, making connections was identified as health promoting.

All of the participants took pictures of the people in their lives. Upon receiving a camera, the first question from many of the participants was, “Can I take a picture of my family?” Spending time with family was generally seen as being supportive and helpful in achieving health. Having someone to do things with, confide in, or spend time with was a common narrative associated with the images. Photographs of friends generally included peers and staff from the day programs, supervised living situations, and community organizations. These relationships held meaningful connections and strong emotions for the participants, as illustrated by Charles when asked about an image of his friend waving his hand in the air:

> Charles: Oh yeah. I like Tomas he is a good guy.
> Beth: What do you like about him?
> Charles: He’s a nice guy. Yeah, he’s nice. That is Tomas’s sign.
> Beth: What does that mean?
> Charles: Love.

This deep emotional bond became a barrier to health when relationships were ended or lost. On several occasions, the topic of discontinued staff came up. Participants often identified staff as the "number one support" in their lives, so when they experienced staff turnover or reassignment, they were left feeling abandoned. Oke, a man who is dependent for personal care, described his relationship with staff as being intimate and requiring an enormous amount of trust, which does not come easily. Two of his past paid caregivers meant so much to him, he had his arm tattooed with symbols to represent each person. Oke expressed, with great emotion, his feelings about the subject by saying:

> Oke: That is a picture of me and my staff. She helps me out with my daily things. But she is no longer my staff. She got transferred.
> Beth: So it seems like when I talk to folks they have pictures of their staff and a lot of them will then say "they are no longer my staff." Does that happen a lot? Your staff switches?
> Oke: Yeah, they just take them out of my house.
> Beth: Mmhmm. What do you think of that?
> Oke: I think that is kind of dumb!…. They learn all about you and then they move them somewhere else. I don't like that.

Connections with animals, nature, and religion were labeled as relaxing and brought about feelings of happiness. Kris describes this sensation while in the mountains, "…up in the mountains, you get fresh air….I don't know I think you, I *(sic)* feel—closer to yourself and nature. And able to—find more peace." Almost all of the participants had pictures related to animals, both pets and wild, in their collection. Ryan described the unconditional relationship felt with animals by saying, "I like to be around them because they are soothing to be around with. And they don't talk back to you." Several individuals said connections can be made at a higher level through religious practices. Josh stated, "I'm a Mormon. I read scriptures all the time. It connects [you] to 'You know who' in heaven [points up]."

Having Something to Do

Participants valued the health benefits of actively engaging in meaningful activity and being busy during their day. Frequently, the conversations supported the notion that being occupied supported health both physically and emotionally. Having something to do generally related to any activity participation, but descriptions ranged from concrete examples of exercising to more abstract concepts of having a sense of accomplishment or contribution.

Representations of exercises were widely visible in the photographs, with images of weight lifting, running, and bike riding. Nearly 1/2 (10) of the participants reported participating in a regular exercise program. A healthy level of fitness was defined as "everyday" or "at least 5 times a week" and several participants stated a lack of exercise as being unhealthy. While viewing a photograph of donuts, Ryan mentions the need to exercise to burn consumed calories by stating, "they just don't—they, they put the weight on you and um—if you don't exercise right they can come on to be an unhealthy food." Josh expressed a concern about his brother's health secondary to a sedentary lifestyle, "My brother is a semi driver and he has no way to—stay active. Just eats and no exercise."

Besides traditional exercise, participants also recognized that the benefits from physical activity can be achieved through everyday tasks. Pictures included many daily activities that contributed to health through movement. The most frequently mentioned items were walking to take public transportation, work tasks, gardening, and dancing:

> Beth: What do they look like they are doing?
> Group: Dancing!
> Beth: They are dancing.
> [Laughter]

Brady: Dancing is good.
Beth: Is dancing good for your health?
Marilyn: Yeah!
Beth: Why is that? Marilyn?
Marilyn: Um, I don't know. It is like exercising.
Sharla: It's good for your muscles.
Charles: Oh yeah!

It was obvious from the images and verbal exchanges that being involved in structured activities was preferred by the majority of the individuals. Outings were mentioned by most participants as a favorite way to get away from the routine of a day program, an opportunity to learn something, and an occasion to be around people. Kevin describes an outing during a summer camp experience as a positive influence on emotional health:

Kevin: I guess, it is a time to get out, enjoy, look at dinosaurs. I guess, I guess it's, I guess it's—I guess it is kind of a mental health thing. Not a physical health thing.
Beth: Mental health is important too, huh?
Kevin: Be happy and get out and do things. Don't be antisocial.

Most of the participants attended some type of programming in the form of day services, evening groups, or weeklong camps. The collection of study images portrayed many aspects of these services and for the most part, individuals stated they enjoyed this aspect of their lives. Beyond just having something to do, purpose seemed to be the important factor mentioned by many. Community programs often provided a way to learn a new skill or complete a project, usually related to arts and crafts. Participants found purposeful tasks pleasurable and enjoyed being able to produce something to give or to display. Besides being a form of relaxation, Samantha learned to crochet so she could create something: "I like to learn to crochet so I can make myself things and maybe make Christmas presents."

Contributions and the feeling of productivity were mentioned in association with working or volunteering. All of the participants expressed a desire to work and the health benefits of having a job, even if volunteering. The ability to work was identified as a facilitator to both physical and emotional health. When Josh was questioned about the value of working, he attributed the benefits to physical activity: “Well, duh! It helps you move a lot, sit down, get up, walk, sit down, up, walk, sit up, walk.” Oke stressed the importance of the emotional fulfillment, “Yeah it is something that keeps my mind—it is something for me to do. Yeah, like I am accomplishing something.”

Many of the routine, enjoyable activities mentioned by participants were inherently sedentary (e.g., watching television and playing on the computer). The participants identified these tasks as a way to stay occupied, but comments indicated they also knew the activities were not ideal for the promotion of health. A picture of a computer was displayed during the group presentation of photographs and Nancy mentioned she loved to visit the computer lab so she could watch videos. The quote below describes the group discussion that followed:

> Beth: So is it healthy for you to watch YouTube videos?
> Nancy: Not always.
> Beth: How come?
> Charles: [You are] on the computer.
> Brady: No!
> Nancy: No!
> Sharla: You sit there all day and do nothing and get fat, fat, fat.
> [Laughter]
> Beth: That can happen with computers.
> Marilyn: Sit still too long and do nothing.
> Jana: Because you would be a [couch] potato.

Conversely, a barrier to emotional health was a lack of things to do. Several individuals mentioned problems with boredom, usually in relation to when the responsibility to generate options for activities was placed on them. Marilyn attended a day program where she participated in activities and work tasks, but in the evenings returned to her apartment. Although she stated she liked living alone, she also expressed feelings of loneliness and boredom:

> Beth: So what do you do in the evenings?
> Marilyn: Just stay home and watch TV.
> Beth: Just hang out? What do you do on the weekends?
> Marilyn: Um—stay home and sleep. That is all I ever do. I've got nothing to do. There is nothing I like to do.

Marilyn felt she did not have the knowledge to identify options for community activities or leisure pursuits and was left to either wait for the staff to come or spend her time alone. Even though Marilyn lived a few blocks from a large shopping center, with a movie theater and restaurants, she stated she rarely went there unless she was with the staff.

Being Part of the Community

In this study, contextual factors, such as accessibility, transportation, and societal attitudes, related to health by impacting the ability to participate and inhibiting feelings of inclusion. A few of the study participants utilized a wheelchair or walker for mobility secondary to physical limitations. Adaptations that facilitate accessibility for people with disabilities were showcased in photographs of adapted doors, grab bars, and accessible parking spots. Although this type of alteration is readily seen in the community, the participants' images also illustrated difficulties accessing the community secondary to improperly designed ramps, inaccessible bathrooms, and poorly maintained sidewalks. Maya and her staff mentioned limitations to where they could go in the community because Maya's electric wheelchair was difficult to get into public bathrooms:

> Staff: None of them are long enough to get her, like her chair in, plus have any room.
> Beth: And then close the door.
> Maya: Yeah, you can't! I can't get in.

Community features that are not properly designed or maintained limit opportunities to participate and are harmful to physical, emotional, and social health. These difficulties of inaccessibility expand beyond just inconvenience by threatening the safety, equipment, and independence of people with disabilities. Several years ago, Oke was hit by a car while out in the community in his electric wheelchair. He sustained injuries that further complicated his disability and he now requires an increase in daily support. Although this was a traumatic experience and he continues to experience difficulties in the community on a regular basis, Oke stated being able to venture into the community helped him maintain his sense of independence and emotional health:

> Oke: Some of the sidewalks and curbs, when you try to get up it, it is too steep….Some of the sidewalks have dips in them that make my wheelchair break….When it snows, how am I going to get here? I have to drive in the middle of the street to just get to a near bus stop. It is a block and a half away from my house….I got stuck at the bus stop, when I got off the bus. The bus took off and I got stuck in a ditch. So I called 911 and they came and pulled me out….I don't care, I still gotta do it [go into the community].

Both facilitators and barriers to health were identified in the use of public transportation. The public bus and train system allowed individuals to access the community and participate in integrated activities. Most of the participants found the system to be extremely useful and stated it enhanced health. While viewing a photograph of someone smiling on the train, I asked Sophie why she thought the person was so happy. Her response indicated an emotional and social influence: "She can go places. I usually take the bus. That helps me [feel] good."

Often discussions included suggestions for making the transportation system more useful. Jana was frustrated by the fact that her ability to participate in Special Olympic events was restricted by lack of transportation. These events were held at a community recreation center that specialized in programs for people with disabilities, yet was not accessible in the evenings by public transit:

> Jana: It is hard to get home on the bus.
> Beth: Why?
> Jana: It's just—it's how they set it up, the schedule. Because I have basketball on Tuesdays and there is no way I can get home.
> Beth: Because it doesn't run late?
> Jana: Yeah, it doesn't run that late.

Additional suggestions from the participants included decreased fares, more routes, and greater accessibility for those in wheelchairs. Although all of the buses are designed to be accessible, some of them have features that are not as useful as others. For example, Oke has difficulty getting his wheelchair onto buses that have a low floor secondary to the turning radius that is required. At times, this requires him to wait as several busses go by before getting one he can access using the lift.

As mentioned above, the importance of having connections with people was evident in all of the participants' photographs. Making these connections with people outside of service providers and peers was difficult for many individuals and restricted the ability to feel included in the community. While out in the community, some of the participants experienced negative societal attitudes and stated this had a negative influence on both social and emotional health. Oke's experience in a public setting reflects a common difficulty people with disabilities have making friends and feeling part of the community:

> Oke: Because people are like, like "look at them like they have a disease."

Beth: Mmhmm.
Oke: All you have to do is come over and get to know a person.
Beth: Right, you are pretty good at that, letting people know who you are.
Oke: Yeah like I went to [the store] and this lady looked at me wrong. So I went up to her and touched her. [Laughter] I went up there and just touched her on the arm. Yeah, I didn't care, you know. You aren't gonna get this. I am just a normal human being in a wheelchair. My legs are my wheels. So, you know, you gotta find people out there to be your friend, that will make you— that are happy and you cheer up.

Discussion

To my knowledge, Jurkowski's (2008) pilot work represents the only other photovoice study with this population. She asked four Hispanic adults with ID to photograph parts of their life that affect health. Similar to the results of this study, the author reported that participants were able to represent a broad understanding of health, one that included relationships, emotions, energy levels, and healthy behaviors.

The results of this study suggest that people with ID understand many concepts related to healthy lifestyle behaviors and have a multifaceted understanding of health, which incorporates many of the areas identified by the WHO. Their impression of health was not solely related to good nutrition and exercise, nor did it just pertain to them as individuals. Many facets of their lives impacted health and the outcomes were often interdependent on interactions, institutions, policy, and the community.

Existing literature defining health determinants and causes of health disparities supports several of the concerns identified by the participants in this study. This information could be used to direct health promotion programming for adults with ID and supports the recommendation of taking a multilevel approach by addressing the individual, institution, and community (Rimmer & Rowland, 2008). Rimmer and Yamaki (2006) identified obesity as "a substantial threat to the livelihood of persons with ID and might have an effect on community participation, independent living and healthy years of life" (p. 22). Educational health promotion classes are generally didactic and offer minimal exposure to interactive or experiential activities (Hodges & Videto, 2011; McKenzie, Neiger, & Thackeray, 2009). Targeted, individual health lessons need to focus less on the basics of nutrition and exercise, areas this group could easily identify, and more on developing the skills needed to incorporate that information. Even though many of the participants in this study could identify health concepts and healthy lifestyle behaviors, the majority of them were overweight and identified significant medical issues. Results from this study suggest classes in simple meal preparation, healthy alternatives, stress and weight management, and how to make informed decisions would be beneficial.

On a community level, increasing involvement will benefit the health of people with ID in many ways. A primary area of concern is changing the negative attitudes often experienced by people with intellectual disabilities (Iezonni, 2011; Marks, Sisirak, & Heller, 2010). This will be no small feat, but the first step in decreasing stigma and stereotypes may be increased exposure through positive social interactions. The positive health effects of social networks and reciprocal relationships have been well documented across many populations. Research supports that people with disabilities often find meaning in life by participating in mutual exchanges (Albrecht & Devlieger, 1999; Hammell, 2004; Lippold & Burns, 2009, Lyons, Orozovic, Davis, & Newman, 2002). In a study on obesity in people with Down's syndrome, results indicated an inverse relationship between social interactions and body mass index (BMI). Those participants with more friends and social contacts had lower BMI. This factor accounted for 21% of the variance in predicting BMI (Fujiura, Fitzsimons, & Marks, 1997). Community participation through purposeful work tasks and the planning of community outings would be motivating for the participants, curtail cycles of boredom, and offer opportunities to develop skills that could be generalize to other situations.

The annual rate of direct caregiver turnover is reported to be 50 % (US Department of Health and Human Services, 2006). What seems like just a part of doing business has emotional implications for those receiving services in this industry. Turnover of these frontline workers has been contributed to decreased resident opportunities and safety, lower quality of life, and negative emotional consequences (Larsen, Hewitt, & Lakin, 2004; Test, Flowers, Hewitt, & Solow, 2003). This concern needs to be addressed at an institutional and policy level. Agencies that provide services to this group need to acknowledge the human implications of frequent staff turnover and make a serious effort to curtail this tendency. Powers and Powers (2010) suggest that increased wages could be one answer. Increasing awareness of the ramifications and educating stakeholders on long-term cost savings could influence policy change.

