

**Participatory intervention research with a Disability Community:  
A practical guide to practice**

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**Biosketches****Pamela Block, Ph.D.**

Dr. Block is a Clinical Associate Professor in the Occupational Therapy Program, School of Health Technology and Management, Stony Brook University. She served as PI of a multi-year study funded by the National Institute on Disability and Rehabilitation Research (NIDRR) entitled "Project Shake It Up! Health Promotion and Capacity Building for persons with Traumatic Spinal Cord Injury and other Neuromuscular Disabilities," (2002-2005). Dr. Block received her PhD in cultural anthropology from Duke University in 1997. Her dissertation "Biology, Culture and Cognitive Disability: Twentieth Century Professional Discourse in Brazil and the United States" addressed the influence of cultural beliefs and professional theories on disability policy and treatment.

She has studied multiple marginalization and the intersections of gender, race, poverty, and disability. She currently studies capacity building and health promotion for people with disabilities through participatory intervention research with community non-profit organizations. Current research involves peer mentoring and overcoming barriers to physical and recreational activity for children and adults with Multiple Sclerosis. Recent publications discuss teaching disability studies in community health and rehabilitation programs.

**Sarah Everhart Skeels, MPH**

Sarah Everhart Skeels has an undergraduate degree in Kinesiology and Exercise Physiology from the University of Virginia (1989), and a Master's Degree in Public Health from the George Washington University, where she concentrated in Health Promotion/Disease Prevention and Disability. She became a T5 complete paraplegic in 1990 when she was involved in a collision with a car while riding a bicycle. Since that time, Sarah has dedicated her professional and personal life toward promoting health, wellness and independence for people with disabilities, with a focus on neurological disabilities.

Currently, Sarah serves as a consultant to the Disability and Health Program, RI Department of Health and the PARI Center for Independent Living, where she is responsible for developing and implementing health promotion programs for adults and teens with physical disabilities. She is also a Co-Instructor for a course titled "From Pathology To Power: Disability, Community and Health" offered through the Department of Community Health at Brown University. She is also Adjunct Faculty of the Physical Therapy Assistant program at the Community College of Rhode Island, and guest lectures on disability issues at Assumption College and the University of Rhode Island.

Sarah helped Dr. Block with the development of the Shake It Up project, and eventually became the Project Director and Co-Principal Investigator. Additionally, she helped develop, implement and facilitate the Educational and Recreational seminars.

Sarah believes in practicing what she preaches and tries to lead an active lifestyle. She is a volunteer ski instructor at the White Mountain Adaptive Snowsports School at Loon Mountain, New Hampshire, and has taught people with disabilities how to sail. She sails competitively, sea kayaks, handcycles, and enjoys any and all outdoor recreation.

### **Chris Keys, PhD**

Dr. Christopher Keys is Full Professor and Chair of the Psychology Department at DePaul University and Professor Emeritus of Psychology and of Disability and Human Development at the University of Illinois at Chicago. Recently, he has co-edited *People with Disabilities: Empowerment and Community Action* and *Participatory Community Research: Theory and Method in Action*.

Professor Keys is a community psychologist and his current research and interventions focus on the empowerment of people with disabilities and their families, the promotion of success in education and in life by youth and young adults with disabilities, and attitudes toward people with intellectual disabilities and disability rights. He is also conducting intervention research concerning the development of the program evaluation capacity of organizations that serve people of color with disabilities. He is particularly interested in the intersections of disability, ethnicity and social class.

A Fellow of the American Psychological Association and the Society for Community Research and Action, Dr. Keys was one of the first to serve as President of the Society for Community Research and Action and as Chair of the Council of Community Psychology Program Directors. His work has been recognized by awards, appointments and honors from the American Psychological Association, The World Bank, the American Institutes of Architects, and the National Government of Australia. He has been invited to present his research in Asia, Australia, Europe and Latin America. He has held visiting faculty appointments at the University of Oregon, Macquarie University in Australia and Shandong University in China.

