

We Are “Both in Charge, the Academics and Self-Advocates”: Empowerment in Community-Based Participatory Research

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Abstract

Background: Community-based participatory research (CBPR) brings academics and community members into research partnerships. Although power is central to CBPR, little is known about community partners' experience with empowerment in CBPR with people with developmental disabilities. We interviewed 15 community partners with and without developmental disabilities about empowerment in CBPR. Community partners identified empowered mindsets and behaviors and CBPR factors that facilitated or hindered their empowerment. Our findings indicate CBPR provides opportunities for people with developmental disabilities to gain and develop important qualities, such as empowerment. However, CBPR partnerships need to be carefully constructed and monitored to fully realize positive outcomes.

Keywords: CBPR, community-based participatory research, developmental disabilities, empowerment, intellectual disability

Introduction

Persons with developmental disabilities often experience marginalization and may lack control over their lives and matters that affect them. Signaling the need for change, the disability rights movement advances the idea “nothing about us without us” (Charlton, 1998). Although more typically directed at community settings, disability rights can also be promoted in scientific inquiry (Walmsley, 2004). Community-based participatory research (CBPR) promotes the inclusion of community members in all parts of research from development to dissemination. CBPR is an equal cooperation between academics and community members that fosters co-learning and empowerment while pursuing academic and community outcomes (Minkler & Wallerstein, 2008). Given the resonance of CBPR principles with disability rights values, CBPR is attractive to researchers who seek to include people with disabilities and improve their quality of life (Stack & McDonald, 2014). CBPR may also be an effective approach to improving the quality of research with people with disabilities, as partnerships may design research that is less harmful to participants and their communities, more accessible, and promote feelings of respect and trust which may subsequently engender greater participation in research (McDonald, 2012; McDonald & Raymaker, 2013; Nicolaidis et al., 2011).

Community partners' empowerment is often championed as inextricably tied to CBPR (Minkler & Wallerstein, 2008).

Empowerment is a contextually bound, multi-level concept (Fawcett, White, Balcazar, & Suarez-Balcazar, 1994). Individual empowerment includes people gaining skills and resources, and having control over important decisions (Zimmerman, 2000); settings that encourage meaningful participation may foster individual empowerment (Rappaport, 1987). Although participatory research does not empower people, it could provide the opportunity to foster empowerment for individuals that decide to empower themselves (Oliver, 1992, 1997). CBPR partnerships may foster community members' empowerment through representation on research bodies and involvement in decision-making (Wallerstein et al., 2008) experiences, which help community members to develop critical thinking and exercise self-determination, noted precursors of empowerment (Zimmerman, 1990). Participation in CBPR may also affect community partners—and subsequently their communities—as they gain advocacy skills and leadership (Ozer & Douglas, 2013). CBPR may also lead to changes in policies and practices, sustainable interventions, and changes in unequal power relations (Wallerstein et al., 2008), changes which may foster individual empowerment.

Given its promise of community and scientific benefits, participatory research with people with developmental disabilities is gaining momentum (Stack & McDonald, 2014). However, conducting CBPR with adults with developmental disabilities—who may have significant experience with segregation and exploitation (Dybwad & Bersani, 1996), experience persistent disparities as a result, and may need accommodation to participate—may require unique qualities or dynamics to achieve theorized goals of CBPR (Ferguson, 2004). However, rarely have individual empowerment and structural factors affecting empowerment in

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CBPR been systematically studied (March, Steingold, Justice, & Mitchell, 1997; Oden, Hernandez, & Hidalgo, 2010; Ozer & Douglas, 2013), particularly with respect to partnerships that include people with developmental disability. To address these pressing knowledge gaps of whether and how these theorized outcomes can be achieved (Cook, 2008), we qualitatively studied community partners' experience of empowerment in one CBPR project with people with developmental disabilities. We sought to understand community partners' understanding of empowerment, as well as their experiences with and perceptions of facilitators and barriers to their empowerment. We were fortunate to have the opportunity to situate our study in a project that appeared to have successfully used CBPR to create research processes and materials that were highly accessible and sensitive to community needs, and which produced highly reliable and valid research instruments (Nicolaidis et al., 2015; Oschwald et al., 2014). We were thus able to study the mechanisms which gave rise to—and presented challenges to—these outcomes. Shedding light on these mechanisms may enable other research teams to effectively use CBPR with people with developmental disabilities and promote valued outcomes such as greater empowerment among community partners.

