

REHABILITATION IN PRACTICE

Shake-It-Up: Health promotion and capacity building for people with spinal cord injuries and related neurological disabilities

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Abstract

Purpose: This is a description of a model demonstration project called Project Shake-It-Up. This project promotes the health and empowerment of people with spinal cord injuries and related neurological disabilities. It also builds the capacity of community organizations that provide services to this population.

Methods: Participants are involved in interactive seminars concerning health and advocacy on topics like nutrition and being assertive with healthcare providers. They take part in physical and recreational activities such as sea kayaking, kite-flying and hand cycling. Case coordinators support their project participation and personal goal attainment.

Results: Community organizations and university researchers developed a successful partnership. Individual members of the first cohort supported one another and benefited physically and psychologically.

Conclusions: Project-Shake-It-Up provides positive initial signs of the value of combining the resources of universities and community agencies. Working together, these organizations can develop distinctive, multi-faceted programmes to support the health and empowerment of people with spinal cord injuries and other related neurological disabilities.

Introduction

People with disabilities face problems in many aspects of their lives, such as employment, housing, and relationships. Existing research asserts that a holistic approach to the multiple challenges faced by people with disabilities will be more successful than an approach that focuses only on one or two specific issues [1–4]. Thus, we suggest an approach utilizing case co-ordination and collaboration with local service providers will be successful at promoting the empowerment of individuals with disabilities. Skills training coupled with individualized holistic support in achieving stability and self-efficacy in major life areas, is likely to promote sustainable positive results that generalize to other life domains. Built on this philosophy, Project Shake-It-Up is a three-year model demonstration project to increase health promotion and empowerment for individuals

with spinal cord injury and related neurological disabilities who live in Rhode Island, USA. The Brown University-based project incorporates capacity-building strategies for independent living and self-advocacy coupled with health education, physical activity, and recreation. Project Shake-It-Up provides peer-support and mentoring complemented by individualized case-co-ordination to assist participants in developing life strategies and positive coping skills to encourage healthy choices. We seek to determine if participation in this programme will result in increased health, independence, and self-efficacy.

Project Shake-It-Up is a collaborative effort between university researchers and two community non-profit organizations that support people with disabilities. Physical and recreational activities are provided by Shake-A-Leg, Inc., a local recreation and rehabilitation programme for individuals with

paralysis. Case-co-ordination and capacity building for independent living are provided by PARI, Inc., a local resource centre for independent living for people with disabilities. Overall project co-ordination, education for health promotion and prevention of substance abuse is provided by research faculty and staff at Brown University, Stony Brook University, and the University of Illinois at Chicago.

Background and need

Estimates suggest that 19.7% of the general US population, approximately 52.6 million people, have some level of disability and that approximately 33.0 million people (12.3% of the population) have a severe disability [5]. Over one million people are totally or partially paralyzed, including over 200,000 individuals with cerebral palsy, an estimated 500,000 with multiple sclerosis (MS) and other related neuromuscular conditions [6]. The National Spinal Cord Injury Statistics Centre [7] estimates that between 183,000 and 203,000 Americans are living with spinal cord injuries (SCI), with about 10,000 new cases reported each year.

The most common health problems experienced by people with neurological disabilities are identified as secondary conditions [8, 9]. These include medical complications such as pressure ulcers and urinary tract infections, and problems of psychosocial adjustment such as depression. In fact, people with physical disabilities are estimated to experience an average of 14 secondary conditions per year [8]. Secondary conditions are significant because they lead to an increased level of disability and decreased level of community integration [10].

People with neurological disabilities face multiple problems of living. In addition to the obvious issues of reduced mobility, managing medical regimens and reorganizing one's time to meet these demands, neurological disability can often lead to social isolation. Social isolation can result from the withdrawal of friends and relatives due to the special needs, demands and restricted ability to interact with them, or because of what Goffman [11] has termed the 'stigma' of disability. An individual with a disability can also initiate social isolation by leaving their circle of friends whom they think are unresponsive, frightened or critical, due to their disability [12]. Social isolation coupled with limited physical ability can have a negative effect on self-esteem by limiting an individual's social and emotional support. It is not surprising that the incidence of depressive disorders in the population of people with physical disabilities is 40–50% higher than that of the general population [13].

Social stigmas compounded by poor self-concept and body image common to persons with neurological disabilities obstruct the desire to participate in

physical activity. Other barriers include a lack of accessible facilities, the lack of knowledge of proper exercise techniques, increased energy demands of ambulating or wheelchair propulsion, and limited accessible transportation [14–21]. However, studies have shown that people with disabilities can engage in physical activity and other types of health promotion activities if they are made accessible and tailored to their needs. Providing a safe and supportive environment allows project participants to take part in recreational activities that will expand their horizons and introduce them to sustainable ways of integrating and finding support within their community. Health promotion can reduce the incidence of secondary conditions and enhance quality of life [23, 24]. Unfortunately, there are few descriptive accounts of health promotion interventions that specifically address the needs of people with neurological disabilities [25].