## **Abstract**

This article is an account of how a 3-year NIDRR-funded participatory intervention research (PIR) project about health promotion, spinal cord injury, individual and organizational capacity-building evolves from inception to completion. Researchers and community collaborators mediate relationships among funding entities, academic institutions, community organizations, and project participants. Each stakeholder has different needs, priorities and paradigmatic conceptions of disability. Using a combination of participatory action and intervention research methodologies, strategies are discussed for developing partnerships and research agendas, seeking funding, overcoming barriers, and implementing, sustaining and disseminating the project and its core activities. We also specify important dimensions and activities necessary for PIR with and within disability communities.

## **Participatory intervention research with a disability community: A practical guide to practice**

### **Introduction**

Our purpose here is to discuss participatory intervention research (PIR), explore some lessons learned, and provide an example of how PIR can be used to create a successful partnership between university researchers and a local disability community. This article presents and analyzes PIR in collaboration with individual disabled people and organizations that serve disabled people and serves as a practical guide to practice relevant to the design and implementation of PIR in the United States at the turn of the 21<sup>st</sup> century. Though the lessons learned may be useful in many other contexts, this example is not meant to be representative of other locations or times. Indeed the research climate even in this particular context has changed a great deal in recent years.

Beginning in 2000, two non-profit organizations staffed primarily by disabled people began collaborating with a group of university researchers. What began as a summer of anthropological participant-observation research evolved into a 3-year participatory intervention research (PIR) study called Project Shake-It-Up. This study, funded by the United States Department of Education's National Institute on Disability and Rehabilitation Research, functioned on two levels. It promoted health and empowerment for individuals with spinal cord injuries (SCI) and related neuromuscular disabilities and it engaged in organizational capacity-building to strengthen disability access and presence in the community. We recount our strategies for developing partnerships and research agendas, seeking funding, overcoming barriers and avoiding pitfalls, implementing and continuing project initiatives and disseminating information about them.

Specific “lessons learned” follow each section of this article. These lessons derived from challenges faced by project investigators, staff and community collaborators during the research process. Challenging situations were documented, discussed by project investigators and staff and community collaborators at regular meetings, and ultimately became part of the project record. The different perspectives provided by members of our multidisciplinary collaboration served as a form of triangulation, giving us the ability to identify current and future challenges and the flexibility to respond with practical and innovative strategies. Perhaps the most important lesson the co-authors learned was that, in addition to the products and results obtained through this form of PIR, the process itself can be a meaningful learning experience for all parties involved. We offer this case example to illustrate how PIR and intervention research can be combined for effective responsive research for health promotion and capacity building for disabled individuals and disability organizations.

### **Participatory Intervention Research**

Participatory intervention research (PIR) is a variant of participatory action research (PAR). PAR was initially developed in the early 1970s in Latin America as researchers from the region used research as a vehicle for radical social change (Bonilla, Castillo, Fals Borda & Libreros, 1972; Freire, 1970; Horton & Freire, 1990; Rappaport, 2007). Since this time PAR has developed both theoretical and methodological sophistication, and it has been used internationally (Reason & Bradbury, 2006). PAR incorporates anthropological and sociological methodologies of participant observation and action research in which the researchers also live and actively participate in the community under study. Formally trained researchers collaborate with community members on a shared vision for social change. In addition, organizational theory and practice emphasizing the application of participatory methodologies sensitive to socio-

cultural and community contexts (Hall & Gillette, 1977; Park et al., 1993; Park, 2006; Fals Borda, 2006, Selener, 1997; Whyte, 1991, 1993). The methodology has been applied in organizational and social movement research as a strategy to work with disenfranchised groups (workers, minorities, etc.) with the goals of knowledge acquisition, empowerment and social or systems change (Balcazar et al., 2004, Rappaport, 2007). The goal is to give groups previously excluded from research and policy decisions a “voice” in these processes and to recognize the formerly invisible contributions of these groups to the success of research and policy endeavors.

In clinical contexts, intervention research generally refers to health or behavior change on the individual level. In contrast, participatory intervention research uses structured strategies for changing individual and group practice to improve quality of life on both individual and community levels (Potvin et al., 2003; Schultz et al, 2002). PIR methodology is developed and disseminated through collaborations between community organizations, individual research participants and formally trained researchers. Community organizations and individual research participants have a stake both in the research design and in the knowledge achieved. PIR also includes a focus on educating important publics about the nature of the research process and outcomes.

