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Payoffs of Participatory Action Research: Racial and Ethnic Minorities with Disabilities Reflect on their Research Experiences

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Abstract

The disability community has experienced a long history of segregation and exclusion. With the passage of the Americans with Disabilities Act of 1990, discriminatory attitudes and behaviors would no longer be tolerated under law. In recent decades, disability researchers have also experienced a shift in how research projects are designed and conducted, with participatory action research (PAR) playing a prominent role. This paper provides an overview of these shifts and presents a qualitative study that explored the extent to which racial and ethnic minorities with disabilities were empowered by a PAR project that aimed to increase the physical accessibility of their communities. Content analysis of individual interviews revealed the following main themes: (1) increased knowledge of disability rights; (2) increased sense of independence; and (3) increased desire to advocate. Implications of this study include the important role that PAR may play in empowering racial and ethnic minorities with disabilities.

Keywords

participatory action research; empowerment; community accessibility; disabilities; racial and ethnic minorities

Within the field of community development, there has been growing interest in participatory approaches for both practical and philosophical reasons. In general terms, participation has been defined as a process that seeks the contributions of diverse stakeholders throughout all phases of community development (Schafft & Greenwood, 2003). Such 'local' contributions are considered critical for understanding the concerns of the community. They are also critical for building community ownership and commitment as planning efforts are designed, implemented, and managed (Schafft & Greenwood, 2003). For researchers engaged in community development endeavors, there is particular attraction toward using methods that embody a participatory action research (PAR) approach.

Participatory action research

The principles of PAR emphasize researcher-participant collaboration to achieve change that is socially relevant, transformative, and sustainable (Boothroyd, Fawcett, & Foster-Fishman, 2004; Kidd & Kral, 2005; Mora & Diaz, 2004). Both researchers and participants are stakeholders invested in the social impact of research projects, with participants demonstrating varying degrees of influence in determining research agendas and processes (Balcazar, Taylor, Kielhofner, Tamley, Benziger, Carlin, & Johnson, 2004). With PAR, researchers and participants work collectively to identify community problems, community resources, and sustainable solutions (Selener, 1997). In essence, PAR acknowledges the expertise of researchers and participants and encourages partnership throughout all phases of research (Taylor, Jason, Keys, Suarez-Balcazar, Davis, Durlak, & Iseberg, 2004). By having participants play an active role in research, a desired outcome of PAR is enhancing their sense of empowerment (White, Nary, & Froehlich, 2001).

When PAR projects are conducted, qualitative research methods are commonly used (Balcazar et al., 2004). Individual interviews and focus groups are particularly appealing for they allow participants to articulate experiences using their own words (Balcazar, Keys, Kaplan, & Suarez-Balcazar, 1998). Qualitative methods may also provide opportunities for instilling critical consciousness and empowerment among individuals representing understudied and disenfranchised groups (Harper, Lardon, Rappaport, Contreras, Bangi, & Pedraza, 2003). For marginalized populations, PAR may allow them to be heard and valued in ways unseen in traditional research.

Principles of PAR are quite relevant for the disability community, given the long history of paternalistic attitudes toward this group as well as segregation and community exclusion (Charlton, 1998). With the passage of the Americans with Disabilities Act in 1990, this nation witnessed a clear shift in attitudes and behaviors toward the disability community. Regarding the far-reaching nature of this civil rights law, Mayerson (1992) wrote:

If the ADA means anything, it means that people with disabilities will no longer be out of sight and out of mind. The ADA is based on a basic presumption that people with disabilities want to work and are capable of working, want to be members of their communities and are capable of being members of their communities and that exclusion and segregation cannot be tolerated. Accommodating a person with a disability is no longer a matter of charity but instead a basic issue of civil rights.

Disability research paradigms

In recent decades, disability researchers have also experienced a shift in how research projects are designed and conducted. In a review of disability paradigms, Scotch (2002) noted that over 40 years ago disability research in the United States relied heavily on medical and vocational rehabilitation models. Such models were grounded in the perspectives of medical professionals and service providers who were seeking to either rehabilitate patients or help clients become employed. Consequently, little was known about the “lived” experiences of individuals with disabilities. Moreover, much of the research had been conducted by non-disabled individuals. A notable paradigm shift occurred during the late 1970s and early 1980s, with the growing influence of the minority group model and sociopolitical model of disability. The United Kingdom experienced a similar shift known as the social model of disability. All these models shared the assumption that the experience of disability was determined by both the environment and impairment. Additionally, the disability community represented a minority group that experienced political and social oppression.

