



A CHRONIC DISEASE  
SELF-MANAGEMENT PROGRAM  
FOR OLDER AFRICAN AMERICANS





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## I. INTRODUCTION/BACKGROUND

### The Burden of Chronic Conditions

Chronic health conditions are the major cause of illness, disability, and death in the United States, affecting almost 100 million Americans. By 2040, that number will increase to almost 160 million, but the economic and social costs are already staggering. The bill for medical care alone for Americans with chronic conditions was \$470 billion in 1995.<sup>1</sup>

Most older adults, who are especially vulnerable, have at least one chronic condition, and many have more than one. Among the most common of these illnesses are hypertension, heart disease, arthritis, diabetes, hearing impairments, and major depression. Typically, these conditions require more care, are more disabling, and are more expensive to treat than conditions that occur more frequently among younger people.<sup>2</sup>

Minority elders—and African Americans in particular—bear an even greater burden of chronic disease and disability compared to Whites. In Philadelphia, this disparity is particularly evident. According to research conducted by the Philadelphia Health Management Corporation (PHMC) in 2004, older African Americans in Philadelphia are more likely than Whites to rate their health as fair or poor and have one or more chronic health conditions, particularly arthritis, high blood pressure, or diabetes.<sup>3</sup>

Given the healthcare costs and significant impact on function and quality of life associated with chronic health problems, developing effective approaches to managing them has become a public health priority. Fortunately, as recent research shows, people can learn to play a major role in effectively managing their diseases.<sup>4</sup> In fact, the most successful programs emphasize chronic disease self-management, risk reduction, and increasing self-efficacy.<sup>5</sup>

Prevention has also been a focus of many recent studies. However, there is a noticeable research gap in the field, as very little of it has focused on what works best with underserved populations.<sup>6</sup> In response, a group of partners in

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<sup>1</sup> National Academy on an Aging Society, "Chronic Conditions: A Challenge for the 21st Century," November 1999.

<sup>2</sup> Ibid.

<sup>3</sup> Philadelphia Health Management Corporation, *2004 Southeastern Pennsylvania Household Health Survey*.

<sup>4</sup> Lorig K, Sobel D, Stewart A, Brown B, Bandura A, Ritter, et. al. (1999). Evidence suggesting that a chronic disease self-management program can improve health status while reducing hospitalization: A randomized trial. *Medical Care*, 37 (1): 5-14 .

<sup>5</sup> Fries JF, Koop CE, Sokolov J, Beadle CE, and Wright D (1998). Beyond health promotion: Reducing need and demand for medical care. *Health Affairs*, 17 (2): 70-84.

<sup>6</sup> Ory MG, De Frises GII, eds. *Self-Care in Later Life, Research, Program, and Policy Issues*. (New York: Springer, 1998), 194-195.

Philadelphia adopted the Chronic Disease Self-Management Program (CDSMP), an evidence-based program that could be successfully implemented to serve those populations.

### **Four Key Partners**

The project planners translated and evaluated the CDSMP with African American older adults in Philadelphia through the collaborative efforts of four organizations:

- The Philadelphia Corporation for Aging, the Area Agency on Aging (AAA), which functioned as the project administrator;
- Center in the Park, the urban senior center that implemented the program;
- Albert Einstein Healthcare Network (AEHN), a community healthcare organization that educated and encouraged referrals from primary care physicians; and
- The Center for Applied Research on Aging and Health (CARAH) at Thomas Jefferson University, which evaluated both the program's effectiveness and the collaborative process among the partners.

These partners selected the CDSMP for several reasons:

- The program model recognizes that many older individuals have multiple chronic diseases and teaches self-care strategies that are effective for many conditions;
- The cross-disease focus fits the health profile of the target population for this effort, namely, low-income, older African Americans;
- The model has been culturally modified successfully for older African Americans in pilot studies;
- Local experience with the CDSMP by aging service providers, researchers, AAA, and the healthcare network had already created an optimal environment for this intervention; and
- As an evidence-based program, the CDSMP provides a complement to medical models of health interventions and may reduce the costs of treating medical conditions.

### **CDSMP: The Original Intervention**

The CDSMP was developed by Dr. Kate Lorig and her colleagues at the Stanford Patient Education Research Center. The CDSMP has been shown to improve health status and self-efficacy and to reduce healthcare utilization in White middle-class income elders in randomized trials<sup>7</sup>.

The CDSMP is a six-week, fifteen-hour, peer-led education program based on the premise that people with one or more chronic conditions present common issues and needs—dealing with symptoms, maintaining complex medication

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<sup>7</sup> Research in Action, Issue 3. *Preventing Disability in the Elderly with Chronic Disease*. AHCPH website, <http://www.ahrq.gov/research/elderdis.htm>.

regimens, making behavioral lifestyle adjustments, and obtaining helpful medical care. The program is designed to empower patients to assume an active role in their own healthcare, enhance their daily functioning, and improve their quality of life.

