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Reflections From Co-Researchers With Intellectual Disability: Benefits to Inclusion in a Research Study Team

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Abstract

Participatory action research methodologies may empower and protect marginalized individuals; however, they remain underutilized. Limited studies have investigated the impact of participatory action research, specifically on individuals with intellectual disability (ID). This study examines (1) the perspectives of co-researchers with ID on their involvement in the research process and (2) the feasibility of their inclusion based on perspectives of research staff (academic faculty and graduate students without ID). Three co-researchers with ID were interviewed regarding their research participation. Thematic analysis of interviews identified four themes: (1) *Shared Experience of Disability*, (2) *Teaching and Guidance*, (3) *Acquisition of Skills and Knowledge*, and (4) *Value of Participation*. Research staff reviewed field notes and identified benefits and challenges to feasibility of including co-researchers with ID. Inclusion of co-researchers with ID was found to be both meaningful and feasible.

Keywords

inclusive research; intellectual disability; co-researcher; participatory methods

The power differential in research that exists between researchers and participants has increasingly been acknowledged, particularly within the context of examining the

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experiences of individuals from marginalized populations, such as those with intellectual disability (ID) (Barnes, 2002). As a result, participatory action research methodologies have emerged. These methodologies incorporate community members and stakeholders as contributing partners in the research process in an effort to empower individuals from marginalized populations and protect participants (Barnes, 2002; Nind & Vinha, 2014). As early as the 1980s, traditional methods for disability research were receiving critique while participatory action research methodologies were emerging and drawing on personal experiences of people with disabilities (Barnes, 2002). A special issue of the international journal, *Disability, Handicap and Society* was released to highlight the issue (Disability, Handicap, and Society, 1992), presenting contributions from scholars, such as Barnes (1992) and Oliver (1992), who advocated for the development of participatory action research methods for the study of disability. To this end, these methods incorporated individuals with disability as co-researchers, or contributing members of the research team (Barnes, 2002; Johnson & Walmsley, 2003; Stevenson, 2010). However, while participatory action research methodologies for individuals with disabilities have been recognized as valuable in the theoretical literature, they remain largely underutilized in research practice.

Participatory action research with individuals with ID was built upon three foundational principles; research must be (1) meaningful to the individuals being studied, (2) accurately representative of their views and experiences, and (3) exemplify that the research community treats individuals with ID with respect (Johnson & Walmsley, 2003; Nind & Vinha, 2014). In an effort to meet these guiding objectives and create meaningful research that is both representative of the experiences of individuals with ID and accessible to the general population, disability researchers are beginning to incorporate non-academic partners, or co-researchers with ID, into their methodological practices (Strnadová & Cumming, 2014). Within this context, co-researchers are individuals who would traditionally be considered participants in a research study (e.g., individuals with ID), but who are now engaged in research in a more collaborative manner. Co-researchers with ID assist in the details of the research process (e.g., data collection, analysis, interpretation) and function as integral members of the research team (Nind & Vinha, 2014). Co-researchers with ID have the opportunity to ensure that the research they are involved in is reflective of the interests of the ID population and enables social change (Bigby & Frawley, 2010). Moreover, the lifetime of personal experience engaging in society as individuals with ID, enables co-researchers with ID to function as experts on the lived experience of individuals with ID in a manner that other research staff are unlikely to achieve (Bigby, Frawley, & Ramcharan, 2014). Inclusion of co-researchers with ID thus presents an opportunity to add strength and validity to research studies.

Reflections from the few studies incorporating co-researchers with ID indicate there are benefits to the research findings as well as the research team (Bigby et al., 2014; Flood, Bennett, Melsome, & Northway, 2013; Nind & Vinha, 2014). However, there are still gaps in our knowledge, specifically in relation to how inclusion in research impacts co-researchers with ID, and the feasibility of including co-researchers with ID.

