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# A Cost-Effectiveness Analysis of a Community-Based Health Promotion Intervention for Adults with Mobility Impairments: Living Well with a Disability

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A Cost-Effectiveness Analysis  
of a Community-Based  
Health Promotion Intervention  
for Adults with Mobility Impairments –

# Living Well with a Disability

## **FINAL REPORT**

Submitted to the  
Centers for Disease  
Control and Prevention

*March 2003*  
RO4/CCR914204-01



The University of Montana  
**RURAL  
INSTITUTE**  
Center for Excellence in  
Disability Education,  
Research, and Service

**CDC FINAL REPORT**

**A Cost-Effectiveness Analysis of a Community-Based Health Promotion  
Intervention for Adults with Mobility Impairments:  
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## **Executive Summary**

This document reports on research conducted by the University of Montana and the University of Kansas for the Office of Disability and Health at the Centers for Disease Control and Prevention. The research project, conducted between August 1, 1997 and July 31, 2001, was conducted in four separate but related studies. The research was conducted in eight States. We contracted with nine centers for independent living (CIL) to conduct 34 Living Well with a Disability health promotion workshops and to collect outcome measures. These programs included 246 individuals.

In the first study, we evaluated the effectiveness and cost outcomes of the Living Well with a Disability health promotion program for adults with mobility impairments. The results of this study, conducted over 18 months, indicated participants' activity limitation due to secondary conditions was substantially reduced. Responding to items from the BRFSS Quality of Life module, individuals reported gaining more than a full day without physical and mental symptoms following the program.

Study One also examined healthcare utilization effects of program participation. These analyses indicated that, based on decreased use of healthcare services, the cost of the program was completely recovered within the first two months after program completion. Further cost savings were evident through the four-month interval of the program evaluation.

The second study examined the relative efficacy of five different methods for recruiting individuals into a health promotion program. The results of this study

suggested the cost-effectiveness was best for direct mailings to CIL consumers and worst for providing information to medical service providers. The greatest proportion of recruited participants came from conversations agency staff had with potential participants.

The third study examined the anticipated and experienced participation barriers for individuals who were recruited into the Living Well workshop. Results indicated that the barriers rated as most problematic by program participants were in fact two secondary conditions: pain and fatigue. Further, results showed that participants expected barriers to be more problematic prior to their participation than they actually experienced them to be during the intervention.

Finally, the fourth study was an experimental follow-up program designed to increase the effectiveness and generalization of the Living Well program results. These results suggested that adding follow-up sessions to the Living Well program was effective in increasing overall program effectiveness.

# **GENERAL INTRODUCTION**



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## GENERAL INTRODUCTION

The United States has by far the most expensive health care system in the world. U.S. health spending as a percentage of gross domestic product, 13.6% in 1998, outdistanced the next most expensive health systems worldwide, with Germany at 10.6% and Switzerland at 10.4% (Bureau of Labor Education, 2001). Current projections suggest that health care expenditures will grow from the current level to over 16% by 2007 (Iglehart, 1999; Smith, Freeland, Heffler, McKusick, 1998). Policy makers involved in addressing the health care crisis are desperate for solutions. Central to the problem are the competing demands to contain costs while preserving quality of life for health consumers.

People with disabilities, defined by at least one limitation in an activity of daily living (ADL), make up approximately 20% of the U.S. population, but account for 47% of medical expenditures (Max, Rice & Trupin, 1996). As such, these individuals are at the crux of the health policy problem. Acceptable solutions will increase quality of life for these individuals while maintaining, or even decreasing, the costs of providing services. Given the recent history in health care policy, including failure of managed care to live up to the promise of containing costs (Trends and Indicators in the Changing Health Care Marketplace, 2002), the desperation for alternative approaches may only be matched by the challenge of finding effective alternative strategies. When faced with stubborn intractable problems, a paradigm shift is often needed.

Health promotion for people with disabilities and chronic illness may be that paradigm shift (Marge, 1988; Rimmer, 1999; Rimmer & Braddock, 2002). Like everyone, people with disabilities can improve the quality of their lives by paying

attention to health status and engaging in health promoting behavior. In fact, the benefits of a healthy lifestyle on the individual's daily life may be greater for people with disabilities than for the general population (Ravesloot, Seekins, & Young, 1998). Unfortunately, while the benefits of participation in health promotion activities may be greater for people with disabilities, the perceived "costs" and potential barriers for engaging in health promotion and wellness activities may be higher as well.

For people with disabilities, the interaction between a medical condition and daily health behavior choices can easily translate into decreased quality of life via the development of secondary health conditions (Ravesloot, Seekins, Walsh, 1997; Seekins, Clay, & Ravesloot, 1994; Seekins, Smith, McCleary, & Walsh, 1990). In addition to the toll on quality of life, the cost of treating many of these conditions through acute medical practices is enormous (Bradley, Rasooly, & Webster, 1994; Hoffman, Rice, & Sung, 1996; Phillips, Morrison, Anderson, & Aday, 1998). Secondary conditions, such as pressure ulcers or depression, present a heavy burden on both individuals who experience the condition and on the health care system (Rice & LaPlante, 1992).

Our research suggests that on average, people with chronic conditions and disabilities report experiencing 14 secondary conditions annually that regularly limit their ability to participate in daily activities. Examining the incidence and severity of 40 such secondary conditions, our data suggests the secondary conditions most problematic for the greatest proportion of people with mobility impairments (e.g. spinal cord injury, arthritis, etc.) are conditions with lifestyle and behavior etiological factors (e.g. chronic pain, physical conditioning problems and depression). Further, behavioral changes associated with health promotion and wellness (i.e. diet and exercise) may reduce the

incidence and severity of a variety of secondary conditions that often require medical attention.

Part of the problem faced by people with chronic conditions is the tendency for both public and private health oriented programs to focus only on acute care. There is virtually no funding available to help people with chronic conditions change health behaviors and prevent secondary conditions (Ipsen, Raveslout, Seekins, & Senninger, 2001). This state of reimbursement exists despite numerous intervention models that have demonstrated efficacy for helping people with chronic conditions improve health status and even reduce healthcare utilization (Lorig, 1996; Lorig, Sobel, et al., 1999; Raveslout, Seekins, Young, 1998).

Raveslout et al. (1997; Seekins, White, et al., 1999) reported a promising model for promoting lifestyle change that people with a wide variety of impairments can use to reduce the limitation they experience due to secondary conditions. This program, titled *Living Well with a Disability*, is the principal focus of this research report. *Living Well* is a consumer-directed, goal-focused health promotion and wellness program that helps individuals develop foundations for lifestyle change. The program was developed from needs assessment data collected from people with disabilities and reflects both theory and consumer involvement. A more detailed description of the program is included in the methods section of this report.

It is important to distinguish the *Living Well with a Disability* program from other, similar health promotion programs. The introductory chapter of the recently published International Classification of Function (ICF) (WHO, 2001) provides a clear distinction between the medical and social model of disability. With respect to disability, the

medical model indicates the primary modality for reducing disability is improvement in functional limitations due to impairment. In the medical model, the disability is equated with the impairment and resultant functional limitation. Health promotion programs developed from a medical model focus on symptom reduction as the primary and often sole outcome of the intervention. To our knowledge, every other health promotion program for people with disabilities is symptom-focused and is best described by a medical model. In these programs, the goal of program participation is symptom reduction.

These disease or impairment specific health promotion programs developed from the medical model are becoming increasingly common. They have the advantage of providing specific information that is useful for individuals facing common problems (e.g., arthritis, spinal cord injury, multiple sclerosis). However, they are not useful for individuals with low base rate conditions (e.g. Fredericks ataxia) and are impractical for implementation in rural areas where base rates are low for even common conditions (e.g. spinal cord injury). In both cases, cross-impairment programming is necessary for viable services to be made available to the most people.

The ICF goes on to suggest that a social model of disability is a viable alternative to the medical model. Using this model, disability outcome is understood to be an outcome of the interaction between an individual's functional capacity and their environment. The World Health Organization (WHO) used the social model of disability in developing the ICF. Within this framework, the ICF codes not only aspects of the individual's medical impairments, but also important aspects of their environment.

The *Living Well* program was developed from a social model of disability. Rather

than focusing specifically on the reduction of symptoms, the *Living Well* program focuses on reducing limitation in participation in chosen activities as an important factor in the development of healthful behavior. Participants develop long-term goals that have the potential to improve quality of life and learn to use health behaviors as objectives toward achieving these goals. Thus, the *Living Well* program is different at its very foundation from other health promotion programs for people with chronic illness and disabilities.

One effect of shifting from a medical toward a social model of health promotion for people with disabilities is the ability to develop programming that is cross-disability appropriate. Where most programs are developed for a specific “patient population” or disease specific group, the *Living Well* program can be applied to groups of individuals representing diverse impairment types and levels of disability.

In contrast to the ICF, the *Living Well* program was not developed from concepts related to classification. Rather, the program was developed from independent living (IL) philosophy (DeJong, 1979; Roberts, 1989; Williams, 1990). IL philosophy developed in reaction to the medical model. Similar to what is now described as the “social model,” the IL movement recognized participation in society as the primary problem associated with functional impairments. From this perspective, the environment, including physical and social structures, became an important factor in etiology and maintenance of disability. Importantly, public health has now taken on a similar perspective by emphasizing the role of the environment in disability outcome as evidenced by Chapter 6 (Disability and Secondary Conditions) of Healthy People 2010.

In summary, the *Living Well with a Disability* program was written using a social model of disability to assist people with disabilities in their efforts to reduce the impact

and cost of treating secondary conditions. The research presented here is conveyed in four separate studies. Study One presents overall results of the efficacy and cost outcomes for the *Living Well with a Disability* program. Study Two presents results of a study designed to examine the efficacy of five alternative recruitment schemes for the program. Study Three presents the results of a study that examined the barriers faced by participants in the research to completing a community-based health promotion program. Finally, Study Four was an exploratory study designed to examine the incremental effects of adding a follow-up program to the *Living Well* curriculum. Because studies Two, Three and Four are nested in the design for Study One, the overall methods will be described first and the method specific to the other studies will be reviewed in separate sections.

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# **CHAPTER 1**

## **Living Well with a Disability**

### **Program Evaluation**



## LIVING WELL WITH A DISABILITY PROGRAM EVALUATION

The primary hypotheses tested with Study One include: (1) participants in the *Living Well with a Disability* program will rate their secondary conditions as less limiting after participating in the program and (2) participants in the *Living Well with a Disability* program will use fewer healthcare resources following their participation in the program. In addition to these primary hypotheses, secondary hypotheses were also tested, including: (1) participants in the *Living Well* program will score lower on a standardized measure of depression, (2) program participants will score higher on a measure of health behavior, and (3) program participants will rate their life satisfaction and quality of life higher following the program.

### Methods

#### Participants

Participants for this research were recruited by Centers for Independent Living (CIL)<sup>1</sup> located in one of eight States (California, Kansas, Mississippi, Montana, Missouri, New Hampshire, New York and Texas). Centers recruited 246 individuals into one of 34 health promotion workshops conducted between April 1998 and December 1999. Of the 246 individuals recruited to begin the *Living Well* program, 188 individuals completed some portion of the program and at least one pre and one post outcome measure. These individuals were on average 45 years old ( $SD = 13.4$ ) with the majority reporting their race as Caucasian (82.4%). Other racial groups included African-Americans (13.8%), American Indians (2.7%), Asian Americans (0.5%), and Pacific Islanders (0.5%). Of those reporting, 3.2% reported either Hispanic or Latino heritage. The sample included a majority of women (64.2%) and the majority of the sample was not married (63.4%). On average, individuals had 13.7 years of education

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<sup>1</sup>Centers for Independent Living are non-residential information, referral and advocacy organizations funded under Title VII of the Rehabilitation Act. At the time of this study, there were 330 CILs in the US.

( $SD= 3.3$ ) and 83.8% reported being unemployed when they began the study. Lastly, individuals reported that they had been living with their disabling conditions on average for 17.5 years ( $SD= 15.7$ ).

### Measures

Effectiveness Measures. Program effects were measured using five different self-report, paper and pencil measures. The primary outcome measure was the Secondary Condition Surveillance Instrument (SCSI). The SCSI was developed to assess the amount of time people are limited because of secondary conditions (Seekins, Smith, McCleary, & Walsh, 1990). This functional approach to assessing secondary conditions has respondents rate 43 potential secondary conditions (e.g. urinary tract infections, pressure sores, depression, etc.) that are presented with simple descriptions of each condition. Respondents are asked to rate the amount of time they are limited each week by each condition on a scale from 0 to 3. A rating of zero means the condition has not been a problem during the previous 2 months, one means it has been a mild or infrequent problem (activity limited 1-5 hours per week), two means it has been a moderate problem (activity limited 6-10 hours per week), and three means it has been a significant problem, limiting activity 11 or more hours per week. In this framework, the total score across secondary conditions for an individual is a global measure of the level of limitation she or he experiences because of secondary conditions. Appendix A includes the pre-measure program survey as it was delivered to respondents. Each measure within the measurement instrument is labeled.

Seekins, Clay, and Ravesloot (1994) reported internal consistency for the SCSI of .88. Construct validity of the SCSI has been examined in factor analytic studies that support its use with samples that include individuals who have diverse impairment types (Ravesloot, Seekins, &

Walsh, 1997). Finally, the total SCSI score correlates .41 with the Craig Handicap Assessment and Reporting Technique (Whiteneck, Charlifue, Gerhart, Overholser, & Richardson, 1992), a measure of disability outcome that measures handicap following the World Health Organization's 1980 model of disability (WHO, 1980). In this present study, participants reported experiencing an average of 14 secondary conditions in the past year, which is very consistent with the mean reported in other similar samples (e.g. Seekins, Clay, & Ravesloot, 1994).

Four additional outcome measures were included to examine additional program effects beyond those captured by the SCSI. To examine treatment effects on depression, we included the Center for Epidemiological Studies of Depression Scale (CES-D), a brief self-report inventory that measures depressive symptoms (Radloff, 1977). To assess effects on health behavior we included the Health-Promoting Lifestyle Profile II, which measures six dimensions of lifestyle: health responsibility, physical activity, nutrition, spiritual growth, interpersonal relations, and stress management (Walker, Sechrist, & Pender, 1987). To examine effects on life satisfaction we used the single item for assessing life satisfaction that is included in the quality of life module to the Centers for Disease Control Behavior Risk Factor Surveillance System (BRFSS). This item asks, "In general, how satisfied are you with your life?" and responses are scaled on a four-point Likert-type scale with anchors for very satisfied, satisfied, dissatisfied and very dissatisfied.

Finally, we used items from the Centers for Disease Control Behavior Risk Factor Surveillance System (BRFSS) Health Related Quality of Life module (HRQOL-14). Specifically, we used eight items scaled by number of days out of 30 that respondents experienced limitations, symptoms, or problems related to physical and mental health. In order

to examine effects of the intervention on the number of days individuals experience limitation due to both physical and mental health problems, we hypothesized that these eight items would define a meaningful scale of limitation. Factor analytic results supporting this hypothesis are reported in the results section. Finally, with respect to study measures, means and standard deviations for measures collected immediately prior to the intervention can be found in Table 1.1.

**Table 1.1 Descriptive Statistics for Study Measures Collected at Baseline**

Measures	<i>N</i>	Mean	<i>SD</i>
Sum of Secondary Conditions	225	30.12	17.57
Health Promoting Lifestyle Inventory II	163	2.49	.43
CES-D (Depression)	217	16.61	11.30
Quality of Life Rating (1-10)	214	6.49	1.95
Life Satisfaction (1-4)	219	2.21	.77
Days physical health not good (past 30 days)	221	9.83	10.12
Days mental health not good (past 30 days)	219	8.49	9.97
Days poor physical or mental health kept from doing usual activities (past 30 days)	218	7.63	9.41
Days that pain made usual activities difficult (past 30 days)	220	9.36	11.09
Days have felt sad, blue, depressed (past 30 days)	220	8.24	9.64
Days have felt worried, tense, anxious (past 30 days)	221	9.90	10.41
Days did not get enough rest or sleep (past 30 days)	220	11.58	10.34

Cost Measures. To assess health care cost outcomes of the *Living Well with a Disability* program, we collected a 2-month retrospective recall of health care services along with the other paper and pencil questionnaires. These questions queried number of hospital days, emergency room visits, outpatient surgeries and procedures, and physician visits. These service utilization reports were converted to costs by multiplying service units by Medicare unit cost estimates. Medicare cost estimates were created using 1998 aggregated Medicare reimbursement rates, national outpatient revenue summary data, and physician reimbursement rates from the Healthcare Financing Administration, Bureau of Data Management and Strategy. These cost

estimates were \$1073.00 per hospital day, \$157.00 per emergency room visit, \$419.00 per patient day surgery visit, and \$89.00 per physician visit. For study participants who were recruited in 1999, cost estimates were increased by 3.7%, the medical care Consumer Price Index.

