

Healthy Lifestyles for People with Disabilities

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Abstract

People with disabilities are more susceptible to compromised health status and preventable secondary conditions. A Healthy Lifestyles curriculum was developed as a health promotion program for people with disabilities. Using the curriculum, ten free 2½-day workshops were provided for people with various disabilities in Oregon and Southwest Washington. Workshops were conducted in collaboration with local entities such as Centers for Independent Living. The workshops took an integrated approach to health, addressing connections among physical, social, emotional, and spiritual health, and health through meaningful activities. During workshops, the participants obtained health information and experienced healthy activities such as yoga and non-impact aerobics, both tailored for people with disabilities. At the end of the workshop, each participant identified two healthy lifestyle goals to work toward. Progress and/or barriers in accomplishing those goals were shared in support groups for 6-9 months. Preliminary results indicate early and sustained improvements in health behaviors and health-related attitudes. The Healthy Lifestyles program offers a promising approach to promoting health among people with disabilities.

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Introduction

Health and wellness are the foundations that allow people to participate in many of the most important aspects of life. The World Health Organization's (WHO) early definition of health as a state of physical, mental, and social well-being, and not merely the absence of disease is as valid today as it was at its inception (WHO, 1946). This approach to health is similar to contemporary notions of "wellness," achieving a harmony or balance across multiple dimensions of living including physical, mental, social, and spiritual components (e.g., Cross, Bazron, Dennis, & Isaacs, 1989; O'Donnell, 1989).

For the nearly 50 million Americans with disabilities (Waldop & Stern, 2003), maintaining good health is imperative in reducing the impact of impairment on functioning and participation. Yet, information from a number of sources consistently documents that people with disabilities as a group experience worse health than the general population (e.g., Drum, 2003;

U.S. Census Bureau, 2001). People with physical and cognitive disabilities are more likely to experience early deaths, chronic conditions, and potentially preventable secondary conditions (Campbell, Sheets, & Strong, 1999; Lennox, Beange, & Edwards, 2000; Turk, Scandale, Rosenbaum, & Weber, 2001); United States Department of Health and Human Services [USDHHS], 2001;). For example, people with disabilities have some of the highest rates of oral disease (The National Institute of Dental and Craniofacial Research, 2002) and higher rates of diabetes than the general population (McDermott & Platt, 2004). Furthermore, people with disabilities report having more unmet health care needs (NOD/Harris, 2004) and receiving fewer preventive services than the general population (Diab & Johnston, 2004). For people with disabilities, poorly controlled health problems can quickly lead to a downward spiral of loss in functioning, jeopardized employment, and erosion of social and personal relationships

(Cooper, Quatrano, Axelson, Harlan, Stineman, Franklin et al., 1999).

Unfortunately, the information, practices, and resources needed to realize a healthy lifestyle are not available for most people with disabilities. Many health care and service providers do not address health and fitness in people with disabilities. Community resources are still inaccessible for too many people with disabilities, and health promotion campaigns have largely neglected the sub-population that experiences disabilities. Very few of the theoretical models of motivation to participate in physical activity have been tested for people with disabilities (Kosma, Cardinal, & Rintala, 2002). In short, people with disabilities have less access to health promotion and maintenance programs than the general population (DeJong, 1997).

In an effort to rectify this problem, a variety of health promotion programs targeting people with disabilities have been implemented in the past decade. These include informational campaigns (e.g., accessible mammography), environmental modification initiatives (e.g., assessing accessibility of fitness facilities), and health promotion training programs (e.g., behavior/lifestyle changes). Among the latter are a number of excellent programs including Living Well with a Disability (Seekins, White, Ravesloot, Norris, Szalda-Petree, Lopez et al., 1999), programs of the National Center on Physical Activity and Disability (2004), Project W.E.A.L.T.H. (Turk, Rosenbaum, & Scandale, 2001), Women Be Healthy (Lunsky, Straiko, & Armstrong, 2002), and Healthy Lifestyles for People with Disabilities (Deschler, Tangeman, & Westwood, 2004). The purpose of this paper is to describe the Healthy Lifestyles curriculum and its implementation, and to discuss the process of establishing an evidence base to support the effectiveness of the program.