Scotch (2002) added that with the “experience of disability” being central to emerging paradigms, subjective methodologies that involve individuals with disabilities in research were essential. Hence, more and more, PAR approaches are being used by researchers (Holt, 2006; Jurkowski, 2008; Ward & Trigler, 2001). By adopting PAR approaches, individuals with disabilities are provided with opportunities to share perspectives on their lived realities. With firsthand knowledge, PAR also allows the disability community to influence the research process and identify relevant issues (White, 2002).

Individuals with disabilities and community accessibility

People with disabilities comprise one of the largest minority groups in the United States, with over 51 million individuals estimated to have a cognitive, medical, physical, psychiatric, or sensory disability (U.S. Census Bureau, 2006). The ADA defines a disability as a significant physical or mental impairment that impacts one or more major life activities (e.g., seeing, hearing, walking); having a record of such an impairment; or being regarded by others as having an impairment. The ADA provides civil rights protection to individuals with disabilities, with the public accommodations provisions (Title III) ensuring the equal and full enjoyment of products and services offered by businesses and places open to the public. Despite the specificity and comprehensiveness of Title III, the lack of strong enforcement procedures has made community access challenging, especially for establishments built before the enactment of the ADA. For the most part, enforcement is dependent on private citizens and the initiation of lawsuits and/or filing of state and federal complaints. Examples of ADA non-compliance may include steps at the only entrance of an establishment that prohibits individuals who use wheelchairs from entering and the lack of visual fire alarm signals in a supermarket for customers with hearing impairments.

Limited community accessibility can have serious repercussions for the lives of people with disabilities. For instance, when examining the low employment rate among this group, inaccessible worksites and transportation were identified as barriers to work (Hernandez, Cometa, Velcoff, Rosen, Schober, & Luna, 2007; Loprest & Maag, 2001). Furthermore, people with disabilities have reported socializing and frequenting restaurants less than those without disabilities (Louis Harris & Associates, 1986, 2004). This gap was evident even when income level was controlled, suggesting that the lack of community accessibility may be playing a role.

The principles of PAR are also relevant for racial and ethnic minorities with disabilities, many of whom are marginalized further given their cultural background and/or socio-economic class (Block, Balcazar, & Keys, 2001; Mora & Díaz, 2004). This potential triple jeopardy may have particular impact on the employment and vocational rehabilitation experiences of African Americans and Latinos with disabilities (Hayward & Schmidt-Davis, 2003; Hernandez, Cometa, Rosen, Velcoff, Schober, & Luna, 2006; Hernandez, 2009). Thus, this paper is noteworthy in that it presents a qualitative study that explored the experiences of racial and ethnic minorities with disabilities, who participated in a PAR project that aimed to improve the physical accessibility of their local communities.

The ADA Project

Using a PAR approach, Hernandez, Balcazar, Keys, Hidalgo, and Rosen (2006) worked with 16 racial and ethnic minorities with physical and sensory disabilities to promote ADA compliance among inaccessible businesses in their local neighborhoods. Specifically, participants were invited to attend a one-day workshop where they: (1) received an overview on the ADA and its public accommodations provisions; (2) learned how to conduct a brief ADA accessibility survey; and (3) participated in a mock assessment. After the workshop, participants were invited to volunteer in a research project that aimed to create change in

their communities. As a part of this project, the 16 participants were asked to select sites that they considered important to assess. The participants then visited these businesses, assessed their level of ADA compliance, and provided hands-on feedback to the business owners and managers. A total of 96 sites were assessed, and these sites were revisited and reassessed by participants 3 and 6 months later. Results were noteworthy in that significant changes were made to the entrances, aisles, and restrooms of the establishments.

Findings from the Hernandez et al. (2006) study suggest that racial and ethnic minorities with disabilities were influential in changing the accessibility of local businesses. Less known is whether participants were impacted (i.e., empowered) by participating in the research. It would be important to gauge such experiences, given that principles of PAR are often linked with empowerment (White et al., 2001). Generally defined, empowerment (on an individual level) refers to one's perceptions of personal control, competence, and power in a given situation; one's behaviors or efforts to exert control and achieve goals; and one's critical awareness of the environment (Zimmerman & Warchausky, 1998; Zimmerman, 2000). Thus, the main purpose of this qualitative study was to explore the extent to which participants of the Hernandez et al. (2006) study were empowered (affectively, cognitively, and behaviorally) once the research ended.