### Procedures

We recruited Centers for Independent Living to participate in this research project by soliciting applications through a national mini-grant competition. Solicitation materials were sent to the 330 CILs around the country. We received completed application materials from 106 CILs. A review panel including researchers, Centers for Disease Control and Prevention staff, and CIL national organization representatives reviewed all materials and selected 9 centers. We issued a contract to the CILs selected to conduct four 8-week *Living Well with a Disability* programs. Additionally, the contract included funding to send two staff members from each center to Kansas City, Missouri for 20 hours of training conducted by the research staff. The training consisted of materials review of the 177-page curriculum, didactic presentation of important concepts, and discussion. Facilitators were trained in two groups of ten so that the researchers could conduct the didactic training as well as model *Living Well* facilitator behavior.

The nine CILs were randomly assigned to one of two blocks. The first block of five CILs began recruiting for the intervention immediately following the training in March 1999. They each conducted two workshop series, with the first beginning in April and the second beginning immediately following the first in June. The second block of CILs began their recruitment in July of that same year and conducted two workshop series, the first beginning in August and the second beginning in October.

Before beginning either workshop series, CIL staff recruited a total of 24 individuals who

indicated they would be willing to begin the intervention either immediately or two months later. These individuals were then randomly assigned to one of the two start dates. Next, measures were sent to all 24 individuals. For individuals who waited two months to begin the intervention, the same questionnaire was mailed immediately prior to the beginning of the workshop. In all cases, the workshop series was conducted in the conference room of the CIL facility.

During year one, research participants were recruited through one of three methods: direct mailings to individuals on the CIL mailing list, public service announcements sent to media outlets (newspapers, radio, television, etc.) and medical provider referral solicitation. Study Two in this report describes results of recruitment using each of these three recruitment methods.

### Interventions

The primary intervention tested in this study is titled, *Living Well with a Disability*. Individuals using this goal-based curriculum develop health objectives as an essential step in the accomplishment of meaningful long-term goals. Accordingly, the initial focus of the *Living Well* program is evaluation and development of meaningful life goals. Individuals typically set goals for improvements in daily activities (e.g. getting a job, doing volunteer work, or improving recreation), interpersonal relationships (e.g. finding a mate, developing more interpersonal connections) or symptom reduction (e.g. pain or weight loss). Conceptually, the intervention model is intended to help individuals motivate healthful behavior as an objective to pursuing long-term goals. When individuals integrate health behavior into achievement of meaningful life goals, they are more likely to establish consistent patterns of health behavior adoption (Raveslout, Seekins, & Young, 1998).

The *Living Well* curriculum is divided into 10 chapters: Goal-setting, Problem Solving,

Attribution Training, Depression, Communication, Information Seeking, Nutrition, Physical Activity, Advocacy and Maintenance. The first six chapters establish goal pursuit and the final four chapters encourage health behavior change. A workshop series consists of eight, two-hour weekly meetings. In the first six meetings, one chapter is reviewed each week; the last two meetings cover two chapters each.

### Experimental Design

The study used a staggered baseline experimental design with random assignment to treatment start date. A *Living Well* workshop series consisted of eight two-hour weekly sessions. Each round of workshops was presented in pairs, with one workshop beginning immediately and the other workshop beginning after the conclusion of the first. All participants were recruited during the month prior to the beginning of the first workshop. Those individuals recruited were randomly assigned to begin either the first or second workshop in the pair. All recruited participants completed a survey that included all measurement instruments. This first round of measurement represented an immediate pre-measure (**B**) for half the participants who began the intervention immediately and an extended baseline measure (**A**) for the participants who waited two months to begin the workshop. A schematic of the experimental design that shows measurement points for the first year of data collection is included in Table 1.2. Twelve months after the conclusion of each workshop a final measure (**F**) was collected.

The exact same sequence of workshops and measures was replicated in the second year of the project. The original quasi-experimental design called for longer baseline periods, but the practical consideration of maintaining participants in the study while completing extensive measurement instruments led us to sacrifice experimental control to increase likelihood of participation.

**Table 1.2 Experimental Design randomizing nine centers across seasons**

CIL Block 1 (five centers)

April	May	June	July	August	Sept	Oct	Nov	Dec
<b>B</b> Group 1 begins		<b>C</b>		<b>D</b>		<b>E</b>		
<b>A</b>		<b>B</b> Group 2 begins		<b>C</b>		<b>D</b>		<b>E</b>

CIL Block 2 (four centers)

August	Sept	Oct	Nov	Dec	Jan	Feb	March	April
<b>B</b> Group 1 begins		<b>C</b>		<b>D</b>		<b>E</b>		
<b>A</b>		<b>B</b> Group 2 begins		<b>C</b>		<b>D</b>		<b>E</b>

Analysis

Data were entered into an SPSS database and checked for accuracy. Analyses were completed primarily with the repeated measures analysis of variance routine of SPSS 10.0. To examine the utility of using the BRFSS items as a measurement scale, we also used the principal components factor analysis routine of SPSS 10.0.

**Results**

Overall, the results of this research support the effectiveness and potential cost-effectiveness of the *Living Well with a Disability* curriculum. For effectiveness, the results suggest statistically significant and substantial change in outcome measures following the intervention period that are not evident prior to the intervention when examined over a two month extended baseline. For cost outcomes, overall results are not significant. However, by examining only health care costs generated by individuals who were not hospitalized for greater than seven days during the course of the study, significant results emerge.

Due to the applied nature of this research in a field setting, the data collection methods and resulting data presents a number of challenges for interpreting study results. Because data

were collected across nine different sites, the study relies entirely on self-reported information. Further, the longitudinal nature of data collection over a sixteen month time period resulted in challenges due to attrition.

#### Analysis of Effects Due to Attrition

The first issue we addressed in the data analysis was that of attrition and the resulting sample available for longitudinal analysis. After reporting on the few differences between those individuals who completed data collection for the research and those who did not, results will be presented on the efficacy and cost outcomes of the main *Living Well* program.

To examine potential differences between those who completed and those who did not complete this study, we analyzed three different types of variables. First we analyzed basic demographic variables such as age, sex, time since disability, income and education. Next, we examined self-report of physical and mental health status including the sum of secondary conditions, depression, number of days limited by mental health, depression, and pain. This set also included self-report of health behaviors. Lastly, we examined differences in perceived barriers to participation that might distinguish these two groups. These analyses included 42 different items and three measurement scales.

Overall, very few differences were uncovered between those who dropped out of the research and those who did not. First, there were no differences in the demographics or health status between the two groups. Next, we examined differences in the reported barriers to participation. The barriers instrument included 28 potential problems people might have with accessing community-based health promotion programs like the *Living Well* program. These items are listed in Appendix A and a more detailed description of the instrument is included in Chapter 3 of this report. Because the response distribution to these items was far from normal,

these variables were analyzed using Chi Square. In these analyses, the only barrier shown to be significantly different was the item, “It is dangerous for me to leave my house.” There were proportionately fewer individuals endorsing danger as a problem who dropped out of the research. This result is contrary to what one might expect.

Finally, we analyzed differences in three measurement scales. We analyzed for potential differences in the incidence or severity of secondary conditions as measured by summing the ratings for all items of the SCSI. The mean SCSI score for those who dropped out of the study was not statistically different from those who maintained their involvement. Likewise, individuals who dropped out were not more depressed, as no significant differences emerged for the CES-D. Finally, the two groups did not differ in their self-reported level of health behavior as measured by the Health Promoting Lifestyle Profile. Here again, scores between groups were not significantly different.

On the basis of the variables collected in this study, we were unable to distinguish differences between those who did and those who did not complete the study with the exception of the single barrier item on safety. Consequently, the results presented here do not appear to be due to attrition in the sample over time. Given the rate of attrition however, we used an intention to treat paradigm by analyzing results for all individuals who completed an immediate pre-measure and at least one post-measure, regardless of the level of program participation (i.e. number of sessions attended).

### **Effectiveness Results**

Turning to the effectiveness results, we analyzed six different outcome measures: the Sum of Secondary Conditions (SCSI), Health Promoting Lifestyle Inventory II, Behavior Risk Factor Surveillance System (BRFSS) disability module items, the CES-D and the two single

items for quality of life and life satisfaction.

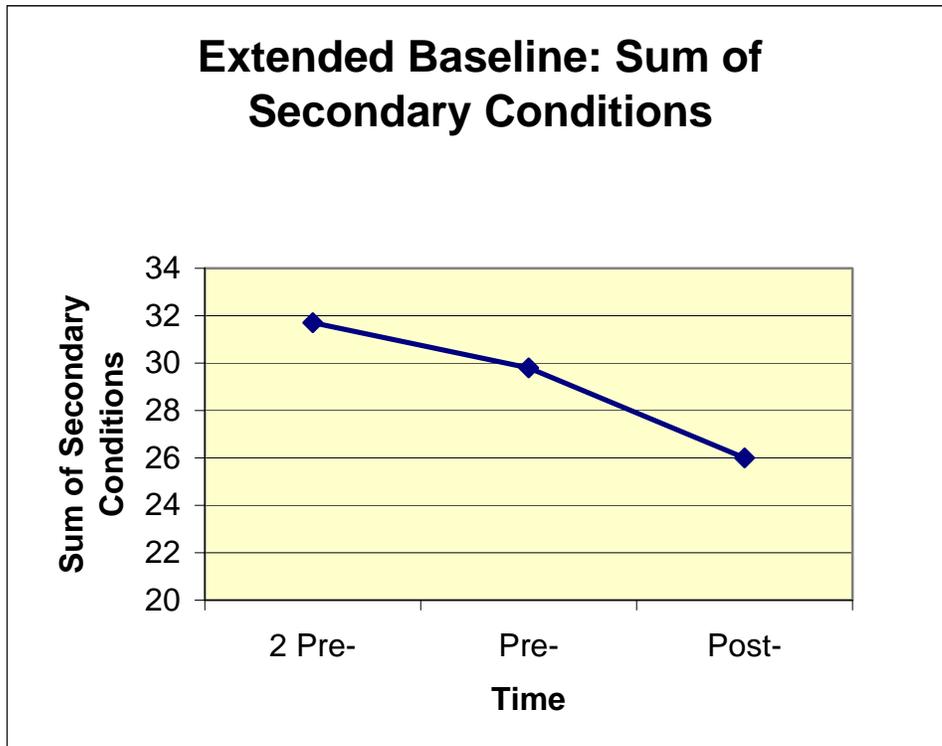
### Secondary Condition Surveillance Instrument

Our primary hypothesis was that individuals would report less limitation due to secondary conditions following the intervention when compared to pre-intervention reports. For this analysis, we collapsed all replications of the *Living Well* program across sites and time periods to get a general picture of overall effects. Given the nature of the experimental design, we tested this hypothesis using three different analyses. First, we tested the hypothesis using our extended baseline data in a repeated measures ANOVA (analysis of variance). However, as per the experimental design for the study, we collected extended baseline data from only half of our sample ( $n=81$ ). Next, to examine the generalization of the intervention effectiveness results to the larger sample, we tested the hypothesis with our largest possible sample using paired sample  $t$  test of immediate pre- and immediate post-intervention measures ( $n=189$ ). Finally, we examined maintenance of effects by testing the effectiveness hypothesis using repeated measures ANOVA for all time points except the extended baseline. The results from each of these analyses will be described next.

Results for the extended baseline analysis are depicted in Figure 1.1. This figure shows a decline of two units over the extended baseline period and a decline of four units over the intervention period. The statistical analysis used data collected from everyone who completed an extended baseline measure two months prior to participation in *Living Well* (2 Pre-), a baseline measure immediately prior to the intervention (Pre-) and a measure immediately following the intervention (Post-). The omnibus F-test indicated significant main effects over time in this analysis ( $F_{(2,79)} = 510.20, p < .001$ ). Post hoc analysis indicated there was no change in SCSI scores between the two-month pre- and immediate pre- measure ( $LSD = 1.82, p = ns$ ). More

importantly, the mean SCSI score changed significantly between the immediate pre- and immediate post-test ( $LSD = 5.70, p < .000$ ). These results indicate the intervention was effective in decreasing limitation due to secondary conditions for intervention participants.

**Figure 1.1**

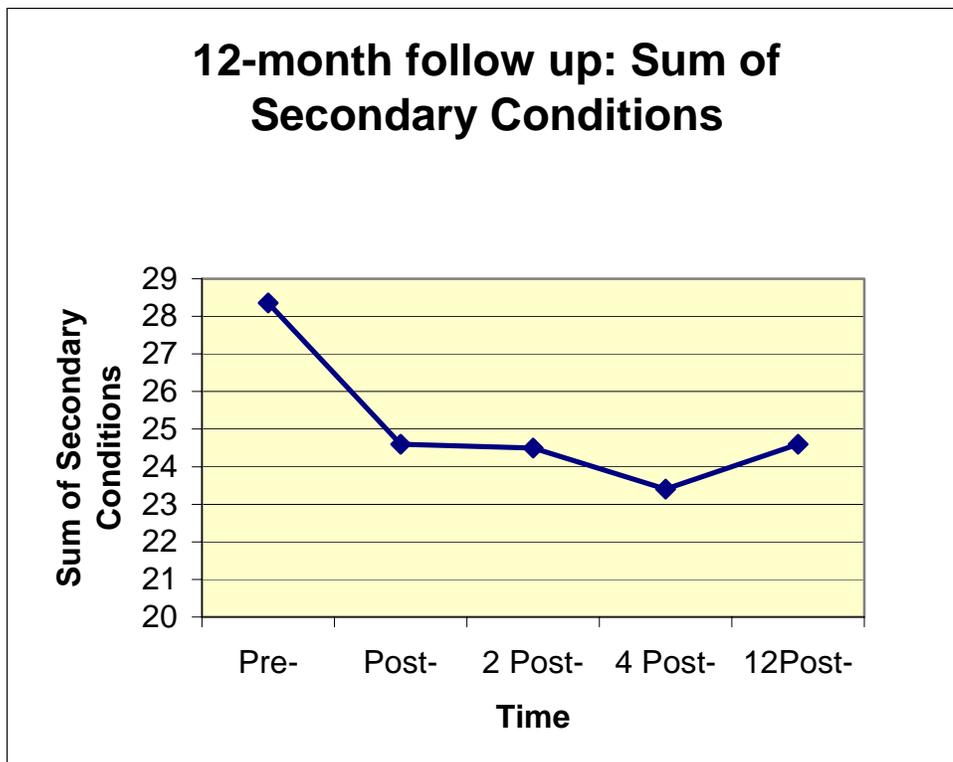


Next, to examine generalization of these effects across the largest possible sample in the study, we conducted a paired-sample  $t$  test using only immediate pre- and immediate post-intervention data points. This analysis included data from 188 individuals. The mean SCSI score at the pre-test in this analysis was 29.7 ( $SD = 17.5$ ) and at post-test was 27.0 ( $SD = 17.6$ ). The value for  $t$  in the analysis was 3.60, which is significant beyond the .001 level. Hence, the effectiveness results from the extended baseline analysis using the SCSI replicate on the largest possible sample of participants that completed the *Living Well* program evaluation surveys.

