Sustaining Community Health Initiatives for People Aging with Intellectual/Developmental

Disabilities

BY

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DISSERTATION

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To my parents, Alessandro and Angelina.
For your unconditional support and love during this journey that started decades ago

…we finally made it.

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CBPR   Community based participatory research

I/DD   Intellectual and developmental disabilities

PARIHS   Promoting Action on Research Implementation in Health Services

KT   Knowledge translation

CBHPI   Community-based health and participation initiatives

NGT   Nominal group technique

NIDRR   National institute on disability and rehabilitation research

SUMMARY

People with intellectual/developmental disabilities (I/DD) are more likely to experience the aging process earlier and at a more rapid rate than individuals without I/DD. Therefore, it is imperative that I/DD agencies are able to support people aging with I/DD so that they may continue to age in their homes and be active members of their community. Community-based health and participation initiatives (CBHPI) play an important role in maintaining the health, functioning, and participation of people with I/DD living in the community. However, implementation and long-term sustainability of CBHPI is often challenging, specifically among I/DD agencies. For this reason, the current dissertation explored the facilitators and barriers associated with CBHPI designed for people aging with I/DD who are living in group homes managed by I/DD agencies. The study utilized participatory action methods and methodologies (i.e., interviews, photovoice, and observations) to meaningfully engage 70 participants—35 individuals with I/DD and 35 management/direct support staff. These multi-methods served to provide a multi-level system analysis of the factors related to the sustainability of CBHPI. From these data, six main themes emerged: agency values and policies; resources and staff competencies; communication between management and staff; community/university partnerships; peer relations; and aging with I/DD. Overall, results not only identified a number of factors that can help or hinder CBHPI, but these findings also support the notion and practice of active inclusion of people with I/DD in the design, development, and dissemination of health and participation research-related initiatives. This approach would result in the generation of evidence that more accurately represents the needs and wants of people aging with I/DD in the community and would, in turn, increase the effectiveness and sustainability of such initiatives.

I. INTRODUCTION

A.   **<u>Aging with I/DD and Health</u>**

People with intellectual/developmental disabilities (I/DD) are at a significantly higher

risk of developing chronic health conditions compared to the general population (Ouellette-

Kuntz, 2005; Taggart & Cousins, 2014), due to genetics, social circumstances, environmental

conditions, and access to health care services (Bittles et al., 2002; Krahn, Hammond, & Turner,

2006). Furthermore, people with I/DD are more likely to experience age related health conditions

at an earlier age and at a faster rate compared to people without I/DD (Connolly, 1998; Evenhuis,

Hermans, Hilgenkamp, Bastiannse, & Echteld, 2012; Glasson, Dye, & Bittles, 2014; Nochajski,

2000; World Health Organization, 2001). Adults with I/DD have a higher prevalence of

cardiovascular disease, hypertension, overweight, obesity, osteoporosis, constipation, and poor

oral health (Haveman et al., 2010). There is a lack of research on how the increased risk and

range of age-related health conditions affects the ability of people with I/DD to participate in

their community as they age (Heller, Fisher, & Marks, 2014). Fortunately, research over the past

two decades has begun to show that the life expectancy of people with I/DD is increasing in a

similar pattern as the general public (Haveman et al., 2010), due to improvements in neonatal

care, nutrition, and socioeconomic conditions (Cooper, Melville, & Morrison, 2004), as well as

research advancements that have developed community-based programs/curriculums that have

specifically targeted improving the health and participation of people with I/DD living in the

community (Heller, Hsieh, Badetti, & Parker, 2012; Lunsky, Straiko, & Armstrong, 2003;

Marks, Sisirak, Heller, & Wagner, 2010). However, sustaining these evidence-based

programs/curricula has been a challenge in community settings (Heller et al., 2014; Mancini &

Marek, 2004; Sharir & Lerner, 2006). For this reason, the purpose of this study was to examine

both the facilitators and barriers associated with sustaining community-based health and participation initiatives (CBHPI) designed for people aging with I/DD living in group homes as managed by I/DD agencies. For the purposes of this study, CBHPI was defined as strategies, guidelines, action plans, programs, or curricula that have been implemented by I/DD organizations to improve health and community participation for people with I/DD who are living in the community.

B.   **Aging with I/DD and Community Living**

The Independent Living Movement, which advocates that people with I/DD live in a community as active and contributing societal members, has been hugely influential in improving the quality of life of people with I/DD. However, there is an unyielding concern to examine the unmet health care needs of people with I/DD who have transitioned from an institutional setting to community-based living. People with I/DD need to have access to health care services and professionals who possess the knowledge, ability, and willingness to effectively interact and engage with them, thus ensuring that people with I/DD receive the proper care to prevent manageable health concerns from developing into potentially life-threatening conditions (Krahn, Hammond, & Turner, 2006). Individuals with mild I/DD who do not receive support services are less likely to utilize in health services or engage in health promotion activities. Specifically, people with I/DD who do not receive support services are significantly more likely to smoke and less likely to visit the dentist, have their hearing or vision tested, feel confident, or experience a lack of social participation and community integration when compared to individuals with I/DD who do receive support services (Emerson, 2011). Community integrated living for people with I/DD is strongly supported; however, there continues to be a gap within the literature about how health services, support and resources are able to adequately

and effectively attend to the needs of people with I/DD living within the community (Krahn et al., 2006). Common access barriers to health services experienced by people with I/DD include: programmatic barriers, attitudinal barriers, physical barriers, communication barriers (Marks, & Heller, 2003), poverty, and social exclusion (Ouellette-Kuntz, 2005).

Robertson and colleagues (2000) reported that adults with I/DD who have transitioned into a less restrictive living environment are not used to the reduced supervision and thus tend to choose to eat high fat foods and less often engage in physical activity (Yamaki, 2005). Adults with I/DD who have transitioned to less restrictive environments may not be well educated on the importance of adopting healthy lifestyle behaviors nor have well developed decision making skills to bring about health conscious decisions without external influences. Having an overall understanding of the body may help individuals with I/DD better understand the importance of adopting a healthy lifestyle through self-regulatory behaviors (Jobling, 2001). In order for individuals with I/DD to self-regulate their own health behaviors, they first require an understanding of health issues. This can be achieved through proper educational programs that provide adaptive strategies to help people with I/DD apply their knowledge to their independent lifestyle. For example, health education programs which discuss disease prevention strategies should incorporate an accessible way of educating individuals with I/DD about how the body functions and how they can apply these new strategies in their everyday life to improve their health. Health education programs can facilitate and support the necessary skills needed to help adults with I/DD become more knowledgeable about their health and may lead to improvements in their quality of life. For this reason, increased importance should be given to health education programs within community-based settings that focus on physical activity, general health knowledge, and social support for health (Jobling, 2001). There have been many effective

evidence-based CBHPI that focused on improving the health and community participation of people with I/DD living in the community (Heller et al., 2012; Lunsky et al., 2003; Marks et al., 2010), however, very few CBHPI have been successfully implemented and sustained in community settings (Heller et al., 2014; Mancini & Marek, 2004; Sharir & Lerner, 2006).

I/DD community-based agencies are a primary source of support for people with I/DD as they provide direct services and resources to people with I/DD to ensure they are able to continue living in the community. However, I/DD agencies typically struggle to implement CBHPI as they lack the structure and resources necessary to sustain such initiatives. Thus it is imperative that we understand the factors involved in sustaining CBHPI for people with I/DD as managed by I/DD community-based agencies so that they are better equipped to support engagement in positive health behaviors and community participate among people with I/DD.

C.   **CBHPI Sustainability**

Community-based health programs have been developed and have shown to be effective at improving the health and quality of life for people with I/DD (Heller et al., 2012; Lunsky et al., 2003; Marks et al., 2010); however, sustainability of these programs continues to be a common barrier. The general health promotion literature suggests that program sustainability is dependent on organizational capacity (Cassidy & Leviton, 2006); however, there is no standardized set of guidelines or methods to evaluate the likelihood that a program will be sustained (Pluye, Potvin, & Denis, 2004). Common factors that have been reported to affect the successful implementation of health promotion programs for people with I/DD are: theoretical basis, stakeholder commitment, educational focus, supportive environment, evaluation process, time commitments required of staff and directors to execute the program, scheduling conflicts, cost, and transportation (Marks et al., 2010). The main barriers to sustaining CBHPI are that they

do not include people with I/DD and they are accessible for this population (Marks & Heller, 2003). Researchers must tailor programs to be realistic to the resources available to people with I/DD to ensure long term sustaining of the program). For example, when researchers are developing a program they should not assume that people with I/DD living in the community have regular access to fitness equipment (Messent, Cooke, & Reader, 1998). Evidence-based knowledge generated by research must be accessible or meaningful to the targeted population it seeks to assist. Knowledge translation (KT) aims to ensure that evidence-based knowledge is effectively applied and utilized by the targeted population (Armstrong, Waters, Roberts, Oliver, & Popay, 2006; Kitson, 2009). KT is a complex bidirectional process that involves the direct input of community members to ensure that research findings are meaningful and accessible to the end users; therefore, increasing the likelihood that evidence-based knowledge is implemented and sustained over time (Colquhoun, Letts, Law, MacDermid, & Missiuna, 2010; Kitson, 2009). Although limited research has examined KT and I/DD populations, the National Institute on Disability and Rehabilitation Research (NIDRR) has recognized that health and community participation research need to include KT to ensure that knowledge generated includes people with I/DD so that polices, practices and systems can be developed to accurately meet/reflect their needs (Sherwood, 2009). Despite the recognized need for KT practices to be adopted in CBHPI the research is still lacking.

D.   **Engaging People with I/DD in Research**

Possible explanation for the current lack of understanding of the factors that influence the sustainability of CBHPI for people with I/DD living in the community include: 1) limited research has been conducted in this area; 2) lack of scientific inquiry that has adopted KT practices utilizing a theoretical framework to help guide the research process; and 3) the minimal

research that has been conducted has taken a quantitative approach. People with I/DD have had a passive role in research (Barr, McConkey, & McConaghie, 2003). Individuals with disabilities must be actively involved in the research process. Their involvement should include developing the research problem, research questions, and methods of data collection as well as determining how findings should be analyzed and represented to different public domains (Myers, Ager, Kerr, & Myles, 1998). It is the responsibility of social scientists not to exclude people with I/DD from research because of limited literacy skills, but rather develop innovative and accessible ways to include this population (Aldridge, 2007). Researchers must be willing to extend research methods beyond objective measures and be open to modifying methods so that people with I/DD can actively participate in the research process (Aldridge, 2007). In order for research to become more inclusive and participatory for people with I/DD, within their communities and their social worlds, it is imperative that research methods become more subjective. Subjective methods allow for a better understanding of the experiences of people with I/DD and this will help facilitate person-centered planning and change to best fit the needs of the individual (Cott et al., 2005). Diaries, interviews, participant observations, focus groups, storytelling, and photovoice are all subjective techniques that have been used to meaningfully include people with I/DD in research (Milner & Kelly, 2009; Myers et al., 1998). Generating knowledge that is directly influenced by people with I/DD ensures that knowledge being disseminated is reflective of the opinions and needs of people with I/DD. With this knowledge, community members can be better equipped to provide resources and supports to people with I/DD that accurately reflect their needs (Aldridge, 2007).

E.   **<u>Dissertation Overview</u>**

Longmore (2003) discusses how disability studies are meant to connect the disability community and academia. A disability studies approach to academic inquiry examines disability as a social phenomenon, rather than examining disability as a construct that requires prevention, treatment, or a cure. By disability studies acting as a vehicle to bridge the gap between the disability community and academia a disability rights perspective, insight, and the expertise of people with the disability can better inform research inquiry, thereby producing knowledge that is reflective of, and meaningful to people with disabilities (Longmore, 2003). Furthermore, Longmore (2003) suggests that ideas between researchers and people with disabilities should be bidirectional and that both parties should be actively involved in knowledge production. The current dissertation takes a disability studies approach to examining health and community participation for people with I/DD as it directly involved them in the research process and they were directly in control of what data was collected to represent their thoughts.

Past research that has focused on improving the health of people with I/DD has typically instructed people with I/DD on what they need to do to improve their health. However, this dissertation contributed to the disability studies field as it generated evidence-based knowledge about health and community participation that was directly guided/shaped by the perspective of people with I/DD as demonstrated by the three manuscripts written. Furthermore, this dissertation demonstrated how people with I/DD can be meaningfully involved when examining system level factors about health and community participation. Researchers show how people with I/DD are being represented to society. Thus they have a powerful responsibility to ensure that their work does not support and encourage the stigmatization and the m marginalization of people with I/DD but accurately represents them.

Aging adults with I/DD have the right to engage in CBHPI; however, they are rarely provided with the opportunity to do so because accessible CBHPI are not generally available. Although current research initiatives have shown improvements in health and participation for people with I/DD, community-based agencies have not been as successful at sustaining long-term implementation of evidence-based CBHPI. For this reason, this doctoral study used a qualitative methods approach to explore the facilitators and barriers to successful sustainability of evidence-based CBHPI. This is the first study to use the Promoting Action on Research Implementation in Health Services (PARIHS) framework to explore the sustainability of evidence-based knowledge for the I/DD population.

Specifically, the current study examined the facilitators and barriers associated with sustaining CBHPI designed for people aging with I/DD living in group homes managed by I/DD agencies. The first manuscript is a critical review paper that explores how I/DD research can adopt KT practices and methodologies, specifically the PARIHS framework to increase the likelihood that CBHPI is sustained by people with I/DD. The second manuscript is a methodological paper that addresses the importance of accessible research methods to meaningful inclusion of people with I/DD in knowledge development. The paper provides a case study example that utilized participatory methods to include people aging with I/DD in generating knowledge about the facilitators and barriers to sustaining CBHPI within group homes managed by community-based I/DD agencies. The third manuscript explores the facilitators and barriers associated with sustaining CBHPI designed for people aging with I/DD living in group homes managed by I/DD agencies.

Although research initiatives have focused on improving the quality of life of aging adults with I/DD through the development of CBHPI, many community-based I/DD agencies

continue to struggle to implement and sustain these initiatives. The current study is an in-depth

exploration of factors that affect the sustainability of CBHPI. The findings will provide

community-based I/DD agencies with a better understanding on how to effectively serve people

aging with I/DD. This study seeks to understand on how people with I/DD and I/DD agencies

(e.g., directors, managers, support staff workers) can work together to develop meaningful action

plans that will facilitate the sustainability of CBHPI at the group home level.

II. EXPLORING HOW KNOWLEDGE TRANSLATION CAN IMPROVE SUSTAINABILITY OF COMMUNITY-BASED HEALTH INITIATIVES FOR PEOPLE WITH INTELLECTUAL/DEVELOPMENTAL DISABILITIES[1]

A.   **Abstract**

Community-based health and participation initiatives (CBHPI) play an important role in maintaining the health, function, and participation of people with intellectual/developmental disabilities (I/DD) living in the community. However, the implementation and long-term sustainability of CBHPI is challenging. The Promoting Action on Research Implementation in Health Services (PARIHS) is a knowledge translation (KT) framework that is particularly relevant to I/DD research as it identifies the barriers and facilitators of implementation and action plans accordingly. This framework provides a foundation for understanding how KT can be used to aid in the implementation and sustainability of CBHPI for people with I/DD. The following paper explores how KT - specifically the PARIHS framework - can be used to help sustain CBHPI for people with I/DD.

Keywords: Knowledge translation, intellectual/developmental disabilities, community health

B.   **Introduction**

The number of people with intellectual and developmental disability (I/DD) transitioning out of institutions and into the community is steadily increasing throughout various countries, such as the United States, Canada, England, Sweden, and Australia (Chowdhury & Benson, 2011). More specifically, from June 1977 to June 2007, in the United States there has been a

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[1] Spassiani, N.A., Parker Harris, S., & Hammel, J. (Under review: JARID-08-2014-OA-0101). Exploring how knowledge translation can improve sustainability of community-based health initiatives for people with intellectual/developmental disabilities. *Journal of Applied Research in Intellectual Disabilities.*

70% decrease in the number of people with I/DD living in institutions. This shift has resulted in an increased number of people with I/DD living in community-based group homes, from 40,000 in 1977 to 437,707 in 2007 (Alba, Prouty, Scott, & Lakin, 2008). Community living has lead to improved quality of life for people with I/DD, and has been associated with positive health outcomes, such as improved physical, psychological, and social health. However, people with I/DD continue to experience health disparities and poorer health outcomes when compared to the general population (Ouellette-Kuntz, 2005). Meaningful community participation for people with I/DD continues to be difficult due to environmental barriers, such as accessibility, lack of resources and social support, attitudinal barriers, and policy/system barriers that do not support participation for people with I/DD (Hammel, Jones, et al., 2008; Marks & Heller, 2003).

