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Photovoice with Individuals with Intellectual and/or Developmental Disabilities: Lessons Learned from Inclusive Research Efforts

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Inclusive research is an approach in which individuals with intellectual and/or developmental disabilities (IDD) are included as co-researchers throughout the research processes, and has demonstrated benefits for people with IDD. Because inclusive research is still not common within disability research, it is important for research teams to provide reflections and lessons learned to encourage future inclusive approaches. This paper provides case studies of two research projects completed in collaboration with adults with IDD using Photovoice as an approach that can increase access to the research process for co-researchers with IDD. Drawing upon previously defined inclusive research criteria, we reflect on lessons learned and challenges. Inclusive research requires time, flexibility, shared power, clear communication, and cultural humility. Across both studies, we discuss the importance of clear communication with Institutional Review Boards and collaboration with the extended support networks of individuals with IDD. We reflect on how the accessible nature of Photovoice supports inclusive research teams to combine the strengths of co-researchers with IDD and academically trained researchers, such that the knowledge production process is shifted to co-researchers with IDD.

Keywords: developmental disability; intellectual disability; community participation; action research; community-based participatory research; photovoice

Introduction

Individuals with intellectual and/or developmental disabilities (IDD) are a population of people who have been historically marginalized and experience health and wellness inequities (Havercamp, 2015). Intellectual and/or developmental disability refers to disabilities in which individuals have physical, learning, and/or adaptive behavior difficulties with onset before age 18, that affect day to day functioning, and last throughout a person's lifetime (American Association on Intellectual and Developmental Disabilities, 2018). Individuals with IDD are less likely to be physically active, report having inadequate social supports, experience social isolation, and are less likely to receive preventative care (Havercamp, 2015). They also face many social barriers, including high rates of unemployment, less access to digital technology, high rates of poverty, and lack of access to reliable transportation (Krahn et al., 2015).

Research with historically marginalized populations, whom have been exploited in research driven by academics, suggests that community engagement has the potential to be more ethical and may be one way to address inequities, as community members may be better able to identify the root causes of inequities and socially valid solutions (Breault, 2006; Mirra et al., 2016; Solomon, 2014). Furthermore, the disability community and disability researchers have asserted that ethical tensions between academics and community members can be reduced when researchers with disabilities direct study design, analysis, and dissemination (Barnes, 2003; Zarb, 1992). Despite the philosophical recognition of the value of community engagement in research, there is need for additional direction for *how* to engage individuals with IDD in inclusive research

(Goode et al., 2014). In this manuscript, we define inclusive research for individuals with IDD and discuss how Photovoice is one methodological tool that can be utilized to fulfill the criteria of inclusive research.

Within the disability research field, inclusive research has been defined as an umbrella term that describes “research in which people with [intellectual] disabilities are involved as more than just research subjects or respondents” (Walmsley, 2001, p. 188). In inclusive research, people with IDD combine their expertise and lived experiences with the research skills of academically-trained researchers to increase the relevance and quality of research (Walmsley & Johnson, 2003). In some inclusive research projects people with IDD receive supports to serve as co-researchers alongside researchers with academic training. People with IDD can draw upon their lived experiences to help identify meaningful research questions, refine data collection approaches, support recruitment and community partnerships, interpret data, develop solutions (e.g., tools and interventions), and support dissemination and translation to practice (McDonald & Stack, 2016). For example, previous inclusive research described how team members with IDD developed essential components of a self-advocacy intervention (Kramer et al., 2013) and a self-report of functional performance (Kramer & Schwartz, 2018). Another inclusive research project developed a battery of accessible health measures for people with IDD to support future research (Nicolaidis et al., 2015).

The five defining criteria of inclusive research emphasize that it is a philosophical approach to research that can be used with *any* method:

1. The research problem must be one that is owned (not necessarily initiated) by people with IDD.
2. It should further the interests of people with IDD; researchers without disabilities should be on the side [allies] of people with IDD.
3. It should be collaborative—people with IDD should be involved in the process of doing the research.
4. People with IDD should be able to exert control over process and outcomes.
5. The research question, processes and reports must be accessible to people with IDD (Walmsley & Johnson, 2003, p. 64).