The mechanisms that underlie the CDSMP's effectiveness include:

- Participants developing weekly action plans based on individualized goals;
- Instruction in multiple approaches to symptom management; and
- Group dynamics that provide opportunities for problem solving, peer modeling, social persuasion, and confidence building.

Classes are led by trained leaders, one (or both) of whom is not a health professional and has a chronic disease. They follow a detailed course manual when leading classes.

These leaders introduce techniques and strategies to participants, who then have opportunities to practice them in their day-to-day lives. Strategies include effectively coping with problems related to chronic conditions, such as frustration, fatigue, pain, and isolation. Also included are appropriate exercises for maintaining and improving strength, flexibility, and endurance; appropriate use of medications; techniques for communicating effectively with family, friends, and health professionals; nutrition; and ways to evaluate new treatments.

### **Harvest Health—Adapting the CDSMP**

A key issue in translating evidence-based programs to community groups is balancing intervention fidelity (i.e., is the program being delivered as it is intended) with program modifications that are necessary to maximize the program's acceptability to the target population and local community.<sup>6,7</sup>

The Philadelphia partners replicated the essential elements of CDSMP, but also implemented cultural modifications to maximize the program's acceptability. One important adaptation was the name choice for the program—**Harvest Health**, which was developed by Center in the Park. The partners endorsed this name based upon historical and biblical associations many African Americans attach to the word "harvest." The program's name is a welcoming and warm, non-medical symbol signifying the concept that one reaps what one sows (e.g., taking care of yourself results in an abundance of health).

Other important adaptations include focusing on ways to prepare culturally preferred foods without added sugar and salt, allowing an opportunity for a moment of silence at the beginning of each session, and looking at ways that patients and healthcare providers of different racial backgrounds can

communicate effectively.<sup>8</sup> At all times, fidelity to the original intervention was assured through close monitoring by a Harvest Health partner.

### **Using an Evidence-based Health Program**

Evidence-based health promotion is a process of planning, implementing, and evaluating community-based programs adapted from tested models or interventions. There are numerous advantages to taking an evidence-based approach to health promotion programming. Evidence-based programs are already proven to work, thus increasing your likelihood of obtaining successful outcomes. Ultimately, this makes it easier to market your program and engage valuable partners.

Also, with an evidence-based program, the methodology needed to implement the program is already in place, thus reducing the time and resources you need to get started. Finally, evidence-based programs provide a means to evaluate your program so that you can determine whether you achieve your goals and, importantly, how you might adapt and sustain your program over time.

For additional information on evidence-based health programming, please see the Center for Healthy Aging Issue Brief, *Using the Evidence Base to Promote Healthy Aging*, Number 1 Revised, Spring 2006 at:

[www.healthyagingprograms.org/content.asp?sectionid=15&ElementID=97](http://www.healthyagingprograms.org/content.asp?sectionid=15&ElementID=97)

### **The Benefits of Harvest Health**

We recommend that other agencies implement Harvest Health or the more traditional CDSMP because it benefits older adults, community-based organizations, healthcare providers, and the community at large. The program:

- Promotes positive healthcare habits for older adults and provides peer support and encouragement in the process;
- Empowers older adults to assume an active role in their healthcare, which allows them to better manage symptoms, enhance daily functional ability, and achieve the highest quality life possible;
- Improves health behaviors (diet and physical activity), increases self-efficacy in managing symptoms of chronic conditions, and reduces professional healthcare utilization;
- Expands capacity of staff and volunteers at community-based organizations to deliver evidence-based programs;
- Expands and builds upon links to other community-based organizations through outreach;
- Introduces evidence-based, health-behavior modification programs to traditional healthcare providers; and

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<sup>8</sup> Developed by Jean Goepfing, RN, University of North Carolina. Pilot tested by Molly Rose, RN, PhD and Christine Arenson, MD, TJU, 2001.

- Builds aging service providers' capacity and knowledge in terms of translating evidence-based programming to a culturally specific audience.

## **II. Planning and Partners**

As described in the introduction, most adults 60 and older have at least one or more chronic diseases, and the African-American population has an even greater incidence. Chronic conditions often lead to increased functional limitations, reduced independence, and poorer quality of life. However, individuals with chronic illnesses can learn to manage their health conditions and maintain or enhance their functional abilities through community-level interventions. Harvest Health, the CDSMP for older urban African Americans, is a culturally-appropriate, evidence-based prevention program that can be implemented in a variety of community settings by aging-service providers.

### **Identifying Local Needs**

When developing any health promotion program, it is important to gain a clear understanding of the local older adult community, such as:

- Demographics, including age distribution, income, educational attainment, racial and ethnic composition, and geographic distribution;
- Incidence and prevalence of chronic conditions, self-rated health, and functional abilities;
- Health behaviors with regard to nutrition, physical activity, and substance use; and
- Older adults' access to health and other community-based services (to determine where and how programs can be delivered).