Methods

Research Context, Approach and Participants

This research is part of a larger study on the use of CBPR with people with developmental disabilities in *The Partnering with People with Developmental Disabilities to Address Violence Consortium* (hereafter referred to as *The Partnering Project*). *The Partnering Project* was a multi-site study examining associations between violence victimization and health among adults with developmental disability. *The Partnering Project* was conducted by a CBPR consortium that included steering committees (SC) and community advisory boards (CAB) at each of the two sites. Consultants and staff also supported the consortium. The SC provided leadership to the project (e.g., prepared materials and made major decisions), and included three academic principal investigators, two project managers, and four community members with developmental disabilities. The majority of academic partners had disabilities and/or family members with developmental disabilities. Academic partners selected SC community members with developmental disabilities from affiliated community-based organizations (e.g., Centers for Independent Living and self-advocacy groups). The CAB provided ongoing guidance to the SC, and included, at each site, four people with diverse types and levels of developmental disability (all were able to verbally participate in meetings with accommodations), one parent of an adult with developmental disability, and one disability services professional. CAB members did not have academic affiliations. CAB members were selected by the SC. CAB members with disabilities were selected primarily based on their identity of having an intellectual disability (ID) or an autism spectrum disorder, though some had other co-occurring disabilities (e.g., deafness, blind), and parents were asked to represent people with developmental disabilities who might not be as

readily able to be accommodated to participate directly in the CAB. All community partners were people that, with accommodation, could participate on *The Partnering Project*. Of the four CAB members not selected because of their personal experience with developmental disability, one had a developmental disability and two had other disabilities. Among all members, some had worked together on prior projects, and as a result knew each other and already had positive relationships. The SC and the CAB were involved in all phases of the project, and co-created guidelines for how to work together. For more information on *The Partnering Project*, including their measurement adaptation process, use of technology to promote private and accessible data collection, and findings see Oschwald and colleagues (2014), Nicolaidis and colleagues (2015), and Platt and colleagues (2015).

We were engaged by *The Partnering Project* to conduct an external study of the use of CBPR with people with developmental disabilities. Our study, *The CBPR Study*, included regular interviews with the SC, annual focus groups with the CAB, and an end of project interview with all members (see McDonald & Stack, 2016 for more). Early findings suggested the importance of empowerment. To explore this idea more fully, we conducted interviews that centered on empowerment with all 15 community members on the SC and CAB when they were about halfway through the project. Four community members interviewed were on the SC (one autistic member, two members with ID, and one member with physical disability) and the remaining nine community members were on the CAB, which included three autistic members, four members with ID (some members had additional disabilities), one parent of an adult with developmental disability, and one human services professional (see Table 1 for more participant information). We used qualitative methods to better engage in critical conversations on under-explored phenomena (Denzin & Lincoln, 2005) and privilege individual perceptions as valuable and credible (Mactavish, Mahon, & Lutfiyya, 2000).

Data Collection and Analysis

We developed a semi-structured interview guide to explore empowerment based on CBPR scholarship, mainly the seminal works of Israel and colleagues (2003) and Minkler and Wallerstein (2008), empowerment scholarship (Rappaport, 1987; Zimmerman, 1990), and our first year findings on empowerment in CBPR with people with developmental disabilities (e.g., several CAB members shared that CBPR was empowering because it provided persons with disabilities a voice and an opportunity to share their life experiences with academic partners). We wanted to better understand perceptions of project roles, how the project has affected individuals, how empowerment is experienced within and outside of the project and how the CBPR structure affected empowerment within the project. Examples of interview questions include: *How has your involvement in The Partnering Project affected you? What does empowerment look like in The Partnering Project? What helps you contribute to The Partnering Project?* To ground questions in participants' perspectives, we began by asking participants how they define empowerment. In most cases, respondents provided a definition of empowerment though at times we shared a definition or worked one out

TABLE 1
Community partner demographic information

Demographic variable	CAB members N (%)
Age	
18–30	3 (20)
31–40	4 (27)
41–50	4 (27)
51–60	1 (7)
61 and older	3 (20)
Gender	
Female	10 (67)
Male	5 (33)
Race/ethnicity	
Caucasian/White	13 (87)
Multiracial	1 (7)
Native American	1 (7)
Education ^a	
Some grade school	1 (7)
High school diploma	4 (27)
Some college	4 (27)
Bachelor's degree	3 (20)
Master's degree	3 (20)
Juris doctorate	1 (7)
Identity/role ^a	
Person with a developmental disability	12 (80)
Person with disability	14 (93)
Family member	6 (40)
Ally	5 (33)
Support provider	2 (13)
Domestic violence service provider	1 (7)
Employment ^a	
Full-time	3 (20)
Part-time	1 (7)
Volunteer	3 (20)
Self-advocacy	5 (33)
Student	2 (13)
Retired	1 (7)
Unemployed	2 (13)
Total	15 (100)

^aParticipants were able to *Select all that apply*.

together. Throughout the interviews, we asked follow-up questions to probe deeper into responses or to clarify meaning.