Nind and Vinha (2014) identified that the inclusion of co-researchers with learning disabilities (LD) exemplified a “bridge to other worlds” during the research process. In

forming this bridge, each member of the research team (i.e., co-researcher with LD, academic faculty, and graduate students) brought their own skills to the table and offered individual and cultural perspectives from their differing backgrounds. Collaboration and sharing allowed for this bridge to emerge, and for co-researchers with ID and research staff to gain insight into each other's unique perspectives. Indeed, previous research indicates that collaboration between co-researchers with ID and research staff allows for the development of richer data collection tools and deeper reflection into analyses, which neither group could obtain alone (Bigby et al., 2014). Yet, an understanding of the perspectives of co-researchers with ID on being involved in research remains scarce as few studies have examined the evaluations of co-researchers with ID on their experience of engagement in the research process. The limited research to date indicates that for co-researchers with LD, the experience of being a co-researcher enables individuals to become more confident and feel as if they are helping others (Abell et al., 2007; Flood et al., 2013). Whether these benefits hold true for co-researchers with ID and other types of developmental disabilities remains unknown.

Despite the potential value in engaging co-researchers in research, barriers to this type of participatory action research remain present. Difficulties lie in accommodating the wide spectrum of ability levels exhibited by individuals with ID who desire to participate in research (Bigby et al., 2014) and supports necessary to establish successful collaborations have yet to be clearly defined (Conder, Milner, & Mirfin-Veitch, 2011). Additionally, power differentials between co-researchers with ID and research staff should be reflected upon thoughtfully to ensure that co-researchers with ID are tangibly involved in the research and that research staff do not encroach upon their assigned roles (Bigby & Frawley, 2010). While several studies have noted a gradual shift toward the inclusion of co-researchers with differing abilities to varying degrees (Bigby et al., 2014; Williams, 1999), successful methodological approaches and specific recommendations for the inclusion of co-researchers with ID in the research process remain ill-defined and elusive. Thus, the disability community has advocated that research become more flexible and incorporate varying levels of participation for interested co-researchers with ID (Layton, 2014; Nind & Vinha, 2014). Further research is necessary to better understand the feasibility of engaging co-researchers with ID in the research process, specifically in terms of the strengths and challenges posed by this methodological practice.

The present study examined the experiences of three individuals who participated as co-researchers with ID in a qualitative evaluation of Special Olympics' Healthy Communities program. The aims of the present study were to (1) examine the perspectives of co-researchers with ID on being involved in the research process and (2) explore the perspectives of research staff (academic faculty and graduate students without ID) on the feasibility of incorporating co-researchers with ID in the research process.

Method

The Qualitative Evaluation of Special Olympics' Healthy Communities Programmes was an international, seven site, qualitative evaluation focused on examining how Healthy Communities programs bring about improved health and lifestyles for persons with ID.

Healthy Communities is a Special Olympics program that seeks to improve the overall health and well-being of individuals with ID through education, free health screenings, and facilitation of healthcare services and related community support. The larger study gathered qualitative information through interviews and focus groups from a variety of Special Olympics stakeholders (e.g., athletes with ID, family members, caregivers, coaches, and community volunteers) to determine whether Healthy Communities was facilitating desired outcomes and meeting project goals. The incorporation of co-researchers with ID was encouraged for all seven international sites, however, only two sites successfully integrated Special Olympics Athletes as co-researchers with ID in their projects. Co-researchers with ID were invited to be part of the research team, provide feedback on interview questions, and assist with data collection. In the present study, a qualitative review of the involvement of co-researchers with ID was conducted. The analysis focused specifically on one site, where reflections from co-researchers with ID on their co-researcher participation and reflections from research staff (academic faculty and graduate students without ID) on feasibility of engaging co-researchers with ID in the research process were obtained.

Participants

Prospective co-researchers with ID were identified through the Special Olympics Wisconsin state office based on their history of involvement in advocacy work for individuals with ID and demonstration of leadership qualities. All prospective co-researchers had participated in a Special Olympics Athlete Leadership Panel, a formal leadership program, or had served as a mentor for fellow athletes and were identified as leaders by their Special Olympics coaches and staff. Identified co-researchers qualified for participation in Special Olympics, which requires a diagnosed ID or cognitive delay. Four potential co-researchers with ID were identified and recruited to join the project. Co-researchers needed to have the language ability necessary to conduct interviews with their peers and to participate in an Institutional Review Board (IRB) approved informed consent process. Human subjects approval was obtained for this study and informed consent was obtained from each co-researcher individually. Separate informed consent was obtained from legal guardians where applicable. One of the invited athletes expressed personal interest in joining the project, however, guardian consent was declined. The guardian expressed concerns about the skills required to participate and maintain confidentiality, as well as challenges with scheduling. The remaining three athletes (two male, one female, ranging from 22 to 34 years in age) were invited to participate as co-researchers with ID.

