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Project Shake-It-Up: Using health promotion, capacity building and a disability studies framework to increase self efficacy

PAMELA BLOCK[1], ELIZABETH A. VANNER[2], CHRISTOPHER B. KEYS[3], JAMES H. RIMMER[4] & SARAH EVERHART SKEELS[5]

[1]*Occupational Therapy Programme, SHTM, HSC, L 2, Stony Brook University, Stony Brook, NY 11794, USA,*
[2]*Department of Health Care Policy and Management, Division of Rehabilitation Sciences, Stony Brook University, Stony Brook, NY 11794, USA,* [3]*Department of Psychology, DePaul University, Chicago, Illinois, USA,* [4]*Department of Disability and Human Development, University of Illinois, Chicago, Illinois, USA, and* [5]*Department of Community Health, Brown University, Providence, Rhode Island, USA*

Abstract
Purpose. Project Shake-It-Up provided a health promotion and capacity building program for individuals with spinal cord injury, multiple sclerosis, and related neurological impairments. Major research aims were to evaluate changes in participants' self-efficacy, ability to set/achieve goals, and perceived independent-living status.
Methods. Participants completed self-efficacy measures at baseline, program completion, 6- and 12-month follow-up, and set health and/or independent living goals. Progress toward goal attainment was monitored periodically and assessed qualitatively.
Results. There was a statistically significant difference in the change in self-efficacy scores for intervention participants compared to non-participants. Participants gained independent-living skills and confidence in their abilities to set and achieve a variety of goals, in the areas of education, employment, housing, transportation, accessing community resources and activities, participation in sports and leisure, and health promotion.
Conclusions. Researchers evaluated results using a disability studies framework of empowerment which recognizes the role of environment, gender, race/ethnicity, and social status in the experience of disability. Participants reported increased independence, community access, and participation. They took action in multiple arenas with changes observed and reported in areas of intrapersonal, interpersonal, and behavioral functioning that indicated greater personal empowerment.

Keywords: *Health promotion, advocacy, self-efficacy*

Introduction

There is an urgent need for empowering strategies and policies that strengthen the health and quality of life of disabled people [1–7]. Project Shake-It-Up was developed using a participatory intervention research strategy and a disability studies framework of empowerment to increase self-efficacy and build capacity to set and achieve independent living [8,9][1] and health promotion goals [3,10,11]. The conceptual basis of the project grew out of related research in the areas of empowerment, capacity building, and participatory methodologies [3,10–15]. Such interventions should include practical skills training for self-advocacy and how to access information and resources. These should also be culturally relevant and have the flexibility to meet individual needs related to gender, age, and other factors.

Study purpose

The purpose of this study was to assess the influence of an intervention for capacity building and health promotion on self-efficacy and the ability to set and achieve goals, to recognize supports, and to navigate barriers to goal attainment for a group of individuals with neurological impairments,

Correspondence: Pamela Block, Occupational Therapy Programme, SHTM, HSC, L 2, Stony Brook University, Stony Brook, NY 11794, USA.
E-mail: pamela.block@stonybrook.edu

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primarily spinal cord injury (SCI) or multiple sclerosis (MS).

This intervention included 10 full-day meetings over a period of 5 months with interactive workshops on health promotion and independent living topics, accessible physical and recreational activities, and peer mentoring. Study Rationale: Project Shake-It-Up was implemented by a team of researchers working in collaboration with a local Centre for Independent Living (CIL) and a non-profit organization that provides accessible community-based recreational opportunities for disabled people with the goal of developing an evidence-based intervention for improving health and building capacity for participants to set and meet personalized goals. The project was also designed to build the capacities of these community-based organizations to provide services of high quality and relevance to their constituents. Additional information about Project Shake-It-Up can be found in Block et al. 2005 [1–7] or at www.projectshakeitup.org. Subsequent to the projects' conclusion the intervention was adapted for continued use by the CIL in collaboration with the state Department of Health. A new nonprofit organization was also formed with the goal of providing accessible community-based recreational activities for disabled people.

Background and significance

Self-efficacy

Self-efficacy is an aspect of empowerment relating to how people perceive their ability to manage challenging situations and accomplish goals; and it influences self-perception, feelings and motivation [16]. Self-efficacy has two domains: 'efficacy expectation,' or personal beliefs of an individual that he/she has the skills necessary to complete a task or meet a challenge, and 'outcome expectation' or an individual's self-perception of the likelihood of successfully navigating the challenge or completing the task [17]. For example, wheelchair users with SCI or MS may refrain from going sailing, because they believe that their mobility impairment prevents them from having the skills necessary to handle the boat, leading to the expectation that any attempt to sail would be unsuccessful.

As articulated in goal orientation theory, self-efficacy is the sense of accomplishment and personal well-being that comes from being able to navigate challenges or attain personal goals. Inability to set and meet goals can lead to decreased quality of life, because individuals with reduced self-efficacy may withdraw from situations or tasks they feel incapable

of managing. Conversely, success leads to increased confidence and greater willingness to meet new challenges and set new goals [18–20]. There is a well-established link between self-efficacy and quality of life for people with MS, SCI, and other impairments and chronic conditions [21–26]. Self-efficacy can also be a predictor of health status [27–29]. Evidence-based programs to increase self-efficacy and capacity building, designed to meet the needs of disabled people, need to be developed and implemented on local and national levels.

Empowerment

This project used a disability studies framework of empowerment as the basis for designing the intervention. Empowerment has been defined as the process of gaining control over events, outcomes, and resources, emphasizing the role of control as the central characteristic of power [1,5,6,30–35]. Additional features include consciousness of individual and group rights, self-efficacy, personal strengths, use of community organizations to assist in meeting individual and group goals, working collaboratively with supportive advisors, and gaining access to resources [34,36–40].