The areas of physical, emotional, and social health are all negatively impacted by limitation in transportation (Ravesloot et al., 2007; Rimmer, 1999) and accessibility (Iezonni, 2011; Marks, Sisirak, & Heller, 2010). These contextual factors were found to be significant predictors to engagement in health promotion programs among people with disabilities (Becker & Stuifbergen, 2004). Significant progress has been made in these areas for people with disabilities, but this study highlights areas that still need to be considered. At a policy level, increasing awareness to the impact these limitations have on health might assist in changing regulations.

Limitations and Future Directions

As with most studies that include people with ID, the results reported only represent those who had the skill level to communicate and operate a camera (Jurkowski, 2009). This means that the viewpoints of people with more severe disabilities or without the ability to communicate are not represented. The ability to participate might have also been limited by the ability to complete the consent process. Several participants at the community agency approached me about inclusion in the study, but I was unable to complete the consent process because of lack of guardian response to the invitation to participate.

Despite that fact that this group demonstrated an understanding of health knowledge, future studies need to investigate how well people with ID are able to translate their knowledge about health into appropriate health lifestyle behaviors. Exploring the efficacy of meaningful health promotion programs that include skill development and target multiple levels of stakeholders should also be included in future inquiries.

Conclusion and Practical Implications

This report represents the outcomes generated by the participants in relation to facilitators and barriers to health. The results reveal two important factors to consider when addressing health promotion for people with intellectual disabilities. First, people with intellectual disabilities had a working knowledge of health and healthy lifestyle behaviors. They were able to describe health facilitators and barriers, along with factors in their lives that contributed to these concerns. The group had obviously learned some of the information through health education classes. Many were able to expand this knowledge to include influences on emotional, social, and spiritual health, but all of the participants lacked skills and/or supports required to adequately implement the information they recited.

Second, this study clearly demonstrates that adults with ID and a variety of ability levels can contribute to research when an accessible method is used to provide the proper amount of support (Walmsley, 2004). A qualitative approach utilizing participant observations, visual methods, and interviews provided a supportive environment to make this research partnership possible and productive. Not only were individuals able to complete the photo assignment, their contributions during the analysis offered insightful information. Participants were able to identify healthy lifestyle behaviors, emotional and social components of health, and contextual factors that impacted health, both positively and negatively.

The effectiveness of health promotion interventions is heavily influenced by the relevance to the priority population's needs and interests (Green & Kreuter, 1999; Stalker, 1998). People with intellectual disabilities deserve an opportunity to contribute to the research and health promotional protocols currently being developed to address their needs. Future studies regarding the health needs and concerns of people with ID need to make every effort to support inclusion. Photovoice is a viable option for collaborative projects and is useful in accessing the perceptions of this group.

In order to address barriers to healthy lifestyles in this population, additional areas need to be addressed in the promotion of health. Customizing health promotion interventions to incorporate the knowledge, interests, and concerns of people with ID is one way of moving toward health equity for this population.

Appendix

Simplified camera instructions

Research on Health

+

What are we doing?

Exploring how people with disabilities understand health

+

Why are we doing it?

To find a way to improve health for people with disabilities

What you will do?

Take pictures of things in your life that have to do with health

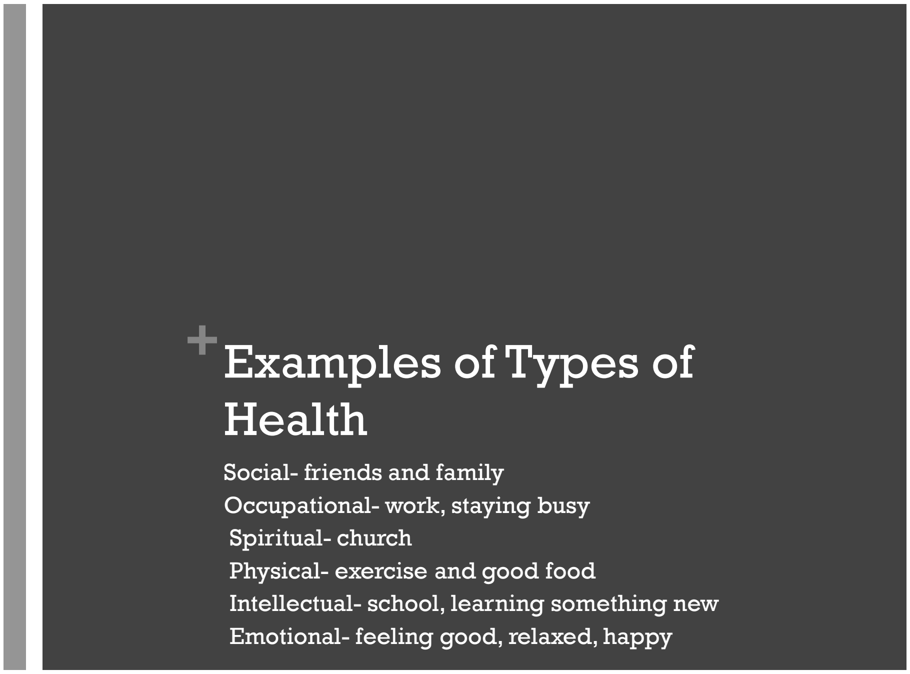
Tell Beth about your pictures

Share some pictures with the group

Talk with the group about health

What is Health?

Not only what we eat or how we exercise
Also things that make us happy
Ways we relax
What we do to have fun
Things that make us feel good about ourselves

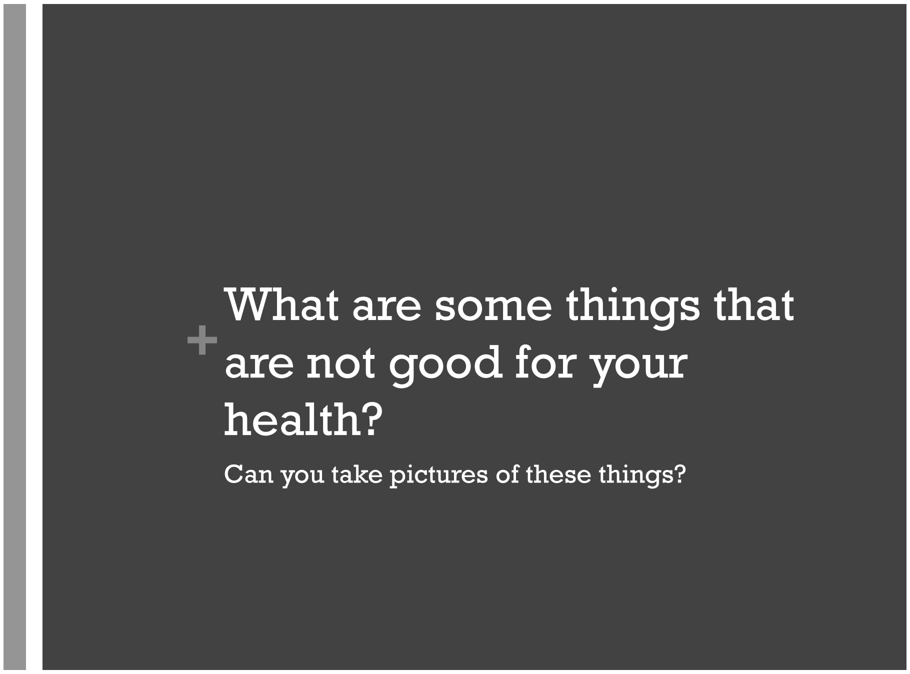


Examples of Types of Health

Social- friends and family
Occupational- work, staying busy
Spiritual- church
Physical- exercise and good food
Intellectual- school, learning something new
Emotional- feeling good, relaxed, happy

What are some things that are good for your health?

Can you take pictures of these things?



What are some things that are not good for your health?

Can you take pictures of these things?

Your job is to find these things and take pictures of them

Getting permission to take pictures

Your pictures don’t have to have people in them

If they do, you should ask if you can take their picture before you take the photo

If it is a large group of people you don’t have to get permission

You can ask someone you know to take your picture with your camera

I will contact you this week to remind you to take pictures

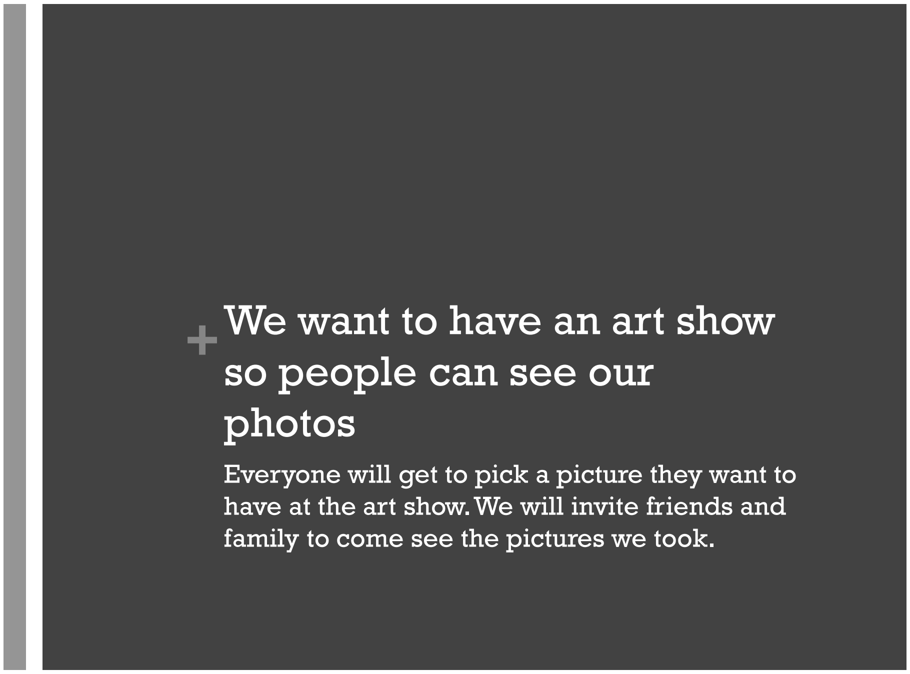
You can take a picture of anything you want.

There are many things that are good for your health and many things that are not.

Be creative!

+ I will meet with you to look at your pictures

Do not erase or download them until I get to see them
When we talk about them you will pick out some you like
I will make copies of some of them for you



+ We want to have an art show so people can see our photos

Everyone will get to pick a picture they want to have at the art show. We will invite friends and family to come see the pictures we took.

+ We want people to know what we think about health

All the things we think are good for your health and all the things we think are not good for your health

+

Camera Use

Kodak EasyShare M550

+
Camera Kit

- Case
- Camera
  - Memory Card
  - Rechargeable Battery
- Instructions Book
- Charging Cord

+
Case

- Belt Clip
- "If found" label

Camera

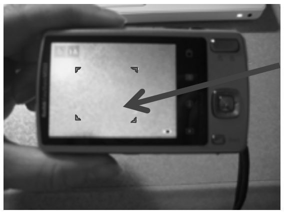
- Kodak EasyShare M550
- Digital Camera

How Does it Work?

- Basic Settings are ready
  - Flash on
  - Date is set
  - Its ready to go!
- Turning it on and off

Taking a Picture

- Lift the camera so your subject is seen in the box
- Hold the camera still
- Press the button on the top



Frame your subject

Press to take a photo

Zoom in and out

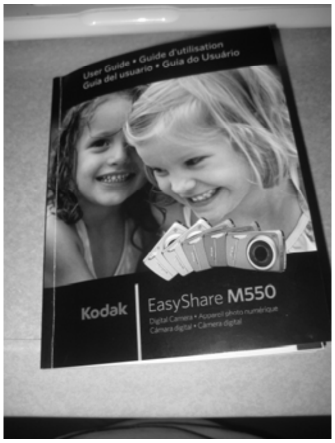
- If you want to see more detail
  - Zoom in T+
- If you want more background
  - Zoom out W-

Reviewing Pictures

- How do I see the pictures on my camera?
- Press the Review button
- Use the arrow button to go forward or backward through the pictures

Instructions Book

- If you want to know more about your camera
- To help solve problems with the camera

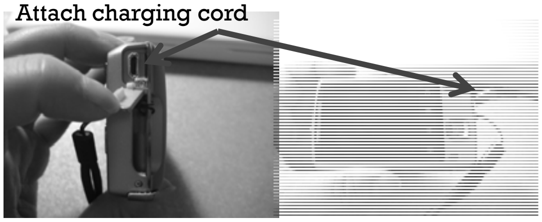


Charging Cord

- Used to charge the battery
- Plugs into the camera and an outlet in the wall
- Should charge battery when you notice the battery is low

Checking the Battery Level

- How do you know when to charge the camera?
- How do you know when it is done charging?



What is your job for the week?

- Take pictures of things you see that are
  - Good for your health
  - Not good for our health
- Call or email Beth if you have any questions
- Do not erase or download your pictures until Beth sees them
- Call or email Beth if you are ready to meet about your pictures
  - I will contact you the week of June 27th to see how you are doing and to schedule some time to meet.

References

Albrecht, G. L., & Devlieger, P. J. (1999). The disability paradox: High quality of life against all odds. *Social Science & Medicine*, *48*, 977-988.

Becker, H., & Stuifbergen, A. (2004). What makes it so hard? Barriers to health promotion experienced by people with multiple sclerosis and polio. *Family and Community Health*, *27*(1), 75-85.

Catalani, C., & M. Minkler (2009). Photovoice: A review of the literature in health and public health. *Health Education & Behavior, 37*, 424-451.

Clark-IbaNez, M. (2004). Framing the social world with photo-elicitation interviews. *American Behavioral Scientist, 47*, 1507-1527.

