Health promotion for people with disabilities: development and evaluation of the Living Well with a Disability program

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Abstract

People with disabilities can benefit from health promotion opportunities to reduce the incidence and severity of secondary conditions that further limit their participation in society. This paper describes participatory action research (PAR) methods we used to develop, implement and evaluate the Living Well with a Disability program. Community-based agencies that provide information and referral services to people with disabilities (independent living centers funded under Title VII, Rehabilitation Act) recruited a convenience sample of 246 people with mobility impairments to participate in a randomly assigned, wait-list control health promotion intervention study. Paper-and-pencil outcome measures included the secondary conditions surveillance instrument, unhealthy days and health care utilization. Logistic regression on outcomes controlling for demographic variables and pre-test measures indicated reductions in all three outcome variables. People with mobility impairments who participated in the Living Well with a Disability program reported less limitation from secondary conditions, fewer unhealthy days and less health care utilization. PAR methods are particularly important to design useful interventions for this population.

Introduction

People with disabling conditions that limit their major daily activities at home or in the workplace represent >20% of the US population [1]. This sizeable group has specific needs for health promotion to mitigate their risk for a variety of disabling secondary conditions [2–6]. These secondary conditions include typical medical sequelae such as chronic pain and pressure sores as well as socio-emotional conditions such as isolation, depression and accessibility problems [3–7]. Secondary conditions are ‘medical, social, emotional, family, or community problems that a person with a primary disabling condition likely experiences’ [2]. Typically, they are conditions for which individuals with a primary disability are at higher risk and experience at higher rates than people without a disability [3].

While the overall economic and human capital burden of secondary conditions remains unknown, the cost of treating specific secondary conditions highlights the overall potential impact. For example, the medical costs associated with spinal cord injury, not including the first year post-injury, are estimated at $24 000 per individual annually [8]. Overall, the cost of disability was estimated at >$300 billion in 1994, with 160 billion attributable to direct costs and 155 billion to lost productivity [9].

There has been anecdotal evidence that the negative effects of secondary conditions on people with disabilities, as well as society as a whole, can

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be managed and even prevented through health promotion activities [2]. However, only recently has the topic begun to receive attention in the public health literature. For example, a physical activity program for stroke survivors resulted in substantial physical and psychological benefits [10]. Likewise, health benefits were observed in a cohort of people with spinal cord injury following a health promotion and wellness intervention [11]. Improvements in health behavior and quality of life for women with multiple sclerosis have been reported following health education [12]. Although these studies indicate health and mental health benefits of health promotion for very specific disability groups, they cannot be generalized to the broad array of impairment types or secondary condition types observed in the broader population of people with disabilities living in the community. Thus, there remains relatively little empirical evidence that examines the link between health promotion and the prevention of secondary conditions in people with disabilities.

Recently, we reported preliminary evidence that a health promotion workshop for adults with mobility impairments [13, 14] was cost-effective for preventing and managing a variety of secondary conditions [15]. Our results indicated that participants experienced less limitation from secondary conditions, fewer symptom days and less health care utilization following participation in the program. However, these results were based on within-subject analyses of a staggered baseline design and did not adequately explore the between-subject effects of the program. The purpose of this paper is twofold. First, we will introduce readers to important disability research topics, including settings and research process that contributed to the development of the intervention. Second, we will report on between-subject analyses using a reduced evaluation measure more suitable to a ‘best practice’ program evaluation.

### Development of the Living Well with a Disability program

The Living Well with a Disability program was designed for delivery through the national network of community-based centers for independent living (CILs) [16]. CILs are non-residential resource centers on disability that focus both on supporting people with all types of disabilities to live in the community and on transforming communities to be more physically and attitudinally accessible for them. They are based on independent living (IL) philosophy that regards disability as a natural part of the human condition, locates the problem of disability in social and physical environments that inhibits autonomy of persons with disabilities and promotes peer counseling, advocacy, self-help, consumer control and removal of barriers as solutions to the problems of discrimination and unequal opportunity [17]. Brown [18] emphasized the importance of IL as a cross-disability movement, noting that empowerment occurs when people with different types of disabilities recognize common experiences and act as role models for others as they mutually advocate for removal of barriers and pursue their life goals.

