What is and isn’t working: Factors involved in sustaining community-based health and participation initiatives for people aging with intellectual and developmental disabilities

Abstract

As people with intellectual and developmental disabilities (I/DD) age it is important that I/DD agencies are prepared to support healthy aging in homes and in communities. This study explored supports and barriers to sustaining community-based health and participation initiatives (CBHPI) for people aging with I/DD living in group homes managed by agencies. The study utilized interviews and photovoice with 70 participants—35 individuals with I/DD and 35 management/direct support agency staff. **Data were analyzed through content analysis and triangulation of data where five themes emerged: Agency values and policies related to healthy aging; resources and staff competencies; communication between management and staff; community/university partnerships; peer relations.** Findings show that I/DD agencies and people with I/DD value CBHPI, but they find them difficult to sustain due to limited resources and lack of training specific to aging with I/DD.

Keywords: Intellectual/developmental disabilities, health promotion, knowledge translation, systems, sustainability

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, Prouty, Scott, & Lakin, 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 a level of control over their own lives, giving them the freedom to exercise their right to access services and activities offered by the community and to improve their overall quality of life (Willer & Intagliata, 1981). To fulfill these objectives, an influx of community-based services were created to support people with I/DD living in the community (Chowdhury & Benson, 2011). Despite the increased number of community-based services offered, researchers find that people with I/DD do not feel they are valued community members (Forrester-Jones et al., 2002) and still struggle to participate meaningfully (Bratt & Johnston, 1988; Hammel, et al., 2008a; Marks & Heller, 2003). These findings lead researchers to wonder if people with I/DD have merely become physically relocated into the community, rather than reintegrated and meaningfully engaged citizens (Cullen et al., 1995).

Research has shown people with I/DD experience the aging process earlier and at a faster rate than people without I/DD (Connolly, 1998; Evenhuis, Hermans, Hilgenkamp, Bastiaanse, & Echteld, 2012; Nochajski, 2000; McKenzie, Ouellette-Kuntz, & Martin, 2017; World Health Organization, 2001). They face an increased risk of age-related chronic diseases which may negatively impact their ability to engage in their community without proper support. Given that an individual’s health and quality of life are related to community integration and social inclusion (Heller, McCubbin, Drum, & Peterson, 2011; Marks, Sisirak, Heller, & Wagner, 2010; Schalock, Bonham, & Verdugo, 2008), this demonstrates a clear need to develop a greater understanding of how aging with I/DD affects a person’s level of community participation (Heller, Fisher, & Marks, 2014).

Community-based agencies provide services and supports to people with I/DD to allow them to engage in positive health behaviors and participate in their community, and subsequently supporting their healthy aging. Little is known, however, about the factors involved in sustaining evidence-based community-based health participation initiatives (CBHPI) being implemented by

I/DD agencies. This is an area of research that warrants further investigation, as the physical and social health outcomes of people aging with I/DD can be improved by sustaining CBHPI for people with I/DD, thereby decreasing the risk of isolation and re-institutionalization due to poor or declining health. Although there are evidence-based programs focused on improving the health and community engagement of people with I/DD that include knowledge translation (KT) strategies (Heller, Hsieh, Badetti, & Parker, 2012; Lunsky, Straiko, & Armstrong, 2003; Marks, Sisirak, & Heller, 2010), the inability to sustain these programs long term remains a common and consistent barrier that requires further investigation (Heller et al., 2014; Mancini & Marek, 2004; Sharir & Lerner, 2006).

Within the general health promotion literature, factors related to successful program sustainability are inconclusive, sometimes contradictory, and have no standardized guidelines or methods available to evaluate potential sustainability (Pluye, Potvin, & Denis 2004). However, research highlights that program sustainability is dependent on organizational capacity and without resources, staffing, and leadership to support offered programs, sustainability is unlikely (Cassidy & Leviton, 2006). Marks 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, verbal communication about program engagement, recruitment facilitators, and reasonable demands of staff’s time. It is important that program providers take into consideration organizational capacity by including community members (i.e., an organization’s management, direct support staff (DSS), and people with I/DD) in the development, design, long-term implementation, and evaluation of a program.