While accounts of inclusive research have increased since the early 1990s (Frankena et al., 2015; Stack & McDonald, 2014; Strnadová & Walmsley, 2018), additional reflections on lessons learned from engaging in inclusive research are required to support future inclusive research efforts. In this paper, we describe two studies that implemented the Photovoice methodology (Wang & Burris, 1997) within the context of inclusive research with individuals with IDD: 1) an exploration of health and wellness with individuals with IDD from a Native American community; and 2) an exploration of social capital with adults with IDD in an urban environment. We then reflect on challenges and lessons learned in order to contribute to a body of literature demonstrating *how* the use of Photovoice can be one approach research teams can use to fulfill the criteria of inclusive research.

Inclusive Research Case Studies

Photovoice

In Photovoice, individuals utilize photography to share their stories around an identified issue. This method is used to facilitate access to the perspectives and experiences of others (Booth & Booth, 2003). Photovoice provides opportunities to record and reflect upon problems and assets of a group or community by promoting critical discussion, generating collective knowledge through discussion of the photographs, and encouraging action to change by reaching out to those who influence or make policy (Wang & Burris, 1997). Photovoice has been successfully implemented in previous research with people with IDD and been found to be an accessible, enjoyable, and interesting method (Aldridge, 2007; Jurkowski, 2008; van Heumen & Schippers, 2016).

Studies that implement Photovoice typically commence with a training on the goals and implications of the method and camera use. After participants take photos, individual interviews and/or group discussions are held with participants to reflect on the photographs they produced. Analysis of the data is participatory, with participants selecting their preferred photos, contextualizing them by sharing stories about them, and codifying them by identifying important issues or themes that arise (Wang & Burris, 1997). Finally, participants exercise control over the presentation of the results. This can take the form of townhall discussions, conference presentations and/or other speaking engagements (van Heumen & Schippers, 2016). The following case studies reflect on utilizing the Photovoice methodology as an inclusive research approach.

Photovoice Case Study 1 – An exploration of health and wellness with individuals with IDD from a Native American community

Background

The overall goal of this project was to explore health equity among Native American adults with IDD and their family caregivers. Honoring self-determination, this current project utilized a community-engaged and inclusive approach. Self-determination is a critical concept for both the IDD population and Native Americans (Forbes, 1998; Shogren et al., 2006). For individuals with IDD, self-determination means individuals with IDD are in charge of decisions about their lives. Research suggests self-determination is associated with greater health and wellness (Shogren, 2013). For Native Americans, self-determination refers to the importance of their ownership of their culture, land, and policies that influence their day-to-day lives (Lomawaima & McCarty, 2006). The interdependent relationship between land, culture, and history among Native Nations makes self-determination necessary to address health equity for Native Americans (Holm et al., 2003).

The project was funded by an American Occupational Therapy Foundation Intervention Research grant. The lead researcher and first author of this manuscript is a Caucasian female who was mentored by a female Native American researcher with over 25 years experience completing community-based research with Native Nations. Two Caucasian female occupational therapy doctoral students assisted with project activities. The yearlong project was overseen by a Community Advisory Board (CAB) of six people who were Native American and/or had a personal and/or professional connection to IDD (e.g. family member, provider, researcher). One member was Native American and a sibling of an individual with IDD, three members were providers of services for individuals with IDD, one member was a researcher who is an aunt to a man with Autism, and one member was a Native American researcher.

The CAB provided key insights which informed the inclusive research approach overseeing all processes from research design to dissemination. At the beginning of the project, the CAB felt that the project should be more specific than health equity and recommended the project focus specifically on the concepts of health and wellness. Additionally, since 71% of Native Americans reside in urban areas and not on tribal lands, the CAB thought this project should recruit specifically from an urban area (Urban Indian Health Institute, 2013). Finally, because 78% of individuals with IDD live with and are supported by family caregivers (Braddock et al., 2015), this project also included family caregivers selected by the Native American adults living with IDD.