Healthy Lifestyles Curriculum Development

The Disabled and Healthy Project, funded by the Administration on Developmental Disabilities, originally developed the Healthy Lifestyles Curriculum in 2000. The curriculum was intended to provide general health information appropriate for women and men with disabilities, including cognitive disabilities, in an interactive and easy to understand format. The curriculum was developed after reviewing existing curricula and obtaining input from a series of focus groups with people with disabilities in Oregon.

Half of the focus group participants were individuals with cognitive disabilities, while other participants included individuals with physical disabilities, visual impairments, and multiple disabilities. Cultural sensitivity was an important objective of the curriculum development team. Consequently, one of the focus groups specifically targeted the African-American population, while a second consisted of Native Americans. Additionally, two focus groups were held with participants in rural areas. Each focus group was asked to discuss what health meant to them. Components of a healthy lifestyle identified by participants included meaningful employment, independence/empowerment, participation in social and family activities, physical health, and recreation.

Using the focus group information, the curriculum was written by three researchers who themselves have disabilities. The curriculum encompasses an integrated view of health, including physical, emotional, social, and spiritual health, and health through meaningful activities. These components are represented in the Healthy Lifestyles wheel (Figure 1). The curriculum provides the core training in a single 2½-day workshop. Supplemental information is provided through monthly support groups following the workshop.

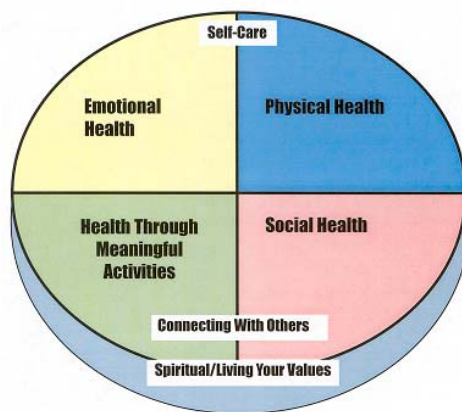


Figure 1
Healthy Lifestyles Wheel
(adapted from Scandurra, 1999)

Program Implementation

Utilizing the Healthy Lifestyles curriculum, ten trainings were conducted in communities in Oregon and Southwest Washington. Trainings focused on empowering participants to a) understand and examine their personal values, choices and health; b) gain knowledge about the five components of a healthy lifestyle, including physical, emotional, social, and spiritual health, and health through meaningful activities; c) increase their own ability to practice healthy lifestyles; and d) develop and follow a self-determined healthy lifestyle plan. Implementation of the curriculum included collaboration with local Centers for Independent Living, recruitment of participants, orientation, the workshop, and support groups.

Collaboration

Recruitment, orientation, workshops, and support groups were conducted in collaboration with local Centers for Independent Living (CILs), non-profit resource centers providing services designed to enhance the ability of people with disabilities to live more independently. Independent Living Resources (ILR), a Portland CIL, was our lead collaborator in recruiting participants and arranging and

conducting workshops. Additionally, ILR facilitated partnership with local CILs who assisted with recruitment and logistics for workshops and support groups in their communities. The communities were selected on the basis of interest and capacity of the local CIL.

Recruitment

Flyers and brochures were distributed through the CILs, and throughout the community in libraries, hospitals, and clinics. Announcements were also made through personal presentations, hosting tables at disability fairs, sending emails to and posting flyers at disability agencies, and through word of mouth. Individuals were eligible to participate if they were at least 18 years of age, lived in the Oregon or Southwest Washington, and had a self-reported disability.

Orientation

The Healthy Lifestyles orientation took place two weeks prior to the first workshop in each community. Orientation provided a brief overview of the workshop, offering participants an opportunity to find out what to expect during the workshop and whether it would be interesting or useful for them. For project staff,

it provided an opportunity to collect baseline data and to ascertain the number of participants and any disability-related accommodations required for the workshop.