Social and minority-group models of disability

The empowerment framework builds on, yet should also be distinguished from, social or minority-group models of disability. Both approaches recognize and emphasize the social dimensions of disability, especially society's negative reactions to impairment–disability [41]. Where the social or minority group models primarily provide a means to develop theories and identify patterns of injustice, the empowerment model seeks to operationalize this understanding and find ways to address injustice and improve quality of life for individuals and groups.

Building upon earlier scholarship in the area of empowerment and self-efficacy, this approach acknowledges that concepts such as empowerment, capacity building to increase independence, and goal attainment will have multiple meanings and pathways depending upon the individuals and communities addressed [6,35,42]. Variations in type and experience of impairment–disability, gender, ethnic, racial, and social status can greatly influence perceptions of personal power and control [1,3,33, 35]. Thus, diverse strategies are adopted by different individuals and groups to achieve meaningful life goals. Project Shake-It-Up was designed to allow individuals to define and achieve individually identified goals in a group setting that provides peer

support, essential information, and access to community resources and activities.

Disability studies empowerment framework

Figure 1 provides a visual model of how our theoretical framework has been translated into practice with measurable outcomes. The disability studies empowerment framework, with its participatory action approach, focuses on action and strategies to overcome barriers to the achievement of individual and group goals. Strategies include capacity building, education, community organizing, action planning, and coalition building with the goal of influencing policy and practice [3,11,33,35,43]. Many of these strategies were used in Project Shake-It-Up at both the individual and community levels, but the focus of this paper will be on capacity building, education, and action planning for goal attainment for individual project participants with some discussion of how the research was translated into policy and continued practice [2,10,11]. Although project participants were primarily individuals with SCI or MS, the Shake-It-Up intervention has since been adapted for use with a variety of different impairments, including cerebral palsy, intellectual disability, and traumatic brain injury. It has also been adapted for youth diagnosed with pediatric MS [44].

Methodology

Research design and setting

Type of study. This project was a mixed methods study using a quasi-experimental repeated-measures quantitative design and triangulating with qualitative data [14,37,45] from semi-structured interviews, Personal Activity Logs, and Independent Living Assessments (ILAs). The research design consisted of an intervention group and two non-randomised control groups: a wait-list control group (with a 6-month lag before receiving the intervention) and a comparison group.

Research participants

Recruitment and retention. Participants were recruited through announcements made in organizational newsletters, a mailing sent by the state Department of Health, and word of mouth from the local CIL and other local disability organizations. There was no charge for participation and retention was facilitated by the participants' interest in the program activities and seminars.

Study population. A convenience sample of 35 individuals (age: $M = 44.2$ years, $SD = 13.3$, 20–73 years) with diagnoses of neurological impairment, mainly with diagnoses of SCI (16) and MS (12), were participants in this study. Inclusion criteria included living within a drivable distance of the research location in the Northeastern state where the project was located Exclusion criteria included inability to speak English and inability to give informed consent.

Group assignment. All individuals who had been recruited by the summer of 2002 were non-randomly assigned to the first intervention group ($n = 13$) or the wait-list control group ($n = 9$) with the goal of balanced numbers of individuals SCI and MS is each group, while accommodating two participants' requests that, for scheduling reasons, they be placed in the second intervention group. Individuals subsequently recruited ($n = 4$) were added to the wait-list control group to form the second intervention group ($n = 13$). There were also 9 in the self-selected comparison group who chose not to participate in the intervention.

Individuals were encouraged to participate in the intervention. However, if they stated a preference not to participate, they were not pressured to do so, as per human subjects' research ethics guidelines. Individuals who desired to participate, but faced transportation or other barriers, were assisted by project staff to develop strategies to overcome barriers and participate in the intervention. In one case, the access barrier was insurmountable as the individual, due to a conflict over who should pay for a wheelchair lift, was trapped at home with no way to get out without help of the local fire department. All
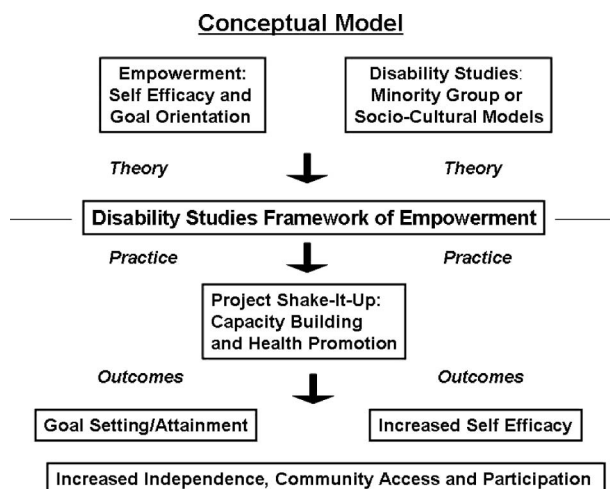

Figure 1. Graphic mode.

appropriate humans subjects research approvals were granted for the study and all participants signed consent forms prior to study enrollment. Participants' demographic characteristics, diagnoses, and initial self-efficacy scores were summarized, by group, in Table I.

Research instrument/assessments

Research instruments included: (1) the General Perceived Self-efficacy Scale (GSE) [46]; (2) an ILA; (3) a Personal Activity Log (PAL), and (4) a semi-structured qualitative interview. The GSE assesses the participant's perceived sense of resourcefulness, ability to deal with unexpected events, and capacity to find solutions to problems. The 10 items are rated using a Likert Scale format, *viz*: (1) not at all true, (2) hardly true, (3) moderately true, and (4) exactly true, and the scale is scored by summing the ratings for all items (possible range 10–40) [47]. Principal components analysis [46] indicated that the GSE is uni-dimensional with internal consistency (Cronbach's α's) ranging between 0.75 and 0.91.