Your local and/or state health departments are good resources for available data on chronic disease to use in your planning efforts. All 50 states use the CDC Behavioral Risk Factor Surveillance Survey (BRFSS), a state-based system of health surveys that collects information on health risk behaviors, preventive health practices, and healthcare access primarily related to chronic disease and injury. For many states, the BRFSS is the only available source of timely, accurate data on health-related behaviors. Your local health department may have BRFSS data for your local community and be able to assist you with accessing and interpreting this information.

We used data from the Philadelphia Health Management Corporation Household Survey of 2004 and combined BRFSS data with these and health statistics on older adults, which enabled us to look at health discrepancies between White and African-American older adults in Philadelphia County, as well as in the specific region of the county where our program was delivered. In your implementation, you may also wish to conduct targeted interviews and/or focus groups with groups to whom you are considering offering the program.

Choosing a program that is consistent with the cultural values and preferences of the target population and local community is key to its success. This may require

making modifications to the original evidence-based program while at the same time maintaining its essential elements.

### **Data and Planning**

Use the data and feedback from the environmental scan to discuss with your current partners how to identify and recruit additional partners interested in chronic disease self-management. To be most effective, be sure to include agencies or groups that serve or represent older adults, as well as some older adults themselves in your planning activities. Partners can help further assess data and research findings. The scan can reveal potential partners, existing collaborations, and possible funding sources that can be leveraged in your work.

### **Harvest Health Partners**

Our four partners, listed below, were chosen because they had previous experience with either CDSMP or the target population, or because of the relationships they had already developed with each other.

***Center in the Park*** is the community aging service provider (CASP) where the Harvest Health intervention is based. Center in the Park is a nonprofit, community-based organization that has served older adults and their families in Northwest Philadelphia for more than 30 years. The Center annually serves almost 6,000 older adults, of whom approximately 90 percent are African American and 85 percent are women. The majority of participants live on low-to-moderate incomes.

***Philadelphia Corporation for Aging (PCA)***, a private nonprofit, is the Area Agency for Aging for Philadelphia County. PCA is the largest AAA in the Commonwealth of Pennsylvania, and the fourth largest in the country. PCA coordinates and manages a broad range of community services and programs for older Philadelphians. PCA had offered the CDSMP at various senior centers over a number of years and served as the lead organization in this effort.

***Thomas Jefferson University's*** Center for Applied Research on Aging and Health (CARAH), Jefferson College of Health Professions, was the academic research partner providing program evaluation for the project. CARAH has a long history of designing, implementing, and evaluating community interventions with frail elders and family caregivers and has collaborated with many community-based organizations to develop and implement evaluation of service programs. In 2001, CARAH sponsored a pilot research study to evaluate the feasibility and acceptability of the CDSMP with older African Americans at a senior center.

***Albert Einstein Healthcare Network (Einstein)***, served as the requisite healthcare partner for this initiative. Einstein is a private, nonprofit healthcare organization, with a multi-facility, multi-organizational network that provides a vast array of services to a diverse elderly population. Einstein has a cadre of more than 25 staff trained to deliver CDSMP to all ages.

Harvest Health partners divided responsibilities in the following way:

- Center in the Park conducted the intervention on-site or off-site; recruited participants for the program, and hired the peer facilitators and outreach coordinators;
- PCA distributed the funding and managed contracts and budgets, monitored quality, and ensured maintenance of fidelity to the original model;
- CARAH analyzed outcomes of the intervention;
- Einstein provided health information on particular chronic diseases and marketed the program through their Physician Care Practices and hospital newsletters; and
- All partners disseminated information about the initiative directly to their respective professional groups and to others through publications.

### **Partnering for Success**

As partnerships form, it is important to reach consensus on the goals and objectives of the initiative. All partners should be clear about expectations, roles, and responsibilities and provide support to staff and other partners in meeting objectives as the initiative moves forward.<sup>9</sup>

Key features for building trust and maintaining a cohesive partnership include establishing and refining systems for ongoing and efficient communication between partners, providing strong project leadership, and creating a safe environment where all partners and project staff can voice opinions.

The Harvest Health project undertook periodic surveys covering individual and group role functions, as well as structured interviews with each team member. Continually assessing and negotiating each partner's role highlighted the importance of the organizations' ongoing commitment to the project's goals and processes. For example, the role of the project's healthcare partner, AEHN, was initially to ensure the quality of the program's health components. As the project proceeded, a more important and innovative role for AEHN developed: working with Center in the Park staff to develop systematic approaches to increasing physician referrals to Harvest Health. These approaches included educating AEHN community physicians about the benefits of the CDSMP for their patients and providing their staff members with efficient methods for making referrals to the community-based program.