We consulted with two community partners with developmental disabilities to ensure accessibility of all materials. We contacted community partners to invite them to participate in an individual interview; all agreed to participate. We worked with them individually to meet their needs and preferences, conducting 12 of the interviews in person, one via Skype text, one via telephone, and one via email correspondence. The interviews took place during a 4-month period at the beginning of the data collection stage for *The Partnering Project*. This time period was not a highly active one for community members because the

instrument was being pilot tested in the field by academic partners and research staff, and there was not a need to make decisions or review materials so there were few meetings with SC and CAB members. The average interview length was about 37 min, with a range of about 15 min to 1 h. There were not qualitative differences between respondents with different interview lengths. Some respondents spoke more at length, but ability to respond to questions did not differ. We conducted an accessible consent process approved by our university ethics committee and provided a \$25 gift card. Only one participant elected to receive a copy of their interview transcript.

We used grounded theory to analyze the data (Corbin & Strauss, 1990). Using ATLAS.ti (Muhr, 2004), we developed codes through an inductive approach using participants' empowerment definitions as a frame. One author did the initial coding, which the other author reviewed for agreement. We engaged in an iterative process that included revisiting and altering codes as necessary until we reached consensus, and agreed to modifications. We organized codes into empowerment definitions, and facilitators and barriers that affect empowerment. We took several steps to ensure the credibility, dependability, and confirmability (Guba, 1981) of findings including prolonged engagement with participants and the data, debriefings with each other, identifying and examining possibilities of inconsistencies, conducting member checks via full transcripts and/or an accessible summary to check congruence of our findings and interpretations. Member checking suggested we had captured participants' perspectives as no participant suggested changes that would meaningfully alter the findings or conclusions.

Findings

Community partners with and without developmental disabilities perceive empowerment as a mindset and set of behaviors, and identified individual and structural factors that facilitate and hinder empowerment in CBPR (see Figure 1 for an overview).

The Meaning of Empowerment

Community partners described empowerment as a set of mindsets and behaviors. Often using examples from their lives, community partners talked about *empowered mindsets* as understanding one's self, including one's strengths and weaknesses, and feeling a sense of self-esteem and self-efficacy (Table 2A; Q1–Q3). Community partners also described *empowered behaviors* that are engaged in when a person is empowered, or when she or he is working toward being empowered. Empowered behaviors included seeking participation and opportunities to have an influence, disability rights advocacy, and exercising control over decision-making in one's life and for people with disabilities generally (Table 2B; Q4–Q7). Using these definitions, some community partners expressed being empowered as a result of the project (Table 2C; Q8); other community partners felt they were already empowered and the project did not necessarily affect their empowerment, though they had opportunity to influence the project (Table 2C; Q9). Relatedly, some community partners, both with and without developmental disabilities, describe *The*