The ILA is a structured qualitative instrument created by project investigators based on a data collection form used by the CIL to gain an overall picture of an individual's life pertaining to: impairment (cognitive, mental, physical, and sensory), diagnosis, services/supports required, self-direction, housing/living arrangements, education, employment, transportation, recreation/leisure time, finances, support systems, personal care, agencies, health, spiritual life, and future direction. The PAL is a loosely structured and open-ended qualitative instrument developed by project investigators to facilitate participants' setting and documenting their

personal goals for the program, progress toward goal achievement, and supports and obstacles encountered. Finally, semi-structured and open-ended qualitative interviews were used to assess a subset of 19 intervention participants' chosen goals for the project, perceived barriers and supports to goal attainment, and the perceived role of the intervention in goal achievement. Questions for the PAL were developed in response to the individual goals set by project participants. Questions for the qualitative interviews were developed based on information project investigators wished to capture in relation to the perceived influence of the project on participants' lives.

Intervention procedure

Project Shake-It-Up included ten full day sessions, twice a month, at various locations around the state, between August and December of 2002 (first intervention group) and August and December of 2003 (second intervention group). Participants provided their own transportation, used public transportation, or arranged carpools. Each day of the program was divided into morning and afternoon sessions. The afternoons were comprised of organized physical or recreational group activities. These included a variety of indoor and outdoor recreational activities. Indoor activities included strength training, aerobic conditioning and indoor team wheelchair sports. Examples of outdoor recreational activities were sailing, sea kayaking, stunt kite flying, fishing, hand cycling, and sled hockey [2]. The intervention took place in community-based settings, including state parks, public libraries, and two university campuses, using local activities and

Table I. Demographic & medical characteristics and self-efficacy scores of participants ($N = 35$) by study group.

| Characteristic | Intervention Groups | | Non-Intervention Groups | | *p* |
	First ($n = 13$)	Second ($n = 13$)	Comparison ($n = 9$)	WLC ($n = 9$)	
Age M (SD)	37.4 (10.8)	51.15 (11.1)	44.1 (15.3)	52.1 (13.1)	0.021*
% Male	61.5	53.8	77.8	66.7	0.711[†]
% European-American	69.2	76.9	87.5	88.9	0.645[†]
% Married	16.7	53.8	22.2	55.6	0.118[†]
Disability type					0.817[†]
Spinal cord injury	53.8	47.7	38.5	55.6	
Multiple sclerosis	30.8	34.1	46.2	33.3	
Other	15.4	8.0	15.4	11.1	
Self-efficacy (pre-intervention) M (SD)	31.9 (6.2)	33.2 (4.6)	32.4 (5.3)	34.7 (5.6)	0.698*
Self-efficacy (post-intervention) M (SD)[‡]	33.7 (3.6)	33.4 (5.5)	29.6 (5.7)	33.1 (4.7)	
Self-efficacy (6-months post-intervention) M (SD)	33.5 (5.2)	31.9 (5.1)	29.6 (9.2)	N/A	
Self-efficacy (12-months post-intervention) M (SD)	32.7 (6.3)	31.8 (4.8)	30.3 (7.8)	N/A	

The nine participants in the Wait-List Control (WLC) group were part of the Second Intervention group.
*one-way ANOVA; age *post-hoc*: WLC & T2 > T1.
[†]Pearson chi-square.
[‡]Wait-List Control did not receive intervention during these 6 months; Comparison group never received intervention.

resources with the intention that participants would continue to access these after the project's conclusion.

The morning sessions consisted of independent living, capacity building, and health promotion seminars providing educational information and skills training. These seminars included lectures, small group discussions and exercises, role playing, and open discussion with peer mentoring. The topics for these seminars were selected in response to the expressed interests of project participants which included team building, self-advocacy, communicating with health-care professionals, and adaptive equipment. Topics with a particular focus on individual capacity building included 'Introduction to Self-Advocacy' and 'Communicating with Health Care Professionals'. Health Promotion topics included 'Nutrition' and 'Sexuality and Relationships'. During the seminars, participants provided each other with peer support, developed individually tailored project goals based on the topics that were particularly important to them, discussed strategies for goal attainment with project staff and fellow participants, and engaged in role playing to practice self-advocacy. Participants were encouraged to use community resources and supports, such as the local CIL and other community organizations and state agencies, to assist them in goal attainment. Once goals were identified, project staff contacted participants periodically for status updates on goal attainment both during the intervention and follow-up periods [2].

To ensure respect and commitment within groups, participants developed a 'Code of Conduct' on the first meeting day. This code contained a set of principles and expectations considered binding on all group members. For example, both intervention groups included a 'non-disclosure' element in their codes, agreeing that private information discussed during the sessions would not be discussed outside of the group ('Whatever happens during ''Shake It Up'' stays at ''Shake It Up'''). Another common element was that no pressure would be put on individuals to participate in activities that they were unsure of, but, similarly, it was important for these individuals to be present and a part of the group during these activities. The code was written on a large poster-board, signed by each contributing member, and brought to every group meeting as a reminder. The researchers felt that developing a code of conduct would build positive group dynamics from the onset and facilitate meaningful, effective, and productive sessions.

In addition to the seminars and recreational activities, participants received case coordination and peer counseling from a collaborating CIL, during the course of the intervention and follow-up period, including individual assistance with goal setting and attainment, support and encouragement, periodic visits from their CIL peer counselors, and monthly phone contact with project personnel, during which PAL information was collected. All participants received support and periodic visits from CIL personnel throughout the intervention and also during the follow-up period, if they chose to continue. If participants so desired, they continued to receive support from the CIL even after the follow-up period of this study.