### **Other Ideas for Partnering**

Other potential partners to help implement a Harvest Health program include senior housing sites, retirement communities, faith-based organizations, libraries, public health departments and clinics, recreation centers, AARP, and health

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<sup>9</sup> Gitlin LN and Keum JL (1996). "The Process of Collaboration." Chap. 10 in *Successful Grant Writing: Strategies for Health and Human Services Professionals*, pp 147-172, Appendix C.

provider networks. Consider approaching private or public foundations and local companies to fund, if not all, at least parts of the CDSMP, for example supporting licensing fees, staff costs, textbooks, and tapes. You may also consider approaching health insurance companies to pilot a CDSMP program with their older adult members—perhaps members who participate could receive a partial reimbursement of their insurance premium.

### **III. Adoption/Site Selection/Staffing**

#### **Primary Intervention Site**

Center in the Park was sought as the CASP partner and primary intervention site for Harvest Health because it offered a number of beneficial attributes:

- A large number of center members who matched the profile of the target population;
- Experience operating health promotion programs for older adults;
- A position of trust and respect in the community;
- The capacity to conduct new health promotion programs; and
- Past success in recruiting older African Americans for health activities.

The site was accessible by public transportation, had parking available, and offered a room that could accommodate 12 to 16 persons per session. It also offered an array of complementary programs available to Harvest Health participants, such as exercise classes, congregate meals, and other health and nutrition programs.

By concurrently running as many classes as possible, Center in the Park made the best use of limited staff. The Center's outreach staff recruited additional participants from the neighborhood. We also conducted the program at a senior housing site, at a church in the intervention area, and in one senior center at another location in the city—areas where older adults naturally come together. Other possible locations include libraries, YMCAs, disease-specific organizations, and other agencies serving the elderly. Health centers and healthcare networks are also appropriate sites, but we believe the intervention is best delivered in a non-medical, community environment.

#### **Recruiting Other Locations for the Program**

The Harvest Health project director initially visited possible locations to hold Harvest Health classes. She spoke first with each organization's manager to explain the benefits of Harvest Health. The organizations were then asked to recruit participants and provide a suitable room. Harvest Health provided the class, refreshments, and training materials (textbooks and tapes) free of charge.

In other Harvest Health or CDSMP programs, new sites can be responsible for recruiting participants and providing space and refreshments for CDSMP classes with a maximum of 20 persons. Perhaps one of your partners can help with technical assistance for recruitment and retention.

To maintain integrity of the program and fidelity to the model at every site, we suggest selecting a partner other than the one delivering the intervention. In our case, each partner organization has a copy of the curriculum which their facilitators follow while presenting. If the facilitator is presenting the program

according to the script, the partner can assure fidelity to the program. In our partnership, PCA provided this service to Center in the Park for Harvest Health.

Some locations may be reluctant to become CDSMP sites, particularly if they do not have the staff and space to accommodate the program or feel that the costs to run the program are too high. They might be likely to participate if you can identify funding to pay for the CDSMP licensing fees, textbooks, and audio tapes/CDs. Sites can also reduce the cost of the latter by jointly ordering large quantities of materials with other agencies delivering the program.

## IV. Reach—Outreach—Recruiting Participants

### Who Will Benefit from Harvest Health?

The target population for Harvest Health is community-dwelling African Americans 60+ who:

- Self-identify as having a chronic disease or are a family member or friend of someone with a chronic disease;
- Have arthritis, diabetes, hypertension, asthma and/or other disease(s);
- Are interested in learning to manage symptoms of the chronic disease(s); and
- Are able to problem-solve.

In your implementation of Harvest Health, your target population should have the same four characteristics.

The number of persons who will be able to participate comfortably in a CDSMP class is determined by location. There should be sufficient room for movement so that individuals can interact during a session, sufficient ventilation, and few distractions. Other considerations include the number of persons with mobility problems the space will allow. Although we sometimes had up to 20 persons in a class, the average number of participants in Harvest Health classes was 16 persons—the highest number for optimal interaction amongst CDSMP participants.

### Creating a Recruitment Plan

In developing a recruitment plan, it is important to keep the target population clearly in mind. It may be helpful to identify potential participants, and through focus groups or interviews, have them inform your strategy development. It generally helps to understand potential participants' culture and background. For example, where is your target population mostly located and how do they access program information? Are there community champions who could help spread the word? It will also be important to set realistic recruitment goals and to periodically assess progress made.

### Harvest Health's Recruitment Approach

There are many ways—many either free or relatively inexpensive—to market your program to your target population. Successful approaches to attract participants to Harvest Health in Philadelphia included:

***Word-of-mouth.*** Personal recommendations by Harvest Health graduates were the single most powerful tools for recruiting new participants, whether at the Center or off-site.

**Center in the Park bulletin board.** Photos of participants and personal testimonials by Harvest Health graduates were posted for Center members to see. They were very effective recruitment tools.

**Waiting lists and telephone follow-up.** These were used when participants expressed interest in Harvest Health after the orientation session.

**Presentations.** These were made to Center in the Park members and to local churches, senior housing, and other senior centers. The project director and the health partner made presentations to Primary Care Physician practices.