Workshop

The Healthy Lifestyles workshops were provided free of charge to participants. Assistance with transportation arrangements and expenses was provided for participants as needed. Each 2½-day workshop was conducted at an accessible location utilized at little or no cost. A roundtable format allowed participants to engage in a conversational manner. The interactive and safe nature of the workshops generated trust and sharing, and promoted friendships.

A team of trainers, including at least one with a disability, led each workshop. Information and activities were divided into four segments. The first segment encouraged participants to self-define health and introduced the Healthy Lifestyle Wheel. In segment two, participants developed their understanding of spiritual health and living one's values. This segment included defining and identifying personal values and realizing unique personal needs for health as a person with a disability. Segment three covered the remaining four components of a healthy lifestyle: physical health, emotional health, social health, and meaningful activities. Segment four allowed participants to apply the knowledge gained in previous sessions to develop personal goals and strategies to accomplish their goals.

Various activities were utilized throughout the workshop to keep participants engaged. Physical activities during the workshop included non-impact aerobics (NIA), yoga, and massage. These activities were tailored to be gentle, and were presented by instructors who had experience working with people with various disabilities. Using pictures from magazines, textured fabric, and craft items, participants created a collage to portray important areas of their lives. Role-play and small group activities were also used to facilitate learning.

Participants were able to follow along with the trainer using a handbook given to them at the start of the workshop and through segment outlines posted on the walls. Workshop materials were in large print and written in clear, easy to understand language. The trainers went over all the materials during the workshop to make sure they were understood. Independent Living Resources converted the materials to Braille as needed. Staff and volunteers were available to assist individuals with visual impairments in completing worksheets and other activities. Sign language interpreters were provided as needed. Frequent breaks helped participants to relax and engage with others. Meals and snacks served during the workshop included a variety of tasteful and colorful food prepared with balance and nutrition in mind.

Support Groups

Following each workshop, active peer support was delivered through monthly support groups for six to nine months. Support groups met for two hours each month. During support groups, participants shared successes with their goals, and challenges and barriers in achieving those goals. Facilitators and participants provided positive feedback, resources, and reflective listening. Volunteer speakers were invited to the meetings to talk about specialized topics such as nutrition, stress management, motivation, vocational rehabilitation, and healthy cooking on a budget. To encourage participation, support groups were conducted at convenient times in easy-to-reach, wheelchair accessible locations. Reminder letters were sent two weeks in advance and reminder phone calls were placed a week before each support group meeting. Healthy snacks were provided to reinforce healthy eating. The support groups served as a non-judgmental, positive, and fun source of encouragement for participants in working toward their goals.

Creating an Evidence Base for a Health Promotion Curriculum

Growing out of the evidence-based medicine movement, evidence-based public health and health promotion have gained considerable attention over the last decade. Modeled on methods used in medicine, public health

promotion efforts have generally used a process of systematic review to generate recommendations on public health practices or health promotion interventions. Experts in the field examine and evaluate the documentation of effectiveness. The resulting evidence-based resources not only allow health practitioners to choose the most effective means to meet their goals, but also provide support for policies and systemic changes to improve health outcomes (Tang, Ehsani, & McQueen, 2003). In order for this process to occur, however, programs must collect data on their interventions using rigorous scientific standards.

Selecting a Research Design

Several research designs were considered for evaluating the Healthy Lifestyles curriculum. A pretest-posttest design, using participants as their own controls, is straightforward in terms of enrollment and data collection. However, the lack of a comparison group results in a failure to control for changes between measurement times that might be due to factors other than the intervention (Rog, 1994). Posttest only comparison group designs, on the other hand, lack control for baseline differences between groups (Rog, 1994). One of the strongest research designs combines the pretest-posttest design with a comparison group that does not receive the intervention. This design however, can be jeopardized by compensatory rivalry in the control group and treatment-related attrition (Cook & Campbell, 1979). Having participants receive the intervention at different times so that participants in later groups can serve as controls while they are waiting to receive the intervention can solve this issue.

