

# Challenges and Successes in Implementing the Chronic Disease Self-Management Program

“Self management programs allow participants to make informed choices, to adopt new perspectives and generic skills that can be applied to new problems as they arise, to practice new health behaviors, and to maintain or regain emotional stability.”

—Kate Lorig, 1993



THE NATIONAL  
COUNCIL ON  
THE AGING



# About The National Council on the Aging

## Who We Are

Founded in 1950, The National Council on the Aging (NCOA) is the nation's first charitable organization dedicated to promoting the health, independence, and continuing contributions of older Americans. NCOA is a 3,200 member national network of organizations and individuals including senior centers, adult day service centers, area agencies on aging, faith congregations, senior housing facilities, employment services, and other consumer organizations.

## What We Do

To accomplish organizational objectives, the following core competencies guide our activities:

- **NCOA is a national voice and powerful advocate** for public policies, societal attitudes, and business practices that promote vital aging. A founding member of the Leadership Council of Aging Organizations, NCOA often leads campaigns to preserve funding for the Older Americans Act. We currently chair and lead the Access to Benefits Coalition to help lower income Medicare beneficiaries find prescription savings. We regularly do public awareness studies such as the Myths and Realities of Aging™ that have helped shape the attitudes of millions.
- **NCOA is an innovator**, developing new knowledge, testing creative ideas, and translating research into effective programs and services that help community service organizations

serve seniors in hundreds of communities. NCOA is the leader in identifying and disseminating best practices and evidence-based programming in community-based physical activity, chronic disease management and health promotion activities. In its long history, NCOA has also shaped many innovative aging programs, including Meals on Wheels and Foster Grandparents.

- **NCOA is an activator**, turning creative ideas into programs and services that help community services organizations organize and deliver essential services to seniors. This includes Family Friends and its Center for Healthy Aging. NCOA also administers two federal Programs (Senior Community Service Employment Service and Senior Environmental Program) and the Maturity Works partnership to provide employment and training opportunities for mature adults through offices nationwide.
- **NCOA develops decision support tools** such as BenefitsCheckUp® and the Long-term Care Counselor™, enabling consumers to make optimal decisions and maximize all available resources and opportunities, whether they are looking for prescription savings or understanding their risk of needing long-term care.
- **NCOA creates partnerships** that bring together a wide variety of voluntary, philanthropic, and public organizations to spark innovative solutions and achieve specific results. Each year, for example, NCOA and the American Society on Aging partner to bring a joint annual conference to 4,000 professionals in the field.

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*“I would like to take my hat off to the people who have stepped up to the plate to actually participate in something that is in almost every walk of life considered kind of strange ... so I think those participants are a very strong partner in this and what they brought is the commitment to living a healthier life with their diabetes and or other chronic conditions.”*

*Master Trainer, Focus Group participant*

The Chronic Disease Self-Management Program (CDSMP) developed at Stanford University was designed to help persons with chronic disease better manage their health conditions. Research has demonstrated the effectiveness of the program in improving the health outcomes of the participants over time. This evidence-based program has drawn interest from medical and aging network organizations that have applied for the license to implement the program in their own settings.

This report summarizes the results of five telefocus groups conducted to assess the experiences of Master Trainers in implementing the CDSMP for the national aging network. The study is part of a larger initiative by the Administration on Aging (AoA) to encourage implementation of evidence-based prevention programs in the aging network.

The objectives of this qualitative research study were to assess the opportunities and barriers in implementing the program in a community setting; identify the benefits of the program to those involved; define implementation barriers and how to overcome them; and define the policy implications in terms of making this program and other evidence-based programs more widely available on a national level through community aging service providers.

Participants of the telefocus groups (N=21) were Master Trainers who were trained by the Stanford Patient Education Center to both teach the CDSMP and train future leaders to teach the program; they were also involved in other key aspects of implementing the program at their organizations. Their motivation to offer the program stemmed from three factors: 1) it offered another avenue of patient education for those with chronic conditions, 2) the program philosophy was a good match to their organization’s mission, and 3) the program stood apart from others in that it was evidence-based with published data to support the outcomes.