Ethical approval

University policies needed to be carefully considered in this inclusive research project. The university's Institutional Review Board reviewed and approved the project, but this required some discussions and awareness raising regarding universal design and the impact this would have on the informed consent documentation and process. Universal design principles call for resources to be accessible to all learners, regardless of skills and abilities (CAST, 2018). This project made efforts to address self-determination and inclusion among participants by utilizing universal design principles to ensure all participants could understand and engage in the consent process.

All potential participants, the individual with the IDD, their self-selected family caregiver, and/or the adult with IDD's legal guardian utilized the same informed consent form. The universally designed informed consent form was designed collaboratively with the CAB. It included simplified language, images, and teach-back questions to ensure understanding of the purpose of the project, their role in the project, and the voluntary nature of their participation. The research team also used written and verbal reminders to ensure that the participants understood that they could determine their level of involvement in all stages of the project and that they were the owners of the photos and stories they chose to share. Funding was available to provide incentives (a \$25 gift card) for participation. The participants identified places they would be interested in getting a gift card from during the informed consent process and then these gift card selections were purchased for participants.

Recruiting and relationship building

With assistance from the CAB, the lead researcher spent six months conducting outreach activities to recruit participants. One individual contacted through the recruitment process, who had been involved serving individuals with IDD in the community for over 35 years, became the "community champion" for the project. This person was instrumental in engaging key providers to promote the project as they

had established trusted relationships in the community (Israel et al., 2013). Finding this trusted community champion was critical to overcoming trust issues and power imbalances between the research team (Caucasian women) and potential participants. Eight Native American individuals took part in the study. Four were young men with IDD (age range 19–24 years; $M = 20.75$) and four were family caregivers (age range 38–63 years; $M = 50.25$).

Knowledge production

The Photovoice process involved three in-person group meetings and one individual in-person interview with each participant. The purpose of the first group meeting was to support individuals to identify their own interests and build a personal sense of what health and wellness meant to them. During this meeting, individuals with IDD and their family caregivers discussed and defined health and wellness through an interactive activity called “talk n’ toss.” They passed a multicolor beach ball to each other; on each colored stripe there was a different question about health and wellness (e.g. “Do you like to play on teams?”; “What are ways you like to relax?”; “Do you attend ceremonies?”). Participants responded to the question their hand touched when they caught the ball. This accessible activity reduced communication, attention, and cognitive demands by limiting the number of questions individuals needed to respond to, while supporting both the collective group and individuals to identify potential topics to photograph.

During this group meeting participants also received individual cameras, practiced using the cameras, and discussed safety and ethics related to taking photos. After the meeting the participants had one month to take photos. During this month, the lead researcher communicated with each participant via their preferred method (e.g., in person, text, phone, email) to check in on the photography process. As this project involved the individual with IDD and their self-selected family caregiver, time was spent explaining to each individual the importance of taking their own photos and not influencing one another. This process was new to some participants who shared a more interdependent relationship with their family caregiver. In two cases, the lead researcher met again with individuals in person to fix camera issues (i.e. forgot how to use, ran out of batteries). This was a time intensive process, as the researcher had to identify preferred communication styles of each person taking their photos and check in (often in person) with each participant individually. At the end of the full month of taking photos, a representative from the university met with each person individually at a time and place of their choosing to review the photos and decide which photos (if any) they wanted to share with the other participants and the CAB. The individual interviews were completed ahead of the group meeting to develop their photo projects based on previous research which identified the benefits of completing individual interviews in combination with Photovoice for people with IDD (Jurkowski & Paul-Ward, 2007; Ottman and Crosbie, 2013).

Presenting the findings

Once their individual photos were selected to share with the CAB, they then decided how they wanted to share their photos. During the second group meeting, some individuals with IDD decided they wanted their photo story to be shared with their family caregivers and others wanted their stories to be their own as individual photo stories. Once they decided the format in which they wanted to present their photos, they put together either their photo story in a booklet or on a poster display during the second group meeting.

The final (third) group meeting involved the individuals with IDD and their family caregivers sharing their photos and their stories with the CAB. The overall themes of their photos reflected that they valued activities they could do independently, including being active, having hobbies, and working. They also shared stories about spending time with family, eating traditional foods, being role models to others, being engaged with their community, staying connected to activities on the reservation, and having friends.

