

Using Photovoice to listen to adults with intellectual disabilities on being part of the community

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This is an Author's Accepted Manuscript of an article published in

Schleien, S., Brake, L., Miller, K., & Walton, G. (2013). Using Photovoice to listen to adults with intellectual disabilities on being part of the community. *Annals of Leisure Research*, 16(3), 212-229. doi: 10.1080/11745398.2013.828364.

as published in the *Annals of Leisure Research* 2013 [copyright Taylor & Francis], available online at: <http://www.tandfonline.com/10.1080/11745398.2013.828364>.

Abstract:

Imagine if you were offered a glance through the lens of a very unique photographer: a member of your community who has an intellectual or developmental disability (ID/DD). A community-based participatory research method, Photovoice, was used to enable seven individuals with ID/DD the opportunity to document their lives through the use of photography and discuss their interests, hopes and dreams. Specifically, this methodology provided them with opportunities to share their concerns about their community access and communicate with the larger community using photographs and the collective ideas of the group. Common themes were revealed among the participants, including their hidden talents, community membership and sense of belonging, consumerism and making choices, desired independence, limited connections to the community and a desire to be treated as adults. Two themes – community membership and desire for independence – are expounded upon, as they appeared to be the most relevant to improving one's quality of life and greater self-determination.

Keywords: community access | community-based participatory research | inclusion | InFocus | intellectual/developmental disability | Photovoice | self-advocacy

Article:

Introduction

There have been numerous efforts in the past several decades to increase the participation and inclusion of people with intellectual and other developmental disabilities (ID/DD) in schools and community environments. These efforts and accomplishments have included self-advocacy and family member advocacy activities, legislative initiatives, development of new programmatic practices and innovative research pursuits. Additional support for increased community access has come from TASH (formerly The Association of Persons with Severe Handicaps) whose national agenda called for an expansion of inclusive educational, employment and community opportunities across the USA (Carter et al. 2012). Relatedly, the National Recreation and Park

Association, through its Position Statement on Inclusion, made a clear statement on the value of inclusive service delivery to participants with and without disabilities in the USA (Schleien, Miller, and Shea 2009). Yet with all of these efforts to increase meaningful access to ongoing community activities, current research suggests that people with significant disabilities remain isolated from their peers without disabilities with community opportunities remaining unavailable (Anderson and Kress 2003; Carter et al. 2012; National Disability Rights Network 2011). Consequently, individuals with ID/DD have restricted social networks that often consist of relationships with other people with a similar label, family members and staff members that are paid to work with them (Clement and Bigby 2009). As a result of this segregation, they have been excluded from full participation within their communities and remain one of the most physically and socially inactive and segregated groups in our communities (Zijlstra and Vlaskamp 2005).

Participating in recreation, sports and social activities with peers is an essential aspect of one's quality of life. Active, vital and socially connected people participate in a wide range of activities and places throughout their lifetime. Community recreation activities promote the learning of new skills; physical, mental and emotional health; provide opportunities for developing new relationships and making friends; and help individuals find a desirable balance between work and leisure (Sable and Gravink 2005; Schleien, Ray, and Green 1997). Although the benefits of inclusive recreation are clearly understood, and a variety of these services have been designed, there remains an abundance of community agencies that still do not practise inclusive services (Anderson and Kress 2003; Devine and King 2006; Miller, Schleien, and Lausier 2009; Schleien, Miller, and Shea 2009). In these cases, either programmes are not accessible to individuals with disabilities or segregated activities serving only people with similar disabilities are available.

To compound this problem, not only are individuals with ID/DD typically inactive and segregated, but they also have few opportunities to participate in decisions that affect their lives (Jurkowski 2008). In research studies, they are often employed as subjects rather than engaged as research participants (Horwitz et al. 2000; Paiewonsky 2011). Individuals with ID/DD are now seen as having unique and important views towards service delivery and available activities and are in need of a strong voice. Service providers cannot remain overly reliant on so-called 'experts' to make all the decisions concerning their livelihoods. What strategies and opportunities can be identified to empower these 'silenced' individuals to help create the change within the community for which society at large strives? Through Photovoice participatory action research, some of these answers may be provided by offering a glimpse into the ideas and perspectives of these self-advocates through the photography lens.

Literature review

Photovoice: what is it?

Photovoice is a creative form of community-based participatory research. Its roots are grounded in both qualitative and action research. Theoretical underpinnings for Photovoice include Friere's (1973) critical education approach, feminist theory and documentary photography (Wang and Burris 1997). Friere's approach is to identify important issues in people's lives, to critically reflect on them through dialogue and to identify root causes and discuss potential solutions, and these form the foundations of the Photovoice methodology, with the exception of one critical detail. Friere provided visual images to those participating in the project, whereas in Photovoice, participants create their own images which could further empower participants. Feminist theory informs Photovoice methodology in its recognition that research may be biased by the dominant culture, and thus the need for individuals from underrepresented groups to serve as authorities of their own lives through methods that assert the value of their experiences. Finally, Photovoice draws on the critical consciousness that is raised through the powerful visual images generated through the practice of documentary photography.