Method

Participants

Ten participants from the ADA Project described in the Hernandez et al. (2006) study were recruited to participate in an individual interview. Participants were between the ages of 23 and 45. Five participants were African American and five were Latino; nine used a wheelchair and one had a sensory disability; and seven were male and three were female. The remaining six participants of the ADA Project were unable to participate because of relocation ($n = 1$), death ($n = 1$), and being monolingual in Spanish ($n = 4$), as the interviewer only spoke English.

Instrument

An interview guide was developed by the authors to explore the experiences of participants as they related to their participation in the ADA Project. The interview guide included nine questions, with follow-up questions added as needed for purposes of clarification. The first four questions assessed participants' knowledge and understanding of the ADA Project and its outcomes:

1. Do you remember the ADA workshop? Can you tell me what it was about?
2. What types of businesses did you evaluate?
3. What were the main ADA issues for these sites when you first visited them?
4. Which sites made improvements and what types of improvements were made?

The next three questions examined the affective and cognitive experiences of participants subsequent to participating in the ADA Project:

- (5) When improvements were made, how did that make you feel?
- (6) How did you feel when improvements were not made?
- (7) Has participating in the ADA research study changed you in any way? If so, how?

The final two questions addressed behavioral experiences related to accessibility both before and after the ADA Project:

(8) Before attending the ADA workshop, did you ever speak to business owners or managers about their establishments not being accessible? If so, tell me about it.

(9) After participating in the ADA Project, have you spoken to business owners or managers about their establishments not being accessible? If so, tell me about it.

To improve item clarity and comprehensiveness, this interview guide was pilot tested with a research assistant who had a physical disability and was familiar with the study.

Procedure

Participants were contacted by telephone approximately one year after participating in the ADA Project. They were provided with a brief description of this study, and if interested, an interview was scheduled. Prior to conducting the interview, informed consent was obtained. The average duration of the interview was one hour. To accommodate participants' schedules, seven interviews were conducted at a rehabilitation hospital, two at an independent living center, and one at a participant's residence. To decrease the likelihood of socially desirable responses, the interviews were conducted by the first author who was not a part of the ADA Project. Each interview was audio-taped and reviewed independently by two of the authors, who coded the content of the responses to each of the nine interview questions. Initial coding was descriptive in nature, whereby units of data were named and then categorized (i.e., reported increased knowledge of the Americans with Disabilities Act). After independently coding each interview, the three researchers met to discuss the categories and central themes for each question. For areas of disagreement, discussion occurred among the researchers until consensus was reached (Miles & Huberman, 1994).

Results

The results of this study are presented under the following subheadings: (1) participants' understanding of the ADA Project; (2) participants' affective and cognitive experiences; and (3) participants' behavioral experiences.

Participants' understanding of the ADA Project

In response to the first four interview items, participants reported more than adequate knowledge of the ADA Project. They were able to recall the purpose of the ADA workshop, their role in the research, types of businesses visited, and general results of their assessments. Participants shared that a variety of establishments were surveyed including supermarkets, restaurants, and department stores. The most common accessibility issues were inaccessible entrances and aisles, and most participants reported some success in creating change (e.g., widened aisles; assistance provided upon request while shopping; and improved accessibility with entrances and bathrooms).

Participants' affective and cognitive experiences

Participants reported a number of affective and cognitive experiences related to participating in the ADA Project, and they were categorized as: (1) increased knowledge of disability rights; (2) increased sense of independence when frequenting neighborhood businesses; and (3) increased desire to advocate.

Increased knowledge of disability rights—Prior to participating in the ADA Project, most participants ($n = 8$) were unaware of the Americans with Disabilities Act and their rights to accessibility in places open to the public. This lack of knowledge also meant that they were unfamiliar with tactics that could be used to create change in their neighborhood businesses. After participating in the ADA Project, the majority reported increased knowledge of the Act; they were also able to describe specific strategies that could be used

to improve community accessibility (i.e., providing curbside delivery, using a portable ramp). Moreover, participants learned about accessibility barriers faced by people with disabilities different than their own. For example, a participant who used a wheelchair shared that she became more aware of the accessibility needs of individuals with visual impairments (i.e., Braille menus).

