

Photovoice: A Collaborative Methodology Giving Voice to Underserved Populations Seeking Community Inclusion

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Abstract

Through a collaborative effort between a local university and an advocacy organization, adults with intellectual and developmental disability participated in a community-based participatory action research project using Photovoice, a methodology that incorporates photography to give a voice to those typically unheard. The process enabled this marginalized group to share stories of barriers and supports to community inclusion. Additional collaboration through support for these adults, as well as increasing community awareness by connecting with large public venues, contributed to the success of this ongoing initiative. By collaborating at multiple levels, the CTRS has an opportunity to serve as a catalyst in this process for any population that finds itself on the outside of the community with a desire to participate and belong.

Keywords: *Advocacy/self-advocacy, collaboration, inclusion, obstacles, Photovoice, university-community partnership*

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If you want to know how people feel, what they experience and what they remember, what their emotions and motives are like, and reasons for acting like they do, why not ask them?

—G. W. Allport

For many years, individuals with intellectual and related developmental disabilities (ID/DD) have relied on family members and others to take a stand and speak for their needs, hopes, and desires at home, at work, and in the community. Family and friends have done so, most often with the intent of doing what they considered best for the individual with a disability. Additionally, paid staff and other professionals, advocacy organizations, and lobbyists have spoken on behalf of these marginalized individuals. There is no doubt that many of these advocates have gathered their information from personal observations or beliefs, study of the social sciences, educators and their beliefs, societal understanding of disabilities, and, less frequently, the individuals themselves. The Arc of the United States (2008) has described the history of people with intellectual and developmental disabilities as one of powerlessness. The Arc (2008) further described the plight of these individuals as one of isolation that has resulted in, among other things, segregation in almost all areas of life.

The impact of isolation is often painfully apparent during the transition from school years to adulthood. Most people are aware that children with ID/DD in the United States have the right to a free and appropriate public education in the least restrictive environment under the Individuals with Disabilities

Education Act (IDEA), initially enacted by Congress in 1975 (as P.L. 94 – 142). Under this act, children receive public school-related services in two programs: a birth to age 3 years early intervention program and a school program for ages 3 to 22 years (National Dissemination Center for Children with Disabilities, 2011). Essentially, children with ID/DD have a routine of skill acquisition, productivity, structured recreational activities, and socialization until they leave the public school system.

But what happens when the school years end? When the school bus returns the young adult home for the final time, there is an immediate loss of approximately 40 hours of organized weekly activity. At age 22 and beyond, adults with ID/DD typically find themselves in the company of their parents, other family members, or paid caregivers rather than their same-aged peers. They are often dependent upon these individuals for transportation, finances, and facilitating social access in the community. While most family caregivers have best intentions and seek to provide for the needs of the adult with ID/DD, they also have lives of their own and personal preferences that naturally influence and narrow the choices offered to the individual with ID/DD. Paid caregivers may be limited by staffing requirements and regulations they must follow, usually related to their funding sources.

The Arc of the United States (2012) includes self-determination and self-advocacy as core values of the organization, stating, "People with intellectual and developmental disabilities, with appropriate resources and supports, can make decisions about their own lives and must be heard on issues that affect their well-being."

Self-Advocacy

The self-advocacy movement began as adults with ID/DD sought to speak for themselves. It is believed that this movement originated in Sweden in the 1960s as a group of individuals with intellectual disabilities, and their supporters, sought organized leisure options (Shoultz, 2008). As self-advocates gathered, a common bond related to their needs and shared experiences evolved and continues to be promoted by advocacy organizations. Some individuals with ID/DD have been hugely successful in expressing their thoughts and living independent lives, while most have remained in the background, dependent on others to speak on their behalf. Self-advocates who have spoken out often do not have the attention of those who can help. Many others with ID/DD do not have the ability to verbalize abstract concepts (Wehmeyer & Obrowski, 2012).