Several key ingredients were identified for successful implementation of the program. At its foundation, program success was predicated upon the development of a program infrastructure and community network to provide the planning and ongoing support to the Master Trainer and the evolving CDSMP. Other key ingredients for success that build on this foundation include developing stable and successful partnerships and collaborations; establishing ongoing organizational support; securing long-term funding; planning for and conducting sustained marketing for the program to the community, sponsors, partners and potential participants; and securing sustained staff support to share the division of labor among more than one or two people.

**Partnerships and Collaborations.** The programs that have longevity and achieve the greatest success are those that understood the value of and invested the resources in developing solid relationships with community organizations. When Master Trainers took time to plan for the program and create collaborative ventures prior to being trained, they found that the implementation phase after training at Stanford was much smoother. The most successful partners were those that bought into the philosophy and practices of the self-management concept. This facilitated the mutual identification of resources (such as workshop location, program leaders, staff support) and division of responsibilities (marketing, recruitment of participants, administrative and logistics, etc.). Physicians, disease-specific support groups, medical centers and systems, senior centers and church leaders proved to be some of the best partners.

**Funding.** There were three types of programs interviewed. The most successful and secure programs are those that began with internal funding sources or sponsoring agencies, or they have established relationships and shared the costs with medical clinics or other community resources. The Master Trainers' time could be used for program development and marketing/partnership building, not continually searching for financial resources to sustain the program. Some programs overcome the long-range funding dilemma by using their start-up funding to successfully secure funding for ongoing programming. The most important dimension of their success is the emphasis they placed on cultivating their constituent groups -- their sponsors, their partners, their professional staff and lay leaders, and even the program participants themselves. Through this networking they obtain both funding and marketing/recruitment support and have been able to build successful, sustainable programs. Some Master Trainers, on the other hand, have been unable to find financial support to continue the program beyond their initial grant funding used to start the program. As a result, some programs are on hold while others are functioning at a minimal level with one staff member doing what he/she can with little or no financial support. These programs are most likely to report that they have not established partnerships or a base of support in the community.

**Staff Support.** The CDSMP is not a program that can be implemented and maintained by one person alone. In addition to facilitating programs, Master Trainers found they had multiple responsibilities to handle in getting their programs launched. Implementation takes advance planning, on-going management and consistent oversight, and allocation of staff time dedicated to make the program work. Those who could call on other staff from their organization or from their partners' organizations to share the tasks were able to focus on overall program growth and development, not just on survival. The distinct labor categories identified for maintaining this program are logistical/administrative, managerial, program coordination and lay leader responsibilities.

**Organizational Support.** Most Master Trainers would agree that neither they nor their organizational leaders had a full understanding of the resources and time needed to implement and run this program. The most successful programs had organizational leader support before and after the Stanford training, involvement from key people identified at various levels, and avenues for reporting on the outcomes. In addition, the most supportive organizations had a good understanding of the program philosophy and practices, realistic expectations of the

resource requirements, and a willingness to give the Master Trainer the time to do the necessary advanced planning.

***Marketing the Program, Recruitment and Retention of Participants.*** The Master Trainers agreed that successful implementation of this program requires a significant effort in the start-up phase lasting six to 12 months, with marketing and recruitment being core activities. Master Trainers with the greatest success at marketing have two elements in common: they effectively established partnerships in the community and/or a sponsoring agency and most had a marketing strategy that included multiple approaches, such as community presentations, targeted outreach to support groups and existing community-based programs, partnership and sponsor staff involvement, networking with community leaders, and attending health screenings and fairs.

**Program Recruitment.** Recruitment strategies vary by type of organization, available resources and community access but some commonalities exist. The most effective recruitment results from personal referrals by trusted leaders and staff of agencies that serve the target population as well as by word-of-mouth of former class participants. Holding classes at familiar locations and providing transportation reaches more people who might not otherwise attend. Organizations with successful programs continuously market the program at health fairs, screenings, community events and conferences. Other programs have demonstrated success in recruitment by having their sponsor's/partner's staff help spread the word after having experienced the program themselves. Many Master Trainers followed Stanford's recommendation to rename their program since a "chronic disease self-management" program was not a name that most people could identify as helpful to them with their disease.