Knowledge translation (KT) practices can be utilized to help evaluate program sustainability as it is rooted in the fundamental principle that researchers should integrate community members in knowledge creation. This ensures that knowledge generated is appropriate, accessible, and meaningful to the targeted population whom it is intended to benefit (Armstrong, Waters, Roberts, Oliver, & Popay, 2006; Kitson, 2009). The majority of KT research is conducted in health care systems and clinical settings (Colquhoun, Letts, Law, MacDermid, & Missiuna, 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 the community (Marks, et al 2010; Rogers & Martin, 2009; Sudsawad, 2007).

KT theories are sometimes 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 active and meaningful contributions by both researchers and community members (Helfrich et al., 2010). Therefore, the PARIHS framework recognizes the personal experiences of community members as valuable evidence, equal to that of knowledge generated by researchers.

To evaluate the implementation of evidence-based knowledge into an organizational structure or system, the PARIHS framework investigates the interplay of three key elements: **1) evidence (i.e., knowledge from various sources including personal and professional experiences of key stakeholders)**; 2) context (i.e., culture, leadership, evaluation); and 3) facilitation (i.e., identification of support that facilitates program implementation) (Helfrich, Li, Sharp & Sales, 2009; Spassiani, Parker Harris, & Hammel, 2015). This approach acknowledges that successful implementation is a complex and unpredictable process and, as such, is a flexible and dynamic framework that can be applied to a variety of settings (Helfrich et al., 2010).

Spassiani et al (2015) discuss the versatility of the PARIHS framework and how it can be utilized in I/DD research as it highlights personal experiences, focuses on context, and enables action planning that facilitates successful implementation and transfer of evidence-based knowledge.

The PARIHS framework was used in the current study to examine the supports and barriers associated with sustaining CBHPI designed for people aging with I/DD living in group homes managed by I/DD agencies. By utilizing a KT framework specific to program sustainability, this study aims to generate a better understanding of the dynamic factors 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, management and DSS as done in previous studies (e.g., Spassiani et al, 2015). **For the purposes of this study, program sustainability was defined as a program that was sustained over a period of time (Shediac-Rizkallah & Bone, 1998). However, in order to gain an in-depth understanding of barriers and facilitators affecting sustainability there was no specific time frame established in order to naturally examine barriers and facilitators of programs that had or had not been sustained.** Community-based health and participation initiatives (CBHPI) were defined as any evidence-based strategy, guideline, curriculum, program, or action plan designed for people with I/DD that aims to improve their overall health and level of community participation. **This research addresses an important gap in the literature that calls for a greater understanding of the different factors that may be affecting the ability of aging people with I/DD to meaningfully participate in CBHPI.** This research will also contribute to a greater representation and more inclusive involvement of people with I/DD in the knowledge production directly affecting the quality of their lives.

Methods

Participants

Two non-profit I/DD agencies that were previously involved in CBHPI participated in the study. With the agencies' directors' assistance, a purposeful sampling method was used to identify group homes that had aging residents with I/DD who were engaging in CBHPI. A total of six group homes were asked to participate in the study - four from one agency, two from the other. **Individuals with I/DD and DSS were informed about the project by the primary researcher visiting each of the six group homes to introduce the project. The primary researcher discussed the research with management at the group home and recruitment of potential participants. Accessible information about the project was provided for individuals with I/DD.** From these six group homes 35 staff were recruited, including six management staff (i.e., directors and managers) and 29 DSS. Of the 35 staff, participants either 1) participated in the semi-structured interview, or 2) facilitated individuals with I/DD during the photovoice exercise, or 3) participated in both activities. All of the 35 residents with I/DD across the six group homes participated in the study and provided written informed consent or assent. **Legal guardians provided written consent for those individuals with I/DD who did not have capacity to consent for themselves.** Demographics of participants are summarized in Table 1. This study was approved by the Institutional Review Board of the University of Illinois at Chicago.

Due to the organization of group homes it is common for younger individuals with I/DD to live alongside older residents with I/DD. Since aging is a natural process that all individuals will undergo, the research team felt it would be inappropriate to exclude younger individuals living in these group homes from the research study. Younger

participants are not only being exposed to aging individuals, but they are also interacting with older residents daily, which can also help inform the research question. Furthermore, these younger participants are likely to spend a considerable amount of their aging years in these group homes and thus, it was a proactive exercise for individuals with I/DD and agencies to think about long term aging.