Researchers have developed community-based health programs to improve health and community participation for people with I/DD. However, the research field commonly has difficulty effectively translating evidence-based knowledge in an accessible manner for people with I/DD so they can benefit from research findings in the communities in which they live and participate daily. One possible reason is the lack of theoretical frameworks utilized to guide research that involves people with I/DD. The knowledge translation (KT) research paradigm focuses on bridging the gap between knowledge and practice, which can ultimately help improve the quality of life for people with I/DD. The Promoting Action on Research Implementation in Health Services (PARIHS) is a KT framework that focuses on sustainability of evidence-based knowledge and may be particularly useful to address the barriers of knowledge utilization for people with I/DD. Although this framework is under-utilized in I/DD research it has been widely used in research on health services in the general population due to the argument that implementation activities and research be based on theoretical frameworks (Bahtsevani,

Willman, Khalaf, & Östman, 2008; Eccles, Grimshaw, Walker, Johnston, & Pitts, 2005; Helfrich et al., 2010; Stetler et al., 2006). The framework is flexible, can be adapted to various settings, and acknowledges that implementation of research findings is a complex process that is unpredictable (Helfrich et al., 2010). The PARIHS framework may be appropriately suited to explore the KT process within the I/DD community because it aims to identify and address facilitators and barriers towards its implementation. The PARIHS framework provides an in-depth understanding of how to action plan in order to increase the likelihood of successful implementation of community-based health and participation initiatives (CBHPI) for people with I/DD and thus is an appropriately suited framework to guide I/DD research. The following paper will explore how KT - specifically the PARIHS framework - can be used to help sustain CBHPI for people with I/DD.

C. **Community-Based Health Initiatives and I/DD Communities**

The health of people with I/DD has received national and international attention as governments and organizations, such as the Special Olympics, and the World Health Organization advocate for improved health (Krahn et al., 2006) and meaningful community participation (Hammel, Magasi, et al., 2008). People with I/DD have significantly poorer health (Ouellette-Kuntz, 2005) and a shorter life expectancy when compared to the general population due to health disparities such as genetics, social circumstances, environmental conditions, health promotion, and medical care access (Krahn et al., 2006). Common access barriers to health services include; programmatic barriers, attitudinal barriers, physical barriers, and communication barriers (Marks & Heller, 2003). Poverty and social exclusion are also key social determinants of health and contribute to the health disparities of people with I/DD (Ouellette-Kuntz, 2005).

People with I/DD residing in community settings have been reported to be at risk of developing adverse health conditions (i.e., obesity, type 2 diabetes, and hypertension) earlier in life when compared to people without disabilities (Beange, McElduff, & Baker, 1995; Jansen, Krol, Groothoff, & Post, 2004; Ouellette-Kuntz, 2005; Rimmer & Yamaki, 2006; Yamaki, 2005). Research strongly supports community integrated living for people with I/DD; however, there continues to be a large gap within the literature and in practical settings on how health services, support, and resources are able to adequately and effectively attend to the needs of people with I/DD living within the community (Krahn et al., 2006) so that they may be able to meaningfully participate in their communities.

KT is an important avenue to explore for community-based health research for people with I/DD as it may provide an in-depth understanding of how knowledge can be utilized, implemented, and sustained by people with I/DD so that they can experience improvements in their health and level of participation in their communities. Emerging research also shows that people with I/DD who actively participate in their communities experience improvement in their physical and social health. Researchers have developed CBHPI with the aim to improve the quality of health for people with I/DD (Marks, Sisirak, Heller, & Wagner, 2010). Community-based health initiatives[2] have helped to address a variety of health concerns that directly affect people with I/DD. Health initiatives that target oral health, nutrition and diet, drug abuse, sexuality, medication, physical activity, social wellbeing, violence, and abuse have been shown to have the potential to improve the health, quality of life and community participation for people with I/DD (Heller, McCubbin, Drum, & Peterson, 2011; Mann, Zhou, McDermott, & Poston, 2006; Marks & Heller, 2003; Marks et al., 2010).

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[2] Community-based health initiatives will be defined as any strategies, guidelines, action plans, or programs that have been implemented by I/DD organizations to improve health and community participation for people with I/DD who are living in the community.

CBHPI are effective when they build on the strengths of a community and utilize their existing resources, such as community safety, transportation options, the accessibility to community centers, schools, park and hospitals, and motivate community members to organize health groups (World Health Organization, 2014). CBHPI allow for shared experiences of the collective group, which creates an accepting environment that empathizes on how a person's disability might affect their health or level of participation. Furthermore, CBHPI can teach people with I/DD about their health and how to meaningfully participate in their community; this in turn can empower them to advocate for their own health and the health of their peers (Marks & Heller, 2003).

Past research has developed community-based health initiatives, such as train the trainer programs that aim to disseminate a fitness and health education package to Special Olympic coaches so that they may learn to tailor and implement health promotion programs in various settings (Marks et al., 2010). Mann and colleagues (2006) conducted a health promotion program for adults with I/DD and found that increasing knowledge about healthy diet and exercise was a significant predictor to weight loss. Tracy and Hosken (1997) developed a smoking education and preventative health strategies course for people with I/DD and utilized various methods to ensure the education program was accessible to people with I/DD by showing videos, role playing, and board games designed specifically for the program. It is important that CBHPI be adapted to meet the needs of the community they are meant to serve to ensure implementation and sustainability of the initiative. For example, the smoking education course developed by Tracey and Hosken (1997) was originally designed to be a smoking cessation course; however, after meeting the participants, researchers modified the focus of the course to be about smoking education as only a few participants expressed a desire to quit smoking, thus researchers wanted

to make sure the course was relevant to the interest and needs of participants. Although researchers are generating valuable knowledge to improve the quality of life of people with I/DD it is imperative that this knowledge be accessible so that people with I/DD can utilize and implement research findings in their own lives.

D.   **Knowledge Translation (KT)**

One of the most common barriers in research is not knowing how to effectively facilitate the transfer of knowledge from researcher to the public (Colquhoun et al., 2010; Jansson, Benoit, Casey, Phillips, & Burns, 2010). The objective of KT is to translate knowledge into practice (Armstrong et al., 2006), where the primary focus is on how to bridge the gap between what is known by researchers and how evidence-based knowledge[3] can be effectively applied and utilized in real world settings (Kitson, 2009). In the past, KT has been viewed as a linear process, rather than as a multidimensional phenomenon. In this linear model, evidence-based knowledge is generated by experts and then passed on to end-users to be implemented in practical settings. Describing the transfer of knowledge as linear implies that systems (e.g., non-profit I/DD agencies) operate in a technical and predictable fashion, much like a machine (Kitson, 2009). The field now asserts that KT is better described as a complex, multidimensional, and multilayered set of processes that is ongoing, cyclical, and interactive. These processes involve constant interaction between people, cultures, communities, organizations, systems, and researchers to ensure that findings are meaningfully presented, implemented, and sustained in the long-term in real communities (Colquhoun, et al., 2010; Kitson, 2009). Examining the transfer of knowledge as a nonlinear, transactional process acknowledges that users (e.g., clients with I/DD, support staff, families/close support) have valuable 'insider' knowledge about what works, what

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[3] Evidence-based knowledge is defined as information gathered from expert or professional knowledge, the collective environment or the lived experiences of participants (Helfrich, Li, Sharp, & Sales, 2009).

does not, and why. Establishing bidirectional communication channels between researchers and users may result in both parties mutually learning how to effectively apply evidence-based knowledge in practical settings (Campbell, 2010).

The complexity involved with translating new knowledge into practice is due to the various factors and the people involved. Researchers should consider: a) the target audience(s); b) the duration of knowledge transfer; c) the physical environment; d) the relationships between users; e) how users will negotiate implementing new ideas into already pre-existing programs; f) guidelines or curriculum; and g) personal factors such as participant characteristics, needs, and perceived barriers to successful knowledge implementation (Kitson, 2009). For these reasons, KT recognizes that a cultural shift in the research methodology is required in order to bridge the gap between research and practice. This shift involves acceptance of diverse ways of generating knowledge and partnership between researcher and participants. Partnership requires researchers to recognize that their role is to be actively involved in collaborating, negotiating, and communicating knowledge alongside participants (Reimer-Kirkham et al., 2009).

Successful translation of new knowledge into practice should consider: a) participants' (the individual, team, and unit) comprehension and acceptance of the new ideas; b) participants' ability to make informed, autonomous decisions on how they will adopt the new idea; c) users' ability to negotiate and renegotiate the new knowledge within their existing relationships; and d) access to resources needed to implement the new idea (Kitson, 2009). Additionally, knowledge transfer is more likely to occur if key stakeholders are involved and invested in the process, and is willing to assist experts in disseminating knowledge throughout the system (Kitson, 2009).

1.   **<u>KT research and I/DD</u>**

The majority of KT research has taken place within health care systems and clinical settings; however, there is an emerging need to bridge the gap from knowledge to action within community settings for people with disabilities (Rogers & Martin, 2009; Sudsawad, 2007). The National Institute on Disability and Rehabilitation Research (NIDRR) identifies KT as one of their core areas of research and has included KT as a goal in their 2010-2014 long-range plan as a means to "increase the use of research and development knowledge to improve policy, practice, behavior and systems related to disability and rehabilitation" (Sherwood, 2009, slide 17). NIDRR views KT as a process of ensuring that new knowledge gained through research improves the lives of people with disabilities and their participation in society (Rogers & Martin, 2009). Additionally, NIDRR includes participation and community living research, as well as health and function research as part of their five domains of research (Sherwood, 2009). This focus further illustrates the need for KT research to be conducted on CBHPI for people with I/DD; however, despite the recognized urgency for KT within disability research, it remains an understudied area.

Health promotion programs have not typically been accessible to adults with I/DD (Marks & Heller, 2003). For example, it is not practical to assume that people with I/DD will easily have daily access to treadmills, cycle ergometers, or a running track. It is important that researchers tailor their study design to the realistic needs and environments of people with I/DD to ensure long-term sustainability (Messent, Cooke, & Reader, 1998). Although limited KT research has been done with the I/DD community, Marks et al. (2010) suggests a number of factors that typically arise when implementing a health promotion program for people with I/DD. There must be a *commitment from all stakeholders*, including participants, instructors, family

members, caregivers, directors, and staff members of the program. *Verbal reminders* should be sent out to participating members about a month before the start of the program. *Recruitment,* although seen to be an issue, can be improved through pre-existing relationships with participants. Additionally, *time constraints of program staff members*, *scheduling issues*, *cost,* and *transportation* have been shown to create barriers in successful program implementation.

Although there are only a few KT-related research studies available as specifically applied to people with I/DD, there has been a growing number of such studies occurring with community-dwelling older adults, many of whom have chronic conditions affiliated with aging. This research has examined the factors that best predict whether health promotion programming can be sustained and used long-term by older adults in real life community settings. Hughes and colleagues (2011) conducted a web-based survey of 132 experts in the field of physical activity and aging, seeking to identify which areas of research require more attention. The experts' consensus agreed that a greater emphasis is required from conducting, translating, and implementing effective evidence-based programs/guidelines to the actual practice, particularly for understudied populations, such as people with intellectual disabilities (Hughes et al., 2011).

Focusing research efforts on understanding the barriers of adoption and implementation of evidence-based physical activity programs, as well as developing problem-solving strategies with community-based organizations may lead to improvements in the effectiveness of the dissemination of knowledge (DerAnanian, Desai, Smith-Ray, Seymour, & Hughes, 2012). DerAnanian and colleagues (2012) examined the perceived versus the actual factors associated with providers maintaining their engagement in an evidence-based physical activity programs for older adults. Results found common perceived barriers to be resources, cost, space, and availability of certified exercise instructors. Actual barriers were noted to be scheduling/space

constrains and participant recruitment. Perceived facilitators of the program adoption were that

the program was evidence-based and structured; actual facilitators were described as space,

equipment, packaged curriculum, and availability of an exercise instructor. Identifying the

differences between perceived and actual factors associated with implementation of evidence-

based programs, as was done in this study, may provide people with I/DD and key stakeholders

with the knowledge and resources needed to sustain such programs within their communities. As

a result of the aforementioned barriers, research needs to examine factors that impact the

implementation of community-based health initiatives. If this does not occur, people with I/DD

will continue to be excluded from beneficial research. For this reason, research that includes

people with I/DD needs to utilize established KT theories to help understand successful

implementation of research findings. Using KT theories as a framework in health research for

people with I/DD can help ensure long-term implementation of findings, thus improving the

quality of life for people with I/DD. The PARIHS framework is widely used in KT research as it

provides a comprehensive analysis of the factors involved that affect successful implementation

of research findings.

E.   **Promoting Action on Research Implementation in Health Services (PARiHS)**

Framework

Theoretical models/frameworks are important in guiding research as they provide an

understanding of a phenomena and influence the way data is collected and interpreted (Alderson,

1998). It has been suggested that applicability (i.e., can an intervention be implemented in a local

setting?) and transferability (i.e., the likelihood that an intervention will be effective in multiple

settings) should be included in any theoretical framework being used in KT research, as these are

two important factors in determining the success of a KT intervention (Armstrong et al., 2006).

The PARIHS framework, developed in 1998 within the field of nursing, is commonly used to examine predictors that facilitate or hinder research utilization (Helfrich et al., 2010). The framework examines the interplay between three key elements, *evidence*, *context*, and *facilitation*, and the effect of these elements on successful research implementation (Helfrich et al., 2010; Kitson, Harvey, & McCormack, 1998; Rycroft-Malone, 2004). This framework is flexible and applicable to a variety of different settings because it recognizes that implementation is a complex and unpredictable process (Helfrich et al., 2010).

The element of *evidence* is derived from four key components: research; clinical experience/professional knowledge; patient reported experiences; and evidence gathered from the collective environment (Helfrich, Li, Sharp, & Sales, 2009). These can be applied in research by using methods that meaningfully involve people with I/DD so that their knowledge, experiences, and perspectives are incorporated in the development of community-based health initiatives. A common KT methodology that can be used to include people with I/DD within research is using an accessible audit/feedback evaluation as a means to determine the types of facilitation (e.g., methods of learning) that people with I/DD respond to best (Sudsawad, 2007). Other accessible data collection methods such as photovoice, focus groups, or nominal group techniques can help generate knowledge about health that is meaningful to people with I/DD, thus increasing the likelihood that the knowledge generated by the research efforts will be utilized.

The element of *context* involves three components: culture, leadership, and evaluation. Culture is defined as the shared values, beliefs, and attitudes of an organization's members. By learning about disability culture researchers can ensure that the development of CBHPI incorporates and respects the values, beliefs, and attitudes of people with I/DD in their

communities. Leadership is identified as teamwork, decision-making, empowerment issues, and effectiveness of organizational structures. For example, if people with I/DD are included in developing a list of accessible community activities that appeal to their interests they may take ownership of the list and are more likely to participate in the activities. Furthermore, people with I/DD may be empowered to continue to take leadership roles in other life domains. Evaluation refers to how/if a performance is measured and the quality of feedback given to people within the organization (Helfrich et al., 2009).

The element of *facilitation* is described as the manner in which an individual is able to make something easier for other people. This is achieved by supporting changes in a person's attitudes, behaviors, abilities, thoughts, and working habits through critical reflection, empathy, and counseling (Helfrich et al., 2009). For example, by better understanding the way people with I/DD perceive their health and community involvement, research will be better able to identify the need for support that can help with the adoption of community-based health initiatives. Additionally, providing constructive feedback to individuals about their engagement in health initiatives will allow for learning to occur, which may also increase the likelihood of implementation and sustainability. For example, a common barrier for people with I/DD to eating healthy is that they typically enjoy drinking soda during meals. However, if a community-based health initiative program suggested individuals eat a healthy dinner without drinking soda; this may be a point of conflict and deter the individual from engaging in the health initiative. An appropriate feedback given to the individual with I/DD may be to compromise by limiting the amount of soda drinking during dinner. Additionally, involving staff and fellow housemates to encourage the individual to achieve their goal can be seen as supportive feedback. If people with I/DD feel as though they have the necessary support to participate in health initiatives they may

feel empowered to be health advocates for themselves and their peers. Each element is rated on the likelihood for the successful implementation (Colquhoun et al., 2010).

The PARIHS framework hypothesizes that implementation of an innovation is likely to occur when the following key indicators are present: 1) there is strong evidence-based research; 2) the environment is positive; 3) feedback is being given to users; and 4) skilled facilitators are present to help users learn how to implement new knowledge (Estabrooks, Thompson, Lovely, & Hofmeyer, 2006). These four factors can be applied to I/DD communities by: 1) examining current community-based health initiatives; 2) examining the willingness of I/DD organizations to implement initiatives; 3) evaluating the type of feedback that is given to people with I/DD and staff as they engage in the initiative; and 4) examining the characteristics of facilitators who are administering the initiative to the I/DD organization.