In addition to the study presented here, there are several exemplars to date of participatory action research with disability communities with an intervention focus. These include collaborating with an Independent Living Center on self advocacy to increase the accessibility of community spaces (Brydon-Miller, 1993), and connecting with grassroots disability leaders and agency staff to create a stronger voice for disability rights among Latinos (Balcazar et al., 1998; Balcazar et al., 2001). In addition, Hernandez et al. (2001) worked with African Americans and Latinos with Spinal Cord Injuries to develop, implement and

subsequently evaluate culturally appropriate peer-support services within rehabilitation facilities. Bartunek et al. (1996) used participatory approaches to develop and document a collaborative advocacy initiative involving people with intellectual disabilities, parents and professionals. To date, the accounts of participatory intervention research with people with disabilities have focused primarily on articulating the conceptual issues most relevant to the research project. With the noteworthy exception of Balcazar et al (1998), these accounts have paid less close attention to the explicit steps taken and challenges faced in building partnerships between university and community members.

In this article, we present a research project narrative that seeks to identify those steps and challenges and to articulate practical insights for the initiation of PIR with lasting results to benefit community organizations, activists and university scholars. The qualitative methods used throughout this research include participant observation, individual interviews with project participants, field notes, photos, and video footage. We have documented both individual perceptions and experiences and group interactions and so have documented how community has been developed and sustained during and beyond the shared experience of project participation. On the organizational level we explore practical strategies for developing successful PIR partnerships. In addition, we discuss how this methodology can be employed with disabled individuals and disability communities. Participatory intervention research should be considered a subcategory of PAR, and it is worthy to note that our experience and insights may at times be specific to this methodology.

### **Developing the Partnership**

This project began with programs developed by two local organizations run primarily by people with disabilities. One organization provided nontraditional secondary rehabilitation,

recreation, and independent living skills training for physically disabled people through a 5-week residential summer program developed by the second author, in her then-capacity of program director. The second organization was the local independent living center (ILC) that collaborated with the recreational organization to add the independent living component to the program. The first author, a cultural anthropologist, met the second author, who invited her to observe the summer program and engage in some preliminary research (Block et al. 2001). Relieved to leave behind a hospital-based research program that she had spent the year designing, the first author happily accepted this invitation. After a fruitful summer of relationship-building, interviews, and participant-observation, the first and second authors began discussing the potential for collaborative research with staff from both organizations and encouraging university mentors, (including the third author).

While some community organizations are research savvy, others have no experience in this area and may hesitate to engage. Likewise, university researchers may have concerns about the stability of community organizations and their ability to fulfill commitments. University researchers need to develop relationships outside the university to establish credibility. Building and maintaining relationships is a key strategy for university researchers wishing to successfully mediate between multiple stakeholders. It also provides research collaborators with the information necessary to design participatory intervention research that is responsive to everyone's needs and priorities.

**Lesson 1:** Build trust. Know the priorities, philosophies, and tastes of the organizations and individuals to be involved in the collaboration and choose a setting that is compatible.

**Lesson 2:** Build upon existing relationships when possible. Involving people with some positive history of working together increases the likelihood of success.

**Lesson 3:** Be aware of the areas of expertise and inexperience of all parties – reassure community organizations that they will receive help and support in new endeavors. Make good on such assurances.

**Lesson 4:** Conduct pilot research so that collaborators can get used to working together and to determine if the project is feasible.

### **Writing the Grant**

The third author suggested applying for funding for a 3-year field-initiated research study through the Department of Education's National Institute on Disability and Rehabilitation (NIDRR). Discussions with NIDRR program officers confirmed that this would be an appropriate place to apply for funding. We gave thought to what audiences might be reviewing the proposal. We surveyed copies of grants that had been successful in earlier rounds of the same competition. Although inexperienced in research grant writing, the community organizations provided information and expertise. They contributed to the grant narrative, helping to develop conceptual aims, literature review, and methodology. University mentors assisted with every section of the grant. Staff at the research institute helped with the budgets and paperwork for the overall project.