Study design

Directors played an active role in shaping the study design and interview questions to ensure the study was meaningful to their agency and that data collection methods were appropriate for participants. For example, the directors suggested data collection methods that were more interactive would be more suited to residents' needs, rather than a questionnaire. To safeguard against bias from director involvement, the directors were not involved in the data collection process or analysis. The study took place over a three-month period and used a qualitative design utilizing semi-structured interviews and photovoice data collection techniques. Semi-structured interviews were conducted to facilitate open dialogue with management and DSS to gain their perspectives on the research questions. Photovoice with participation observations were chosen as these techniques are shown to be accessible research methods to meaningfully engage people with I/DD in the research process (Aldridge, 2007; Jurkowski, 2008; Heffron, Spassiani, Angell, & Hammel, in press).

Semi-structured interviews with staff

Of the 35 staff members, 19 agreed to participate in a semi-structured interview (6 management and 13 DSS). Interviews were conducted at agency offices and the group homes, ranging from 25 to 75 minutes in length. **Interviews with staff were not meant to be a substitution for the voices of the people with I/DD, but rather to provide a greater**

understanding from the perspective of management and direct support staff, people who are actively involved in providing services and support for these clients.

A literature review was conducted on CBHPI initiatives (e.g. Marks & Heller, 2003; Heller et al, 2011; Marks et al., 2010) and KT models to inform the interview guide (Helfrich et al., 2009; Helfrich et al., 2010). The 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 who are aging?* Or *how would you describe your motivational level for implementing healthy community participation programs/activities within the agencies for adult residences who are aging?*

Management and direct support staff were given the opportunity to discuss other relevant key issues which may not have been covered in the interview guide. Two separate interview guides were created for management and direct support staff. Interviews conducted with management focused on understanding of the factors involved in sustaining CBHPI for people aging with I/DD from a broader system perspective, whereas interviews with direct support staff focused on a front-line perspective. The use of semi-structured interviews allowed for open discussion and new ideas to be generated while providing a framework of themes to keep both parties focused on the research question (Charmaz, 2006; Glesne & Peshkin, 1992; Patton, 2002). **Interviews were digitally recorded and transcribed verbatim. Appendix A provides a sample of the interview guide questions for DSS.**

Photovoice

Each participant with I/DD was given a digital camera for a five-day period and was encouraged to take pictures of 1) things that make it easy for them to be healthy and active in their community and 2) things that make it hard. DSS were instructed to encourage individuals with I/DD to take pictures around their homes and out in the community. Cameras were returned to the research team who printed the photos and brought them back to each of the group homes to meet with residents where they discussed the photos as a group. The photos were utilized to facilitate discussion, and subsequently used to develop a poster board to identify common barriers and supports that affect their health and community participation. Participants 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. DSS were present during this time to facilitate the poster session activity where assistance was ne

Analysis

Data were inductively analyzed to generate key areas that affect the sustainability of CBHPI for people aging with I/DD living in group homes. **The two data sources 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 two 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 raw data (Strauss & Corbin, 1998). After the data were coded, codes were compared across the two data sources identifying any similarities and differences, and then grouped together to represent the overall, triangulated, methodological approach. From these grouped codes, primary themes and subthemes emerged from the data (Patton, 2002). A second researcher conducted an independent analysis of the raw data following the same procedure as the primary researcher. Together the two researchers reviewed the codes, themes and subthemes noting the similarities and differences in their interpretation. Where there were differences, the two researchers engaged in an in-depth discussion about the findings until a consensus was reached. If consensus was not reached the data was removed from the analysis to ensure transparent results.

Results

Five major themes emerged from the triangulated data. These five themes included: 1. agency values and policies related to healthy aging; 2. resources and staff competencies; 3. communication between management and direct support staff; 4. community/research partnerships; and 5. peer relations. Some themes consisted of subthemes that highlight specific factors that operate as either a support and/or barrier of implementing and sustaining CBHPI identified by participants (Table 2).

1. Agency values and policies related to healthy aging

Support: Health promotion as a value

Management and DSS stated that the core value of their agency was to promote independence, choice, and community integration for people with I/DD. They stated that this is more likely to be achieved if people with I/DD are able to maintain good health, referencing the four domains: physical, emotional, mental, and social. Management, DSS, and people with I/DD all spoke about the increasing number of people aging with I/DD, and further both agencies reported focusing their efforts towards better meeting the health needs of people aging with I/DD. Management and DSS 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 disease, hypertension, and menopause. Awareness around these health conditions is low among younger or new DSS and management: "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" (Management).