The PARIHS framework addresses two types of implementations: task-oriented and organizational implementations. The former is focused on short-term implementation, such as introducing a new procedure or process that is unlikely to focus on broad structural changes within an organization (Stetler, Damschroder, Helfrich, & Hagedorn, 2011). An example of task-oriented implementation is examining accessibility (e.g., transportation and money) or motivational levels among people with I/DD and staff to engage in health promotion programs (Heller, Hsieh, & Rimmer, 2004; Stanish, Temple, & Frey, 2006). The latter type of implementation, organizational implementation, is targeted more towards developing strategies to transform change within an agency's structure (Stetler et al., 2011); for example, agency policy and staffing ratios have been shown to influence the implementation of health promotion programs for people with I/DD, thus they should be examined when developing strategies for program implementation (Heller et al., 2011). Both types of implementation examine broad

systemic factors and local organizational issues, thus addressing major issues for people with I/DD and the communities and systems in which they live, work, and seek to participate. Both are equally important factors to consider when researching whether evidence-based research actually reaches and is being used by the very people and communities for which it was intended.

1.   **PARIHS and I/DD communities**

The PARIHS framework addresses several factors that should be considered when conducting research with people with I/DD: highlighting personal experiences, focusing on context, and a focus on action.

a.   **Highlighting personal experiences**

The PARIHS framework recognizes the users' personal experiences as a source of valuable evidence that should be considered when conducting interventions. Disability communities advocate for the voices of people with I/DD and is a much-needed shift. The framework also recognizes evidence gathered from the collective surrounding community environment as a valuable source of knowledge (Helfrich et al., 2009). This is an important consideration as directors, managers, direct support staff from I/DD agencies, as well as families/close support of people with I/DD have a better understanding of what works, what does not, and why.

Naturalistic observation is a common KT methodology that can provide an in-depth understanding of the personal experiences of people with I/DD and ensure their experiences and voices are not lost in the research process (Sudsawad, 2007). For example, a researcher is able to immerse themselves in the participants' environment and observe what may be effecting

implementation, translation, and sustainability of CBHPI as an I/DD individual, directly experiencing issues.

        b.   **<u>Focusing on context</u>**

        The PARIHS framework also addresses the importance of context, which includes understanding the culture of a system as a key element in determining the successful implementation of an initiative. Naturalistic observation can be used to gain a comprehensive understanding of the environment, culture, and influential factors that may affect implementation of evidence-based knowledge (Sudsawad, 2007). For example, when implementing a health program within a group home where people with I/DD live, researchers need to understand the past experiences, values, and beliefs of both the group home and direct support staff, the roles and duties of each individual, the resources available (e.g., financial, human, equipment), the power dynamics between clients and direct support staff, and peer relationships. Research conducted with the I/DD community has been criticized for not considering the culture which surrounds this population, thus limiting the research effectiveness (Ferguson & Ferguson, 2001). For this reason, the PARIHS framework may be able to provide guidance for future research on how to incorporate the active participation of end-users as well as culture into knowledge implementation for I/DD communities.

        Unlike other KT theories, the PARIHS framework identifies facilitation as one of the key elements that should be considered when conducting implementation research (Sudsawad, 2007). Facilitation involves training community members to become program facilitators (e.g., using train the trainer models with staff and peer mentors). Facilitation may be key to sustaining CBHPI in I/DD communities because people with I/DD and staff would be given the skills needed to implement initiatives and overcome adversity. Additionally, involving community

members in the training process may increase the likelihood of sustainability by giving people with I/DD and staff a sense of ownership in the initiative.

c. **<u>Focus on action</u>**

The PARIHS framework is most appropriately used when conducting implementation research, or actions to transfer knowledge to the community. The implementation focus is another reason why the framework may be well suited for KT research being conducted with I/DD communities. There have been various CBHPI that have supported positive improvements in the quality of life and participation of people with I/DD. For example, participation in a community-based health program is associated with improvements in the health of people with I/DD living within the community (Marks et al., 2010); however, these research initiatives struggle to sustain long-term implementation of their programs/curriculums (Heller et al., 2011). A potential reason for the lack of long-term sustainability is that when a research study ends, so do the resources needed to implement the program. These resources include financial support to conduct the program, the transportation required to attend fitness facilities, and facilitator support, leaving people with I/DD and their caregivers ill-equipped to continue the program. KT has adopted many strategies from community-based participatory research (Israel, Eng, Schulz, & Parker, 2005; Minkler, 1997; Minkler &Wallerstein, 2003), such as using action plans to sustain long-term program involvement. The use of community-based participatory research methodologies ensures that participants are directly involved with the creation, implementation, and sustainability of knowledge developed during the research process.

d. **<u>Application to I/DD</u>**

The PARIHS framework can be adapted to various environments and allows the researcher to extensively explore the dynamics of a community. The emphasis it

places on personal experiences is vital as it allows for the research to truly understand the individual and the collective community's interactions, within a particular system. Through examination of the context, a comprehensive systematic understanding is gained about an organization, such as beliefs, values, evaluation process, policies, and resources that make up a system, and how these factors affect the implementation of CBHPI for individuals with I/DD. With the knowledge gained by examining personal experience and context, researchers are better equipped to work together with community members to develop action plans for implementation that directly meet the needs of an organization. Being able to highlight the strengths and weakness of a system can allow CBHPI to be more appropriately designed towards the strengths of a system and develop effective strategies that can compensate for the weaknesses of that same system.

For example, by examining *personal experiences* a researcher may discover that individuals with I/DD would like to engage in more physical activity in their community, but are bored of constantly doing the same activities (i.e., walking around the block or to the corner store) and are looking for more variety. Additionally, examining *context* may disclose that direct support staff understands the importance of individuals with I/DD being more active in their community; however, they feel overwhelmed with their current workload and state that engaging individuals with I/DD in CBHPI is not part of their job requirement, thus, not a priority. With this knowledge, researchers can action plan accordingly with management, direct support staff, and individuals with I/DD by generating a list of community activities that are of interest. Additionally, an *action* plan can be developed to ensure that management is providing the appropriate support for individuals with I/DD and direct support staff to engage in CBHPI that do not create added stress to either party involved. Working with I/DD community agencies is a

dynamic and involved process; however the PARiHS framework provides a clear structure on navigating through a complex system and is flexible enough to be adapted to various settings, thus making this framework appealing to use in research involving I/DD communities.

F.   **<u>Conclusion</u>**

This paper explored how KT - specifically the PARIHS framework - can be used to help sustain CBHPI for people with I/DD. Although KT is a relatively new area of research, it aims to solve an old yet critical issue which has been present in the realm of research, bridging the gap between the underutilization of research results and their targeted populations (Rogers & Martin, 2009). The purpose of the current paper was to explore the use of KT to help sustain CBHPI for people with I/DD. KT acknowledges the value of knowledge being a bidirectional process, thus ensuring that the voices and lived experiences of people with I/DD are part of the knowledge creation process, which has been grossly lacking in research. The PARIHS framework addresses key factors that can improve the role people with I/DD play in knowledge creation by providing researchers with a detailed structure to navigate barriers and facilitators that affect the sustainability of CBHPI for I/DD communities. The framework recognizes personal experiences to be a type of evidence-based knowledge, examines the context in which the community-based health initiative will occur, and focuses on action through purposeful planning, facilitation, and peer learning. These are key factors that can help improve the implementation and sustainability of CBHPI for people with I/DD as they address common barriers within the research process that impede the translation of knowledge in an accessible manner for this population.

Research has commonly taken a paternalistic approach to people with I/DD taking the stance of 'researcher knows best,' consequently silencing the voices and experiences of people with I/DD. This may be why I/DD research struggles with the implementation and sustainability

of evidence-based findings due to people with I/DD not agreeing with the knowledge created on their behalf. It is of vital importance that evidence-based findings include the beliefs, attitudes, values, and lived experiences of people with I/DD as this will help to ensure that knowledge created is appropriately representative, thus more likely to be adopted by people with I/DD. Meaningfully engaging people with I/DD in the research process can be an empowering experience; when individuals feel their opinions and actions are valued and respected they are more likely to take ownership of research findings.

Inclusion of people with I/DD in the research will ensure that the knowledge generated will accurately reflect the facilitators and barriers that people with I/DD encounter when participating in community-based health initiatives. This will benefit people with I/DD by ensuring that CBHPI are being designed appropriately to meet their needs. Furthermore, this knowledge will inform policy makers of the important factors that need to be addressed so that policies appropriately support people with I/DD to participate in health initiatives within their communities. Currently, I/DD policies about health and community participation lack the voices of people with I/DD and thus may not provide appropriate support. I/DD policies have been found to be restrictive and are preventing the meaningful, desired participation of people with I/DD. They lack funding to support individual choices, interventions, and programming, and the proper coordination and resources to execute programs; thus they risk being in violation of civil rights; therefore not allowing full participation in the community (Hammel, Jones, et al., 2008). KT research, however, works to ensure that people with I/DD play an active role in the knowledge that shapes policy, which may help dispel misconceptions and stereotypes about I/DD and their ability to be in control of their health and participate in their community. The PARIHS framework provides an in-depth understanding of key elements (evidence, context, and

facilitation) that effects successful implementation of knowledge generated through research. The framework is a way to better understand research findings that can be incorporated into policies to better support people with I/DD. I/DD research requires further investigation to gain an in-depth understanding of how the KT paradigm may be able to effectively facilitate the translation, implementation, and sustainability of CBHPI for people with I/DD. This will ensure that people with I/DD experience improved health outcomes and community participation.

III. MEANINGFULLY ENGAGING PEOPLE WITH AN INTELLECTUAL/DEVELOPMENTAL DISABILITY IN THE CREATION AND DISSEMINATION OF KNOWLEDGE

A.   **<u>Abstract</u>**

People with an intellectual/developmental disability (I/DD) have traditionally taken a passive role in research because it is not clear how to effectively collect data from people with intellectual impairments (Barr et al., 2003). Fortunately, there has been a shift in research which has advocated for inclusive and participatory methods to include people with I/DD as active participants in the generation of knowledge which directly affects their health and quality of life. Actively engaging people with I/DD in research may increase the likelihood that they will adopt, implement and sustain knowledge generated from scientific inquiry. For this reason, the purpose of this paper was to explore how accessible research methods can facilitate the creation and dissemination of knowledge produced by people with I/DD to better inform I/DD agencies on how people with I/DD would like to be supported as they engage in CBHPI as they age. The inclusivity of research methods can ensure that evidence-based knowledge, that influences policies and system change, are directly reflective of the needs and opinions of people with I/DD.

Keywords: participatory methods, intellectual/developmental disabilities, community-based research, knowledge creation, dissemination, inclusivity

B.   **<u>Introduction</u>**

People with intellectual/developmental disabilities (I/DD) are likely to experience age related health conditions earlier in life compared to people without disabilities (Connolly, 1998; Evenhuis, Henderson, Beange, Lennox, & Chicoine, 2001; Glasson, Dye, & Bittles, 2014;

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Nochajski, 2000; World Health Organization, 2001), which may jeopardize their ability to live independently and participate in their community. Fortunately, it has been found that community-based health promotion programs can improve the health, community participation, and overall quality of life of people with I/DD (Heller et al., 2011; Marks et al., 2010). However, long term implementation and sustainability of these programs within I/DD community agencies remains a common barrier in research. In order to ensure that knowledge generated in research is disseminated, implemented, and sustained by people with I/DD it is imperative that they are actively engaged in the research process. Involving people with I/DD in research has become increasingly important because there has been a shift away from institutional living to community-based living, thus a greater understanding of the needs, desires, goals, and concerns of people with I/DD with regards to independent living is warranted (Thorn, Pittman, Myers, & Slaughter, 2009). Furthermore, I/DD agencies should actively include people with I/DD in the development of policies, producers and systems to ensure that they are meeting the needs of people with I/DD. However, people with I/DD have limited opportunities to meaningfully participate in research affecting programs and policies which directly affect their livelihood (Jurkowski, 2008).

Turning evidence-based knowledge into practice has gained much attention in the general health literature. It is imperative that I/DD research also take into consideration how knowledge production can not only involve people with I/DD, but also that this evidence-based knowledge is created in an accessible matter that is meaningful and useful for people with I/DD. Knowledge translation (KT) should not only focus on how research findings can be utilized, but also explore how accessible research methods can be translated into real world settings, so that people with I/DD can utilize these accessible methods to advocate for change in other aspects of their lives.

Community-based health programs have been developed and are shown to be effective in improving the health and quality of life for people with I/DD (Heller et al., 2012; Lunsky et al., 2003; Marks et al., 2010); however, researchers struggle to effectively include people with I/DD in the creation and dissemination of evidence-based knowledge.

Researchers have an important responsibility to ensure that the evidence-based knowledge they are disseminating to the public does not perpetuate stigmatizing views, but accurately represents people with I/DD to society. Especially since society typically views people with I/DD as having neither meaning associated with their behavior, nor discourse associated with their words (Ferguson & Ferguson, 2001). Although researchers support the inclusion of people with I/DD in research, the practically of effectively executing accessible methods is unclear. There is a lack of and a need for researchers to focus on how specific research methods can be adapted to include people with I/DD so that they can play an active role in knowledge production (Jurkowski, 2008). For this reason, the purpose of this paper was to explore how accessible research methods can facilitate the creation and dissemination of knowledge produced by people with I/DD to better inform I/DD agencies about how people with I/DD would like to be supported as they engage in CBHPI as they age.

C.   **Literature Review**

Research recognizes and supports the importance of knowledge production to include people with I/DD (Jurkowski, 2008; Timmons, 2013). A greater focus has been directed towards policy and service development which is person-centered to ensure that the choices, priorities, needs and goals of people with I/DD are being represented (Timmons, 2013). Community-based participatory action research has gained attention within I/DD literature as a means to facilitate knowledge production which is representative of the voices of people with I/DD (Hammel,

Jones, et al., 2008; Heller, 2008). Mactavish, Lutfiyya, and Mahon (2000) found that individuals with I/DD felt empowered when given the opportunity to be contributing members of the research process. However, there is a hesitation among researchers to administer self-reported measures to people with I/DD due to the assumed limited intellectual ability to accurately respond to the researchers inquires. For this reason, researchers typically involve proxies – caregivers, supports staff, family members – to compare and contrast findings, to those given by people with I/DD (Ready, 2007). This is problematic as subjective outcomes, such as quality of life or health status are influenced by an individual's own biases, thus inconsistency between responses should not assume that responses provided by individuals with I/DD are not accurate (Patrick, Guyatt, & Acquadro, 2008; White-Koning et al., 2005).

Research has suggested that the severity of intellectual impairment does not equate to individuals with I/DD not having a preference or opinion, rather they simply require the opportunity to express themselves through accessible and creative methods (Stancliffe, 2001). For example, Lindsay, Michie, Baty, Smith, and Miller (1994) examined the emotional states of 67 adults with mild or moderate I/DD and found that participants were consistent in reporting their emotions across various measures. Having people with I/DD participate in research methods which are accessible provides insight into how they experience and interpret complex issues (Mactavish, Mahon, & Lutfiyya, 2000). Qualitative methods, such as, photovoice, participant observations, and nominal group technique (NGT) have been shown to be accessible methods to effectively engage people with I/DD in the research process, in order to be meaningfully involved in the generation of knowledge which directly effects them (Milner & Kelly, 2009; Myers et al., 1998; Tuffrey-Wijne, Bernal, Butler, Hollins, & Leopold, 2007).

Photovoice is a qualitative methodology which is commonly used within community-based participatory research and is based on health-promotion principles (Hergenrather, Rhodes, & Bardhoshi, 2009; Wang, Cash, & Powers, 2000). Photovoice provides participants with an opportunity to express themselves through taking pictures of important community concerns which are impacting the individual. Photos allow critical discussions to occur when personal experiences, knowledge, and concerns are shared within a group setting (Aldridge, 2007; Hergenrather et al., 2009; Jurkowski, 2008). Photovoice has been effectively used by various culturally diverse groups within different settings. The flexibility of photovoice as a participatory method has made it an accessible research tool for people with I/DD (Hergenrather et al., 2009; Jurkowski, 2008).

Participant observations are an accessible participatory research method which can engage people with I/DD in research and be utilized in various settings as they provide a rich description of the participant's behavior by taking into consideration the context in which the behavior occurred (Alder & Alder, 1994; Geertz, 1973), as well as interacting with participants in their own environments (Patton, 2002). Participant observations have been used by researchers to gain a better understanding of the factors which influence the lives of people with I/DD. For example, examining social interactions in school settings with peers (Carter, Hughes, Guth, Copeland, 2005), exploring factors involved with developing relationships, expressing sexuality and love (Löfgren-Mårtenson, 2004) or examining the social interactions of adults with severe I/DD (Johnson, Douglas, Bigby, & Iacono, 2012). Additionally, participant observations allow for the researcher to interact with people with I/DD in context and ask probing questions to gain a comprehensive understanding of what is being observed. The researcher is able to ask

clarifying questions about the behaviors and actions being recorded and ensure people with I/DD are being accurately represented in the researcher's field notes (Johnson et al., 2012).