Thus, three levels of support were present: peer support from other intervention participants, information and resources offered through the seminars, and the individualized support provided by peer counselors from the CIL. This combination of information and supports (peer and professional) enabled participants to follow self-determined pathways to individualized empowerment which met their specific needs and interests. For example, some chose to focus on employment or education, others on transportation and housing, while others selected health promotion goals related to nutrition, weight loss, or reduction of prescription drug use [2].

Data collection procedure

Study participants in the intervention groups were assessed before the intervention, immediately following the intervention, and at 6- and 12-months post-intervention. The comparison group and the wait-list control group were assessed at the same times as the first intervention group, except that the intervention began for the wait-list control group at approximately the same time as the 6-months post-intervention assessment for the first intervention group. A flowchart of the participant groups is shown in Figure 2 and a timeline of the project is shown in Figure 3.

The GSE and the ILA were administered prior to the first session (baseline), immediately after the last session (post), and also at 6- and 12-months post-intervention to both the intervention and comparison groups. Progress in goal attainment for intervention participants was tracked monthly through Personal Activity Logs. In addition, a subset of 19 intervention participants, a random sample taken from both intervention groups, participated in semi-structured qualitative interviews in which they discussed their chosen goals for the project, perceived barriers and supports to goal attainment, and the perceived role of the intervention in goal achievement. The interviews were divided between individuals with SCI ($n = 10$) and MS ($n = 9$), and individuals from first ($n = 10$) and second intervention groups ($n = 9$). Ten individuals from the first group, who had completed the intervention 6 months previously, were asked to
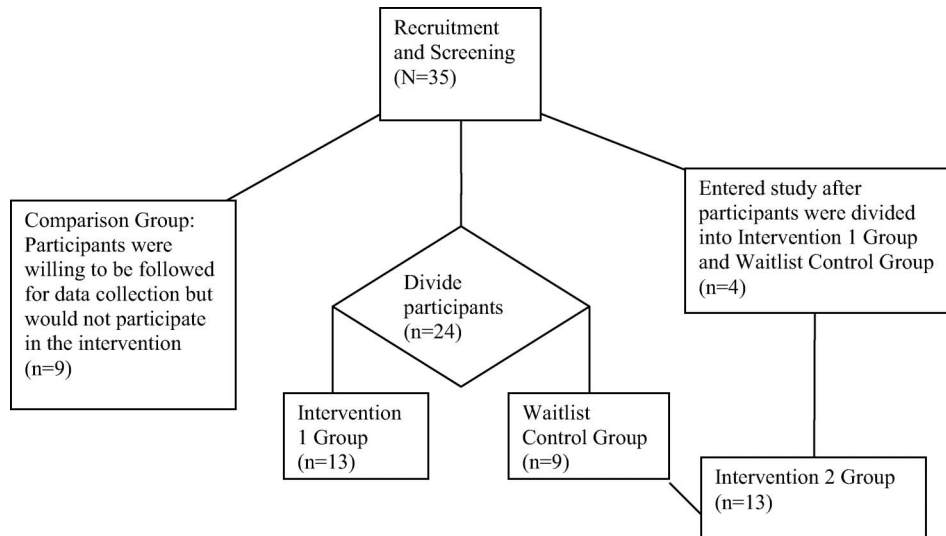
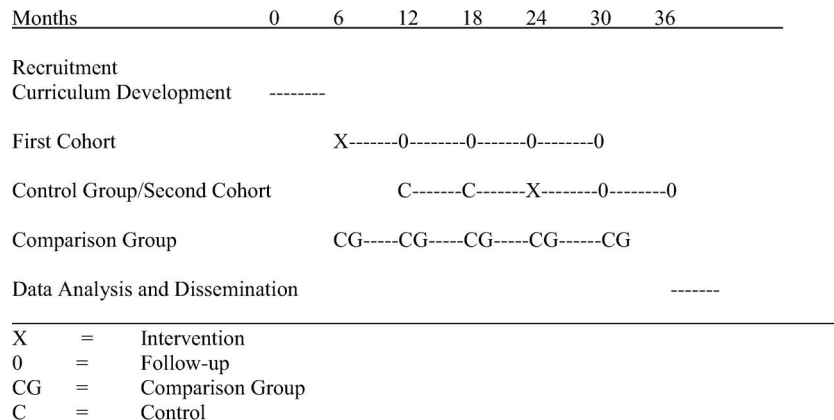Figure 2. Flowchart of study participants.

Figure 3. Project timeline.

identify life barriers, assess which of the barriers were addressed during the program, as well as what goals were met as a result of participation. Unless otherwise noted, all quotes in this text came from interviews that took place 6 months after intervention completion, with these 10 individuals from the first group. Eight individuals from the second group, who had not yet participated in the intervention, and one subsequently reassigned to the comparison group, (when access barriers prevented participation in the intervention), were asked to identify perceived barriers and goals which they sought to achieve through program participation. All interviews took place in a location convenient to the research participant, generally took 20–40 min, and were recorded.

Data analysis

Quantitative analyses were conducted using SPSS [48] to explore whether or not the program had an effect on self-efficacy, whether the effect differed by demographics or type of impairment, and whether the effect persisted after the conclusion of the program. All statistical tests were done at a 5% significance level. An independent-samples *t*-test assessed the change in self-efficacy scores when people participated in the program as compared to when people did not participate in the program (i.e. before-and-after). Independent samples *t*-tests also assessed whether or not the change in self-efficacy scores, of the intervention participants, varied by gender, marital status, type of impairment (SCI or MS), or race. To determine whether or not self-efficacy changes were maintained over time, a general linear model assessed the differences in GSE scores at time 2 (post-intervention), time 3 (6 months post-intervention), and time 4 (12 months post-intervention), with time 1 GSE score as a covariate, for the intervention participants only. A general linear model was used, rather than repeated-measures ANOVA, because this allowed the

inclusion of data from participants who had a missing self-efficacy score for one or more time periods. However, the sample size in this study was too small based on generally accepted norms for a general linear model [49]. Therefore, the results of this analysis should be considered only as preliminary.