As an advocacy organization, a local chapter of The Arc of the United States in Greensboro, North Carolina, has facilitated a number of adult self-advocacy programs over the years. Like many organizations serving this population, The Arc has relied on family members, friends, and professionals to advocate for the needs of people with disabilities. Building on the self-advocacy movement, this local chapter of The Arc desired to hear and help share the voices of self-advocates who wanted to tell their stories to the greater community in an effort to promote community awareness and, ultimately, the opportunity for increased community access, participation, and inclusion. Knowing that verbal communication skills often do not adequately portray the thoughts of individuals

with ID/DD, it was necessary to seek other means of empowering them to share their voices. Community-based participatory action research, using Photovoice methodology, appealed to those at The Arc working with many adults who live largely segregated lives and subsequently lack social access to their community.

Collaborative Advocacy Effort

Collaboration has been defined as a team of people who work together to realize a common vision through common goals (Peterson & Anderson, 2001). In the recent years of diminished funding for nonprofits, collaboration with other agencies and organizations has become a necessity. As important as funding has become, we cannot lose sight that effective collaboration is valuable because of a need for community partnership and engagement that ensures success of the process and benefit beyond the organization itself. The combined strengths and talents of more than one organization can result in a strong team with diverse backgrounds and skill sets. For some organizations, this partnering has allowed for the development of a more in-depth understanding of an issue and increases the chance that the organization's goals will be achieved (Nissan & Burlingame, 2003). Additionally, Waide's description of successful collaboration between nonprofit organizations requires the collaborating partners to have similar values and mission (as cited in Nissan & Burlingame, 2003). The Arc of Greensboro's (The Arc) partnership with researchers from the University of North Carolina at Greensboro, Department of Community and Therapeutic Recreation (CTR), provides an example of a successful col-

laboration with a shared value to support self-advocates and create a more inclusive community.

Literature Review

Participatory Action Research

Participatory action research (PAR) is an invaluable form of research due to its capacity to include participants as researchers to generate representative and relevant results. There are common features that differentiate PAR from other types of research. A few of the more significant of these features include the community being at the center of the research, commitment to balancing the power between researchers and subjects, nontraditional role for the main researcher, participants are actively engaged throughout all stages of the research, creation of useful knowledge, and commitment to action (Northway, 2010). The collaboration between The Arc and CTR produced an environment that was ideal for a balance of power, active engagement, an in-depth understanding of the issues, creation of knowledge, commitment to action in the community, and sustainable efforts.

PAR has been described further as being concerned not only with producing new knowledge but also with the values and goals of those who conduct the research promoting change in the community (Cornwall & Jewkes, 1995). This interinstitutional effort created a more cohesive vehicle to gain a better understanding of the barriers and supports to social access and participation, to increase awareness, and to initiate community conversations and action steps that lead to a more inclusive community.

A number of researchers previously utilized PAR, working in partnership with individuals with disabilities. For example, Walmsley and Mannan (2009) examined the outcomes of including family members of individuals with intellectual disabilities (ID) in a series of focus groups and analyses. Garcia-Iriarte, Kramer, Kramer, and Hammel (2009) investigated the use of focus groups, participatory engagement, and reflexivity to increase the capacity for advocacy among individuals with ID. Both of these studies found PAR to be successful in generating and increasing group advocacy among participants. Walmsley and Mannan "found a number of empowering outcomes of the PAR process, including family members taking action to get what they want" (p. 275). The results were encouraging for Garcia-Iriarte et al. who stated, "A PAR approach can be used to increase a group's capacity for advocacy and meaningfully involve self-advocacy groups in research that leads to change" (p. 21).

Photovoice: An Assessment and Advocacy Tool

Photovoice is a creative form of PAR. Its roots are grounded in both qualitative and action research. Some of the initial Photovoice researchers defined it as a method of seeing the world through the viewpoint of people who are leading different lives (Wang & 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 contrast with the majority of viewpoints found in society.

The Photovoice process has three main goals that work together to bene-

fit the participants, including to enable, to promote, and to reach. They 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 discussion of photographs, and reaching policy makers (Wang & Burris, 1997). Photovoice programs focus on building voices, creating portals for communication, and instigating community impact and change.