Finally, we were interested in the maintenance of treatment effects following the

intervention. For this repeated measures ANOVA, we used data collected from participants immediately pre-, post-, two months post-, four months post- and 12 months post- intervention. To be included in this analysis, individuals needed to return surveys for each time-point. Consequently, these results reflect a somewhat truncated sample ( $n = 126$ ). As before, the omnibus F-test indicates that these results account for significance variance over time ( $F_{(4,122)} = 5.12, p < .001$ ). These results are depicted in Figure 1.2.

**Figure 1.2**



Inspection of this figure shows that, consistent with results already presented, individuals report reductions in limitation due to secondary conditions between the pre- and post-measures ( $LSD = 3.75, p < .000$ ). However, these results go on to show that this intervention effect is maintained two, four and 12 months after the conclusion of the intervention. Post-hoc analysis confirms, the mean difference over the intervention period between the pre- and post- test is

statistically significant, as are the differences between the pre- and each of the follow-up post measures, including the one-year follow up.

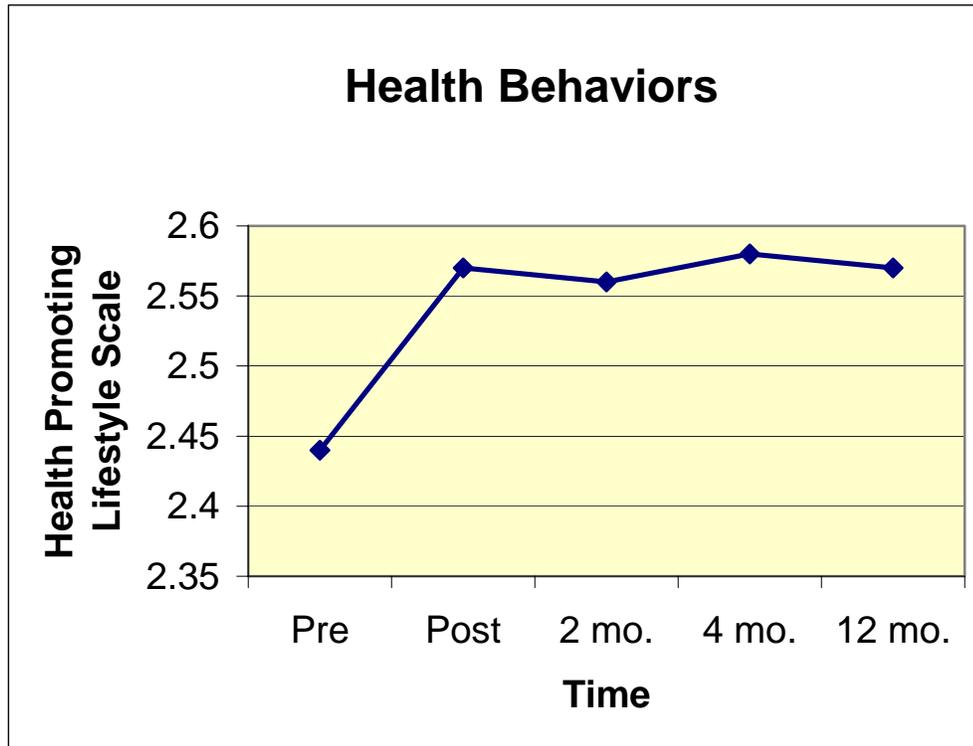
Taken together, these results offer strong support for rejecting the null hypothesis that the *Living Well with a Disability* health promotion intervention has no effect on secondary condition ratings. On the contrary, it appears the *Living Well* intervention is instrumental in reducing the average degree of limitation people report due to secondary conditions. The maintenance of gains 12-months after baseline argue against threats to internal validity posed by reactivity or instrumentation.

### Health Promoting Lifestyle Inventory II

Results for each of the additional outcome measures parallel those already presented for the SCSI very closely. That is, change in each measure was observed following the intervention and then was maintained during follow-up. Again, no change was observed in these measures during the extended baseline period.

Results on the Health Promoting Lifestyle Inventory II are depicted in Figure 1.3. This measure uses the mean value across items for the summative score. Inspection of Figure 1.3 shows the same pattern of results as was seen with the SCSI. On average, individuals reported engaging in more health promoting behavior following the intervention than they had done prior to the intervention ( $F_{(4,105)} = 4.27, p < .01$ ). More detailed analyses indicated this difference is largely due to increases in physical activity, with mean activity subscale scores increasing from 1.71 to 1.79 over the intervention period (paired sample  $t_{(158)} = -2.05 p < .05$ ).

**Figure 1.3**



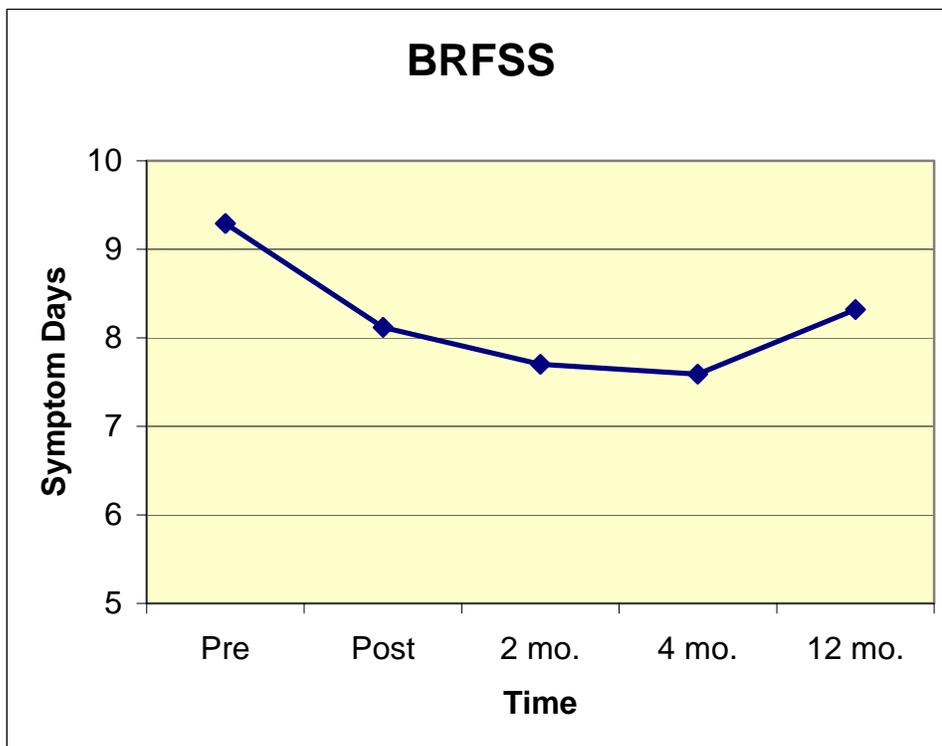
BRFSS, QOL, and Supplemental Disability Items

We collected responses to disability items included in the quality of life and disability modules of the BRFSS and hypothesized that those items scaled with “days per month” would combine to form a useful scale of symptom limitation. These items, along with the means and standard deviations, are included in Table 1.1 (page 22). To test this hypothesis, we examined the covariance structure of eight items using principal components analysis. In this analysis, the first component accounted for 56% of the variance across all eight items. A second component emerged and accounted for another 13% of the variance. These two components accounted for nearly 70% of the variance, suggesting construct validity of using these items as a measurement scale. However, one item was dropped as it loaded only marginally and negatively on each of the two major components. The resulting symptom limitation scale has seven items. The item

dropped has respondents indicate the number days they “felt very healthy and full of energy.” To aid in the interpretation of results, we took the average of the seven items in this scale as the scale score. Taking the average across all items gives us an estimate of the number of days individuals experience symptoms and limitations.

Next, we used this symptoms scale to examine the effectiveness of the *Living Well* program. Results are depicted in Figure 1.4. Similar to other results, there is no change across

**Figure 1.4**



the extended baseline on the average number of days participants report symptoms. However, over the intervention phase and through the first two follow up phases, there is a significant decline in the average number of days that individuals report limitation due to physical and mental health problems with a slight return to baseline. This quadratic effect is statistically

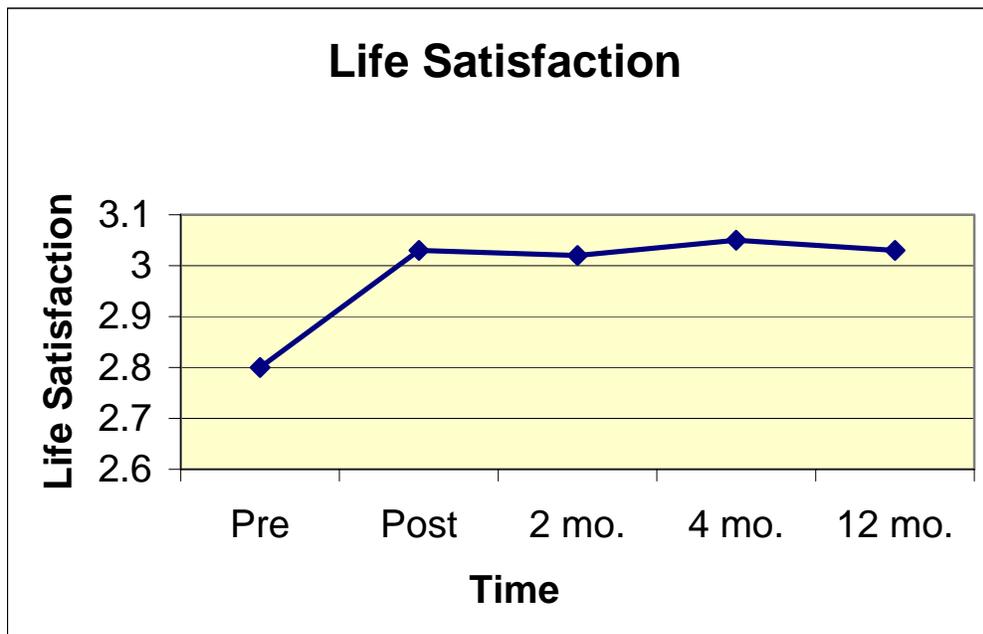
significant ( $F_{(1,123)} = 10.24, p = .002$ ). Post hoc comparisons indicate the pre-intervention scores were significantly different from the immediate post, 2 months post- and 4 months post-intervention scores.

Examination of the maintenance of this effect over twelve months showed rebound in scores at twelve months, with the post hoc comparison non-significant when compared to the pre-intervention mean. However, individuals report a reduction of about one less symptom day on average following the intervention than they experienced prior to the intervention through at least the first four months following the intervention.

### Life Satisfaction

Statistically significant results were also observed on the single life satisfaction item from the quality of life module of the BRFSS. At the pre-measure, the average response was 2.8, indicating a slight dissatisfaction with life overall. At all post-measures, the mean score is above

**Figure 1.5**



three, indicating average satisfaction with life. While the absolute difference in scores is small, it is statistically and substantively significant ( $F_{(4,114)} = 4.74, p = .001$ ). These results are presented in Figure 1.5.

#### Non-significant effectiveness results

Lastly, we failed to reject the null hypothesis of no treatment effect on two measures, the Centers for Epidemiological Studies of Depression Scale (CES-D) and the quality of life item. In these analyses, the omnibus repeated measures F test was not significant at the .05 level for either variable, indicating there was no significant change in the scores over time. Hence, the *Living Well* program does not appear to affect depression as it is measured by the CES-D.

#### Effectiveness results for specific demographic groups

In addition to overall results, we also examined data for results specific to each of two demographic groups: women and African Americans. Unfortunately, it was only these two groups for which we had enough data to conduct meaningful analyses. First, on the SCSII outcome, we found no statistically significant differences between groups or interactions involving gender in these data. For African Americans, within group differences were observed but not between groups. That is, African Americans did not differ from the rest of the sample in their overall report of secondary conditions. However, the interaction between the treatment effect on secondary conditions over time was related to African American racial status. Whereas the rest of the sample demonstrated linear effects on secondary conditions over time, the African American sample effects over time were curvilinear. Statistically significant treatment effects that were evident at the immediate post-test became non-significant by the four-month follow-up. However, given the limited number of African Americans in the sample, this result clearly needs replication on a larger sample.

On the BRFSS items, statistically significant between group differences were observed between men and women, with women reporting on average 2.94 more symptom days than men. However, gender did not interact with the treatment effect over time, indicating the intervention was equally effective for men and women on symptom days. For African Americans, results indicated no differences on symptom days.

Life satisfaction also changed significantly over time for the entire sample in these analyses. No differential effects were found for either the gender or African American samples.

### **Cost Results**

Overall, results of analysis on cost variables were encouraging, however they did not support intervention effectiveness on cost unequivocally. When cost variables for all subjects were analyzed, the overall results were not statistically significant. However, these cost estimates included costs incurred by individuals who, during some phase of the evaluation, were hospitalized for more than one week (and in some cases, for the entire two-month period of the measurement phase).

Health care cost estimates were skewed by a small number of extremely high medical care users. Specifically, cost estimates associated with hospital stays showed that 3.6% of the sample accounted for 80% of hospitalization expenditures. To mitigate this effect, results are presented for the entire cohort and a trimmed data set that excludes hospital stays longer than 7 days for any 2 month retrospective. To examine effects beyond overall cost reduction, we trimmed the sample by eliminating those individuals who had greater than three standard deviations from the mean medical service expenditure. The rationale for presenting a trimmed data set comes from the assertion that individuals requiring hospitalization for more than a week are experiencing medical conditions that would not be prevented by health promotion

interventions examined within a six-month time frame. This in effect trimmed out individuals with more than seven days in the hospital. By examining this trimmed data, a different, statistically significant, set of results emerged.

The cost analyses were approached from two perspectives. From an economic perspective, costs were totaled for all participants who reported data at each wave regardless of whether respondents had completed either previous or subsequent waves of data. These estimates provide the best estimates of healthcare expenditure at each point in time. Because the composition of the sample changes across time, however, the estimates are not applicable to assessing the efficacy of the intervention on healthcare costs. As interventionists, we also computed cost estimates using a repeated measures analysis for the consistent sample of individuals who returned outcome data at each wave of data collection.

First, results are reported from an economic perspective on costs incurred by the total cohort at each wave. Next, costs are presented using the intervention evaluation perspective using a repeated measures analysis of variance.

### **Economic Perspective**

From an economic perspective, we can project savings due to declines in medical service utilization pre- to post-intervention. A financial cost-benefit analysis from the perspective of a third party payer measures the program's net benefits (program outcomes minus programmatic costs) and shows a six-month return on investment.

Programmatic costs include costs for contracted services to implement the *Living Well* workshop, instructor training, and variable costs for participant workshop materials. Based on 188 participants, programmatic costs are \$596 per participant.

Program outcomes are measured as changes in medical care utilization costs. In each

survey round, participant medical utilization rates were multiplied by unit Medicare cost estimates to generate total medical expenses at each survey point. Program outcomes (PO) measure the change between pre-intervention medical costs (COST\_B) and three post-intervention medical cost measures (COST\_C, COST\_D, and COST\_E) to generate a six-month change in medical costs. Specifically:

$$PO = (COST\_B - COST\_C) + (COST\_B - COST\_D) + (COST\_B - COST\_E)$$

Table 1.3 shows the mean cost estimates for each survey point and the projected program outcome and net benefit measures. Data are presented for both the entire cohort and the trimmed data set. The net benefits show a remarkable payback for the *Living Well* intervention. For the entire cohort, programmatic costs are completely recovered within the first two-month interval and for the trimmed data set in the first six months. While the entire cohort shows a much larger intervention payback than the trimmed data, paired comparisons were not significant after the initial intervention period.

**Table 1.3: Mean Cost Estimates**

<b>Economic Perspective Costs</b>	<b>Entire Cohort</b>	<b>Trimmed Data</b>
COST_B	\$2,089	\$725
COST_C	\$686	\$487
COST_D	\$1,215	\$593
COST_E	\$1,139	\$372
Program Outcomes	\$3,227	\$723
Net Benefits	\$2,631	\$127

Using non-parametric paired Wilcoxon signed ranks tests, results show significant cost decreases from the immediate pre- to immediate post-measures for both the entire cohort (p=.005) and trimmed data (p=.033). The trimmed data also show significant decreases from immediate pre- to 4-months post-intervention (p=.035).