### Participatory action research and IL

Consistent with IL philosophy, many disability researchers have adopted an ecological model of disability [19]. However, community ecologies can be extremely complex. To design interventions that fit within the ecology of the delivery systems in which they are to be used, researchers can use detailed information about the range of variables affecting a situation. Participatory action research (PAR) is one method to gather and understand information about contextual details. In PAR, those who are familiar with the context and those who might be expected to use an innovation are involved in the development of the intervention [20, 21].

We practiced PAR in the development and evaluation of the Living Well with a Disability program. We involved people with disabilities and those who provide services for them in several phases of the research, development and demonstration process [22]. First, we conducted an extensive literature review to identify a range of secondary conditions that might be experienced by adults with disabilities related to mobility impairments. This review led to the identification of 26 conditions. Next, we conducted a series of focus
groups and open-ended surveys with adults with disabilities. This led to the identification of 14 additional conditions we had not found in the literature [23]. Third, we worked with consumers and disability service providers to develop a surveillance instrument to assess the prevalence and severity of limitation due to these conditions. Several studies identified 10 of the 15 most significant secondary conditions to be those contributed by consumer participants but not identified in our literature review. Analysis of these data also showed that secondary conditions were not associated with primary impairments, but rather grouped together in factors consistent with organizing influences such as pain, depression and severity of impairment [24].

Discussions of these findings with focus groups of consumers led us to modify our proposed plan for an intervention. Originally, we had proposed an individually focused, in-home, health education and support intervention. Consumers and service providers argued that, since isolation was one of the major problems, such an intervention could actually exacerbate that situation. They argued that, despite the difficulties in arranging transportation, a group intervention was needed.

As our field trials unfolded, consumers spontaneously formed groups at the end of the program either to continue providing social support for healthy lifestyle changes or to pursue community advocacy. We integrated this naturally occurring practice into the program’s structure. Finally, we used the instrument developed in collaboration with consumers to examine the effectiveness of the Living Well with a Disability intervention.

The Living Well with a Disability program

The Living Well with a Disability program that emerged from this process of PAR consists of a curriculum divided into 10 chapters: goal setting, problem solving, attribution training, depression, communication, information seeking, nutrition, physical activity, advocacy and maintenance [25]. The first four chapters establish goal pursuit and the final six chapters encourage health behavior change as objectives to meeting the consumer’s quality of life goals. This is a departure from more traditional health promotion programs that have individuals-set health-oriented goals. The curriculum is based on three social cognitive models of health including sense of coherence (SOC) [26, 27], attribution style (AS) [28] and hope [29]. The intervention helps people identify a pathway (hope) for reaching meaningful life goals (SOC). Personal agency (hope) is developed via problem solving (SOC) and attribution retraining (AS). The workbook that guides the curriculum is written at an eighth-grade reading level (Flesch–Kincaid method).

Evaluation strategy

As implementation of the living well program progressed, the need for a comprehensive program evaluation strategy became evident. Our approach to the development of the evaluation of the living well program can best be understood within the context of the emerging public health debate regarding the relative utility of efficacy versus effectiveness research. Efficacy research examines treatment effects under tightly controlled experimental conditions that are often impractical if not impossible to replicate under ‘real-world conditions.’ Effectiveness research, on the other hand, examines treatment effects under real-world conditions. Efficacy research tends to have greater internal validity, whereas effectiveness research tends to have better external validity. Glasgow et al. [30] argue that interventions developed and tested under efficacy conditions rarely translate into effective interventions based, in part, on the rigorous procedures and design used to meet the demands of the efficacy research phase. They argue that translation of public health interventions into practice has suffered under these conditions.

While the Living Well with a Disability evaluation has emphasized effectiveness, this study represents an improvement to prior evaluations of living well. These prior evaluations relied on within-subject methods. This present study used a between-subject experimental design to improve the external validity of the evaluation results and increase the confidence with which we can generalize these
results to larger populations within the disability community.

The PAR strategies and IL philosophy used to develop the living well program are consistent with an effectiveness research strategy. This approach leads to the development of robust procedures that fit the service delivery context. The evaluation design is also consistent with this objective. The major goal of the evaluation design is to produce usable information to inform public policy and practice regarding the impact of health promotion interventions on secondary conditions, quality of life and health care costs.