Both the first and second authors and the community organizations were new to the complexity of the paperwork involved, so they found the help provided by the university Research Institute and Office of Research Administration to be invaluable. Since the community organizations did not have experience in research administration, it was decided that university would be the appropriate site to administer this initial grant. Extra time must be reserved to compile last-minute paperwork and to navigate through university bureaucracy. If the true deadline is October 30<sup>th</sup>, tell collaborators that all paperwork must be received no later than the

15<sup>th</sup>, and send out regular reminders. Some stakeholders may wait until the very last minute to complete essential paperwork. People forget, forms are misplaced, Express-mail packages fail to arrive. Allow plenty of time to get all the necessary paperwork assembled. In a participatory, capacity-building framework, these stressful occasions are also opportunities to educate community organizations about the complexities of grant submission.

In the summer of 2001, the first and second authors received a small grant from the Research Institute at the university allowing them to conduct additional pilot research. During this time they learned that Project Shake-It-Up had received funding from NIDRR. It is not unusual to have to revise and resubmit multiple times before receiving funding; Shake-It-Up was fortunate to be funded at the first submission (Block & Rimmer, 2000).

**Lesson 5:** Ascertain funding agency priorities and funding climate. Review successful grant applications. Ask questions. Know the audience. Find models.

**Lesson 6:** Leave plenty of time to get all the necessary paperwork assembled. Give early deadlines.

**Lesson 7:** Determine who should administer the grant, according to the priorities of the funding source and the experience, abilities, and comfort levels of all the parties involved.

### **Project Implementation**

The project was officially set to begin in January 2002, and certain goals for the initial phases of the project were easy to accomplish. Key staff had already been identified, with clearly defined tasks. The researchers and community collaborators began meeting immediately to plan for the next steps in the project.

The intervention design consisted of 10 full-day sessions divided into two parts (Block et al., 2005). The morning sessions involved skills training for self-advocacy, independent living,

and health promotion. The afternoon sessions consisted of recreational and physical activities (kayaking, sailing, kite flying, strength and conditioning, etc.). Recreational program staff provided expertise in rehabilitation and recreation. ILC staff provided expertise in independent living, case coordination, and peer support. The research team provided expertise in research methodology and scholarship in the areas of health promotion and empowerment. Study participants listed activities and topics of particular interest to them, and these were incorporated into the final intervention design. At the center of this web of relationships, the co-investigators (first and second authors) kept everyone connected, communicating, and working together efficiently. Everyone met regularly and performed functions that they did best and enjoyed the most, while dividing some of the more tedious project administration tasks. Additionally, all of the team members had extensive histories of working together successfully with some other members of the team. For example, the community collaborators did not know most of the researchers, but had a long-established working relationship with each other. Over the course of a year, they had grown to trust the first author, who had established working relationships with the third author, Co-Principal Investigator James H. Rimmer and other mentors who assisted with the project.

Some unexpected barriers to the project took some time to resolve. The most daunting barrier involved human subjects research approvals. The investigators understood that the research design would have to be approved through the university's institutional review board (IRB). However, the funding agency also mandated that the community organizations obtain separate approvals for their participation, and suggested that they "borrow" the university's IRB for a single-project assurance. Unfortunately, the university research administration did not have the resources to accommodate this request. The community organizations were left with three

options: (1) establish their own IRBs; (2) find a for-profit IRB who would review their activities for a hefty fee, or; (3) find another local IRB that would review their activities and grant a single-project assurance without charge. These options were distressing, since it was impractical for community service and advocacy organizations to establish independent IRBs for a single project. In fact, the time-consuming frustrations involved in human subjects review were a real disincentive for the organizations to participate in future community-university research partnerships. They did not have the financial ability to pay a for-profit IRB, and, not realizing it might be necessary, the expense was not included in the grant's budget.

Fortunately the State Department of Health volunteered its IRB for use by the community organizations. In exchange, the community organizations agreed to provide volunteers to serve the IRB both as regular members and as disability experts for individual cases. In the long term, community organizations wishing to engage in significant research activities should consider establishing their own IRBs or banding together with other community organizations to establish a community IRB. Universities should offer to help community agencies, especially those with whom they plan to work with on future research, set up their own IRB. Several area universities could even pool their IRB expertise to establish an agency team of experienced IRB members to support agency efforts to protect human subjects.