## Interventionist perspective

Using a repeated measures analysis of variance, Table 1.4 presents results for a consistent sample of participants who provided complete data at each intervention point. Although sample size is compromised, intervention efficacy of health care costs can be determined.

**Table 1.4: Repeated Measures ANOVA Cost Estimates**

<b>Repeated Measures ANOVA Costs</b>	<b>Entire Cohort (n=120)</b>	<b>Trimmed Data (n=107)</b>
COST_B	\$1,508	\$712
COST_C	\$724	\$403
COST_D	\$896	\$474
COST_E	\$1,306	\$323
Program Outcomes	\$1,598	\$936
Net Benefits	\$1,002	\$340

The repeated measures results parallel trends presented using the economic perspective. For both evaluation methods, net benefits are positive, which sends a clear message to third party payers to support health promotion efforts for individuals with disabilities. ANOVA pairwise comparisons show corresponding significance levels in Table 1.5.

**Table 1.5: ANOVA Pairwise Comparisons**

<b>Paired Comparisons</b>	<b>Entire Cohort</b>	<b>Trimmed Data</b>
COST_B to COST_C	0.240	.019*
COST_B to COST_D	0.319	0.132
COST_B to COST_E	0.781	0.008**
COST_B to COST_F	0.740	0.802

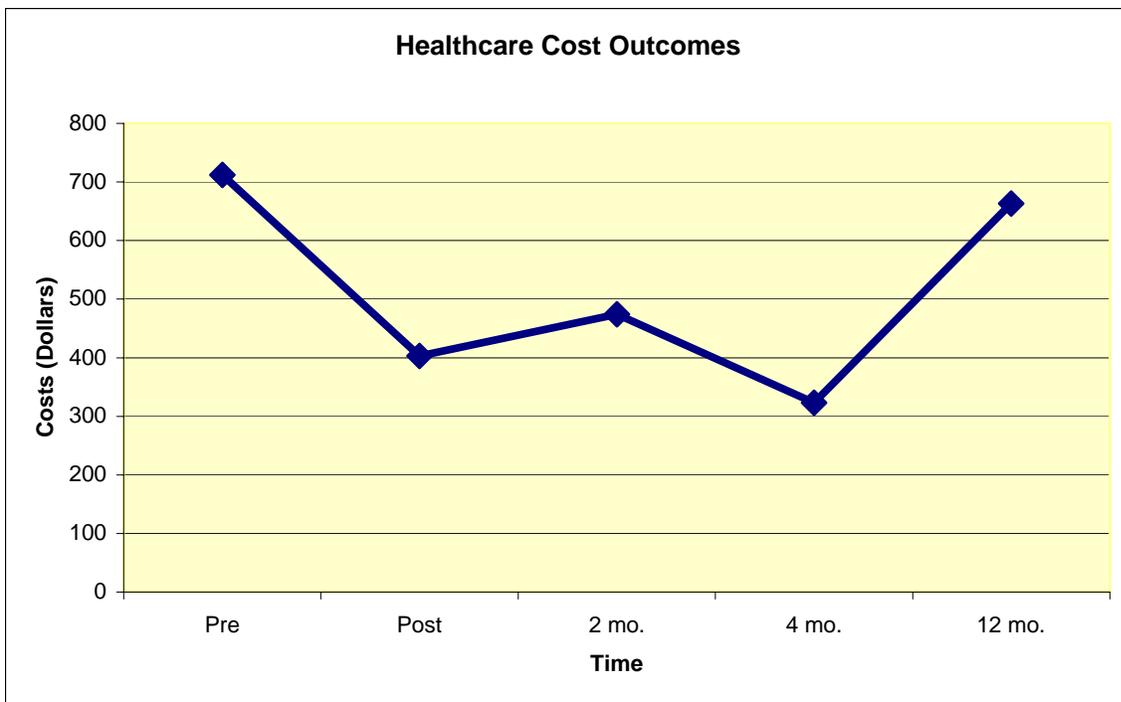
\* Significant at the .05 level

\*\* Significant at the .01 level

The statistical differences between the entire cohort and the trimmed data set are attributed to a small group of participants ( $n=13$ ) who inflated cost outcomes and variances

through significant hospitalization costs. For the trimmed data, tests of within-subjects contrasts show significant quadratic ( $p=.005$ ) and Order 4 ( $p=.004$ ) effects indicating an initial decrease in medical costs with rebound outcomes over time. Figure 1.6 charts the repeated measures values across the one-year study span. Despite the longer term rebound effects shown, the *Living Well* workshop paid for itself through decreased medical utilization costs within the first six months of program implementation.

**Figure 1.6**



### Cost Implications

During one year, if a State contracted with CILs to conduct 30 *Living Well* programs averaging eight participants per program, a total of 240 participants would be served. Based on our repeated measures data, we project the State would save approximately \$81,000 to \$240,000 above the cost of the *Living Well* program for each year. If we use all available data presented in the economic perspective this savings expands to \$631,440 per State. Nationally, **annual**

savings to Medicare, Medicaid, and private insurers would be in the range of \$4 to \$31 million.

## **Discussion**

The need for efficacious health promotion interventions in the current health care environment cannot be overstated. The results presented here suggest one promising approach to addressing the dilemma of increasing quality of life without increasing cost of care. The *Living Well with a Disability* health promotion intervention focuses on overall life goals as a context for improving health status through the adoption of healthful behavior. Further, the results presented here represent an important paradigm shift. Traditionally, health outcomes have been viewed primarily as a medical matter to be addressed in medical settings. The *Living Well* program shows promise for reducing costs of this traditional paradigm by shifting the venue of service delivery from the medical context to an independent living context. These results suggest that such a paradigm shift may help control healthcare costs.

The study has a number of weaknesses that should be considered in discussing the implications of the results. First, the results depend entirely on self-reported data. It is possible subjects perceived the purpose of the research and altered responses accordingly, a phenomenon known as the Hawthorne effect. However, one expects such an effect to be evident across all conceptually similar outcome variables. For example, one might expect similar results for life satisfaction and depression variables based on the Hawthorne effect. We found different results for these variables.

Attrition is another problem with the present study. We examined the data to discover differences between those who completed the evaluation and those with only a baseline who did not complete the intervention. Based on these analyses, we were unable to detect any meaningful differences between the two groups. Nonetheless, the 20% attrition from the immediate pre- to the immediate post-measure is somewhat disconcerting. On the other hand,

intervention programs often have substantial attrition between the sample of individuals who agree to participate in an intervention and the sample that actually completes it. For the present study, we simply cannot determine whether or not treatment effects may have been similar for the 20% who did not complete the program. We can only generalize our results to the population of people who voluntarily agree to participate and then complete the intervention.

Another important threat to the internal validity of any longitudinal study is reactivity to the measures. To examine reactivity as an alternative hypothesis for observed changes over time, we designed the research with an extended baseline component. Analysis of this baseline period indicated there was no change in scores on any one measure over this period. Hence, the reactivity hypothesis is rejected.

#### Discussion of Effectiveness Results

The effectiveness results indicate that individuals who completed the intervention experienced less limitation due to their secondary conditions following the intervention than they had prior to it. Further, the treatment effect was observed for a sub-sample who completed all follow-up measures. Analysis of the follow-up measures for this somewhat smaller sample indicated the treatment effect lasted at least 12 months, the last timeframe of the study. The importance of these results is two-fold. First, the results suggest the *Living Well* program is not only effective in reducing limitation due to secondary conditions but the treatment effect is enduring. Second, because this study was a replication of two smaller studies with similar results (Ravesloot, 1998; Ravesloot, Seekins, & Young, 1998), we have multiple studies with similar results across a 5-year time period. At this time, we can be reasonably confident the *Living Well* program is an effective intervention when delivered by CIL staff who have received facilitator training.

In addition to effects observed on our outcome measure of secondary conditions,

significant effectiveness results were observed in analyses conducted on the BRFSS items. Because these items are scaled by days per month, this measure provides a different metric for evaluating effectiveness than the SCSI. In evaluating these items, we used the mean days per month for each symptom queried, which gives us an indication of the disease burden expressed in symptom days per month. As such, the *Living Well* evaluation results may reflect that individuals had fewer days per month with symptoms and limitations following the intervention than before the intervention. The average decline across all seven symptoms was more than one day

Finally, results on measures of life satisfaction and quality of life were inconsistent with the life satisfaction measure demonstrating significant results but not the quality of life measure. This inconsistency may be due to scaling differences between the two measures. The life satisfaction item has four response categories. The pre-measure mean was equivalent to a “slightly dissatisfied” response on the item. The post-test mean was equal to “slightly satisfied.” In contrast, the quality of life item has ten response categories. The greater number of response categories might have allowed these individuals to rate slightly greater QOL that might not translate into statistically significant results.

#### Discussion of Cost Results

While not as strong as the effectiveness results, the results on cost are also an important aspect of the current research. The results suggest that the *Living Well with a Disability* program is effective in reducing health care costs for a subset of the sample that included 93% of the entire cohort. The individuals not included in the trimmed data set reported hospitalizations greater than seven days during the study period, which in effect, put the dollar amounts for their health care three standard deviations above the mean for the entire cohort. Thus, the *Living Well* intervention impacts only healthcare costs only for individuals who did not have extended

hospitalizations during the study period.

The fact that the *Living Well* program was not effective in reducing lengthy hospitalizations during the study period is not surprising. One might expect that the pathology requiring greater than seven days of hospitalization would not respond to a health promotion intervention within a six-month timeframe. In these results, the costs associated with extended hospitalizations increased the variance in the cost outcome results to a level that obfuscated the cost results for the rest of the sample.

Similar to the symptom-day results, we observed a return to baseline for the cost results somewhere between four and 12 months. From an economic perspective, costs savings in the first four months following the intervention recovered the costs of providing the *Living Well* program. Thus, even without effects on cost at 12 months after the intervention, the program is worth funding, especially in light of the effectiveness results that are observed at 12 months post intervention.

Overall, this evaluation indicates the *Living Well with a Disability* program is effective for helping individuals reduce the impact of secondary conditions and for reducing the costs of providing health care services to individuals with disabilities. Individuals report less functional limitation due to secondary conditions and fewer days with symptoms and limitations. However, the importance of these results goes beyond the effectiveness of the intervention. These results demonstrate that an unconventional intervention founded on principles of independent living and delivered through Independent Living Centers may offer an important perspective on addressing aspects of the current health care crisis.

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## **CHAPTER 2**

# **Participant Recruitment from Independent Living Center Consumers, the Media and Medical Service Providers**



## PARTICIPANT RECRUITMENT FROM INDEPENDENT LIVING CENTER CONSUMERS, THE MEDIA, AND MEDICAL SERVICE PROVIDERS

An ongoing problem for disability and health public health programs is recruitment of participants. Health promotion for the general population has similar challenges with attracting prospective clients into services that have the capacity to protect health status (Wardle, et al., 2003; Healthy People 2010). It seems likely that the problems and barriers people with disabilities typically experience with going to public events makes recruiting these individuals even more difficult. Research questions for this exploratory study included: What is the relative effectiveness of five alternative recruitment strategies? Is it possible to engage the medical community to assist with recruitment into health promotion activities for people with disabilities? What is the relative cost-effectiveness of these five alternative approaches?

### **Methods**

#### Sample

We identified 330 centers for independent living (CILs) and mailed materials to each, soliciting participation in all studies of the research. Materials mailed to the centers included a brief description of the research program, the amount of money available for reimbursement to centers for participating in the program, and a brief three-page application packet. Completed and usable applications were received from 106 CILs, representing a 30% response rate to the program announcement.

The research team assembled a panel of reviewers to score the applications, including representatives from the research team, the Office on Disability and Health at CDC, and two national independent living organizations, the Association of Programs for Rural Independent Living (APRIL) and the National Council on Independent Living (NCIL). The reviewers scored all applicants independently and scores for each application were aggregated across reviewers.

A teleconference call was convened with reviewers to select the centers for participation in the study. Nine centers were selected to represent broad geographic distribution across the United States, as well as urban and rural environments.

### Procedures and Materials

In order to prepare facilitators to conduct the *Living Well* program, we invited two staff from each selected center to participate in a 2 ½ day training event in Kansas City, Missouri. In addition to learning how to facilitate the *Living Well* program, staff were also trained in procedures for recruiting participants and recording data.

To facilitate recruitment of participants, we provided materials for staff to use when recruiting individuals into the *Living Well* program. We developed materials for four recruitment strategies including direct marketing to CIL consumers through personal letters, direct marketing to community members through flyers and posters, direct marketing to community members through mass media including newspaper, radio and television, and indirect marketing to consumers through medical service providers. The CIL staff recruited participants using each of the methods outlined above during the 30 days prior to the start date of the workshop.

CIL staff tracked and reported the occurrences of each recruitment strategy they used. Further, when individuals were recruited into the *Living Well* program, staff asked each person how they learned of the program and recorded that information separately.

### **Results**

Of the nine centers selected to participate in the research, one center dropped out of the research due to management difficulties and their inability to complete research activities. During year two, a CIL, independent of the original nine, requested training for the *Living Well* program and, in exchange, agreed to follow the research protocol for recruitment.

We will report results of all recruitment strategies used by the centers first without

reference to the efficacy of these strategies. Then, for the six observations with complete data, we will report the efficacy results for each recruitment strategy. Table 2.1 includes the total occurrence of each recruitment strategy. The total number of participants recruited to participate from these methods was 246. Inspection of the table indicates the intensity of effort CILs put forth to recruit participants.

**Table 2.1 Recruitment Method Implementation**

Recruitment Method	# of Occurrences
Letters sent CIL consumers	1373
Flyers posted in the community	642
Media	
Interviews	20
Fact sheets distributed	275
Press releases	540
Public service announcements	166
Advertisement	20
Total Media Contacts	1021
Medical Providers	
General Practice MD	122
Physiatrist	12
Other MD	82
Nurse	35
Public Health Nurse	28
Social Worker	41
Physical therapist	82
Occupational therapist	50
Respiratory therapist	3
Dietician	0
Pharmacist	11
Medicaid case manager	4
Medical receptionist	0
Total Medical Provider Contacts	470
Spoke directly with participant about the program	445

With eight CILs recruiting subjects in two different calendar years, plus the addition of a center, we had a total of 17 possible recruitment data points. Of these, we collected six useable records from five different centers. These six records included 126 of 240 individuals recruited

for the program. Overall, centers consistently reported on their use of recruitment strategies, but often failed to track how participants were actually recruited. Table 2.2 includes the number of contacts for each of the five recruitment methods, the number of individuals recruited using each method, and the estimate of the cost per person recruited using the recruitment method.

The cost of recruitment for each method was computed as follows. All mailings were computed at fifty cents per piece for copying, postage and materials. Additionally, two hours of staff time per site for mailing preparation was included at \$40 per hour. Next, we allotted two minutes for each flyer or poster delivery, given that flyers were often distributed in bundles. We computed photocopies of materials at \$0.05 per page. Finally, we allotted 10 minutes of staff time per conversation with participants billed at \$40 per hour. Clearly, our conclusions are dependent on our cost assumptions. The reader may wish to apply different cost estimates that more closely reflect the costs of these alternative methods to determine relative cost-effectiveness.

**Table 2.2 Outcomes for each recruitment method**

Recruitment Method	# of Contacts	# Recruited	Percent	Cost per Recruit
Letters sent CIL consumers	639	55	8.6	\$14.54
Flyers posted in the community	250	6	2.4	\$57.64
Media contacts	374	25	6.7	\$26.68
Medical provider contacts	268	2	0.7	\$407.50
Spoke with participants directly	164	38	23.2	\$28.77

Inspection of Table 2.2 suggests substantial and informative differences in the effectiveness of the alternative recruitment methods for the research program. From a cost-effectiveness perspective, the best method was the direct contact of participants via mailings from the CILs. In contrast, mailing program materials to medical professionals for referrals to the program was clearly the worst approach in cost-effectiveness terms.

However, cost is not the only variable on which a service agency might want to

maximize. In some instances, when the size of the target population is small, for example, the proportion of those recruited might be even more important than the cost-effectiveness. From a proportion-effectiveness perspective, the conversations CIL staff had with potential participants were the most effective.

