

Living Well with a Disability, a Self-Management Program

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Summary

Approximately 56.7 million persons in the United States have functional impairments that can lead to disability. As a group, persons with disabilities show disparities in measures of overall health when compared with the general population. Much of this can be attributed to secondary conditions rather than to the impairment itself. Persons with disabilities can prevent and manage many of the conditions that contribute to these disparities. The Living Well with a Disability program was developed to support persons with disabilities to manage their health. The curriculum helps participants achieve early success in self-management of quality-of-life goals to build confidence for making health behavior changes; it includes 11 chapters that facilitators use to conduct an orientation session and 10 weekly, 2-hour sessions. The program has been implemented by 279 community-based agencies in 46 states. On the basis of the data from the field trial, these community applications have served approximately 8,900 persons since 1995, resulting in an estimated savings of \$6.4–\$28.8 million for health care payers. Persons with disabilities have unique needs that can be addressed through multiple levels of intervention to reduce health disparities. The Living Well with a Disability program is a promising intervention that has demonstrated improvements in health-related quality of life and health care use.

Introduction

Approximately 56.7 million persons (18.7%) in the United States live with one or more communicative, mental, or physical disabilities (1). Disability occurs when a person's environment does not accommodate their functional ability (2). Persons with disabilities are at higher risk for poor health (3–9). Evidence indicates that approximately half of all health care expenditures can be accounted for by the 15%–20% of the population who have a disability (10). However, persons with disabilities often have not been included in health promotion research or programs (6,11,12). Disability advocates and those studying disability and health have demonstrated that, among other factors, improved self-management skills among persons with disabilities can lead to improved health and wellness and improved ability to advocate for structural changes, which can improve their access to quality health care in the United States (12–14).

The definition and operationalization of disability is the subject of ongoing discussion (15,16), which has helped to clarify and distinguish disability status from health outcomes (11,17,18). The *International Classification of Functioning, Disability, and Health* combines medical and social models to

highlight the interaction of function and environment in the creation of disability (2). This framework for understanding disability presumes that disability and related health disparities can be improved through improved physical and social functioning (e.g., assistive technology, physical therapy, peer support, and employment) and through modifications that make the environment accessible to persons regardless of functional ability (e.g., accessible buildings, information technology, and social policy) (19,20).

A growing body of literature indicates that persons with disabilities experience significant health disparities including poorer overall health and more chronic conditions (6,21), some of which have been referred to as secondary conditions (13,22). Secondary conditions are health conditions that are more frequent among persons who have disabilities than among those without disabilities. Various studies have shown that persons with disabilities frequently have to manage multiple secondary conditions that might further limit activities and participation, stress health-promoting routines, and lead to acute health care episodes, including emergency care visits and hospitalizations (5,23–25). In 2010, approximately five times more persons with disability reported fair or poor health compared with persons

without disability (39.4% versus 8.6%) (26). Furthermore, persons with disability reported 10.2 days of poor physical health in the past 30 days, whereas persons without disability reported 1.8 days of poor physical health (26).

Health disparities have led to a growing interest in public health interventions that can have far-reaching effects and that can make healthy behavior easier and more likely among diverse populations (27). For persons with disabilities, multiple levels of intervention are needed to address environmental, health systems, and individual behavior determinants of health (6). Many health problems experienced by persons with disabilities can be prevented and managed by health education interventions that target a person's ability to self-manage chronic disease risk and overall health status (11,14,28). Significant improvements in health status following implementation of health promotion programs have been reported for persons with spinal injury (29), amputation (30), stroke (31), multiple sclerosis (32), arthritis (33), and intellectual and developmental disabilities (34,35). All of these studies focused on subsets of the population with disabilities defined by a single specific medical condition; few have investigated effects among diverse populations with disabilities. To address this gap, the Living Well with a Disability program was developed in partnership with the national network of Centers for Independent Living (CILs) as a self-management program intended to support healthy living among persons with mobility impairments irrespective of their medical condition.

CDC's Office of Minority Health and Health Equity selected the intervention analysis and discussion that follows to provide an example of a program that might be effective in reducing disability-related disparities in the United States. Criteria for selecting this program are described in the Background and Rationale for this supplement (36).

Methods

Intervention Methods

Living Well with a Disability was developed to address self-management needs of persons with mobility impairments. A community-based participatory research (CBPR) approach was used to shape the curriculum content based on participant input and epidemiological research (37–40). Input from this process confirmed that adults with mobility impairments experienced a wide range of secondary conditions (e.g., pain, depression, and obesity) and social conditions that limited their ability to participate in desired events and activities. These findings led to discussions on the ecological context of persons with mobility impairments to design suitable interventions. Persons in the general population can learn skills to prevent

and manage chronic conditions (41,42). Because strategies for effectively delivering health promotion content to persons with functional impairments were unknown, CBPR methods were used to help specify the nature of the problem more accurately and to design an inclusive intervention.