Barrier: Lack of formal policy

Although management and DSS spoke about how their agency values health and community participation for people aging with I/DD, they stated that their agency did not have formal - written policies with regards to these two areas. Several participants stated that the only written CBHPI may be found in monthly client goals, which are usually generic and difficult to sustain. **Management and DSS spoke about CBHPI that have taken place throughout the agency in the past. For example, nutritional programs, falls prevention programs, and physical activity programs, however, they have not been sustained long term**.

Management and DDS 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:

> "But somehow or another, it always seems to fall through the cracks (…) and then all the hard work, effort, time, and energy that has been put in, it just ceases. We tend to keep going back and starting over and over again" (DSS).

DSS discussed how a lack of clear written policy caused confusion in defining whose responsibility it is to implement CBPHI. The management believed DSS was responsible for implementing CBHPI, whereas DSS felt it was management's responsibility to ensure CBHPI were being executed. DSS felt that supporting CBHPI was not a priority as it was not written as part of their job description, and they were already overwhelmed by their existing workload. Several DSS stated that CBHPI would be more likely to be sustained if it was part of their job description or if incentives were provided for their efforts. Management acknowledged that DSS had no incentive to engage people with I/DD in CBHPI and that DSS were sometimes overwhelmed by the added responsibility.

Support: Informal CBPHI practices

Most participants spoke of informal CBHPI being successfully sustained in their agency. Examples included efforts to decrease the intake of package foods that are low in nutritional value and high in calories, commonly consumed by people with I/DD, providing healthy snacks as an alternative at holiday parties, and encouraging DSS to organize community outings during the evenings and weekends. DSS spoke about making thoughtful efforts to promote client choice, seeking out opportunities to engage people with I/DD in the community, and encouraging them to make healthy meal choices.

Through photovoice, people with I/DD showed 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 included helping them eat healthier, growing their own vegetables, learning to prepare their own meals, and supporting them to be physically active. As one participant with I/DD stated: “We love to work out”.

2. Resources and staff competencies

Barrier: Budget cuts and lack of structure

Management and DSS discussed how budget cuts have made CBHPI difficult to sustain. 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: “It [budget cuts] affected everything. It really did. It affected our staffing levels. We had to convert everybody to the Medicaid waiver program, so it hurt us tremendously” (Management). **Management spoke about how DSS did not have a good understanding of why budget cuts had occurred. However, DSS typically spoke about budget cuts with 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, and guidance from management.**

Barrier: Lack of training and knowledge on aging

Management and DSS also spoke about their apprehension and discomfort in taking aging individuals with I/DD out into the community or engaging them in physical activity working, who they often perceived as too fragile and at a greater risk of falls: “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” (DSS). Participants spoke about how they have received training from their agency with regards to health and safety, medication administration, CPR and first aid, abuse and neglect, and behavior management; however, managers and DSS felt as though they would benefit from adequate training in how to formally support people aging with I/DD in CBHPI. People with I/DD

stated getting older affected their ability to participate in the community as a result of health conditions that can come with aging. For example, one participant with I/DD stated: "Age and balance make it hard." Another participant with I/DD said: "We get tired quickly when walking," however, participants with I/DD were unable to discuss how they can continue to be active as they age.

Support: Adaptability of staff

Due to the lack of structured action plans, DSS had to apply their own personal knowledge and creativity to support healthy lifestyles and community engagement for people with I/DD, regardless of barriers they encountered:

> "[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" (DSS).

It was noted that having a van at the group home made planning community outings significantly easier. In some cases, both management and DSS 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, DSS had to plan activities within walking distance so that people with I/DD could still be involved in their communities. However, even activities within walking distance posed an issue for people aging with IDD as some were not able to walk long distances due to arthritis, joint pain, or cardiovascular health problems.

3. Communication between management and direct support staff

Support and barrier

Management and DSS talked about how communication between management and DSS was a support and a barrier to sustaining CBHPI. The main source of communication reported by staff was the use of communication logs that each group home is required to maintain. At the end of each shift, DSS document important notes such as behaviors and moods, meals, community outings, or reminders for doctor appointments. Each DSS is required to review the communication log before they start their shift. The communication log is viewed as a key source of information regarding the activities, health, and overall wellbeing of people with I/DD. Participants spoke about examples where good communication between management and DSS resulted in not only sustaining but also improving informal CBHPI within group homes. When management and DSS were able to communicate effectively, they identified ways to best meet the needs of people with I/DD.