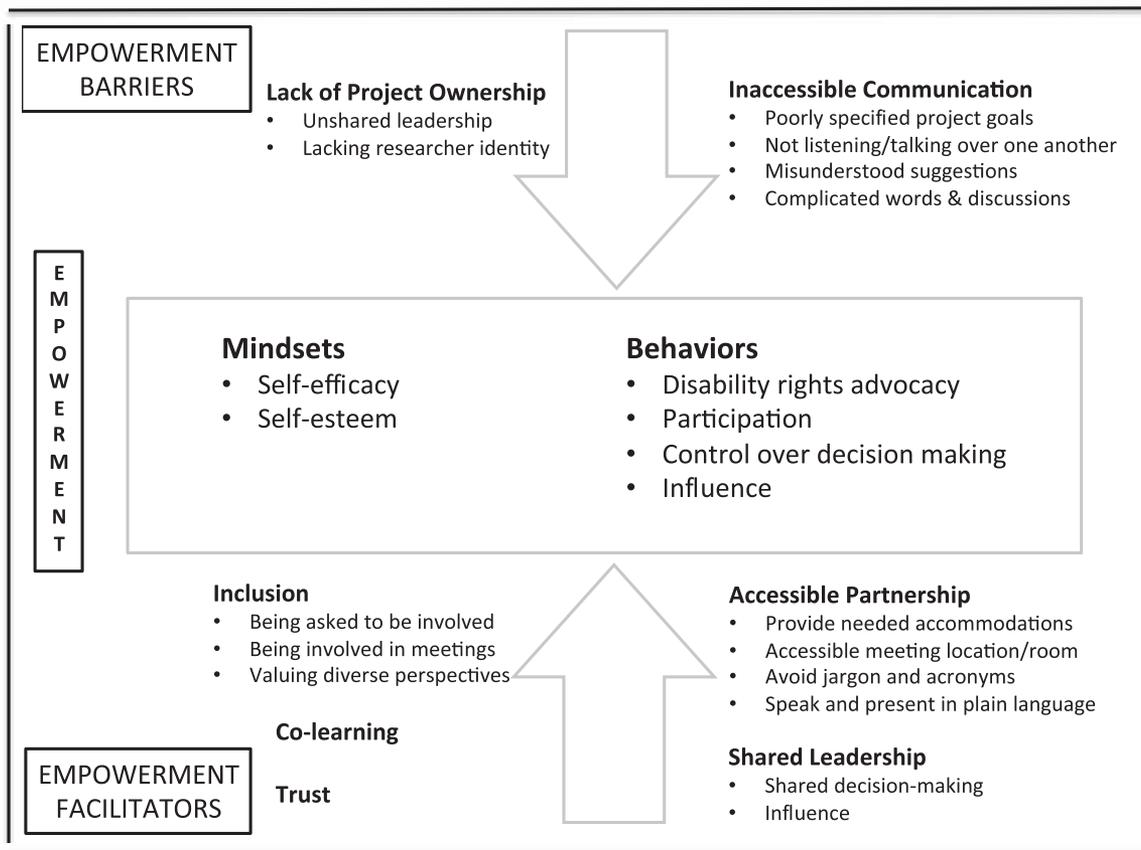


FIGURE 1
Empowerment definitions and CBPR barriers and facilitators affecting empowerment.

Partnering Project team as an empowered group and believed they witnessed other individuals be empowered (Table 2C; Q10). Overall, participants felt more aspects of *The Partnering Project* facilitated feelings of empowerment than hindered them.

CBPR Factors Supporting Empowerment

In reflecting on their experience, community partners discussed five structural, dynamic qualities of CBPR that can positively affect an individual’s empowerment: inclusion, shared leadership, an accessible partnership, co-learning, and trust. First, community partners spoke about the importance of project leadership valuing *inclusion*, a possible antecedent to empowerment. Academic partners’ commitment to inclusion was signaled by inviting community members to collaborate. Community partners appreciated the commitment to inclusion as it helped them feel valued and worthwhile, and gave them the chance to directly represent themselves and the developmental disability communities (Table 2D; Q11). Some felt that their voices should be heard more often, and that such opportunities needed to happen more frequently (Table 2D; Q12). The initial emphasis on the importance of inclusion was stressed to all subsequent project members

(Table 2D; Q13), and a shared commitment grew to inform all dynamics among academic and community partners.

Second, community members described the value of *shared leadership* over the project. Shared leadership may foster empowerment because community partners can demonstrate control and mastery over a project that is examining issues of personal and community importance. For some community partners, shared leadership led them to identify as researchers themselves, a feeling that appeared to signal an authentic partnership between academic and community partners (Table 2E; Q14–15). Importantly, shared leadership likely promoted additional dynamics (described below), and their effectiveness, that fueled empowerment.

Third, community partners noted that an *accessible partnership* allowed them to be fully involved and thereby better develop and demonstrate empowerment. Community partners described signs of an accessible partnership as the presence of academic partners who proactively and reactively recognize and acknowledge needed accommodations, seek resources for accommodations, and provide accommodations. They also noted that this initial emphasis on the importance of accommodations influenced subsequent dynamics as community members learned to accommodate one another. The accessible partnership involved

TABLE 2
Community partners' comments

Meaning of Empowerment

A. Mindsets

- Q1 "Knowing your strengths, being aware of your weaknesses, overcoming challenges based upon your strengths" (Michael,^a SC member).
- Q2 "Relates to my life. . . it has to do with self-esteem, self-consciousness, self-exploration" (Tamara, CAB member).
- Q3 "The feeling of empowerment is self-efficacy" (Renee, SC member).

B. Behaviors

- Q4 "Control what my own thoughts are, my own feelings, what I want to do with my life. I feel empowered. . . that I can make my own choices" (Betty, CAB member).
- Q5 "A kind of united element of trying to make life better for people with disabilities. We are not going to probably solve any huge things, but I think it is important to start looking at why some things are the way they are. It goes back to making things better. (Brian, CAB member)"
- Q6 "More involved in the community" (Thomas, CAB members).^b
- Q7 "Community exploration and figuring out the impact and/or the footprint I can leave in the world" (Tamara, CAB member).

C. Empowered in the Partnering Project

- Q8 "[The Partnering Project] has helped me in long ways to be empowered" (Joseph, SC member).
- Q9 "I have seen all people in The Partnering Project make successful changes during the course of our work together and do feel we have an empowered group" (Renee, SC member).
- Q10 "[The Partnering Project] gives me feelings of empowerment just because. . . it just feels good to be a part of something that seems relatively unique and special" (Timothy, CAB member).^b

CBPR Factors Supporting Empowerment

D. Inclusion

- Q11 "The freedom to share our experience is, I know at least for me, it has made me feel. . . important or that the contribution and efforts I bring to this are looked at positively" (Brian, CAB member).
- Q12 "I think it is really great that people take interest in us and want to know about us and everything because we need more of that" (Jean, CAB member).
- Q13 "I can't speak for other people and I wouldn't want other people to speak for me" (Amanda, CAB member).^b

E. Shared leadership

- Q14 "Both in charge, the academics and self-advocates" (Joseph, SC member).
- Q15 "[Academic and community partners] are finding it together, so that makes us researchers" (Michael, SC member).