I feel prepared now because I have the tools. I know my rights and I know how to use them...I learned the law, which I didn't know about, and about places that aren't accessible. (Marc, African American male, used a wheelchair)

I now know the law and am more aware of how to bring about change. (Alex, Latino, used a wheelchair)

Increased sense of independence—In addition to gaining knowledge, participants were able to put their knowledge to work with businesses they had selected as important to assess. Some establishments were selected because they were frequented highly by the general community (e.g., Dollar stores), while others were chosen because they had known issues related to ADA non-compliance. With knowledge of the law, participants visited establishments and formed educational relationships with business owners and managers through the baseline and follow-up assessments. In a number of cases, these relationships paid off with changes being made to improve accessibility. As a result of these experiences, several participants reported an increased sense of independence that seemed to extend beyond the sites assessed.

I know that I am able to make change with what I've got. I can go out and just do it. I can help. (Eric, African American male, used a wheelchair)

It made me feel real good - independent. It made me radical...the workshop made me stronger to help myself and everyone else. (Isaac, African American male, used a wheelchair)

Increased desire to advocate—Given their newfound knowledge of disability rights and positive outcomes associated with the ADA Project, a number of participants ($n = 5$) expressed an interest in advocating for the disability community at large. Specifically, participants reported a desire to continue educating business owners and managers about the ADA, with the hope that others with disabilities could benefit from improvements in community access. Additionally, participants felt that the disability community could benefit from more knowledge of the ADA provisions. Having experienced firsthand the "power" of knowledge, two participants recommended that educational and intervention efforts (similar to the ADA Project) occur nationally.

I need to continue to advocate. It's not only for me, there's many people with wheelchairs in public places and it's the law. (Kendra, Latina, used a wheelchair)

I didn't know about other's disabilities. Now, I'm aware of them and want to advocate for them. (Erica, Latina, used a wheelchair)

I have a greater sense to help advocate for people with disabilities and am more willing. (Corey, African American male, had a sensory disability)

Participants' behavioral experiences

Participants also reported behavioral experiences that were consistent with empowerment. Most participants ($n = 7$) shared that prior to participating in the ADA Project they were unable to address accessibility issues with businesses because they simply lacked knowledge of their rights. The remaining three participants expressed a lack of success in their attempts to create change, citing limited knowledge of the Act's enforcement procedures. The ADA

Project provided detailed information about the law, concrete strategies to address accessibility concerns, and an educational approach to confront business owners and managers. These three components appeared to have resonated with participants after the research project was over. In all, seven participants reported addressing accessibility issues with owners and managers after the ADA project had ended.

I didn't know my rights and it never crossed my mind. Now, I talk to businesses all the time...I know how to get support for my rights. (Eric)

I don't try to fight with the people anymore, I try to help people know the law and respect the rights of people with disabilities. (Marc)

I didn't like inaccessibility and was ill-mannered...[after the ADA Project] I have seen a big improvement in my efforts, I came around. (Shawn, Latino, used a wheelchair)

Following their involvement with the ADA Project, a couple of participants reported success with their efforts to create community change. Kendra approached two large department stores that had steel posts at their entrances, placed to prevent the public from stealing shopping carts. These posts also prevented customers with wheelchairs from independently entering and exiting the stores. During hours of operation, the gates permitting cart (and wheelchair) access were kept locked. As a result of the ADA Project, Kendra learned that the locked gates were not ADA compliant and she approached the managers to create change. When changes were not made, she filed complaints against the stores and eventually they responded by unlocking the gates. Alex noticed that his place of employment had inaccessible work areas (i.e., inaccessible restrooms, high counters) and helped develop a three-year plan to create accessibility changes with the support of administrators. For his efforts, Alex was recognized as employee of the month.

Although most participants reported "empowering" experiences related to the ADA Project, it is significant to note that there were two participants who seemed to experience empowerment to a lesser degree. Both acknowledged that as a result of the project they were better informed about their rights under the law. However, during their interviews, they also spoke at great length about frustrations related to business owners and managers who were unresponsive, describing them as "apathetic" and "unwilling to change." In spite of the frustration, the two participants expressed a commitment to creating accessibility changes in their communities.