NGT is an organizational planning tool, which has commonly been used as an accessible problem-solving method to identify and prioritize community concerns through voting (Delbecq, Van de Ven, & Gustafson, 1975; Elliott & Shewchuk, 2002; Harvey & Holmes, 2011; Miller, Shewchuk, Elliott, & Richards, 2000). NGT has been shown to be an efficient and reliable data collection method because of its ability to produce knowledge which identifies the importance of key issues in a hierarchy (Harvey & Holmes, 2012). NGT is an accessible research method which has the ability to explore group opinions and priorities and allows each individual's opinion to be equally represented (Roeden, Maaskant, & Curfs, 2012). This method has been used as an effective research tool to meaningfully involve people with I/DD in research to express their concerns about their health (Tuffrey-Wijne et al., 2007), community living, employment and social relationships (Bostwick & Foss, 1981). For example, NGT has been used by researchers to understand the views of people with I/DD with regards to end-of-life care (Tuffrey-Wijne et al., 2007), and the relationship dynamics they have with their caregivers (Roeden, Maaskant, & Curfs, 2011)

Participatory research methods are versatile and can ensure that the voices of participants with I/DD are represented accurately not only during the research process but also in regards to the dissemination of knowledge. This paper will explore how accessible research methods can facilitate the creation and dissemination of knowledge produced by people with I/DD to better inform I/DD agencies on how people with I/DD would like to be supported as they engage in CBHPI as they age. This will be done by providing a detailed description of methods used from a larger study and examine how people with I/DD responded to participating in such research

methods. The objective of this paper is to spark ideas in the reader on how they can adopt and adapt accessible research methods in their own research to ensure people with I/DD are being included in research.

D.   **<u>Background of Research Project</u>**

Community-based I/DD agencies provide services and support to people with I/DD offering these individuals the opportunity to participate in their community and engage in positive health behaviors. However, little is known about the factors involved in sustaining community-based health and participation initiatives (CBHPI) among I/DD agencies. It is important to gain a better understanding of the facilitators and barriers which are involved in sustaining CBHPI initiatives being implemented by community-based I/DD agencies in order for individuals aging with I/DD to experience positive physical and social health outcomes as they age, thus potentially decreasing the risk of institutionalization due to poor health. The purpose of the current study was to explore the facilitators and barriers of sustaining CBHPI initiatives for people aging with I/DD living in group homes as managed by I/DD agencies. In order to answer this question three phases were conducted, each with its own purpose, to explore the research question. Past research has suggested that people with a disability commonly experience physical, social, and cultural barriers which limit their participation. Therefore, it is unlikely that a single measurement tool is able to achieve a complete understanding of the factors affecting participation for people with a disability (Heinemann, 2010). A community-based participatory action research approach, utilizing multiple methods, was done to capture an in-depth understanding of the research question being explored.

1. **<u>Methods</u>**

     a. **<u>Participants</u>**

Two non-profit I/DD agencies participated in the study. Purposeful sampling was used to recruit participants (Patton, 2002). Directors of both organizations were asked to identify management, direct support staff, and people with I/DD living in group homes who had participated in CBHPI initiatives in the past. More specifically to target, 1) group homes where CBHPI worked, 2) group homes which sustained CBHPI through modifying them to meet the needs of people with I/DD, and 3) group homes who struggled with adopting CBHPI, but want to improve health and community participation. A total of six group homes participated in the study (4 group homes from one agency and 2 group homes from the other).

The directors of both agencies were involved in the study design of the project to ensure the research question was relevant and meaningful to the needs of the agencies and people with I/DD, as well as to ensure data collection methods were appropriate. Data collection occurred over a three month period and a total of 70 participants from the two community agencies participated in the study: 35 people with I/DD and 35 management/direct support staff. The mean age of people with I/DD and management/direct support staff were 52 and 44 years respectively, 53% of participants where female. Participants were predominantly from minority groups: 49% African American, 40% Hispanic, and 11% White. People with I/DD had mild to moderate I/DD and resided in low income neighborhoods. The research study was approved by the Institutional Review Board of the University of Illinois at Chicago. All participants provided written informed consent, for those individuals who had legal guardians they were also contacted and provided written consent.

b. **Phase one: Issue identification**

The objective of this phase was to provide an initial organizational-level overview of the facilitators and barriers involved in sustaining CBHPI initiatives for people aging with I/DD as identified by management and direct support staff. A total of 19 semi-structured face-to-face interviews were conducted (6 with management and 13 with direct support staff). Interviews were not meant to be a substitution for the voices of the people with I/DD, but rather to provide a greater understanding of the research question from the perspective of management and direct support staff who are actively involved in providing services and support for people with I/DD. A literature review about CBHPI initiatives and KT models informed the interview guide. More specifically, the Promoting Action on Research Implementation in Health Services (PARIHS) framework was chosen to guide question development because it: 1) addressed key issues of sustainability; 2) is flexible and applicable to various settings; 3) acknowledges that research is a bidirectional process and recognizes personal experience as a valued source of knowledge; and 4) provides a system level approach to understanding factors within a system that may be affecting implementation and sustainability (Helfrich et al., 2010). Key areas addressed within the interview guide were: consumer input, professional knowledge, the environment, culture, leadership, evaluation, facilitation, and motivation (Helfrich et al., 2009).

The interview guide consisted of questions such as; *What are the main barriers you face when implementing programs and activities which are meant to improve healthy community participation with adult residences?* Or *how would you describe your motivational level for implementing healthy community participation programs/activities within the agencies?* Management and direct support staff were given the opportunity to discuss other key issues

which may not have been covered in the interview guide, but felt that they were important to

discuss. Two separate interview guides were created for 1) management and 2) direct support

staff. Interviews conducted with management provided an understanding of the factors involved

in sustaining CBHPI for people aging with I/DD from a broader systemic perspective, whereas

interviews with direct support staff provided a "front line" perspective of the factors which may

be affecting sustainability within group home settings. Semi-structured interviews allowed for

open discussion and new ideas to be discussed while providing a framework of themes to keep

both interviewee and interviewer focused so as not to divert into topics unrelated to the research

question (Charmaz, 2006; Glesne & Peshkin, 1992; Patton, 2002). Interviews were digitally

recorded and ranged from 25-75 minutes in length.

c.   **Phase two: Strategic gap analysis**

The objective of this phase was to gain a ground level understanding of

the facilitators and barriers involved in sustaining CBHPI initiatives within group homes. This

phase consisted of participant observation, photovoice, and nominal group technique conducted

with each of the six group homes. These data collection techniques were chosen as they have

been shown to be accessible methodologies to meaningfully include people with I/DD in the

research process (Milner & Kelly, 2009; Myers et al., 1998).

i.   **Participant observation**

Participant observation took place within each of the six group

homes. Detailed field notes were taken on the interactions between: 1) people with I/DD, 2)

direct support staff, and 3) people with I/DD and direct support staff within the group home and

when out in the community. Group homes were visited twice within the same week, which

consisted of one week night and during the day on the weekend. These observation times were

identified by directors as being optimal times when people with I/DD could be engaging in CBHPI due to extended periods of free time. Conducting observations during these periods would allow for a better understanding of why CBHPI initiatives are/are not being engaged in during these time frames. Date and times of observations were discussed with the house managers to make sure observation periods reflected typical house behaviors and activities. Observation sessions lasted between 1-4.5 hours depending on the events/activities taking place.

For this study the researcher took an active membership role in the observation process, this mode of observation was taken because it was the most appropriate to help understand the research question. Active membership allowed the researcher to interact with people with I/DD and understand their perspectives. Community-based research is a partnership between researcher and participant, and for this reason, the traditional research role of being disengaged and distant was not taken, rather the researcher was engaged and interactive with the environment.

The primary researcher immersed herself in the home and community settings with participants in order to interact and engage in dialogue with people with I/DD as well as gain a better understanding of the lives of people with I/DD living in group homes. The naturalistic inquiry allowed the researcher to interact with people with I/DD in an environment where they felt comfortable and could engage in regular daily activities. The researcher engaged people with I/DD with in-context discussions about their health and community participation. This allowed people with I/DD to not have to recall past events, feelings, or behaviors which would be required in a more formal research setting (i.e., interview setting), but rather reflect on how they were currently experiencing facilitators and barriers as they were presently occurring. Additionally, this type of observation allowed people with I/DD who may experience difficulties

verbally articulating their thoughts to point to objects or call on their peers to help express their thoughts, thus, ensuring that their experiences are also represented in the research process. For example, when participants with I/DD were out shopping for new clothes, the researcher was able to engage in dialogue about the facilitators and barriers they experience to support them as they go out into the community and shop. In order to ensure that interactions and behaviors were being interpreted correctly the researcher asked people with I/DD clarifying questions, such as 'how does that make you feel?', 'why are you doing that?', or 'does this happen often?' This allowed for an in-depth understanding of what was being observed and to accurately reflect on the perspectives of people with I/DD.

ii.   **Photovoice**

People with I/DD from the six group homes participated in photovoice. Each person with I/DD was given a digital camera for a four day period and were encouraged to take pictures of things that 'make it easy and difficult for them to be healthy and active in their home and community'. Direct support staff were asked to remind people with I/DD to take pictures when they were at home and out in the community. Each person with I/DD received individual training on how to use their camera. Direct support staff were also taught how to use the cameras to provide assistance if needed. Once the four day period was over the primary researcher retrieved the cameras, printed the pictures and returned to each of the group homes to engage in photo-discussions with participants. Along with the pictures the researcher returned with a blank poster board entitled '*Being healthy and active in our home and community'*. The poster board was divided down the middle with headers that read '*Things that make it EASY*' and '*Things that make it HARD*.' The purpose of the photos and poster board was to help guide discussions regarding how people with I/DD experience health and community

participation. The blank poster board was placed in the middle of the table as people with I/DD gathered around. Manager/direct support staff led the activity by asking people with I/DD what makes it easy or difficult for them to be healthy and active in their home and community. People with I/DD were asked to find pictures which depicted issues that they wanted to put on their poster board. Once pictures were placed on the poster board in their respective areas people with I/DD taped the pictures on the board and instructed managers/direct support staff regarding what to write beneath each photo describing why the picture was chosen. Additionally, people with I/DD were encouraged to add any other concerns to the poster board that went beyond the chosen photos. People with I/DD were encouraged to decorate the board with stickers, decorative tape, and markers.

iii. **NGT**

After the poster boards were completed, NGT was conducted so that each person with I/DD could vote on the top three photos they identified as barriers affecting their health and community participation. House managers (if present) and direct support staff also voted with respect to what they perceived to be barriers affecting the health and community participation of people with I/DD. House managers and direct support staff were given a vote because their opinion is also important as they work closely with people with I/DD and have an understanding of what barriers affect the house unit. The poster boards with the votes were taken to the town hall to be showcased, presented to the community and facilitated short term action plans to improve CBHPI initiatives within each of the group homes.

d. **Phase three: Action planning via community capacity building**

The purpose of this phase was to disseminate research findings within the community. A town hall was organized and people with I/DD, house managers, and direct

support staff from the study were in attendance, along with a few other community members who wished to attend. During the dissemination process each of the six group homes developed short-term action plans to address the barriers they felt warranted immediate community focus. Each of the six group homes brainstormed short term action plans to present to their respective directors to initiate change. Action planning included people with I/DD, direct support staff and house managers (if present). Action plans consisted of 1) strategies they could implement at the group home level to improve health and community participation and 2) things they wanted to ask their community agency to help improve health and community participation. This twofold action plan was drawn up to show management that people with I/DD and direct support staff were willing to take ownership of their action plan and be pro-active about finding strategies to overcome barriers. As the group homes were brainstorming a research assistant was present within each group to observe group dynamics and facilitate action plan development if required. Participants were given 30 minutes to brainstorm after which people with I/DD presented their action plans to the larger group at the town hall.

E.   **Accessible methods? A critical reflection**

This section provides a critical reflection of how people with I/DD responded to the research methods used in the current study described above. Because the actions, words, and behaviors of people with I/DD are typically viewed by society as being meaningless or without purposeful thought (Ferguson & Ferguson, 2001), it was important to provide a detailed description of how people with I/DD responded to the methods utilized in the study and to demonstrate that people with I/DD can meaningfully engage in critical discourse.

1.   **<u>Reactions to photovoice</u>**

The study supports past research findings that have found photovoice to be an accessible method to involve people with I/DD in the research process (Aldridge, 2007; Hergenrather et al., 2009; Jurkowski, 2008). Photovoice allowed people with I/DD to become engaged regardless of their level of impairment. Direct support staff and management were surprised and impressed to witness certain individuals with I/DD become invested in participating because they assumed their level of impairment would not allow them to be effective at using a digital camera or taking pictures. Thus, photovoice may be an effective method to enlighten community members of the capabilities of people with I/DD. Photovoice was an empowering experience for people with I/DD as people with I/DD took pride in taking their pictures (i.e., making sure their photos were in focus, and checking to make sure objects where properly centered), and were eagerly willing to offer assistance to their peers who were struggling to use their digital cameras. Being able to offer assistance to peers displays a level of confidence and competence

Using photos to facilitate discussion was an effective means to engage people with I/DD not only to talk about the content of the pictures, but also to discuss other factors regarding health and community participation which were not present in pictures. For example, one individual with I/DD wanted to add that his fear of dogs makes it difficult for him to go to the park or walk around the community; however, there was no picture to represent a fear of dogs. Interestingly, this particular individual was not very vocal, but through photovoice he was able to organize his thoughts and discuss his concerns about a barrier he faces when in the community. As with any research study there were some participants who were more vocal than others. For this reason, it is important that research methods be adapted to include individuals regardless of

their level of impairment. For example, in the current study people with I/DD were asked to decorate their poster board to ensure that individuals who took a more passive role during the photo-discussion were still able to be involved and not feel as though their contributions were less signification. Having people with I/DD decorate the poster board was an accessible way to allow people with I/DD who were more passive become involved in the research process, so that they too could claim ownership of their poster board. Interestingly, several of the participants decided to sign their names on their poster boards to ensure that management knew the concerns listed on the board were created by them.

2. **Reaction to NGT**

Although NGT has not been widely used in research for people with I/DD the current study was consistent with past research findings suggesting that NGT is an accessible and effective data collection tool for people with I/DD (Roeden et al., 2012; Tuffrey-Wijne et al., 2007). NGT requires that each person voice their options through voting, thus ensuring that even those individuals who may not be as vocal can still have an impact on facilitating change. Similarly, with photovoice findings, management and direct support staff were also surprised to witness certain people with I/DD being able to prioritize barriers and vote on issues which affect their health and community participation. NGT facilitated group homes (people with I/DD, direct support staff, and house managers) to better understand the viewpoints of each house member with regards to what they believed to be the main barriers to sustaining CBHPI within their home unit. This method allowed group homes to organize and prioritize barriers and develop action plans that specifically targeted these barriers. People with I/DD were able to work together with their peers, direct support staff and house managers to develop an action plan that addressed the collective needs of the home unit. Furthermore, by prioritizing barriers, community agencies are

able to see the main issues people with I/DD are experiencing and this knowledge can help

management support people with I/DD.

3.   **Putting knowledge into action**

Each of the group homes developed action plans to address the main barriers that

affected their group home. Action plans involved asking management for exercise equipment in

their homes, addressing aging concerns such as making their homes more accessible for people

with I/DD experiencing balance issues (i.e., requesting a walk in shower, or requesting a

walker/cane for people), addressing transportation concerns, such as requesting regular access to

an agency vehicle so that people with I/DD could go to their local library, beaches, or parks, as

well as asking management to obtain accessible parking permits in order that people aging with

I/DD not have to walk long distances to the entrance of a building. People with I/DD were

excited about attending the town hall and discussing with management their needs and concerns.

Representatives from each group home presented their materials on stage. Interestingly, it

was not planned for people with I/DD to get up on stage in front of 50 attendees and present their

action plans; however, people with I/DD approached the primary researcher and stated they

wanted to, not only present their short term action plans to the larger group, but also their poster

boards which they had created within their homes. Each group home varied on how many people

went up on stage to present. Some group homes had only people with I/DD present, other group

homes had people with I/DD speak as direct support staff stood nearby as a source of support

(i.e., helping hold the microphone, or helping people with I/DD read the poster board and action

plans), while other group homes had people with I/DD hold the poster boards/action plans and

point to things they wanted their direct support staff to present to the group. This unexpected

event displayed how the research process was empowering to people with I/DD as they showed

ownership over their poster boards and action plans by presenting the data they generated to a large audience.