F. Accessible partnership

- Q16 "[Academic partners] accommodate really good. Like even with the files when they send an attachment. They send it in a file that works for my computer" (Meghan, CAB member).
- Q17 "Often we stop things and go back and make sure that. . . one or more people who have expressed confusion about what we are talking about, we can address that" (Timothy, CAB member).^b
- Q18 "One good thing is that [academic partner] sits by me and she helps me with words that are hard or any information that I don't understand" (Jean, CAB members).
- Q19 "They wheeled me out to car to go home and helped me to my front porch" (Barbara, CAB member).
- Q20 "I am very lucky that [academic partner] can help me go over there" (Jean, CAB member).
- Q21 "Having food and something to drink around so that I feel physically well during the meeting. . . that helps" (Timothy, CAB member).^b
- Q22 "Every time at the end of our meetings. . . pros and cons of what could be done differently. How could we make this better? And people are more than welcome to bring up what they need, so when you revisit it, obviously you keep growing" (Tamara, CAB member).

G. Co-learning

- Q23 "I have knowledge of the CBPR process, which I didn't have before, so I would say that is empowering" (Timothy, CAB member).^b
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TABLE 2
Continued**CBPR Factors Supporting Empowerment**

Q24 “I didn’t know any of the stuff that we know now, and now I can learn all the stuff like I learn now. . . really powerful” (Barbara, CAB member).

H. Trust

Q25 “Going back to the very beginning the feelings of respect have been present. . . It has developed into trust” (Thomas, CAB member).^b

Q26 “We have a lot of trust in each other. And trust that we are going to get help that we need” (Jean, CAB member).

Q27 “I am not going to deny that there are just things that people in public think about people with disabilities. That is just the way it is. Well, everybody walks into. . . The Partnering Project, regardless of what people have thought of them. . . on their way here. . . they are an equal person and they know that they will be respected there” (Tamara, CAB member).

I. Examples of influence in the Partnering Project

Q28 “We are changing questions so they are more understandable for people with developmental disabilities” (Meghan, CAB member).

Q29 “[CBPR] supplements the investigator knowledge and it provides a sounding board in terms of. . . communicating effectively with the respective research group or research populations. . . Are we asking all of the questions? And are we asking them in ways that can be understood? I think that is our principal responsibility, to provide some guidance and insight and some supplemental knowledge about the population under study” (Thomas, CAB member).^b

Q30 “Seeing my suggestions considered and implemented without [academic partners] giving me the ninth degree was also quite lovely” (Sarah, CAB member).

CBPR Factors Challenging Empowerment**J. Inadequate communications**

Q31 “Sometimes they don’t listen to me when I am talking” (Mindy, SC member).

Q32 “I find it real hard sometimes when like [academic partners] are talking and they have real hard words. . . That is real frustrating to me. . . and I think with anyone, when you don’t understand something, it is pretty hard.” As a result, she questioned her presence within the team at times. “When it gets too complicated, then I feel like, ‘Why am I here?’” (Jean, CAB member).

Q33 “I am not exactly sure why we have the CAB” (Jean, CAB member).

K. Lack of project ownership

Q34 “The ones in power being [academics partners]. . . they run it” (Michael, SC member).

Q35 “I know what being a researcher is and I am not doing that” (Thomas, CAB member).^b

^aAll names are pseudonyms.

^bIndicates community partner not selected for their developmental disability.

the content and format of materials, as well as group processes such as using plain language, taking time, and providing personal support before and during meetings to make sure everyone understood (Table 2F; Q16–Q18). It also involved ensuring the accessibility of the physical environment such as having meetings in a space that was easy to get to and had natural light, working out transportation assistance for those who needed it, and providing refreshments (Table 2F; Q19–Q21). Community partners noted that it was important for academic and community partners to be mindful and flexible with the diversity of needed accommodations, and noted that accommodation needs may change as the group and its functions developed over the course of the project. One structure that supported ongoing attention to accessibility was the “check-out” at the end of meetings. The check-out provided an opportunity to discuss things that

members would like to keep and things they would like to change for future meetings (Table 2F; Q22). As before, this quality further fostered subsequent outcomes.