Therefore, a delayed intervention (DI) comparison group design was selected and implemented with one cohort of participants at a time. After completing baseline measures at orientation, each cohort of participants was divided into two groups. One group (the intervention group) received the training immediately, while the second group (the DI group) served as a control. Three months later, after assessment data were collected from both groups, the DI group then received the training. Thus, each group served as its own pre/post-

training control, while comparisons were also made to separate control groups who had not yet received the training. This design allowed participants to be recruited one cohort at a time instead of all at once. It required less than a year's time commitment from participants and it met the program goals of controlling both for group effects and for changes that might simply have been due to the elapse of time or other confounding factors outside the intervention. Lastly, it provided everyone who participated in the study with an opportunity to benefit from the training.

Identifying Appropriate Measures

One strategy considered for measuring the impact of the Healthy Lifestyles curriculum was to develop a measure of health and wellness paralleling the content of the curriculum. A drawback to this strategy, however, was the time that would be needed not only to develop the measure but also to properly validate it to ensure the quality of the results. Another drawback was the lack of comparability to other studies that would be possible if each health promotion program continued to develop its own measures. For these reasons, the decision was made to adopt an existing measure with established psychometric properties that had been used in other health promotion research, preferably with people with disabilities.

One of the most widely used measures is the SF-36 Health Survey (Ware, Snow, Kosinski, & Gandek, 1993). Despite the fact that the SF-36 is considered the "gold standard" in a number of circles, it was rejected because it lacks face validity in measuring wellness for people with disabilities. By interpreting functional impairment as reflecting reduced health and quality of life, the SF-36 and similar health-related quality of life measures preclude the possibility of being healthy and well with a disability.

Patrick, Richardson, Starks, Rose and Kinne (1997) proposed measuring quality of life of people with disabilities in broader terms, more in keeping with the concept of wellness and life balance. A number of multidimensional measures of wellness fit into this framework,

and were considered for use in evaluating the Healthy Lifestyles curriculum. The measures reviewed included the Mental, Physical, and Spiritual Well-Being Scale (Vella-Broderick & Allen, 1995); the Leddy Healthiness Scale (Leddy, 1996); the Optimal Living Profile (Renger, Midyett, Soto Mas, Erin, McDermott, Paperfuss et al., 2000); the Perceived Wellness Survey (Adams, Bezner, & Steinhardt, 1997); the What's Right with Your Life?: Wellness Appraisal (Cannon, 2000); and the Health-Promoting Lifestyle Profile (Walker, Sechrist & Pender, 1987).

An updated version of the Health-Promoting Lifestyle Profile (HPLP II) was chosen due to its content, manageable length, and previous testing. The HPLP II consists of 52 items that address many of the topics covered by the Healthy Lifestyles curriculum. It measures health-promoting behaviors in the domains of health responsibility, physical activity, nutrition, spiritual growth, interpersonal relations, and stress management. Items are scored on a four-point scale indicating how often respondents engage in specific behaviors or have certain feelings: never, sometimes, often, or routinely.

Internal consistency of the HPLP II subscales is strong, with alphas ranging from 0.79 to 0.94 (Susan Nobel Walker, personal communication, October, 2001). In addition, the HPLP measure has previously been used successfully with people with disabilities.

Data Collection

The HPLP II was administered at baseline to all participants. Delayed intervention groups completed the measure again immediately before participating in a workshop. All participants received the HPLP II at three months and six months following the training. Intervention groups completed data collection again at nine months following the training. Each group thus had four data collection points (Figure 2). The delayed intervention groups' pre-workshop data collection coincided with the intervention groups' first post-workshop data collection, allowing a control period comparison. Assistance with filling out the HPLP II was provided for participants as needed. Participants were compensated for their time spent completing data collection with a one-time payment.