Cooper, C. M., & Yarbrough, S. P. (2010). Tell me show me: Using combined focus group and photovoice methods to gain understanding of health issues in rural Guatemala. *Qualitative Health Research, 20*, 644-653. doi:10.1177/1049732310361894

Coulter, D. L. (2005). Comprehensive health supports and health promotion. In K. C. Lakin, & A. Turnbull (Eds.), *National goals & research for people with intellectual & developmental disabilities* (pp. 109-124). Washington, DC: American Association on Mental Retardation.

Creswell, J. W. (2007). *Qualitative inquiry & research design: Choosing among five approaches*. Thousand Oaks, CA: Sage.

Drum, C. E., Peterson, J. J., Culley, C., Krahn, G., Heller, T., Kimpton, T.,… White, F. W. (2009). Guidelines and criteria for the implementation of community-based health promotion programs for individuals with disabilities. *American Journal of Health Promotion, 24*(2), 93-101. doi:10.4278/ajhp.090303-CIT-94

Flick, U. (2006). *An introduction to qualitative research*. Thousand Oaks, CA: Sage.

Fujiura, G. T., Fitzsimons, N., & Marks, B. (1997). Predictors of BMI among adults with Down syndrome: The social context of health promotion. *Research in Developmental Disabilities, 18*, 261-274.

Goodley, D. (1996). Tales of hidden lives: A critical examination of life history research with people who have learning difficulties. *Disability & Society, 11*, 333-348.

Green, L. W., & Kreuter, M. W. (1999). *Health promotion planning: An educational and ecological approach* (3rd ed.). Mountain View, CA: Mayfield.

Guajardo, M. A., & Guajardo, F. J. (2002). Critical ethnography and community change. In Y. Zou & E. T. Trueba (Eds.), *Ethnography and schools: Qualitative* *approaches to the study of education* (pp. 281-304). Lanham, MD: Rowman & Littlefield.

Hammell, K. W. (2004). Dimensions of meaning in the occupations of daily life. *Canadian Journal of Occupational Therapy, 71*(5), 296-305.

Hergenrather, K. C., Rhodes, S. D., Cowan, C. A., Bardhoshi, G., & Pula, S. (2009). Photovoice as community-based participatory research: A qualitative review. *American Journal of Health Behavior, 33*, 686-698.

Hodges, B. C., & Videto, D. M. (2011). *Assessment and planning in health programs*. Sundbury, MA: Jones and Bartlett.

Iezonni, L. (2011). Eliminating health and health care disparities among the growing population of people with disabilities. *Health Affairs, 30*, 1947-1954.

Jurkowski, J. (2008). Photovoice as participatory action research tool for engaging people with intellectual disabilities in research and program development. *Intellectual and Developmental Disabilities, 46*(1), 1-11.

Kannenberg, K., Amini, D., & Hartmann, K. (2007). *Occupational therapy services in the promotion of psychological and social aspects of mental health*. Retrieved from American Occupational Therapy Association, Position Papers: http://www.aota.org/ Practitioners/Official/Position/40878.aspx.

Kerr, A. M., McCulloch, D., Oliver, K., McLean, B., Coleman, E., Law, T.,…Prescott, R. J. (2003). Medical needs of people with intellectual disability require regular reassessment and the provision of client-and carer-held reports. *Journal of Intellectual Disability Research, 47*(2), 134-145. doi:10.1046/j.1365-2788.2003.00453.x.

Kielhofner, G. (2009). *Conceptual foundations of occupational therapy practice* (4th ed.). Philadelphia: F. A. Davis.

Koch, T., Marks, J., & Tooke, E. (2001). Evaluating a community nursing service: Listening to the voices of clients with intellectual disabilities and/or their proxies. *Journal of Clinical Nursing, 10*, 352-363.

Krahn, G. I., Hammond, L., & Turner, A. (2006). A cascade of disparities: Health and healthcare access for people with intellectual disabilities. *Mental Retardation and Developmental Disabilities Research Reviews, 12*, 70-82.

Lakin, K. C., Gardner, J., Larson, S., & Wheeler, B. (2005). Access and support for community lives, homes, and social roles. In K. C. Lakin, & A. Turnbull (Eds.), *National goals & research for people with intellectual & developmental disabilities* (pp. 179-215). Washington D.C.: American Association on Mental Retardation.

Larson, S. A., Hewitt, A. S, & Lakin, K. C. (2004). Multiperspective analysis of workforce challenges and their effects on consumer and family quality of life. *American Journal on Mental Retardation, 109*, 481-500.

Lippold, T., & Burns, J. (2009). Social support and intellectual disabilities: A comparison between social networks of adults with intellectual disability and those with physical disability. *Journal of Intellectual Disability Research, 53*, 463-473.

Lorenz, L. S., & Kolb, B. (2009). Involving the public through participatory visual research methods. *Health Expectations, 12*, 262-274. doi:10.1111/j.1369-7625.2009.00560.x

Lyons, M., Orozovic, N., Davis, J., & Newman, J. (2002). Doing-Being-Becoming: Occupational experiences of persons with life-threatening illnesses. *American Journal of Occupational Therapy, 56*, 285-295.

Marks, B. A., & Heller, T. (2003). Bridging the gap: Health promotion for adults with intellectual and developmental disabilities. *Nurse Clinician North America, 38*, 205-228.

Marks, B., Sisirak, J., & Heller, T. (2010). *Health matters: The exercise, nutrition, and health education curriculum for people with developmental disabilities.* Baltimore, MD: Paul H. Brookes.

Marshall, C., & Rossman, G. B. (2006). *Designing Qualitative Research* (4th ed.). Thousand Oaks, CA: Sage.

Matysiak, B. (2001). Interpretive research and people with intellectual disabilities: Politics and practicalities. *Research in Social Science and Disability, 2*, 185-207.

McKenzie, J. F., Neiger, B. L., & Thackeray, R. (2009). *Planning, implementing, & evaluating health promotion programs: A primer.* San Francisco, CA: Pearson.

Melville, C. A., Hamilton, S., Hankey, C. R., Miller, S., & Boyle, S. (2007). The prevalence and determinants of obesity in adults with intellectual disabilities. *Obesity Reviews, 8*, 223-230.

Moore, T. & Huerena, J. (2005). Can you really be healthy as a person with a disability? In W. N. Nehring (Ed.), *Health promotion for persons with intellectual and developmental disabilities* (pp. 343-346). Washington DC: American Association on Mental Retardation.

Morse, J., & Field, P. (1995). *Qualitative research methods for health professionals* (2nd ed.). Thousand Oaks, CA: Sage.

Portney, L. G., & Watkins, M. P. (2009). *Foundations of clinical research: Applications to practice* (3rd ed.). Upper Saddle River, NJ: Pearson.

Powers, L., Dinerstein, R., & Holmes, S. (2005). Self-advocacy, self-determination and social freedom and opportunity. In K. C. Lakin, & A. Turnbull (Eds.), *National goals & research for people with intellectual & developmental disabilities* (pp. 257-287). Washington DC: American Association on Mental Retardation.

Powers, E. T., & Powers, N. J. (2010). Causes of caregiver turnover and the potential effectiveness of wage subsidies for solving the long-term care workforce ‘crisis.’ *The B. E. Journal of Economical Analysis and Policy, 10*(1).

Ravesloot, C. H., Seekins, T., Cahill, T., Lindgren, S., Nary, D. E., & White, G. (2007). Health promotion for people with disabilities: Development and evaluation of the Living Well with a Disability program. *Health Education Research, 22*, 522-531.

Rimmer, J. H. (1999). Health promotion for people with disabilities: The emerging paradigm shift from disability prevention to prevention of secondary conditions. *Physical Therapy*, *79*, 495-502.

Rimmer, J., & Rowland, J. L. (2008). Health promotion for people with disabilities: Implications for empowering the person and promoting disability-friendly environments. *American Journal of Lifestyle Medicine, 2*, 409-420. doi: 10.1177/1559827608317397

Rimmer, J., & Yamaki, K. (2006). Obesity and intellectual disability. *Mental Retardation and Developmental Disabilities Research Reviews, 12*, 22-27. doi: 10.1002/mrdd.20091

Saldana, J. (2009). *The coding manual for qualitative researchers*. Thousand Oaks, CA: Sage.

Sandelowski, M. (2000). Whatever happened to qualitative description? *Research in Nursing & Health, 23*, 334-340.

Stalker, K. (1998). Some ethical and methodological issues in research with people with learning difficulties. *Disability & Society, 13*(1), 5-19.

Stanish, H. I., Temple, V. A., & Frey, G. C. (2006). Health promoting physical activity of adults with mental retardation. *Mental Retardation and Developmental Disabilities Research Reviews, 12*, 13-21. doi:10.1002/mrdd.20090

Taylor, S., (1996). Disability studies and mental retardation. *Disability Studies Quarterly*, *16*(3), 4-13.

Temple, V. A., Frey, G. C., & Stanish, H. I. (2006). Physical activity of adults with mental retardation: Review and research needs. *American Journal of Health Promotion, 21*(1), 2-12.

Temple, V. A., & Walkley, J. W. (2007). Perspectives of constraining and enabling factors for health-promoting physical activity by adults with intellectual disabilities. *Journal of Intellectual and Developmental Disability, 32*(1), 28-38.

Test, D. W., Flowers, C., Hewitt, A., & Solow, J. (2003). Statewide study of the direct support staff workforce. *Mental Retardation, 41*(4), 276-85.

U.S. Department of Health and Human Services, (2006). *The Supply of Direct Support Professionals Serving Individuals with Intellectual Disabilities and Other Developmental Disabilities: Report to Congress*. Office of the Assistant Secretary for Planning and Evaluation, Office of Disability, Aging and Long-Term Care Policy.

U.S. Department of Health and Human Services. Office of Disease Prevention and Health Promotion. Healthy People 2020. Washington, DC. Retrieved March 2, 2012 from http://www.healthypeople.gov/2020/topicsobjectives2020/pdfs/Disability.pdf.

U.S. Public Health Service. (2002). *Closing the gap: A national blueprint for improving the health of individuals with mental retardation*. Washington, DC: U.S. Department of Health and Human Services.

Walmsley, J. (2004). Involving users with learning difficulties in health improvement: Lessons from inclusive learning disability research. *Nursing Inquiry, 11*(1), 54-64.

Wang, C., & Burris, M. A. (1997). Photovoice: Concept, methodology, and use for participatory needs assessment. *Health Education & Behavior, 24*(3), 369-387. doi:10.1177/109019819702400309

Wang, C. C., Yi, W. K., Tao, Z. W., & Carovano, K. (1998). Photovoice as a participatory health promotion strategy. *Health Promotion International,13*(1), 75-86.

Wilcock, A. A. (2006). *An occupational perspective of health.* Thorofare, NJ: Slack, Inc.

Woodgate, R. L., & Leach, J. (2010). Youth’s perspectives on the determinants of health. *Qualitative Health Research, 20*, 644-653. doi: 10.1177/1049732310370213

Young, A. F. (2007). Determining research questions on health risks by people with learning disabilities, carers and care-workers. *British Journal of Learning Disabilities, 36*, 22-31. doi:10.1111/j.1468-3156.2007.00444.x

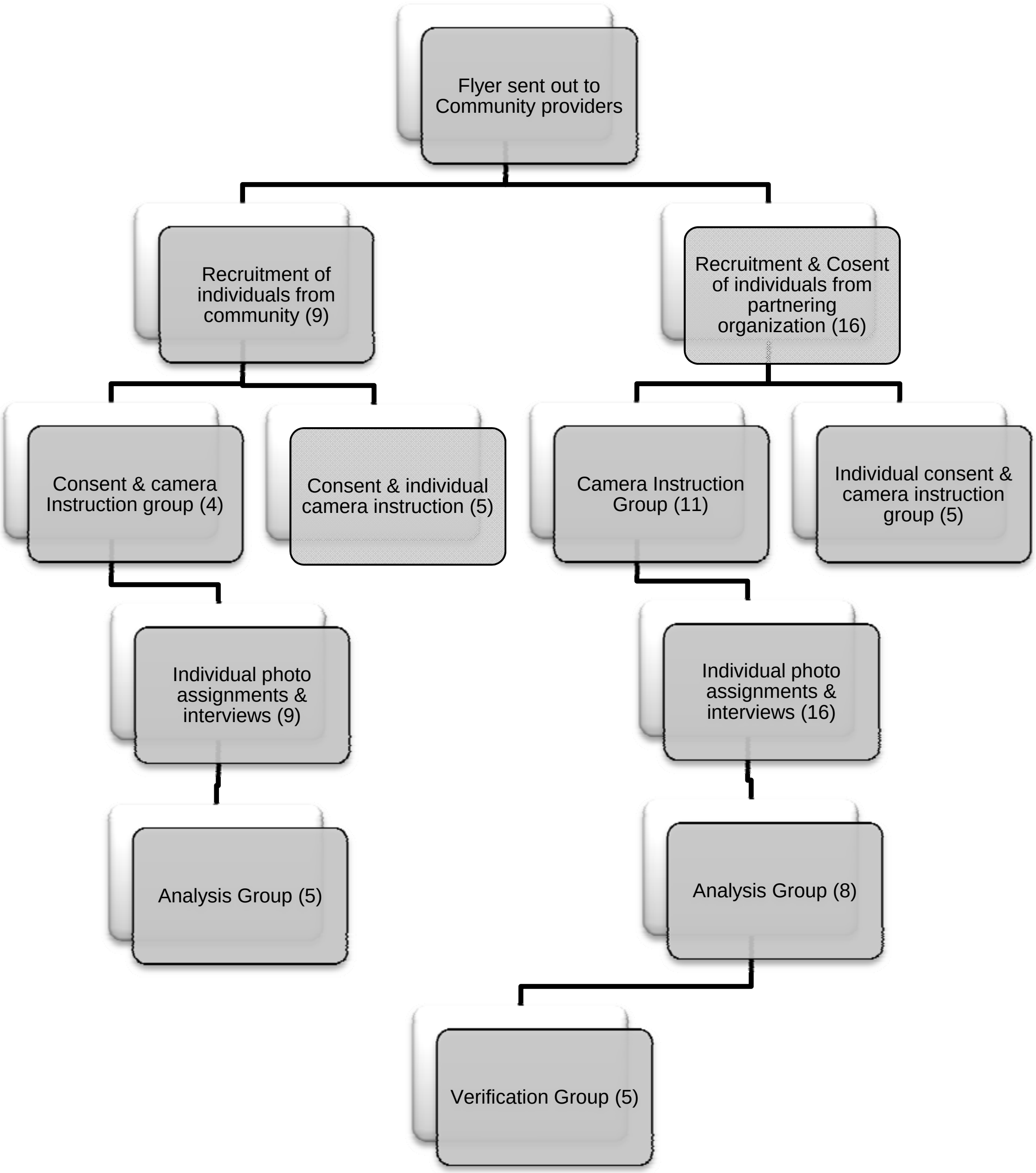


Figure 1. Recruitment and Study Procedure

Table 1

PHOTO Format

Describe your **P**icture.
What is **H**appening in your picture?
Why did you take a picture **O**f this?
What does this picture **T**ell us about health?
How can this picture provide **O**pportunities for us to improve health?