For the between-subject data analysis reported here, three hypotheses will be tested. First, we anticipate that it will be more likely that individuals below the median on secondary conditions at the post-test (i.e. indicating less limitation from secondary conditions) were in the treatment group. Second, we anticipate that it will be more likely that individuals below the median on the unhealthy days index at the post-test (i.e. indicating fewer days of poor health) were in the treatment group. Third, we anticipate that it will be more likely that individuals below the median on health care costs at the post-test (i.e. indicating lower costs for health care) were in the treatment group. (The rationale for using the median to define outcome groups in these analyses is described in Methods.)

Methods

Participants

We recruited study participants through CILs located in eight states (California, Kansas, Mississippi, Montana, Missouri, New Hampshire, New York and Texas). Agency staff mailed announcements to individuals on agency mailing lists and advertised the study using public service announcements on television and radio. Approximately three-quarters of participants were recruited from agency mailing lists. Selection criteria included the presence of a mobility impairment without cognitive impairment, substance-use disorder or active suicidal ideation. Evaluations for these characteristics were conducted by agency staff who relied on self-report of prospective participants.

These eight CILs recruited individuals to participate in one of 34 health promotion workshops conducted over a 2-year period. Of the 246 individuals recruited and randomly assigned either to treatment or to a wait-list control condition (127 and 119, respectively), 200 completed pre- and post-evaluation instruments and are included in these analyses (96 and 104, respectively). The mean age of participants was 45 years (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 Hispanic 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 (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). Table I includes the percentage of the sample representing common mobility impairment groups.

Table I. Proportion of the sample reporting each impairment type

<table>
<thead>
<tr>
<th>Condition</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Amputee</td>
<td>4.1</td>
</tr>
<tr>
<td>Arthritis</td>
<td>18.5</td>
</tr>
<tr>
<td>Cardiopulmonary disorders</td>
<td>4.5</td>
</tr>
<tr>
<td>Cerebral palsy</td>
<td>16.2</td>
</tr>
<tr>
<td>Multiple sclerosis</td>
<td>14.9</td>
</tr>
<tr>
<td>Muscular dystrophy</td>
<td>5.0</td>
</tr>
<tr>
<td>Post-polio</td>
<td>6.8</td>
</tr>
<tr>
<td>Spina bifida</td>
<td>2.8</td>
</tr>
<tr>
<td>Spinal cord injury</td>
<td>26.6</td>
</tr>
<tr>
<td>Other</td>
<td>29.2</td>
</tr>
</tbody>
</table>

Measures

The Living Well with a Disability evaluation instrument was developed by staff of disability and health capacity-building programs (disability
and health capacity-building programs are funded by the Disability and Health Team in the National Center on Birth Defects and Developmental Disabilities at the Centers for Disease Control and Prevention to increase the capacity of state health departments to improve the health status of people with disabilities by providing services and working for the inclusion of disability issues in existing health department programs in four states (Montana, New Mexico, Iowa and New York) under existing health promotion grants from the Disability and Health Program in the National Center for Birth Defects and Developmental Disabilities at the Centers for Disease Control and Prevention. This paper-and-pencil instrument included socio-demographic status (i.e., gender, age, ethnicity and education), health care utilization, unhealthy days and secondary conditions.

We used four items to measure health care utilization, including frequency of physician visits, emergency room visits, outpatient surgeries and hospital days, using a 2-month retrospective recall. To arrive at health care costs, we multiplied Medicare unit cost estimates by health care utilization rates reported by participants. The Medicare unit cost estimates were created using 2002 aggregated Medicare reimbursement rates, national outpatient revenue summary data and physician reimbursement rates from the Health Care Financing Administration, Bureau of Data Management and Strategy.

We used two items drawn from the HRQOL14 of the Behavior Risk Factor Surveillance System to measure physical and emotional symptoms. These two items were used to compute the unhealthy days index [31], a measure which combines days of poor physical and mental health into a single index with a range from 0 to 30 days.