Unfortunately, management was unable to attend the town hall; however, the primary researcher had a follow up meeting with management to ensure action plans developed by people with I/DD had been brought to their attention. Follow up meetings with management disclosed that actions were already in place to address the concerns identified by people with I/DD. For example, management had acquired accessible parking permits for their agency vehicles, had purchased exercise equipment such as yoga mats and were in the process of ordering larger exercise equipment, such as treadmills. Management had also begun to address the diets of people aging with I/DD exploring the possibility of mechanical soft diets for older individuals who are having trouble chewing their food and already purchased plates and cutlery which is more accessible for older people with motor difficulties to use.

Furthermore, management from both agencies discussed that they found the research methods of the study accessible and likely to be adopted within their agency to ensure that people with I/DD are able to vocalize their needs and concerns. For example, one of directors spoke about how she was going to get the individuals involved in the study to present their poster-boards to their peers and have other people with I/DD develop poster-boards to address their own needs/concerns. Future research is needed to explore how I/DD agencies can adopt accessible research methods such as photovoice and NGT to ensure the voices of people with I/DD are being represented within the agency.

F.   **Conclusion**

There is a much needed shift in research to stop viewing people with I/DD as passive subjects to be studied and helped, but rather recognize that people with I/DD should be active

key players in generating knowledge about issues which directly affect their quality of life. People with I/DD are information rich sources about their lives and experiences, for this reason researchers should employ accessible methods to ensure the voices of people with I/DD are being represented in research. This article helps address the gap in the literature which calls for articles demonstrating how research methods can be adapted to include people with I/DD in research (Jurkowski, 2008). Academia is a public platform that has the power to either reaffirm or reject dominant stereotypes about I/DD. People with I/DD have individually and collectively rejected the oppressive stereotypes and stigmatizing labels that surround having an I/DD, and have joined together to advocate for their human right to have access to full community participation (Williams & Shoultz, 1982). Longmore (2003) states that research should be seen as a tool to facilitate the accurate representation of people with disabilities. For this reason, researchers should critically examine how to provide accessible methods that support the meaningful participation of people with I/DD so that evidence-based knowledge – which is so highly regarded by society – can accurately represent this group. Researchers have the opportunity and responsibility to educate society about I/DD so that dominant ideologies can be rejected through the creation and dissemination of knowledge that is directly influenced by the voices of people with I/DD, thus ensuring accurate representation of their experiences, beliefs, and opinions.

IV. WHAT IS AND ISN'T WORKING: FACTORS INVOLVED IN SUSTAINING COMMUNITY-BASED HEALTH AND PARTICIPATION INITIATIVES FOR PEOPLE AGING WITH I/DD

A. **Abstract**

People with intellectual/developmental disabilities (I/DD) are more likely to experience the aging process earlier and at a more rapid rate than individuals without I/DD. Therefore, it is important for I/DD agencies to be able to support people aging with I/DD so that they may continue to age in their homes and be active members of their communities. The current study explored facilitators and barriers associated with sustaining community-based health and participation initiatives (CBHPI) designed for people aging with I/DD living in group homes managed by I/DD agencies. The study utilized participatory action methodologies (interviews, photovoice, and observations) to meaningfully engage a total of 70 participants—35 individuals with I/DD and 35 management/direct support staff. The data was analyzed through content analysis and triangulation of data, six main themes emerged: agency values and policies; resources and staff competencies; communication between management and staff; community/university partnerships; peer relations; and aging with I/DD. Overall findings show that I/DD agencies and people with I/DD value CBHPI; however, find them difficult to sustain due to limited resources and lack of training specific to aging with I/DD. Community-based recommendations to increase sustainability for future CBHPI included: utilizing peer-to-peer mentorship; improving formal and informal communication between management and direct support staff; developing stronger partnerships between researchers and I/DD agencies; and actively including people with I/DD in the design, development, and dissemination of research

initiatives so that the evidence generated more accurately reflects the needs and wants of people aging with I/DD.

B.   **Introduction**

The deinstitutionalization movement that began in the 1960s has resulted in a steady increase of people with intellectual/developmental disabilities (I/DD) transitioning from state operated institutions to community-based group homes (Alba et al., 2008; Braddock, Hemp, & Rizzolo, 2004; Rizzolo, Hemp, Braddock, & Schindler, 2009). The goals of community-based care were to support people with I/DD to have the freedom to exercise their right to access services/activities offered by the community, to have a level of control over their own lives, and to improve their overall quality of life (Willer & Intagliata, 1981). To fulfill these objectives, there was an influx of community-based services designed to support people with I/DD living in the community (Chowdhury & Benson, 2011). In spite of the increased number of community-based services offered, researchers have found that people with I/DD continue to struggle with experiencing meaningful community participation (Bratt & Johnston, 1988; Hammel, Jones, et al., 2008; Marks & Heller, 2003) and do not feel they are valued community members (Forrester-Jones et al., 2002). These findings have led researchers to wonder if people with I/DD have merely become physically relocated into community settings but are still not necessarily meaningfully engaged with community living (Cullen et al., 1995).

Furthermore, people with I/DD are likely to experience the aging process earlier and at a faster rate than people without disabilities (Connolly, 1998; Evenhuis et al., 2012; Nochajski, 2000; World Health Organization, 2001). The increased risk and range of age-related chronic diseases that this population experiences may negatively affect an individual's ability to meaningfully engage in their community if proper support is not readily available. There is a

clear need to develop a greater understanding of how aging with I/DD affects an individual's

health and community participation (Heller et al., 2014) especially important given that an

individual's health and quality of life are related to community integration and social inclusion

(Heller et al., 2011; Marks, Sisirak, Heller, et al., 2010; Schalock et al., 2008). Although there

have been many effective evidence-based programs that have focused on improving the health

and community participation for people with I/DD through adopting translational strategies

(Heller et al., 2012; Lunsky et al., 2003; Marks, Sisirak, & Heller, 2010), sustaining or

continuing evidence-based programs within the community remain a common barrier that

requires further investigation (Heller et al., 2014; Mancini & Marek, 2004; Sharir & Lerner,

2006). For the purposes of this paper, program sustainability will be defined as the continuation

of a program (Shediac-Rizkallah & Bone, 1998) and community-based health and participation

initiatives (CBHPI) will be defined as any evidence-based strategy, guideline and any

curriculum, program, or action plan that is designed for people with I/DD to improve their health

and community participation.

Within the general health promotion literature, program sustainability findings have been

inconclusive, sometimes contradictory, and there are no known standardized guidelines or

methods available to evaluate the potential sustainability of a program (Pluye et al., 2004).

However, research has highlighted that program sustainability is dependent on organizational

capacity. If an organization lacks the resources, staffing, and leadership to support the program,

sustainability is unlikely to occur (Cassidy & Leviton, 2006). Marks, Sisirak, Heller et al. (2010)

described several factors that typically affect successful implementation of health promotion

programs for people with I/DD, such as the level of commitment from all stakeholders including

people with I/DD, support staff, and family members, verbal reminders about engaging in the

program, recruitment facilitators, and respecting the time of staff members. It is important that programs being developed take into consideration organizational capacity by including community members (i.e., an organization's management, direct support staff, and people with I/DD) in the development, design, and long-term implementation of a program. Furthermore, community-based I/DD agencies provide people with I/DD the necessary services and support to allow them to engage in positive health behaviors and participate in their community and in turn these services help to support their aging process. Little is known, however, about the factors involved in sustaining evidence-based CBHPI being implemented by I/DD agencies. This is an area of research that warrants further investigation because by sustaining programs for people with I/DD, the physical and social health outcomes of people aging with I/DD will improve thereby decreasing the risk of isolation (i.e., re-institutionalization) due to poor or declining health.

Knowledge translation (KT) practices can be utilized to help understand program sustainability as it is rooted in the fundamental principle that researchers should incorporate community members in the development of knowledge creation to ensure that knowledge being generated is appropriate, accessible, and meaningful to the targeted communities who are meant to benefit from the program (Armstrong et al., 2006; Kitson, 2009). The majority of KT research has been conducted in health care systems and clinical settings (Colquhoun et al., 2010); however, KT has gained popularity within disability research as a means to bridge the knowledge-to-action gap for people with disabilities living in community settings (Marks, Sisirak, Heller et al., 2010; Rogers & Martin, 2009; Sudsawad, 2007). KT theories have been criticized for being too linear in their protocol such that evidence-based knowledge is generated by researchers and then passed along to consumers to be adopted and implemented into already

existing systems (Kitson, 2009). However, the Promoting Action on Research Implementation in Health Services (PARIHS) framework views knowledge creation as a bidirectional process that requires the active and meaningful contributions of both researchers and community members (Helfrich et al., 2010). Therefore, PARIHS recognizes that evidence-based knowledge stems from the personal experiences of community members, not solely from knowledge generated by researchers.

The PARIHS framework examines implementation of evidence-based knowledge into a system by investigating the interplay of three key elements: 1) evidence (i.e., knowledge from various sources); 2) context (i.e., culture, leadership, evaluation); and 3) facilitation (i.e., identification of support that facilitates program implementation) (Helfrich et al., 2009). The framework acknowledges that successful implementation is a complex and unpredictable process and, as such, it has been described as a flexible and dynamic framework that can be applied to a variety of settings (Helfrich et al., 2010). Although the PARIHS framework has not been utilized in I/DD research, it has the potential to be useful in I/DD research not only for its versatility and general use but also because it highlights personal experiences, focuses on context, and supports action planning that facilitates successful implementation and transfer of evidence-based knowledge.

The PARIHS framework was used in the current study to examine the facilitators and barriers associated with sustaining CBHPI designed for people aging with I/DD living in group homes as managed by I/DD agencies. By utilizing a KT framework specific to program sustainability we will be better able to understand the dynamics involved in sustaining CBHPI for people aging with I/DD through a multi-level perspective that includes the direct input of people with I/DD, as well as management and direct support staff. This research addresses an

important gap in the literature that calls for 1) a greater understanding of how the aging process affects the health and community participation of people with I/DD, and 2) a greater representation of people with I/DD that are involved in the knowledge production directly affecting their livelihood.

C.   **Methods**

   1.   **Participants**

            Two non-profit I/DD agencies who had previously been involved in CBHPI participated in the study. With the agencies directors' assistance, a purposeful sampling method was used to identify group homes with the following criteria: 1) had people aging with I/DD living in them; and 2) had people with I/DD engaging in, or experiencing difficulties to engage in CBHPI. A total of six group homes were asked to participate in the study (i.e., four from one agency, two from the other). From these six group homes, a total of 35 staff were recruited including six management staff (i.e., directors and managers) and 29 direct support staff. Additionally, all of the 35 residents living in the six group homes were invited and participated in the study. All participants provided written informed consent forms. Legal guardians were contacted to provide written consent where appropriate. The research study was approved by the Institutional Review Board of the University of Illinois at Chicago (Protocol 2009-1156). Overall, participants were mostly from minority groups (49% African American, 40% Hispanic, and 11% White), living in low income neighborhoods, and there was a relatively equal distribution of males (47%) and females (53%). The average age of participants with I/DD was 52 years (range 26-98 years) who were previously diagnosed with mild to moderate I/DD. The average age of management/direct support staff was 44 years (range 18-65 years).

2.   **<u>Study design</u>**

Directors played an active role in shaping the study design and interview questions to ensure the study was meaningful to their agency and data collection methods were appropriate for participants to execute. The study took place over a three month period and used a qualitative design utilizing semi-structured interviews, photovoice, and participant observations. Semi-structured interviews were conducted to facilitate open dialogue with management and direct support staff in order to gain their perspective of the research question, not to overshadow the voices of people with I/DD. Photovoice and participation observations were chosen as they have been shown to be accessible research methods to meaningfully engage people with I/DD in the research process (Aldridge, 2007; Jurkowski, 2008).

a.   **<u>Semi-structured interviews</u>**

A total of 19 interviews were conducted ranging in length from 25 to 75 minutes and took place at the agency offices. An interview guide of open-ended questions, developed using the PARIHS framework (Helfrich et al., 2010), was used to facilitate discussion with management and direct support staff. Interviews conducted with management sought to understand the factors involved in sustaining CBHPI for aging with I/DD from a broader systemic perspective; whereas interviews with direct support staff explored a front-line perspective of the factors affecting sustainability within group home settings. Interviews were digitally recorded and transcribed verbatim.

b.   **<u>Photovoice</u>**

Each participant with I/DD was given a digital camera for a five day period and was encouraged to take pictures of "things that make it easy and hard for them to be healthy and active in their home and community." Photos were printed and brought back to each

of the group homes where people with I/DD gathered around the kitchen table and, as a group, discussed the photos. The photos were not only used to facilitate discussion, but also to develop a poster illustration board that people with I/DD used to identify common barriers and support that affect their health and community participation. More specifically, people with I/DD mounted their photos onto the poster board and wrote a brief description under each photo explaining why they identified the photo content as a barrier or a support to CBHPI.

      c.   **Participant observations**

Each of the six group homes took part in participant observations. The researcher observations focused on how people with I/DD interact with their environment in regards to engaging in health behaviors in their homes and out in the community. Participant observations allowed for the researcher to engage people with I/DD in in-context discussions about how they experience and interpret barriers and facilitators to sustaining CBHPI. Each home was observed twice in a one week period. The first observation occurred during a week night after people with I/DD returned home from a workshop/day program and the second observation occurred on a weekend day while people with I/DD were engaged in a community outing. The timing of these two observations was chosen because they were identified by directors as opportune times for people with I/DD to be engaged in CBHIP. The timeframe of the 12 observations ranged from 1 to 4.5 hours. The researcher took an active role during the observation period, engaging with participants in their homes and out in the community to gain a better understanding of the actions and behaviors of people with I/DD. Semi-structured field notes were taken immediately after each observation and focused on the three main elements of the PARIHS framework (i.e., evidence, context, and facilitation).

3.   **<u>Analysis</u>**

Data were analyzed to determine key areas that affect the sustainability of CBHPI for people aging with I/DD living in group homes. The three data sources (i.e., interview dialogue transcripts, participant photovoice descriptions, and researcher observation field notes) were compiled and analyzed according to the constant comparative method (Glaser & Strauss, 1967). The constant comparative method was chosen as it allows for similarities and differences to be examined within and across different types of data and ensures that participants' experiences are approached in a systematic manner resulting in theme identification, description, and organization (Corbin & Strauss, 1990). The three data sources were read multiple times until the primary researcher was familiar with these data, after which open coding followed by axial coding were conducted to assign codes (e.g., short phrases or descriptive words) to these raw data (Strauss & Corbin, 1998). After all three data sources were coded, codes were compared across the three data sources, identifying any similarities and differences, and then grouped together to represent the overall, triangulated, methodological approach. From these grouped codes primary themes emerged from the data (Patton, 2002). TABLE I illustrates how themes emerged from raw codes. A second researcher reviewed the codes and themes noting the similarities and differences in their interpretation. Where there were differences, the two researchers engaged in in-depth discussions about the findings until a consensus was reached.

TABLE I
EXAMPLE OF HOW THEMES EMERGED FROM THE RAW CODES

Examples of Raw Codes	Emergent Theme
• Lack of policies on health/community participation • Agency's values of client health and empowerment • Definition of health/community participation	Agency values and policies
• Training in health/community participation • Budget cuts/lack of money • Confidence of staff/management (creative/adaptable)	Resources and staff competencies
• Good communication: log books • Poor communication: budget cuts effects on resources • Staff communicating needs of people with I/DD	Communication between management and staff
• Agency values community/university partnerships • Poor research dissemination • Supportive community resources	Community/university partnerships
• House unity (lack thereof) • Peer support/teamwork • Advocating for peers	Peer relations
• Age and mobility issues • Age and getting tired quicker • Agency's lack of training and knowledge on aging	Aging with I/DD

D.   **<u>Results</u>**

Emerging from these triangulated data were six themes that represent the factors that influence the sustainability of CBHPI for people aging with I/DD living in group homes that are managed by I/DD agencies: agency values and policies; resources and staff competencies; communication between management and staff; community/research partnerships; peer relations; and aging with I/DD (TABLE II).