Fourth, community partners related co-learning in CBPR to empowerment. They felt that being involved in a project where they had the opportunity to share and gain knowledge, particularly in working with, learning from, and learning about a diverse group of people, was empowering. Community partners learned about diverse disabilities, violence victimization, and research, including CBPR (Table 2G; Q23–Q24). Some also noted the potential for them to apply what they learned about creating an inclusive partnership to other settings.

And last, and perhaps as a result of earlier factors, community partners mentioned *trust* as an important aspect of the partnership that creates an opportunity for them to be empowered.

Community partners described trust as related to feeling comfortable working with others, sharing ideas, and asking questions; it also involved feelings of mutual respect, and was described as developing from feeling respected (Table 2H; Q25–Q26). Although many community partners had negative experiences in other contexts, they felt that while working with *The Partnering Project* that they could trust that academic and other community partners would appreciate their input. As an example of how this setting differed from others, one community partner talked about her appreciation that her ideas were considered and implemented without significant resistance (Table 2H; Q27). Shared values and commitments related to working on a CBPR project focused on important community issues likely helped promote feelings of trust.

Community partners provided examples of their influence on *The Partnering Project*, which supports that these five factors—inclusion, shared leadership, an accessible partnership, co-learning, and trust—promoted their empowerment within the project. For example, community partners changed how academic and community partners worked together and the research materials (Table 2I; Q28–Q30; for more examples see Nicolaidis et al., 2015; Oschwald et al., 2014).

CBPR Factors Challenging Empowerment

We identified two qualities of CBPR partnerships that can disempower or challenge an individual's empowerment, one structural and one experienced at the individual level as a result of structural dynamics. Community partners themselves did not always explicitly describe these experiences and feelings as disempowering, though our analysis classified them as disempowering as they challenged community partners' understanding and feelings of being fully involved in the project, which are necessary conditions for empowerment.

First at the structural level, some community partners talked about *inadequate communications*. Inadequate communications included times when community partners felt they were not being listened to or respected, or did not understand what others were saying; these experiences appear to challenge meaningful inclusion in the project (Table 2J; Q31–Q32). Inadequate communications also reflected instances in which community partners appeared to lack a complete understanding of the purpose and structure of the project or what was happening within it because that information either was not shared with them or was not shared with them in ways that facilitated their full understanding (Table 2J; Q33). Such experiences were difficult for those who encountered them.

At the individual level, we also noted *lack of project ownership* as a possible barrier to empowerment as this feeling may inhibit community partners from making contributions and experiencing an equal partnership. Some community partners appeared to have less, or no, sense of ownership (Table 2K; Q34), and some did not identify as researchers (Table 2K; Q35). It is possible that this lack of researcher identity suggests an unequal partnership, or a lack of understanding of CBPR and the role of community partners therein. However, for one community partner, his refusal to identify as a researcher was linked to his lack of

scientific training and subsequent preference to not identify himself as a researcher.

Discussion

Although empowerment is a highly regarded theorized outcome of participatory research (Brydon-Miller, 1997), rarely has it been studied, especially in CBPR projects that involve people with developmental disabilities (March et al., 1997; Stack & McDonald, 2014). We examined whether and how community partners with and without developmental disabilities working on a CBPR project experienced empowerment through their work. Our findings indicate that community partners see empowerment as a set of mindsets and behaviors, and that structural features of CBPR projects can both foster and impede their empowerment. We did not find differences between community partners with and without developmental disabilities.

We grounded our study of empowerment in community members' views: their definitions that emphasized empowered beliefs including self-efficacy and self-esteem and the political goals inherent in empowerment mirrored scholarly definitions (Carr, 2003; Maton, 2008; Zimmerman, 1990, 2000). Here, goals were related to empowered behaviors such as seeking influence over one's life and society, often with a focus on disability rights. Maton defines empowerment as a "group-based, participatory, developmental process through which marginalized or oppressed individuals and groups gain greater control over their lives and environment, acquire valued resources and basic rights, and achieve important life goals and reduced societal marginalization" (p. 5); supportive settings may be crucial in the promotion of empowered mindsets and behaviors (Zimmerman, 2000). Our findings suggest that *The Partnering Project* largely succeeded in creating a setting in which empowering mechanisms came to life and fueled processes that promoted empowerment among community members. These structural dynamics may prove beneficial to promoting empowerment in other settings, and their use therein should be explored.