Although DSS viewed communication logs as effective, they felt as though communication beyond the logs could improve. DSS talked about the importance of verbal communication through meetings rather than always communicating in writing: “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” (DSS). Regular DSS meetings, however, do not occur at either agency. DSS felt that management expects them to sustain CBHPI, but they felt that they do not have an appropriate communication system or culture to openly discuss suggestions and feedback about how to improve the engagement and sustainability of CBHPI.

4. Community/university partnerships

Support: Informal community partnerships

Management and DSS talked about building community/research partnerships with local businesses and organizations as an important way to support CBHPI sustainability within their agency. Further, there were some management and DSS who were motivated to seek out informal community partnerships to ensure people with I/DD were engaging in their community. They 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.

DSS suggested that the agency develop agreements with local organizations to reduce or eliminate costs for people with I/DD and DSS. For example, several DSS 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 DSS. DSS also spoke about collaborating with other community agencies to learn from each other's efforts at sustaining CBHPI. Community interaction between people with I/DD and those outside the I/DD community was also highlighted as important:

> "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. I mean there's a couple things I know the agency does… but I think it happens too infrequently and it's also with just I/DD consumers. So, I mean, you can say it's somewhat of a community, but it's a I/DD community and not so much as, you know, the outside community" (DSS).

Support and barrier: Formal university partnerships

Management spoke about how they built strong partnerships with nearby universities as a means to improve the health and well-being 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. Management and DSS stated they valued the expertise of researchers and used these partnerships to learn new strategies to engage people with I/DD in healthier behaviours and community involvement. Some DSS said they liked it when researchers showed an interest in working with people with I/DD because this shows that people care about the well-being of people with I/DD.

Additionally, management valued partnerships with universities because they were able to maintain and increase funding by reporting research findings to their funding agencies as evidence of the benefits of CBHPI:

> "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] I 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" (Management).

Although participants understood the value of having established community partnerships with universities, some DSS felt as though researchers pushed their programs on the agency without understanding the dynamics of the agency or the people they serve. DSS 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 to the individuals who would be taking part in their research. DSS 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. Further, DSS 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.

5. Peer relations

Support and barrier

This theme speaks to the complex interactions among people with I/DD in the group homes. Management, DSS, and people with I/DD all discussed how sustaining CBHPI can be difficult due to disagreements among people with I/DD regarding what community activity they would like to participate in as a group. People with I/DD discussed how they struggle at times to collectively decide on what community activity they wanted to do, resulting in in-house tension as well as DSS frustration. One participant with I/DD said: "[there] is no house unity."

Some management and DSS also 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 that is required for conflict resolution and/or multiple group outings into the community.

Although people with I/DD disagreed at times on community outings, DSS felt that people with I/DD generally had each other's best interests in mind. For example, when a new DSS began working at the group home, people with I/DD would inform the new DSS of a peer's diet restrictions to make sure that their peer is being properly supported. 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. As one individual with I/DD stated: "We stick together and help each other when at the store." Some examples of how they supported each other included helping each other read the restaurant menu, crossing the street, and paying for items at the store. There was also mention of supporting older people with I/DD who needed 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. For example, one participant with I/DD stated: “it’s good to be easy going when picking an outing.”

Related to this finding on peer relations, DSS felt that CBHPI should focus more on peer mentoring to improve the likelihood of sustainability, perhaps as a means to cope with DSS turnover: “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” (Management).

Discussion

Research that has been conducted on 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 et al., 2010; Tracey & Hosken, 1997). However, there has been minimal research examining the factors involved in sustaining these evidence-based programs so people with IDD can continue to participate.

The findings of the current study provide an in-depth system-level analysis of the supports and barriers related to sustaining CBHPI in group homes of I/DD agencies, as identified by management, DSS, and people 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 aspect of service provision for I/DD agencies. While it is not clear how to best support people aging with I/DD, organizations will have to re-address the way they provide services such as CBHPI as a greater understanding is developed.