Some of the initial Photovoice researchers defined it as a method of seeing the world from the viewpoint of people who are leading different lives (Wang and Burris 1994). Cameras are provided to members of underrepresented groups, and a 'voice' is created through the photographs that are taken. The viewpoints of these underrepresented groups can be eye-opening since they often vary substantially from the typical and stereotyped viewpoints found in society.

Utilization of Photovoice

In the past, Photovoice has been used with a variety of populations with voices that have often gone unheard. People who are homeless (Wang, Cash, and Power 2000) and aboriginal breast cancer survivors (Poudrier and Mac-Lean 2009) are underrepresented groups that have benefited from this 'technique that places the selected individuals in charge of documenting their lives' (Booth and Booth 2003, 432). Participants are also empowered to become community change agents while enhancing personal growth and social connections (Killion and Wang 2000). The Photovoice process usually contains three primary and complementary goals to benefit a number of segregated groups. These goals include enabling people to record and reflect upon their community's strengths and concerns; promoting critical dialogue and knowledge about important community issues through large and small group discussions of photographs; and reaching policy-makers and initiating change in the community (Wang and Burris 1997).

Individuals with ID/DD have become empowered by Photovoice, such as when Booth and Booth (2003) worked with mothers with learning disabilities to, 'challenge discriminatory views about this group of vulnerable families by narrowing the gap between how others see them and how they see themselves' (440). The researchers found that Photovoice was an effective means of revealing different perspectives for these underrepresented groups. To these researchers, Photovoice offered a method for 'grasping what is going on at the point in people's lives where biography and society intersect' (440).

The Photovoice methodology was implemented by Jurkowski and Paul-Ward (2007), Jurkowski (2008), and Jurkowski, Rivera and Hammel (2009) who worked with Latinos with ID on changing their perspectives on healthy living. They discovered that Photovoice ‘enabled individuals with intellectual disabilities to express their real-life experiences through photographic images that represent their perspective as they interact in their environment’ (Jurkowski 2008, 9). Through this initiative, Jurkowski, Rivera and Hammel (2009) found that Photovoice acted as an empowering tool that enabled photographers to reveal themes related to social relationships, emotional states, energy, interconnection between work and health, beliefs about healthy behaviour and culturally centred beliefs about health. Their findings were presented in a town hall meeting attended by service providers, community leaders, caregivers and people with disabilities. Meeting attendees discussed the findings and generated recommendations and action steps which were presented to agency administrators for use in future programme development (Jurkowski and Paul-Ward 2007).

Through her work with college students with ID, Paiewonsky (2011) adapted a combined methodology of Photovoice and a web-based digital storytelling technology called VoiceThread. Through this technology, college students developed, implemented and accomplished action steps as an integral part of their Photovoice project. The students' findings were presented to university partners and at conferences. They developed training materials for students, parents and professionals, as well as an online consortium of college options for individuals with ID.

Researchers have been encouraged by the success of this relatively new research methodology that is revealing new and different perspectives of individuals who had previously been marginalized from society. It is with this foundation in mind that we instigated this Photovoice study with two primary intentions: (a) to provide individuals with ID/DD a voice concerning their access, participation and inclusion in the community and (b) to attempt to instigate change in the community by sharing these voices with myriad audiences.

Methods

The Arc is a national grassroots organization comprising more than 700 state and local chapters across the USA, which started more than 60 years ago. The Arc's mission, in part, is to actively support community participation and inclusion of individuals with ID/DD. A local chapter of The Arc, located in a mid-size, southeastern city in the USA, reached out to a university research team with a desire to gain a better understanding from the perspective of their members with ID/DD of the barriers experienced and supports needed for increased community participation and inclusion. Through focus groups conducted by this collaborative team prior to the current study, a range of different perspectives were gained from self-advocates concerning their needs, wants and dreams to become more accepted and engaged within their communities. This research team believed Photovoice methodology aligned well with the desire to expound on these focus group results in a manner consistent with The Arc's promotion of self-advocacy among its constituents. A Photovoice initiative was implemented in 2011 to address the

following research questions: (a) how do individuals with ID/DD perceive community access, participation and social inclusion? And (b) how does Photovoice inform community members about the inclusive community participation of individuals with ID/DD?

Phase one

The Photovoice project progressed through three discrete phases (see Figure 1). The initial phase began with preliminary and organizational tasks, as well as instructor training. Each participant was assigned to a single instructor that (s)he worked with throughout the entire project. Participants were selected based on their responses to an invitation letter from The Arc. This letter explained a number of important details including a description of the need for a committed ‘assistant’ who would be comfortable and willing to work with the participant throughout the Photovoice programme. Assistants were necessary due to their vital role of providing support in the technical aspects of utilizing digital cameras (e.g., need to recharge batteries and what to do if the wrong button was pushed), prompts to complete photography assignments, and transportation to and from programme meetings or photography locations. By clearly differentiating roles between the photographers and assistants, participants were empowered to share their personal perspectives, but with support available when necessary in order to do so.