TABLE II
SUPPORT AND BARRIERS TO SUSTAINABLE CBHPI AS DISCUSSED BY
PARTICIPANTS

Themes	Description	Support	Barrier	Discussed by
Agency values and policies	Agencies and individuals respect and value health and community engagement of people with I/DD. However, agencies lack formal CBHPI policies to sustain such initiatives.	X	X	Management
		X	X	Staff
		X	X	People with I/DD
Resources and staff competencies	Staff competencies to execute CBHPI are viewed as a support; however, the lack of resources to sustain initiatives is a challenge.	X	X	Management
		X	X	Staff
		X	X	People with I/DD
Communication between management and staff	Communication between management and staff is effective when communicating through log books. However, staff feel their opinions/thoughts are not necessarily taken into consideration by management.	X	X	Management
		X	X	Staff
				People with I/DD
Community/ University partnerships	Agencies value community/university partnerships to improve their knowledge about CBHPI and also feel that strengthening partnerships could improve CBHPI sustainability.	X	X	Management
		X	X	Staff
				People with I/DD
Peer relations	People with I/DD support each other in the home and community. However, sometimes disagreement on activities makes it difficult for staff to meet residents' wants and needs.	X	X	Management
		X	X	Staff
		X	X	People with I/DD
Aging with I/DD	Management, staff, and people with I/DD are unsure about how to effectively address negative aging outcomes.		X	Management
			X	Staff
			X	People with I/DD

1.   **<u>Agency values and policies</u>**

    a.   **<u>Support: Health promotion as a value</u>**

Management and direct support staff stated that the core value of their agency was to promote independence, choice and community integration for people with I/DD (TABLE III: Quote #1). They further stated that this is more likely to be achieved if people with I/DD are able to maintain good health. Management and direct support staff described the four components of health: physical, emotional, mental, and social health.

- Physical health: maintaining a healthy weight, exercising and eating the right foods, managing chronic health conditions, and requiring minimal medication to manage blood pressure, cholesterol or diabetes.
- Emotional health: feeling good about oneself, having a positive outlook, feeling ready to take on the day when you wake up, and being able to talk about your feelings with someone you trust.
- Mental health: keeping your brain refreshed, alert, and energized.
- Social health: being out in your community, interacting with community members (e.g., the banker, grocer, employee), building relationships with neighbors, exploring activities the community has to offer (e.g., festivals and fairs), and being able to have the choice to do what you want in the community.

TABLE III
AGENCY VALUES AND POLICIES QUOTES

Participant	Quote #	Quote	Support or Barrier
Staff	1	Our mission statement is to support quality programs which promote choice, independence and community integration for adults with developmental disabilities or other special needs (…) those are components of our mission that people try to operationalize as much as possible. For the most part, we've got many staff that are very seasoned, that have worked within the organization in different divisions and sort of gotten around, and are really committed to the individuals in our programs and to supporting them, protecting them, offering them meaningful activities.	Support
Staff	2	But somehow or another, it always seems to fall through the crack. It's like we get right at the tip of the iceberg, and then all the hard work, effort and time and energy that has been put in, it just ceases. We tend to keep going back and starting over and over again.	Barrier
Staff	3	It's kind of like how do you expect me to fit this kind of stuff in? Motivational is mediocre at best where is the reward? Not getting paid financially, going out here and run around doing all this kind of stuff. I think, once again, it's down to economics - bonuses, financial bonuses. I mean it's a rough world out there, and staff is being asked to do a lot of stuff for very little in return financially.	Barrier
Management	4	…There's no real motivation. Staff wise, a lot of their motivation comes from what's going on in their own personal life. If they feel like, "Okay, I'm at the point I need to diet," then they diet. And then they start to teach the clients about dieting, they start to teach them about exercising. (…) They're not motivated to do it, and it goes back to the question of the organization having some type of employee discount at a fitness center. I'm sure if that were in place, you would have more people taking them to the fitness center and working out and things like that because the employee benefits – sometimes, you look at it like, "Why am I doing this? What do I get out of it?"	Barrier
Person with I/DD	5	We love to work out	Support
Person with I/DD	6	We watch too much TV	Barrier
Person with I/DD	7	We eat too many chips and drink too much juice with sugar	Barrier

b.   **Barrier: Lack of formal policy**

Although management and direct support staff spoke about how their agency values health and community participation for people aging with I/DD, they stated that their agency did not have formally written policies in regards to these two areas. Several participants stated that the only written CBHPI may be found in monthly client goals, and these are usually generic and difficult to sustain. Management and staff acknowledged that their agency was making an effort to promote CBHPI for people aging with I/DD, but recognized the struggle to sustain these initiatives over time (TABLE III: Quote #2).

Findings showed that the lack of clear policy caused confusion in defining whose responsibility it is to implement CBPHI. The management believed direct support staff was responsible for implementing CBHPI; whereas staff felt it was management's responsibility to ensure CBHPI were being executed. Direct support staff felt that CBHPI were not a priority since it was not written as part of their job description. Direct support staff talked about being overwhelmed by their mandatory work responsibilities, leaving no time to engage people with I/DD in CBHPI. Several direct support staff stated that sustainable CBHPI would be more likely to occur if it was a part of their job description or if incentives were given for their efforts (TABLE III: Quote #3).

Management acknowledged that direct support staff had no incentive to engage people with I/DD in CBHPI and were easily overwhelmed by the added responsibility (TABLE III: Quote #4). Management described how direct support staff typically does not follow the program correctly when a new CBHPI is introduced. Consequently, the implementation of the program becomes overly complex, leaving direct support staff feeling stressed and discouraged from sustaining the program. Direct support staff spoke about the benefits of receiving formal

evaluations to provide constructive feedback on how well they are sustaining CBHPI and how they could improve. Although management stated that direct support staff received yearly evaluations, many staff that were interviewed stated that they either never received a performance evaluation or had not received one for 3 years or more.

c.   **Support: Informal CBPHI practices**

Most participants did describe informal CBHPI their agency had been successfully sustaining. Examples of successful informal CBHPI include: an agency-wide initiative to decrease the intake of soda and junk food consumed by people with I/DD; providing healthy snacks as an alternative at holiday parties; and encouraging staff to organize community outings during the evenings and weekends. Observations within the group home supported interview findings as it was evident that direct support staff made a thoughtful effort to promote client choice, seek out opportunities to engage people with I/DD in the community, and encourage people with I/DD to make healthy meal choices.

Through photovoice, people with I/DD felt that informal CBHPI made it easier for them to be healthy and active in their home and community. Examples given by people with I/DD include: helping them eat healthier, growing vegetables in their backyards, learning to make their own dinners, preparing their own lunches to take to workshops, and supporting them to be physically active (TABLE III: Quote #5; Figure 1). People with I/DD indentified the following barriers to sustaining CBHPI: enjoying chips and soda, eating at fast food restaurants because they can get a lot of food for little money, and watching too much television (TABLE III: Quote #6 & #7).

Figure 1. Health values. This photo was taken by an individual with I/DD describing how informal CBHPI, such as staff teaching people with I/DD how to make their own meals has supported healthy eating habits, resulting in less fast food being consumed. The photo was captioned as "Making our own dinners and lunches to take to workshop."

2.   **Resources and staff competencies**

a.   **Barrier: Budget cuts and lack of structure**

Management and direct support staff discussed how budget cuts have made it difficult to sustain CBHPI. Management spoke on the impact of state wide budget cuts on the agency, leaving limited funds available for people with I/DD to participate in the community (TABLE IV: Quote #8). Interestingly, direct support staff did not have a good understanding of how budget cuts affected the agency. Direct support staff typically spoke about budget cuts in regards to having inadequate support and resources to engage people with I/DD in CBHPI. They highlighted the need for transportation, exercise equipment, sufficient staffing (TABLE IV: Quote #9), and guidance from management. For example, when a person with I/DD was placed on a weight loss program, direct support staff was not given an action plan or exercise equipment to help the person achieve their weight loss goal. Although direct support staff felt confident in executing CBHPI, lack of structured action plans created a barrier in

sustaining CBHPI because direct support staff was uncertain about which methods worked best

to ensure sustainability.

TABLE IV
RESOURCES AND STAFF COMPETENCIES QUOTES

Participant	Quote #	Quote	Support or Barrier
Management	8	"It [budget cuts] affected everything. It really did. It affected our staffing levels, we sold a building for cost savings. We had to convert everybody to the Medicaid waiver program, so it hurt us tremendously. It hurt many agencies tremendously"	Barrier
Staff	9	Over time, things started to be cut and cut and cut and cut, and it seemed like each time the pie got shorter, it affected the clients. It affected the program. It affected the methodologies. It affected the material. So yes, there are barriers in community living where health is concerned, where staff don't have the material or might not have the ideology or things that need to be able to truly carry out responsibilities where health-related issues are concerned.	Barrier
Staff	10	I'm good at my job. I'll brag on myself. I read; I keep up with social history. I know what they're physically able to do and what they're not able to do. You can always come up with something for them (…) [A] technique I do use is I'm a very good cook. I would come in and all of them get a chance to ask me to cook something for them. Once I cook something that they like, then I show them how to cook that meal. That's motivation, right there. I use their taste buds for their motivation.	Support
Management	11	That [having an van] allows the clients to get up and go, and I love that! One client goes to the bank by himself, and that's amazing to me. To be able to walk into the bank and deposit his own check every week because the staff is able to get in the van and take him.	Support
Person with I/DD	12	Going to the park [with staff] to play basketball, soccer, or for a walk"	Support
Person with I/DD	13	Need more staff support when out in the community	Barrier

b.   **Support: Adaptability of staff**

Because of the lack of structured action plans, direct support staff had to utilize their own personal knowledge and creativity to support healthy lifestyles and community engagement for people with I/DD, regardless of barriers they encountered (TABLE IV: Quote #10). For example, transportation was identified by management, direct support staff and people with I/DD as both a support and barrier for sustaining CBHPI. Having a van at each group home made planning community outings a lot easier (TABLE IV: Quote #11; Figure 2). However, group homes who did not have their own van had to plan activity days in advance so they could secure transportation. In some cases, both management and direct support staff were willing to take people with I/DD in their own cars so that people with I/DD could participate in the community. If transportation was not available, direct support staff had to plan activities within walking distance so that people with I/DD could still be involved in their communities. These findings were confirmed by observation. Management and staff talked about how agencies need to keep transportation in mind when they are developing CBHPI for people with I/DD.

Figure 2. Resources. This photo was taken by an individual with I/DD to depict how having access to a van made it much easier for the group home to plan community activities, such as going to the bank or to the mall. This photo was captioned as "Van makes it easy to get places."

3. **Communication between management and staff**

    a. **Support: Communication**

Management and direct support staff talked about how communication between management and direct support staff was a support and barrier to sustaining CBHPI. The main source of communication reported by participants was communication logs that each group home is required to maintain. At the end of each shift, direct support staff documents important notes such as behaviors and moods, meals, community outings, or reminders for doctor appointments. Each direct support staff is required to review the communication log before they start their shift. Management and direct support staff view the communication log as a key source of communication regarding the activities, health, and overall wellbeing of people with I/DD (TABLE V: Quote #14). Through observation it was evident that direct support staff and management were diligent in completing the communication log book at the end of each shift to ensure that it was complete and accurate. Participants spoke about examples where good communication between management and direct support staff resulted in not only sustaining but improving informal CBHPI within group homes. For example, management and direct support staff spoke about a time when some of the people with I/DD at various group homes did not like the catering service that prepared their meals because the food was "boring" and they wanted the opportunity to choose their meals. Management and direct support staff were able to communicate effectively and identify alternatives to better meet the needs of people with I/DD.

TABLE V
COMMUNICATION BETWEEN MANAGEMENT AND STAFF QUOTES

Participant	Quote #	Quote	Support or Barrier
Staff	14	Everything is done with the communication log. If something isn't right, say a particular client isn't washing the dishes, you leave me a note – or the next staff that comes in a note – so we parlay on that same concept. We keep working that. If it still doesn't work, the next staff person leaves another note and, say, I'm coming in next, then I'll work on that. That's the way we do it as a team.	Support
Staff	15	This is one that really gets me. They talk through paper. They won't have staff meetings. I think sometimes, when you have staff meetings and you allow people to vocalize or verbalize some of the stuff that's going on, I think that's a sense of release for that person.	Barrier

b. **<u>Barrier: Communication</u>**

Although direct support staff views communication logs as effective, they feel as though communication that extends beyond the content of the communication logs could be improved. Direct support staff talked about the importance of verbal communication through meetings rather than always communicating in writing, on paper (TABLE V: Quote #15). Regular direct support staff meetings, however, do not occur at either agency. Direct support staff felt that management expects them to sustain CBHPI but does not have an appropriate communication system or culture to openly discuss suggestions and feedback about what was working/not working for people with I/DD.

4. **Community/university partnerships**

    a. **Support: Informal community partnerships**

        Management and direct support staff talked about building community/research partnerships with local businesses and organizations as an important way to support CBHPI sustainability within their agency. Furthermore, there were some management and direct support staff who were motivated to seek out informal community partnerships to ensure people with I/DD were engaging in their community. Management and direct support staff discussed how community outings typically follow the same routine, such as going to fast food chains, the store, or social events with other members of the I/DD community. This finding confirmed the observations that group homes struggled to find cost-effective community outings other than eating lunch at a fast food restaurant or buffet. For outings that require admission fees, some direct support staff discussed how they are expected to pay this fee out of their own pocket, which was seen as a barrier to sustaining CBHPI initiatives. Direct support staff suggested that the agency develop agreements with local organizations to reduce or eliminate costs for people with I/DD and direct support staff. For example, several direct support staff talked about speaking with community centers or the park district to explore the possibility of free or cost reduced gym memberships for both people with I/DD and staff. Direct support staff talked about partnering with other community agencies to learn from each other's efforts at sustaining CBHPI. Direct support staff would also like to see more community interaction outside of the I/DD community (TABLE VI: Quote #16).

TABLE VI
COMMUNITY/UNIVERSITY PARTNERSHIPS' QUOTES

Participant	Quote #	Quote	Support or Barrier
Staff	16	I think sometimes the community itself could possibly be more supportive in the sense that they want to help a disadvantaged individual do something different. You know? I mean there's a couple things I know the agency does like Boogie Nights but I think it happens too infrequently and it's also with just DD consumers. So I mean you can say it's somewhat of a community, but it's a DD community and not so much as, you know the outside community.	Barrier
Staff	17	Oh, God, please, yes. If you can walk in here and make something easier for me. You can say oh, well yeah, that's a good idea, but let's try this. That's what I'm looking for.	Support
Management	18	The research is really very important because it's bringing the best practice, and it's evidence based (…) What helps us [are the] findings. So it's not only me just saying I know this is what happens (…) But now, here is the research findings [then] go back out and ask for the dollars to support it (…) because then, the staff will continue to implement it (…) So they're doing that right now (…) I'm trying to get money so we can go back and continue this health initiative and expand it.	Support
Staff	19	We felt like we were doing something good for ourselves, as well as the clients, so it worked out well. Our morale was up. The clients' morale was up. But the only drawback was when they leave here, those clients who are self-travel, independent and live at home, as well as those clients who live inside of the CILA, they did not have control over their money or the food that's being bought.	Support and Barrier

b.   **Support and barrier: Formal university partnerships**

In particular, management spoke about how they built strong partnerships with nearby Universities as a means to improve the health and wellbeing of people with I/DD. University partnerships have allowed these two agencies to take part in numerous evidence-based research projects that have provided the knowledge, resources, and support needed to implement CBHPI for people with I/DD. Management and direct support staff stated they valued the expertise of researchers and used these partnerships to learn new strategies to engage people with I/DD in healthier behaviors and community involvement (TABLE VI: Quote #17). Some direct support staff said they liked it when researchers showed an interest in working with people with I/DD because this shows that people do care about the wellbeing of people with I/DD. Furthermore, management valued partnerships with universities because they were able to maintain and increase funding by reporting research findings to their funding agencies as scientific proof of the benefits of CBHPI (TABLE IV: Quote #18). Direct support staff talked about how they enjoy participating in research projects; however, they stated that once the research project ended so did the support to fund the project, making sustainability very difficult (TABLE VI: Quote #19).

Although participants understood the value of having established community partnerships with universities, some direct support staff felt as though researchers pushed their programs on the agency without understanding the dynamics of the agency or the people they serve. Direct support staff suggested that researchers would benefit from spending the day with people with I/DD to get to know them so that they could better tailor their program for the individuals who would be taking part in their research. Direct support staff stated that researchers do not disseminate research findings back to them, leaving them unsure of the outcome of their

investment of time and efforts and most importantly, which components of the research study were shown to be effective and should be continued.

     5.   **<u>Peer relations</u>**

          a.   **<u>Barrier: Conflicting peer interests</u>**

This theme speaks of the complex interactions between people with I/DD. Management, direct support staff and people with I/DD discussed how sustaining CBHPI can be difficult due to disagreements between people with I/DD regarding in what community activity they would like to participate. Observations confirmed that people with I/DD struggled at times to collectively decide on what activity they wanted to do, resulting in in-house tension as well as direct support staff frustration. Some direct support staff explained how one client not wanting to participate in a community outing often resulted in the entire group staying home because of limited staff support (TABLE VII: Quote #20).