Addressing barriers

People with neurological disabilities face an enormous array of barriers to participating in health promotion and recreation activities. Many project participants were unemployed and socially isolated. Several participants reported that they did not leave their home on a regular basis because of limited access to transportation. Other barriers to participation included programme cost and lack of knowledge on how and where to exercise. These barriers are similar to those found in previous work involving persons with mobility limitations [25]. In order to successfully implement the programme, we also had to address these concerns. We arranged for project activities to take place near Rhode Island transit bus lines so that participants could use public transportation. We helped participants arrange carpools to assist those who could not access public transportation. The programme was offered free of charge, and we provided the necessary information and equipment to enable participants to try a wide variety of physical and recreational activities.

Programme model

The overall programme model is built upon a dynamic, interactive framework combining health promotion, case co-ordination, recreation and physical activity, and independent living skills-training (See Figure 1). Project Shake-It-Up has just completed its first year of implementation. To date, we have 33 people with spinal cord injury, multiple sclerosis, cerebral palsy, and spina bifida enrolled in the project. Slightly less than half of this number ($n=14$) served as the first cohort during 2002, the first year of the project. The remaining participants

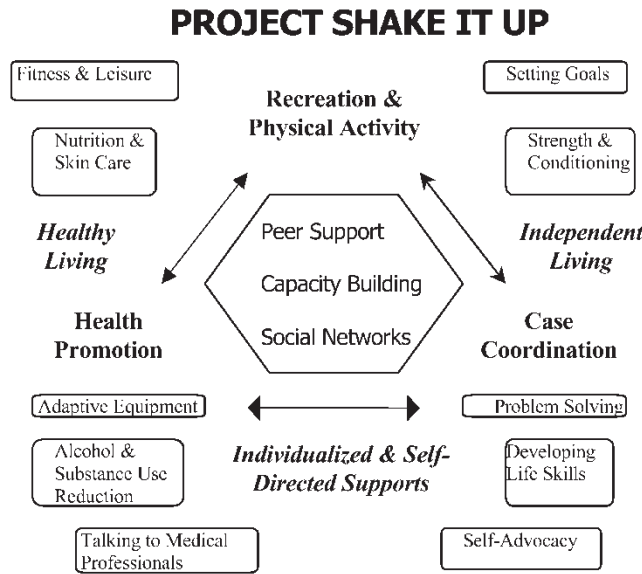


Figure 1. Project Shake-It-Up.

Table I. Project Shake-It-Up Activity Schedule.

Date	Seminar topic	Recreational activity
August	Team-building	Kayaking
August	Self-advocacy	Sailing
September	Assistive technology	Fishing
	Wheelchair maintenance	
	Van/driving adaptations	
October	Communication with healthcare professionals	Kite-flying
October	Bladder & bowel management	Hand-cycling
October	Alcohol/substance use	Strength & conditioning
	Medications/pain management	
November	Nutrition	Strength & conditioning
November	Skin care	Strength & conditioning
December	Sexuality, self-image, and self-defense	Sledge hockey
December	Holistic therapies	Team-building/closure

formed the second cohort in 2003, year two of the project.

Ten full-day project sessions take place twice monthly between August and December. Days are divided into two parts: Mornings are spent in health promotion and capacity-building seminars, and afternoons are spent in organized physical or recreational group activities. Table I describes the 10-session schedule.

Independent living and health promotion seminars

Ten two-hour seminars provide educational information, skills training, and peer support in the areas of independent living and health promotion. Each seminar addresses issues that project participants identify as significant to their lives. These seminars

use an open-discussion format, where participants are encouraged to ask questions and share experiences. Peer-support and peer mentoring are important facets of this programme component, as people learn from each other’s experiences and adopt healthy role models for growth, personal change, and increased participation in community life.

The independent living seminars include team building, self-advocacy, communicating with healthcare professionals, and adaptive equipment. We used the team-building seminar as a way to introduce participants to each other and to facilitate group dynamics because many of these individuals had extensive contact with family members and personal care attendants, but little or no interaction with disabled peers. At the end of this session, project participants developed a code of conduct and an agreement of how they could encourage and support

each other throughout the project. Participants were quiet and reserved at first, but became more comfortable as the morning progressed, and were talking freely by the end of the seminar. Adaptive equipment and communicating with healthcare professionals were also compelling seminars. Following these seminars, two project participants enrolled in a driver's education course and one participant was motivated to renew his license and subsequently purchased a car. He was driving himself to project sessions by the end of the programme. 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 psychiatrist to wean himself from a few prescription medications that he believes are affecting his energy level.