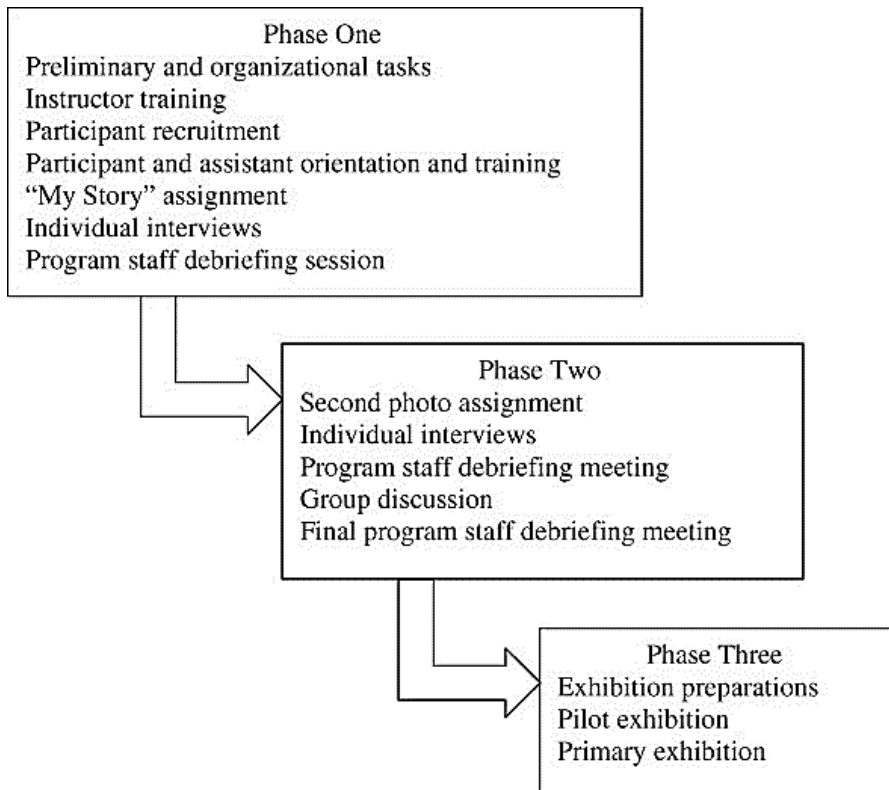


Figure 1. Programme tasks for phases one, two and three.

A list of required meetings and events, along with a participant consent form, were other essential components of the invitation letter. Four criteria were established for the recruitment of participants for Photovoice. Participants had to be (a) 18 years of age or older, (b) a member of the local Arc, (c) able to demonstrate sufficient verbal communication skills to express meanings associated with their photographs and had to (d) demonstrate the ability to understand the consent process. A total of seven participants, all with mild to moderate ID, were engaged in the Photovoice initiative. Table 1 provides a brief description of the seven participants.

Table 1. Photovoice participant demographics/characteristics.

Participant (pseudonym)	Age	Disability	Employment	Living arrangement	Photovoice assistant
Garrett	48	Intellectual disability	16 h/wk	With mother	Brother
Patrick	34	Down syndrome	8 h/wk	With parents	Father
Lisa	35	Intellectual disability	None	With mother	Mother
William	21	Intellectual disability	Student	College housing	Parents
Taylor	38	Intellectual disability	8 h/wk	With parents	Mother
Sam	32	Down syndrome	6 h/wk	With parents	Mother
David	26	Intellectual disability	8 h/wk	With parents	Father

The second component of this first phase included holding a group meeting which all participants and assistants attended. The orientation began with a discussion of the programme goals and methods. A detailed explanation was provided to explain the differentiated roles of participants and their assistants and is depicted in Table 2.

Table 2. Differentiated roles of participants and assistants.

Participant	Assistant
Being responsible for camera	Providing assignment reminders to participant
Generating ideas for photos	Providing assistance only when necessary
Getting written consent from photo	Appropriate assistance: support with camera operation;

subjects	transportation; taking a photo when asked
Asking someone to take a photo if participant wanted to be in the photo	Inappropriate assistance: influencing what photos should be taken; speaking on behalf of participant during interviews

The use of the digital camera was demonstrated with specific adaptations. A slide show was used to illustrate use of the digital camera and participants were walked through step-by-step instructions with their cameras in hand. Supplemental learning tools included a detailed list of camera instructions, a brief pocket-size set of camera instructions and a photo packet that displayed each button on the camera. These supplemental learning tools were provided to both the participants and assistants. Additional time was provided for the participants and their assistants to practise using their cameras after instruction was completed.