The investigative team worked with three different IRBs during the course of this project, and so learned more about the subjective nature of IRB determinations. We found that IRBs may have limited, outdated knowledge of current practices in disability research. There may be an inclination to place disabled people in the "vulnerable population" category, although this is not consistent with federal guidelines, current research practice or the abilities of many people with specific impairments. IRB committee members questioned whether certain disability populations

(e.g. people with traumatic brain injury) were capable of informed consent under any circumstances, despite nationally recognized protocols for working with these populations. Ironically, for several months the second author was running a project in which she was technically barred from participating. In addition to her spinal cord injury, she had a diagnosis of traumatic brain injury and thus was deemed by some IRB committee members to be potentially incapable of giving informed consent. Another barrier was the lack of respect or understanding for qualitative research. One IRB committee member expressed the unfounded opinion that a study with less than 50 participants did not constitute legitimate research.

Strategies that we used to meet these challenges included soliciting advice from university IRB staff when preparing IRB proposals for submission. We asked to attend key IRB sessions, especially if discussions involved an area of research that might be unfamiliar to some IRB committee members. We focused on educating the IRB staff and committee, and found that on-the-spot explanations could save months of fruitless resubmissions. When committees had questions about our chosen methodologies we submitted expert testimony from local and national sources to confirm the appropriateness of our research practices with under-researched or vulnerable populations.

Several implementation challenges emerged of particular note to participatory intervention research. Word of mouth was crucial to successful recruitment of intervention participants, and the Independent Living Center was very helpful in this area, as were several other disability organizations and support groups. Working with disability groups that had strong state and regional networks and local peer-support groups helped recruitment. Study participants and support-group leaders often took it upon themselves to write about the project in their newsletters and actively encourage peers to join. Committing to this kind of project involves

trust and comfort, something tough to get without direct human contact with someone you know. Thus, accessing existing disability community networks can be crucial.

Finding appropriate facilities that were affordable and accessible for intervention activities proved challenging. We required three types of disability-accessible facilities: (1) accessible office and meeting spaces for project staff, (2) meeting spaces for our independent living workshops, and (3) locations for our outdoor and indoor recreational activities, including alternative rainy-day sites for the days where outdoor activities were scheduled.

We were assigned accessible office space and the buildings we used were partially accessible, however, the ramped entrances to the building were sometimes blocked by snow or leaves. More than once we were forced to hold meetings in the second author's van outside our office building. Finding a meeting space that could accommodate multiple wheelchair users was a constant challenge. The few accessible parking spaces on our campus were all fairly distant from our office and required travel through a variety of carpeted surfaces, heavy doors and level changes. This was difficult for some manual wheelchair users. Often, we opted to meet in community settings, at the offices of the community organizations, or by phone instead of meeting on campus. For a period of time, our administrative assistant was moved to an inaccessible office with three steps at the entrance. The second author was told that the secretary could meet her at the top of these stairs, if required. We lodged formal and informal complaints, but rather than using substantial time and energy struggling, we tended just to spend less time at the office, and more time working in the community or from home.

For the project intervention, university facilities were not always available, and sometimes required a fee. Often, community locations such as libraries and state parks were more accommodating and more easily accessible to participants. Because there is no fully

accessible public indoor recreational facility anywhere in the state, we often had to make do with less than perfect circumstances. We surveyed many outdoor facilities and had to exclude some beautiful locations because parking or bathrooms did not meet our accessibility needs. At the sites we ultimately used, ramps, parking and bathrooms were sometimes not fully accessible. Facilities with ramps were not always efficient at keeping them free of leaves, ice and snow. We had to ensure study participants did not get trapped in bathrooms with heavy doors. We helped participants park their cars when handicapped accessible spaces were unavailable. Fortunately, the staff at the recreational program were flexible and experienced at finding creative ways to adapt to environmental barriers. Knowing the accessibility needs of study participants allowed us to ensure that all research locations had the necessary requirements for parking, ramps, and bathrooms. We gave participants advanced warning and engaged in a problem-solving dialogue if the facilities are not up to the accessibility standards needed to accommodate them.