**Media.** Several articles on Harvest Health appeared in the local paper.

**Printed materials.** Center in the Park used one flyer describing the program.

**Direct mail.** Center in the Park direct-mailed information about Harvest Health to 6,000 of their members when the program was launched, inviting them to information sessions. Premier Years, an Albert Einstein Healthcare Network program that serves adults 55+, included an article on Harvest Health in one of their newsletters to 55,000 members.

In addition to these approaches, we recruited participants from the community by holding introductory meetings to explain the program at faith-based organizations, senior housing sites, and other senior centers. The project director briefly described the six-session program and how individuals developed action plans and shared them with each other in class. She spoke about the benefits and successes of Harvest Health and read letters participants wrote to their doctors describing the changes they experienced as a result of participating in the program. A note of caution: If you use participants' testimonials to recruit later on, remember to obtain releases from them, and to quote them without attribution.

You can also recruit potential participants with similar presentations from places where seniors gather: health centers; recreation centers; libraries; assisted living facilities; social service agencies serving seniors; and rehabilitation centers.

### **Recruitment Challenges**

Evidence-based programs are designed to help participants make informed decisions about their health and support appropriate behavior change. Change interventions are especially useful in addressing lifestyle modification for disease prevention, chronic disease self-management, fall prevention, healthful eating, and similar activities. The failure of participants to make appropriate behavior changes or even to participate in programming is often ascribed to a lack of motivation.

The classroom model and two-and-one-half-hour time commitment may be intimidating to participants with a limited educational background. Their perception of their own “good” health may make them feel there is no need to participate. They may not perceive that they have a chronic condition or do not understand what chronic condition means.

In Philadelphia, we faced considerable difficulties recruiting from the Primary Care Physician practices. Initially, we were unable to meet with doctors at their practice locations because of scheduling problems. We then targeted the PCP Office Managers. Einstein created tabletop displays for waiting rooms with tear-off slips that patients could use to follow through with Harvest Health on their own. To streamline the referral process, our Einstein partner also created a special Rx pad that their PCPs could use to make referrals. We received two referrals from PCPs.

Einstein and the partners felt that Harvest Health could benefit from a physician champion to help get other doctors interested in the program. Two efforts to engage doctors in this manner, however, were unsuccessful.

Once people are in the program, barriers to full participation can include bad weather and illness. Poor street safety, sidewalks, street lighting, or public transportation, and few local stores that sell fresh fruits and vegetables can also be impediments to Harvest Health participants.

### **Tools for Marketing**

The recruitment flyer and a photo of Center in the Park’s board are included in Section VIII. A still photo of the tabletop and Rx are in Section VIII.

The video “Chronic Disease Self-Management Program (Provider Version and Patient Version).” *Kaiser Permanente, 2002*, and “Healthier Living: Managing Ongoing Health Conditions.” *Kaiser Permanente, 2002*. For more information, see <http://patienteducation.stanford.edu/materials>. Available from Bull Publishing Company, P.O. Box 1377, Boulder, CO, 80306. Phone: 1-800-676-2855. Website: <http://www.bullpub.com>.

## **V. Implementation**

### **A Portrait of Harvest Health**

Harvest Health, a Chronic Disease Self-Management Program (CDSMP), is a workshop given for two and one-half hours, once a week for six weeks, in community settings such as senior centers, churches, libraries, and hospitals. People with different chronic conditions attend together. Two trained leaders facilitate the workshops, one or both of whom are not health professionals—and at least one of whom is managing his/her own chronic condition.

Subjects include:

- 1) Techniques to deal with problems such as frustration, fatigue, pain, and isolation;
- 2) Appropriate exercise for maintaining and improving strength, flexibility, and endurance;
- 3) Appropriate use of medications;
- 4) Communicating effectively with family, friends, and health professionals;
- 5) Nutrition; and
- 6) Techniques for evaluating new treatments.

Although 20 is the maximum class size, we recommend 15 as optimal.

The core mechanisms that underlie the program's effectiveness include:

- 1) Weekly action plans developed by participants and based on their individual goals;
- 2) Instruction in multiple approaches to symptom management; and
- 3) Group discussions providing opportunities for problem solving, peer modeling, and social persuasion.

Harvest Health demonstrates the usefulness of the CDSMP with a traditionally underserved population, African-American older adults, and has added modifications that encompass the cultural practices and values of that population.

We found that Harvest Health delivered an impact in four important areas of clinical significance:

- 1) Quality of life—improved self-efficacy and decreased health distress;
- 2) Symptomatology—reduction in illness intrusion & health distress;
- 3) Social significance—enhanced healthcare utilization; and
- 4) Social validity—acceptability and perceived benefit by participants.

### **The Importance of Fidelity**

Evidence-based programs are grounded in research. There are specific core components or constellations of components that make up the essence of these

programs. To be certain of achieving the positive health outcomes these program can deliver, you must utilize all core components, unchanged, in your implementation—that is, you must maintain “fidelity” to the model.