The ethics of photography and the importance of consent were discussed with the group, including the need to explain to potential photograph subjects why participants wished to take their picture, were asking for their permission, and were obtaining a signature of consent. The fact that some people may not want their photograph taken was also discussed. In order to minimize the reliance on communicative abilities, a pocket-sized photo-release booklet was provided to the participants, which provided a brief written explanation of the project, how the photos would be utilized and space to obtain signatures from individuals who the photographers desired to photograph. Towards the end of the meeting, the first assignment was introduced with a supplemental worksheet to assist the participants to organize their ideas. This 'My Story' assignment asked participants to take photos of people, places, and activities that were important to them. The participants were given two weeks to complete this assignment, with a 30-photo maximum.

The third component of phase one included a discussion between the instructor, participant and his/her assistant. Instructors reviewed the photos with each participant and allowed them to explain each of them in turn. During this process, the instructor noted several primary ideas the participant appeared to be communicating through their photographs. The instructor discussed these ideas with the participant and they were validated or altered based on the participant's feedback. The participant was then asked to choose the three ideas he/she felt were most important and one photo that best represented each idea. A series of prompts were used to discuss each of the three photos in further detail that included: Why did you take this photo?, What are the people, places and activities in this photo?, What do you like about these people, places and activities?, and What bothers you about these people, places and activities?

At times during these individual interviews, input was provided by the assistants. The interviewers managed this input by redirecting the conversation to the photographer and asking him/her to validate any ideas that may have been influenced by the assistant. Once the individual

interviews were completed, programme staff (i.e. researchers, Community Resource Specialist of The Arc and instructors) held a debriefing meeting to discuss similarities, differences and themes across the participants' photos.

Phase two

Phase two resembled several of the steps within phase one, with a few exceptions. The instructors provided their respective participants and assistants with the next assignment through the participant's preferred method (i.e., face-to-face, phone call, text message or e-mail). Participants were asked to take new photos in response to the following two questions: what people, places and activities make you feel important and what are your skills and talents? The participants were given two additional weeks to complete this assignment with a 20-photo maximum. The same procedures from the initial assignment were used during individual meetings with participants to discuss their second assignment photos with only minimal revision to the probing questions to reflect the differences in assignments.

Upon completion of these interviews, programme staff once again conducted a debriefing meeting to discuss similarities, differences and themes across participants' photos. Using the two assignments, six primary themes were identified that were consistent across the participants. One photograph was selected to represent each of the primary themes, being careful to ensure that each photographer was represented in this final selection (two participants' photos were used to jointly illustrate one theme resulting in six themes across the seven photographers). The resulting seven photographs and six themes were used to lead a group discussion with the participants.

Phase two progressed to a group discussion where each participant was asked to explain his/her photo to the entire group of participants. Then all of the participants were encouraged to respond to the photo and theme. This group discussion also served as a member check in order for researchers to verify the relevance of the identified themes and whether the themes were 'true for them' (i.e., representative of the group as a whole). It also provided an opportunity for the participants to further elaborate on their perspectives and what they wanted the community to know about these themes. Programme staff conducted a final debriefing session to review the information gathered during the group meeting. Programme staff were unanimous in agreement that the identified themes had been validated by the group discussion and proceeded to identify quotes that best illustrated participant perspectives in their own voice.

Phase three

Phase three consisted of final preparations for two community exhibitions: a pilot exhibition at the local Arc and a primary exhibition at a community location. The exhibitions consisted of one large group display, as well as individual displays for each photographer. The large group display included one enlarged (i.e., 54 cm×74 cm), framed picture from each of the participants representing one of the six prominent themes. Each photograph was accompanied by a narrative that described the theme using quotes from the group discussion and individual meetings to

reflect the 'voice' of the group. In addition, each photographer had an individual display that consisted of one poster collage containing five photos that represented the participant, one 'My Story' photo book containing all of the photos the participant had taken and props that related to the participant's displayed ideas (e.g., fishing pole for a participant who was a knowledgeable fisherman). Individual poster collages were also accompanied by narratives using quotes from the individual interviews. Additionally, participants stood by their displays during the exhibitions so that attendees could ask them any questions about their photographs and experiences in the Photovoice project.

The participants were also encouraged to invite their friends and families to the pilot exhibition that was held at the local Arc headquarters. The purpose of this exhibition was to provide a venue for participants to display their findings to their friends and family in a comfortable and familiar environment, and to practise speaking to others about the meanings of their photographs. The pilot exhibition provided an opportunity to experiment with the display in order to make the necessary adjustments for the primary exhibition. Once the pilot exhibition ended, preparation for the primary exhibition focused on marketing so as to create maximum community impact. It was beneficial and necessary to invite key members of the community who represented a broad variety of constituents. Held at the city's Chamber of Commerce located in the downtown area, the primary exhibition attendees included an invitation list consisting of friends and family members of the photographers, local policy-makers, service providers, government representatives and general citizens.