Federally funded CILs are organizations that meet criteria for having access to the target population and organizational features that make these centers capable of meeting intervention objectives (43,44). CILs are nonresidential resource and advocacy centers that support the needs of persons with disabilities to help them live independently in the community. They are organized into a national network with approximately 600 offices that share 1) a common philosophy about the nature of disability consistent with the social model of disability; 2) a consistent approach to helping persons live independently that focuses on personal responsibility, choice, and control; and 3) a core set of services including information and referral provisions, peer support, independent living skill development, and personal and systems advocacy to increase the accessibility of community environments (45). Before development of the Living Well with a Disability program, health promotion was not a service commonly provided by CILs (45).

Previous research suggested that an effective self-management strategy should incorporate life skills that facilitate the development of meaningful life activities to provide a context for addressing health behavior change (46). This strategy encourages persons with disabilities to set quality-of-life goals that include health behavior changes as essential objectives.

The Living Well with a Disability curriculum is geared to helping participants achieve early success in self-management of quality-of-life goals that build confidence and motivation for making health behavior changes (47). The program includes 11 chapters that facilitators use to conduct an orientation session and 10 weekly, 2-hour sessions. The first chapter, an orientation session, addresses the recruitment and retention challenges identified by community sites (and identified in research as barriers to program participation experienced by persons with disabilities). In this session, participants explore potential obstacles to attendance (e.g., fear and anxiety when going to a venue that might not accommodate their needs, such as having an accessible restroom), examine the potential benefits of participating in the program, and consider strategies they might use to overcome barriers. The next four sessions encourage peer support through a supportive solution-focused group process; they help participants develop hope that they can achieve a more meaningful and healthy life while addressing the early challenges of pursuing new goals. These sessions build analysis and problem-solving skills (e.g., frustration management and self-monitoring for depression to

identify needs for clinical intervention). The last six sessions focus on specific self-management skills for improving health status, including 1) strategies for effective communication with health care providers, 2) strategies for information acquisition and use, 3) strategies for increasing activity (through six levels from sedentary to recommended levels of exercise), 4) strategies for improving diet (based on U.S. Department of Agriculture guidelines), 5) strategies for advocating for both personal and health care systems improvements, and 6) cognitive and behavioral strategies for maintaining health behavior changes over time (Table 1). Additional program information is available at www.livingandworkingwell.org.

Data Collection and Analysis

The Living Well with a Disability program has been assessed in several published studies that are summarized in this report. No new findings are presented. The program was originally evaluated in a pilot study in 1992 (46) and revised before evaluation (1998–1999) using a randomized, quasiexperimental, staggered baseline design that included a convenience sample of 246 CIL consumers from nine sites geographically distributed across eight states in the United States (California, Kansas, Mississippi, Montana, Missouri, New Hampshire, New York, and Texas) (48,49). Participant demographics (e.g., mean age: 45 years; range: 18–85 years; 82.4% white; 64.2% women) were representative of the U.S. population of persons with mobility impairments. Participants had been living with an impairment for an average of 17.5 years (standard deviation [SD] = 15.7) (49).

Program effectiveness was evaluated by collecting data on secondary conditions (23), symptom days, life satisfaction (50), health care use as reflected by costs (e.g., primary care and emergency department visits, outpatient surgery, and hospital days), and healthy lifestyle (Table 2) (51). Data were collected 2 months prior, immediately before the intervention, immediately after the intervention, and at 2 months, 4 months, and 12 months after the intervention. Because of the staggered baseline design that requires implementation of the intervention with all participants, outcome data were analyzed by using separate between-subject (i.e., logistic regression) and within-subject procedures (i.e., repeated measures analysis of variance). The level of statistical significance for all analyses conducted was $p < 0.05$.

Results

Between-subject results indicated that participants in the intervention group were significantly more likely than those in the control group to be below the median for secondary

conditions (adjusted odds ratio [AOR]: 3.05; 95% confidence interval [CI]: 1.33–7.01), symptom days (AOR: 1.96; 95% CI: 0.91–4.26) and health care use (AOR: 1.94; 95% CI: 1.03–3.67) after adjusting for demographics and preintervention status with respect to the median of each variable (49).