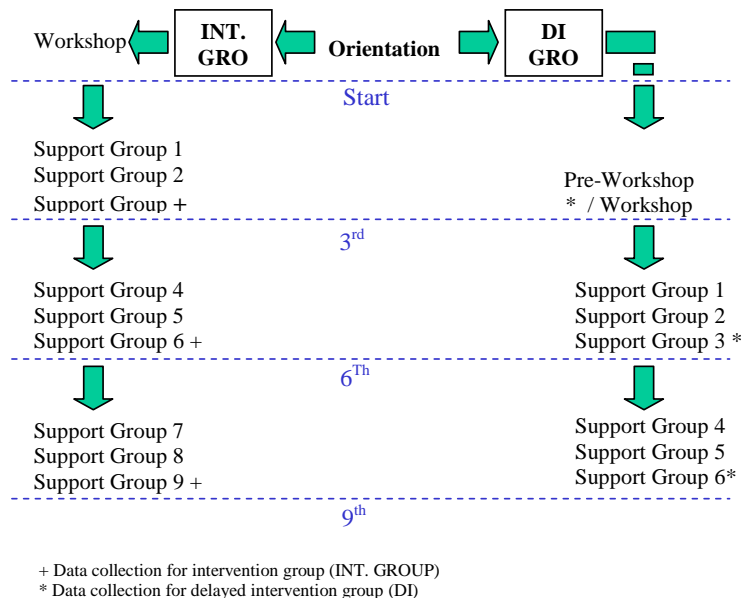


Figure 2
Data Collection

Data Analysis

Wilcoxon signed ranks tests were used to identify significant differences between pre- and post-test scores for each group. The Wilcoxon signed ranks test is a nonparametric statistical procedure for comparing paired observations (such as pre- and post-tests from a single sample) on a continuous dependent variable. It is similar to a t-test, but has fewer restrictions and is appropriate for small samples that may or may not be normally distributed (Pett, 1997).

Preliminary Results

HPLP II tests administered at orientation showed no significant difference in mean scores between the intervention group and the DI group. Moreover, there was no significant difference in mean scores in the DI group between the HPLP II they took at orientation and the one they took just prior to attending their workshop. Delayed intervention group scores did increase post-workshop, suggesting that changes in scores were due to the intervention and not another outside influence or temporal trend experienced prior to their workshop participation.

All groups have showed a statistically significant increase in their mean HPLP II scores from their pre-workshop questionnaire to their post-workshop questionnaires. Increased scores were evident at three months post-workshop and so far have been maintained through to the point at which individuals complete the study at either six or nine months post-workshop.

These preliminary results indicate that the workshop and subsequent support groups had positive effects for the people who attended. This sample (N=162) primarily consisted of middle aged, Caucasian females with above average levels of education (Table 1). The mean age was 47 years of age, with a range of 18 to 82. Future studies, including focused recruitment in communities and among individuals who

were underrepresented in our sample, will help address questions of generalizability to other demographic groups.

Qualitative data on barriers and facilitators participants have encountered in working toward their healthy lifestyle goals are currently being analyzed. These data will be compared to changes in HPLP II scores. The qualitative data will elucidate what worked well for participants and what additional intervention components might be needed to help individuals with disabilities achieve a healthy lifestyle.

Lessons Learned

The HPLP II was selected to measure change in behaviors and beliefs -- proximal changes that are conceptualized as preceding changes in health outcomes. However, the study design did not initially include measurement of more distal health outcomes. Midway through the study, additional measures were included to assess changes in health care utilization, secondary conditions, and health status. As these data are analyzed, they will provide further information about the effects of the Healthy Lifestyles program.

The data collection schedule was established based on the conception of the workshop itself as the intervention. From a research perspective, the support groups were initially viewed as a means to keep participants engaged in the study and provide opportunities for follow-up data collection. As the study unfolded, the role of the support groups in supplying additional benefits to participants became clearer. Thus, the support groups themselves could be considered part of the intervention. For future research, it will be important to study the entire time period from workshop through final support group. This will necessitate equal numbers of support groups for all participants, standardized content of support groups, and longer involvement of participants.