Dynamically related, and reinforcing over time, our findings highlight how factors in CBPR with people with developmental disabilities unfold to create empowering mechanisms. This process begins as inclusion of people with developmental disabilities is valued and acted upon. However, presence is insufficient; instead, settings must promote participation and influence to empower its members (Rappaport, 1987). Meaningful inclusion can add credibility to findings because people with the lived expertise are contributing to the research development, implementation, and interpretation (Kitchin, 2000). In the case of people with developmental disabilities, specific factors may be necessary to engender meaningful engagement. For example, accommodations are crucial for the inclusion of persons with developmental disabilities (Ferguson, 2004). Accommodations signal to community members that project leaders value their presence and want to create a supportive, welcoming environment. More fundamentally, accommodations alter environments to enable participation and opportunity for significant roles, thereby creating conditions so that people with developmental disabilities are authentic members rather than tokens of inclusion. In *The Partnering Project*, two simultaneous conditions

appear necessary: academic partners needed to demonstrate a flexible willingness to provide accommodations and community partners needed to be comfortable speaking up about their needs and preferences. One structure that promoted these conditions was the regular opportunity to reflect on how each meeting went, which included the invitation to discuss potential improvements. This provided a formal space for community partners to influence group processes, and the opportunity for project leaders to demonstrate their respect for community members' viewpoints and genuine commitment to fostering their engagement.

Shared leadership, on the SC and through important roles in the CAB (e.g., time keepers, process rule minders, and keep/change moderators), helped generate structures that more fully fostered engagement, including greater insight and responsiveness into effective accommodation strategies. As described in the methods section earlier, community partners had opportunities to develop and demonstrate skills, gain knowledge and experience, and make meaningful contributions. For example, SC members helped identify selection criteria for and select CAB members, SC and CAB members helped adapt research instruments, and SC and CAB members co-authored presentations and publications. Findings from *The Partnering Project* suggest these contributions benefited the quality of the science (viz. private data collection strategies, accessible, reliable, and valid research processes and materials; Nicolaidis et al., 2015; Oschwald et al., 2014; Platt et al., 2015).

Early attention to the selection of diverse SC and CAB members also promoted *co-learning*: for example, younger members were exposed to and inspired by more experienced advocates and almost everyone gained additional insight into disabilities. Community partners emphasized the role that these opportunities to learn—a key principle in CBPR (Minkler & Wallerstein, 2008)—played in their empowerment, both within and outside of the project as they began to feel more confident in what they know and how they can contribute to decision-making. It appears essential that CBPR partnerships with people with developmental disabilities establish formal and informal roles to promote empowering outcomes.

Initial actions and processes to promote an *accessible partnership* set into motion subsequent factors, which appear to further spur empowerment in CBPR. For example, building and maintaining relationships is key to achieving CBPR goals (Minkler & Wallerstein, 2008). In the case of CBPR with people with developmental disabilities, these relationships may need to be transformative. Early actions acknowledged an understanding of the common practice of exclusion and unequal relationships, and reflected efforts to avoid recreating normalized power structures. Attention to these structural and interpersonal dynamics demonstrates respect, may help avoid roadblocks down the line (Minkler & Wallerstein, 2008), and may decrease barriers to empowerment. Importantly, these relationships may serve as key counter forces to dynamics often experienced by people with developmental disabilities.

Transformative relationships and opportunities to influence the project allowed community partners to realize their importance and feel their value; key experiences to realizing greater control and empowerment (Fawcett et al., 1994; Maton, 2008). Furthermore, these dynamics promoted feelings of belonging and membership, thereby helping community partners to feel

that they are authentic project members and not just there as tokens of less authentic inclusive practices (Riger, 1993). Collectively, these also set the stage for *trust* to develop and strengthen between academic and community partners; community partners described how trust contributed to their empowerment. Trust appears to facilitate empowerment by creating an environment in which community partners feel safe, welcomed, and respected, and thereby more confident in sharing as they feel that their ideas and experiences are taken seriously and will impact the project. Importantly, the opportunity to influence may go beyond an impact on the current project and may motivate community partners to work to get involved with other important issues (Ozer & Douglas, 2013). In *The Partnering Project* there was a mix of established and new relationships: for some, trust existed from the start; for others, trust developed as a result of feeling respected. These successful dynamics that fostered empowering mechanism suggest the value of long-term partnerships between academic and community partners and of attending to and demonstrating respect in newer relationships; these dynamics may be essential to transforming broader unequal societal power dynamics.

Often a CBPR approach is used to address unequal power relations. Using a participatory approach in disability research may be the only way to address unequal power relations between academic and community partners and ensure research results will be presented and used in a way to effectively improve and adequately represent the lives of people with disabilities (Kitchin, 2000; Oliver, 1992). In CBPR, researchers work alongside and share power with marginalized populations as both groups work toward positive social change (Goodley & Lawthom, 2005; Wallerstein et al., 2008). Equalizing power may foster individual empowerment for community partners with and without developmental disabilities, but power balances across groups need to be monitored to ensure voices are heard, opinions are respected and valued, and the community is represented accurately and fully in the research. The CBPR process should be cyclical; academic and community partners work together to gather significant and applicable information, think and expound on that information, and finally act and evaluate the results. The CBPR cycle should be repeated and monitored until the community and academic partners are satisfied with the outcome. Adequately addressing power imbalances is often the most difficult part of a CBPR partnership (Stringer, 1996), but it is an essential step to ensure the research and the research findings will contribute to positive social change for people with disabilities (Oliver, 1992).