Data collection and analysis

Research question #1: photographer perceptions

This research was approved by the university's Institutional Review Board and all participants provided informed consent for the collection of data prior to the programme. Photographs taken by participants were collected as the primary data-set. Digital images were downloaded from participants' cameras to portable hard drives (for secure data storage purposes) and viewed on laptop computers during the individual interviews. Individual interviews and the group discussion were digitally audio-recorded. Interviews ranged from 60 to 90 minutes, and the group discussion was 90 minutes in length. All digital audio-recordings were transcribed verbatim, and participant photographs were systematically assigned numbers. During individual interviews and group discussion, these assigned numbers were referenced in order for the statements to be linked to the photographs under discussion. This documentation procedure enabled the researchers to examine photographs as well as the accompanying statements from the transcripts during data analysis.

A constant comparative approach (Patton 2002) was taken to data analysis. After interviews had been completed with each participant, programme staff met to discuss the content of pictures and transcripts. Through the discussion, arising themes were identified. Identified themes were then

discussed in relation to each participant and across participants to ensure that they were truly representative and to explore alternative explanations. This systematic approach was used until consensus was reached regarding the dimensions of the identified themes. Individual interview transcripts were then systematically coded using the identified themes and reviewed again by the researchers to ensure that they were consistent within and across participants and that all primary concepts had been captured.

As described earlier, six prominent themes were identified by programme staff during the debriefing meetings. These themes were presented to the Photovoice participants at the group discussion as a member check (Jurkowski 2008; Patton 2002), where their accuracy and relevance were validated and the meaning of themes was further expounded upon by the participants. Based on this validation, the transcript of the group discussion was coded using the same system that was implemented for the individual interviews. This allowed for easy retrieval of coded statements representative of the identified themes. Narratives that accompanied photographs in the exhibitions were developed and based on thematic coding using the prominent themes of all the Photovoice data.

Research question #2: community outcomes

Attendees of the primary Photovoice community exhibition were asked to complete an anonymous survey upon exiting. The survey consisted of a demographic question regarding the respondent's role in the community, six Likert scale questions and two open-ended questions. The survey collected information regarding their perceptions of the exhibition and the issues which were identified, how it impacted them personally, if they planned to take any actions based on their experience and the community's capacity to address the issues that surfaced. Descriptive analyses (i.e. frequencies, means and standard deviations) were conducted on the data collected from the exhibition attendees. Due to the small sample size and limited variance in subject's respective roles in the community, it was not possible to conduct one-way analysis of variance to assess whether community outcomes differed significantly by community role.

Results

The two research questions that were used to address the photographers' perspectives on their own place and inclusion within the community, and any impacts that these photos and narratives had on a community generated many ideas. It was revealed that the participants had many strengths and talents that, if recognized, would be valued in the community. Additionally, these photographers had a strong desire to be connected to others and to their larger communities however this was defined. Many wished to live independently and be gainfully employed. That said, several individuals spoke about their loneliness, hurt feelings and a sense of being dependent on their family members and church for their social connections and to gain a sense of their own importance.

Perceptions on community access, participation and inclusion

Specifically, six themes were identified and included: (a) a desire for community membership and to achieve a sense of belonging, (b) a desire for independence and to live independently, (c) having talents and abilities to share that were not readily recognized by the community, (d) consumerism and a sense of independence and opportunities for choice that were associated with the earning of money, (e) a desire to be treated as adults and (f) limited connections to and opportunities in the community. We decided to expound upon the results of the first two themes (i.e. community membership and desire for independence) as the participants' needs to belong and live actively in the community appear to be the most relevant themes that were associated with an improved quality of life and greater self-determination. However, the remaining four themes are supportive of these two prominent ones and will be discussed within that context.

A desire for community membership and a sense of belonging

The participants explained how simple it was to be made to feel welcomed, including such common courtesies as, 'being friendly, smiling and speaking to me'; 'asking me my name'; 'knowing my name'; and 'when you ask them something, they are willing to help'. Patrick emphasized that 'The one thing that comes to mind is being respected'. When asked to elaborate on what this meant, he stated, 'Respect is having friends who actually say "I'm glad you're here. I hope you have a great time"'. Feeling unwelcomed was associated with a lack of basic courtesy on the part of others, such as 'They walk away when you speak to them', and 'They don't listen to me'. Garrett also stated, 'Sometimes when you go to a place you don't know, you have mixed feelings ... they don't want to help you'. Church was mentioned by several participants as a place where they felt welcomed. Lisa remarked that 'I feel welcomed at church because every Sunday we have to get up and shake everybody's hand'.

The participants identified few other places where they truly felt welcomed and accepted, except for family and church events. These limited community connections, another recurrent theme revealed in this research, were apparently reinforced by the unwelcomed feelings described above. There is a hesitancy to step out of the comfortable, familiar relationships provided by family and church. However, Garrett found a sense of belonging connected with his place of employment. He had worked in the dining hall of a university campus for the past 15 years. Even though his job did not begin until 4 pm in the afternoon, he arrived on campus three hours prior, not out of necessity but because he liked to arrive early. Pointing to a photo he took on campus, he proclaimed, 'It's the Elliott Center. That is where I spend half of my day'. He stated that he used the extra time before work to go to the library to check his email, visit the food court, socialize with friends and sometimes visit the shops near to the campus. He felt secure on the campus, 'Because I have friends that work on campus'. Having friends that worked there had increased his sense of belonging which was supported by his statement, 'It makes me feel important'. He also noted the importance of feeling independent on campus. In addition to several faculty and staff members, he knew a number of students. He proudly noted that 'Some of the students know me through class, from presenting in class. We talk every once in a while'.