Note. Adapted from "Photovoice as community-based participatory research: A qualitative review," by K. C. Hergenrather, S. D. Rhodes, C. A. Cowan, G. Bardhoshi, & S. Pula, 2009, *American Journal of Health Behavior*, 33(6), p. 693.

ARE WE MISSING THE MARK? HEALTH PROMOTION FOR PEOPLE WITH INTELLECTUAL DISABILITIES

Abstract

The World Health Organization calls for health promotion to expand beyond the healthcare system by considering social determinants of health, engaging multiple levels, targeting policy change, and including social action. This qualitative study embraces this holistic stance as a means to address the health disparities and inequities experienced by people with intellectual disabilities by supporting the development of interventions that consider components of social justice along with embracing this population's potential and acknowledging influences of the context. A content analysis of the data is presented to illustrate how an occupational viewpoint can promote positive health and well-being of people with intellectual disabilities. The four gerunds of Wilcock's *Occupational Perspective on Health*--doing, being, belonging, and becoming--are utilized and supported by the literature to offer actions that can be taken by health promotion professionals to address the health needs of people with intellectual disabilities.

Introduction

The topic of health promotion for people with intellectual disabilities (ID) has become prevalent in recent literature, in part, as an effort to address the widespread health disparities and inequities currently experienced by this population. The causes of these differences continue to be studied and debated, but are generally attributed to insufficient preparation of healthcare professionals and limited healthcare delivery flexibility. Specifically, they are negative provider attitudes and stigmatization, poor health practitioner preparation, diagnostic overshadowing, inaccessible medical facilities and equipment, and communication breakdowns between providers and patients with ID (Fisher, 2004; Iezzoni, 2011). As the focus of healthcare shifts beyond disease management to include education, prevention, and promotion, professionals need to seize this opportunity by exploring ways to expand health directives for people with ID to address health as an integral part of life and "as a resource of everyday life, not the objective of living" (World Health Organization, [WHO] 1986, p.1).

Green and Kreuter (1999) defined health promotion as "any planned combination of educational, political, regulatory, and organizational supports for actions and conditions of living conducive to the health of individuals, groups, or communities" (p. 506). This broad definition leaves the actual interventions for health promotion open to interpretation, but at the same time, might limit the reader to apply only traditional methods toward achieving health, for example, physical exercise and nutrition. Within the last decade, several health promotion programs have been developed to address the needs of people with disabilities (Abdullah & Horner-Johnson, 2006; Marks, Sisirak, & Heller, 2010; Ravesloot et al., 2006). The content of these programs tends to focus on this foundational health knowledge and individual health behavior change. Although health promotion approaches have been successful in facilitating health behavior changes in a variety of populations, the evidence supporting these theories in people with disabilities is sparse (Drum et al., 2009; Mallinson, Fischer, Rogers, Ehrlich-Jones, & Chang, 2009).

The Ottawa Charter for Health Promotion (OCHP) calls for health promotion to expand beyond the healthcare system and consider the social determinants of health by engaging multiple levels, targeting policy change, and including social action (WHO, 1986). By establishing effective interventions that influence multiple levels, health professionals can move beyond a focus on changing individual health behavior to acknowledging the dynamic interaction between social factors and individual behaviors (Peterson, Hammond, & Culley, 2009). Utilizing a broad approach to health promotion minimizes victim blaming by acknowledging the multiple forces that influence healthy behavior rather than just individual choices and/or behaviors (McLeroy, Bibeau, Steckler, & Glanz, 1988). Given the limitations many people with ID experience in decision making, this seems to be a relevant concern.

The OCHP defines health promotion as “the process of enabling people to increase control over, and to improve, their health. To reach a state of complete physical, mental and social well-being, an individual or group must be able to identify and to realize aspirations, to satisfy needs, and to change or cope with the environment” (WHO, 1986, p. 1). This is a more holistic and descriptive definition that goes beyond commercialized health aspects by considering the influence of environment, including emotion and social components, and linking health to capacity utilization and satisfaction. This document continues to expand the focus of health promotion by stressing the importance of social justice and its relation to health (Peterson et al., 2009) stating, “Health is created by caring for oneself and others, by being able to make decisions and have control over one’s life circumstances, and by ensuring that the society one lives in creates conditions that allow the attainment of health by all of its members" (WHO, 1986, p. 1).

A thorough appreciation of the social determinants of health in people with ID requires identification of the needs and wants of the population, consideration of skills and experiences, and an acknowledgment of the influence of the environment in which they live, work, and play. Without this understanding, health promotion interventions stand little chance of being successful (Rimmer, 2006). For example, health professionals will be ineffective if they suggest attending a gym to increase activity without considering transportation needs or if they propose incorporation of vegetables without evaluating meal preparation skills.

The health promotion profession has long understood the value behind incorporating the priority population in the planning process. Green and Kreuter (1999) suggested that health promotion starts by engaging the Precede-Proceed model. This model offers several steps to assessing and developing interventions that address health and quality of life needs. The initial stages of the model, the Precede phases, focus on the identification and appraisal of the health determinants prior to program planning. This framework encourages beginning with the outcomes and asking the question *why* before *how*. Starting by identifying what precedes the outcomes allows the health promotion professional to direct education and behavior change methods to meet the needs of the priority population. The first step of this phase, the Social Assessment, guides the planner to involve people from the priority population in a self-study in order to identify hopes, needs, and goals.

Purpose

People with intellectual disabilities need health promotion programs aimed at risk factors and determinants specific to this population. Little research has been done that includes the perspective of this priority population. To address this concern, a qualitative, descriptive study was conducted to identify the perceptions of health in adults with ID. Information was gathered through observations and the direct elicitation of adults with ID. The study participants identified four themes: Defining Health, Feeling Connected, Having Something to Do, and Being Part of the Community. Details of these results are reported elsewhere.

The purpose of this paper is to acknowledge an alternate, or at least supplemental, direction for promoting the health of people with ID. By analyzing the data through the lens of occupational science, I suggest the results support the proposal that inequities experienced by this group go beyond individual behaviors and healthcare delivery and are related to aspects of social justice. Implications for practice are considered and recommendations for the development of meaningful, holistic interventions are provided.

Method

Successful utilization of conventional health-related data collection methods, such as questionnaires, self-reports, and journaling, requires complex cognitive skill and is therefore often difficult for people with ID. Besides being ineffective, researchers who use these methods risk highlighting participants' limitations and contributing to feelings of inadequacy (Wang & Burris, 1997). The objective in designing this study was to choose a method that was both accessible and inclusive for the population's range of abilities. I chose to utilize photovoice after considering my priority population and the

WHO’s call to address health promotion through reciprocal participation, consideration of the environment, and across multiple levels of influence.

Photovoice is a qualitative method that utilizes photography to elicit information and empower participants to be self-advocates (Wang & Burris, 1997; Wang, Yi, Tao, & Carovano, 1998). Photographs, taken by the participants, are utilized to obtain thick descriptions and meaning of everyday experiences during group discussions. This is a community-based participatory research (CBPR) method that considers the participants to be experts in their own lives with the ability to offer insight that professionals are often unable to access. The goals of this method are to identify the assets and concerns of the group, empower individuals through participation, and increase awareness in the public and stakeholders (Wang & Burris).

Study Procedure

I recruited a total of 25 adults with ID, all of who lived in the community with various levels of support. The majority of individuals lived with someone: 10 with parents, 2 with a spouse, and 11 with roommates (and assistance of staff). Only 2 individuals lived alone but did so with the support of part-time staff. The participants’ ages ranged from 23-64 (mean 33) and 12 were men. The majority of individuals (16) were involved in some type of formal day program, 6 were employed at least part time in the community, and 3 had no employment or structured services. No specific IQ range was identified during recruitment in an attempt to represent a range of abilities. No medical records were accessed to verify diagnosis because this was a CBPR method and participants were recruited from several community agencies. For this reason, specific diagnoses of the individuals are unknown and irrelevant for the purposes of this study.

I followed the established steps of photovoice, with the exception of two additional components: initial interviews and participant observations. The details of the entire process have been documented elsewhere. Individual interviews were included as a part of the analysis phase to allow each participant an opportunity to share their experiences and photographs with the researcher. Conducting interviews facilitated by the participants' photographs allowed me to collect rich data and negotiate the interpretation with my participants (Pink, 2007).

Traditionally, the photovoice method places the academic researcher in the role of a silent partner, facilitating the process, but not contributing beyond constructing the final written product. Because many people with ID often have difficulty with communication skills in both articulation of words and expression of ideas, I utilized participant observations in conjunction with the visual methods to assist the participants in telling their stories. These observations add the context in which to frame the participants' comments. This practice is in line with ethnographic methods (Angrosino, 2007) and allowed for a co-created research experience and outcomes. The setting of the observation was chosen by the participant and generally occurred in the familiar, routine context of the participant's home, volunteer, or day program.

The individual interviews and the group discussion were initiated using a semi-structured interview format. The participants were encouraged to discuss any relevant information related to the photographs or health. This method allowed the participants to be involved in the steps of analysis and the researcher to direct the questions in a way that allowed for richer description and deeper meaning (Creswell, 2007; Woodgate & Leach, 2010). The use of the photographs not only allowed me to elicit information about health, but also gave me a glimpse into the lives of the study participants, events and details I would have otherwise not been exposed to during our interactions. The subjects in the photographs cued me into meaningful components of the participants' lives and broadened my understanding of their perspectives and the determinants of health.

Analysis

The data for this study were gathered from multiple sources: groups, individual interviews, and observations. All interviews and group discussions were transcribed by the researcher verbatim and entered, along with field notes, into ATLAS.ti.6.2. This report includes a combination of data assembled from the participants' interviews and from analysis of the field notes taken during participant interactions and observations, a total of 830 pages of text.

Goodley (1996) supports utilizing a narrative process to confront generalizations and opinions of people with disabilities by stating: "…our 'truths' are quickly challenged by the personal narrative" (p. 335). There is only a brief description of the analysis process in the original photovoice articles; no details are present (Wang & Burris, 1997; Wang et al., 1998). Based on the information gained from these articles, I decided to use an inductive thematic analysis to identify patterns of information that related to the original inquiry. This recursive procedure requires examination of the entire data set to discover themes of interest and offered a way to crosscheck the patterns in the data across the entire set of transcriptions and field notes (Morse & Field, 1995). The results composed during this first phase of analysis are reported elsewhere.

My clinical experience as an occupational therapist (OT) includes nearly 25 years working in the community with people who have a variety of cognitive disabilities. When

I set out to do this study, my intent was to gather information that would improve health promotion for this population, not from the perspective of an occupational therapist but from the perspective of the participants. After co-constructing results with the participants and reflecting on my experiences during the research observations and my clinical work, I concluded that there was a larger story that needed to be told. This compelled me to return to the literature and complete an additional step of analysis. After reexamining the related literature, I discovered many of the aspects revealed in the data were similar to those discussed in the field of occupational science. In the reanalysis of the data, I examined the data again utilizing content analysis to discover the details that align with an occupational viewpoint (Portney & Watkins, 2009). I applied the four interrelated segments identified in Wilcock's (2006) *Occupational Perspective of Health*- doing, being, belonging, and becoming, to the data for a retroductive content analysis by occupational health categories.

To increase the result's credibility and dependability, triangulation was created through the use of prolonged engagement, multiple methods (interviews, groups discussion, and observations) and several analysts of the data (the researcher and participants) (Creswell, 2007; Flick, 2006; Hergenrather, Rhodes, Cowan, Bardhoshi, & Pula, 2009; Portney & Watkins, 2009). The partnership in the research process and the use of the final groups served as forms of member checking, the traditional way of confirming results with the participants. Initial insights and procedural decisions were documented throughout the process via careful field notes and detailed memos. This audit trail made the decision process and conclusions transparent, increasing the dependability of the study (Creswell; Flick; Portney & Watkins).

Results

The results of this study are presented under four headings, as Wilcock (2006) has presented them, but the dynamic interaction Wilcock proposes between the four dimensions should be kept in mind. This separated representation is an effort to emphasize the distinct characteristics of each component and stress how they each impact health.

Doing

What we do is at the heart of who we are. Think of how often you ask, "What do you do?" when becoming acquainted with someone. *Doing* includes goal-oriented activities that offer interaction, engagement, and productivity. It is through *doing* that individuals develop the skills needed to meet basic needs (Wilcock, 2006).

The participants described having something to do, or the lack thereof, as a determinant of health. Those participants who were *doing* during their day took photographs at the library, going on hikes, working at day programs, volunteering at community agency activities, and visiting with family. Many of them talked about the positive aspects of being busy, especially if the activity was productive, for example, making gifts for others, working, or volunteering. Quite a few participants took pictures of gardens and mentioned the satisfaction they felt when participating in the activity of gardening. When I asked the group how gardening was good for your health, the ideas of healthy food, along with exercise, nurturing, and being productive were all mentioned:

> Sharla: My grandma has [a garden].
> Jana: Vegetables!
> Marilyn: You can plant vegetables, tomatoes, beans, carrots.
> Brady: I love to garden with my dad.
> Jana: It's like exercise.
> Sharla: And you can pick all the vegetables and eat them.

> Brady: I love working in the garden because it makes me take care of plants and – you get to grow things.