The within-subject analysis indicated that observed changes in all outcome measures occurred during the intervention period and were maintained up to 12 months for secondary conditions, healthy lifestyle, and life satisfaction. Symptom days returned to baseline at 12 months, and health care costs returned to baseline at 2 months (Table 2). No change was observed over the extended baseline period (i.e., period without treatment prior to the intervention) on any of the outcomes measured, indicating that observed differences resulted from the Living Well with a Disability program rather than from instrumentation effects associated with the measurement procedures (48).

Discussion

In addition to person-level outcomes, a cost analysis of the Living Well with a Disability (Living Well) program was conducted. The cost analysis used the payer perspective, which reflects the costs incurred by health insurers and other payers (52). Self-reported health care utilization data were used to compute health care unit costs incurred by study participants at each measurement period (53). Overall, cost outcomes for the entire sample indicated a 6-month cost savings of \$3,227. To examine outcomes for participants without high health care expenditures (i.e., more than three standard deviations above the mean), a sample trimmed to include only persons with seven or fewer hospital nights during any measurement period was also reported. The 6-month health care cost savings for this sample was \$723. Overall, the Living Well program recovered all costs of program implementation, including in-person facilitator training and data collection (\$596 per participant), within 4 months of program delivery for both the complete and the trimmed sample populations (53).

By May 2015, the Living Well program had been implemented by 279 community-based agencies in 46 states to approximately 8,900 persons with disabilities. On the basis of the 6-month cost savings observed in the field trial (i.e., \$723 and \$3,227), these community applications are estimated to have saved \$6.4–\$28.8 million, which would have been incurred since February 1995 by health care payers without program implementation.

Several factors might affect dissemination of this program. Historically, health promotion has not been a mandated service in the U.S. health care system. In addition, many organizations,

TABLE 1. Living Well with a Disability curriculum content, objectives, and rationale for intervention components

Chapter	Primary objective	Rationale
Orientation	Provides introductory information about the program, so persons can learn about it before committing to attend	Persons are reluctant to commit to a class and need information to make an informed choice.
Goal setting	Introduces the process for identifying and setting meaningful quality-of-life goals; develops skills for writing goal statements	Setting meaningful quality-of-life goals provides motivation for participants to improve their health and to achieve their goals.
Problem solving	Teaches skills in identifying problems and generating solutions; helps participants anticipate and plan for problems while working toward goals	Problem-solving skills help participants anticipate problems and identify solutions in support of making progress towards goals.
Healthy reactions	Teaches cognitive-behavioral skills and encourages peer support for dealing with frustration and setbacks as participants work toward goals	Learning to be optimistic and develop healthy reactions to setbacks supports goal-directed activity.
Beating the blues	Provides an overview of discouragement and depression and offers additional resources for seeking help with prevention and management	Depressed mood can occur as a result of frustration and discouragement and disrupts goal-directed activity.
Healthy communication	Teaches the importance of clear communication with a focus on developing skills for communicating health issues with physicians and service providers	Goal-directed activity often depends on the help and support of others in the community. Communication skills promote cooperation in support of goal achievement.
Information seeking	Provides resources for identifying needed health information, evaluating the reliability of health information sources, and effectively using the information once found	Learning to find and apply reliable information specific to the individual needs of the participants is an important skill for improving health in support of goal achievement.
Physical activity	Presents information on and provides guidelines for increasing healthy activity and motivates participants to make simple changes to incorporate more physical activity into daily life	Secondary health conditions can be reduced or prevented through healthy physical activity.
Eating well	Provides information on nutrition and nutrition resources and presents strategies for monitoring eating habits and increasing the intake of healthy foods while limiting the intake of unhealthy foods	Secondary conditions can be reduced or prevented through improvements in nutrition.
Advocacy	Provides information and resources for self and systems advocacy and draws upon the skills learned in previous chapters to support participants' advocating for and meeting their needs	Learning the steps and skills of self and systems advocacy can solve problems that impede goal-directed activity (e.g., problems with access to exercise facilities).
Maintenance	Offers information and strategies for monitoring progress toward goals and maintaining health behavior changes	Health-behavior change must be supported with strategies for maintenance.

Sources: Adapted from Ravesloot C, Seekins T, Young Q-R. Health promotion for people with chronic illness and physical disabilities: the connection between health psychology and disability prevention. *Clin Psychol Psychother* 1998;5:76–85; Ravesloot C, Ruggiero C, Ipsen C, et al. Disability and health behavior change. *Disabil Health J* 2011;4:19–23.

such as CILs, that serve persons with mobility limitations struggle to meet their core mission across a large geographical area on small budgets. When they add a service, such as the Living Well program, they do so with limited funds. For other organizations, the functional approach adopted by the Living Well program might be unfamiliar and substantially different from the medical model of disability (2), which also might limit their ability to implement it.