The research staff consisted of four members without ID—the principal investigator, co-investigator, and two graduate students. All four staff members had previous experience working with individuals with ID in both clinical and research settings. The principal investigator and one graduate student administered all trainings for the co-researchers with ID and supported co-researchers with ID during interview administration. The co-investigator and second graduate student were present during the larger qualitative evaluation of Special Olympics' Healthy Communities program activities and joined the research team for data coding and analysis of co-researcher with ID data. However, they did not directly support co-researchers with ID during their research involvement.

Training

Each co-researcher with ID received one individualized research preparation and training session prior to their participation in the project. The primary investigator or one graduate student met with the co-researcher with ID for between one to three hours to review the scope of the qualitative evaluation of Special Olympics' Healthy Communities program and their potential roles in data collection. The length of training session was based upon the individual characteristics of the co-researcher with ID and their prior experience in administering interviews. The IRB granting agency did not require any further research specific training for the co-researchers with ID to join the study.

The primary focus of the individualized training was to provide co-researchers with ID with the skills necessary to participate in the project and cultivate confidence with interview questions and protocols. A co-researcher with ID training manual was developed as part of the larger qualitative evaluation of Special Olympics' Healthy Communities program and was used to guide the training. This manual was written in accessible language with the use of pictorial representations. Detailed information on the project aims, roles of researchers and co-researchers with ID, interview skills, confidentiality procedures, and voluntary participation were included in the manual. Each co-researcher with ID was given the opportunity to practice administering the interview guide with a research staff member. Trainings also included a review of the co-researcher with ID specific informed consent.

Procedures

Following the completion of the trainings, co-researchers with ID, with the support of the principal investigator or one graduate student, engaged in interviewing between four and eight Special Olympics athletes with ID regarding their health habits, health care, and use of the Healthy Communities program. Two of the three co-researchers with ID felt more comfortable working as a pair, and thus they administered athlete interviews together. The third co-researcher with ID individually administered athlete interviews. Co-researchers with ID had previous acquaintance with the athletes being interviewed through participation in Special Olympics Sports and related activities. The principal investigator and one graduate student led the informed consent process for all the athletes with ID being interviewed, and assisted during the interview by answering questions that the co-researcher with ID was unable to answer, operating the recording device (as all interviews were audio-recorded), and facilitating the interview as needed. Co-researchers with ID independently guided the Special Olympics athletes through the interview protocol and supplemented the interview guide with prompting questions, as needed.

After the completion of their participation in the qualitative evaluation of Special Olympics' Healthy Communities program, the co-researchers with ID were asked to participate in a semi-structured interview to reflect on their co-researcher participation and involvement. A graduate student, who was the supporting researcher for 2 of the 3 co-researchers with ID, completed all three co-researcher reflection interviews. Interviews were completed in a private space, within a week of completing athlete interviews. Confidentiality was reviewed prior to the start of each interview to assure co-researchers that they could reflect freely on individual interviews and the research process without consequences and without violating

the confidentiality of the individuals who participated in the co-researcher administered interviews. The supporting researcher and co-researcher with ID discussed that their individual reflections would remain confidential and would not impact their participation in Special Olympics or future research projects in any way.

During their reflection interview, co-researchers with ID were asked to discuss the benefits and challenges they encountered as co-researchers and what they valued about their participation in the project. Co-researchers with ID were also asked to provide an overall perspective on the importance of incorporating co-researchers in disability research. Finally, co-researchers with ID were asked if and how the research process had impacted them personally. Interviews were individually completed with each co-researcher with ID, using an interview guide, and lasted up to 50 minutes. Interviews were conducted using five primary questions listed in Table 1. Interviews were conversational in nature to evoke descriptions of the co-researcher with ID's perceptions of their individual involvement. Each question was followed with multiple prompts and follow-up questions used to confirm responses of the co-researcher with ID, expand on the response to each question, and clarify understanding as needed. All interviews were audio-recorded and transcribed verbatim.