We measured secondary conditions with a brief measure constructed for the national evaluation effort. We reduced the overall length of the secondary condition surveillance instrument [22] (SCSI) in order to maximize response rates. Using empirical methods based on statistical significance, we selected 13 items from the SCSI; items sensitive to change on the basis of the living well program were selected for this reduced version. Items selected, along with item means and standard deviations, are included in Table II. To complete the SCSI, participants were asked to rate the amount of limitation they experience using a four-point anchored rating scale for each of the secondary conditions. A rating of 0 meant the condition had not been a problem during the past 2 months, 1 meant it was a mild or infrequent problem (activity limited 1–5 hours per week), 2 meant it had been a moderate problem (activity limited 6–10 hours per week) and 3 meant it had been a significant problem (limiting activity ≥11 hours per week). Construct and concurrent validity for the full SCSI has been reported elsewhere [22–24]. In this study, coefficient alpha for the 13 items selected was 0.78, which compares favorably with the coefficient alpha of 0.88 reported for the full instrument (40 items) [4]. Given the breadth of the secondary conditions domain included in the SCSI (i.e., medical, social and environmental) and the internal consistency observed between items, the total SCSI score was interpreted as a proxy for participants’ ability to participate in their regular, daily activities.

**Procedures**

Two staff members from each CIL attended a 2.5-day interactive training workshop that focused on the content as well as the process of facilitating

| Table II. Descriptive statistics for secondary conditions |
|-----------------|-------|-------|
| Secondary conditions | Mean | SD    |
| Fatigue          | 1.65  | 1.10  |
| Joint and muscle pain | 1.51  | 1.17  |
| Sleep problems/disturbances | 1.43  | 1.16  |
| Eating or weight problems | 1.30  | 1.19  |
| Access problems  | 1.12  | 1.00  |
| Arthritis        | 1.08  | 1.19  |
| Contractures     | 0.95  | 1.12  |
| Isolation        | 0.90  | 1.00  |
| Circulatory problems | 0.87  | 1.19  |
| Sexual dysfunction | 0.80  | 1.18  |
| Injuries due to loss of sensation | 0.56  | 0.96  |
| Equipment failures | 0.52  | 0.85  |
| Anemia           | 0.28  | 0.67  |

Secondary conditions are rated using a four-point anchored rating scale.
discussions about the Living Well with a Disability curriculum. Many facilitators had disabilities themselves and had some experience with facilitating peer support groups. The training also included procedures for distributing and collecting evaluation measures.

Facilitators scheduled weekly 2-hour meetings for 8 weeks to conduct the intervention. Meetings were held at the CIL, and when appropriate, transportation services were arranged for participants. During each weekly meeting, facilitators presented chapter content, led discussions about chapter content and helped participants complete written exercises. To protect the integrity of the intervention implementation over time, facilitators used a checklist for each section and exercise of the curriculum to record the sections completed by the class. The research team collected and reviewed these checklists. Facilitators reported completing the entire curriculum for each workshop session, with only minor exemptions noted.

One week prior to the first session, facilitators mailed out study pre-measures requesting that participants (in both the treatment and control groups) complete the questionnaire. For treatment group participants, they distributed the post-measure, along with a self-addressed stamped envelope at the final workshop session. Control group participants and treatment group participants not in attendance at the final meeting were mailed the post-test at the same time. Participants were paid $10 for each measure they completed during the study.

Data analysis
All data were entered into SPSS 11.5 and checked for accuracy. We dichotomized all continuous variables using the median due to the skewed distributions of the data and to limit degrees of freedom given our limited sample size. The data were transformed using multiple algorithms; however, the transformed data did not approximate multivariate normality primarily due to the health care utilization data. Data across intervention sites were collapsed based on previous analyses that indicated treatment effects across sites was uniform [15]. We computed three separate logistic regression models for each outcome variable (i.e. sum of secondary condition ratings, unhealthy days and health care costs) followed by a multinomial logistic regression to examine effects across the three dependent variables taken together. Finally, we used an ‘intention to treat’ analytic paradigm by analyzing data for all participants who returned study measures, regardless of whether or not they completed the entire intervention [32]. This conservative analytic strategy helps to protect against external validity threats associated with different attrition rates often observed between treatment and control groups. All study recruitment and intervention procedures were approved by the institutional review boards at the University of Montana and the University of Kansas.