Discussion

As disability paradigms have evolved over the years, there has been growing interest in research that is participatory in nature. When using PAR approaches, one goal of the research is participant or community empowerment (White et al., 2001). Although numerous PAR projects have been conducted with individuals with disabilities (Holt, 2006; Jurkowski, 2008; Ward & Trigler, 2001), limited research exists on whether they were empowered by the process. This paper presented a qualitative study that explored the extent that racial and ethnic minorities with disabilities were empowered by a PAR project that aimed to improve community accessibility. When affective and cognitive experiences were examined, participants reported that their knowledge of disability rights had improved, their sense of independence when frequenting local businesses had strengthened, and their desire to advocate for disability issues had increased. Moreover, on a behavioral level, a number of participants continued to be active in creating community change. Overall findings suggest that PAR projects may enhance the empowerment of individuals with disabilities.

PAR is also relevant for racial and ethnic minorities with disabilities, a group that often lives in poverty and thus experiences social marginalization on three levels (Block et al., 2001). Historically, this group has not had a voice in research despite it having much to contribute (Balcazar et al., 1998). For example, Balzacar, Keys, and Suarez-Balzacar (2001) aimed to promote ADA compliance by engaging 60 Latinos with disabilities and their families in capacity-building workshops and actions groups. With increased knowledge of the ADA and assistance from project staff with identifying and implementing action steps, participants increased their involvement in the community to create accessibility changes. However, what is unclear is whether participants were empowered by their involvement in the research. Results from this study suggest that they may have been. Although the current study involved only ten participants, the payoffs of PAR were noteworthy in that participants acknowledged the “power” of knowledge. By having an understanding of the ADA and specific strategies to create change, they were in a better position to advocate for their rights. Perhaps even more important, participants expressed a desire to advocate for others with disabilities in order to make communities accessible for all.

Implications for disability research and community development initiatives

As community researchers continue to design PAR projects, it is important to keep in mind that participant involvement should occur at all phases of research including the dissemination of findings. For some projects (including the current one), this may be challenging as researchers also seek scientific rigor (Scotch, 2002). Regardless of level of participant involvement, it is critical to assess the experiences of participants to determine whether projects were indeed participatory in nature, whether participants were empowered by their participation in research, and whether empowering experiences (affective, cognitive, and behavioral) were sustained over time. Too often, the short- and long-term impacts of PAR projects on participants are not examined despite their end goal of empowerment (White et al., 2001). Qualitative methods are well-suited for such examinations as they allow participants to shed light on their experiences.

Disability organizations and advocates who work toward a fully inclusive society may also want to consider using participatory approaches with private citizens to realize the promise of the Americans with Disabilities Act. Although enacted 19 years ago, environmental and attitudinal barriers continue to present serious challenges that extend beyond public accommodations. Namely, the disability community struggles with achieving equality within housing, education, transportation, and employment (Hernandez et al., 2007; Loprest & Maag, 2001). These struggles may be particularly pronounced for African Americans and Latinos with disabilities (Hayward & Schmidt-Davis, 2003; Hernandez et al., 2006; Hernandez, 2009). Participatory methods may prove fruitful in engaging racial and ethnic minorities when addressing these inequitable social conditions as well.

Limitations

An important limitation of this study was that baseline data were not gathered, thereby limiting pre-post response comparisons. When the ADA Project (Hernandez et al., 2006) was designed, its main purpose was to create community change. However, as data were collected, it became apparent to researchers that the participants were experiencing change as well. Thus, the design for the current study evolved as the ADA Project was being conducted. The second limitation relates to sample size as this study involved only ten participants. As such, results reported herein should be viewed as exploratory and with limited generalizability. Lastly, it is important to consider that participants from the ADA Project, who were not fluent in English, were unable to provide their insights. In retrospect, it would have been important to include this group, given that potential language barriers could have impacted their empowerment experiences.

Notwithstanding the limitations mentioned above, the general themes that emerged from this study suggest that PAR approaches may be an effective means to enhance community development and research endeavors, while empowering marginalized groups. Indeed more research is needed to verify this finding, but the initial evidence is promising. People with disabilities and racial and ethnic minorities can be active participants of community research efforts, and the benefits of such participation may be felt on both an individual and community level.

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