



# Project Shake-It-Up and Beyond: Building a Community-Based Disability Studies Research Program



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## Abstract

Using the example of Project Shake-It-Up, we seek to show ways in which community-based, participatory action, and other research strategies have influenced community policy and practice. Project Shake It Up began as a collaboration between university researchers in a clinical research institute, community disability organizations and, eventually, the state health department. Initially the focus of this research was health promotion and capacity building for people with spinal cord injury and related neuromuscular disabilities. However, when the intervention strategy was adopted by the state, it was expanded to include a more diverse disability population. Presenters will discuss how this collaboration was initiated and where it has led in terms of research and community development initiatives.

## Project Description

Shake-It-Up!: Health promotion and capacity building for people with spinal cord injuries and related neurological disabilities (2002-2005) was a National Institute on Disability and Rehabilitation Research (NIDRR) field-initiated research project for health promotion & capacity building for adults with spinal cord injuries and related neuromuscular disabilities, (Block & Rimmer, 2000). The Brown University-based research project was developed in collaboration with two community-based organizations organized and run primarily by people with disabilities: PARI, Inc., an independent living center (ILC), and Shake-A-Leg, Inc, which sponsored recreation and rehabilitation programs, (Block et al., 2005).

The intervention consisted of 10 full-day sessions divided into two parts. The morning sessions involved skills training for self-advocacy, independent living, and health promotion. The afternoon sessions consisted of recreational and physical activities such as kayaking, sailing, kite flying, strength and conditioning. Shake-A-Leg program staff provided expertise in rehabilitation and recreation. PARI (ILC) staff provided expertise in independent living, case coordination, and peer support. The Multiple Sclerosis Society, RI Chapter and the RI Department of Health assisted with recruitment and problem-solving throughout the project. The research team provided expertise in research methodology and scholarship in the areas of health promotion and empowerment.

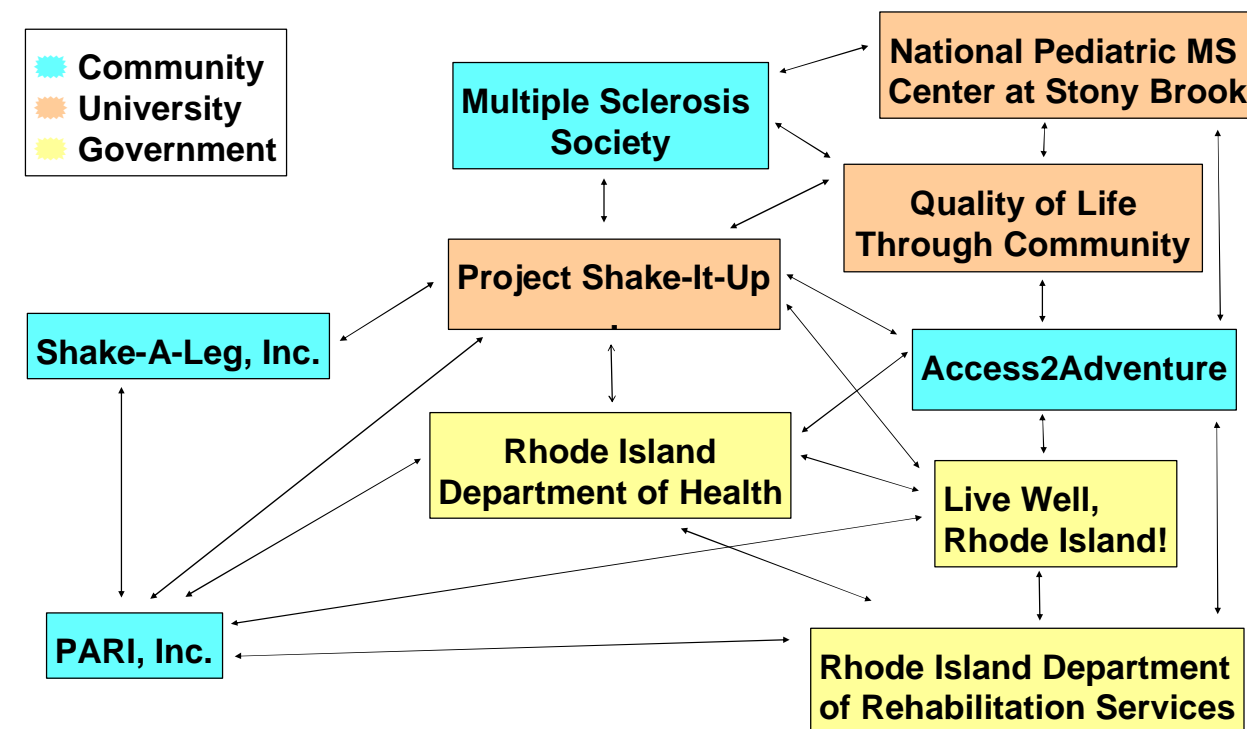
Self-efficacy levels of participants rose after project participation and were sustained six months following project completion. Self-efficacy levels of non-participants fell during this same period.