Results
Prior to computing treatment outcome analyses, we computed logistic regression on treatment assignment to examine potential pre-intervention differences between control and treatment conditions. There were no statistically significant differences between groups on either demographic or outcome measures indicating effective randomization of participants to treatment group. Next, given that 18.7% of the randomized and recruited sample did not return post-measures, we analyzed data for effects due to attrition using demographics, outcome measures and experimental condition. The only significant difference in this analysis was for health care costs. Individuals who returned post-measures and were included in these analyses were 2.2 times more likely to be above the median for health care costs at baseline than those not returning post-measures [odds ratio (OR) = 2.28, 95% confidence interval (CI) = 1.00, 5.20].

Table III includes the logistic regression results on the models tested for each of the three outcome variables (i.e. secondary conditions, unhealthy days and health care costs). For secondary conditions, participants below the median on the secondary conditions post-test were three times more likely to
have been in the treatment condition after controlling for pre-intervention secondary condition status, gender, education, age and race (OR = 3.05, 95% CI = 1.33, 7.01). Participants below the median on post-test health care costs were nearly twice as likely to have been in the treatment condition after controlling for pre-intervention health care cost status, gender, education, age and race (OR = 1.94, 95% CI = 1.03, 3.67). Participants below the unhealthy days index median at the post-test were nearly two times more likely to have been in the intervention group after controlling for pre-intervention unhealthy days status, gender, education, age and race (OR = 1.96, 95% CI = 0.91, 4.26). In each of these logistic equations, the relationship between treatment outcome on the dependent variables and treatment condition of the participants was corrected for both pre-treatment status (i.e. above or below the median on each variable) and demographic variables. For each dependent variable, the pre-treatment status accounted for a significant proportion of the variance in post-treatment status; however, the intervention effect remained significant for each dependent variable. The demographic variables, on the other hand, did not account for a significant proportion of the variance in post-treatment outcome for any of the three dependent variables. Hence, the demographics were unrelated to treatment effects in these analyses.

Finally, we examined the data for unique treatment effects, taking into account all three dependent variables in a multinomial regression analysis. This analysis allows the researcher to examine overlap in the treatment effect on dependent variables. In this analysis, we entered post-test status (i.e. above or below the median) as factors and pre-test status as covariates. These results showed the strongest effect was evident for participant’s ratings of secondary conditions (OR = 2.44, 95% CI = 1.07, 5.56), followed by the unhealthy days index (OR = 1.47, 95% CI = 0.68, 3.20) and health care costs (OR = 1.45, 95% CI = 0.76, 2.77). These results show that when outcome measures are analyzed together, the likelihood that participants below the median for secondary conditions were in the treatment group remains approximately the same as in the univariate analysis. However, the ORs and CIs for health care costs and unhealthy days suggest these variables contribute less unique variance to the prediction of treatment group assignment.

**Discussion**

We set out to describe the development, implementation and evaluation of the Living Well with a Disability program. Overall, the results support the effectiveness of the Living Well with a Disability intervention when delivered by CIL staff who
completed training to implement the program with individuals who have a mobility impairment. This evaluation used items from the Living Well with a Disability evaluation instrument to examine the sensitivity of this brief measure for assessing program effectiveness when delivered in the natural context. Using this evaluation instrument, we found evidence to support our hypotheses regarding program effects on limitations due to secondary conditions, days of poor physical or mental health and health care costs in a between-subject design.

These study results replicate and complement results for the Living Well with a Disability program reported elsewhere [13, 15], adding to the external validity of these results and adding to the evidence for the program’s effectiveness. However, from an efficacy perspective, this study has a number of limitations in the study design and procedures that potentially limit its validity. First, the study used a convenience sample of adults with mobility impairments, most of whom had been receiving services at IL centers. Second, the study relied on self-report of outcome variables and includes the limitations associated with that measurement strategy. Third, the control condition used a wait-list strategy rather than comparison to any other treatment. Hence, this study cannot address incremental effectiveness of the intervention beyond what might be observed by placebo or other non-specific effects (e.g. socialization). Fourth, the geographic distribution of study sites was insufficient to adequately represent all minority groups (e.g. Hispanic), leading to a predominantly Caucasian sample. Finally, neither participants nor program facilitators were blind to treatment condition.

In addition to these limitations, the design of this study precluded follow-up procedures to evaluate potential degradation of the observed between-subject treatment effect. However, in another report from this study, Ravesloot et al. [15] reported within-subject effects that suggest maintenance of treatment effects over 12 months for the secondary condition outcome and over 4 months for unhealthy days and health care costs. Hence, there is evidence that the treatment effects endure beyond the post-test results reported here.