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, Smith, Evans, Meyer, & Gottlieb,

2001; O'Loughlin, Renaud, Richard, Gomez, & Paradis, 1998; Shediac-Rizkallah & Bone, 1998); 2) providing clear job exceptions and role definitions for frontline personnel to execute and sustain the programs (Hewitt et al., 2004; Jansson, Benoit, Casey, Phillips, & Burns, 2010); 3) management's support and encouragement of the program (Savaya, Spiro, & Elran-Barak, 2008); and 4) the agency internally monitoring the effectiveness of the program and providing constructive feedback to frontline personnel (Elsworth & Astbury, 2004). Frontline personnel are instrumental in the execution of programs (Burchard & Thousand, 1988; Lakin, 1988). The following discussion offers a brief synthesis on how the five key themes that emerged in this study integrate into the existing literature.

Agency values and policies related to healthy aging

Agency and individual values played an important role in the sustainability of CBHPI; however, the lack of formal policies specific to health and community participation was a barrier due to the absence of clear guidelines and role descriptions of key stakeholders involved in executing and sustaining CBHPI. It is known that program sustainability is dependent on the organization's recognition that the program is a fundamental part of the organization's values and how well the program can be integrated within the existing system (Goodson et al., 2001; O'Loughlin et al, 1998; Shediac-Rizkallah & Bone, 1998). Programs are more likely to be sustained, 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.

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 vital that I/DD agencies are proactive, rather than reactive, in adopting polices, services, and procedures to effectively support people with I/DD as they age (Jokinen et al., 2013).

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. Frontline personnel are an invaluable resource because they have first-hand knowledge and 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 DSS and collaboratively identify these service needs and strategize to meet them. 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 agency management and DSS, people with I/DD, researchers, as well as other stakeholders openly discuss how to be proactive in sustaining CBHPI despite the issue of restricted finances.

Because budgetary constraints are a significant barrier to sustaining CBHPI, it may be beneficial for management to inform DSS about the financial status of the agency and help DSS understand why and how budgetary constraints affect programs and services. By having DSS understand the complex dynamics of budget constraints, they may be more likely to pursue other means to sustain CBHPI despite the limited resources available. This in turn can enrich their understanding that the lack of resources is not due to poor management or lack of job support, but rather due to more external factors that are beyond the full scope of the agency's control.

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 is suggested that government policies be taken into consideration when examining program sustainability (Savaya et al., 2008). This is particularly important given that 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 supporting 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 is the primary funding source to provide long-term community services for people with I/DD (Rizzolo, Friedman, Lulinski-Norris, & Braddock, 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 and if these efforts are cost effective and 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 affecting I/DD agencies and be open to working with agencies on how to best utilize their strengths as an agency (i.e., staff competencies, existing resources, partnerships) to counterbalance barriers (i.e., budget) to increase the likelihood of CBHPI sustainability.

Communication between management and direct support staff

Communication between management and DSS was a support and a barrier to sustaining CBHPI. As a support, communication ensured that both management and DSS were well informed about their clients and, thus, allowed them to provide them with appropriate support. This finding is represented in the previous literature as researchers have found the frontline workers' knowledge, attitudes, and skills, including communication, 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 DSS are not only kept well informed on system level issues, but also encouraged and supported by management to communicate their ideas and concerns about sustaining CBHPI for people aging with I/DD.

Past research highlights program sustainability is more likely to occur if frontline personnel have clear job expectations and defined responsibilities (Hewitt et al., 2004; Jansson et al, 2010), if management supports and encourages the program (Savaya et al, 2008), and if the program is internally monitored (i.e., evaluating the program's effectiveness within the organization and monitoring staff performance) (Elsworth & Astbury 2004). As such, management should encourage open communication and transparent discussions with DSS regarding agency issues, such as systems, policies, resources, and budget cuts, so that DSS have a better understanding of how and why these factors influence the services being provided to people with I/DD.

When examining the sustainability of CBHPI, researchers should take into account the communication dynamics between management and DSS. As a barrier, 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.