This project sought to honor the values of self-determination and inclusive research; this meant that any knowledge produced from the project was owned by the participants. In the end, the participants decided to only share their photos and stories with the CAB and did not want them shared elsewhere. While some of the photos reflected discussions of culture and connection to Native Nation lands, this information belonged to the participants and not the researchers. This means that the only knowledge that can be shared externally is in the format of lessons learned from the project and the overall themes regarding health and wellness from the collective group. This choice ensured individuals with IDD were in charge and not subjects to be studied, which is a paradigm shift from traditional research approaches.

Photovoice Case Study 2 – An exploration of social capital with adults with IDD in an urban environment

Background

Many adults with IDD have small social networks, spend free time alone and experience loneliness (Stancliffe et al., 2007). Improved social relationships are associated with positive health outcomes (Umberson & Montez, 2010). Meaningful community participation can be a first step in building social relationships of adults with IDD. Being involved and included in social structures such as volunteer organizations, churches, and businesses, fosters the development of friendships and social networks, and ultimately, social capital (Gotto et al., 2010). Social capital can be understood as ‘the personal and collective power of people with disabilities and organizations to further their full inclusion within the community, to access social support networks, and to increase their quality of life’ (Walker et al., 2011, p. 14).

A large service provider for people with IDD in Chicago, Illinois designed an intervention called ‘Life Like Any Other.’ This program was funded by the Illinois Council on Developmental Disabilities. The aim of this intervention was to better integrate 30 residents of four Community Integrated Living Arrangements into their neighborhoods through participation in community, civic, faith-based, and special interest organizations. This project afforded local organizations a chance to understand the skills and abilities that people with disabilities can bring to the work of the community. The intervention used people-focused and asset-based community development principles (Mathie & Cunningham, 2013). Direct support staff from the service provider received training on asset-based community development. Interest inventories were completed with the residents and they were matched with local activities.

The second author was contracted to evaluate the impact of the intervention on the engagement and relationships of the intervention participants within their communities—components of social capital. The study aimed to retrieve the experiences of the program participants using inclusive research principles and strategies and the Photovoice method.

Ethical approval

The University’s Institutional Review Board raised several concerns about the study. Their first concern was related to the safety of research participants with IDD while taking photos. During the Photovoice process, participants may take pictures of themselves and their surroundings, including other people present. Researchers had to implement procedures to minimize risk to participants when taking pictures in the community, specifically when approaching individuals to be in a photo. This was accomplished by including role plays during a photovoice training for participants so they could practice asking for permission to take photos.

The use of accessible handouts that included visual information, raised red flags for the Institutional Review Board. The Board felt that if research participants with IDD required a high level of supports for access, they must have “very low capacity” and thus not be able to provide informed consent and to participate in the research. The researchers explained that by supplementing text with visual information and adjusting to the communication style of people with IDD, the research and consent process is made accessible to people with IDD.

Finally, in order to receive approval to collaborate with a community agency (the service provider) on this research project, the university’s Institutional Review Board had several requirements. Non-university team members needed to complete research ethics training before participating in the research. Furthermore, the community agency had to be approved as a research site. An authorization agreement was put in place and the agency needed a federal wide assurance number to be able to be covered by the University’s Institutional Review Board.

Recruiting and relationship building

The research team consisted of a University faculty member (second author, white female immigrant), a doctoral student (Asian male international student), a member of management of the service provider (white female), and their social work intern (white female). The principal investigator had 10 years of experience conducting research in collaboration with people with IDD. All research procedures were designed to meet the individual needs of research participants during the Photovoice process. The team created all research materials with accessibility in mind. For example, all research materials (e.g., recruitment materials, consent forms, handouts, etc.) consisted of or were accompanied by brief handouts with short sentences and images (pictures or pictograms) to increase the accessibility of the research, a key principle of inclusive research.

When academic researchers make the effort to ensure all research procedures are accessible, including the recruitment process, researchers with disabilities feel more included and empowered (Stack & McDonald, 2018).