Use of Photovoice

In the past, Photovoice has been used with a number of populations with voices that have gone unheard. Aboriginal breast cancer survivors (Poudrier & Mac-Lean, 2009), people who are homeless (Wang, Cash, & Powers, 2000), and youth (Gant et al., 2009) are a few underrepresented groups that have benefited from this "technique that places the selected individuals in charge of documenting their lives" (Booth & Booth, 2003, p. 432). Individuals with learning disabilities (LD) were empowered by Photovoice when Booth and Booth (2003) worked with mothers with LD to advance the work of a supportive learning project and to "challenge discriminatory views about this group of vulnerable families by narrowing the gap between how others see them and how they see themselves" (p. 440). Photovoice proved to be an effective means for an underrepresented group to reveal their perspectives. 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" (p. 440).

The Photovoice methodology was adapted by Jurkowski and colleagues (Jurkowski, 2008; Jurkowski & Paul-

Ward, 2007; Jurkowski, Rivera, & Hammel, 2009) who worked with Latinos with ID on perspectives of healthy living. The researchers discovered that Photovoice was not only effective but also "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, p. 9). Through this initiative, Jurkowski et al. (2009) found that Photovoice acted as an empowering tool, enabling the photographers to reveal themes related to social relationships, emotional states, energy, interconnection between work and health, beliefs about healthy behaviors, and culturally centered beliefs about health. The findings of the Photovoice process, in this case, were not produced for research purposes only. Results were presented in a town hall meeting attended by service providers, community leaders, caregivers, and individuals with disabilities. Attendees discussed the findings and generated recommendations and action steps that were included in a final report presented to agency administrators for use in future program development (Jurkowski & Paul-Ward, 2007).

In the only other published study where individuals with ID used Photovoice, Paiewonsky (2011) adapted a combined methodology of Photovoice and VoiceThread, a Web-based, digital storytelling technology. College students with ID developed, implemented, and designed action steps that were presented to the community and at professional meetings. They also developed training materials for students, parents, and professionals and created an online consortium of college options for other students with ID.

It is with this foundation that the interinstitutional collaboration generated Photovoice methods with two primary intentions: (a) to partner with individuals with ID/DD to help provide a voice and (b) to increase awareness in the community concerning their access, participation, and inclusion.

Photovoice Methodology

Two consecutive Photovoice programs were implemented over a 12-month period, as additional self-advocates in the community expressed an interest in participating. To date, 22 individuals have participated in the Photovoice initiative. The overarching long-term goal of the Photovoice program is to promote systems change toward a more socially inclusive community.

This program was approved by the university's Institutional Review Board, and all participants provided informed consent for the collection of data prior to the program. Gaining informed consent was a collaborative effort between the university and its community partner, The Arc. The program was introduced to each participant by the Community Resource Specialist of The Arc, who encouraged discussion and questions about participation. Information was then mailed to each participant reviewing information previously discussed. Verification of informed consent was completed in the first season of Photovoice through a telephone conversation between the university-affiliated principal investigator and each participant, and it was completed in season two through an in-person verification between the principal investigator and the participants before the commencement of the first training

session. The programs included orientation, roles clarification, and camera skills instruction; photography assignments; individual/group discussions and processing; and exhibitions to display their work and to engage the community. The Photovoice methodology is best described by depicting the three primary phases of the Photovoice program. For a more comprehensive description of this methodology and results, the reader is referred to Schleien, Brake, Miller, and Walton (in press).

Photovoice: Phase One

Each program began with a group meeting for all participants that was facilitated by the codirectors and coordinator of this collaborative effort representing The Arc and CTR. This orientation included a discussion of program goals and methods, an explanation of participant roles, demonstrations on how to use digital cameras, an explanation of photography ethics and consent, and an introduction to the first photography assignment. In the initial Photovoice program, each participant with ID/DD was assigned a single instructor with whom he/she worked throughout the program. A requirement for participation was the availability of a family member or a friend (described as "assistants" hereafter) who could be enlisted to assist the participant as necessary through the program's duration. In season two of Photovoice, participants with and without ID/DD were matched in inclusive dyads. The balanced efforts between photographer and assistant and between participants with and without disabilities were essential to the success of the group.