Our strategy for addressing the skewed distribution of our data by dichotomizing the data around the median is somewhat unusual and deserves comment. Of the three outcome variables presented here, health care utilization had the most skewed distribution and presented the greatest problem for analysis. Given the time frame of the measures (i.e. 2 months) and the target population, it is not surprising that many participants reported using no health care resources while others, for example, those who were hospitalized, reported using many resources. Likewise, when considering symptom days over the past 30 days, many people report only a few days while a few report a majority of days. These health-related variables in this target population are quite volatile, changing dramatically from one measurement period to the next. Given the skewed distributions of these data, examining change around the median requires fairly substantial change on the dependent variables for a significant number of participants. However, this would not be the case if the variables were normally distributed. If these data were normally distributed, wherein the mean and median were essentially the same, then this strategy could represent only minor changes in the dependent variable and could be misleading.

The effectiveness of the living well program to reduce the impact of secondary conditions experienced by adults with disabilities is probably related to the components included in its development. These components included (i) designing the intervention using a philosophy that is known and trusted by people with disabilities, the IL philosophy; (ii) using PAR strategies to involve people with disabilities in the development and implementation of the intervention and evaluation strategy and (iii) using health behavior theories that are consistent with the values and experiences of the target population. Consumers and service providers contributed significantly to the development of the living well program. Had consumers not been involved in the early stages of this research, it is unlikely that the relevant issues would have been selected for research.

In addition to the positive results of this study, results have been presented for other behavior
change programs implemented with people who have physical impairments [33]. Each of these studies adds support to the importance and promise of providing health promotion services to this population. Too often, published reports do not translate into policy change. The Living Well with a Disability evaluation instrument was designed to collect information that should be of interest to policy makers. By including items that reflect both improvements in burden of disease and cost outcomes of the program, this evaluation strategy has the potential to attract the attention of policy makers and lead to broader support for programs such as the living well program. One prominent example of this is the Health Promotion and Prevention America Act (HeLP America Act of 2005) (Senate Bill 1074) introduced by Iowa’s Senator Harkin in May 2005. The bill, which includes funding for health promotion interventions for people with disabilities, is based in part on reports of the Living Well with a Disability outcomes [34].

Lastly, 202 organizations have sought training and support for implementing the living well program since early reports of its effectiveness 6 years ago. This adoption rate suggests that the development stage met criteria for ‘designing for dissemination.’ Not only is the program empirically sound but also it appears to meet consumers’ and service providers’ standards of contextual acceptability. However, wider dissemination has raised new issues in implementation. For example, the wide range of cognitive and sensory problems exhibited by people with disabilities poses potential challenges for broader use of the living well program with diverse participant groups. In response, during recent statewide implementation of Living Well with a Disability in Iowa, program staff adapted living well concepts for a wider audience by summarizing core information in handouts targeted at a fourth-grade reading level. Additionally, they provided modifications in instruction formats to accommodate vision and hearing impairments. Finally, they have attempted to extend positive intervention effects through a ‘refresher course’ that includes ongoing peer support and adds sections on improving quality of life, healthy lifestyles, safety and self-esteem. While making significant accommodations to meet individual participant needs, program integrity has been maintained through extensive training for group facilitators, mentoring of facilitators during initial living well sessions and sharing strategies and ideas among facilitators.

Living Well with a Disability is an intervention that holds promise for improving the health of people with disabilities. Additionally, the development, implementation and evaluation of the program has highlighted important philosophical and methodological issues to guide the development of effective public health practice in providing health promotion for people with disabilities.

Acknowledgements

The authors would like to thank the CILs and their consumers for their support of this research project. We also want to thank Larry Burt, Joe Smith, Jack Stubbs, Mary Helen Whitten and John Hough at the Centers for Disease Control and Prevention for their support and contributions to this project. This research was supported by Cooperative Agreement Number R04CCR914204 from the Centers for Disease Control and Prevention. The contents of this article are solely the responsibility of the authors and do not necessarily represent the official views of the Centers for Disease Control and Prevention.

Conflict of interest statement

None declared.

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Received on February 2, 2006; accepted on August 24, 2006