TABLE VII
PEER RELATIONS QUOTES

Participant	Quote #	Quote	Support or Barrier
Management	20	For example, in one of our eight-person homes, on a weekend if four people wanna do one thing, two people wanna do something else, two people wanna do something else, and you've only got two staff on, it's sort of like how could we accommodate everybody's interest if people wanna go different places and do different things?	Barrier
Person with I/DD	21	Easy going when picking an outing	Support
Person with I/DD	22	No house unity	Barrier
Management	23	"The more high-functioning clients can be trained to teach the other functioning clients because you never know when the staff decides to leave for whatever reason"	Support

b. **Support: Supportive peer relationships**

Although people with I/DD may disagree at times on community outings,

direct support staff felt that people with I/DD had each other's best interests in mind. For

example, when a new direct support staff began working at the group home people with I/DD

would inform the new direct support staff of a peer's diet restrictions to make sure that their peer

is being supported properly. People with I/DD talked about how their peers made it easy for

them to engage in CBHPI because they encouraged each other while doing physical activity and

supported each other when they were in the community (Figure 3). Some examples of how they

supported each other included helping each other read the restaurant menu and cross the street,

paying for items at the store, supporting older people with I/DD who may need to take a break from walking, and sticking together so they do not get lost. People with I/DD talked about how engaging in CBHPI is easier when everyone gets along and everyone wants to participate in the activity (TABLE VII: Quote #21). Disagreement over a community activity or meal often resulted in frustration and poor execution of CBHPI (TABLE VII: Quote #22). This finding was also confirmed by observations that people with I/DD were enthusiastic to support each other around the house and when out in the community direct support staff felt that CBHPI should focus more on peer mentoring to improve the likelihood of sustainability, as a means to cope with staff turnover (TABLE VII: Quote #23).

Figure 3. Peer support. This photo was taken by an individual with I/DD and represents how people with I/DD value the support they receive from their peers when out in the community. This photo was captioned as "We stick together and help each other when at the store."

6. **<u>Aging with I/DD</u>**

Management, direct support staff, and people with I/DD all spoke about the increased number of people aging with I/DD. Both agencies began to focus their attention on the health of people aging with I/DD to become familiarized with the aging process and how they can better serve this growing population. Management and direct support staff discussed how an increased number of people with I/DD are experiencing age-related health conditions, such as arthritis, dementia, Parkinson's disease, Alzheimer's, hypertension, menopause, and how these health conditions were not known to younger direct support staff and management (TABLE VIII: Quote #24).

TABLE VIII
AGING WITH I/DD QUOTES

Participant	Quote #	Quote	Support or Barrier
Management	24	So we're seeing individuals with more aging issues – chronic health conditions. So that was our big initial move towards this whole health and wellness. The biggest change started because our population is aging. We're starting to see more of these issues related to aging and mobility issues, visual, hearing. A lot of our population – specifically, more tend to be in the residential settings – that had dementia, Parkinson's disease, Alzheimer's.	Barrier
Staff	25	I think staff are scared to have clients do something because they're afraid of what can happen, or they don't know how to exercise appropriately with an older person.	Barrier
Person with I/DD	26	Age and balance make it hard.	Barrier
Person with I/DD	27	We get tired quickly when walking.	Barrier

a.   **Barrier: Lack of training and knowledge**

Management and staff also spoke about their apprehensions in working with people aging with I/DD, whom they often perceived as too fragile and at a greater risk of falls (TABLE VIII: Quote #25). They talked about not being comfortable taking aging individuals out into the community or engaging them in physical activity because of their age and health conditions. Participants spoke about training they received from their agency (i.e., health and safety, medication administration, CPR and first aid, abuse and neglect, and behavior management) and stated that they felt the training they received was valuable and allowed them to feel confident in their job. However, managers and direct support staff felt as though they had not received adequate training in how to engage people aging with I/DD in CBHPI. This was a point of concern as participants recognized the importance of being active and engaged in the community as an individual ages. The limited training in this area worried direct support staff that they might not be able to properly serve people with I/DD. This finding was confirmed by observations that staff were often concerned about taking older individuals out of the house because of their poor balance and physical instability, which typically resulted in outings that required minimal walking such as going to eat at a restaurant. People with I/DD stated getting older affected their ability to participate in the community due to getting tired more easily, experiencing joint pain in their legs, and having trouble keeping their balance (TABLE VIII: Quote #26 & # 27; Figure 4). People with I/DD also talked about how eating healthy is important to maintaining good health but that it is sometimes hard to chew certain foods like vegetables and meats due to having issues with oral health and missing teeth.

Figure 4. Aging with I/DD. This photo was taken by an individual with I/DD and depicts how older house mates find it difficult to keep up with younger house mates when they are out in the community due to age related health issues, such as becoming tired quicker and not being able to walk as far due to arthritic pain. This photo was captioned as "Getting older. We get tired when walking."

E.   **Discussion**

The findings of the current study provide an in-depth system-level analysis of the support and barriers in sustaining CBHPI in group homes of I/DD agencies as identified by management, staff, and people aging with I/DD—a topic area that has been greatly under-researched. The PARIHS framework was used to guide this multi-methods investigation to meaningfully identify the barriers and facilitators that influence the sustainability of CBHPI for people aging with I/DD. The following discussion offers a brief synthesis on how the six key themes that emerged in this study integrate into the pre-existing literature.

1.   **Discussion of themes**

a.   **Agency values and policies**

Agency and individual values played an important role in the likelihood of CBHPI being sustained; however, the lack of formal policies specific to health and community participation was a barrier due to the lack of clear guidelines and role descriptions that result in a mutual understanding of the responsibilities involved in executing and sustaining CBHPI. This

finding supports past research that highlights program sustainability is more likely to occur if

frontline personnel have clear job expectations and role definitions (Hewitt at al., 2004; Jansson,

Benoit, Casey, Phillips, & Burns, 2010), management supports and encourages the program

(Savaya, Spiro, & Elran-Barak, 2008), and if the program is internally monitored (i.e., evaluating

the program's effectiveness within the organization and monitoring staff performance) (Elsworth

& Astury 2004). Program sustainability is dependent on the organization's recognition that the

program is a fundamental part of the organization's values and the integration of the program

within the existing system of the organization (Goodson, Smith, Evans, Meyer, & Gottlieb, 2001;

O'Loughlin, Renaud, Richard, Gomex, & Paradis, 1998; Shediac-Rizkallah & Bone, 1998).

Programs are more likely to be sustained after the researchers, who have created and

implemented the program leave, if an organization's formal policies are directly in line with the

objectives of the program. Therefore, having formally written policies on health and community

participation for people with I/DD would facilitate the likelihood that CBHPI will be sustained.

b. **Resources and staff competencies**

Staff competencies in health and community participation were supportive

in sustaining CBHPI as they contributed to increased staff confidence in their abilities to adapt to

the limited (and often decreasing) resources available to execute CBHPI. Frontline personnel are

an invaluable resource because they have inside knowledge and a first-hand perspective of where

(and why) there are gaps within the existing services being provided (Jansson et al., 2010).

Management should acknowledge the opinions and experiences of direct support staff and create

a means to collaboratively identify and strategize needs and gaps. Conversely, budget constraints

acted as a barrier to sustainability and sometimes the lack of resources to execute CBHPI was too

dire for staff to overcome. Therefore, it is important that researchers, management, direct support

staff, people with I/DD, and other stakeholders to openly discuss how to be proactive in sustaining CBHPI and how to mitigate the issues of restricted finances.

Non-profit I/DD agencies rely on the financial budgets they receive from the state to support the majority of services they provide for people with I/DD; however, as it currently stands there are no state or federal policies that mandate I/DD agencies to allocate public funds to sustaining health and community participation programs for people with I/DD. Accordingly, it has been suggested that government policies should be taken into consideration when examining program sustainability (Savaya et al., 2008), especially since financial resources affect the availability of other important resources needed to execute CBHPI, such as transportation, purchasing healthy foods, memberships in local community centers, and comprehensive staff training on healthy aging. Within the United States, people with I/DD are primarily supported by the Medicaid program, which funds over 77% of all publicly funded long-term services and supports for people with I/DD (Braddock et al., 2013). Specifically, the Medicaid Home and Community Based Services (HCBS) Waiver has become the primary funding source to provide long-term community services for people with I/DD (Rizzolo et al., 2013). States should consider funding activities through their Medicaid HCBS Waivers that support the provision of evidence-based health and community participation programs. States have an exceptional amount of leeway in determining the services and supports they offer through their Medicaid programs and should consider providing incentives to I/DD agencies that successfully implement evidence-based programs, such as outcomes-based funding rates. Researchers should examine the cost-benefit ratio of providing health promotion activities. If these efforts are found to be cost effective and to prevent secondary conditions, states may be more likely to incorporate them into their list of reimbursable Medicaid services. Researchers should be also aware of the political

climate that is effecting I/DD agencies and be open to working with agencies on how to best

utilize their strengths as an agency (i.e., staff competencies) to counterbalance barriers (i.e.,

budget) to increase the likelihood of CBHPI sustainability.

     c.   **Communication between management and staff**

Communication between management and direct support staff was a

support and barrier to sustaining CBHPI as it ensured both management and staff were well

informed about their clients (people with I/DD) and, thus, allowed them to provide their clients

with appropriate support. Researchers have found the frontline workers' knowledge, attitudes,

and skills play an important role in the way people with I/DD experience community living

(Burchard &Thousand, 1988; Lakin, 1988). For this reason, it is imperative that they are not only

kept well informed on system level issues, but also be encouraged and supported by management

to communicate their ideas and concerns about sustaining CBHPI for people with I/DD. When

examining the sustainability of CBHPI researchers should take into account the communication

dynamics between management and direct support staff. Poor communication networks may lead

to important information and/or issues not being adequately discussed which may potentially

contribute to a lack of clarity, direction, and sustainability of CBHPI.

As such, management should encourage open communication and transparent discussions

with direct support staff regarding agency issues, such as systems, policies, resources, and

budget cuts, so that direct support staff have a good understanding on how and why issues

affecting the agency influence the services being provided to people with I/DD. Because budget

constraints are a barrier to sustaining CBHPI, it may be beneficial for management to inform

direct support staff about the financial status of the agency and help direct support staff to

understand why and how budgetary constraints affect programs and services. By having direct

support staff that understand the complex dynamics of budgetary cuts they are more likely to want to sustain CBHPI despite the limited resources available because they will understand that the lack of resources is not due to poor management or lack of job support, but rather due to budget constraints outside the agency's control.

d. **Community/university partnerships**

Community and university partnerships was a facilitator in sustaining CBHPI as I/DD agencies relied on such collaborations to improve the knowledge about aging, health, and opportunities for community participation that better serve people with I/DD. More specifically, participating in evidence-based research projects was a facilitator to sustain CBHPI; however, poor dissemination of research findings was a barrier as agencies are often uncertain about what came from their research efforts and unsure of what parts of the program were effective in improving the health and community participation of people with I/DD. Poor dissemination of knowledge generated during research studies is a common problem faced in the research realm (Colquhoun et al., 2010; Jansson et al., 2010) and it holds true for the current study. Because community partners are mostly responsible for implementing and sustaining an innovation, it is important that they have a sense of autonomy and an investment in the knowledge that is being created (Jansson et al., 2010). Researchers must take into consideration the expertise of management, staff, and people with I/DD when designing CBHPI to ensure they are appropriately reflecting the needs of I/DD agencies. By including I/DD agencies and people with I/DD in the development of a study design, researchers will be better able to understand the values, beliefs, and attitudes of the agency and accurately design CBHPI that are relevant to the agency needs.

e.   **Peer relations**

Since direct support staff play such a vital role in sustaining CBHPI and high staff turnover rates within I/DD agencies was an important barrier, future policies, procedures, and services should focus on peer mentorship among people with I/DD as findings highlighted that peer mentoring may be a facilitator to help sustain CBHPI. Although this is an under researched area, it was suggested that peer mentoring may be able to bridge the gap between passive inclusion and full meaningful participation for people with I/DD (Hammel, Magasi, et al., 2008). Long term sustainability of health promotion programs/interventions may be more likely to succeed when peer mentoring is used because it involves peers translating knowledge directly to the community, rather than knowledge coming from professionals only (Hammel, Jones, et al., 2008; Lorig & Holman, 2003; Marks, Allegrante, & Lorig, 2005). The general KT literature suggests that peer mentorship may be a useful strategy to promote implementation of knowledge because it can facilitate the development of new skills, support continued learning, help peers become better informed about their own choices/decisions, and help build relationships with internal and external experts (Gagliardi et al., 2009). Furthermore, peer mentoring may allow people with I/DD to be advocates r not only for their own health and community participation, but also for their peers.

f.   **Aging with I/DD**

Providing support for people aging with I/DD so that they can remain in the community as they age is a relatively new component of service provisions for I/DD agencies and there is uncertainty on how to best support people with I/DD as they age. It has been suggested that organizations will have to re-address the way they provide services, such as CBHPI, for people with I/DD as they age. Because people with I/DD experience the onset of

age-related health issues earlier and more rapidly compared with people without I/DD, it is vitally important that I/DD agencies be proactive and preventative rather than reactive to adapting polices, services, and procedures to effectively support people with I/DD as they age (Jokinen et al., 2013).

An interesting finding of this study was that it showed that people with I/DD did not mention any positive aspects of the aging process and only focused on the negative attributes. This finding is consistent with the general aging literature that shows older adults typically report negativity towards aging (Meisner, 2012). As people with I/DD are now living longer, we must gain a better understanding of the aging perceptions of this population and explore how negative aging stereotypes may be effecting the health and community participation of people with I/DD. This is an important line of inquiry given that older adults who report having negative aging perceptions practice fewer health-related behaviors and have poorer outcomes across multiple health domains (Meisner, 2012).

2. **Limitations and future research**

As with any qualitative study researcher bias is present. The current study was designed and analyzed through a disability studies lens, thus the researcher may have been more sensitive to identifying themes that were representative of the social model of disability (i.e., social support or environmental barriers to participation). Future research should continue this line of investigation with a larger sample size involving I/DD agencies from other geographical locations to see if findings can be generalized in other settings, explore how aging is experienced between men and women, noting gender differences, and examine how younger caregivers, who are unfamiliar with the aging process can be better supported as they serve people with I/DD who are aging. Participants (i.e., management, direct support staff, and people with I/DD) all

valued the importance of health and community participation; so, for this reason, investigating I/DD agencies who may not value the importance of health and community participation may present other interesting findings that effect program interest and sustainability. Furthermore, the people with I/DD involved in the study primarily had mild to moderate I/DD and findings may not be consistent with individuals with more severe I/DD.

F.   **<u>Conclusion</u>**

The current study contributes to the knowledge base by providing a multi-level systems analysis of the facilitators and barriers influencing the likelihood of CBHPI being sustained by I/DD agencies, which included the direct perspectives of people with I/DD, direct support staff, and management within larger I/DD agencies. Past I/DD research has commonly evaluated the effectiveness of evidence-based programs that have been designed; however, limited research has examined the factors that affect the likelihood of sustainability. The current study helps address this gap. The study also demonstrated how participatory action methods can be effectively used to meaningfully engage personnel from various agency levels to provide a multi-level understanding about the topic, while still ensuring the voices of people with I/DD were represented in the production of knowledge, and not overshadowed by the views of management and direct support staff. An interesting note is that people with I/DD, direct support staff, and management identified similar facilitators and barriers to sustaining CBHPI. The findings of this study can help ensure that I/DD agencies have the appropriate policies, resources, and practices in place to adequately support the growing population of people aging with I/DD in the community. By expanding the program sustainability knowledge base, that is rooted in both the voices of people with I/DD and at multiple-levels within I/DD agency organizations, we can

learn how to more effectively support the needs of people with I/DD to improve their health and

community participation as they age.

V. DISCUSSION

A.   <u>**Summary**</u>

This dissertation provides a system level understanding of the barriers and facilitators associated with sustaining CBHPI designed for people aging with I/DD living in group homes managed by I/DD agencies. The research question speaks for a call to a greater understanding of the factors involved in sustaining evidence-based programs/curricula in community settings, particularly for understudied populations, such as people with I/DD (DerAnanian et al., 2012; Hughes et al., 2011). This dissertation contributes to the knowledge base by providing three manuscripts that present a critical examination of sustaining CBHPI for people aging with I/DD living in the community by 1) providing a critical literature review about knowledge translation and the implications for I/DD research to adapt the PARIHS framework to better understand how evidence-based knowledge can be sustained by people with I/DD as well as the I/DD agencies that provide services to this population, 2) discussing how accessible methodologies can meaningfully include people with I/DD to be involved in the production and dissemination of knowledge. Directly speaking to the need for people with I/DD to be given greater opportunities to participate in research inquiry that directly effects their livelihood, and 3) providing a multi-level systems analysis of what management, direct support staff, and people aging with I/DD identify as key factors to sustaining CBHPI within group home settings.