The Living Well program improved the health-related quality of life and reduced health care utilization in a randomized controlled trial. Some health-status and health-related, quality-of-life improvements were still evident 12 months after the intervention. Scalability of the program is possible because it has been tested in geographically diverse parts of the United States and implemented across various organizations, including CILs, Aging and Disability Resource Centers, outpatient rehabilitation centers, and interdisciplinary wellness centers. In addition, three payers, L.A. Care Health Plan,

Inland Empire Health Plan, and the Montana 1915(c) Home and Community-Based Waiver Medicaid programs, have provided reimbursement to CILs for delivering the program. The facilitator and client workbooks are available in English, Spanish, and Korean.

The Living Well program was designed for compatibility with implementation in rural areas that often lack health promotion resources. Approximately 7.24 million noninstitutionalized persons with disabilities live in rural areas of the United States (54), and CILs have conducted Living Well trainings successfully even in remote counties and frontier counties, which have fewer than six persons per square mile. The combination of a distance training program with a workbook focused intervention has facilitated availability of the Living Well program in areas where limited resources exist for persons with disabilities.

The Living Well program has had a long history of development with funding from various sources including

TABLE 2. Mean scores of five outcome measures collected from participants* in the Living Well with a Disability program before, immediately after, and at 2, 4, and 12 months after intervention — eight states,† 2000

Measure	Pretest	Posttest	2 months	4 months	12 months
Secondary conditions [§]	28.3	24.6 [¶]	24.6 [¶]	23.4 [¶]	24.7 [¶]
BRFSS symptom days ^{**}	9.3	8.1 [¶]	7.7 [¶]	7.6 [¶]	8.3
Healthy lifestyle ^{††}	2.4	2.6 [¶]	2.6 [¶]	2.6 [¶]	2.6 [¶]
Life satisfaction ^{§§}	2.8	3.0 [¶]	3.0 [¶]	3.0 [¶]	3.0 [¶]
Health care costs ^{¶¶}	\$1,507	\$724 [¶]	\$895	\$1,306	\$1,296

Source: Adapted from Raveslout C, Seekins T, White G. Living well with a disability health promotion intervention: improved health status for consumers and lower costs for health care policymakers. *Rehabil Psychol* 2005;50:239–45.

Abbreviations: BRFSS = Behavior Risk Factor Surveillance System; HPLP II = health-promoting lifestyle profile II; HRQOL = health-related quality of life.

* N = 126.

† California, Kansas, Mississippi, Montana, Missouri, New Hampshire, New York, and Texas.

§ Secondary conditions values are summed across 43 conditions (item range: 0–4) using the Secondary Conditions Surveillance Instrument (Source: Seekins T, Smith N, McCleary T, Clay J, Walsh J. Secondary disability prevention: involving consumers in the development of a public health surveillance instrument. *J Disabil Policy Stud* 1990;1[3]:21–36).

¶ Denotes statistically significant posthoc difference (t-test or least significant difference test) from the pretest (p<0.05).

** BRFSS symptom days is the average number of days experiencing the seven symptoms included in the HRQOL-14 questionnaire (range: 0–30 days).

†† Healthy lifestyle is the average item score across all 52 items included in the HPLP II questionnaire (range: 0–3) (Source: Pender NJ, Walker SN, Sechrist KR, Frank-Stromborg M. Predicting health-promoting lifestyles in the workplace. *Nurs Res* 1990; 39:326–32).

§§ Single item (range: 1–4).

¶¶ Health care costs (i.e., doctor visits, emergency department visits, outpatient surgery, and hospital days) in 2000.

the CDC. In September 2015, funding was received from National Institute on Disability, Independent Living, and Rehabilitation Research to develop and evaluate a multimedia version of the Living Well program that will update delivery methods, improve fidelity of program implementation in the field, and extend programmatic reach. Additional program information is available at <http://rtc.ruralinstitute.umt.edu/health-wellness/motivation-for-self-management>.

Limitations

The findings in this report are subject to at least two limitations. First, self-reported outcomes and convenience sampling can produce biases not accounted for in the experimental design. Second, the results are not generalizable beyond the population of persons with disability using CIL services.

Conclusion

Persons with disabilities have unique needs that can be addressed through multiple levels of intervention to reduce health disparities (6). CDC has responded to these needs by developing a novel effective intervention that has already realized a return on investment through its many applications at multiple sites. Because of the aging of the U.S. population, this intervention might generate greater returns as the need intensifies for interventions that address health disparities experienced by persons with disabilities.

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