## **Discussion**

This relatively small study of recruitment into the *Living Well* program is instructive and may help future health promotion intervention programs develop strategies for maximizing the cost-effectiveness of recruitment efforts. However, this study had a number of limitations, including a small sample size, self-report of all data by the contractors, non-random sampling of centers and substantial missing data, discouraging generalization of results from this study alone. For this reason, we presented results descriptively to inform future research about recruiting people with disabilities into health promotion programming.

Without suggesting generalization of these results to other recruitment, we will discuss these results as observations from our own experiences in this research program. We can examine these results from two perspectives. First, from a program evaluation perspective, we can consider the efficiency of each recruitment strategy for the proportion of contacts that generated participation. Second, from a payer's perspective, we can consider the cost-efficiency of each recruitment strategy.

Beginning with the proportion of individuals recruited, the recruitment methods that recruit a higher proportion of participants increase the likelihood that the program evaluation results will generalize. In our study, the conversations CIL staff had with potential participants generated a much larger proportion of response than did any of the other strategies. The attempts to enlist the help of medical providers in recruitment generated the lowest proportion of response.

From a payer perspective, the mailings to CIL consumers were the most cost-efficient, and again, the medical provider contacts were least efficient. However, this direct mailing approach required a large pool of potential participants, which may not always be available.

## References

Wardel, J., Williamson, S., McCaffery, K., Sutton, S., Taylor, T., Edwards, R., and Atkin, W. (2003). Increasing attendance at colorectal cancer screening: Testing the efficacy of a mailed, psychoeducational intervention in a community sample of older adults. *Health Psychology, 22*, 99-105.



## **CHAPTER 3**

# **Barriers to Health Promotion: Pain, Fatigue and Environmental Barriers to Participation in Health Promotion Programs**



## BARRIERS TO HEALTH PROMOTION: PAIN, FATIGUE AND ENVIRONMENTAL BARRIERS TO PARTICIPATION IN HEALTH PROMOTION PROGRAMS

Study Three of the research examined the barriers that might be present for individuals with disabling conditions who intend to engage in health promotion activities. People with disabilities face many barriers to engaging in community events, including problems with transportation, building access and having personal care needs addressed. To this end, a barriers instrument was constructed and included in the measurement instruments of the study.

Our research questions were exploratory and included, “What are the most significant and problematic barriers people with disability must address in order to attend a community-based health promotion program?” Further, we wanted to know, “Are participant’s appraisal of barriers prior to engagement in community-based health promotion different from their appraisal of barriers after engagement?”

### **Methods**

#### Participants and Measures

Participants for Study Three were the same as for Study One, however the study was conducted over the extended baseline period and consequently, only includes data for 75 individuals. For Study Three, we examined the potential barriers program participants might face in attempting to access the *Living Well* health promotion program. Working from a previous measure of barriers developed by Stuifbergen, Becker and Sands (1990) we developed an instrument to assess these barriers. This instrument, titled The Disability and Health Perceived Barriers Questionnaire, is a 28-item questionnaire that has individuals rate the degree of difficulty they would have with each of 28 potential barriers for engaging in health promotion. Coefficient alpha for this scale was 0.87 for its application in this study, suggesting the scale has

good internal consistency. This scale measures environmental and interpersonal barriers that might affect an individual's ability to attend a health promotion program. Additionally, this scale assesses secondary conditions such as pain, fatigue, hearing, and reading problems.

### Procedures

The barriers scale was delivered at three time periods, two months before intervention, immediately before intervention and immediately after the intervention, along with the rest of the study outcome measures. The items for the first two measurement periods, which were each a pre-intervention phase, were stated as anticipated problems. The items presented for the post-measure phase were stated as barriers the individual experienced when attending the *Living Well* program.

### **Results**

Overall, results indicated that people with disabilities face substantial barriers to participating in community-based health promotion activities such as the *Living Well* program. Interestingly, however, the participants in this study expected barriers to be a greater problem than they actually experienced them to be.

Descriptively, pain and fatigue were the most problematic barriers faced by individuals who participated in this study. On average, respondents rated pain and fatigue 1.26 and 1.18 out of 3, indicating each as a mild to moderate problem. These average ratings were each statistically greater than the third ranked problem, "My disability is limiting me too much these days." Further, pain and fatigue were statistically more problematic than such problems as need for personal assistance ( $M = .64$ ) and lack of accessible transportation ( $M = .52$ ). Thus, for this sample of individuals who committed to attending a health promotion workshop, secondary conditions of their impairment (e.g. pain and fatigue) are rated as greater problems than problems of the environment. The list of all barriers and their average rating for each time period is

included in Table 3.1. Inspection of this list shows that each mean rating declines from pre- to post- with the exception of the rating for the item, “I’m too busy to take time away from other important activities” which increased slightly.

**Table 3.1 Disability and Health Perceived Barriers Questionnaire item means**

Barrier	2 Pre (n=115)	Pre (n=240)	Post (n=204)
*15. I get tired easily.	1.25	1.26	.76
16. I have pain when I do too much.	1.21	1.18	.63
11. My disability is limiting me too much these days.	.84	.73	.37
26. I will need someone to help me.	.80	.64	.53
9. I don’t have accessible transportation.	.78	.52	.27
13. I lose control over my bowel and bladder	.69	.58	.39
6. The weather is often too bad to get out.	.66	.61	.31
8. Buildings are not accessible to me.	.66	.57	.23
12. I have a hard time thinking and concentrating.	.60	.74	.48
25. My daily self-care needs take too much energy.	.58	.42	.24
2. My neighborhood has too few curb cuts.	.53	.39	.30
7. I have trouble reading printed material.	.49	.54	.35
14. My weight makes it hard to get around.	.40	.42	.26
1. It’s difficult to get in and get out of my house.	.39	.37	.28
4. It would take too long to get to the program.	.39	.37	.26
10. I don’t have the assistive equipment that I need.	.32	.37	.19
18. I have trouble hearing what people say.	.32	.39	.22
5. Chemicals in the environment bother me.	.31	.29	.20
21. I’m too busy to take time away from other	.24	.25	.32
17. I can’t see well enough to get around.	.19	.19	.17
3. It is dangerous for me to leave my house.	.17	.22	.16
20. I will have to take time off from my job.	.17	.17	.11
24. My family will not support my coming.	.12	.15	.10
22. I will have to arrange day care for my children.	.08	.08	.05
28. Other important people will tell me not to come.	.06	.10	.08
23. I take care of another family member.	.05	.11	.08
27. My doctor will not approve of my coming.	.04	.06	.03

\* Numbers correspond to original arrangement within the survey. See Appendix A, pages 26-27.

Beyond descriptively examining the relative severity of barriers, we also examined whether or not individuals would rate the barriers they actually experienced as they attended the program as greater than, equal to, or less than their anticipation of these barriers. To examine this hypothesis, we computed repeated measures ANOVA to examine whether or not the overall

scores on the barriers changed across the three time periods. This analysis indicated that individuals rated their experience of barriers following the program 35% less problematic than their anticipation of barriers at the pre-measure. This difference was statistically significant beyond the .001 level ( $F_{(2,73)} = 10.68, p < .001$ ).

### **Discussion**

This brief study of the barriers our participants expected, and later experienced, as they attended the *Living Well* program is unique in its presentation of common physical limitations with environmental concerns as barriers to participation. As such, it allows us to report on the problems individuals who have agreed to engage in a multi-session health promotion workshop perceive they will encounter. Further, the longitudinal nature of the study allows us to examine differences between expected and experienced problems.

Before examining the implications of these results, we must highlight that the individuals in Study Three are people who have agreed to participate in community-based health promotion. The relative rank-order of barriers listed in this study cannot be generalized to the population of people with disabilities at large. It is very likely that individuals not recruited to attend the program would have a different rank ordering of the barriers, perhaps accounting for their lack of participation in the program. Further, we cannot comment on the differences between those recruited and not recruited based on the results of this study. Nonetheless, these results are important because they speak to the problems expected by individuals who have already committed to engaging in a health promotion program.

Our unique combination of secondary conditions and environmental conditions in this study is instructive. The substantial difference in ratings between these two categories may reflect that many individuals feel more able to address environmental barriers than these somewhat intractable secondary conditions. If so, an important step in the further development

of health promotion for people with disabilities may be development of information for addressing these two secondary conditions. For example, as managed care became more prevalent in the insurance market place, materials began to emerge to help people with disabilities access managed healthcare services. These materials were intended to reduce barriers to quality care by educating people with disabilities about their rights in the managed care context. In a similar way, materials for addressing pain and fatigue could be developed that give people with disabilities a starting place to reduce limitation due to these secondary conditions, thereby increasing their capacity for engaging in health promotion activities.

Also of interest from this study is the difference between anticipated and experienced problems with attending the *Living Well* program. This result may reflect a protective strategy people inadvertently take on when they experience a disabling condition. That is, it may reflect a cautious approach to an environment that all too often does not accommodate their needs. By overestimating the degree of a problem, one is less likely to commit to situations that prove to be uncomfortable at best and perhaps even dangerous. While such a protective strategy may be useful in many situations, when it interrupts an individual's intention to do things that can improve health and decrease disability, it has in fact contributed to the disability.

The lesson learned may be that recruiting people into health and wellness services may include helping individuals examine their anticipated barriers and providing accommodating environments that encourage appropriate "risk taking" for some individuals. This might include using marketing messages that highlight accommodations and expressly minimize the difficulties of participation.

## References

Stuifbergen, A. K., Becker, H., & Sands, D. (1990). Barriers to health promotion for individuals with disabilities. *Family and Community Health*, 11-22.

# **CHAPTER 4**

## **Discussion and Conclusion**



## DISCUSSION AND CONCLUSION

The *Living Well with a Disability* program is a useful health promotion intervention to adults with mobility impairments who wish to reduce the amount of time they are limited by secondary conditions. The results of Study One clearly showed that the reduction in participants' ratings of secondary conditions occurred in response to the intervention. Even more, this reduction was evident 12 months after the conclusion of the intervention. We observed a similar pattern of results on measures of health behavior, symptom days and overall life satisfaction.

In addition to the effectiveness of the *Living Well* program, the results of Study One also suggest the intervention has an impact on an important subset of health care costs. By limiting analysis to data from individuals without extended hospitalizations during the study period, we observed statistically significant decreases in cost during the intervention period and up to four months after the conclusion of the intervention. Examining the cost-benefit to third party payers, we find that the cost of program implementation was recouped within four months of program implementation.

The *Living Well* program rests on different assumptions about the mechanism of health promotion, which may explain the study results. Rather than focusing primarily on health behavior, the *Living Well* program encourages a focus on participation and personal goals first, and then encourages participants to use health behaviors to improve their potential for full participation and goal attainment.

In addition to a unique approach to health promotion, the intervention was conducted in a unique setting. Centers for Independent Living have been helping individuals with disabilities achieve full participation for nearly 25 years. These community-based advocacy and service

agencies are a natural setting for helping adults with disabilities consider the role of health behavior in their goals and daily lives.

Studies Two and Three examined the methods and potential problems of recruiting individuals with disabilities into a health promotion program. The results of Study Two suggest that, in addition to being an effective setting for conducting health promotion, CILs are also effective at recruiting individuals into health promotion services. Study Three suggested that the central problems to participation that people with disabilities face when they intend to engage in CIL based health promotion are pain and fatigue. Combined, these two studies suggest it may be useful to develop materials that CILs can use to help their consumers address pain and fatigue issues as a component of recruiting individuals with disabilities into health promotion programming.

In conclusion, when delivered through Centers for Independent Living, *the Living Well with a Disability* program appears to be effective in helping to control health care costs. Both the content and delivery of the program are unique, which may contribute to its success. Funding for the program is currently available through a few State Departments of Health. Additional funding mechanisms will be required for broader program dissemination so that all people who live with a disability can Live Well.

## **Chapter 5**

# **Behavioral Strategies for Maintaining and Building on Health Gains**



## BEHAVIORAL STRATEGIES FOR MAINTAINING AND BUILDING ON HEALTH GAINS

The purpose of Study Four was to increase participants' maintenance of improved health outcomes achieved through the *Living Well with a Disability* (LWWD) program intervention. Much research has been conducted to identify how individuals can effectively make and maintain changes in their behavior. Specific research has focused on several techniques such as self-monitoring (Schultz, 1993), peer counseling (Porzelius, Houston, Smith, & Arfken, 1995; Sloane & Zimmer, 1993) and goal setting (Fiester, 1979; Balcazar, Fawcett, & Seekins, 1991) to determine their effectiveness in making long-term change. Goal-setting and self-monitoring have been two strategies that have successfully been used by people with disabilities (Gleason, Michals, Matalon, & Langenberg, 1992; Schultz, 1993; Camaione, Burns, & Chatterton, 1997; Rathouz et al., 1998). Self-monitoring has been used extensively in behavioral treatment for smoking cessation (Niaura, Marcus, Albrech, Thompson, & Abrams, 1998) and weight loss and weight control in persons who are obese (Foreyt & Goodrick, 1994; Foreyt & Poston, 1998; Jette et al., 1999; Mattfeldt-Berman et al., 1999). It has also been used in diet and exercise interventions (Hayes, 1997; Smith, 1996).

Peer support has also been shown as an effective method of facilitating personal change, self-management, and adjustment for people with disabilities (Beyers-Lang & McCall, 1993; Felton, Stastny, Shern, & Blanch, 1995; Griffin & Martin, 1979). According to Berkman (1995) a substantial body of evidence indicates that “the extent to which social relationships are strong and supportive is related to the health of individuals who live within such social contexts” (p. 245). An environment that supports change is recognized as a necessary step for long-term maintenance of healthy behaviors, since healthy people tend to have an extensive social network and therefore, tend to report more positive health practices (Redland & Stuifbergen, 1993). There is a high correlation between the success of individual participation in social-support programs,

and the positive effect of peer social influence during follow-up of behavior-change interventions (Berkman, 1995). Social support is one of six dimensions of the health-promoting lifestyle proposed by Walker, Sechrist, and Pender (1987). It has been used to address a variety of health-related behaviors, including obesity, smoking, and alcoholism (Coletti & Brownell, 1982) and is an important factor in the acquisition and maintenance of physical activity behaviors (Strecher et al., 1995). The use of social support has successfully helped individuals develop self-management programs to reduce the impact of chronic illness on functional capacity (Lorig, Mazonson, & Holman, 1993). Social support has also been designed to help people cope with chronic conditions such as Multiple Sclerosis (Clark et al., 1992; Lorig, Mazonson, & Holman, 1993). The most efficient application of social support in behavior change has been in the area of weight control programs (Redland & Stuijbergen, 1993; Stahnik et al., 1990).

The original purpose of Study Four was to determine the relative effectiveness of two different interventions that were used alone and in combination to increase the likelihood of maintaining any behavioral health gains that were previously acquired through the *Living Well with a Disability* (LWWD) intervention. After receiving the cooperative agreement and in further discussion with all project members, the original approach was modified to examine the differential effects of participants who went through the LWWD program alone versus those who participated in both the LWWD program and the Maintenance (later named Maintenance Plus) program. As indicated earlier, researchers for this study changed the study from just focusing on maintenance to Maintenance Plus. The “plus” component suggests that in addition to strategies for maintaining goals for increased health and independence of LWWD participants, there was something else, hence the “plus” designation.

In following up with participants after their completion of the LWWD program, it was noted that besides continuing with the maintenance package (consisting of self-reinforcement

and social support), participants needed to re-examine their originally set goals. This was due to a number of reasons, including unclearly specified goals they may have originally set, goal abandonment, goal modification, and a need for setting new goals if previous goals were already accomplished. Work with pilot groups in Springfield, Missouri, and Columbia, Missouri, helped to determine that additional work (i.e., a booster session) on goal-setting was needed as another component of the maintenance program.