Prior, throughout, and following, the completion of the qualitative evaluation of Special Olympics' Healthy Communities program, the primary investigator, co-investigator, and both graduate students reflected individually and as a team on the strengths and challenges of including co-researcher with ID as partners in the research process. At each step of the research process (e.g., following each consent procedure, training, or data collection activity with the co-researchers with ID), the research team was asked to reflect individually on the benefits, challenges, and feasibility of including co-researchers with ID in the process. Reflections were documented through individual field notes. Individual field notes were completed for each individual consenting or assenting session, each co-researcher training session, or one day of co-researcher participation in several individual interviews.

Analysis

A thematic approach, as outlined by Braun and Clark (2006), was used to analyze co-researcher with ID interview data. All reflective interviews conducted with co-researchers with ID were transcribed verbatim and transcripts were reviewed several times by three research staff members (principal investigator and two graduate students without ID) to develop familiarity with the data and the responses of the co-researchers with ID as a whole. All analysis was completed by academic faculty and graduate students. Transcripts were coded independently by the three research team members for recurrent and patterned responses within and across interviews. To minimize the impact of individual researcher perceptions, potential themes were initially identified and described by each research staff member prior to team discussion. Once individual coding was completed, research staff members (principal investigator and graduate students without ID) met for three discussion meetings where co-researcher with ID reflective interview transcripts were reviewed together. During the first meeting, each research staff member presented their individual coding of the transcripts including identified themes and patterns within the interviews. Responses and patterns that were identified by all research members were discussed and

categorized into roughly defined themes. Responses that were not identified by all three members were flagged to be considered by all team members in their next reviewing of the transcripts. Following the initial meeting and discussion, research staff reviewed interview transcripts again to confirm and expand preliminary themes and identify any additional themes. During the second analysis meeting, research staff again presented their individual findings and themes were further clarified and defined through discussion. Prior to the third and final analysis meeting, research staff independently coded all the transcripts. The final analysis meeting consisted of comparing coded transcripts, coming to a consensus of final themes and definitions, and drawing conclusions based on the responses of the co-researcher with ID.

Consistency and reliability of themes was established according to recommendations by Braun and Clark (2006) and Fereday and Muir-Cochrane (2006). Themes were checked against one other and the original data to establish each theme as internally coherent, consistent, and distinct (Braun & Clarke, 2006). Themes were deemed consistent when each code from the text could be captured by the theme definition. Themes were considered to be distinct when each code from the text was represented by a single theme. To ensure the developed theme definitions were reliable and representative of the data, research staff members completed a final review of interview transcripts. Reliability of themes was established when no further theme definition modifications were made by research staff during the final review of the data (Fereday & Muir-Cochrane, 2006).

To appraise the feasibility of the study, research staff discussed primary study aims prior to data collection and reflected on questions of feasibility after co-researcher with ID participation, and again post co-researcher with ID reflective interviews. Research staff participated in two group meetings to discuss the feasibility and benefits of including co-researchers with ID in a research study. All individual field notes were reviewed and discussed as a group to identify strengths of the methodological approach and potential barriers to feasibility. Each research staff member presented their personal field notes including reflections on participation with co-researchers with ID, procedural challenges faced, and benefits gained by the research team from the inclusion of co-researchers with ID. Notes and reflections were reviewed and categorized to identify strengths and challenges of the methodology as experienced by the research team, as well as to determine future feasibility of including co-researchers with ID in similar studies. Finally, these summaries of key strengths and challenges were approved by consensus of all research staff.

Results

Perspectives on Co-Researcher Experiences

A thematic analysis was used to identify themes from interviews with three co-researchers with ID who were asked to reflect on their co-researcher experience and participation. Four themes were identified across interviews: (1) *Shared Experience of Disability*, (2) *Teaching and Guidance*, (3) *Acquisition of Skills and Knowledge*, and (4) *Value of Participation*.