Ten of the 30 participants with IDD in the intervention consented to participate in this research study. All 10 participants (age range 23–59 years; $M = 46.6$ years of age) lived in Chicago, Illinois. Because the community agency financially supported the study and had staff available to assist with the implementation of the Photovoice method, this study could meet the individual needs of all participants.

Knowledge production

Successfully implementing an inclusive photovoice study requires significant resources. Additionally, there are many complicated logistics involved due to the nature of the method, as well as the support needs of individuals with IDD (Stack & McDonald, 2014). Navigating these required expertise, time and persistent effort.

After completion of recruitment for the study, a group meeting was held with the participants to introduce them to the photovoice process, train them in camera usage and the ethics of taking pictures and provide them with a simple digital camera to use. They were then provided with their photo assignment, consisting of verbal instructions accompanied with an instructional handout with pictograms and short sentences. The photo assignment asked participants to photograph people, places, and things that were: a) important to them, b) made them happy, and c) made them sad. The first part of these instructions was informed by the work of Booth and Booth (2003). The team added criteria b and c to provide additional guidance to participants as photovoice is a method designed to capture both problems and positive experiences (Wang & Burris, 1997).

The participants used their cameras for one month, a period of time successfully used in previous research with adults with IDD (van Heumen & Schippers, 2016). The participants were individually supported during the photography process by members of the research team. After the first week, members of the research team checked in with each participant to see if they had started taking pictures and if they needed additional supports. The members of the research team met with the participants several times to provide additional supports, and all participants invited the research team members to accompany them to community activities.

Throughout this process the research team members took field notes. These notes provided insights into the daily supports provided to the individuals with IDD to be able to participate in their chosen activities, as well as in the research study. Residential support staff assists with coordination of transportation to and from activities (not all adults with IDD travel independently), setting schedules, and other daily tasks. These supports can serve as facilitators as well as barriers to the individuals. For example, one of the research participants missed scheduled rides because his staff required him to complete chores before volunteering instead of after. Training and involvement of staff is essential in improving supports to individuals with IDD to participate in community and social activities and inclusive research studies.

After one month of using the cameras, the pictures taken were printed by the research team and individual interviews were conducted with all participants. After completion of the individual interviews, all participants selected their five favorite pictures to include on a poster during a second group meeting. Discussion among the group on the photographs took place in small groups facilitated by a member of the research team using questions based on the Photovoice research by Hergenrather, et al. (2009). The participants received a handout with pictograms and short sentences to assist with the discussion of the photographs. Each participant provided short descriptions of the five selected photos picked a favorite photo. To conclude, each participant chose a color for the poster the pictures were placed on, and gave the poster a title that reflected the significance of the final product.

Presenting the findings

All participants presented their posters to each other and the research team during this final meeting. Research participants spoke about their experiences in activities in their local communities. Examples of the activities the participants became involved in included volunteering at an animal shelter, food pantry, local gym, and community garden. At the end of the final meeting, the participants took their posters home.

Four participants chose to present their posters and their experiences at two local conferences, one at the Illinois chapter of the Arc of the U.S., and one at the Illinois Council on Developmental Disabilities. Finally, a number of participants were members of their local chapter of the Illinois Self-Advocacy Alliance for Change. They spoke about the project and presented their posters at their local meeting and were paid

to present at a state-wide webinar of the Alliance. Additionally, several of the participants were invited by the principal investigator for guest lectures for undergraduate courses in disability and human development at the University. These opportunities improved participants' opportunities to represent their experiences.

Study findings indicated that the participants had positive experiences in pursuing volunteer roles in local community groups of their interest. Their engagement allowed them to learn new skills, gain self-esteem, make new social connections and to engage in a continued process of personal growth and learning. A number of participants expressed the desire for competitive integrated employment.

Discussion

These studies demonstrate how Photovoice is one research method that can be used within an inclusive research framework. In this discussion, we briefly review how these studies met the five criteria of inclusive research defined by Walmsley and Johnson (2003). In addition, we discuss challenges faced and lessons learned. Finally, we conclude by describing how these two case studies contribute to ongoing conversations about knowledge production and "added value" as related to inclusive research.