Table 1
Demographic Characteristics (N=162)

Characteristic	Percent
Gender	
Men	27
Women	72
Race/Ethnicity	
White	87
American Indian	5
African American	1
Hispanic	1
Other	13
Education	
College	67
High School or GED	25
< High School	9
Employment	
Employed/Self-Employed	33
Out of Work	39
Retired	16
Student/Homemaker	12

Discussion

This article describes Healthy Lifestyles, a health promotion program for people with disabilities. As noted earlier, prevention of secondary conditions among people with disabilities is imperative, and is a priority for the Centers for Disease Control and Prevention (CDC), the National Institute on Disability and Rehabilitation Research (NIDRR), and the National Institutes of Health (NIH), as well as other organizations that serve people with disabilities. Healthy Lifestyles takes a holistic approach to the prevention of secondary conditions through a 2½-day workshop followed by six to nine months of support groups.

Strengths

Several strengths of Healthy Lifestyles have been recognized. The curriculum was developed by people with disabilities for people with disabilities. The Healthy Lifestyles Wheel incorporates multiple aspects of health: physical, emotional, social, and spiritual health, and health through meaningful activities. The curriculum appeals equally to people with

varying abilities and levels of health, as it is based on a self-determination model (Ryan & Deci, 2000). This model allows each participant to self-define a healthy lifestyle based on his/her own values, and to create an individualized health plan and goals. The short duration of the workshop and the resources and support offered during the support groups following the workshop, worked well for the participants.

The strengths of the Healthy Lifestyles workshop and support groups are best summarized by the participants themselves:

“I learned that Healthy Lifestyles isn’t just about hard work like exercise and diet; it’s also about being kind to myself and meeting my social and psychological needs.”

[I learned that] “I can be a better me! [The workshop] gave me insight to options available to me; guidance and support. I have quit smoking after 30 years. I am exercising more and trying to cut down on sugar and calories in my food.”

“[Healthy Lifestyles] introduced me to new concepts, constantly supported me even when I failed, held me accountable in a very positive, supporting way, introduced new ideas each month, and reinforced the whole person concept of health.”

Program Limitations

The program also faced several challenges, including recruitment and retention. As mentioned previously, assistance was needed to recruit participants in collaboration with the CILs. Through flyers, brochures, newsletters, websites, and presentations, a large number of interested individuals were identified. However, the nine-month [note: it is nine months for everyone] commitment required to complete the research aspect of the program precluded several individuals from participation. Once enrolled, participants dropped out for various reasons, as often occurs with long-term programs. In most cohorts, the delayed intervention group had higher attrition due to the three-month delay between the orientation and the workshop. Additional contact information was obtained to reduce the likelihood of losing track of participants. Participants were called and mailed reminders periodically to maintain contact.

Support group meetings were held in the afternoon. Consequently finding a volunteer speaker during working hours was difficult. Due to participants' conflicting schedules, selecting a suitable date, day and time for support group meetings was also challenging. Another program challenge was finding accessible facilities available at minimal or no cost.

Barriers to Participation

As with any program of this kind, individuals faced several barriers to participation in Healthy

Lifestyles. Participants found transportation a barrier, although the Portland Metropolitan Area has an excellent public transportation system and paratransit service. Fortunately, Healthy Lifestyles had available funding to provide transportation to participants who needed it, but few participants took advantage of this resource.

Scheduling of workshops created a barrier for some participants. Because workshops and support groups were held during the workweek, many individuals with jobs were unable to participate. Scheduling for childcare was often a barrier as well. The duration of the workshop posed a challenge for some participants who had fatigue issues or who had to work around complicated schedules. Nevertheless, most individuals were able to fulfill their commitment. The most commonly mentioned reasons for dropping out of the program included family commitments, finding employment, lack of interest in the project, finding support outside the project, and change of residence.

Conclusion

The Healthy Lifestyles curriculum, developed by and for people with disabilities, takes an integrated approach to health promotion through a 2½-day workshop followed by monthly support groups. Participant comments indicated that the curriculum appeals equally well to people with a variety of disabilities and with varied levels of health. The short duration of the workshop combined with the resources and encouragement offered during follow-up support groups worked well for the participants. Preliminary results show early and sustained improvements in health behaviors. The Healthy Lifestyles program offers a promising approach to promoting health among people with disabilities.

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