Overwhelmingly, all the co-researchers with ID reflected on their *Shared Experience of Disability*, with one another and with the Special Olympics' athletes they interviewed during

the qualitative evaluation of Special Olympics' Healthy Communities program. Co-researchers with ID felt as if this *Shared Experience of Disability* provided them with additional insight and understanding into the perspectives of the individuals with ID they interviewed. As individuals with ID themselves, the co-researchers with ID understood the depth of mistreatment towards individuals with disabilities and the barriers to healthcare they faced. These ideas are ones that were frequently described by the Special Olympics athletes interviewed by the co-researchers with ID during the qualitative evaluation of Special Olympics' Healthy Communities program. One co-researcher with ID specifically noted:

I mean my whole thing is that a lot of, a lot of these people with disabilities aren't I don't feel like are treated right. They don't get healthcare, they don't get nothing. And that's a problem. And I'm not afraid to fix that. And I mean a lot of athletes like myself, they, it's not that they don't know how to, they just they're worried that when they stand up and talk you know to somebody, they're going to get bullied.

Another co-researcher with ID similarly stated, "not many people know about disabilities and what causes them and what umm, re-really umm, what really non-sensible words people say to us that don't apply." Developing out of this *Shared Experience of Disability*, the co-researchers with ID felt as if they could more easily understand and approach the Special Olympics athletes than other researchers on the project, often setting the athletes they were interviewing more at ease and developing connections in ways that the other researchers on the project were not able. One co-researcher with ID said, "it's easy for me to understand and coexist with people," while another said, "I got people to (um)... understand the questions and, and (um)... they, they smiled." Co-researchers with ID also reflected that their *Shared Experience of Disability* gave them ideas on how to better prompt and follow through with the primary questions from the interview guides.

Another theme, *Teaching and Guidance*, captured the importance co-researchers with ID placed on being provided with adequate training and education to feel prepared and comfortable engaging in the research process. All co-researchers with ID commented that although they felt well-prepared and experienced a level of expertise as they conducted interviews with the Special Olympics athletes, they continued to value the presence of an experienced research staff member supporting them as needed. One co-researcher with ID said:

I just kinda let her (experienced research team member) you know, go, and then I just watched. I wasn't tuning out, I was totally watching, paying attention to what she was doing and what she was talking about so that then I could do it. It just made it easier.

Similarly, another co-researcher with ID mentioned:

You could get, both of them (co-researchers) to learn, about the questions, and you could teach the other co-researcher how to, you know, if like, if he doesn't know how to say one, you could tell him, you could teach him how to say that word [...] it's a teaching opportunity.

Importantly, co-researchers with ID recognized that although overseeing researchers were critical in helping them gain confidence as novice researchers, they also felt as if given enough time and practice, they would be comfortable independently conducting interviews with athletes and engaging in the research process. For example, one co-researcher with ID said:

I would probably still need someone to be with me, but if I did them over and over with like ten other people, or if I just did them constantly, and never, and didn't stop, I would probably get used to the questions, and they would probably, I would probably be so focused and they would be drilled in my mind.

Another said, "I mean I feel like the training was good but I mean, I think like, honestly I think I could do it individually or as like a whole group." Finally, one co-researcher with ID pointed out the need to individualize training and preparation to the needs and ability level of the co-researcher with ID. He noted, "It really depends on the athlete. How much, how much they have in them. If they have it, then in any speaking, I would say definitely work on speaking more with them."

The third theme that was identified was the *Acquisition of Skills and Knowledge* by the co-researcher with ID. Co-researchers with ID described how they developed interview skills and the ability to ask questions in a way Special Olympics athletes could understand. A strong report of the ability to identify a peer's limits and boundaries within the context of an interview was apparent for two of the three co-researchers with ID. They described how they were able to identify and respect the boundaries of individual Special Olympics athletes being interviewed. One co-researcher with ID stated: "It is what you really need in a co-researcher, you have to know your limitation and what you can ask." Later in the interview she returned to the idea of boundaries stating: "It's trying to be more comfortable but trying not to go over the boundary. The boundary is like not trying to be intrusive, not trying to be like a therapist." This skill was described as both a contribution the co-researcher with ID innately brought to the project and as a skill that was further developed and honed through the course of participation.