Inclusive Research Criteria

In these studies, the research teams took different approaches to ensuring that the research problem was owned by people with disabilities and furthered their interests. See **Table 1** for a summary of how these studies met the inclusive research criteria described by Walmsley and Johnson (2003). In both studies, the research was initiated by academic researchers based on their previous knowledge about disparities experienced by people with IDD. Yet, the community members felt a degree of ownership over the research process, because they valued these research topics and felt the data collection process made the research relevant to their lives. Herein, by supporting community members to engage in research about topics important to their lives and exert control over this process, the researchers served as allies (criteria 1 and 2). Across studies, we observed that it was easy to make Photovoice accessible for community members with

Table 1: Inclusive Research Criteria.

Walmsley & Johnson's (2003) Criterion	Case Study 1	Case Study 2
1. The research problem must be one that is owned by people with disabilities.	While community members did not develop the research question, they stated a value for the question and identified a shared understanding of the research topic.	While community members did not develop the research question, they valued examining the people, places and things that were salient factors of their everyday lives.
2. The research should further the interests of disabled people; non-disabled researchers should be on the side of people with disabilities.	<ul style="list-style-type: none"> • Learning about this community's perspective on health and wellness may lead to approaches that may decrease disparities. • Researchers served as allies in the project and accepted the community's decision to not share findings/photos. 	<ul style="list-style-type: none"> • Evaluating the efficacy of an intervention to improve community-participation and social capital of people with disabilities is aligned with this community's need for efficacious interventions. • Researchers served as allies to people with disabilities throughout their research participation.
3. The research should be collaborative in that people with disabilities should be involved in the process of doing the research.	Both projects developed accessible methods to ensure community members were able to actively engage in all stages of the research process. The use of photography helped community members take control of the research process, as they were able to independently select content for data collection and dissemination.	
4. People with disabilities should be able to exert some control over process and outcomes.	People with IDD selected what to photograph, where to meet, and how to share findings.	People with IDD selected what to photograph, and how to share findings.
5. The research question, processes and reports must be accessible to people with disabilities.	<ul style="list-style-type: none"> • The Photovoice and consent procedures were accessible. • People with IDD selected how to share photos within the group. 	<ul style="list-style-type: none"> • The Photovoice and consent procedures were accessible. • People with IDD selected the approach for dissemination and led dissemination efforts.

IDD (criterion 3). People with IDD are increasingly using technology in their daily lives (Borg et al., 2015), and we observed that most community members know how to take photographs or are able to learn with support and enjoy doing so. Not only does this accessible approach promote collaboration with people with IDD during the research process, but photography also confers power to people with disabilities. In Photovoice, nearly all stages are controlled by the community members. While a researcher may provide a prompt to community members, as they select subject matter for photographs, these individuals have the power to interpret the prompt in a way that is meaningful to them (criterion 4). Community members continue to exert control by selecting the photos that they believe are most salient, interpreting these photos, and controlling their dissemination, conferring community members power over the research narrative (criteria 5). While Photovoice is an action research approach intended to drive social change, in each of these case studies social change was not necessarily the achieved outcome (Wang & Burris, 1997).

Challenges and Lessons Learned

During the course of this research, we experienced several challenges. A frequent challenge encountered by inclusive research teams is collaboration with Institutional Review Boards. These boards often question the abilities of people with IDD to collaborate in research due to assumptions about their capacities. Both research teams had to educate their Institutional Review Boards about how adaptations and accommodations can and should be made to effectively include people with IDD as research collaborators (Booth & Booth, 1996; Northway et al., 2015).

Second, both teams had to negotiate with the extended support networks of their research partners. People with IDD are often enmeshed within systems that support their independence in daily life activities (Priestley, 2003). In many cases, these systems can support their participation in research by providing transportation and helping them complete assigned tasks. However, sometimes these systems can be a barrier or complex to work with. Additionally, because research may require that service providers and individuals with IDD relate to each other in new way, researchers may need to educate individuals' support networks about these differences. For example, in the health and wellness study, the researchers needed to clearly communicate the importance of taking photos that elicited the unique perspectives of each individual involved; this was in contrast to the interdependent relationships between the adults with IDD and their family member often experience.