Transportation was perhaps the most difficult challenge of all for project participants. Many did not have access to their own transportation, and some lived in areas where public transportation was unavailable. Lack of transportation was the most common single reason why participants missed sessions (secondary health issues being the second biggest reason). We worked with the ILC to encourage participants to take responsibility for resolving their own transportation issues. Some arranged rides with personal care attendants or family members. Some used public transportation for the first time. Some arranged to carpool with staff or other participants. Other researchers have met this challenge to their projects by providing door-to-door transportation using vans or paying for cab-fare (cf. Bartunek et al., 1996), but besides being beyond our means, we felt this solution undermined independent living goals.

Another intervention implementation challenge was the need to respond to unexpected events. During the course of Project Shake-It-Up, we experienced torrential rains, snow, traffic jams, seizures, vehicle break-downs, and family emergencies. There were times when several of these events took place on the same day! Participants and project staff have had secondary health problems, and personal life circumstances that interfered with project participation. During the course of the project, key personnel experienced divorce, weddings, pregnancies, childbirth, and career changes. Fortunately, both participants and staff were sufficiently motivated to engage in creative problem-solving in order to remain connected to the project, even when life events interfered. Expecting the unexpected and having additional staff and/or volunteers available can help provide some of the human resources necessary when difficulties arise.

A final challenge was the need to respond to unexpected research findings. This project was initially formulated to include alcohol and substance use reduction. However, due partly to a recruitment procedure dictated by IRB guidelines, we ended up with a relatively self-selected population who reported themselves to be virtual teetotalers. The consent procedure required by the IRB for use on individuals with traumatic brain injury (TBI) was nonstandard. Instead of a brief Mini Mental Status exam used by many TBI researchers, we were obliged by the IRB to create a long and complicated consent process that some individuals found patronizing and insulting. This served to discourage the participation of people from a disability group at highest risk for alcohol and substance use. However, we found that many participants used tobacco and all were using multiple prescription medications which interacted negatively with each other or negative side effects in themselves. Additionally, participants sometimes used alcohol or other substances while on these medications.

In response to this unexpected, unaddressed need, we organized our substance use seminar to educate about the effects of all types of substances, with a focus on tobacco and specific prescription medications taken by participants. This provided relevant learning experiences for all. We also discovered that our participants faced disability-related social isolation issues, as well as the expected barriers to health promotion and physical activity. Fortunately, our expert consultants were knowledgeable and experienced in these areas. They assisted us in refocusing the project to address the topic areas most relevant to our participants. We ultimately changed the title of our grant to reflect our revised focus.

**Lesson 8:** Assign responsibilities based on the capacities and interests of the collaborating individuals and organizations. Develop mechanisms to ensure everyone stays connected, communicating, and working together efficiently.

**Lesson 9:** Prepare for challenges in obtaining human subjects research permission for community organizations.

**Lesson 10:** Accessing existing community networks can be crucial to successful recruitment efforts. Word-of-mouth can be an effective recruitment tool.

**Lesson 11:** Plan for environmental barriers and the accessibility needs of staff and participants.

**Lesson 12:** Be proactive regarding the challenges of recruitment, research approvals, facilities and transportation. Budget for unexpected expenses. Be flexible and prepared to modify the research design.

### **Student Participation: Disability Studies in Three Dimensions**

Throughout the project, we were blessed with the enthusiastic participation of more than a dozen dedicated undergraduate volunteers, paid interns and research assistants. Many of these students were recruited from a disability studies course taught by the first and second authors to

pre-medical students. While assisting with the project intervention, students were given the opportunity to listen to and interact with people with disabilities in a non-clinical and non-medical context. Students experienced disability, away from pathology, in a context that emphasized the strengths and potential of disabled individuals and the disability community. It gave students a glimpse of what having a disability means for people in their daily lives.

Students used personal journals to record their experiences. The following quote represents the response of many students: “I was really nervous about doing this because I had never worked with disabled people before. I had to ask myself why I was so nervous, and I think it’s because I have this notion that disabled people can be fragile...but I learned that they know how to deal with themselves best. All I had to do was ask ‘how do you want me to help?’ and I would receive a simple, direct answer. I guess disabled people may be fragile, but it’s nothing to be anxious or afraid of. As a result of the experience, I learned a lot about disabled people and myself.” A distinctive benefit that well-organized university efforts can contribute to community partnerships is the availability of high-quality student involvement with all the passion and thoughtfulness that students can bring to a project.