In the final theme, *Value of Participation*, co-researchers with ID described the unique and important opportunity the project had provided them. They described perceived personal benefits and the value of their participation. Two co-researchers with ID specifically highlighted how individuals with ID too often sit at home with limited opportunity for meaningful engagement. One of the co-researchers with ID stated "a person like me doesn't get to do things very often, it's a once in a lifetime opportunity." All three co-researchers with ID described how they would continue to participate in research and advocacy given the chance. One co-researcher with ID cited that her participation in the project "has made me want to adjust things in my life (to) what matters." All three co-researchers with ID identified that their participation had a large impact on the lives of individuals with disabilities, specifically with regard to access to healthcare and health promoting activity. One co-researcher with ID stated, "I might not learn everything, but at least at the end of the day, my whole thing is that I believe that doing all this stuff... will at least change someone's life, and that's my big thing." Co-researchers with ID unanimously reported that through their contributions to the qualitative evaluation of Special Olympics' Healthy

Communities program, they felt as if they were not only helping people, but they were also bringing attention to the disparities that exist for individuals with disabilities.

Perspectives on Feasibility

Field and meeting notes from research team members were reviewed to examine the feasibility of including co-researchers with ID in the research process and to identify and describe benefits and barriers. Through field note reflections, research staff identified several benefits in including co-researchers with ID. First, the development of easy rapport between co-researchers with ID and participants with ID was highlighted. This rapport building was perceived as contributing to greater depth in interviews. In addition, it was evident that co-researchers with ID were able to increase the comfort of participants with ID being interviewed. For example, participants with ID provided short verbal responses and made limited eye contact with research staff during the consent process. However, once a co-researcher with ID was present and participating in the interview, the participant's verbal responses were expanded and the participant with ID appeared to relax, smile, and made regular eye contact with the co-researcher with ID as well as research staff. Finally, research staff recognized that co-researchers with ID expanded on interview questions in novel ways by asking follow-up questions that appeared to be a result of the co-researcher with ID and participant with ID sharing an understanding of unique challenges faced by individuals with disability. For example, one co-researcher with ID expanded on questions about the participant's living situation by asking specifics about their level of independence, staffing, and the support provided by staff to participate in cooking meals or attending events. Another co-researcher with ID reflected on how his own experience of poor quality health care and discrimination helped him to relate to the participant he was interviewing. Having co-researchers with ID work in a pair to complete peer athlete interviews did not negatively affect the feasibility of completing interviews. However, it did support the ease of participation for the two individuals with ID. Both individual and paired co-researchers with ID were able to complete scheduled research activities and required comparable levels of support from the research staff.

Recruitment, guardianship, and scheduling were identified through field note and follow-up discussion as three primary challenges to feasibility. The recruitment of co-researching partners with ID was complex and lengthy. Initial direct contact with many of the individuals who were identified as potential co-researchers with ID was not possible. The research team heavily relied upon paid staff and/or family members to provide information and assist co-researchers with ID in returning calls or emails. Several potential co-researchers with ID were capable of participating in phone calls and emails; however, lack of consistent access to these services delayed the scheduling of trainings and co-researcher activities. Guardianship added an additional layer of complexity to feasibility. Once initial contact was made, potential co-researchers with ID were not always able to give their own informed consent for participation due to guardianship limitations. Interactions among guardians, potential co-researchers with ID, and research staff were complicated and time intensive. Guardians who were unfamiliar with the research process were skeptical of research staff and potential co-researcher with ID participation. A foundation of trust was essential before recruitment could continue and voluntary, informed consent could be obtained from both the guardian

and the co-researcher with ID. Finally, scheduling was a consideration, as transportation was often unavailable or required arrangement far in advance. The research team dedicated time and resources to working within and around the schedules of co-researchers with ID, providing individualized trainings at various locations, meeting at individuals' homes, and scheduling co-researchers with ID to complete Special Olympics athlete interviews during previously scheduled community events.