Across the literature on inclusive research, there is agreement that this research approach requires significant time and flexibility (Di Lorito et al., 2017; McDonald & Stack, 2016). We observed this in both of our studies, as all researchers with IDD required individualized supports to complete their assigned research tasks. In the health and wellness study, the research team had to exercise cultural humility and be responsive to the stated preferences of the researchers with IDD. Cultural humility involved the researchers practicing ongoing self-evaluation and self-critique regarding their cultural understandings and their role in the process of research (Tervalon & Murray-Garcia, 1998). This meant changing their plans for the action phase of research as the researchers with IDD elected to not share their stories for action.

Future Research

We reflected on challenges and lessons learned during two inclusive research studies with individuals with IDD. While both studies utilized Photovoice, there are many examples of inclusive research that draw upon other methods. In our own work, we have conducted inclusive research in which people with IDD conduct interviews (Schwartz et al., 2019), create visuals of their life histories (van Heumen, 2015), and analyze qualitative focus group data (Schwartz et al., 2020), and the literature provides many examples of inclusive research using additional research designs (Raymaker et al., 2017; Stack & McDonald, 2014). Future research should more systematically study inclusive research that utilizes a range of methodologies. Systematic observation of the inclusive research process may be required to move the field forward beyond case study description. Although it is generally accepted that inclusive research is an effective approach to addressing health inequities, additional research is needed to understand under what circumstances this positive outcome is realized.

Knowledge Production

Inclusive research implores the research community to consider its beliefs about knowledge production. Some researchers have suggested that when academic researchers train people without academic training to perform traditional research skills, it reifies the superiority of these traditional knowledge production approaches (Janes, 2016; Walmsley & Johnson, 2003). These researchers and others argue for knowledge production processes that draw upon individuals' strengths and existing skills (Milner & Frawley 2018). While Photovoice has become a mainstream research approach (Jurkowski, 2008; Lal et al., 2012), it is

one way of exploring alternative modes of knowledge production while drawing upon everyday skills, specifically photography, and meaning-making from images.

This conversation about knowledge production is closely related to an emerging discussion in inclusive research about “added value.” In many research environments, articulating the value of inclusive research is critical, given the extensive time and resources this approach requires (Stack & McDonald, 2014). However, the definition of “value” is inherently contextual. While in some settings, “value” may be defined monetarily or in terms of social change, in many settings in which inclusive research is conducted (e.g., universities, research centers), “value” is defined by advances in knowledge. In our current research climate, knowledge production is judged by its adherence to traditional methodologies that are codified by academia. Therefore, to gain recognition and be granted necessary resources, inclusive research teams may need to adhere to these methodologies (Janes, 2016). When these methodologies do not draw upon the strengths of people with disabilities, the research community risks missing out of the inherent added value of partnering with these community members (Schwartz et al., 2019).

Therefore, we suggest that added value can only be achieved when inclusive research methodologies are selected for their fit between research question(s) and community members skills. This proposition leaves open the possibility that it may be appropriate to generate knowledge using traditional approaches, but emphasizes that rigorous research capitalizes on individuals’ unique strengths, rather than requiring academic researchers to mold community members to work within traditional research methodologies (Milner & Frawley, 2018).

In these case studies, community members and academic researchers gained a greater understanding of individuals’ personal connections to daily activities related to health and wellness (case 1) and community participation (case 2). In addition, the teams learned about conducting research together, knowledge which is being shared with the academic community and will carry into future community partnerships. When the strengths of academically-trained researchers and individuals with IDD are combined, there is great potential to effectively address inequities.

Conclusion

Inclusive research may be one approach to reducing inequities for people with IDD. Photovoice can be adapted to serve as an accessible methodology that supports individuals with IDD to collaborate in research. Across two inclusive research studies utilizing Photovoice, we identified challenges and lessons learned, including the importance of communication and collaboration with institutional review boards and extended support systems of people with IDD. The underlying values of inclusive research implore researchers to expand their conceptualization of knowledge production, thus inviting new methodologies that draw upon the strengths of people with IDD.

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Competing Interests

The authors have no competing interests to declare.

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