## **Methods**

### Participants

Study participants were two hundred and forty-six individuals with physical disabilities, also called consumers, who were recruited by facilitators from nine Centers for Independent Living (CIL) around the United States. All participants were between the ages of sixteen and eighty-four, with a mean age of forty-five years old. Two-thirds of the participants were between the ages of thirty-two and fifty-eight. Consumers originally participated in LWWD training to achieve their personal goals and become healthier. After the participants of the LWWD training completed the 8-week workshop, they were given the option to continue working on their goals by attending an additional Maintenance Plus program. All two hundred and forty-six participants participated in the LWWD program. Only forty-four participants elected to continue on and participate in the Maintenance Plus booster program (M+).

Experimental groups were defined by whether or not the participant participated in the Maintenance Plus condition. Those consumers who only participated in the LWWD program constituted the control group (LWWD). Those participants who self-selected to continue on and complete the Maintenance Plus intervention made up the treatment group (M+).

*LWWD participant recruitment.* Participant recruitment consisted of CIL facilitators contacting people with physical disabilities who actively participated in CIL activities. Centers

for Independent Living are not residences. Rather, they are storefront operations that offer independent living services such as advocacy, skills training, information and referral, etc. to their consumers. Interested CIL participants were randomly assigned to one of multiple LWWD workshops, each of which lasted eight weeks.

*Maintenance Plus participant recruitment.* After participants completed the LWWD workshop, they were invited to return to the CIL three weeks later to attend the first meeting of the Maintenance Plus (M+) sessions. Thus, all participants in the Maintenance Plus program were self-selected rather than randomly assigned. The second M+ session was held 2 weeks later followed by sessions three and four, which followed at one-month intervals. Maintenance Plus was designed to fade facilitator involvement while empowering participants to independently pursue goal attainment in their natural environment over a three-month period that began after the completion of the LWWD program. Figure 1 outlines the sequence of events for all study participants.

### Procedures

The Maintenance Plus intervention was a multi-component treatment package designed to increase participants' goal-setting achievement. This package consisted of: a) "Chapter 11: Maintenance Plus" from the LWWD program manual, b) Maintenance Plus facilitator's guide, and c) Maintenance Plus program components including goal book for self-monitoring, goal club for social support, and mailed prompt and reward cards. The Maintenance Plus program was developed in a format similar to other chapters in the LWWD manual in order to maintain consistency across materials.

Figure 1. **Study timeline including meeting dates and survey administrations.**

In Chapter 11, participants were provided with descriptions on how to enhance personal goals and maintain their progress towards reaching personal goals. This chapter included descriptions of the Maintenance Plus components including the goal book, goal club, and the importance and application of these components. Participants were provided with examples of efficient and inefficient goal planning, and operational definitions of the goal, task, and steps. The following definitions are also presented in “Chapter 11: Maintenance Plus”.

Goal: A goal is a targeted area of your life that you want to change. The goal is the end of the pathway, a long-term objective, and to achieve it you need to successfully complete a certain number of tasks, necessary steps, and overcome any obstacles. Once the tasks (and the steps to achieve them) are completed and the obstacles are overcome, you will have achieved your goal.

Task: Once you have identified your goal, you break it down into smaller units, which are called tasks. The task is a short-term objective, a sub goal as opposed to the goal, which is a long-term objective. The task will help you structure the way you tackle your goals.

Steps: Steps are the components of a task. Steps are the small, measurable, and very specific behaviors that you will be working with on a daily basis to achieve your task, and are the ones that will help you achieve your goal.

*The Maintenance Plus Facilitator Guide.* Facilitators were provided with a facilitator guide, which was an outlined version of the Maintenance Plus chapter. To the left of each key teaching point was a small box that the facilitator was instructed to check once the item was covered during the workshop. This checklist procedure was designed as a completeness check to

ensure that the chapter contents were completely covered during the training sessions. It also served as a validation check on how consistently the intervention was carried-out. In addition to the facilitator guide, overheads of the different topics to be covered during the meetings (e.g., goal book, self-reinforcement, efficient and inefficient goal examples, etc.), as outlined in chapter 11, were given to the CIL facilitators.

*Additional Maintenance Plus Components.* In addition to receiving the Maintenance Plus chapter, participants also received three other Maintenance Plus components: goal book (a self-monitoring device), Goal Club (a social support system to encourage goal attainment and maintenance), and mailed prompts and reward cards.

The goal book contained many of the same features of a regular bank checkbook (with carbon copies and a register for “deposits”). The goal book complemented the goal-setting chapter, and this format allowed participants to write in the steps that they needed to complete in order to make progress towards their goal achievement each week. Participants were encouraged to complete each new goal book sheet on the same day each week, circling the appropriate number to indicate how much progress they made toward achieving each of their specific steps (i.e., none = 0, some = 1, all = 2). The total numbers of points were then added and transferred to the check register. The register contained the total number of points that participants earned, and could be used when participants wished to reward themselves by subtracting points for self-rewards (e.g., 25 points for a compact disc).

Goal Club met four times. The first meeting was two weeks after completion of the LWWD workshop; the second meeting was conducted two weeks after the first meeting, or four weeks after the completion of the LWWD program; and the third and fourth meetings were held at one-month intervals, eight weeks and twelve weeks after the completion of the LWWD program. Figure 1 shows the frequency of Goal Club meetings. Meetings were scheduled this

way so that the participants and the facilitators could fade from this arranged social support in a systematic fashion.

The first Goal Club meeting was structured to allow participants to reassess and clarify the goals they set during the LWWD workshop. Specifically, participants were instructed to review their original goals to: (a) modify them, (b) abandon them, and (c) if they have achieved an original goal, to set a new one. To help participants reassess their goals, facilitators provided materials that included three key components. First, a copy of the blue goal sheet was given to participants to identify their goals, tasks, and develop the steps towards goal achievement. The blue goal sheet was a component of the original LWWD workshop. Second, a laminated pathway planner chart served as a visual aid regarding participants' progress on their goals, tasks, and steps. Participants received a dry erasable pen to update their current steps on the laminated chart each week, and were encouraged to place the laminated pathway planner in an area where they would see it often (e.g., the refrigerator door). Finally, participants received exemplars of how to write goals, tasks, and steps in an efficient and measurable manner. These examples were provided in several interest areas (e.g., health, employment, housing).

Throughout Goal Club meetings, identified participants discussed progress on their tasks and steps and discussed obstacles to goal attainment. Participants also identified future steps they would take toward goal completion during Goal Club meetings.

*Prompt and reward cards.* Researchers requested that participants send in a carbon-less copy of their goal book every week so that the researchers could measure the progress the consumers were making on their steps toward goal-attainment. If participants did not return their weekly goal book forms, a reminder postcard was sent to prompt them to complete their goal books. When researchers received the weekly goal book sheets, a postcard was sent to participants to acknowledge receipt of their goal book sheets and to provide a positive statement

to them on the achievement of their weekly steps (part of the intervention). Participants kept track of their own goal progress by entering the appropriate points in the goal book register. These points were based on the points earned on their goal book sheets each week.

*LWWD Survey.* Periodically, colleagues from the University of Montana administered a 27-page survey to all LWWD participants by mailing a form to their home address according to the schedule in Figure 1. The first administration of the survey (“A”) referred to a period of time two months before the start of the LWWD program. According to the study design, half of the participants started the LWWD program immediately upon recruitment. For these consumers, the survey was administered at recruitment, but participants were asked to respond retrospectively, considering the time period two months prior to recruitment into the program. For logistical purposes, the other half of the participants did not start the LWWD program until two months after recruitment, or after the other half of the participants had finished the LWWD program. They were also administered the survey at recruitment. However, for these consumers, the survey instructions were to reflect on their current state that was truly two months prior to the beginning of the LWWD program. See Study One of this Report for further details.

The second administration of the survey (“B”) occurred during the first week of the LWWD program and served as the baseline measure for the LWWD program. For the half of the participants who began the LWWD program immediately following recruitment, this administration coincided with the survey administration for time A. For the half of the participants who had a two-month delay in beginning LWWD, the time B administration occurred two months after the time A administration.

The rest of the survey administrations occurred at the same relative position of study participation for both the immediate-start group and the delayed-start group. The third administration occurred during the last week of the LWWD program (“C”) and constituted the

post-test administration for the LWWD program. Three follow-up versions of the survey were administered as well: two months since the end of LWWD (“D”), four months since the end of LWWD (“E”), and one year after the completion of the LWWD program (“F”).

Surveys administered at times C, D, E, and F differed from earlier administrations in that they contained two additional pages with questions specifically related to goal behavior. Figure 1 illustrates how survey administrations relatively corresponded with LWWD and M+ meetings over the course of the study.

Surveys were mailed to the participant at their home address and were to be returned by mail. Each participant was paid ten dollars each for every survey administration that they completed and returned.

A copy of the survey itself can be found in Appendix A. The survey contains demographic questions including health care coverage and primary disability information. It also contains Likert-type questions regarding overall health and independence, the frequency of occurrence of several secondary conditions, the frequency of health care service use, medication use, costs of medical care, income, health status, support needs and life satisfaction, limitations, feelings, personal habits, potential problems with attending the program itself, and goal behavior.

### Analysis

All analyses focus on the comparison of mean differences between those participants who only completed the LWWD program versus those who self-selected to participate in the Maintenance Plus intervention. The data collected in addressing the research questions for this study lent themselves to three categories of information in need of analysis: information provided by the Goal Book and Goal Club attendance, variables from the LWWD survey that address specific goal-related behavior, and those questions from the same survey that address issues related to general health and independence.

*Goal book and Goal Club attendance.* Information obtained from the returned goal books and the attendance records from the Goal Club meetings were investigated in a separate pilot research project conducted using a multiple baseline analysis design. The methods, results, and discussion from this study are contained in a completed thesis. Since the main intent of Study Four was to investigate the differences between participants who were involved with the Living Well with a Disability (LWWD) program compared to those who completed the LWWD program as well as the Maintenance Plus intervention, the results of the pilot research are not included in this report. Instead, readers are referenced to a completed thesis by Vivian Chapman, which was defended in Spring of 2001. The complete results of this pilot study are available upon request.

*Goal behavior.* Goal behavior was operationalized as a summary of several individual items from the periodic LWWD survey instrument. An additional question addressing the frequency that a participant works towards achieving long-term goals was analyzed separately from the summary measure. The other individual questions were analyzed as well, but due to experiment-wise error-rate concerns, any resulting information was taken as purely descriptive. Table 1 describes all of the individual items that were used and the location within the instrument.

The composite Goal Behavior variable was created by summing the following variables in the following manner. The variables “Work” and “Reward” are both yes/no questions, so they received one point each for an affirmative response. The variables “#Set” and “#Met” are both discrete ratio variables and could range from zero to a reasonable positive number, so they contributed the total number of goals that were set and the total number of goals that were met for that particular time period. “Import” and “Prog” will be re-scaled to 0-4 instead of 1-5, multiplied together, and divided by four. The multiplication was done to reflect the interactive

nature of the two questions, and the division prevented these two variables from inflating the summary score.

**Table 1. Variables related to goal behavior**

Label	Page	#	Description	Score
Long	23	30	“How often do you...work towards long-term goals in (your) life?”	1-4
#Set	27	2	“Did you set any goals in the last two months? What were these goals?”	0+
#Met	27	3b	“How many goals have you met in the last two months?”	0+
Reward	27	4	“In the last two months, did you reward yourself for any progress on your targeted goals?”	0/1
Import	28	5	“How important is the attainment of these goals to you?”	1-5
Prog	28	6	“How satisfied are you with the progress/outcome of these goals”	1-5
Work	28	9	“Are you still actively working to achieve any of your goals?”	0/1

*Health variables.* Health-related variables were further divided into three “families” of inquiry: secondary conditions, health and independence, and emotional support and life satisfaction. Within these “families”, efforts to minimize any experiment-wise error rate concerns were made.

*Secondary conditions.* The LWWD survey contains questions that address the severity and frequency of forty-three secondary conditions. Only six of those forty-three secondary conditions were of interest in this study. The six secondary conditions of interest can be found in the first part of Table 2. To control for experiment-wise error in this family of items, two summary scores were created. First, the Likert scores for the six conditions of interest were

summed to create the variable “SCsum”. Analyses in other related studies used all forty-three secondary conditions, so a summary variable was created that encapsulated all conditions addressed by the survey – variable “SCsum-A”. Both summary variables were analyzed to address the study hypotheses related to goal behavior. The six secondary conditions of interest were analyzed as well but only for descriptive purposes.

*Health and independence.* Six items in the LWWD survey address health and independence issues. Three of those items are Likert scale items and three are measured on a continuous scale. All six items were analyzed separately. These items can be found in the middle of Table 2.

*Emotional support and life satisfaction.* Two questions on the LWWD survey addressed whether a participant received the necessary emotional support and how satisfied that person was with his or her life. These items were also addressed separately. These questions are summarized at the bottom of Table 2.

*Mixed Model Analysis.* A mixed linear model was fit for each variable of interest. The benefit to this study of a mixed linear model over a general linear model is that a mixed linear model allows the researcher to account for the missing data that occurs in this type of longitudinal research.

**Table 2. Variables related to health and independence**

Label	Page	#	Description	Score
<b>Secondary Conditions</b>				
Depression	7		Depression	0-3
Pain	7		Chronic Pain	0-3
UTI	5		Urinary Tract Infection	0-3
Eating	5		Eating or Weight Problems	0-3
Cond	5		Physical Fitness or Conditioning Problems	0-3
Sores	3		Pressure Sores	0-3
SCsum	--		Sum of above 6 Secondary Conditions	0+
SCsum-A	--		Sum of All Secondary Conditions	0+
<b>Health and Independence</b>				
H-rate	2	2	"... would you say your HEALTH over the past two months was...?"	1-4
Ind	2	2	"... would you say your ability to INDEPENDENTLY engage in desired activities... over the past two months was...?"	1-4
H-status	16	1	"In general, how would you rate your health?"	0-4
Health	16	2	"... for how many days during the past 30 days was your physical health not good?"	0-30
Mental	16	3	"... for how many days in the past 30 days was your mental health not good?"	0-30
Act	16	4	"... for how many days in the past 30 days did poor physical or mental health keep you from doing your usual activities?"	0-30
<b>Emotional Support and Life Satisfaction</b>				
Soc	16	5	"How often do you get the social and emotional support you need?"	4-1
Life	16	6	"In general, how satisfied are you with your life?"	4-1

The mixed model used here contains a covariate and three fixed effects. Due to the self-selecting nature of the experimental group, an attempt was made to remove any participant characteristics that existed prior to participation in the study. Depending on the variable of interest, a “baseline” score on that particular variable, taken at time C, was used as the covariate. The model then tested a fixed effect of treatment (LWWD-only versus LWWD and M+), a linear effect of time elapsed since the beginning of the LWWD program (in weeks), and the interaction effect between the treatment and time. Time elapsed can be treated as a continuous variable or as a discrete variable in this case, but time treated as a continuous variable is more meaningful when the research question involves the analysis of a trend over time. Since the focus of this study was to evaluate differences between the conditions at varying time-points, time was treated as a discrete variable. The time periods that were examined depend on the covariate. Since C was the covariate, then the time effect only reflects times D through F. An example of the SAS syntax used in this analysis that details the exact model specifications used is as follows.

```
PROC MIXED;  
  
class id treatment time; /* DISCRETE treatment of time */  
  
model variable = covariate treatment time treatment*time /solution ddfm=BW;  
repeated / type=vc subject=id;  
  
run;
```

*Follow-up investigations.* In the event that the mixed model analysis of a variable of interest that is a composite or summary of individual survey items was found to contain statistically non-significant effects, the individual items were analyzed to see if any interesting information was lost in creating the summary variable. However, as stated above, any results from such analyses were taken as descriptive due to experiment-wise error rate concerns.

*Completers versus study dropouts.* Due to the longitudinal nature of the study, some

participants invariably discontinued study participation, and more participants stopped participating the further time progressed beyond the completion of the LWWD program or the M+ intervention (depending on the comparison group). A descriptive analysis was undertaken to address the characteristics of the consumers who dropped out at various times in the study versus those, in either comparison group, who completed the study through time F.