<b>Lesson 16:</b> Encourage student involvement.
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### **Continuation and Dissemination Activities: Process vs. Product**

University and community partners were interested in achieving three types of outcomes from Project Shake-It-Up. We sought to: (1) Improve the lives of project participants; (2) Develop resources (manuals, journal articles, etc.) that disseminate our results, and; (3) Continue to build upon the research partnerships.

### *Quality of Life Improvements*

Many participants reported an improved quality of life resulting directly from their program participation. Coping with the transportation challenges yielded some positive results. Because of the importance of attending program sessions, two project participants enrolled in driver's education courses. One participant was motivated to renew his license, purchased a car, and began driving to project sessions. Following a session on mobility options, other participants made plans to acquire new wheelchairs, or to adapt their existing chairs to better meet their needs. During the session on communicating with healthcare professionals, the group helped one participant formulate and implement a plan to return an ill-fitting brace, and by the end of the project she reported asserting herself with medical and rehabilitation professionals on a regular basis. Another project participant reported that he is successfully working with his physiatrist to wean himself from a few prescription medications that he believes lower his energy level. One participant was thrilled with the kite-flying session, because it was a fun, low-cost activity that she could easily pursue with her children. The hand-cycling clinic was also very popular, as many participants rode bicycles before their disability and were unaware that they could still engage in this activity.

Project findings suggest that the Shake-It-Up program is beneficial to participants who are socially isolated and rarely get the opportunity to participate in a dynamic program with their peers. The majority of participants joined Shake-It-Up because they wanted to be among others dealing with a similar disability, and they wanted to be more active. One participant stated that "getting out of the house and seeing other people dealing with their disability has shown me that there is a future for me." Another commented: "My morale has improved, and I see myself as actually living with this instead of MS defeating me." This final comment from a participant

sums up the experience: “I have better confidence because I accomplished Project Shake It Up.” Our participatory intervention research (PIR) approach allowed us to collect information as we progressed and respond immediately to ensure participants were receiving supports and engaged in activities that best matched their needs.

### *Dissemination*

In addition to conference presentations and journal publications, we have an interactive manual available on the internet or CD-Rom/DVD. This manual allows interested individuals to learn about the activities undertaken during the project and allows researchers and organizations to replicate or expand upon our model in their own communities.

We continue to share the training and instructional materials developed and collected over the course of the project with project participants, advisory board members, and relevant institutions. Alternative media formats like large print and electronic versions of the materials are also available for distribution. We offer technical assistance to other communities interested in replicating the Shake-It-Up model.

### *Future Activities and Research*

Rather than view the project as an end in itself, the community organizations and researchers are looking for ways to continue to work together and build on the successes of Project Shake-It-Up. Researchers have encouraged the community organizations to reach out to other interested research and community entities and to seek additional funding. Over the years of Project Shake-It-Up, some members of our local advisory board, most notably representatives from the State Department of Health’s Living Well with a Disability Program, became increasingly involved. They provided information and referrals, financial support, and help with grant submissions. Project collaborators were motivated by the challenges of project

implementation, for example, the lack of accessible recreational facilities, to propose new programs and research projects that would address these needs. They are also motivated by the successful, enjoyable experience of working together.

A group of project staff and one of the volunteers were motivated by the experience to form a new chapter of Disabled Sports USA dedicated to providing recreation services to people with disabilities living in the state and regionally. Many project participants, staff and volunteers continue to enjoy recreational activities together as a result of this new organization. Project Shake-It-Up, has also led to new friendships, volunteer opportunities, and working relationships among project participants, staff, and community advisors. The second author works with the Independent Living Center and State Department of Health on a CDC-funded project developing programs for health promotion and therapeutic recreation. The first author is developing new research collaborations with independent living centers. She has recently focused on adapting the Shake-It-Up intervention for children, adolescents, and adults with Multiple Sclerosis (Wildasin, 2006).

**Lesson 14:** Continue to expand successful partnerships. Seek new partners and new funding opportunities for continued research and program development.

**Lesson 15:** Reflect upon the process as well as the product when conducting continuation and dissemination activities.

### **Conclusion**

This presentation of the stages of project development, the challenges faced and surmounted is meant to be helpful to researchers and community partners interested in using the methodologies of participatory intervention research to develop community-based research projects. For a summary of our strategies for participatory intervention research, see the table presented below. Although our case study focuses upon a disability community, we believe that many of the strategies presented are applicable to a variety of different community groups.