The fact that 'They know me without my [university work] name tag on' really seemed to boost his sense of belonging and feeling connected to students and staff alike.

Similar stories were not forthcoming from the other photographers. There were even times when Garrett felt excluded. He described seeing activities occurring on campus in which he would like to take part but did not. He stated that 'We [people with disabilities] feel sheltered sometimes. The public does not welcome many people with disability. And I am afraid that I couldn't do it'. When asked what someone might say if he were to try to participate, he stated that 'They will say look at that handicapped person'. When asked, 'So you just don't even want to try'? he replied, 'Right'. However, he knew exactly what it would take for him to feel more comfortable participating, 'Yeah if I could ... an instructor could come up to you and show you. Like if you had a one-on-one to show how and go over the steps with you'.

Yet, even when skills were apparent to family and church members, there was a disconnect in using these skills to access the greater community. Typically, people use their talents and skills to access venues for connecting with others (Anderson and Kress 2003). However, these photographers had limited opportunities to share their strengths. For example, David was an avid fisherman and had developed significant skill in this pursuit. He readily explained how he managed multiple reels at once, stating, 'See, I have one [rod] in my hand, and three out there waiting for a fish'. When asked who knew about his fishing skills and knowledge, he replied that he only went fishing with his family. The lack of community participation and inclusion precluded the sharing of these talents with others, and their talents were not being used as tools to connect to the community in social ways.

A desire for independence and to live independently

One particular photo stood out to the project staff, but not for the reason that was intended by the photographer. The photographer, William, was a student in a post-secondary education programme associated with the local university and lived in a student apartment complex near the campus. William's focus was on his prized Special Olympics medal, which he had displayed on his desk in his apartment among a pile of papers and dirty dishes. Photovoice staff, however, noted how much the photo reminded them of their college days and the newfound independence that comes with not always having to clean your dishes and being able to do what you want in your own apartment. When asked if he got into trouble for not cleaning his dishes and putting them away, he stated proudly and with a great deal of satisfaction, 'Nope'! This photographer proceeded to share with the other participants, all of whom lived with their parents, what independence felt like. William declared:

I'm living on my own and it's just a great life for me. When I'm there [campus housing], I have freedom and I get out in the community and make friends, meet new people, and it's just been a great life for me ... living with your parents, they tell you what to do, and living on your own, you don't have all that, so it's a great life.

Perhaps more telling than this young man's words was the smile that was clearly evident as he spoke of his independent living situation.

In addition to their desire for independence, photographers shared a parallel theme of a desire to be treated as an adult, rather than continuing to be regarded as a dependent child. Feelings of embarrassment were discussed, including comments such as 'it hurts your feelings', 'being picked on is one of my biggest things', and 'you don't feel comfortable', with specific examples of being offered children's menus in restaurants and questions being posed to accompanying adults, rather than directed to the individual with a disability. Participants expressed frustration with the general public who frequently treated them as if they were children. Patrick summed up the group's sentiments by stating, 'You should treat us the way we are. We are adults. We're not kids'.

When the other photographers were asked if they ever thought about living on their own, there were several affirmative responses such as 'in the future' and 'I think about it'. In fact, when asked if they would like to live on their own, all participants responded in the affirmative. However, there was also some noticeable apprehension, as Taylor admitted:

I've talked to Mom and Dad about it ... I told them I wish I could be on my own; to be independent and on my own. But I have to live with my parents. It would be better for me. I can't live on my own. I can't do it.

The one exception was a photographer who had previously admitted that he paid for room and board. Patrick's pictures included depictions of himself helping out with household chores. He stated:

I'd like to one day own a house, where I can do the dishes, the laundry, the cooking and the cleaning, all of that. I just love to do it ... It makes me who I am; a person who is more independent.

Yet, even Patrick could not identify a clear plan for establishing his independent living scenario. There was also some apprehension about what the future held since most were not living independently. For example, one participant asked, 'What's out there for us, say if our parents are gone in the future'?

Nonetheless, the pride associated with paying your own way and preparing for the responsibility of maintaining a household was evident and was closely tied with being treated as an adult who is gainfully employed and has the rights of any consumer in the community. Discussions revealed that consumerism was highly valued by all of the photographers, who expressed their need, and indeed their right, to make choices and purchases with their well-earned money. For example, Taylor said of his purchasing power, 'I work really hard for that money. I deserve it'. Lisa equated the opportunity to use her own money with her independence and stated, 'I pay for the movie ticket with my own money. I like to be independent; on my own'.

Community outcomes

The primary Photovoice exhibition was attended by 122 community members, while the exit survey was completed by 74 attendees. The majority of respondents to the exit survey were family members and friends of the Photovoice participants (48%). The remaining attendees were general community members (24%), university students and faculty (23%), and service providers to individuals with disabilities (5%).