The development of empowerment in CBPR should not be taken for granted: explicit, continued attention is necessary. In addition to promoting empowering mechanisms, attention must also be paid to factors that work against empowerment. In CBPR with people with developmental disabilities, inaccessible communications, and lack of perceived authentic project ownership may challenge empowerment. As noted earlier, involvement of people with developmental disabilities in project leadership and spaces for discussion about how the process is experienced may be fruitful in ensuring accessible partnerships. That some community partners felt a lack of project ownership may relate to the history of the project under study, and the ongoing impact of that history: although community partners were consulted during the development of the grant application and participated in project

leadership, none are named investigators on the awarded grant and did not directly significantly control the budget or project administration. So while SC and CAB members may have had significant leadership, not being named as a leader on the grant proposal nor having responsibilities for administering the grant may have hindered their full sense of project ownership. This history coupled with the technical aspects of research and educational disparities among many people with developmental disabilities may have led some community partners to feel that academic partners were the genuine owners. It is also possible that larger societal power dynamics infiltrated project power dynamics despite desire to challenge them (Zarb, 1992). To counter such experiences and their ongoing legacies, partnerships should discuss project goals, CBPR principles and practices, and roles and responsibilities of all project members at the onset of and throughout collaborations. It may be especially critical that funding timelines and expectations allow adequate time for the development of fully shared leadership; creating an equal partnership may require such circumstances. Despite these barriers, overall, community partners do not feel *The Partnering Project* was disempowering, and at times did not explicitly relate these barriers to empowerment. Nonetheless, these barriers represent roadblocks that may limit one's capacity to be empowered through work on a CBPR project.

One mechanism that may foster equitable, empowering partnerships is reflection. Self-reflection may inspire academic partners to engage in "unlearning" processes about how to engage in a power-sharing research partnership with persons with developmental disabilities (Chambers, 2007; Stack & McDonald, 2014). Similarly, through critical reflection, community partners may recognize and assess socially constructed barriers placed on them and pursue control over their lives (Dworski-Riggs & Langhout, 2010). This dynamic may help community members experience a distinct setting and CBPR may thereby nourish empowered mindsets, though changing larger social inequities may be required to fully achieve this outcome. The cyclical nature of CBPR (Minkler & Wallerstein, 2008) and empowerment (Carr, 2003) are well-matched to encourage reflection within a group or project. CBPR partnerships can benefit from creating structures that elicit regular reflection and plan deliberately for the evolution of group needs. In CBPR with people with developmental disabilities, external partners available to receive and reflect back feedback may be important in the face of real or perceived power imbalances. For example, initial experiences and findings of *The CBPR Study* led to a restructuring of *The Partnering Project*; a change welcomed by project members as allowing them to provide accommodations more effectively and work together.

Although we found evidence that community partners can develop and demonstrate empowerment in CBPR, some have been critical toward ideas that CBPR merits credit for empowering community partners (Goodley, 1999). For example, community members may already be empowered, which leads them to be involved in a research project relevant to their community (Zimmerman, 2000). Nonetheless, it remains important to attend to empowerment facilitators and barriers in CBPR both to ensure influence on the project as well as to promote the acquisition and development of knowledge, experience, and skills that may be used to exert greater control over one's life and matters that affect it.

Our findings should be considered with limitations in mind. Our focus on empowerment grew from early findings, so we did not fully examine these questions longitudinally. A prospective study of empowerment in CBPR may reveal different or unique findings. It is also unclear what empowerment in CBPR might look like for individuals with more significant forms of developmental disability. Moreover, our data are self-report and tied to one context; other methods for examining empowerment or focal contexts may present distinct findings. Future research can further illuminate when, and under what conditions, the involvement of persons with developmental disabilities on research teams can foster critical CBPR principles and outcomes, and affect individuals and communities more broadly. It is possible that this sense of empowerment, and related behaviors, does not generalize outside of CBPR contexts, perhaps because of current or historic oppression which may thwart one's control or lessen one's willingness to attempt to exert control.

In conclusion, attention to accessible implementation of core CBPR principles (Minkler & Wallerstein, 2008) may generate empowering mechanisms and promote empowerment among community members, a much celebrated, theorized outcome of CBPR. Similar to disability advocacy groups, CBPR provides opportunities for persons with developmental disabilities to acquire leadership skills necessary to spark positive social change for the disability community (Caldwell, 2010). Bringing disability rights into science can improve the quality of developmental disability research, and serve as a catalyst for developmental processes that may lead to positive impacts that reach beyond the scientific realm.

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