B.   <u>**Implications of Policy and Practice**</u>

These findings can be useful in supplying information on policies and system changes at the I/DD agency level and at the state and federal level about how to better support people with I/DD to engage in CBHPI as they age, especially since current policies and practices lack the perspective of people with I/DD (Shakespeare, 2013). Currently, the involvement of people with

I/DD in system changes is limited. One of the main reasons contributing to this fact is that key stakeholders are unaware of how to meaningfully include people with I/DD in the process. There is a lack of research examining how people with I/DD are actively involved in developing new policies, procedures, and programs related to aging in their community. The current dissertation provided people with I/DD the opportunity to be involved in knowledge production and dissemination through utilizing participatory methods, such as photovoice and participant observation, as well as providing people with I/DD an accessible mode to organize and articulate their thoughts about CBHPI sustainability.

Additionally, there is also a lack of I/DD agency employee representation when examining both agency-level and government level issues pertaining to people with I/DD. Management and frontline employees can provide insightful knowledge into why certain policies/producers may or may not benefit people with I/DD. For example, direct support staff provide a 'ground level' understanding about how to execute policies and procedures relating to CBHPI; such as being able to identify the factors that facilitate or prevent the successful implementation; whereas management possess a logistics perspective on how their agencies operate, and how sustaining CBHPI are effected by state and federal regulations and funding mechanisms. For these very important reasons, the current dissertation incorporated the input of management and direct support staff, not to overshadow the voices of people with I/DD, but to provide a comprehensive analysis of CBHPI sustainability.

In order for agencies to best support people aging with I/DD, researchers have a responsibility to conduct and disseminate evidence-based knowledge to agencies so that they are well informed about the practices that have shown to be beneficial. Research that has been conducted about the health of people with I/DD has primarily focused on identifying disparities

(Rimmer & Yamaki, 2006; Yamaki, 2005), and developing evidence-based health promotion programs (Heller et al., 2012; Mann et al., 2006; Marks, Sisirak, Heller et al., 2010; Tracey & Hosken, 1997). However, there has been minimal research examining the factors involved for people with I/DD to sustain this evidence-based programs so that they can continue to participate in positive health behaviours and remain active in their community.

The current dissertation identified six main themes that contribute to CBHPI sustainability for people aging with I/DD living in group homes: agency values and policies; resources and staff competencies; communication between management and staff; community and university partnerships; peer relations; and aging with I/DD. Agency values and policies was described as both a support and barrier. Management, direct support staff, and people with I/DD stated that the agency values and respects health and community participation for people aging with I/DD; however, the lack of the agencies' policies to support CBHPI is a barrier to long term sustainability. Management, direct support staff and people with I/DD discussed resources and staff competencies to be both a barrier and support to sustaining CBHPI. More specifically, staff competencies to execute CBHPI was viewed as a support to sustainability; however, the lack of agencies' resources, such as lack of transportation, and budget constraints, was viewed as a barrier. Only management and direct support staff spoke about communication as a barrier and support to CBHPI sustainability, stating that the agency does well when communicating about the needs of people with I/DD in written format; however, direct support staff feel as though verbal communication with management is a barrier, leaving direct support staff feeling voiceless and not well informed about how to implement/sustain CBHPI. Community and university partnerships were identified as a barrier and support by management and direct support staff as they valued community and university partnerships to improve their knowledge

and access to CBHPI; however, it was felt as though university partnerships could be improved as poor dissemination of research findings was a common experience noted by participants. Peer relations were described as interactions between people with I/DD and their peers, which were seen as both a barrier and support. Management, direct support staff and people with I/DD discussed how people with I/DD would support their peers in engaging in CBHPI in their homes and when out in the community; however, peers often would disagree on what community outings they wanted to participate in, thus resulting in unresolved conflict. Aging with I/DD was identified as a barrier by management, direct support staff, and people with I/DD as participants were unsure how to engage in CBHPI for people who are aging with I/DD.

Findings are consistent with past research that has found that program sustainability is dependent on: 1) the agency recognizing that the program is aligned with the fundamental values of their organization (Goodson et al., 2001; O'Loughlin et al., 1998; Shediac-Rizkallah & Bone, 1998); 2) providing clear job exceptions and role definitions for frontline personnel to execute and sustain the programs (Hewitt at al., 2004; Jansson et al., 2010); 3) management's support and encouragement of the program (Savaya et al., 2008); and 4) the agency internally monitoring the effectiveness of the program and providing constructive feedback to frontline personnel (Elsworth & Astury, 2004). Frontline personnel are instrumental in the execution of programs (Burchard & Thousand, 1988; Lakin, 1988). For this reason, findings from the current study suggest that direct support staff be informed about the system level dynamics of the agency so that they have an understanding of not only how the agency functions at the boarder level, but also are aware of how the financial constraints of the agency are effecting the resources and programs available to people with I/DD. By being better informed about the external and internal factors, front line personnel may feel more included and motivated to sustain CBHPI. Another

interesting finding of the current study was that aging with an I/DD was seen as a barrier to sustaining CBHPI. The gerontology literature has found that negative aging stereotypes typically lead to poor social and physical health (Meisner, 2012). If people with I/DD only view aging as a barrier to engaging in health behaviors and participating in their community, they may not be motivated or understand the value of participating in CBHPI as they age. Examining negative aging stereotypes among people with I/DD requires further exploration to ensure that evidence-based programs/curricula are developed to include a healthy aging component to educate not only people with I/DD about successful aging, but management, direct support staff and other key stakeholders.

It is essential that people with I/DD become active players in the production of knowledge to ensure evidence-based findings are meaningful and relevant to their needs. Unfortunately, people with I/DD have had limited opportunities to be meaningfully involved in research (Jurkowski, 2008). Consistent with past research, the current study found that agencies felt as though their partnerships with universities could be improved, specifically, by including people with I/DD as well as key personnel (management and direct support staff) in the study design so that the research purpose is relevant to addressing the actual needs of people with I/DD rather than perceived needs. There are limited studies that have been conducted which included both people with I/DD and I/DD agency personnel in the production and dissemination of knowledge. The current study is a notable example of how to conduct a multi-level systems analysis while including people with I/DD as active players in the production and dissemination of knowledge so that they can advocate for change to improve their ability to sustain CBHPI as they age.

C.   **Knowledge Translation and I/DD Research**

The current dissertation contributes to the KT and disability literature as it is the first study to adopt the PARIHS framework in I/DD research. The PARIHS framework was a useful tool to guide agencies to better understand the factors involved in sustaining CBHPI as they specifically relate to agency dynamics; thereby , directly addressing the call in the literature for I/DD agencies to take a proactive, rather than a reactive approach to understanding how the aging process effects people with I/DD and adapt their policies, procedures and services to better support aging consumers (Jokinen et al., 2013). The framework can be implemented to guide I/DD agencies in the development of CBHPI policies because it identifies the strengths and weaknesses of an organization and how to optimize strengths to support long term implementation (Helfrich et al., 2009). For example, management and direct support staff within the current study made a thoughtful effort to build formal/informal community partnerships to improve the health and community participation of people with I/DD, despite budgetary constraints and limited resources. By developing CBHPI that are directly in line with how an organization operates, researchers, I/DD agencies and people with I/DD can take a proactive design approach and develop action plans to address common barriers (i.e., budgetary constraints, limited resources) that organizations encounter when trying to sustain CBHPI.

While the PARIHS framework and its interconnected elements - context, facilitation, and evidence - explain the findings of this study, it lacks representation of people with I/DD in the process. The study shows that it is imperative that the framework be adapted for I/DD agencies so that it not only focuses on system dynamics that involve management and direct support staff, but also centralizes the framework's three elements around input from people with I/DD as suggested in Figure 5. Having the involvement of people with I/DD at the forefront of the

framework may ensure that I/DD agencies and researchers remember to meaningfully engage
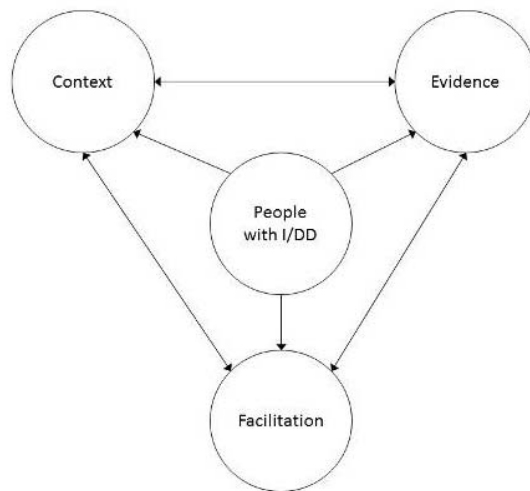
people with I/DD when discussing system dynamics.

Figure 5. PARIHS framework centralizing around people with I/DD.

D.   **<u>Contributions to Disability Studies</u>**

Thomas and Corker (2002) state that in order to understand disability it must be actively discussed and not silenced simply because people may find it too intimating or challenging to talk about. Disability studies is a dynamic field of research that recognizes the value of examining disability through a variety of paradigms to help understand the complexity of living life with a disability. The current dissertation chose to utilize a KT paradigm to understand factors related to sustaining CBHPI for people aging with I/DD. This paradigm acknowledges that people with I/DD are their own experts about how I/DD affects their ability to engage in CBHPI. Surprisingly (at least for disability scholars and advocates), people with I/DD did not identify I/DD as a factor in not being able to sustain CBHPI engagement, but rather discussed how environmental and resources barriers were impeding their ability to participate in CBHPI.

Although society has become more accessible for persons with disabilities (e.g., transportation, education, technology), many factors still remain that prevent people with disabilities from experiencing the same opportunities as people without disabilities (e.g., access to good health care). The reason for this has been suggested to be a direct result of government programs and policies that shape the way people with disability experience society (National Council on Disability, 2011). For example, policies are based on entitlement and non-entitlement, narrow guidelines that limit the number of benefits that a person can apply, and how medical doctors are the gatekeepers for individuals to access these benefits (Scotch, 1989). In order for significant change in how people with disabilities experience society - and how society experiences people with disabilities - those in a position of power need to critically re-examine and deconstruct the frameworks whereby disability policy and governmental programs have originated. Without this critical understanding, new policies and programs will still be rooted in

past ideologies, such as the medical model, and thus falling into an all too familiar trap whereby people with disabilities are simply seen as less than substandard citizens whose 'entitlement' to certain benefits and services will be judged by medical doctors who may have little knowledge and understanding of disability.

Since evidence-based research is highly regarded by society, it is vital that disability scholars utilize scholarly research as a platform to reject stigmatizing labels about I/DD and advocate for accurate representation of people with disabilities, particularly for those with I/DD as they continue to struggle to be seen as 'real human beings' who have purposeful and meaningful thoughts and actions (Ferguson & Ferguson, 2001). In order to achieve accurate representation of people with I/DD in the production of knowledge, researchers must utilize accessible research methods to actively involve people with I/DD in the research process. This dissertation demonstrated that if given the opportunity and a supportive environment, people with I/DD can contribute meaningful insight on factors they believe are affecting their ability to engage in CBHPI, over time. Since there is such limited research in regards to aging with I/DD this is an optimal time to ensure that the knowledge base being generated actively includes the perspectives and concerns of people with I/DD. Furthermore, people with I/DD should be included in the dissemination of knowledge so that they can advocate for policy and system change that are directly reflective of their needs to support successful aging.

APPENDICES

APPENDIX A

IRB Approval Letter

UNIVERSITY OF ILLINOIS
AT CHICAGO

Office for the Protection of Research Subjects (OPRS)
Office of the Vice Chancellor for Research (MC 672)
203 Administrative Office Building
1737 West Polk Street
Chicago, Illinois 60612-7227

Approval Notice
Amendment to Research Protocol and/or Consent Document – Expedited Review
UIC Amendment # 10

June 27, 2013

Joy Hammel, PhD, OTR
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RE: Protocol # 2009-1156
         "Healthy Homes & Communities: Examining How Managing the Environment I
         Influences the Health and Participation of People with ID"

Dear Dr. Hammel:

Members of Institutional Review Board (IRB) #2 have reviewed this amendment to your research and/or consent form under expedited procedures for minor changes to previously approved research allowed by Federal regulations [45 CFR 46.110(b)(2)]. The amendment to your research was determined to be acceptable and may now be implemented.

Please note the following information about your approved amendment:

Amendment Approval Date: June 17, 2013

APPENDIX B

Interview Guide for Management

Can you tell me about the mission and purpose of your agency?

Can you describe the overall environment of your agency?

Can you describe your typical day at work?
- Attend meetings, conferences, visit group homes, etc.

How would your agency define healthy community participation?
- How would you describe the health of clients in your agency?

How would your agency describe the health status of clients?
- How would you describe the level of community participation of clients you serve?

How does your agency define community participation for people with I/DD
- How would you describe the level of community participation of your clients agency?

Can you tell me about any research programs or initiatives that your agency has taken part in specific to health and community participation?
- What did you like/didn't like about these programs?

- Is your agency still doing any of these programs/initiatives? If so why or why not?

What are the main barriers you face when implementing programs and activities that are meant to improve health and community participation for adult clients?
- How do you think some of these barriers can be overcome?

Can you tell me about any evaluation process that regional managers and support staff receive with respect to how well they are actively engaging adult clients to participate in positive health behaviors in their communities?

How would you describe the motivational level of regional managers and support staff for implementing health and community participation programs/activities at the group home level?

How would you describe the competency level of your staff to implement programs/activities independently at the group home level?

How would you describe the culture of your agency? (beliefs, morals, values)

Can you tell me about the economic trends and constraints your agency is facing that might be effecting the implementation of healthy community participation initiatives for residences?

APPENDIX B (continued)

Can you tell me about the funding mechanisms of your agency?

Can you tell me about how your agency documents health and participation for adult clients living in group homes?

Can you tell me about any continuing education classes that are offered to regional managers and support staff specifically about how to improve health and community participation for clients living in group homes?

What is the professional background of your staff (e.g. level of education, trained professionals?) What is your professional background? (e.g., level of education, years of experience working in a non-profit organization)

Is there anything you would like to comment on that was not addressed?

APPENDIX C

Interview Guide for Direct Support Staff

Can you describe your typical day at work?
- Duties, responsibilities, etc.

How do you define what it means to be health?
- How would you describe the health of the clients you serve?

How do you define community participation?
- How would you describe the level of community participation of the clients you serve?

Can you tell me about any staff training you have received from the agency to improve the health of clients?

Can you tell me about any staff training you have received from the agency to improve the level of community participation of clients?

Can you tell me about any research programs or initiatives that you have taken part in at the agency that dealt with improve health and community participation of clients?

Can you tell me what you liked/didn't like about these programs?
- Are you still doing any of these programs/initiatives? If so why or why not?

What are the main barriers you face when implementing programs and activities that are meant to improve healthy community participation with clients?
- Time? Physical resources? Willingness of clients to participant? Transportation?

Can you tell me about the economic trends and constraints the agency is facing that might be effecting the implementation of healthy community participation initiatives for residences?

Can you tell me about any evaluation process that you receive with respect to how well you are actively engaging adult clients to participate in positive health behaviors within their communities?

How would you describe your motivational level for implementing health and community participation programs/activities for adult clients?

How confident do you think you and other managers/support staff are with implementing programs/activities independently?
- What are some barriers you face? What are some ways you think these barriers can be addressed?

Can you describe to the culture of your agency you work for? (beliefs, values, morals)

APPENDIX C (continued)

Can you describe the atmosphere and dynamic of the group homes that you work for?
- physical environment, social environment, age of clients, hobbies of clients,

What is your professional background (e.g. level of education, number of years with the agency?)

What is your age?

Is there anything that you would like to comment on that was not addressed?

APPENDIX D

Participant Observation Worksheet

Date and Time:
Location:
Observation #:
Duration of Observation:

Individuals involved	Location of Observation	Description of Observation

APPENDIX E

Photovoice Guide

Creating a Photobook

a. Now they will create a photobook with the pictures they have taken during the past week.

b. Distribute pictures and ask them to choose up to 6 pictures they like.

c. Once participants have mounted their pictures on photobook pages, help them write a sentence or two describing the picture (e.g., I read books at the library and it was fun)

d. Also assist them to identify one picture that supports and one picture of barriers [in regards to their health and community participation]. Participants will place them on the pages of the photobook and will write down how that helped them or made things difficult for them.

e. Now participants will present their photobooks to other group members. Ask for a volunteer to start and then go around the group.

Note: As participants present their photobooks pictures, you may want to point out whether the picture presents a support [facilitator] or barrier. Use "things that helped you do things" and "things that did not work" instead of "supports [facilitators] and "barriers"

Photovoice guide taken from: Hammel. J. (2010). Facilitator Guide: Engaging while aging: Staying in your home and engaging in the community. University of Illinois at Chicago.

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