Community organizations, researchers and state agencies continue to collaborate in research and program development.

## Collaborators

- Shake-A-Leg, Inc:** Non-profit organization providing recreation and non-traditional rehabilitation. Inspiration and research partner for Shake-It-Up ([www.shakealeg.org](http://www.shakealeg.org))
- PARI, Inc.:** Independent Living Center. Research partner for Shake-It-Up, Currently runs "Live Well, Rhode Island" for the RI Department of Health ([www.pari-ilc.org](http://www.pari-ilc.org)).
- Project Shake-It-Up:** NIDRR-funded collaborative research project (2002-2005) for health promotion and capacity building at Brown University, ([www.projectshakeitup.org](http://www.projectshakeitup.org)).
- Rhode Island Department of Health (RIDOH) Disability and Health program:** Advised and assisted Shake-It-Up. Shake-It-Up methodology was incorporated into their CDC-funded program "Live Well, Rhode Island!" ([www.health.state.ri.us/family/disability](http://www.health.state.ri.us/family/disability)).
- Multiple Sclerosis (MS) Society:** Advocacy organization with chapters in every state. Rhode Island chapter advised and assisted with Shake-It-Up. RI and national offices now assist with Pediatric MS research ([www.nationalmssociety.org/rir/home/](http://www.nationalmssociety.org/rir/home/)).
- National Pediatric MS Center at Stony Brook University Hospital:** Sponsors research and treatment of Pediatric MS ([www.pediatricmscenter.org](http://www.pediatricmscenter.org)).
- Quality of Life through Community:** Collaborative research with the Pediatric MS Center and access2adventure using a "Teen Adventure Weekend" to build community and raise self-efficacy in children and teens with MS ([www.pediatricmscenter.org](http://www.pediatricmscenter.org)).
- access2adventure:** Rhode Island chapter of Disability Sports USA. Started by former staff from Shake-A-Leg and Shake-It-Up. ([www.access2adventure.net](http://www.access2adventure.net)).
- Live Well, Rhode Island:** CDC-funded program for health promotion and wellness. Collaboration between the Rhode Island Department of Health, Rhode Island Office of Rehabilitation Services, PARI, Inc. and access2adventure.

## Web of Relationships



Before                      During                      After  
Project Shake-It-Up

## Lessons Learned

- ✓ 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
- ✓ Build upon existing relationships when possible. Involving people with some positive history of working together increases the likelihood of success.
- ✓ Conduct pilot research so that collaborators can get used to working together and to determine if the project is feasible.
- ✓ Ascertain funding agency priorities and funding climate. Review successful grant applications. Ask questions. Know your audience. Find models. Leave plenty of time to get all the necessary paperwork assembled. Give early deadlines.
- ✓ Assign responsibilities based on the capacities and interests of the collaborating individuals and organizations. It is beneficial when collaborators are invited to perform tasks that they ordinarily perform, enjoy performing, and are extraordinarily good at performing.
- ✓ Develop mechanisms to ensure everyone stays connected, communicating, and working together efficiently.
- ✓ 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, to set up their own IRBs.
- ✓ If possible, attend the IRB session where the project is under review, especially if the project involves an area of research that might be unfamiliar to IRB committee members.
- ✓ Continue to expand successful university-community partnerships. Look for ways to grow. Seek new partners and new funding opportunities for continued research and program development.

## References & Acknowledgements

Block, P. & Rimmer J. H. (2000). *Shake It Up for Alcohol and Substance Use Reduction: Health Promotion and Capacity Building for Persons with Traumatic Spinal Cord Injuries*. National Institute on Disability and Rehabilitation Research. CFDA Program 84.133, Award No: H133G010094.

Block, P., Skeels, S.E., Keys, C.B. & Rimmer J. (2005). Shake-It-Up: Health promotion and capacity building for people with Spinal Cord Injuries and related neurological disabilities. *Disability and Rehabilitation*. 27(4): 185-190.

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