Although still considered *doing*, many of the participants stated much of their time was spent in sedentary activity. These tasks were generally nonproductive and offered limited engagement, for example, watching television and movies or going for a ride in the van. The majority of the individuals could identify that sedentary tasks were not health promoting and stated a preference for more active tasks like bowling, dancing, and sports.

Doing also includes the development and application of skills to meet daily needs. Skill development is vital to achieving the independence required to live in the community and negotiate situations experienced in adulthood. In this study, those who received additional staff support outside of a day program were more inclined to be involved in some type of skill development than those without a daily program or those who just attended day services. Clients reported learning how to ride public transportation, manage health conditions, and complete household tasks.

The majority of the participants seemed to have a working knowledge of healthy lifestyle topics, but for many of them, a lack of daily living skills presented an obstacle to incorporating this information. Through cooperative review of the photographs, conversations, and observations, underdeveloped skills related to healthy lifestyle behaviors were most obvious in planning and preparing meals and making good choices concerning food and activity. Several people either stated the desire to learn to cook or spoke of making food choices (convenience foods) based on an inability to cook. Iris had a pantry that was so full of food, she was unable to close the doors. When I asked her why she had so much food, she stated she received a food box from the food bank each week. The food was accumulating because she was unsure what most of the products were and did not know how to prepare them. Before I left her apartment, she tried to give me a bag of fresh lettuce stating, "I have nothing to eat it with and I will just end up throwing it away."

The ability to make good, informed choices was difficult for many of the participants. Behaviors were observed that reflected a decreased ability to practice what they knew to be healthy. Discussions of healthy choices were often followed by recent examples of when they did not employ good decision making. Participants were often torn between choosing a healthy option or one they thought tasted good. After Josh identified healthy items on the menu at the restaurant where he works and the importance of making wise decisions, I questioned his choice to have french fries for lunch. He replied

> Josh: Cheese fries! Those are my favorites. Oh, they are with ranch dressing on them. Ohohohoh! You dip them in. Even better when it is hot and cheesy! And bacon bits on top. That is dressed up.
> Beth: Wow! Are those healthy for you?
> Josh: HA! What do you think?
> Beth: I think they are not.
> Josh: You are right. I don't know, but you have choices to make, right?
> Beth: Yep.
> Josh: I choose cheese fries all the time.

Although some participants had evening and weekend staff available to assist with tasks and instruct in daily living skills, not all of the staff were effective. Brady showed me a photograph of a staff member lying on the couch. When I inquired about the purpose behind having staff in the evening he replied:

> Brady: Um—they are usually laying [in the living room] watching TV and I am watching TV in my room.
> Beth: That doesn't sound very interesting. Why do they even come?
> Brady: Because—I want to learn to cook on my own.

Beth: You want to learn to cook on your own but you are watching a movie in your room while they watch TV [in the living room]. How does that help you learn to cook?
Brady: Um—well sometimes I help [a different staff member] when she comes and cooks.

Another skill area that impacted the participants' level of *doing* was difficulty with social participation outside of structured services. Planning social activities with friends is a task that can require a high level of cognitive performance. Organizing times, matching interests and abilities, and coordinating schedules takes knowledge of your community and the capability to make appropriate decisions. Most of this study population stated limited experience doing these tasks, either secondary to inadequate knowledge or opportunity. The combination of limited planning abilities and a strong desire to *do* created a predicament for some of the participants. This dilemma not only negatively impacted health by affecting both *doing* and *belonging* (discussed in more detail to follow) but also led some individuals to become involved in unsafe activities. A few of the participants told me stories about injuries that occurred while in the community, involvement with the police, and near-miss situations. In a desperate attempt to do, one participant decided to take a tour bus to a casino, approximately 90 minutes from her home. When she missed the bus, she solicited a ride from a man at the nearby gas station. This stranger agreed to drive her to the location, but once there abandoned her, leaving her with no transportation home. Although the problem of being stranded was apparent to her, at the time of the incident, she was unaware of the danger she placed herself in by accepting a ride from a stranger. She stated, "Well, I get that now. I just wanted something to do!"

Being

Being has been defined as maintain your true self, finding meaning and purpose, and discovering and utilizing your capabilities (Wilcock, 2006). Hammell (2004) expands on this definition by stating *being* involves opportunities to “reflect, be introspective or meditative, (re)discover the self, savor the moment, [and] appreciate nature, art, or music in a contemplative manner” (p. 301).

Acknowledging strengths and contributions promotes a sense of *being* by encouraging people to live a life that represents their true self. People with ID might require assistance to maximize their skills and recognize opportunities to contribute. Making the most of the abilities in people with ID was seen on several occasions during this study, mostly at the community agencies and during formal services, when staff members were able to match capabilities with activity demands. Clark, a participant who spoke infrequently and offered minimal eye contact, appeared to have limited abilities that would transfer to a vocation, yet his job at the day program was to keep the activity room clean. This task highlighted Clark’s strengths of being observant and detail oriented. While reviewing a photograph of the activity room, he stated he loved attending the program. When asked why, he reported:

> Clark: Work.
> Beth: What is your job here?
> Clark: Cleaning.
> Beth: I noticed you are always throwing things away. Are you in charge of keeping this room clean?
> Clark: Yes.
> Beth: You do a good job.
> Clark: Yes, I do.

At a community fund raiser for Down's syndrome, Kevin was able to contribute and showcase his passion for music. He described this opportunity, to be true to himself and share his talents, as good for his health:

> Kevin: I was playing my guitar. I guess that's good for you. Having fun, singing, and showing your skills in front of everyone.
> Beth: So you like performing?
> Kevin: Yes, [even though] I can't sing very well but—I can play. Bob Dylan can't sing very well—but he does.

Unfortunately, an underappreciation for peoples' abilities was also experienced during this study, while I was in the recruitment phase. In an attempt to increase awareness of the study, I attended community activities where at times I was discouraged from recruiting participants. Group home staff members stated the individuals did not have the ability level required to take part in the study. Even when the inclusion criteria were explained and the minimal skill level was defined, the staff continued to doubt that participants would be able to fully participate. If staff members do not set high expectations for the people with whom they work, these individuals might miss out on opportunities to achieve their potential through *being*.

Utilizing the method of photovoice along with observations offered me a glimpse of the participants' true *being*. Upon entering their homes, the first thing each person did was offer me a tour. I interpreted this act, along with many photographs of bedrooms, belongings, talents, and awards, as an expression of pride and satisfaction in their *being*. Charles was proud of the photographs he took, several showing his bicycle, television, and athletic posters.

> Charles: I took a lot of pictures. That is me, I am handsome. I did a good job, huh?
> Beth: Yes!

> Charles: That's pretty. These are good pictures. I did a good job. I took a lot of pictures of my room.
> Beth: You did fabulous!
> Charles: Look at my stuff, what do you think of my room?

This research study supported the participants' sense of *being* by empowering them to contribute and by offering them an opportunity to discover something about themselves. Individuals displayed pride in their abilities by asking people to view their photographs and making statements like "You will be amazed!" when introducing their slideshow. For several of the individuals, this study exposed a new talent in photography and sparked a desire to learn more about the camera and taking pictures.

Times to reflect and contemplate are also included in the concept of *being*. It is through this process that people define values, aspirations, goals, and dreams (Wilcock, 2006). This component of *being* was acknowledged through interactions with nature. The local mountain range symbolized a place for relaxation and time to think.

> I love the fresh clean water, the smell of the pine trees and the sounds of the birds. You know, the birds relax me when they—they, they, they cheep and stuff. I took a picture of this because— um, it reminds me of a very healthy place to sit and—and think about things, about healthy reasons. Yeah a peaceful place where I can think and say "Hey this is what is not good for you or hey this is good for you."

A photograph of a rose was projected during a group discussion and the participants stated beauty was a catalyst to thinking and health.

> Iris: It's pretty.
> Jamie: It is nature.
> Beth: Do you think nature is good for your health?
> Iris: Yes, it's nice to be around.
> Jamie: I like to look at nature stuff, and think about— the beauty of it.

When asked, "What do you do most days?" participants could identify activities they did on a weekly basis. Some of the tasks they named were seen in their photographs, but what might be just as telling were those things that were not seen in the photographs.

Participants tended to take photographs of the things that were most important to them and although mentioned, they did not take as many pictures of the routine tasks, time-filling activities, or moments of boredom. As mentioned earlier, having something to do contributed to positive health but the effect is most powerful when meaning and purpose can be found in *doing* (Hasselkus, 2011). Meaning and purpose, as components of *being*, were often found through hobbies and community activities. Visiting the zoo, attending classes, knitting, making jewelry, and playing music were all present in the photographs and described as enjoyable. Samantha was not involved in formal day services, but found meaning and purpose by attending classes and events at the local Independent Living Center each day.

> That impacts my health a lot because it helps me with daily living skills and gets me out of the house and be around people. Like for 4-6 weeks, they have a class and then after that class is done, they do something else.

Sadly, not all of the participants felt they had opportunities to utilize their capabilities or find meaning and purpose in daily life. On several occasions Marilyn referred to being depressed to the point of being suicidal. Although there certainly could be many contributing factors to this emotion, Marilyn also complained often of being bored with her life. She attended a day program, but failed to see the meaning behind the activities offered there.

> Marilyn: I'm depressed sometimes. I don't like [the day program]. I keep telling them and they don't listen.
> Beth: So what is it? Why don't you like it?
> Marilyn: I don't know. Are they ever going to let me do something else? I don't understand why—how hard is it to work at [a grocery store]? Or get a job? Or how hard is it to bag groceries? I don't know why, it just makes me nuts.
> Beth: So have you ever tried to apply for jobs on your own?
> Marilyn: Yes, lots of times and they don't call me back or maybe I don't call them back. So I guess I will just stay at [the day program] forever.

Marilyn lacked the skill set to acquire a job on her own, but didn't feel like she received the support she needed from the day program either. She was caught in a nonproductive cycle. Because she did not find meaning or purpose in the day program, she did not attend regularly. On the other hand, she was told the staff would assist her in finding a job when she demonstrated consistent attendance, a skill that reflects a reliable employee. Marilyn's frustration with the situation places her at risk for ill-health by impacting her *being*.

Belonging

The word *belonging* describes mutual relationships along with feelings of connection and inclusion. The results of this study indicated *belonging* was an important determinant to health for the participants and deserves further facilitation. Participants stressed the value of having a feeling of connections with people, animals, nature, and religion. Often the experiences of *belonging* occurred while participating in groups that shared common values. Special Olympics events, day program services, volunteer settings, religious activities, and family activities provided a sense of inclusion. Two individuals reported an extensive community on the Internet through social networking sites.

> Sophie: I'm on [the website] for at least 2 hours a day.
> Beth: What do you do on there? Just read everyone's pages?
> Sophie: Yeah, I have over 600 friends.

Tomas stated he was close to his family, spending Sunday dinner with them every week, but he enjoyed living in his own apartment because of the connection he had with his friends.

> Tomas: I [use to] live with my mom.

> Beth: Which do you like better?
> Tomas: Here.
> Beth: Why is that?
> Tomas: Cuz I see my friends here.

Belonging most often referred to relationships with friends and staff. Although these relationships were important to the participants, they also expressed difficulties in maintaining these friendships and a sense of *belonging*. Friends often related to peers who attended the same community services. Although several individuals who attended community agencies together also lived in the same neighborhood, they rarely saw each other outside of the day services. Brady pointed out friends in one of his photographs of an outing with the day program.

> Brady: Yeah, he is my friend. Scott is my friend. Oke is my friend.
> Beth: They live close to here, don't they?
> Brady: Yeah.
> Beth: Do you ever do anything with Scott or Oke on the weekends?
> Brady: Um—no, I just see them at [the day program].

Many of the individuals had difficulty fostering these relationships beyond structured services. They did not plan activities or initiate communication with friends, even though they lived only a few apartments away.

Staff members who had a sense of humor, were helpful, happy, and spontaneous were praised by the participants. These relationships were cherished, but the reality of staff turnover and reassignment was often difficult for the participants to understand and at times left them feeling deserted. Although most of the participants only had their cameras for a few weeks, several people took images displaying "old [previous] staff":

> Sophie: That is a picture of my old staff, being goofy. Um—she's the best staff ever.
> Beth: Old staff?
> Sophie: She got transferred to a different house.
> Beth: How do you feel about that?

Sophie: I wasn't too happy, I was sad.

People with ID are often involved in relationships that are one-sided. Staff and family are often in a position to do for the person with ID, rather than do with or request from. Besides presenting an opportunity to discover new talents, participation in this study engaged the individuals in a collaborative process and revered what they had to offer. The level of excitement each time I interacted with the participants was palpable. Participants were aware of my status as a student and appreciated the opportunity to help me with my "homework." Questions about the status of the study, results, future opportunities, and what more could be done were constant.

Ryan: Did I help you with your project?
Beth: You did.
Ryan: Do you think your teacher is going to be happy with this?
Beth: I think she will be.
Ryan: I think so too.

In general, literature supports the health benefits of having friends and a social network. Although conversations with participants also supported this notion, situations observed during this study indicate there might be a negative aspect to *belonging*. Some of the individuals attended a day program and then returned home in the evenings to a supervised living situation where their roommates were the same group of people. Although behavioral issues are common in people with ID, some of the incidences I witnessed involved arguments between individuals who spent a good portion of the day together. Hasselkus (2011) speaks of overconnectedness as a possible deterrent to health. This concept is based on the idea that people need time for solitude, opportunities for *being*. Although anecdotal, these situations suggest that overconnectedness might be an area for future inquiry.

Becoming

The process of *becoming* is continuous throughout life as we are constantly evolving into something different, positive or negative. The ideal process of *becoming* involves moving toward personal development and potential (Wilcock, 2006). For people with ID, this includes recognizing and utilizing talents, contributing to their community, having choice, and learning from daily experiences.