Qualitative analyses of semi-structured interviews, ILAs and PALs, were conducted to identify perceived barriers, goals, and goal attainment of project participants. For the purpose of consistency, the authors focus here on a subset of the ILA and PAL data, collected from the 19 participants who also participated in the semi-structured qualitative interviews. Investigators used content and thematic discourse analysis to analyze data, coding interview text to discover common goals or themes among participants as well as to understand perceived barriers or supports to goal achievement [50–52]. Four members of the project team reviewed and coded all qualitative data independently and then made comparisons and final decisions regarding the establishment of codes and themes. The ILA and PAL data were organized into various categories including: individual participant goals, dates goals were addressed, any supports or obstacles encountered, and dates the goals were accomplished. This system provided a clear timeline from the initial identification of a goal, to how/when it was addressed, and if/when it was accomplished. The ILAs were also coded and assessed thematically to document life changes over the course of the intervention and follow-up periods. Investigators used data from three sources: interviews, ILA, and PAL, to triangulate and confirm the existence of persistent themes in the different data sources. All qualitative data were organized, coded, and analyzed using qualitative research software, NVivo 1.1 [53].

Results

An independent-samples *t*-test indicated that there was a statistically significant difference in the change in self-efficacy scores when people participated in the program as compared to when people did not participate in the program (t (38) = 2.855, $p = 0.007$, $d = 0.925$), indicating a large standardized effect size [54,55]. For the 6 months of the program, participants' ($n = 24$) self-efficacy scores improved, on average, 1.83 points (SD = 4.440), whereas for the 6 months without the program, the non-participants' ($n = 16$) self-efficacy scores declined, on average, 2.86 points (SD = 4.246). Independent-samples *t*-tests also indicated that this difference in the change in self-efficacy scores was consistent for males and females, married and non-married people, for European-Americans and non-European-Americans,

and people with both MS and SCI. However, these non-statistically significant differences may be due to reduced power because of the small sample size. The results of these independent-samples *t*-tests can be found in Table II.

The general linear model, which used the pre-treatment self-efficacy score as a covariate, indicated that, for intervention participants, there were no statistically significant differences in self-efficacy scores for the post-treatment follow-up periods (post-treatment, 6-months post-treatment, and 12-months post-treatment). This indicates that the effect on self-efficacy provided by the program was maintained over time, but some decrease in self-efficacy scores was observed. Therefore, these non-statistically significant differences may be due to reduced power because of the small sample size. The results of the general linear model can be found in Table III.

Through careful qualitative evaluation of the subset of 19 participant interviews, PALs, and ILAs, researchers discovered that common themes were expressed by participants when setting goals including: live more independently ($n = 8$), get a job ($n = 6$), increase healthy habits ($n = 6$), drive ($n = 5$), increase activity ($n = 5$), increase social interaction ($n = 4$), increase physical activity ($n = 4$), and go back to school ($n = 3$). For each of the goals, several barriers were identified that hindered their accomplishment. Also, some participants identified aspects of their lives that facilitated goal attainment.

The ability to advocate for oneself or mobilize others to do so was a common theme in the interviews and also evident in the PALs. Supports identified included positive support that contributed to the achievement of personal goals, from professionals and support groups ($n = 13$), support from family members ($n = 7$), environmental adaptations to home and vehicles ($n = 6$), and perseverance ($n = 2$). Barriers ranged from societal and structural barriers ($n = 12$) such as lack of transportation, inaccessible environments, and disability-related social discrimination; physical/cognitive limitation ($n = 7$); personal perspectives of ability/impairment ($n = 4$); financial issues ($n = 4$), to lack of support of friends and families ($n = 1$). As Joan stated, 'I think the only barriers that keep me from being independent are social barriers and access barriers.'

Independence, community access, and healthy living

A primary purpose of the Shake-It-Up intervention was to help participants achieve increased independence, as per their own subjective interpretation of what this means to them. Prior to the intervention, some participants had very rigid and pessimistic

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Table II. Demographic assessment of self-efficacy change during intervention.

	Yes			No					
Reference category	*n*	*M*	SD	*n*	*M*	SD	*df*	*t*	*p*
Male	13	1.08	4.52	11	2.73	4.38	22	−0.904	0.951
Married	8	2.38	3.29	15	1.33	5.08	21	0.521	0.201
European-American	17	2.18	5.16	7	1.00	1.83	22	0.823	0.419
Diagnosis of SCI (*vs.* MS)	11	2.00	5.59	10	1.90	3.54	19	0.048	0.962

Table III. General linear model for maintenance of self-efficacy scores over time.

Parameter	Estimate	*df*	*t*	*p*
Intercept	19.77	24.1	4.427	0.000
Pre-treatment self-efficacy score	0.43	23.8	3.173	0.004
Post-treatment self-efficacy score	0*			
6-months post-treatment self-efficacy score	−0.97	47.8	−1.001	0.322
12-months post-treatment self-efficacy score	−1.41	47.8	−1.455	0.152

*Parameter set to zero because it is redundant.

notions concerning their potential for independent living. During a pre-intervention interview one participant, when asked whether he felt that was independent, responded: 'I would love to but ... I can't because I'm handicapped now'. It was this sort of attitude that Project Shake-It-Up sought to change. Of the eight participants who indicated independent living as a goal, six stated they had achieved their goals and discussed what had helped and hindered them in this process. Support groups were mentioned by three participants as facilitating factors to this success. Four mentioned lack of transportation and accessibility as barriers to independence. Andrew[2] stated, 'I think the only barriers that keep me from being independent are social barriers and access barriers'. Five participants identified social discrimination as a barrier to being more active and independent. For example, Dora spoke about what happened when she applied for a job:

> [The prospective employer] shot me down that I wasn't trainable at this point, that because I could not have a PCA [personal care assistant] go with me to any form of work and at this point, I was not independent enough to not have a PCA with me, therefore I was not employable.