Attendees overwhelmingly provided positive feedback about the exhibition (see Table 3 for a presentation of findings from the exit survey). This may not be a surprising finding given the large percentage of respondents who were family members or friends of the participants. All respondents found that attending the exhibition was a valuable investment of their time and they felt that it had positively impacted on their perceptions of individuals with intellectual disabilities. All but 3% felt that the exhibition increased their awareness of issues concerning community participation and inclusion. Although attendees were confident in the community's capacity to address the main issues identified at the exhibition (i.e. 72% strongly agree, 28% agree), they had somewhat less confidence in their own abilities to address these issues (i.e. 53% strongly agree, 44% agree).

Table 3. Photovoice exhibition attendees' perceptions of their experience.

Variable	<i>N</i>	<i>m</i>	<i>sd</i>
Valuable investment of my time	74	3.81	0.394
Increased my awareness of issues	74	3.73	0.505
Changed my understanding of the issues	73	3.66	0.506
There are things I (or my organization) can begin to do to address the issues	68	3.47	0.657
Positively impacted my perceptions of people with intellectual disabilities	73	3.79	0.407
Community has the capacity to address the issues	72	3.72	0.451

Note: Likert scale: 1 =strongly disagree, 2=disagree, 3=agree, 4=strongly agree.

Two open-ended questions were asked on the exit survey: (1) which photo and caption did you learn the most from or find the most interesting? Why? And (2) is there anything else that you would like to share with us about the Photovoice exhibition and this experience? Responses to

the first question demonstrated that all of the primary photos and narratives presented at the exhibition had a strong impact on attendees' understanding of the issues the photographers wished to communicate to the community. Attendees had obviously taken the time to read the narratives accompanying the photographs and process their meaning. Responses included statements such as:

The photo of the mailbox – waiting for the mail every single day as a highlight was pretty powerful. The photo of one photographer eating pizza and drinking a beer as it relates to being treated as an adult. The photo of church and the caption that many individuals had strong connections with church (e.g. shaking hands at church really makes them feel welcomed). The photos of the photographers as consumers who have money to spend.

No specific one ... but reading the narratives greatly expanded my understanding of some of the issues these people face and also ways that I can better relate!

The views of the participants plus their accomplishments – that they know they are adults, that life has difficulties and that they want to be taken seriously.

Responses to the second open-ended question were overwhelmingly positive, and many found it to be a 'powerful learning experience'. As one individual stated, 'This was a much needed experience for the participants and for those who came to view their work. They all have a voice that needs to be heard'. However, visitors to the exhibition also noted that there was a need to attract additional attendees (e.g. 'Get more people out here so that people can be exposed to these issues') and to display the pictures and narratives in different locations (e.g. 'Spread these photos and captions for local companies to exhibit;' 'The more they are seen, the more people will understand and enjoy!;' and 'More venues for people to see this excellent exhibit').

Discussion

Through Photovoice we observed a cohort of adults with myriad talents, skills and gifts. Gardeners, choir singers, expert fishermen and competent photographers were noted among the group. Nevertheless, we observed and heard reports of minimal access and limited acceptance in recreational, physical and social activity programmes. Participants reported being ignored and patronized, and rarely felt welcomed to join programmes of their own choice as active members. Social isolation was a significant concern, since access to peers and activities had not been effective components of their school, post-school or vocational programmes. Although a majority of the participants were employed, they typically only worked 6 to 8 hours per week. A report of substantial amounts of discretionary time with little to do was the norm. Consequently, individuals frequently experienced anxiety, boredom and loneliness due to the social isolation and abundance of free time they had, despite their desire to be active members of their community. The social isolation experienced by this group of adults with ID/DD was consistent with that described in the literature (e.g. Carter et al. 2012; National Disability Rights Network 2011; Zijlstra and Vlaskamp 2005).

Our findings have implications for the self-advocacy movement, the local community and the sharing of responsibility for inclusion, as well as future research using Photovoice with individuals with ID/DD and the research questions that we need to be studying in the future. Self-advocates must be the experts regarding their own lives, as nobody understands their needs or sees the obstacles to their access, as well as they themselves do. It should be left up to these individuals to help determine which issues and plans have currency within the broader community. With a voice, self-advocates help communities identify practices and solutions to overcome what was once considered to be unsolvable.

It was evident from the research that participants were socially isolated, lonely and lack (i.e. but desire) greater community access and membership. While exhibition attendees felt that the community had the capacity to address these issues, their lack of confidence in their own abilities to assist with this effort demonstrated a potential disconnect with the meaning of 'community'. Perhaps attendees' perceptions of a community as they relate to individuals with intellectual disabilities are of the compulsory provision of government services that support these individuals. Rather, it should be a collection of residents, such as themselves, who share a collective responsibility for the quality of life of all of their neighbours. It will be the responsibility of the entire Photovoice team, including self-advocates, to secure additional locations to display the photos and the accompanying narratives across the community to further the impact on the local community. In addition, the research team will continue to work with Photovoice participants to identify and take advocacy steps to increase their social inclusion and community participation.