On the day I arrived to complete Sharla's interview, the staff stated it might not be the best day because she was angry and they were currently trying to control her behavior. Sharla was pacing the room, yelling, and attempting to hit those around her. Apparently Sharla had chosen to not participate in the morning program and so, per protocol, she was not allowed to partake in her activity of choice (sitting in the sun) in the afternoon. Although it was not clear to me how or why she made that choice in the morning, one of her peers stated the activity Sharla refused was coloring. This could have been a contributing factor, indicating Sharla felt the demands of the task did not provide an opportunity to contribute and did not match her capabilities. Although the morning activity did not offer an ideal situation to encourage *becoming,* this situation presented the perfect opportunity for Sharla to experience the results of her choice. I observed the staff review the situation with her and offer her an opportunity to make another choice based on a different set of options; did she want to take time to relax in the quiet area or did she want to meet with me to review her photographs? Sharla chose to meet with me and the interview was completed without incident, in fact she became happy upon seeing her photographs. Offering choice, experiencing consequences, and highlighting abilities decreased Sharla's agitation and assisted her in her journey to *becoming*.

Discussion

Achieving positive health is a continuous process impacted by daily circumstances, the context, and life stages. This process has been described by many authors from a variety of disciplines. Wilcock's Occupational Perspective of Health (2006) asserts health can be achieved when people engage in an occupation that is based on meaningful pursuits that provide opportunity for growth, the use of capabilities, and the freedom to adapt to the context and individual choice. Wilcock, an occupational therapist, defines the term occupation as "all the things that people need, want, or are obliged to do; what it means to them: and its ever-present potential as an agent of change" (p. 9). The terms--doing, being, belonging, and becoming--are used to illustrate how the use of occupation can promote health and well-being. These gerunds reflect the ever-incomplete nature of the process, while emphasizing the dynamic relationship between the four segments. They also symbolize actions that can be taken by people with intellectual disabilities and health promotion professionals.

Clark et al. (1997) found the use of an occupational perspective supported health and well-being in a population of well elderly. This study concluded there was a relationship between engagement in meaningful activity and health. As opposed to the control groups, one that had no intervention and one that participated in social activities, the group that engaged in meaningful activities received significant health benefits from the study. These tasks were deemed influential because they were relevant to the individuals' lives, context, and needs and included lessons on overcoming identified barriers, community resources, self efficacy, and internal locus of control.

The results reported here reflect Wilcock's (2006) occupational perspective that health is impacted by the ability to do, be, belong, and become. They also support the use of an occupational perspective of health by aligning with the WHO's holistic definition of health promotion:

> The process of enabling people to increase control over, and to improve, their health. To reach a state of complete physical, mental and social well-being, an individual or group must be able to identify and to realize aspirations, to satisfy needs, and to change or cope with the environment. (1986, p.1)

Several of the aspects of health identified in this study aligned with this definition. The most relevant of these are skill development to meet daily needs, control achieved through choice and meaning in daily activity, realizing potential by utilizing talents and acknowledging goals, and inclusion in the community through positive social networks. These health characteristics demonstrate that health is impacted by many aspects of life and beckon a reassessment of how health promotion is currently addressing the needs of this population. By utilizing only didactic lessons that review traditional nutrition and fitness knowledge, we might be missing the mark when it comes to promoting health for people with ID. In a study on health care in adults with ID by Parish, Moss, and Richman (2008), the majority of the participants had received standard health promotion information in the past. On a whole, the group could identify the importance of physical activity, proper nutrition, weight management, and follow-up physician visits. In order to address barriers to healthy lifestyles in this population, additional skills need to be addressed in the promotion of health. A holistic approach that addresses individual skill development as well as social determinants seems appropriate. Among the five health promotion actions identified by OCPH, creating supportive environments and developing personal skills correspond best with the outcomes of this study (WHO, 1986) and offer intervention alternatives for health promotion professionals.

Supportive environments can be created for people with ID first and foremost through acceptance. The health benefits of participating in positive social interactions have been reported by many researchers. In a meta-analysis of positive health predicators, social support was the factor studied most often and results indicated it was the second most powerful predictor, second only to the related concept of loneliness (Yarcheski, Mahon, Yarcheski, & Cannella, 2004). Being involved in reciprocal relationships, those based on give and take, contributes to self-worth by projecting respect and an assessment of competence (Hammell, 2004). Positive social interactions which accept assistance from someone or request help demonstrate confidence in their skills, value in what they have to offer, and acknowledge their significance. Incorporating reciprocal relationships and affirmative social interactions into the lives of people with ID is an important step to promoting health, one that asks them to *do*, encourages their *being*, promotes *belonging*, and fosters *becoming*.

Another method of providing an environment of support for people with ID is to address concerns regarding direct support providers. Two concerns seen in my study, frequent staff turnover and inadequate service provision, are exaggerated by the fact that frontline caregivers for people with ID are usually poorly paid, education requirements for employment are minimal (Powers & Powers, 2010), and services are often provided in the community or an individual’s home where supervision and accountability are inadequate. These issues need to be addressed at an institutional and policy level. Health promotion professionals can influence institutional changes by designing health promotion educational programs that increase the skill level of direct caregivers and provide them with content to incorporate into their interactions with people with ID.

Involvement in advocacy movements can strengthen efforts on a policy level and influence regulations related to service reimbursement.

Educational health promotion classes are generally didactic and have minimal exposure to interactive or experiential activities (Hodges & Videto, 2011; McKenzie, Neiger, & Thackeray, 2009). The basic tenet of *doing* is not only one that comes from an occupational perspective. This concept is also supported by the *Jakarta Declaration on Leading Health Promotion into the 21st Century* (WHO, 1997) which states, "Health promotion is carried out by and with people, not on or to people" (p. 4). Bates, Cuvo, Miner, and Korabek (2001) explored instructional methods for people with ID and concluded that the best generalization of skills happened when participants were allowed opportunities to practice skills both in simulated tasks and in the natural context of the activity. In order for health promotion interventions to be effective with this population, they must include hands-on, interactive components that include the development of personal skills specific to healthy lifestyle behaviors and meeting daily needs, such as preparing meals, planning leisure pursuits, obtaining employment, and developing social networks.

Personal development through an emphasis on active participation not only provides useful skills, but can also enhance health by promoting feelings of choice, meaning, and purpose. Hammell (2004) supported the use of an occupational perspective to address health by linking it to the components of quality of life, which she described as purpose, meaning, choice and control, self-worth, and occupation. These aspects are further supported by Christiansen (1999) when he suggested depression was the outcome of limited "opportunity to gain personal meaning from everyday activities" and could be averted by offering people the belief "that there is choice and control in their lives" (p. 555).

Most of these components are facets of self-determination, which has been recognized as a viable intervention to promote health for people with ID (Krahn, Hammond, & Turner, 2006). Choice making, a component of self determination, contributes to control by acknowledging the ability to make choices and providing opportunities to learn from the consequences (Agran, Storey & Krupp, 2010). Self-determination training is often included in educational programs of people with ID when they are in the school system, but the focus diminishes beyond this developmental period. Palmer (2010) suggests by incorporating self-determination skill development throughout the life span, professionals can assist people with ID in achieving outcomes that enhance "a full range of capacities and opportunities" (p. 2). In order for people with disabilities to be active partners in their health care, autonomy should be encouraged in health promotion programs through skill training in: self advocacy, decision making, assertive communication, and acquisition of knowledge (Wullink, Widdershoven, van Schrojenstein Lantman-de Valk, Metsemakers, & Dinant, 2009).

Conclusion

The Ottawa Charter on Health Promotion stresses the importance of addressing issues of social justice through health promotion, stating health is achieved by, "reducing differences in current health status and ensuring equal opportunities and resources to enable all people to achieve their fullest health potential. This includes a secure foundation in a supportive environment, access to information, life skills and opportunities for making healthy choices" (WHO, 1986, p. 1). Wilcock (2006) expands social justice to include occupational justice, which encompasses: equity, empowerment and fairness that allows people to meet daily needs, develop potential, and achieve satisfaction. She continues by clarifying that this equity is not a call for everyone to be able to do identical things, but rather a need for a "justice of difference" (p. 247),which facilitates people to meet daily requirements by providing meaning and by matching opportunities with abilities, desires, and values. Along with addressing social determinants, health promotion interventions could be enhanced through an explicit inclusion of an occupational perspective. By including client-centered activities that tap into individual values and strengths, are inclusive, and focus on possibilities health promotion, professionals send people with ID the message that we have confidence in their potential, see value their contributions, acknowledge their desires for a meaningful, healthy life, and respect them as members of a just society.

References

Abdullah, N., & Horner-Johnson, W. (2006). Promoting healthy lifestyles among people with disabilities. *Northwest Public Health*, *Spring/Summer*, 8-9.

Agran, M., Storey, K., & Krupp, M. (2010). Choosing and choice making are not the same: Asking "what do you want for lunch?" is not self-determination. *Journal of Vocational Rehabilitation, 33*, 77-88.

Angrosino, M. (2007). *Naturalistic observation*. Walnut Creek, CA: Left Coast Press.

Bates, P. E., Cuvo, T., Miner, C. A., & Korabek, C. A. (2001). Simulated and community-based instruction involving people with mild and moderate mental retardation. *Research in Developmental Disabilities, 22*, 95-115.

Christiansen, C. (1999). Defining lives: Occupation as identity: An essay on competence, coherence, and the creation of meaning, 1999 Eleanor Clarke Slagle lecture. *American Journal of Occupational Therapy, 53*, 547-558.

Clark, F., Azen, S. P., Zemke, R., Jackson, J., Carlson, M., Mandel, D.,…Lipson, L. (1997). Occupational therapy for independent-living older adults. *Journal of the American Medical Association*, 278, 1321-1326.

Creswell, J. W., (2007). *Qualitative inquiry & research design: Choosing among five approaches*. Thousand Oaks, CA: Sage.

Drum, C. E., Peterson, J. J., Culley, C., Krahn, G., Heller, T., Kimpton, T.,… White, F. W. (2009). Guidelines and criteria for the implementation of community-based health promotion programs for individuals with disabilities. *American Journal of Health Promotion, 24*(2), 93-101. doi:10.4278/ajhp.090303-CIT-94.

Fisher, K. (2004). Health disparities and mental retardation. *Journal of Nursing Scholarship, 36*(1), 48-53.

Flick, U. (2006). *An introduction to qualitative research*. Thousand Oaks, CA: Sage.

Goodley, D. (1996). Tales of hidden lives: A critical examination of life history research with people who have learning difficulties. *Disability & Society, 11*(3), 333-348.

Green, L. W., & Kreuter, M. W. (1999). *Health promotion planning: An educational and ecological approach* (3rd ed.). Mountain View, CA: Mayfield.

Hammell, K. W. (2004). Dimensions of meaning in the occupations of daily life. *Canadian Journal of Occupational Therapy, 71*(5), 296-305.

Hasselkus, B. R. (2011). *The meaning of everyday occupation* (2nd ed.). Thorofare, NJ: Slack.

Hergenrather, K. C., Rhodes, S. D., Cowan, C. A., Bardhoshi, G., & Pula, S. (2009). Photovoice as community-based participatory research: A qualitative review. *American Journal of Health Behavior, 33*(6), 686-698.

Hodges, B. C., & Videto, D. M. (2011). *Assessment and planning in health programs*. Sundbury, MA: Jones and Bartlett.

Iezonni, L. (2011). Eliminating health and health care disparities among the growing population of people with disabilities. *Health Affairs*, 30, 1947-1954.

Krahn, G. L., Hammond, L., & Turner, A. (2006). A cascade of disparities: Health and health care access for people with intellectual disabilities. *Mental Retardation and Developmental Disabilities Research Reviews, 12*, 70-82.

Mallinson, T., Fischer, H., Rogers, J. C., Ehrlich-Jones, L., & Chang, R. (2009). The issue is- human occupation for public health promotion: New directions for occupational therapy practice with persons with arthritis. *American Journal of Occupational Therapy, 63*, 220-226.

Marks, B., Sisirak, J., & Heller, T. (2010). *Health matters: The exercise, nutrition, and health education curriculum for people with developmental disabilities*. Baltimore, MD: Paul H. Brookes.

McKenzie, J. F., Neiger, B. L., & Thackeray, R. (2009). *Planning, implementing, & evaluating health promotion programs: A primer.* San Francisco, CA: Pearson.

McLeroy, K. R., Bibeau, D., Steckler, A., & Glanz, K. (1988). An ecological perspective on health promotion programs. *Health Education & Behavior, 15*(4), 351-377.

Morse, J., & Field, P. (1995). *Qualitative research methods for health professionals* (2nd ed.). Thousand Oaks, CA: Sage.

Palmer, S. (2010). Self-determination: A life-span perspective. *Focus on Exceptional Children, 42*(6), 1-16.

Parish, S. L., Moss, K., & Richman, E. L. (2008). Perspectives of health care of adults with developmental disabilities. *Intellectual and Developmental Disabilities, 46*(6), 411-426.

Peterson, J. J., Hammond, L., & Culley, C. (2009). Health promotion for people with disabilities. In C. E. Drum, G. L. Krahn, & H. Bersani (Eds.), *Disability and public health* (pp. 145-162). Washington, DC: American Association on Intellectual and Developmental Disabilities.

Pink, S. (2007). *Doing visual ethnography.* Thousand Oaks, CA: Sage.

Portney, L. G., & Watkins, M. P. (2009). *Foundations of clinical research: Applications to practice* (3rd ed.). Upper Saddle River, NJ: Pearson.

Powers, E. T., & Powers, N. J. (2010). Causes of caregiver turnover and the potential effectiveness of wage subsidies for solving the long-term care workforce 'crisis.' *The B. E. Journal of Economical Analysis and Policy, 10*(1), 1-28.

Ravesloot, C. H., Seekins, T., Cahill, T., Lindgren, S., Nary, D. E., & White, G. (2006). Health promotion for people with disabilities: Development and evaluation of the Living Well with a Disability program. *Health Education Research, 22*(4), 522-531.

Rimmer, J. H. (2006). Use of the ICF in identifying factors that impact participation in physical activity/rehabilitation among people with disabilities. *Disability and Rehabilitation, 28*, 1087-1095.

Wang, C., & Burris, M. A. (1997). Photovoice: Concept, methodology, and use for participatory needs assessment. *Health Education & Behavior, 24*(3), 369-387. doi:10.1177/109019819702400309

Wang, C. C., Yi, W. K., Tao, Z. W., & Carovano, K. (1998). Photovoice as a participatory health promotion strategy. *Health Promotion Internationa*l, 13(1), 75-86.