For both comparison groups (LWWD-only and M+), sub-samples were identified that represented those participants who turned in a survey at C and failed to return any subsequent surveys, those who turned in surveys through D and then dropped out, those who turned in surveys through E but failed to return F, and those consumers that completed the study as indicated by the return of survey F. However, although a participant returned survey F, they may not have returned every survey prior to F, so missing data may occur prior to study attrition. For each sub-sample and on each variable of interest, a mean score was determined based on available data and a plot of means was inspected for descriptive trends that illuminate the phenomenon under investigation. It is important to emphasize that these analyses were only descriptive in light of multiplicity concerns, sample size limitations, and in some cases, excessive missing data. Figures are provided to visually illustrate any notable relationships, and tables of means are presented as well.

## **Results**

### **Participants**

Due in large part to the non-random assignment to conditions that occurred, and the largely disproportionate numbers of participants who participated in only the LWWD program versus those who continued on into the M+ condition, a smaller sample was selected from the total sample based on specific matching criteria: age (within +/- five years), gender, and type of primary disability. This resulted in a matched sample consisting of seventy-eight participants –

thirty-nine participants who only completed the LWWD program, and thirty-nine participants who completed both the LWWD program and the M+ program.

*Matched sample characteristics.* The matched sample was comprised of thirty-two males and forty-six females, evenly split between the two conditions. The mean age of consumers in the matched sample who only completed the LWWD program was 46.05 versus a mean age of 45.79 for those who continued into the M+ intervention. The mean age difference was not statistically significant,  $t(76) = .086$ ,  $p = .931$ . Some participants had more than one type of disability, but when matching occurred, it was done so on the basis of the primary disability. Table 3 illustrates the proportion of disabilities across the LWWD-only and the Maintenance Plus groups. Chi-square tests of homogeneity of proportions show that the frequencies of occurrence of all types of primary disabilities were not significantly different between groups.

**Table 3. Frequency of disabilities between conditions in the matched sample**

Primary Disability	LWWD-only	LWWD w/ M+	Chi-square	df	Sig.
Amputee	1	2	0.347	1	0.556
Cerebral Palsy	7	6	0.092	1	0.761
Multiple Sclerosis	7	5	0.394	1	0.530
Post Polio	3	3	0.000	1	1.000
Arthritis	5	5	0.000	1	1.000
Cardio-Pulmonary Disorder	2	0	2.053	1	0.152
Muscular Dystrophy	4	4	0.000	1	1.000
Spinal Cord Injury	10	12	0.253	1	0.615

	LWWD-only	LWWD w/ M+	Chi-square	df	Sig.
<hr/>					
<b>Other Disabilities</b>					
<hr/>					
Leg problems	1	1			
Diabetes		2			
Charcot Marie	1				
Lyme Disease		1			
Still's Disease	1				
Ataxia		1			
Auto accident	1				
Back & neck injuries	2				
Eyesight		2			
Brain injury		1			
Cerebellar degeneration		1			
Generalized dystonia		1			
Spina bifida	1	1			
Spinal disease	1				
Tardive akathisia	1				
<hr/>					

*Goal behavior.* Table 4 illustrates the mean levels for the Goal Behavior summary variable, the independent question from the survey (LONG), and the variables that contributed to the Goal Behavior summary variable. These mean levels reported here are for time B, the LWWD pre-test, and for time C, the LWWD post-test. Since the variable LONG appeared in the body of the survey, it was assessed at all time points. The rest of the goal-related items appeared in the last two pages that were only included in the survey from administration C on. For consistency, only the information at C will be used for covariate purposes.

A plot of the means indicated that there might be mean differences between the comparison groups at the completion of the LWWD program (time C). Independent samples Student's *t* tests were conducted to determine whether visible mean differences were statistically significant. As can be seen in Table 4, there were no significant mean differences between

comparison groups on any of the variables related to goal behavior. This suggests that there may not be a need for using data at time C as a covariate to adjust for pre-existing comparison group differences. However, in light of the self-selected nature of the sample, the covariate was still included in the mixed model analysis in order to control for any potential initial group differences.

Table 4. **Mean score on goal behavior variables at pre- and post- LWWD**

Variable	<u>Pre-LWWD</u>					<u>Post-LWWD</u>				
	LWWD- Only	LWWD w/ M+	t	df	Sig.	LWWD- Only	LWWD w/ M+	t	df	Sig.
Long	3.14	2.76	1.79	73	.08	3.06	3.22	-.85	67	.40
#Set	--	--	--	--	--	1.57	1.58	-.02	59	.98
#Met	--	--	--	--	--	1.39	1.67	-.60	40	.55
Reward	--	--	--	--	--	.61	0.60	0.11	64	.92
Import	--	--	--	--	--	4.68	4.46	1.25	66	.22
Prog	--	--	--	--	--	3.90	3.43	1.80	66	.08
Work	--	--	--	--	--	.97	0.94	0.48	64	.63
Goal Behavior	--	--	--	--	--	7.34	7.05	0.29	36	.77

*Mixed model analysis.* When participants' scores at time C were controlled for involving the question, "How often do you...work towards long-term goals in (your) life?" all effects were not statistically significant: treatment -  $F(1,65) = 0.12$ ,  $p = .7308$ ; time -  $F(2,93) = 0.68$ ,  $p = .5096$ ; and interaction -  $F(2,93) = 0.68$ ,  $p = .5111$ . As with the LONG variable, all effects for the summary goal behavior variable were non-significant at the  $p < .05$  level, but the time effect and the interaction could be considered marginally significant and warrant further inspection:

treatment -  $F(1,24) = 2.11, p = .1588$ ; time -  $F(2,20) = 3.08, p = .0684$ ; and interaction –  $F(2,20) = 3.39, p = .0540$ .

*Follow-up investigations.* In light of the marginal effects found with the Goal Behavior variable, and for descriptive purposes only, mixed model analyses were also conducted on the individual variables that comprise the summary Goal Behavior variable. However, while the covariate was significant for all individual variables, none of the main effects or interaction effects were even marginally significant. In search of some understanding as to the marginal effects that were observed in the summary variable, a detailed investigation was undertaken to understand what might have occurred between the groups taking the unfortunate situation of participant attrition into consideration. Table 5 is a table of means by comparison group and subgroup for all variables for which follow-up analyses were conducted. Visual representations of the relationships can be found in Figure 2.

**Table 5. Mean scores and sample sizes (*n*) by comparison group for goal behavior variables**

		LWWD-only					Maintenance Plus				
		Survey					Survey				
		<i>n</i>	C	D	E	F	<i>n</i>	C	D	E	F
Goal Behavior	All	39	7.34	7.58	10.48	9.71	39	7.05	8.15	8.17	7.54
	Comp	7	8.30	8.17	11.00	9.71	12	7.67	8.32	9.06	7.54
	After E	7	6.50	8.00	10.18		10	6.62	8.05	7.45	
	After D	4	8.00	6.94							
	After C	7	6.71								
#Set	All	39	1.57	1.32	1.94	1.76	39	1.58	1.71	1.73	1.82
	Comp	17	1.47	1.33	1.92	1.76	17	1.65	1.87	2.00	1.82
	After E	4	1.33	2.00	2.00		12	1.50	1.54	1.42	
	After D	4	2.00	0.75							
	After C	7	1.86								
#Met	All	39	1.39	1.21	2.30	2.50	39	1.67	1.64	2.06	1.58
	Comp	10	1.57	1.60	4.57	2.50	19	2.00	1.50	2.33	1.58
	After E	13	0.33	0.25	1.08		9	1.33	1.80	1.78	
	After D	5	1.67	1.60							
	After C	2	3.50								
Prog	All	39	3.90	3.58	3.79	3.79	39	3.43	3.84	3.68	3.64
	Comp	19	3.89	3.65	4.06	3.79	25	3.42	3.91	3.73	3.64
	After E	7	3.83	3.40	3.14		12	3.46	3.70	3.58	
	After D	4	3.33	3.50							
	After C	3	4.67								

Import	All	39	4.68	4.08	4.33	4.68	39	4.46	4.52	4.27	4.19
	Comp	19	4.63	4.22	4.53	4.68	26	4.56	4.65	4.55	4.19
	After E	7	5.00	3.40	3.86		11	4.25	4.20	3.73	
	After D	3	4.00	4.33							
	After C	4	4.75								
Reward	All	39	0.61	0.54	0.52	0.61	39	0.60	0.73	0.65	0.58
	Comp	18	0.65	0.47	0.60	0.61	24	0.61	0.81	0.59	0.58
	After E	10	0.44	0.63	0.40		12	0.58	0.58	0.75	
	After D	3	0.67	0.67							
	After C	2	1.00								
Work	All	39	0.97	0.77	0.88	0.83	39	0.94	0.94	0.88	0.92
	Comp	18	1.00	0.81	0.88	0.83	25	1.00	1.00	0.95	0.92
	After E	10	0.89	0.75	0.90		12	0.85	0.82	0.75	
	After D	2	1.00	0.50							
	After C	2	1.00								

*Completers versus study dropouts.* Nineteen consumers in the LWWD-only comparison group completed the study, as defined by completing a survey at F. For this sub-sample, a slight decrease from C to D followed by a strong rebound from D to E and a strong decrease to F was observed for the Goal Behavior variable. The same pattern was also true for the number of goals set (#Set), working toward goals (WORK), number of goals met (#Met), and goal progress satisfaction (Prog) variables. For goal importance (Import), there is mean increase from E to F, and for rewarding goals (Reward), there does not appear to a change from E to F.

Twenty-five consumers who self-selected to participate in the Maintenance Plus intervention showed a moderate increase from C to D and also from D to E followed by a slight decrease from E to F for the goal behavior variable and number of goals set. For the number of met goals, the pattern is similar to those consumers in the LWWD-only group: a slight decrease to D, a slight increase to E, and then a slight decrease through F. For goal progress satisfaction, there is an increase from C to D, then participants' satisfaction decreases slightly from D to E, and satisfaction continues to decrease from E to F. In terms of working towards goals and the importance of goals, means stay relatively constant from C to D then decreases slightly from D to E and from E to F.

Figure 2. **Mean plots for goal behavior variables used in follow-up analyses**

Seven consumers who only participated in the LWWD program elected to discontinue participation after E. They showed a strong increase in goal behavior from C to D and D to E.

Consumers who participated in the Maintenance Plus intervention but dropped out after E ( $n = 12$ ) showed steady behavior over the course of the study in terms of goal behavior. They showed moderate increases in comprehensive goal behavior from C to D with a slight decrease from D to E, a pattern that is reflected in the number of set goals and their satisfaction with their progress. They show slight increases in the number of met goals across the three time points, while showing some decrease in working towards their goals and the importance.

Four participants from the LWWD-only group dropped out of the study after D. This group had a decrease in goal behavior. They met an average of 1.5 goals at time C and time D and showed a slight increase in their satisfaction with goal progress and with goal importance. They were quite steady and had relatively high means on rewarding themselves.

Only one participant in the Maintenance Plus group dropped out at after D. The M+ group was still in the midst of the intervention, so attrition could be expected to be minimal for this group, while the LWWD-only group had been finished with any type of group meetings for two months at that point.

*Health variables.* Table 6 illustrates the mean levels for the Health and Independence variables, including secondary condition, emotional support, and life satisfaction variables. Like Table 4, these mean levels are for time “B”, the LWWD pre-test, and for time “C”, the LWWD post-test, and were used to evaluate the need for a covariate in the mixed model analyses. All variables in the section appeared in the body of the survey and were assessed at all time points. As can be seen in Table 6, there were no significant mean differences between comparison groups on any of the variables related to health and independence. However, to be conservative, the covariate was still included in the mixed model analysis.

**Table 6. Mean score on health and independence variables at pre- and post- LWWD**

Variable	<u>Pre-LWWD</u>					<u>Post-LWWD</u>				
	LWWD- Only	LWWD w/ M+	t	df	Sig.	LWWD- Only	LWWD w/ M+	t	df	Sig.
<u>Secondary Conditions</u>										
Depression	1.13	0.82	1.34	76	.18	1.09	0.76	1.36	68	.18
Pain	1.36	1.33	0.09	76	.93	1.36	1.22	0.53	68	.60
UTI	0.50	0.59	-.45	75	.65	0.55	0.43	0.62	68	.54
Eating	1.39	0.92	1.84	73	.07	1.18	1.00	0.73	68	.47
Cond	1.72	1.49	0.85	76	.40	1.73	1.43	1.06	68	.29
Sores	0.39	0.24	0.91	74	.36	0.36	0.22	0.90	68	.37
SCsum	6.46	5.53	1.04	71	.30	6.27	5.05	1.35	68	.18
SCsumA	31.2	29.5	0.43	76	.67	30.5	24.7	1.37	68	.18
<u>Health and Independence</u>										
H-rate	3.00	2.94	0.22	73	.83	2.94	3.03	-.35	68	.73
Ind	2.69	2.59	0.49	76	.63	2.42	2.41	0.10	68	.93
H-status	2.39	2.33	0.32	75	.75	2.33	2.30	0.19	68	.85
Health	9.90	9.11	0.34	74	.73	8.31	7.46	0.37	67	.71
Mental	9.05	6.38	1.21	73	.23	8.50	4.56	1.98	66	.05
Act	8.00	7.22	0.34	72	.74	6.13	6.76	-.26	67	.80
<u>Emotional Support and Life Satisfaction</u>										
Soc	2.37	2.42	-.26	74	.79	2.28	2.30	-.08	67	.94
Life	2.16	2.22	-.34	73	.73	2.00	2.05	-.32	67	.75

The *t* test on the “Mental” variable had a *p*-value that rounded down to .05 (from .052) for the post-LWWD data (time C). Although this result may be considered in isolation as a marginal significance, there were no adjustments made to control the Type I error-rate in this set of thirty-two separate analyses. In addition, to be conservative, all covariates are included in the

mixed model analyses anyway. Consequently, the marginal significance of the “Mental” variable *t* test does not merit any further consideration.

*Mixed model analyses: Secondary conditions.* As with the goal behavior variables, for the sum of the six secondary conditions of interest, once scores at time C were controlled for there were no significant effects: treatment –  $F(1,63) = 0.16, p = .6920$ ; time –  $F(2,86) = 0.22, p = .8030$ ; and interaction –  $F(2,86) = 0.52, p = .5955$ . The results for the sum of all forty-three secondary conditions were the same as for the sum of the six principal conditions: treatment –  $F(1,66) = 0.57, p = .4530$ ; time –  $F(2,98) = 0.99, p = .3749$ ; and interaction –  $F(2,98) = 0.26, p = .7682$ .

*Follow-up investigations.* Even though there were no significant effects found in the mixed model analysis of the secondary condition summary variables, for descriptive purposes only, mixed model analyses were also conducted on the six individual secondary condition variables of interest. However, while the covariate was significant for all individual variables, none of the main effects or interaction effects were even marginally significant. To ensure a comprehensive look into the data, a detailed investigation was undertaken in a manner similar to the follow-up procedure employed with the goal behavior variables above to understand what might have occurred between the comparison groups and in light of the unfortunate situation of participant attrition. Table 7 summarizes the mean scores for all variables and sub-groups and Figure 3 visually represents the relationships.

*Completers versus study dropouts.* For all of the secondary condition variables, both individual and summary types, a lower score is considered as healthier and/or better.