It’s understandable that to better match a program to your target population, you may wish to alter some of the program’s characteristics. However, before making changes, be sure you know which adjustments can be made without affecting core components. The following discussion will help familiarize organizations with Harvest Health’s core elements.

### **Adaptations that Maintain Fidelity**

A key issue in implementing evidence-based health programs in community settings is balancing program fidelity (i.e., is the program being delivered as intended) with the modifications necessary to maximizing the program’s acceptance among the target population. Harvest Health replicates the essential elements of CDSMP as described above and includes cultural modifications to maximize the program’s acceptability. One important adaptation is the name chosen for the program: Harvest Health. Developed by Center in the Park, the partners endorsed this name based upon the historical and biblical associations many African Americans have with the word “harvest.” The program’s name is a welcoming and warm, non-medical symbol signifying the concept that you reap what you sow—taking care of yourself results in an abundance of health. We recommend that other groups using CDSMP select names that resonate with their target population and that emphasize health rather than disease.

Other important adaptations may include augmentation of the nutrition component to include ways to prepare culturally preferred foods without added sugar and salt, and a component that focuses on effective communication strategies with healthcare providers of different racial and cultural backgrounds. At the beginning of each class, participants might also elect to include a moment of silence or prayer, a common practice in many African American gatherings. An additional session is held prior to the beginning of the program to orient prospective participants. This adaptation helps to build realistic expectations of the structure and program requirements such as action planning, group participation, and attendance in at least four of six classes. We believe it may help with retention as well.

### **Adaptations that Do Not Maintain Fidelity**

Not requiring action plans or changing the number of classes are examples of changes that take away the core elements of the program and would undermine the success of the CDSMP. Such omissions would compromise fidelity to the CDSMP model and to understanding the effectiveness of the evidence-based program. Most importantly, adaptations that remove the core elements described above would affect key outcomes as described in the original intervention done at Stanford University.

Potential adopting agencies such as CASPs, faith-based communities, and other non-medical services that are well respected in the community and among the target population, would be good choices in developing a successful program. Agencies that serve populations of different nationalities, ethnicities, and persons of limited English proficiency would be a good fit, as long as they retain the core elements listed above.

### **Staffing and Selecting Lay Facilitators**

Center in the Park hired a full-time project director for Harvest Health. She became the primary program facilitator, coordinated outreach, attended partner meetings, and presented on panels disseminating information about Harvest Health. The Harvest Health project director was a health professional, a registered nurse by training, and her resume included extensive experience in health education.

The project director recruited participants in the community and met with doctors and office managers in physician practice plans to encourage referrals to the Harvest Health program. The project director administered the baseline questionnaire; reviewed individual action plans; maintained the attendance log; and collected the evaluations. In addition, she was the representative for Center in the Park at all partner meetings.

The Harvest Health project director was closely involved with Harvest Health classes. In addition to scheduling the classes, she alternated with the lay facilitators in leading and assisting facilitation of CDSMP classes. She also observed classes led by lay facilitators to provide them with feedback. The majority of her feedback was on educational technique, especially on ways in which to redirect a discussion if a participant wandered off track. When the program began, the project director met weekly with the lay facilitators to review each class. However, the lay facilitators became more adept at leading classes, and soon she needed to meet with them only once a month.

Two non-professionals were recruited as lay facilitators. One was a staff member at the senior center, and the second was a graduate of the Harvest Health program. These facilitators worked 20 hours a week and were paid a stipend to act as lay facilitators. It might be helpful to consider paying stipends to your own lay facilitators or developing a corps of volunteer lay facilitators. Staffing, hours, and payment may depend on the number of classes you wish to run. And, of course, it is a requirement of the model that lay facilitators have a chronic disease.

A potential source for lay facilitators is your CDSMP pool of graduates. Some may show a particular interest in the program—people who are excited about creating and completing their action plans and who clearly enjoy participating in discussions. Staff members from the intervention site who have experience in

health promotion and education programs may also be recruited to become lay facilitators. This may help embed the program at the site.

### **Training Facilitators**

Harvest Health facilitators received three days of CDSMP training. The Stanford Patient Education Research Center strongly suggests that health professionals bring a lay person with a chronic disease with them. Persons may receive lay facilitator training at Stanford University or from a CDSMP T-Trainer in your area. (CDSMP T-Trainers have been trained at Stanford University specifically to train persons to become lay facilitators). Because the program is most powerful when taught by peers with chronic diseases, lay persons 60+ years of age were sought for Harvest Health. Each trainee receives a detailed leader's manual, and a copy of the program textbook and relaxation audio tape or CD to be used in their classes.