Wilcock, A. A. (2006). *An occupational perspective of health*. Thorofare, NJ: SLACK.

Woodgate, R. L., & Leach, J. (2010). Youth's perspectives on the determinants of health. *Qualitative Health Research*, *20*, 644-653, doi: 10.1177/1049732310370213

World Health Organization (1997). *Jakarta Declaration on leading health promotion into the 21st century*. Retrieved from http://www.who.int/hpr/NPH/docs/jakarta_declaration _en.pdf.

World Health Organization (1986). Ottawa Charter for Health Promotion. Retrieved from http://www.who.int/hpr/NPH/docs/ottawa_charter_hp.pdf

Wullink, M., Widdershoven, G., van Schrojenstien Lantman-de Valk, H., Metsemakers, J., & Dinant, G. J. (2009). Autonomy in relation to health among people with intellectual disability: A literature review. *Journal of Intellectual Disability Research, 53*(9), 816-826.

Yarcheski, A., Mahon, N. E., Yarcheski, T. J., & Cannella, B. L. (2004). A meta-analysis of predictors of positive health practices. *Journal of Nursing Scholarship, 36*(2), 102-108.

SUMMARY

The health disparities and inequities experienced by people with intellectual disabilities are well documented and have recently become a national priority (US Department of Health and Human Services, 2009). The initial step in addressing these issues is to define the cause. If done correctly and thoroughly, the information gathered in this step can lead professionals to focus efforts on the most salient areas and develop effective solutions. Baker, Metzler, and Galea (2005) suggest by including priority populations in all aspects of problem identification and planning, practitioners can make informed decisions and avoid many of the difficulties experienced when developing programs and evaluation tools. The inclusion of adults with intellectual disabilities in health promotion planning and evaluation requires deliberate collaborations that include efforts to develop accessible instruments and the use of innovative, inclusive methods that will assist in defining health concerns and, in turn, appropriate solutions.

More and more often, health is being referred to as a multifaceted concept that is impacted by the interconnected relationships of many factors. It would stand to reason that the interventions targeting this holistic concept must also be holistic in their approach. Health-related literature includes many proposals to address health issues both from a microlevel (individual health changes) and a macrolevel (social determinants) (Harrison, 2006). Krahn, Hammond, and Turner (2006) strongly suggest that the only way the health needs of people with ID can be met and sustained is through system-wide

changes, addressing the barriers to health at multiple levels, including those with ID, their caregivers, the community, and through policies that impact services and inclusion. By addressing health-related concerns through the use of a broad process, victim blaming is minimized (McLeroy, Bibeau, Steckler, & Glanz, 1988). Acknowledging that health is influenced by many aspects of a person's context relieves one segment from bearing the responsibility for negative health outcomes.

To fully address the health needs of people with intellectual disabilities, health promotion practice guidelines should expand beyond fitness and nutrition, address barriers on multiple levels, and integrate social factors. The Ottawa Charter on Health Promotion (OCHP) and the World Health Organization's (WHO) holistic definition of health promotion stress the importance of addressing health and issues of social justice through health promotion at multiple levels of influence (WHO, 1986). Krahn et al. (2006) compiled a list of future health promotion actions recommended in the OCHP as well as those of several international governments and organizations. These areas include developing life skills to meet daily needs, enhancing control by encouraging opportunities to making choices about health and meaningful daily activity, realizing potential by utilizing talents, inclusion in the community through positive social networks, and the development of supportive environments through empowering paid and unpaid caregivers.

Currently, there are only a handful of programs tailored to address the health needs of people with ID and the curricula content are largely focused on fitness and nutrition. In a literature review of these interventions, Heller, McCubbin, Drum, and Peterson (2011) found that none of the studies involving these programs reported durable outcomes and many of them experienced challenges similar to those identified by the participants in this study: limited knowledge, decreased motivation, issues with accessibility and transportation, and restrictions secondary to practices at partnering agencies.

Several of the suggestions and experiences recorded in the literature, in relation to people with ID, support the results of this study. As the final stage of this document, I will recap my views on including people with ID in research, make suggestions for health promotion intervention content, and comment on the relevance to future practice.

Research Collaboration

The experiences and beliefs of this group must be incorporated from the beginning stages in order for health promotion programs to successfully meet the needs of people with intellectual disabilities (Kielhofner, 2009; Rimmer & Rowland, 2008). Abma, Nierse, and Widdershoven (2009) suggest the only way the values of all stakeholders can be represented in a program is by starting the process with the group that has the least amount of influence, yet people with ID have historically been excluded from direct participation in most health research and intervention development (Kielhofner, 2009; Rimmer & Rowland, 2008; Wilcock, 2006). This alarming omission contributes to health inequities and is often based on assumptions about the population, including limited skills in expressing opinions, attitudes, and/or needs regarding health (Catalani & Minkler, 2009), an inability to properly analyze life situations (Bogdan & Taylor, 1976; Goodley, 1996), and inadequate learning abilities needed to carry through with health promotion strategies (Catalani & Minkler).

Contrary to the above beliefs, people with ID have been recognized in recent relevant literature for their abilities to reliably express opinions, values, and experiences about their lives (Lefort & Fraser, 2002). In fact, some authors have begun to acknowledge this population as authorities on their own lives (Stalker, 1998) and encourage researchers to analyze the life stories of this group (similar to this study) in order to identify concerns as well as solutions to common health-related issues (Keith, 2001).

I went into this study feeling I had an open mind and had confidence in the abilities of the study population. I was one of those researchers who believed adults with ID could offer meaningful contributions to a research study. As mentioned in the first manuscript of this document, I have a strong opinion on researchers making assumptions about their study population and I make the argument that every effort should be made to avoid marginalization of these vulnerable groups. With this in mind, I felt as though I had to share an experience that demonstrates how easily assumptions can happen. I am almost ashamed to say, but do so in an effort to illustrate the point (and clear my conscience), that at the start of this study, my interactions were influenced by an assumption of abilities. While interviewing the first few participants about their photographs, I assumed the concept of "healthy" might be difficult for some of the participants to fully comprehend, so I changed the question to ask, "Is this something that is good for you?" I quickly realized that when this question was asked in regards to a picture of food the participant interpreted the question to mean, "Is this something that tastes good." The answer was usually "yes" but when I switched the question back to ask "Is this something that is healthy?" the participants could offer answers that were specific to health concerns. In an effort to simplify terminology, based on an assumption, I almost compromised the results of my study.

Although not without its challenges and near misses, the benefits of directly including this population in the development stage of health promotion research were clearly illustrated in this study. By utilizing a community-based participatory research approach, a collaboration was formed between the researcher and the adults with ID which encouraged equity, respect, and the co-creation of knowledge (Guajardo & Guajardo, 2002). The results of this study contribute to the area of health promotion by adding to the existing literature that documents the importance of targeting specific health needs in people with intellectual disabilities and by offering practical information that can be incorporated into planning and intervention development to address the health needs of adults with intellectual disabilities. Insights were gathered directly from 25 adults with intellectual disabilities through the use of a flexible method that accommodated the participants' skills and empowered them to be advocates for their own health. The perspectives of these adults illustrate their understanding of health along with their descriptions of facilitators and barriers to health, including participation, inclusion, and accessibility. They were able to demonstrate a detailed awareness of healthy lifestyle behaviors as well as negative influences on health. The multiple facets of health were represented and individuals stressed the importance of emotional, social, and spiritual aspects to well-being.

A multilevel approach was promoted by identifying areas of concern related to individual skills, community inclusion, institutional procedures, and political influences. The viewpoints and experiences of the participants in this study offer unique perspectives for practitioners to consider when setting goals for the promotion of health. This information directs us to develop meaningful health promotion curricula that include opportunities for choice, contextual factors, and the population's strengths, preferences, and needs.

Intervention Recommendations

As a part of this summary, I would like to propose a blueprint for the development of holistic health promotion interventions that impact multiple levels of influence and keep the health of people with ID as the main focus. This plan was developed after contemplating the results of my study, my experience facilitating this study, my clinical years as an occupational therapist, and the literature on health, disabilities, and self determination. In an effort to organize my final thoughts, I produced a diagram depicting an idea of how all of this information is related and how it can be used to influence the health of people with ID (Figure 2). The gradient color and layered circles represent the notion that these concepts are related and influenced by each other, but that some of them need to be initiated prior to success in other areas. This figure will guide the following discussion on how health promotion professionals might develop interventions to address health in this population.

The concept of self determination has been discussed and debated in the literature on disabilities for many years. This construct is based on the idea that people with ID learn to become the primary causal agent in their lives by taking action to alter obstacles, utilizing skills, making decisions based on preferences, and growing through the experiences and results of those decisions (Agran, Storey, & Krupp, 2010; Palmer, 2010; Wehmeyer, Palmer, Agran, Mithaug, & Martin, 2001). This model should be the basis of health promotion intervention for people with ID and will be interwoven into the layers of my recommendations.

Strengths and Potential

The first ring of the diagram represents a basic component of self determination, identifying strengths and abilities in order to set goals and acknowledge potential. Participants of this study noted health was influenced by whether they had something to do or not. Boredom was noted as a barrier to health, while being engaged in a task that matched capabilities was seen as a facilitator. All of the participants expressed an interest in working, were proud of the skills they had to offer, and had a desire to contribute to relationships with others. Being able to participate in meaningful activities that provide the appropriate amount of challenge was sought by the participants. Rew, Hoke, Horner, and Walker (2009) identify a strengths-based approach as a key element to addressing health disparities and propose that this method strengthens overall outcomes of research and intervention. Because this group has experienced negative attitudes, discrimination, and stigmatization throughout history (Fisher, 2004; Iezonni, 2011; Kielhofner, 2009; Marks, Sisirak, & Heller, 2010), basing an intervention on the idea that all participants have something to offer, aspire to goals, and have potential seems like the place to start when conceptualizing an intervention and an integral part of any work done with people with intellectual disabilities. This step not only helps the caregivers and service providers identify strengths, it also assists the person with ID to self-evaluate abilities, a foundation of self determination (Suarez, 2010). The action needed in this phase includes the evaluation of abilities and client-centered goal development for each participant involved.

Inclusion and Positive Attitudes

By promoting a genuine belief in the potential of people with ID and gearing interventions towards the group's assets and preferences, health promotion professions offer reverence for the population and role model supportive, positives attitudes that can influence other service providers, caregivers, and the community. During my observations of the participants, there were examples of providers who fostered inclusion and acknowledged potential in the persons with whom they were working, but there were also staff that placed limits on the participants. Changing this mind-set is the second part of my proposed intervention plan, which encourages inclusion and supportive environments for the context of the intervention. This step is dependent on positive attitudes and supported by Commissioner Sharon Lewis from the Administration on Developmental Disabilities (USDHHS) who states, "Integration and inclusion without respect become merely symbolic" (para. 1). Her posting, entitled *From Awareness to Respect,* supports the need for society to move beyond increasing awareness and argues that it is time to progress to actions that make a difference in the lives of this population (Lewis, 2012).

Skill Development

One of the main conclusions from this study was that the participants' abilities to incorporate health knowledge was limited by decreased independence in life skills. Several of the participants lacked skills in meal preparation, menu planning, and grocery shopping. Health was also impacted by the fact that the participants had little experience planning leisure pursuits, obtaining employment, or independently developing social networks. These tasks were often done by or in collaboration with caregivers, so the ability to participate in these basic daily skills was not possible without the support of a caregiver. A reduction in disability-related activity and participation limitations can be achieved by enhancing the functional abilities of the person (WHO, 2003), which leads to the next step in my intervention plan: skill development.

Learning healthy lifestyles in a didactic format is of little use if the participant is never given the chance to use the skills or knowledge gained. Including skill development in interventions with opportunities to practice the skills in simulated or naturally occurring activities offers the best chance of those skills generalizing to the person's life (Bates, Cuvo, Miner, & Korabek, 2001). In order for health promotion to be effective with this population, the interventions must include interactive components that promote the development of personal skills specific to healthy lifestyle behaviors and choices.

Opportunities and Choice

Choice influences all areas of life by contributing to control and is a main component of self determination (Agran, Storey, & Krupp, 2010). A lack thereof reduces the control one has on aspects of life by increasing dependence on others. Choice for people with ID is often limited, sometimes explicitly and other times implicitly. An example of an explicit limitation during this study was when participation in meaningful daily activities was determined by the plan at the day program. These decisions were made by staff based on the supplies available, the skills of the other participants involved, and/or the talents of the supervising staff member. Because many of the participants spend their days in a collective, with the other members of the day program or their living situation, one task is often planned for all (Temple & Walkley, 2007). The choice becomes, you can do the activity planned or you can do nothing: not much of a choice.

Declining the planned activity led to sedentary tasks, boredom, and at times, maladaptive behavior. This outcome is also influenced by an implicit limitation of choices; because the participant did not possess the skills to initiate a different activity, there were no options available. Without independent life skills, choice is limited to what is available or what is offered rather than what is possible. Another example of implicit limitations involved food selection. Many of the participants in this study commented that their meal choices were influenced by their inadequate cooking skills and/or what was within walking distance secondary to restricted transportation options.

Although many of the participants understood their rights to make choices and the impact choices have on your health, they also voiced a concern that options were limited and dependent on other influences. It is projected that an improvement in life skills in the previous step will increase opportunities and choices for the participants. Knowing how to plan an activity or cook a meal not only increases independence but also opens up possibilities.

Causal Agents

The literature on self determination strongly supports people with disabilities becoming a causal agent in their lives. This refers to the person being the primary actor in initiating changes in life that promote success towards self-selected goals (Wehmeyer et al., 2001) and is achieved through skill training in self-advocacy, decision making, assertive communication, and acquisition of knowledge (Wullink, Widdershoven, van Schrojenstein Lantman-de Valk, Metsemakers, & Dinant, 2009). Self-determination has been recognized as a practical intervention for promoting the health of people with ID (Krahn et al., 2006). Palmer (2010) suggests incorporating self-determination into interventions can assist people with ID in achieving outcomes that enhance capabilities and increase opportunities. By teaching asset appraisal through self-evaluation, encouraging inclusion, and by providing training in decision-making and life skills, service providers can facilitate people with ID to become causal agents in promoting their own health.