Dora benefited during the intervention from information about her rights with regard to employment discrimination and the services, supports and assistive technologies to which she was entitled. She found the project's role-playing exercises, in which she practiced her self-advocacy skills for attaining her specific goals, very helpful.

Increased community access was another common theme listed among the participant goals, as indicated by the mention of employment ($n = 6$), driving ($n = 5$), community-based physical activity ($n = 4$), social interaction ($n = 4$), and returning to school ($n = 3$), and as goals. Participants mentioned other opportunities for 'getting out of the house' such as attending workshops and becoming active in organizations. Calvin, who began the intervention 6-months post-SCI, having spent most of his time prior to the intervention in primary recovery from his injuries, had not had much chance to access community information and resources. He learned to use public transportation with the help of project staff in order to attend Project Shake-It-Up, and subsequent to the intervention became an active presence in his community, stating:

> You never know where I'm going to be. The minute I learned to get on public buses and stuff like that – I do not like to be home. Just because I'm a quadriplegic doesn't mean I can't be out in public.

Calvin's primary goal during the intervention was to live independently, something he achieved during the follow-up period. He also became a peer mentor, leading a support group for individuals with recent SCI and was making plans to go back to school. Undoubtedly, this resourceful individual would have eventually achieved many of these goals without the help of Project Shake-It-Up. However, he credits the project for a smoother and more rapid transition to independence and community life.

Project Shake-It-Up educated participants about the importance of healthy living and opportunities for physical and recreational activities in the community. Several participants developed and implemented plans to wean themselves off excessive levels and of prescription medication and to lose weight. Other participants increased their level of physical activity following the intervention, by joining a sailing team, hand-cycling club, or participating in

other accessible community-based physical and recreation activities. Julia stated:

> One of the last things I did with Shake It Up was go kayaking and sailing. I connected with the sailing programme and I raced all summer. I joined the sailing club and was able to do competitive racing. I love it.

Julia gives Project Shake-It-Up full credit for her increased physical activity levels and access to community-based recreational activities that she had thought lost to her.

Advocacy and supports

The need to fight to achieve important goals and to advocate for necessary services was frequently expressed and was perhaps the most significant over-riding theme of the interviews. Some participants spoke of self-advocacy, while others spoke of getting assistance from friends and/or family members to advocate for their needs. Some participants felt that it was the job of health care professionals to advocate for their needs. The importance and value of advocacy is demonstrated through Mark's statement: 'I have no problem saying what I need and looking for it, talking to the right people. If it's something that I don't feel right about, I have no problem speaking my mind'. Feelings of frustration in relation to self-advocacy were a common experience among the participants. As Joan stated:

> Like when they sold me that wheelchair I told them it had to be a certain width and they didn't pay any attention. I can use it outside, I can use it at work but I can't use it in the house because it doesn't fit through the doors. People don't listen.

During Project Shake-It-Up Joan learned about and engaged in role plays about her rights to insist on assistive technologies that fit her environment and needs.

Some of the participants were older quadriplegics who lived, by choice, in a large residential institution. These individuals, who were not able to move from the neck down, were extremely savvy self-advocates participating in human rights committees on local and state levels and negotiating successfully with the administration of their residential institution to arrange transportation to the distant Shake-It-Up intervention sites. Indeed, as the intervention took place in multiple outdoor and indoor sites across the state, many participants needed to self-advocate for transportation. They asked family, friends, fellow participants and project staff for rides, and/or learned to navigate the public transportation system.

Self-advocacy abilities and needs varied greatly by person and context, and the researchers were cognizant of the importance of not making generalizations based on living status or level of impairment. Individuals did not always feel comfortable advocating for themselves nor did they always recognize their own individual acts of self-advocacy as such. Responses varied greatly on this issue, as illustrated by Dora's declaration, 'I'd rather hide' when she was asked about advocating for her own needed services. Some participants remained apprehensive about the concept of self-advocacy and were intimidated by the process of asserting themselves to get their needs met.

There were participants who perceived advocacy as something done by activists and lobbyists rather than as the daily acts of individuals. These individuals perceived advocacy only as systems advocacy and not as self-advocacy. When asked about whether he advocated for himself, Paul responded, 'I would say no'. When asked why not, he responded, 'I'm not really into or haven't really been exposed to going through the state house and doing some type of legislating type of deal'. Some participants progressed from self-advocacy to systems advocacy, as with Jim, who went from being a service recipient to becoming an employed peer counselor at a CIL, and Calvin who became a peer educator and strong advocate, while others, like Paul, remained uninterested in community or systems level advocacy.

Disabled peers were also commonly listed as support systems for advocacy. Several participants described the power of peer support, 'I think the more [people with] spinal cord injuries I meet the more we benefit from each other. Able bodies tell us, 'do this, do that' but at the same time they're not in the same situation as us'. Participants mentioned the involvement and willingness of friends to provide peer support and advocacy, saying 'my friends will fight for me, they'll help me get things done' or 'I have friends that might know more about how to go about it than I would'. During the intervention, participants continuously provided peer support for each other, offering suggestions on what strategies might work best in various situations, sharing concerns, examples of where self-advocacy was needed, and success stories.