Figure 3. **Mean plots for secondary condition variables used in follow-up analyses**

Table 7. Mean scores and sample sizes (*n*) by comparison group for secondary conditions

		LWWD-only						Maintenance Plus					
		Survey						Survey					
		<i>n</i>	B	C	D	E	F	<i>n</i>	B	C	D	E	F
SCsum	All	39	6.46	6.27	6.04	5.39	5.25	39	5.53	5.05	4.34	4.58	5.65
	Comp	--						20	5.89	5.37	5.00	5.12	5.65
	After E	--		Not investigated				19	5.17	4.72	3.50	3.93	
Sores	All	39	0.39	0.36	0.54	0.25	0.29	39	0.24	0.22	0.24	0.33	0.21
	Comp	--						24	0.09	0.26	0.30	0.19	0.21
	After E	--		Not investigated				15	0.47	0.14	0.15	0.58	
Cond	All	39	1.72	1.73	1.54	1.32	1.67	39	1.49	1.43	1.15	1.18	1.39
	Comp	--						23	1.39	1.41	1.15	1.16	1.39
	After E	--		Not investigated				16	1.63	1.47	1.14	1.21	
Eating	All	39	1.39	1.18	1.25	1.14	1.29	39	0.92	1.00	0.85	0.97	1.08
	Comp	--						25	0.96	1.13	0.95	1.05	1.08
	After E	--		Not investigated				14	0.85	0.77	0.67	0.83	
UTI	All	39	0.50	0.55	0.43	0.32	0.10	39	0.59	0.43	0.50	0.32	0.42
	Comp	--						24	0.63	0.43	0.48	0.23	0.42
	After E	--		Not investigated				15	0.53	0.43	0.54	0.50	
Pain	All	39	1.36	1.36	1.43	1.21	1.14	39	1.33	1.22	1.06	0.94	1.20
	Comp	--						25	1.40	1.25	1.22	1.13	1.20
	After E	--		Not investigated				14	1.21	1.15	0.73	0.55	
Depress.	All	39	1.13	1.09	1.07	1.14	0.95	39	0.82	0.76	0.71	0.74	1.08
	Comp	--						26	1.12	0.92	0.87	0.87	1.08
	After E	--		Not investigated				13	0.23	0.42	0.36	0.45	

For the depression variable, there were no significant effects and a visual inspection of the plot of means suggested that there was no change in depression levels over the length of the study. However, those participants in the M+ group who did not complete the study had the lowest, and best, scores overall. Through the final survey administration, the LWWD group had higher scores than the M+ group, but they converged at F.

There appears to be a general decrease over time in the amount and frequency of chronic

pain regardless of group membership. Those M+ participants who failed to complete the study have the overall lowest scores, and the M+ group in general has lower scores than the LWWD group with a convergence at time F. Although there were no significant urinary tract infection (UTI) effects, visually there appeared to be a general decrease over time regardless of group. Those M+ participants who dropped out were “average” through D, maintaining a constant level while the rest of the participants declined through E and F. Overall, M+ consumers could not be distinguished from LWWD-only participants.

It appeared that there was no change in problems related to eating or weight over the course of the study for either group, and again, those M+ participants who dropped out had the lowest scores overall. M+ participants had generally lower scores than those in the LWWD-only group, but scores for both groups converged by F. There were also no changes in problems related to physical fitness or conditioning. M+ dropouts were indistinguishable from those who completed the study. M+ participants were generally lower scoring than the LWWD group, and the two groups maintained a parallel relationship through F.

Finally, the pressure sore information was very inconsistent over the course of the study. Those M+ participants who dropped out started out with the highest scores at B, dropped to the lowest scores from C to D, and rebounded to the highest scores at E before dropping out. The M+ group, in general had lower scores than the LWWD-only group. The LWWD-only group started higher than the M+ group, but the M+ group remained constant while the LWWD group decreased over time

*Mixed model analyses: Health and independence.* For the 4-point health rating variable (H-rate), as with previous variables, once scores at time C were controlled for, there were no significant effects: treatment –  $F(1,66) = 0.01$ ,  $p = .9413$ ; time –  $F(2,97) = 0.45$ ,  $p = .6380$ ; and interaction –  $F(2,97) = 1.89$ ,  $p = .1572$ . The 5-point health status variable (H-status) showed a

marginal treatment effect ( $F(1,66) = 3.60, p = .0623$ ), but the time effect and the interaction effect were not statistically significant: time –  $F(2,95) = 0.51, p = .5996$ ; and interaction –  $F(2,95) = 1.06, p = .3505$ .

Once again, as soon as the Independence variable scores at time C were controlled for, there were no significant effects: treatment –  $F(1,65) = 0.66, p = .4204$ ; time –  $F(2,95) = 0.53, p = .5880$ ; and interaction –  $F(2,95) = 0.78, p = .4596$ .

There were no significant effects of the number of hospitalized days due to physical health problems after scores at time C were controlled for: treatment –  $F(1,65) = 1.79, p = .1859$ ; time –  $F(2,93) = 0.12, p = .8875$ ; and interaction –  $F(2,93) = 1.51, p = .2273$ . While there were non-significant treatment and time effects for the number of hospitalized days due to mental health problems after the covariate was controlled for, (treatment –  $F(1,64) = 0.06, p = .8146$ ; time –  $F(2,94) = 0.41, p = .6619$ ), there was a significant interaction between the treatment and time,  $F(2,92) = 6.10, p = .0033$ . There was a significant treatment effect for the number of days of limited activity due to health problems as well,  $F(1,65) = 6.43, p = .0136$ , although the time effect and the interaction effect were not statistically significant: time –  $F(2,94) = 0.06, p = .9456$ ; and interaction –  $F(2,94) = 1.64, p = .1985$ .

*Follow-up investigations.* All variables in this family were analyzed separately from the start, so the only follow-up investigations involve the in-depth visual inspection of the means plots. For all of these variables, a lower score was considered a better score in that a lower score indicates better health and increased independence. Figure 4 and Table 8 summarize the information appropriate to the health and independence variables.

Figure 4. **Mean plots for health and independence variables used in follow-up analyses**

Table 8. Mean scores and sample sizes (*n*) by comparison group for health and independence variables

		LWWD-only						Maintenance Plus					
		<i>n</i>	Survey					<i>N</i>	Survey				
			B	C	D	E	F		B	C	D	E	F
H-status	All	39	2.39	2.33	2.41	2.46	2.33	39	2.33	2.30	2.29	2.31	2.64
	Comp	--	Not investigated					25	2.48	2.42	2.41	2.39	2.64
	After E	--	Not investigated					14	2.07	2.08	2.08	2.17	
H-rate	All	39	3.00	2.94	3.10	3.11	3.10	39	2.94	3.03	2.91	2.79	3.19
	Comp	--	Not investigated					26	3.04	3.16	3.09	2.91	3.19
	After E	--	Not investigated					13	2.75	2.75	2.55	2.55	
Ind	All	39	2.69	2.42	2.46	2.54	2.43	39	2.59	2.41	2.32	2.35	2.63
	Comp	--	Not investigated					24	2.79	2.43	2.33	2.29	2.63
	After E	--	Not investigated					15	2.27	2.36	2.31	2.46	
Health	All	39	9.89	8.31	10.6	10.4	8.50	39	9.11	7.46	7.71	7.41	10.4
	Comp	--	Not investigated					25	9.92	8.67	10.0	8.55	10.4
	After E	--	Not investigated					14	7.71	5.23	3.50	5.33	
Mental	All	39	9.05	8.50	11.7	9.15	6.80	39	6.38	4.56	5.12	5.12	10.2
	Comp	--	Not investigated					26	8.25	5.36	6.35	6.00	10.2
	After E	--	Not investigated					13	2.92	2.73	2.55	3.27	
Act	All	39	8.00	6.13	9.21	7.93	5.90	39	7.22	6.76	4.29	4.65	8.16
	Comp	--	Not investigated					25	9.22	9.20	5.91	6.27	8.16
	After E	--	Not investigated					14	3.69	1.67	0.91	1.67	

*Completers versus study dropouts.* For both the 4-point health rating variable and the 5-point health status variable, there appeared to be a slight trend towards lower scores. Those M+ participants who dropped-out had lower scores, and thus a better health status than their LWWD-only counterparts. Those M+ participants that completed study were just as healthy as those in the LWWD-only group.

The independence variable suggested that there may be a slight decrease in scores as time

increased, but there was no differentiation between any comparison groups, completers or dropouts. In general, those Maintenance Plus participants that did not complete a survey at F had fewer days of hospitalization due to physical health and fewer hospital days due to mental health. They also had fewer days of limited activity due to their conditions. Those M+ participants who completed the study had more days of hospitalization due to physical problems than those who dropped-out but had approximately the same number of days as those in the LWWD-only group. While both groups of participants started out the study with about the same number of hospitalization days, the LWWD-only group increased from C to E while the M+ group remained constant. Those participants in the M+ intervention that completed the study had more days of hospitalization due to mental illness than those who drop-out, but fewer days than those in the LWWD-only group. The interaction occurred between E and F when the LWWD-only group switched relative positions with the M+ group and exhibited fewer days of mental-health-related hospitalization. It appeared that the LWWD and M+ groups were equally limited in activity through time C, but the M+ group became more active through E while the LWWD groups increased the number of limited activity days. While the groups reversed positions from E to F so that LWWD had fewer days of inactivity than M+, the LWWD-only group overall was never as active as the M+ group.

*Mixed model analyses: Emotional support and life satisfaction.* For the social and emotional support variable, after the covariate was controlled for, there were no significant effects: treatment –  $F(1,65) = 2.46, p = .1213$ ; time –  $F(2,94) = 1.32, p = .2730$ ; and interaction –  $F(2,94) = 0.18, p = .8334$ . There also were no significant life satisfaction effects either after scores at time C were controlled for: treatment –  $F(1,65) = 0.23, p = .6364$ ; time –  $F(2,91) = .28, p = .7569$ ; and interaction –  $F(2,91) = 0.63, p = .5351$ .

*Follow-up investigations.* Both variables in this family also were analyzed separately

from the start, so the only follow-up investigations involved the in-depth visual inspection of the means plots. For both of these variables, a lower score was considered a better score in that a lower score indicates higher satisfaction. Mean information and mean plots can be found in Table 9 and Figure 5 respectively.

**Table 9. Mean scores and sample sizes (*n*) by comparison group for emotional support and life satisfaction**

		LWWD-only						Maintenance Plus					
		<i>n</i>	Survey					<i>N</i>	Survey				
			B	C	D	E	F		B	C	D	E	F
Soc	All	39	2.37	2.28	2.34	2.30	2.48	39	2.42	2.30	2.21	2.12	2.46
	Comp	--	Not investigated					26	2.48	2.44	2.17	2.26	2.46
	After E	--	Not investigated					13	2.31	2.00	2.27	1.82	
Life	All	39	2.16	2.00	2.04	2.08	1.90	39	2.22	2.05	2.12	2.00	2.19
	Comp	--	Not investigated					26	2.38	2.20	2.22	2.00	2.19
	After E	--	Not investigated					13	1.92	1.75	1.91	2.00	

*Completers versus study dropouts.* There does not appear to be any change in a participant’s satisfaction with their social and emotional support over the course of the study, regardless of comparison group. Those M+ participants who dropped out had slightly lower scores than their LWWD-only counterparts, but there did not appear to be a general difference between M+ and LWWD-only in terms of satisfaction with social and emotional support.

There did appear to be a slight trend towards higher life satisfaction (through a lower score) over the course of the study, and again, those M+ participants who dropped out early had slightly lower scores and were more satisfied. Overall, there did not appear to be a difference between the M+ and LWWD-only comparison groups in terms of life satisfaction.

**Figure 5. Mean plots for emotional support and life satisfaction variables used in follow-up analyses**

## Discussion

Drawing inferences from the available data is difficult, if not impossible, due to the self-selecting nature of the sample. Since the critical assumption of random assignment to treatment conditions was not met, even the statistically significant results that were obtained may be suspect. Hence the general discussion will hinge more upon a description of those consumers who elected to participate in the Maintenance Plus intervention versus those who chose not to continue participation after the completion of the LWWD program.

*Goal behavior.* For the nineteen participants in the LWWD-only condition who returned a survey at time F, the slight decrease at the end of the program (time C) could reflect a temporary letdown or lack of stimulus to continue goal behavior. The subsequent recovery after time D is reflected in a large number of goals met at time E. The decline following E at time F could be due to not having set new goals to replace those already met.

Twenty-five consumers self-selected to continue on into the Maintenance Plus intervention and complete the study by returning a survey at time F. While they were actively engaged in M+ (C to D), their responses were consistent with being motivated to set and reach goals. From D to F, they showed a letdown. This could have been a letdown similar to the one that was noticed with the LWWD-only completers following a period of active intervention. An alternative could be that the M+ group tended to set more goals to begin with and were successful in meeting them by time E. That would have led to an inevitable decrease in the last time period.

The seven LWWD-only participants who dropped out after returning survey E showed a strong increase in goal behavior from C to D and then from D to E. This may have been primarily due to setting lots of goals, but as the personal importance of goals decreases, their working towards the goals also decreases, and their satisfaction with their progress toward those goals decreases from C to D. However, they do increase rewarding themselves from C to D. As

a consequence, they meet, on average, only one goal by time E (almost one goal less than any other group that is still participating). Although they do increase their efforts at working towards goal-completion, and they do raise the level of importance that they place on goals, from D to E, they become even more dissatisfied with their progress and decrease their self-rewards. A possible interpretation for this is that at time C (exit from the LWWD program), this group of consumers became very excited and set some high goals, but when they did not make much progress towards meeting those goals by time D, they may have become dissatisfied and quit after time E.

The group of twelve consumers who completed the M+ intervention but failed to return survey F appeared to be realistic in their goal setting and showed rather steady behavior. They showed an increase in goal behavior after completing the LWWD program reflecting a number of set goals and a higher satisfaction with their progress towards meeting their goals. They showed an increase in the number of goals they actually met during this time while showing a decrease in work-effort directed towards their goals as well as a decrease in the importance of their goals. These patterns are consistent with the fact that this sub-sample appeared to meet most of the goals they set for themselves. They did what they needed to do to meet their goals, and they dropped out of the study when they accomplished what they intended to do.

The group of LWWD-only consumers ( $n = 4$ ) that dropped out after time D appeared to be relatively successful in setting and meeting goals. The decrease in goal behavior that was observed for this group may have been partly due to a very large decrease in the number of goals that were set and a resulting decrease in working towards their goals. They were quite steady in their behavior and rewarded themselves at a relatively high level. This group probably dropped out because they no longer needed the program.

*Health, independence, and satisfaction.* Overall, those consumers who elected to

participate in the Maintenance Plus intervention were healthier than their counterparts who only participated in the LWWD program. In particular, those M+ participants who further elected to not return a survey at time F were the healthiest participants of all. In general, those participants who participated in Maintenance Plus had relatively less frequent and less severe cases of secondary conditions, specifically depression, chronic pain, urinary tract infections, eating or weight problems, physical fitness or conditioning problems, and pressure sores.

Overall, those participants who decided to continue on into the Maintenance Plus program were also more independent with fewer days of hospitalization and fewer days of inactivity due to their disabilities. The same thing here is true as with the secondary condition information: those M+ participants who chose to drop-out immediately following completion of the M+ meetings and prior to survey F had the fewest days of hospitalization due to both mental and physical health, fewest inactive days due to their disability, and considered themselves to have the highest levels of independence.

Those participants who completed the Maintenance Plus intervention but dropped out before the final survey administration, in general, also appear to be more satisfied with their emotional and social support as well as their lives in general. However, there does not appear to be any differences between those who just completed the LWWD program and the M+ group overall in terms of their life satisfaction and satisfaction with their support systems.

### **General Conclusions**

The sample of consumers who self-selected to participate in the Maintenance Plus intervention had different goal behavior characteristics than the LWWD-only sample. They may just be psychologically different. It is also conceivable that they may be psychologically similar, but the time periods selected for examination may not pick-up on those similarities. An observer may not be able to pick-up on the cyclic behavior or the influence of repeated measurements at

these specific time periods. Frequently, a letdown or general decrease can be observed in the LWWD-only group immediately following the completion of the program (the two months from C to D). This corresponding time period for the M+ group begins at E but ends sometime before F. The LWWD-only group then tends to begin recovering from D to E and returns towards previous levels. This corresponding period also occurs sometime between E and F for the M+ group. It may be that the time periods chosen for survey administration are not sensitive enough to detect similar patterns of behaviors between groups that occur at intervals offset by the two months that half of the participants are engaged in M+ meetings.

The self-selecting Maintenance Plus intervention group also experienced fewer secondary conditions and fewer lost days due to hospitalization. They rated their health status equal to or slightly lower than the LWWD-only group, and they scored better on the social, emotional, and life satisfaction measures. It may be that they were a group of psychologically well-adjusted people who enjoyed social interaction, and that is why they chose to continue on and participate in Maintenance Plus. They may also be well-balanced people who don't reach for more than they can grasp, and they just set reasonable goals and meet them.

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