Meaning and Purpose

Whitehead and Irvine (2011) support the expansion of health promotion by encouraging health professionals to include it in the intervention repertoire of their profession. Health promotion is listed as an intervention approach in the Occupational Therapy Practice Framework and defines the focus of intervention as performance skills, performance patterns, context, activity demands, and client factors (American Occupational Therapy Association, 2008). Hammell (2004) supported the use of an occupational perspective to address health by linking it to quality of life, which she described as occupation, self-worth, purpose, meaning, choice and control. This brings us to the heart of an occupational perspective of health and the final layer to achieving health in the intervention diagram, finding meaning and purpose in what we do in our everyday lives. By addressing the aforementioned areas of the intervention plan, people with ID can have opportunities, act as a causal agent, and make choices based on preferences, values, and abilities. This will lead to meaningful and purposeful participation and ultimately, a state of well-being and health.

Conclusion

In her presidential address, Gomez (2012), the President of the American Association on Intellectual and Developmental Disabilities, focuses on the need to create and support inclusion in all communities. While explaining her vision of what inclusive communities would look like and how we might achieve them, Gomez uses many of the same words discussed in this manuscript: growth, contributions, opportunities, meaningful, strengths, and belonging. Her pathway to achieving this goal includes 11 steps, 6 of which are supported by the results of this study. They include (a) a focus on abilities versus deficits, (b) training and support for caregiver professionals, (c) opportunities for expanded social networks, (d) encouraging contributions to others, (e) meaningful, productive activity based on interests and capacities, and (f) promotion of public policy changes that support integration.

Additional studies exploring the effectiveness of holistic interventions would benefit the profession and this population. Research indicates that education alone does not produce health behavior change (Nieuwenhuijsen, Zemper, Miner, & Epstein, 2006). A curriculum that includes life skills training, self-determination, social skills, and advocacy training is recommended. In addition, a qualitative study exploring the opinions and experiences of direct support caregivers would offer insight into effective changes at an institutional level. Efforts to increase community and stakeholder awareness should be tracked and measured to determine outcomes. Awareness campaigns should not only include knowledge of the health inequities and social determinants experienced by this population, but should also emphasize the contributions, potential, and capabilities of this group.

Although further research is needed in the areas of measurement development, intervention efficacy, and policy change, I would also like to make a call for action (Jackson, 2011). Many of the areas identified by the participants in this study have been supported by research literature for decades (as can be seen by my references), yet little change has been seen. Services for people with ID have advanced with the implementation of policies like the Olmstead Act, the Individuals with Disabilities Education Act, and the American Disabilities Act, among others, but these changes need to come with the proper support in order to successfully support the needs of people with ID (Freidman, Helm, & Marrone, 1999; Jackson, 2011). I propose the action that must be taken involves meaningful services and interventions that utilize a strengths-based approach and are developed through collaborations with adults with ID.

Conducting health promotion programs for people with ID is an emerging avenue for health promotion professionals. In order for the health needs of this population to be properly addressed, innovative techniques and topics must be included. Health for this population goes beyond healthy eating, daily activity, and weight management. Social issues must be addressed along with active participation, skill training, and opportunities for practice. Using a multidimensional approach that focuses on empowerment, social determinants, and environmental adaptation will allow people with intellectual disabilities to live healthy and happy.

References

Abma, T. A., Nierse, C. J., & Widdershoven, G. (2009). Patients as partners in responsive research: Methodological notions for collaborations in mixed research teams. *Qualitative Health Research, 19*(3), 401-415. doi: 10/1177/1049732309331869

Agran, M., Storey, K., & Krupp, M. (2010). Choosing and choice making are not the same: Asking "what do you want for lunch?" is not self determination. *Journal of Vocational Rehabilitation, 33*, 77-88.

American Occupational Therapy Association (2008). *Occupational therapy practice framework: Domain and practice*. Bethesda, MD: AOTA Press.

Baker, E. A., Metzler, M. M., & Galea, S. (2005). Addressing social determinants of health inequities: Learning from doing. *American Journal of Public Health, 95*, 553-555.

Bates, P. E., Cuvo, T., Miner, C. A., & Korabek, C. A. (2001). Simulated and community-based instruction involving people with mild and moderate mental retardation. *Research in Developmental Disabilities, 22*, 95-115.

Bogdan, R., & Taylor, S. (1976). The judged, not the judges: An insider's view of mental retardation. *American Psychologist, January*, 47-52.

Catalani, C., & Minkler, M. (2009). Photovoice: A review of the literature in health and public health. *Health Education & Behavior, 37*, 424-451. doi: 10.1177/1090198109342084

Fisher, K. (2004). Health disparities and mental retardation. *Journal of Nursing Scholarship, 36*(1), 48-53.

Friedman, S. L., Helm, D. T., & Marrone, J. (1999). Caring, control and clinicians' influence: Ethical dilemmas in developmental disabilities. *Ethics & Behavior*, *9*(4), 349-364.

Gomez, S. (2012). Presidential address 2012 creating inclusive communities: Pathways to the vision. *Intellectual and Developmental Disabilities, 49*, 360-364.

Goodley, D. (1996). Tales of hidden lives: A critical examination of life history research with people who have learning difficulties. *Disability & Society, 11*, 333-348.

Guajardo, M. A., & Guajardo, F. J. (2002). Critical ethnography and community change. In Y. Zou & E. T. Trueba (Eds.), *Ethnography and schools: Qualitative approaches to the study of education* (pp. 281-304). Lanham, MD: Rowman & Littlefield.

Hammell, K. W. (2004). Dimensions of meaning in the occupations of daily life. *Canadian Journal of Occupational Therapy, 71*(5), 296-305.

Harrison, T. (2006). Health promotion for persons with disabilities: What does the literature reveal? *Family and Community Health, 29* (1S), 12S-19S.

Heller, T., McCubbin, J. A., Drum, C., & Peterson, J. (2011). Physical activity and nutrition health promotion interventions: What is working for people with intellectual disabilities? *Intellectual and Developmental Disabilities*, 49(1), 26-36.

Iezonni, L. (2011). Eliminating health and health care disparities among the growing population of people with disabilities. *Health Affairs*, 30, 1947-1954.

Jackson, R. (2011). Challenges of residential and community care: 'The times they are a-changing.' *Journal of Intellectual Disability Research*, *55*(9), 933-944.

Keith, K. D. (2001). International quality of life: Current conceptual, measurement, and implementation issues. *International Review of Research in Mental Retardation*, *24*, 49-74.

Kielhofner, G. (2009). *Conceptual foundations of occupational therapy practice* (4th ed.). Philadelphia, PA: F. A. Davis.

Krahn, G. L., Hammond, L., & Turner, A. (2006). A cascade of disparities: Health and health care access for people with intellectual disabilities. *Mental Retardation and Developmental Disabilities*, *12*, 70-82.

Lefort, S., & Fraser, M. (2002). Quality of life measurement and its use in the field of learning disabilities. *Journal of Intellectual Disabilities*, *6*(3), 223-238.

Lewis, S. (2012, March 26). From awareness to respect [Web log post]. Retrieved from http:// usodep.blogs.govdelivery.com/2012/03/26/from-awareness-to-respect/

Marks, B., Sisirak, J., & Heller, T. (2010). *Health matters: The exercise, nutrition, and health education curriculum for people with developmental disabilities.* Baltimore, MD: Paul H. Brookes.

McLeroy, K. R., Bibeau, D., Steckler, A., & Glanz, K. (1988). An ecological perspective on health promotion programs. *Health Education & Behavior, 15*(4), 351-377.

Nieuwenhuijsen, E. R., Zemper, E., Miner, K., & Epstein, M. (2006). Health behavior change models and theories: Contribution to rehabilitation. *Disability and Rehabilitation, 28*, 245-256.

Palmer, S. B. (2010). Self-determination: A life-span perspective. *Focus on Exceptional Children*, *42*(6), 1-16.

Rew, L., Hoke, M. M., Horner, S. D., & Walker, L. (2009). Development of a dynamic model to guide health disparities research. *Nursing Outlook*, *57*(3), 132-142.

Rimmer, J., & Rowland, J. L. (2008). Health promotion for people with disabilities: Implications for empowering the person and promoting disability-friendly environments. *American Journal of Lifestyle Medicine, 2*, 409-420. doi:10.1177/1559827608317397

Stalker, K. (1998). Some ethical and methodological issues in research with people with learning disabilities. *Disability and Society*, *13*(1), 5-19.

Suarez, S. C. (2010). Show me again what I can do: Documentation and self-determination for students with social challenges. *Theory into Practice*, *49*, 21-28.

Temple, V.A., & Walkley, J. W. (2007). Perspectives of constraining and enabling factors for health-promoting physical activity by adults with intellectual disability. *Journal of Intellectual & Developmental Disability*, *32*(1), 28-38.

U.S. Department of Health and Human Services, Office of Disease Prevention and Health Promotion. (2009). *Healthy people 2020.* Retrieved from http://www.healthypeople.gov /About/goals.htm.

Wehmeyer, M. L., Palmer, S. B., Agran, M., Mithaug, D. E., & Martin, J. E. (2001). Promoting causal agency: The self-determination learning model of instruction. *Exceptional Children*, *66*(4), 439-453.

Whitehead, D., & Irvine, F. (2011). Ottawa 25+ — 'All aboard the dazzling bandwagon'— developing personal skills: What remains for the future? Health Promotion International, *26*(S2), ii245-ii252.

Wilcock, A. A. (2006). *An occupational perspective of health.* Thorofare, NJ: Slack, Inc.

World Health Organization (1986). Ottawa Charter for Health Promotion. Retrieved from http://www.who.int/hpr/NPH/docs/ottawa_charter_hp.pdf

World Health Organization (2003). Social determinants of health: The solid facts. Retrieved from http://www.euro.who.int/__data/assets/pdf_file/0005/98438/e81384.pdf

Wullink, M., Widdershoven, G., van Schrojenstien Lantman-de Valk, H., Metsemakers, J., & Dinant, G. J. (2009). Autonomy in relation to health among people with intellectual disability: A literature review. *Journal of Intellectual Disability Research, 53*(9), 816-826.

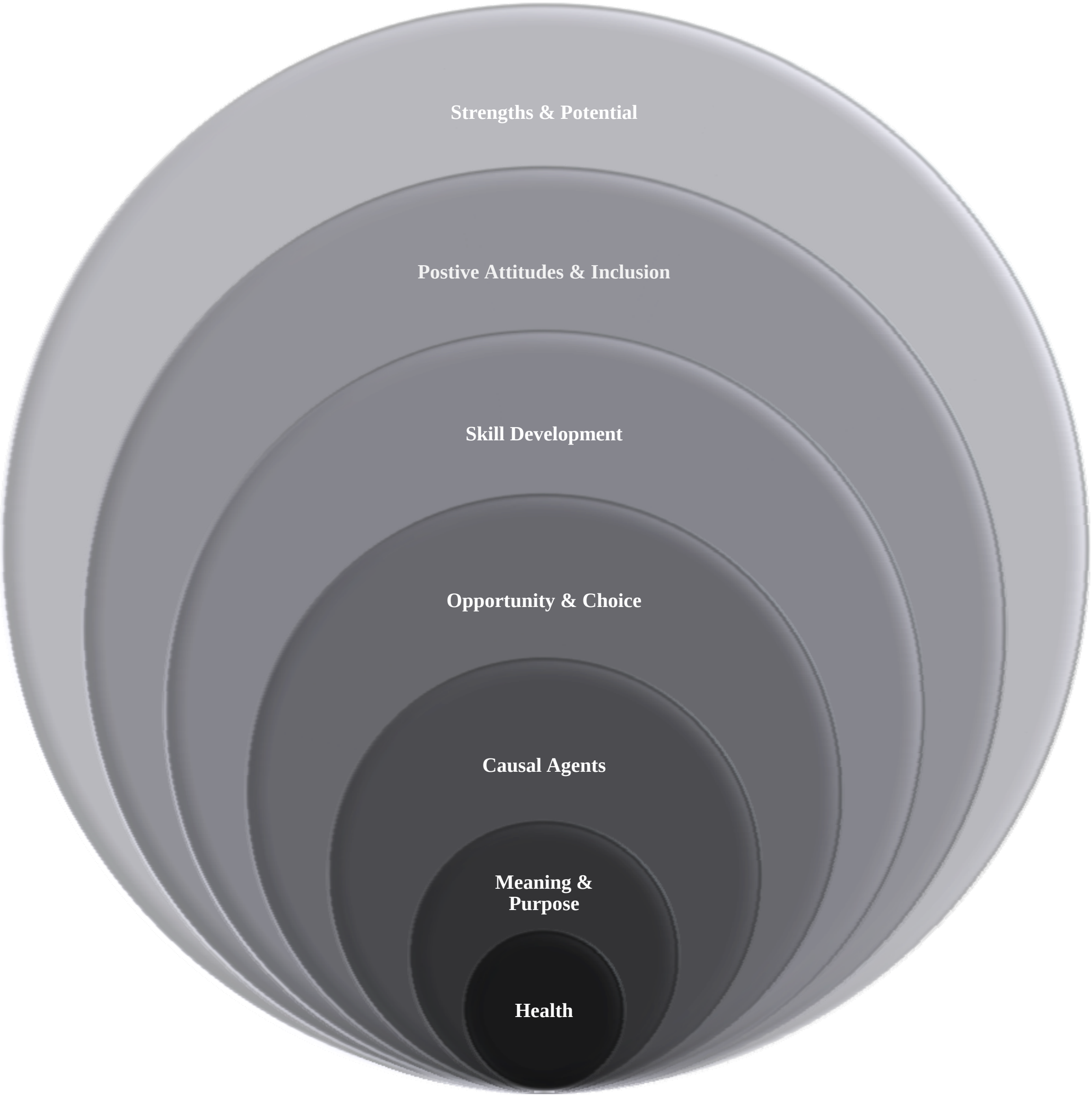


Figure 2. Health Promotion Intervention Recommendations