The first assignment for each program was titled "My Story," where par-

ticipants were asked to take photos of people, places, and activities that were important to them. When a participant completed the assignment, individual meetings took place to describe and discuss the photographs. This collaborative effort between photographers and interviewers was guided by the responses of each photographer. The photographers were encouraged to first provide their own description of their photographs. Predetermined questions were asked to reveal relevant information, and all other probing questions were based on photographer responses. Once interviews were completed, program staff from The Arc and CTR held a debriefing session to identify and discuss similarities, discrepancies, and overarching ideas of the participants' photos.

Photovoice: Phase Two

Phase two commenced with a second photography assignment. Participants were asked to take photos that represented the people, places, and activities that made them feel important and that highlighted their skills and talents. They were also encouraged to take photos that represented the activities in which they desired to participate and the barriers that interfered with their successful community participation.

During follow-up individual meetings, participants identified primary themes that represented their efforts and photos. Ensuing group discussions engaged participants to create critical dialogue where they were encouraged to identify and discuss themes that were formerly revealed. This collaborative effort between photographers was guided by the conversations of each photographer. The photographers ex-

plained each of their thematic photos and experienced a sense of ownership for their photos, themes, and ideas. This led to a group discussion among all of the participants where group opinions and ideas were generated and validated for each theme. This collaborative process allowed each photographer's voice to become part of each theme, which was then shared through the narratives exhibited along with the photographs in phase three.

Photovoice: Phase Three

The final phase of the two Photovoice programs consisted of preparations for community exhibitions, including pilot exhibitions at the local Arc for family and friends and primary exhibitions in the community to reach the broader community. While the thematic photos were representations of group opinions, every participant had at least one of his/her photographs displayed at each exhibition. Photographs and their related themes were accompanied by narratives using quotes from group discussions. Participants stood by their displays during community exhibitions and answered questions that were asked by attendees, providing these self-advocates with a voice in the community.

Goals of the community exhibitions were to create awareness and, over the long term, to promote greater access, participation, and inclusion in the community by individuals with ID/DD. Marketing efforts targeted key members of the community who could help create change for increased accessibility and broader participation by underserved populations. Primary exhibitions to date have been held at the city's downtown Chamber of Commerce, at a coffee shop located in a

popular shopping center, and at a university art gallery. Attendees of the primary exhibitions, totaling over 1,000 people, included friends and family members of the photographers, local policy makers, recreation providers, advocacy organization representatives, students, teachers and other service providers, and ordinary citizens.

Photovoice Results: Multilevel Outcomes

Self-Advocates

The Photovoice programs produced myriad outcomes for the photographers, collaborating organizations, and community at large. Participants with ID/DD developed photography skills and further refined their competencies as self-advocates; were empowered as leaders to share their voices regarding barriers and facilitators to community inclusion; increased their communication, expressive language, and socialization; and enhanced personal understanding of needs related to access, participation, and social inclusion. As reported by Wang and Burris (1997), these individuals, often feeling powerless, were empowered to advocate for themselves through the use of Photovoice.

It is anticipated that Arc members with ID/DD will be motivated to continue to engage the community as self-advocates and help facilitate a more welcoming community in the months and years ahead. It is our hope that these self-advocates will present this work at future self-advocacy conferences at the state level and, potentially, the national level, with the support of the university-community partnership team. Dissemination of the process and findings will continue to be

shared with constituents throughout the community through planned public photography exhibits. It could be assumed that this research will engage many additional Arc members, as well as policy makers, community administrators, and practitioners, as we continue to contemplate how to best accommodate individuals of varying abilities in our community.

Family Members

During the Photovoice initiative, family members as well as peers without disabilities who served as assistants to the participants gained new knowledge. Outcomes included verification or change in perceptions about family members with ID/DD and greater understanding of issues related to an inclusive and accessible community.

Collaborating Agencies

The Photovoice program also made a substantial impact on the collaborating agencies. The local Arc gained a greater understanding of members' needs. Arc staff are currently in a better position to assist their members in eliminating barriers in their quest for community inclusion. The Arc's historically strong role in community education was also strengthened through Photovoice. An increase in the community recognition of the important advocacy work of this nonprofit organization could result in enhanced community and financial support.