Discussion

Perspectives on Co-Researcher Experiences

The present study found that the inclusion of co-researchers with ID in the research process was both meaningful to the co-researchers with ID and feasible. Four themes were identified that described the perspectives of the co-researchers with ID on engaging in research: *Shared Experience of Disability, Teaching and Guidance, Acquisition of Skills and Knowledge, and Value of Participation*. Overall, co-researchers with ID valued their participation, as it provided them with meaningful occupation and an opportunity for pragmatic skill development. Co-researchers with ID acknowledged the importance of training and support from research staff members, while simultaneously recognizing their own potential for independence with greater experience. Findings align with previous studies including individuals with LD that indicate that co-researcher participation is meaningful, builds self-confidence, and provides co-researchers with a feeling that they are helping others (Abell et al., 2007; Flood et al., 2013).

Co-researchers with ID in the present study demonstrated strong insight into their own interviewing abilities and the benefit and impact of their participation. Co-researchers with ID and the larger research team reflected on how the *Shared Experience of Disability* between co-researchers with ID and Special Olympics athletes with ID contributed depth to athlete interviews. This is in line with research from a peer-educator program with young adults with ID, which showed that participants found peereducators to be more approachable and relatable than professionals (Frawley & Bigby, 2014). These reflections are also consistent with a previous study, which indicated that matching interviewers and interviewees based on attributes, such as gender and culture, creates a more open and accurate conversation (Byrne, Brugha, Clarke, Lavelle, & McGarvey, 2015). Peer-interviews contain an inherent sense of trust that diminishes power differentials and allows for the use of a common language and a dialogue unique to the shared characteristics (Abma, Nierse, & Widdershoven, 2009; Byrne et al., 2015). *Shared Experience of Disability* eased the process of building rapport and was mutually beneficial for the co-researcher with ID, the Special Olympics athlete with ID being interviewed, and the qualitative evaluation of Special Olympics' Healthy Communities program. Therefore, *Shared Experience of Disability* expands the application of previous research findings in support of inclusive research methodologies.

Co-researchers with ID in the present study also expressed a desire to increase their engagement in research activities following their participation in the study. This interest in engaging in additional activities is consistent with existing literature. In a previous study, McDonald, Kidney, and Patka (2013) found that individuals with ID believed that

engagement in research was worthwhile and improved their quality of life. Previous research also suggests that through engagement in research as co-researchers, individuals with ID often feel an increased sense of empowerment, which leads to greater access to and desire for active participation in worthwhile activities (Frankena, Naaldenberg, Cardol, Linehan, & van Schroyenstien Lantman-de Valk, 2015; McDonald et al., 2013). Importantly, autonomous motivation for engagement in activities is a central component to the development of self-determination (Ng et al., 2012), which is considered a key component of quality of life (Lachapelle et al., 2005; Nota, Ferrari, Soresi, & Wehmeyer, 2007; Wehmeyer & Schwartz, 1998). Co-researchers with ID identified skill improvement as a result of their participation and considered their participation to be meaningful. Co-researchers with ID were also self-motivated to expand their research participation given the opportunity. Thus, co-researcher with ID reflections suggest that co-researcher participation has the potential to contribute to the development of self-determination skills and thereby impact co-researcher's quality of life.

Perspectives on Feasibility

While the benefits of increased rapport building, participant comfort, and potentially expanded interview content, significantly outweighed coordination and scheduling challenges, there are several considerations in incorporating individuals with ID as co-researchers in the research process that merit reflection. The recruitment of co-researching partners with ID was complicated by indirect lines of communication and a reliance on paid staff and/or family members to assist in relaying information. In a review of previous inclusive research with individuals with ID, potential communication barriers were also identified (e.g., differences in language use and recall challenges; Frankena et al., 2015) and should be considered when incorporating co-researchers with ID in future studies. Guardianship guidelines also presented challenges and should be considered when outlining recruitment, informed consent strategies, and study timelines. Finally, consistent with previous research, transportation and scheduling was noted as a significant consideration. Individuals with ID often note reliance on others for transportation as a barrier to active involvement (Haigh et al., 2013; Harada & Siperstein, 2009; Temple, 2007). These considerations exemplify the need for researchers to work to overcome barriers and accommodate a variety of needs in order to promote inclusive research practices.