Considering how essential qualitative research strategies were to the success of our project, it is disturbing to consider the skepticism with which these methodologies are sometimes viewed. At different phases of the project, researchers were called upon to defend their choice of using primarily qualitative methodologies. Pilot funding was initially denied until a quantitative component was introduced. While federal funding agencies are increasingly comfortable with projects contain a qualitative component, it remains a challenge to gain funding for a project that is primarily or entirely qualitative. The right to receive human subjects review or even to call the project “research” was also challenged due to our small number of participants and the qualitative aspects of the study. These experiences reflect power relations that selectively sanction or discourage different forms of research and research methodologies. It appears that decisions by authority figures are still sometimes based on subjective criteria and an incomplete understanding of the value of qualitative research.

While funding agencies encourage community-based research and universities welcome the research monies generated, they do not always provide the necessary supports and mentoring that community-based organizations may need in order to be full research partners. Many aspects of research practice, such as institutional review boards or the appropriate wording for a university subcontract, are completely foreign to community organizations. We believe it is necessary for the university and its representatives to meet the organizations more than half way, and unfortunately this does not always happen. This oversight by the university is certainly not deliberate, but is rather the result of insufficient information in addition to significant differences in perspective, size and scope. A more mindful and conscientious approach on the part of university researchers, with the full knowledgeable support of university administration, would

do much to improve the potential for success of community-based participatory intervention research.

This experiment in building community using participatory intervention research has been a success in ways both expected and unexpected. The researchers are encouraged and inspired by the process to continue to work with community groups, and the community groups endeavor to remain engaged in research. In addition, some project participants have strengthened ties with the community organizations, serving as advisors, group leaders, peer-mentors, and employees. This case study contributes to our understanding of how to conduct participatory intervention research (PIR) in the United States, and perhaps elsewhere. Defining qualities of PIR include: (1) structured strategies for practical strategies for individual and community development with the goal of improving quality of life, (2) collaborations between community collaborators and researchers, and; (3) responsibility for research design and dissemination of outcomes is shared by all stakeholders. In addition this paper contributes an understanding of how this methodology can be applied to study disability and disability community. Our capacity to understand the strengths and challenges of community projects that promote individual and supraindividual change is clearly enhanced when investigators use participatory intervention research as one of their approaches.

-----**Insert Table 1 about here**-----

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**Table 1****Lessons Learned from Participatory Intervention Research****Developing the Community Partnership**

1. Build trust. Know the priorities, philosophies, and tastes of the organizations and individuals to be involved in the collaboration and choose a setting that is compatible.
2. Build upon existing relationships when possible. Involving people with some positive history of working together increases the likelihood of success.
3. Be aware of the areas of expertise and inexperience of all parties – reassure community organizations that they will receive help and support in new endeavors. Make good on such assurances.
4. Conduct pilot research so that collaborators can get used to working together and to determine if the project is feasible.

**Seeking Funding**

5. Ascertain funding agency priorities and funding climate. Review successful grant applications. Ask questions. Know the audience. Find models.
6. Leave plenty of time to get all the necessary paperwork assembled. Give early deadlines.
7. Determine who should administer the grant, according to the priorities of the funding source and the experience, abilities, and comfort levels of all the parties involved.

**Implementation**

8. Assign responsibilities based on the capacities and interests of the collaborating individuals and organizations. Develop mechanisms to ensure everyone stays connected, communicating, and working together efficiently.
9. Prepare for challenges in obtaining human subjects research permission for community organizations.
10. Accessing existing community networks can be crucial to successful recruitment efforts. Word-of-mouth can be an effective recruitment tool.
11. Plan for environmental barriers and the accessibility needs of staff and participants.
12. Be proactive regarding the challenges of recruitment, research approvals, facilities and transportation. Budget for unexpected expenses. Be flexible and prepared to modify the research design.

13. Encourage student involvement.

**Continuation/Dissemination Activities**

14. Continue to expand successful partnerships. Seek new partners and new funding opportunities for continued research and program development.

15. Reflect upon the process as well as the product when conducting continuation and dissemination activities.