Participants also spoke of having motivated family members who served as advocates for their needs, such as Paul's mother and Margie's husband. According to Margie, who was interviewed immediately prior to participation in the intervention, her husband advocates 'sometimes too much. He wants me to get things that I don't need yet'. Project Shake-It-Up educated participants about and promoted strategies for self-advocacy. Margie's comment illustrates that there is often a difference between

what a family considers helpful and what the participants themselves want. Several participants were unhappy at being pressured by family members into specific courses of action concerning employment, living arrangements, assistive technologies, medicines, and medical interventions.

Financial difficulties

When asked to identify barriers that hindered their independence, financial difficulty was a common theme. Paul's response to questions about barriers, illustrated this, 'I would say money, unfortunately. You're not supposed to let money, you know, run your life, but you need it, especially with my medication. It all costs a lot'. Mark stated, 'The only difficult thing is financial because you're on a fixed income'. Financial concerns were also caused by poor funding from insurance agencies for necessary assistive devices, such as wheelchairs, wheelchair accessories, and adaptive equipment for the home. Dora asserted, 'If I could get everything I need when I need it, it would have shaved years off of where I am. It took 2 years to get the custom chair, and they're still working on the stander'. The frustration experienced by Dora is due to the prolonged period of time taken by insurance companies to approve individual equipment requests. As Dora expressed, '"red tape" income guidelines' create challenges when individuals need to 'fight for' access to medical equipment with an income too high to qualify for assistance, but too low to afford purchasing such necessities themselves.

Combating isolation: the influence of Project Shake-It-Up

Feelings of loneliness were also a common theme in the interviews. Contributing to these feelings was the loss of relationships, isolation, and/or perceiving that one is a burden to family/friends. Feelings of isolation were expressed as, 'I'm stuck in the house by myself'. Isolation is also related to the distance between family and friends, making socialization more difficult. Project Shake-It-Up addressed these concerns and issues by providing participants with knowledge that a wide variety of community-based physical and recreational activities are still possible for them, opportunities to try a variety of activities, and finally information about community resources if they wished to continue to engage in any of the activities after the intervention's conclusion. Paul stated that the Shake-It-Up program was, 'very positive, showing [him] the different activities that [he] could still accomplish'. Andrew commented on

this experience stating that the program has 'made me think of the things that I'd like to do and why I don't do them'. Julia said:

> I found it helpful to find out that sometimes it's just a matter of equipment or making modifications, and most of the time those can be done. When I start looking at things I want to do, and thinking, 'okay, what equipment do I need to do it?' it's a much better attitude. Instead of thinking that I'm closed out of activities. Y'know, I'm not going to ice skate, and I don't really want to, but I found with Shake It Up that there are people who are willing to help. I think that was the most wonderful thing, was to find people willing to help me simply recreate. Not necessarily to be a better teacher or do a better job, but simply that recreation has a value.

Through education about self-advocacy and opportunities to participate in recreational and physical activities, some participants changed the way they perceived both their own abilities and environmental barriers, allowing them to combat isolation and increase community access. Dora stated, 'I [had not] left my house in 3 years before I met you guys'. After the conclusion of Project Shake-It-Up some participants began to sail competitively, others purchased or rented hand cycles to join the local cycling club. Some sought out exercise classes, volunteer positions, and opportunities to participate in disability communities to receive or give peer support. Others simply maintained the friendships that started during the intervention.

Discussion

The difference in the changes in self-efficacy, and the maintenance of this difference over the 12-month follow-up period suggests that program such as Shake-It-Up might improve the health and quality of life for disabled people, since a link between self-efficacy and quality of life for people with MS, SCI and other impairments and chronic conditions, has been established [21–26]. Also, higher levels of self-efficacy can predict better health status [27–29].

Though the research participants came from distinct impairments groups (e.g. primarily had SCI or MS), as commonly reflected in the literature, environmental, attitudinal, or policy barriers, as opposed to individual impairments, were among the most commonly identified barriers by participants in the Shake-It-Up study [3,11,33,35,43]. This reflects the disability studies perspective as incorporated in social, minority-group, and empowerment models [7]. Some participants progressed from assuming that a persons' physical and mental

capacities automatically dictated their ability to live as they choose, to recognizing that it is their interaction with the environment and society around them that dictates their abilities. This progression illustrates an evolution in beliefs and assumptions regarding the abilities and potential accomplishments of individuals living with impairment and chronic conditions. This progress is documented in the empowerment research such as Shake-It-Up. It may also explain the success of policies and program with peer support strategies commonly implemented by Centres for Independent Living. These resources promote independence, not through physical rehabilitation, but by modifying the environment through assistive technology, promoting self-advocacy to get needs met, and encouraging participation in community life.

Consistent with the disability studies literature, few participants listed their bodies and/or capacities as barriers to living independently [41]. This lack of focus on physical impairment underscores a disability studies approach that independence and access to community, however defined by different individuals, is not automatically determined by bodily functions and capacities. Project Shake-It-Up promoted this perspective through its education and advocacy components, as well as by exposing participants to activities previously thought of as unachievable. The experience of accessing recreational and functional activities, despite bodily differences, promotes the concept that impairment does not determine capacity to lead a full and meaningful life [21–26].

Personal perspectives concerning physical capacity may act as an inhibiting factor in obtaining increased independence. A skewed perception of personal capabilities may be more limiting than physical impairment itself [1–6]. The results from the Project Shake-It-Up program provide insight into both the personal and communal experiences and perceptions of living with disability. It reveals how social and environmental barriers can impede both private life and community access. Low expectations of oneself and one's abilities, as noted throughout the interviews and PALs, further underscore the importance of encouraging the development of self-efficacy, leadership, and self-advocacy skills.