Strengths and Limitations

The present study is one of the first to examine the reflections of co-researchers with ID on their roles as active members in research and to provide insight into the pragmatics of incorporating co-researchers with ID in research. However, the present study is limited by a small sample size and lack of diversity. Additionally, two of the three co-researcher reflection interviews were conducted by the research staff member who facilitated the research participation of the co-researcher with ID. As such, reflection responses may have been influenced by this relationship. Another limitation is that the present study was unable to include information from other sites participating in the qualitative evaluation of Special Olympics' Healthy Communities program. Therefore, perspectives from sites that were unsuccessful in recruiting and including co-researchers with ID have not been included and additional challenges to feasibility have not been identified. Finally, the use of a single

reflective interview, post-participation may limit this study. Interviewing co-researchers with ID more frequently or before and after participation could strengthen findings, more clearly demonstrate changes from participation, and provide increased interview detail.

Future Research Directions

Including co-researchers with ID provided value to both the research team, through more indepth interviews with athletes, and to the co-researchers with ID, through skill building and meaningful activity participation. However, adequate time, resources, and personnel need to be available to accommodate for the unique needs of co-researchers with ID, specifically those related to guardianship, transportation, and training. Future research should pursue the flexibility and accommodations necessary to include co-researchers with ID in order to expand the depth and quality of data collected.

A primary implication of this study is that it offers support for the benefits of including co-researchers with ID in research studies and highlights their potential contributions to both the research process and individual co-researcher. The benefits presented in this particular study are solely in relation to the data collection process. Future research may benefit from co-researcher with ID participation from the initiation of the study to support study design, assist with participant recruitment, or to provide insight during data analysis. Providing increased opportunities and practice for co-researchers with ID could additionally support greater independence in research tasks. Co-researchers with ID's shared sense of disability and unique personal insights may lend perspective on the meaning of the data collected and could lead to the identification of novel themes and findings. A second implication of our findings is the identification of potential barriers to the successful recruitment and participation of co-researchers with ID. From these findings, future researchers should consider solutions to each barrier during the phase of study design in order to accommodate the specific challenges impacting the participation of co-researchers with ID.

Additionally, future research exploring the feasibility of including co-researchers with ID should work to overcome the limitations of this study by including perspectives from sites that were unable to successfully include co-researchers with ID in their study as well as identifying potential impacts of co-researchers with ID working independently or in pairs. Expanding the dataset to include sites without successful co-researcher participation may help to identify additional barriers and lead to the development of potential strategies for recruitment and inclusion. Developing an understanding of how working independently or in pairs impacts the experience of co-researcher with ID and the feasibility of the study would further clarify the most successful approaches for studies incorporating co-researchers with ID in research activities.

Conclusion

The present study found the inclusion of co-researchers with ID in the research process both meaningful and feasible. Benefits of involving co-researchers with ID, including easy rapport and increased comfort of participants, significantly outweighed potential challenges and difficulties. Moreover, the shared experience of disability between co-researchers with ID and participants with ID allowed the Special Olympics' athletes being interviewed to

share and provide perspectives on issues that research staff (academic faculty and two graduate students without ID) might not have been able to access. Perhaps most importantly, co-researchers with ID and the research team alike found the experience to be meaningful and valuable, at both the individual and community-level. Co-researchers with ID gained skills and knowledge, and felt as if their participation provided value and perspective to research with individuals with ID and other developmental disabilities. While considerations need to be made in advance regarding recruitment of co-researchers with ID, guardianship, and scheduling, thoughtful planning at the outset of a project can balance these challenges.

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Table 1**Primary Questions Used for Co-Researcher With ID Reflective Interview**

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1. Please tell me about your experience as a co-researcher. What were the benefits of being included as a co-researcher? What types of challenges did you experience while being a co-researcher?
 2. Was the experience valuable to you? Why or why not? In what ways was it valuable?
 3. Was there a benefit to including a co-researcher with ID in this project? Why or why not?
 4. Do you think it is important for people with disabilities to be included in research about people with disabilities? Why or why not?
 5. How did your participation as a co-researcher impact you personally?
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Note. Multiple prompts and follow up questions were used as needed.