Lay facilitators can also be recruited from senior housing projects, senior center members, faith-based organizations (parish nurses), and other aging service providers, as well as through AARP and other professional associations. To develop a volunteer lay facilitator program, look for volunteers who were either health professionals or educators and who have skills related to the CDSMP. However, anyone who has a strong interest in the program is appropriate. National programs such as the Retired Senior Volunteer Program also may be a good source. You may wish to consider paying peer volunteers for transportation or a small stipend for their time. If you decide to use volunteer lay facilitators, develop a plan to reduce “volunteer fatigue” and continuously recruit new volunteers. We recommend you support volunteer lay facilitators by observing them while leading and by holding individual supervisory sessions as well as group meetings.

### **Implementation and Fidelity Tools**

The Harvest Health CDSMP used several tools that helped maintain fidelity to the original Stanford model over time, and generally facilitated implementation. They included:

- Attendance logs, which note the program's participant retention rate;
- Individual action plans, used throughout the 6-week program;
- A baseline questionnaire, used during the introductory session to gather demographic information, identify types of chronic diseases, and note each individual's perspective of his or her ability to manage his or her illnesses;
- A course evaluation, used at the end of the last session to evaluate how effective the class was in helping individuals manage their health activities on a daily basis; and
- An AAA monitoring tool, modified to monitor fidelity of Harvest Health to the CDSMP model.

Samples of all of these are available in Section VIII. Of note, we have simplified the original tools to make it more manageable for new intervention sites to sustain the project. Both the long form and the newer short form are included in Section VIII.

## **VI. Maintenance**

In order to continue to sustain the CDSMP over the long term, an organization/partnership should plan to continue recruiting new sites to reach new participants; maintain the partnerships that have already formed and/or seek new partners; participate and present at professional conferences; and identify new potential sources of funding, such as:

- Fees-for-service to other agencies, healthcare organizations, or AAAs in local regions where the program is not offered;
- Healthcare insurance companies for Medicare patients;
- The American Association of Retired Persons (AARP);
- Associations for specific chronic diseases and related problems;
- City and state grants; and
- Private foundations interested in aging, healthcare, and/or chronic conditions.

In our experience, the Philadelphia Corporation on Aging, the local AAA, acquired city funding for an evidence-based program grant, which includes Harvest Health. The healthcare network also continues to offer the Harvest Health classes to venues and groups of all ages throughout the city.

It is also important to monitor the program to maintain fidelity to the original CDSMP model. We recommend you use the simplified baseline questionnaire, satisfaction survey, attendance log, and action plan also available in Section VIII. Your partnership or organization can use the information from the above tools to collect data on the program to report back to funders for the program.

## **VII. Effectiveness, Performance Measures, and Outcomes**

The primary outcome measures used to evaluate the Harvest Health program were the same as those used in the original randomized control trial study of the CDSMP. This allowed us to compare the outcomes of our translated program with those of the evidence-based model and to determine the program's effectiveness with African American elders. Program outcomes were measured in four critical domains of well-being that are of high public health and clinical significance:

- 1) Health status—measured as self-reported health;
- 2) Health behaviors—positive changes in important health behaviors including physical activity, symptom management, and communication with a primary care physician;
- 3) Self-efficacy—confidence in one's ability to manage symptoms of chronic conditions, which has been shown to be significantly related to overall well-being;
- 4) Healthcare utilization—visits to physicians, use of the ER; and Hospitalizations.

Secondary outcome measures included the rate of attendance at the CDSMP sessions, satisfaction with each session and the overall program, and effective team functioning among the project partners.

Thomas Jefferson University conducted an annual evaluation of team functioning, which provided the partners with ongoing feedback and the opportunity to make adjustments in the collaboration as needed.

Harvest Health used both individual- and organizational-level measures. Individual-level measures included:

- 1) Session One—Results of intake form from each participant, which included information on demographics (age, sex, race/ethnicity, education), chronic condition/s, and personal goal/s for participating in the program;
- 2) Each session—Number in attendance;
- 3) Each session—Number of participants who have an action plan; and
- 4) Session Six (last session)—Results of a program satisfaction survey composed of:
  - An evaluation of program leaders;
  - An evaluation of program content;
  - Perceived benefit/s;
  - Comments on whether participants met their goal/s; and
  - Information on how they will use what they learned from the classes in the future.

Organizational measures included:

- 1) Number of participants recruited per class;
- 2) Attendance/retention for whole class at the end of the six-week program;  
and
- 3) Satisfaction survey results for the whole class at the end of the six-week program.

The results of both the individual and organizational measures can be used to gauge the program's successes and benefits and to improve program quality. The results can also be used to provide feedback to agency and program funders. Satisfaction survey results can provide testimonial statements from participants that can be used to market the program and recruit new participants to the program.

Class retention rates for our study, which included more than 500 participants, ranged from 33 percent to 100 percent. Participants had to attend four of six sessions to be considered as having completed the course. This allowed for variation in attendance due to illness or weather, the two main reasons given for not attending sessions. The overall retention rate for the three-year study was approximately 85 percent. Five of the 38 classes fell below the 85 percent retention rate.