The collaborating partner from the university also benefited in various ways. Preexisting efforts to increase community inclusion were enhanced, and community partnerships were strengthened. University students embraced the experience of learning about the obstacles and strategies to support

community inclusion from the real experts: those with ID/DD. Because these students are currently being prepared within the therapeutic recreation discipline to serve as community inclusion facilitators, the mastery of Photovoice methodology should assist them in their future programmatic and scholarly endeavors. The knowledge, academic, and professional development in collaborative work should also enhance success of these students as practitioners and advocates throughout their careers.

The Community

Perhaps most importantly, this collaboration continues to make contributions in the community. Brazg, Bekemeier, Spigner, and Huebner (2010) found the success of their *Our Community in Focus* Photovoice project to suggest "that other communities with coalitions in place might find the Photovoice method a valuable tool" (p. 510). Similar to their findings, our collaborative program was and continues to make an impact in the community. The exhibitions proved to be a valuable investment of time for attendees by increasing their awareness of the issues surrounding access to the community by marginalized segments of the population. Across the community exhibitions, attendees reported high levels of confidence in the community's ability to support and include individuals of varying abilities. The impact of our community exhibitions continues to grow and is reflected in the shared comments of attendees who continue to provide their own voices in response to the displays through a variety of interactive methods (i.e., post-it notes, comment cards, chalkboard thoughts, and comments on wall posters).

Implications for Practice

A welcoming and accommodating community recognizes the contributions of many people and perspectives as crucial to its work. However, it is only through ongoing community conversation and collective thought that we are led to broader access, diversity, participation, and inclusion. Unfortunately, a substantial gap exists between what the research says about the important roles of therapeutic recreation specialists and the beliefs of other key players in a community who have the power to instigate systems change. In a majority of cases, people with disabilities and their families are not invited to the discussion; consequently, the community never hears their voices. Because of "barriers of omission," many citizens with disabilities are overlooked and not extended the same courtesies when planners consider the needs, interests, and preferences of the community (Schleien, Ray, & Green, 1997). As a result, these individuals may choose not to become involved in the lifestyle of the community, remaining dependent on family members, caregivers, therapists, school personnel, and advocacy agencies to address their needs.

Communities must recognize that people with disabilities are a significant part of the picture (as they happen to be the largest minority group in the United States) and should be provided with opportunities to exercise choice concerning the leisure activities and opportunities they wish to pursue. Only with their values and voices heard by others within the community, and at multiple levels of organizations, will underrepresented people be enabled to make an impact. Only then will they be able to use their expertise to assist

in the design of policies, practices, and research that affects their recreation, fitness, socialization, and personal growth.

It is not merely sufficient to make available programs to people with disabilities; therapeutic recreation professionals must go further and actively recruit and encourage the participation of people with disabilities and provide them with successful and ongoing mechanisms of support. If we as service providers, researchers, and advocates continue to listen to the needs, preferences, and dreams of people with disabilities, if we continue to build upon their strengths and contributions, and if we cultivate the development of community groups that are truly open to diverse ideas, people with disabilities will prosper in areas of the community that formerly appeared out of their reach.

Concluding Remarks

The process of Photovoice went well beyond the acquisition of skills in digital photography. Individual and group processing of the symbolism of photos presented was often sensitive, and for many individuals a "baring of the soul" in describing painful events and uncertain futures. Now that these

individuals have been empowered to share their stories through Photovoice, the collaborative research team feels a sense of obligation and commitment to extending the reach of their voices. We are charged with not only increasing community awareness but also developing action steps that will gradually result in a change for the betterment of the entire community. It is simply not enough to identify a problem. The problem now needs and deserves to be addressed.

With increased community awareness and purposeful conversations, leaders with an interest and the authority to instigate change will have the opportunity to develop action steps, appropriate to their community, which will ultimately benefit all. Collaboration with the community, by way of contact and influence with a multitude of individuals, can best be accomplished with the diversity of background and skills of the Photovoice team members, whose professional connections will be varied. Continued collaboration between the advocacy organization and university research team is essential to extending the reach of this initiative and ultimately making a powerful impact where it is most needed: in the community.

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