Health Promotion seminars cover topics on alcohol, substance, pain management, prescription medications use, nutrition, sexuality, bowel and bladder care, pressure-sore prevention, and relaxation and stress reduction. Topics were selected and seminars organized around the expressed interests and needs of the programme participants. Participants were encouraged to make comments and ask questions throughout the sessions so that presenters could continue to adapt the presentation to provide the information most relevant to particular individuals and the group as a whole. The nutrition seminar was striking in that many participants were unaware of how to use the food pyramid to determine their daily food intake. Some participants wanted to lose weight, but were frustrated with previous attempts. They had been trying to use very low-calorie diets to lose weight, not understanding the importance of eating breakfast and maintaining a balance of calories during the day so as not to feel excess hunger, which often triggers overeating. Following this seminar, several participants tried to change their eating habits to incorporate more fruits and vegetables in their diets. One participant has lost 25 pounds to date. After the sessions about sexuality, skin care, and bowel and bladder management, participants felt less alone in dealing with these important yet rarely discussed issues and appreciated hearing about the experiences of others. Participants benefited from peer-support as much as from the expertise of the presenters.

We developed some of these seminars independently (self-advocacy, team-building, speaking to medical professionals, sexuality), found guest speak-

ers for specialized topics (holistic health practices, adaptive equipment, alcohol and substance use) and also used several health promotion chapters from 'Living Well with a Disability' (nutrition, skin care, bowel and bladder management) [26].

Recreation and physical activity sessions

The recreational and physical activity components of the project are organized into 10 half-day afternoon sessions (post-seminar and lunch). Five of these sessions focus on strength training and aerobic conditioning exercises as well as indoor team wheelchair sports. These activities take place at the Brown University athletic complex. Individualized exercise programmes are developed for each participant under the direction and supervision of a certified athletic trainer and a physical therapist. During the first year of project implementation, these were the most popular sessions, since most of our participants wanted to improve their physical strength and conditioning, but did not know how. We designed the programmes so that participants can continue with them independently at home or at an accessible gym.

The remaining five sessions consist of outdoor recreational activities that promote team-building, group dynamics and exploration of increased physical activity. Outdoor recreational activities are scheduled at locations that have wheelchair accessible facilities and available shade during the late summer and early fall months. Most of the first-year participants had not participated in these activities since the onset of their disability, and did not realize that such activities are even possible for them. These sports include: sailing, sea kayaking, stunt kite-flying, fishing, hand-cycling, and sled hockey. Information and referrals are provided for participants who wish to continue the sports and activities outside of the programme. We had great success with all of our recreational sessions, but there are a few that made profound impacts on our participants. During the sea kayaking session, several participants stated that they had not tried this activity since the onset of their disability, and expressed pleasure in learning that they could still kayak. 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. Some of the participants were eager to try hand-cycling, but others thought that it looked too difficult or were nervous about transferring from wheelchair to hand-cycle. However, with the encouragement of project staff and other participants,

even the most timid eventually tried hand-cycling, and expressed how enjoyable it was.

Case-co-ordination

Case-co-ordination is the final aspect of the Shake-It-Up programme. Case-co-ordinators talk with each participant individually, and ask him or her to express goals they wish to attain. The case-co-ordinators provide support and encouragement to participants through periodic visits and ongoing phone contact to promote continued progress toward goal attainment, provision of needed support systems, and ongoing analysis of needs. Support services include, but are not limited to, agency co-ordination, advocacy, co-ordination of support services, and one-on-one support to assist participants in maximizing their potential in working to achieve life goals. We believe that many of the goals Shake-It-Up participants achieved both during and after project participation (e.g., finding housing, transportation, better equipment) have been strongly supported through case-co-ordination.

General discussion/future directions

The 83% attendance rate for the first iteration involving 14 participants demonstrates an impressive commitment on the part of first-year project participants. Successfully addressing some of the barriers, especially transportation, greatly influenced the attendance rates. The majority of participants (92%) reported that they participated in Shake-It-Up because they wanted to be among others who were dealing with a similar disability, and they wanted to be more active. These preliminary findings suggest that the Shake-It-Up programme is beneficial to the participants who are socially isolated and rarely get the opportunity to participate in such a dynamic programme with their peers. All of the study participants requested that Shake-It-Up become a permanent programme offered on a monthly basis. A number of the participants indicated that they wanted to initiate individual and group activities following their participation in the project.

The Shake-It-Up project team is currently involved in an informal coalition of interested organizations and institutes, including: the Rhode Island Department of Health Living Well with a Disability Programme, researchers from Brown University, the University of Rhode Island, and Rhode Island College, Shake-A-Leg, Inc. and PARI, Inc. All of these entities are interested in continuing the project Shake-It-Up activities after the project is completed. They are also interested in initiating new projects and are actively seeking funding opportunities to allow for maintenance and continued growth.

In conclusion, Project-Shake-It-Up provides positive initial signs of the value of combining the resources of universities and community agencies. Working together, these organizations can develop distinctive, multi-faceted programmes to support the health and empowerment of people with spinal cord injury and other related neurological disabilities.

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