Community/university partnerships

Community and university partnerships was a support of sustaining CBHPI as I/DD agencies relied on these collaborations to improve the knowledge about health and opportunities for community participation that better serve people with I/DD. More specifically, participating in evidence-based research projects was supportive of sustained CBHPI; however, poor dissemination of research findings was a barrier, as agencies were often uncertain about what outcomes came from their research efforts and unsure of what parts of the program were effective in improving 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). Because community partners are mostly responsible for implementing and sustaining an intervention, it is important that they have autonomy and are included and invested in the knowledge being created (Jansson et al., 2010). Researchers must take into consideration the expertise of management, DSS, and people with I/DD when designing CBHPI to ensure they are appropriately reflecting the needs of I/DD agencies. By including I/DD agency staff as well as people with I/DD in the development of a study or CBHPI program design, researchers will better understand the values, beliefs, and attitudes of the agency and accurately develop CBHPI that are directly relevant to the agency needs and goals.

Peer relations

Findings highlighted that peer mentoring may be a facilitator to help sustain CBHPI. Given that DSS 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. 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 in CBHPI for people aging with I/DD (Hammel, et al., 2008b). Long-term sustainability of health promotion programs and interventions may be more likely to occur if peer mentoring is used because it involves peers translating knowledge directly to the community, rather than knowledge coming from agency staff and other professionals (Hammel, et al., 2008a; 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, assist 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 not only for their own health and community participation, but also for each other.

Limitations and future research

Future research should continue this line of investigation with a larger number of I/DD agencies from other geographical locations to see if findings are transferrable to other settings. Future work could also explore how aging with I/DD is potentially experienced differently among men and women, and/or examine how younger service providers or those who are relatively less familiar with the aging process can be better supported in providing care for people with I/DD who are aging in group homes. Participants (i.e., management, DSS, and people with I/DD) all valued the importance of health and community participation. Thus, investigating I/DD agencies who may not value the importance of health and community participation may present other interesting findings that affect CBHPI program interest and sustainability.

The study found 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 feeling negatively towards aging (Meisner & Levy, 2016). As people with I/DD are now living longer, we must gain a better understanding of this population's perceptions of aging and explore how negative stereotypes may be affecting 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; Meisner & Levy, 2016)**.**

Participants with I/DD involved in this study primarily had mild to moderate I/DD thus findings may not be consistent with individuals with more severe I/DD. This study **found that the relationship between universities and agencies played a positive role in supporting the sustainability of CBHPI, however, this finding may not be generalizable to other areas and may be unique finding of the current study, thus further research in this area is needed. As with any qualitative study, the role of the researcher(s) is present. The current study was designed and analyzed through a disability studies lens, when analyzing and interpreting these data and findings there may be a heightened sensitivity to identifying themes that were representative of the social model of disability (i.e., social support or environmental barriers to participation); however, this lens falls directly in line with the objectives of the study.**

Conclusion

The current study contributes to the current knowledge by providing a multi-level systems-based analysis of the supports and barriers influencing the likelihood of CBHPI being sustained by I/DD agencies, which included the direct first-person accounts of people with I/DD, DSS, and management within I/DD agencies. Past I/DD research has commonly evaluated the effectiveness of existing evidence-based programs; however, limited research has examined the factors that affect the likelihood of sustainability of these programs. The current study helps address this gap. This study also demonstrates how participatory methods can be effectively used to meaningfully engage persons and personnel from various agency levels to provide a comprehensive understanding on the topic, while still ensuring the voices of people with I/DD were represented in the production of knowledge. An interesting note is that management, DSS, and people with I/DD groups identified similar supports 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, which is rooted in both the voices of people with I/DD and at multiple-levels within I/DD agencies, 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.

Table 1. Participant demographics

	Residents with I/DD	**Management**	**DSS**
Men	47%	28%	23%
Women	53%	72%	77%
Mean Age	52	44	43
Range	(26-98)	(28-64)	(18-65)
African American	49%	43%	55%
Hispanic	40%	43%	35%
Caucasian	11%	14%	10%

Table 2. Themes and subthemes from triangulated data

Agency values and policies related to healthy aging
Support: Health promotion as a value
Barrier: Lack of formal policy
Support: Informal CBHPI practices
Resources and staff competencies
Barrier: Budget cuts and lack of structure
Barrier: Lack of training and knowledge on aging
Support: Adaptability of staff
Communication between management and direct support staff
Support: Improved communication through logs
Barrier: Use of one method of communication
Community/research partnerships
Support: Informal community partnerships
Support: Formal university partnerships
Barrier: Formal university partnerships
Peer relations
Support and barrier

Appendix A. 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 affecting 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)

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?

What is your age?

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

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