Our empowerment framework, as articulated in Project Shake-It-Up, provides guidance for policy makers by modeling an alternative to 'cookie-cutter' approaches to achieving 'independence'. Because not only do perceptions and goals vary, but the very concept of 'independence' is experienced differently depending on a person's social position, personal history, gender, and ethnic/racial background, it is important to develop program and policies that take this into account [6,9,56]. Project Shake-It-Up provides an example of how this might be implemented. A disability studies empowerment framework, that is prepared to operationalize theoretical constructs developed in recent decades, may provide a powerful tool to develop program and policies to engage individuals and communities in self and systems advocacy and increase quality of life and community access.

The Project Shake-It-Up intervention was subsequently adopted by the state Department of Health in collaboration with the CIL. Subsequent iterations were offered for groups of disabled individuals with a variety of impairments and conditions. In addition, several members of the project staff subsequently formed a chapter of Disabled-Sports USA to increase opportunities for disabled people in the region to participate in physical recreational activities in the community. Replication of the Shake-It-Up model has been implemented in a context providing more diversity of participants in terms of differences in ethnicity, race, impairment, and socio-economic status.

Limitations

This project's limitations include the small sample size, especially the very small numbers within ethnic and racial subgroups, and the lack of randomization between the intervention, wait-list control, and comparison groups. There was a statistically significant difference in age among the groups, so one cannot rule out the possibility that age differences confounded the changes in self-efficacy. However, it is impossible to determine the nature of this potential confounding without another study. Also, participation was limited to those residing in one relatively small geographic region. The peer support community that resulted from this project might not be possible if participants lived further apart. It would be helpful for the project to be replicated with more diverse participants from different geographic regions and with groups that are more homogeneous with respect to participant age. Most participants had either SCI or MS, which are two quite distinct impairments. Data have not been collected to confirm whether the same results would occur if people with different impairments were included in the program or if the program were to be limited to people with more diverse or more similar impairments. However as noted above, most of the barriers described by research participants were related to environmental and attitudinal issues and not related to specific impairments.

Directions for future research

Although Project Shake-It-Up was subsequently implemented as a state-subsidized program, systematic

data have not been collected to measure changes in self-efficacy and assess goal setting and attainment in subsequent groups to receive this program. Such data might provide additional examples of differences in how independence is perceived by different individuals and groups and also what factors might constitute barriers or facilitators to operationalizing a disability studies empowerment framework. It would be useful for the intervention to be replicated in different geographical regions in order to acquire more ethnic/racial/regional diversity and also to include larger number of individuals from different impairment groups. People who have, or are at risk for, concurrent conditions might especially benefit from this intervention. For example, disabled veterans returning from, among other places, Iraq, are a racially diverse group who, in addition to physical impairments, are at risk for mental health conditions such as post-traumatic stress and addiction [57]. This is a group for whom a holistic intervention to promote health promotion and capacity building might be particularly beneficial.

Further study could be made of the coalition of organizations that supported the project and how each organization was influenced by this experience. Additional research concerning the empowering value of recreation and physical activity, especially for disabled people, would be beneficial. It is also important to further develop the empirical basis for a disability studies perspective that identifies barriers as initiating from the environment rather than the individual. Future research is needed to document and demonstrate this reality and provide a basis for further policies to adapt society to facilitate the inclusion of disabled people. It might also be beneficial to assess the benefits of seeing this intervention adopted on a larger scale by mainstream wellness and fitness organizations in addition to organizations, such as CILs, that cater specifically to disabled people.

Conclusion

Using a disability studies empowerment framework [3,10,11], Project Shake-It-Up, provided and assessed an intervention for people with SCI, MS, and related neuromuscular impairment. There was a statistically significant difference in the change in self-efficacy scores for intervention participants compared to non-participants. This indicated that participation in Project Shake-It-Up may have improved and/or prevented a decline in participants' perception of their ability to manage challenging situations and accomplish goals. There was also evidence that the differences in self-efficacy were maintained at least 12 months after the conclusion of the intervention.

A thorough qualitative analysis of the participants' interviews and personal activity logs, led to the identification of common themes that included both supports and barriers influencing access to full participation in family and community life. Factors that promoted greater independence included self-motivation, environmental adaptations, and positive support from professionals, family, friends, and peer support groups. Common barriers that hindered participation included societal or structural barriers, lack of support of friends and families, lack of transportation, inaccessible environments, discrimination, physical and/or cognitive limitations, financial hardships, and self-limiting beliefs about personal capacity.

These qualitative results indicate that Project Shake-It-Up provided more than just enhanced self-efficacy. Participants also received social support and took action in recreational and advocacy arenas. In short, changes were observed and reported in areas of intrapersonal, interpersonal, and behavioral functioning that indicated greater personal empowerment [36–40]. These changes were consistent with greater empowerment as construed by the disability studies perspective which emphasizes the role of environmental barriers and the need for disabled people to address these through a variety of different strategies such as circumnavigation or advocating for change. The disability studies empowerment framework [7] provides a powerful tool to enable researchers and policy makers to move from disability studies theory to action for health promotion as well as individual and community change.

Acknowledgements

undergraduate volunteers Lisa Colaco, Leslie Koren, Johanna Chang, and Kiki Nin.

Notes

1. The authors are aware of critiques that problematize the notion of 'independence' as primarily western, and especially North American concept that does not accurately portray the complex interactions and interdependencies of community life [8,9]. However we have chosen to use the terms 'independent living' and 'increased independence' here, since they were frequently used both by project participants and CIL personnel as descriptors for a set of community-access goals achieved in concert with an independent living centre or as coming from an 'independent living' philosophy.
2. This and all subsequent names are pseudonyms.

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