We recommend a participant retention rate goal of 85 percent as a measure of retention success. If you are not meeting this rate of retention we suggest you do the following:

- 1) **Look at fidelity monitoring**—Is the program being delivered as intended? Are all parts of the curriculum being delivered when and as they are intended?
- 2) **Look at satisfaction surveys**—Is something missing from the program for participants?
- 3) **Follow up with absentees**—If people drop out or miss more than one class, contact them to investigate the reason. The project director, outreach coordinator, and lay facilitators at Harvest Health helped with this. A program director or volunteer working on the program could make these calls as well.

Replicating organizations may also want to consider using a brief introductory/ orientation session to describe the program to interested participants. Harvest Health held an initial orientation meeting during which participants completed a baseline interview for the research component of the program. The lay facilitator also spent time describing the program, the number of sessions, the length of the sessions (two-and-one-half hours), requirements to complete the course and

receive a certificate (attend four of six sessions), completion of weekly action plans, etc. We believe this may have helped create appropriate expectations among participants and helped them decide if the program was right for them. Some people attended the orientation and then decided not to participate.

### **Program Outcome Evaluation**

Procedures for measuring program effectiveness may vary depending on organizational resources as well as funder requirements. A tiered approach to outcome evaluation is described below for agencies to consider, depending on their resources and requirements.

#### ***Simplified Pre-Post Outcomes Evaluation***

The Harvest Health evaluation partner developed a streamlined intake questionnaire to be administered prior to the beginning of the CDSMP and a course evaluation form for post-program evaluation based upon the areas of greatest impact we saw in our three-year project. Taken during the orientation or first class session, the intake questionnaire provides participant-specific information (i.e., health conditions, symptoms, healthcare utilization) and an understanding of the specific issues and overall goals of participants. It is helpful if course leaders are available to answer questions when this is administered.

Given before session six, the course evaluation form measures program satisfaction as well as areas of program impact. These brief self-administered tools should take no more than 15 minutes to complete. It is best if this is administered by someone other than course leaders (e.g., volunteers or other agency staff, etc.) to ensure authentic evaluation and participant confidentiality. Analysis should be relatively simple given the reduced number of program outcomes being measured. It is important that the organization/agency have the commitment and capacity to evaluate the program outcomes so that needed modifications can be implemented.

#### ***Delayed Pre-Post Outcomes Evaluation***

Anytime from four to six months following the initial intake, you can administer a brief follow-up course evaluation. It can be done with all participants or with a random sample of courses and/or participants. They can return evaluations in postage-prepaid return envelopes. Evaluations can also be done over the telephone or at class reunions—although this last option will yield best results if course leaders are not in attendance.

This type of evaluation will provide information on the longer term impact of the CDSMP and determine maintenance of participant knowledge and behavior change. It will require additional human and financial resources, which may present challenges for smaller organizations.

If the program organization and/or funder would like more extensive program outcome data, Dr. Lorig has developed an abbreviated questionnaire that can be

used for this purpose. It is recommended this tool be utilized with a four-to-six month post-evaluation.

Remember to monitor the program to maintain fidelity to the CDSMP. We recommend you use the simplified baseline questionnaire, satisfaction survey, attendance log, and action plan also available in Section VIII.

Your partnership or organization can also use the information from the above tools to collect data on the program to report back to funders for the program.

## VIII. List of Appendices of Tools and Resources

The following tools were used during the three-year grant study from October 2003 to September 2006. Some of the tools will be revised or no longer used as the program continues.

### I. Introduction/Background

- Articles on original intervention
- Background research reference list

### II. Planning and Partners

- Needs assessment
- Meeting agendas
- Minutes of meetings
- Work plan grid for the project
- Stanford Patient Education Center lay facilitator training
- Job Descriptions—project director; lay facilitator; outreach coordinator
- Tracking tool

### III. Adoption/Site Selection/Staffing

### IV. Reach—Outreach—Recruiting Participants

- Participant recruitment flyer
- Board at senior center with photos of participants and their testimonials about the program
- Tabletop board with tear-offs
- Prescription pad
- Graduation certificates of class completion
- Incentives—pedometers, water bottles, pill boxes, and medication lists were available for participants to take after graduation
- Article in Center in the Park's newsletter
- Articles on the program in local papers
- Article on Harvest Health in PremierYears' newsletter

### V. Implementation

- Attendance log
- Action Plan template on page 24 of the booklet, **Chronic Disease Self-Management Program (Provider Version and Patient Version)**. Kaiser Permanente, 2002.

### VI. Maintenance

- Monitoring form—Observational tool in which the program delivery, content, participant acceptability, and fidelity to the original CDSMP program were monitored by staff from the lead agency.

## **VII. Effectiveness, Performance Measures and Outcomes**

- Baseline interview—interview completed prior to beginning the program
- Four month follow-up interview—completed four months after beginning the program
- Session evaluation—completed by each participant at the end of the sixth session
- Collaboration survey—Individual  
Collaboration survey—Group  
Qualitative collaboration interview conducted by telephone
- Kate Lorig’s abbreviated program evaluation