Conclusions

There are limitations to the presented study that should be considered. Firstly, the findings are representative of a small group of individuals with ID/DD from a southeastern US community with a population of nearly 300,000 people. There may be limited generalizability beyond these individuals and their community.

Secondly, the potential influences of both participants' assistants and project staff must be acknowledged. Great effort was put into mitigating these types of influences by clearly delineating the roles of assistants from those of participants, continually reminding participants that it was their voice that needed to be heard, redirecting interviews back to participants if assistants stepped in unnecessarily and empowering participants to disagree and communicate their own points of view (e.g. a programme staff member responding to a participant in the group discussion who shook his head 'no' by stating, 'Sam, I noticed you shook your head "no", and I'm glad you did that because we don't all have to agree. Can you tell us how you feel?'). However, individuals with ID/DD are sometimes easily influenced in a desire to please others (Snell et al. 2009), and comments made by assistants and staff members may have unintentionally impacted participants.

Thirdly, the majority of respondents to the primary exhibition exit survey were family members and friends of the participants. Therefore, we gained little perspective on how the Photovoice exhibition impacted community perspectives on the inclusion of individuals with ID/DD. Despite these limitations, we believe the findings are still of relevance since they are consistent with the literature, yet expand upon our understanding of community access, participation and inclusion, as they directly represent the perspectives of individuals with ID/DD in their own voices.

Few adults with ID/DD have had sufficient experiences to influence the very communities in which they live and to improve their quality of life. This is because they generally lack the skills and opportunities to make choices (Brown and Brown 2009), have low self-esteem, lack assertiveness skills and the communities in which they live lack any concern for their welfare (Schleien, Ray and Green 1997). As practitioners, agencies and communities attempt to address problems associated with accessibility to encourage broader participation by under-served populations, and encourage system changes that support inclusive service delivery, it is necessary for these approaches to be undertaken and skills learned by myriad stakeholders. Only with their values and voices clearly heard by others within the community, and at multiple levels of organizations, will underrepresented people, such as those with ID/DD, be empowered to influence their communities and become more self-determined. Only with a voice at the table will they be able to share their perspectives, needs and desires to assist in the redesign of policies and practices that affect their recreation, fitness, socialization, inclusion and personal growth.

In essence, community leaders, recreation practitioners, teachers and citizens must assess the health of their agencies, programmes and activities with assistance from those individuals who are seen to be underrepresented and marginalized. This willingness and ability to listen to and collaborate with these under-served consumers is a far cry from the usual manner in which we typically design experiences, and should help the community better meet the needs of those they wish to serve. The perspectives of individuals with ID/DD are blatantly missing from service delivery, community inclusion and quality of life research. Several researchers argue that the professionally driven research that dominates the literature to date is missing 'the voice' of those who are most impacted by the policies and practices in place, and that there is a need for change (e.g. Aldridge 2007).

The results of this project point to a number of additional research questions that should be addressed so that we may further understand the recreation and social needs, as well as the desire for acceptance and independence, of those who have been excluded from our communities. For example, what are the barriers (or constraints) that individuals with ID/DD perceive to community access and participation; how do they define friendship and other social relationships; and what actions are they taking to gain greater access and become more engaged in the community? Moreover, how does Photovoice contribute to preparing individuals with ID/DD to be competent and influential self-advocates and community leaders? This also points to the need to complete the Photovoice process with additional stakeholders. For example, how do parents and other caregivers of persons with ID/DD perceive their sons' and daughters'

community preferences, access and participation, and what do recreation and park professionals see as the barriers and supports to including this population in their programme offerings?

The field and society in general have come a long way in making recreation programmes more available and communities more accessible to people with ID/DD. However, agencies must go much further by actively recruiting and encouraging their participation through the shaping of service delivery so as to provide opportunities to articulate their opinions, concerns and desires. Perhaps self-advocacy tools such as Photovoice will help fill this void by empowering all parties to get a better handle on individuals' needs and wishes to become more engaged and gain greater access to the community. If family members, advocates, service providers, researchers and policy-makers continue to listen to the preferences and dreams of people with disabilities, and to build on their abilities and contributions, and if we cultivate the development of community groups that are truly open to diverse ideas, people with ID/DD will prosper in areas of the community that formerly appeared to be out of their reach. We believe it is most fitting to conclude with the words of Patrick, one of the Photovoice participants: 'We all have a voice. What we say with that voice, we show through our pictures'.

Funding

The development and dissemination of this manuscript was partially supported by Cooperative Agreement No. H325K070330 funded by the Office of Special Education Programs, Office of Special Education and Rehabilitative Services, US Department of Education.

Conflict of interest

The content and opinions expressed herein do not necessarily reflect the position or policy of the US Department of Education, and no official endorsement should be inferred.

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Notes

Note: Likert scale: 1 =strongly disagree, 2=disagree, 3=agree, 4=strongly agree.

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