**Program Retention.** Organizations with successful programs use personal contact from the lay leaders to encourage initial and ongoing attendance. They also rely heavily on the buddy system component built into the program for establishing lasting relationships among participants as well as the skill building activities and eventual empowerment of participants. The lack of ability to retain participants is most often related to factors outside of the program itself so programs often "over-recruit" participants, expecting that some will not be able to continue. Sometimes, there are a few participants who drop out because they expected a didactic form of education, rich with factual information in a content, not process-based program. What they discover is that they are asked to create personal action plans and commit to making personal behavioral changes based on activities aimed to help them develop an enhanced sense of self-efficacy. Most organizations have learned to minimize these drop outs by explaining the nature of the program at the time of registration.

***Lay Leader Approach.*** Most Master Trainers agree that one of their greatest challenges is the recruitment and retention of lay leaders who maintain a commitment and active involvement to the program. Successful strategies Master Trainers use to find and keep lay leaders include carefully identifying leaders with characteristics they have learned work best, training more lay leaders than needed, clearly explaining the commitment before investing in training, and pairing newly trained lay leaders with experienced leaders. Master Trainers quickly learn how to identify potential lay leaders, and just as importantly, how to screen those candidates who may not agree with how the course is presented. The program's structured protocol does not allow leaders to "teach" in the traditional sense nor can they expand on the subject matter of that

week's session. Most often, Master Trainers try to identify past participants that were enthusiastic about the program and would want to share it with others by becoming lay leaders. Close-knit rural and ethnic communities may have some resistance to sharing personal information in the sessions, while others do not. Language barriers have to be overcome as well, in some communities. If English is not the participants' first language, the program materials may not be easily understood and examples given in the manual may not be culturally sensitive and relevant. Ideally, if one of the leaders is of the same ethnic or cultural background and can help to modify and/or translate the materials for that particular audience, the acceptability of the program will be enhanced.

### **Why the CDSMP is Successful**

The program itself was lauded in terms of the outcomes for patients and the ancillary impact on staff of organizations that have adopted the processes (such as brain-storming, goal-setting, etc.) taught in the program. All the Master Trainers, including those who faced challenges in securing funding or organizational support to continue the program, had strong convictions regarding the program benefits to the participants and the community at large. Some of the benefits listed from the organizational level include: increased community recognition, broadening scope of organization's service to their community, healthier and happier patients with lower utilization rates, and generating good will within the community. The benefits for partners and funders include: better-informed patients or members, ability to offer another educational approach to self-management, expanding their services to their patients or members, and fostering good will within the community particularly for private organizations.



### **Background**

The purpose of this study is to assess the opportunities and barriers that exist in implementing the Chronic Disease Self-Management Program (CDSMP) for the national aging network. The study will be used to inform discussions at a meeting of national leaders convened to prepare recommendations related to making the CDSMP and other evidence-based health programs more widely available through community aging service providers.

The Chronic Disease Self-Management Program was created by Kate Lorig, RN, DrPH, Diana Laurent, MPH, and Virginia González, MPH, from Stanford University to teach individuals how to manage their chronic health conditions. The Stanford Patient Education Research Center offers training for the Chronic Disease Self-Management Program and Tomando Control de su Salud (the Spanish CDSMP). To enable an organization to sustain their program locally, Stanford trains and authorizes Master Trainers for a facility, who in turn, serve as that organization's on-site trainers for the future. A license to give the program(s), issued to the trainee's organization, is included with the training.

The program consists of six structured workshops offered in community settings such as senior centers, churches and hospitals and is not disease-specific. Workshop sessions are highly participative with attendees learning processes and skills to better manage their own health and become actively engaged in their treatments. The workshops are facilitated by a team of two trained leaders, pairing either a health professional with a community volunteer who has a chronic disease (hereby referred to as a lay leader) or two lay leaders. Research to provide evidence for the program's effectiveness was conducted among 1,000 people with chronic conditions over a period of three years, in a randomized, controlled test of the program, and indicated significant improvements in health outcomes among those who participated in the CDSMP compared to those who did not.

This study is part of a larger initiative by the Administration on Aging (AoA) to encourage implementation of evidence-based prevention programs in the aging network. The National Council on the Aging (NCOA) Center for Healthy Aging serves as AoA's National Resource Center on Prevention Programs. NCOA was assisted in this study by Ms. González, a nationally-recognized expert in the CDSMP. Dr. Lorig, Director of the Stanford Patient Education Research Center served as an advisor to this project. The study was conducted by Carolyn Holmes, MScN, PhD of Holmes Research & Consulting, LLC in collaboration with Ms. González and Nancy Whitelaw, PhD, of NCOA. Dr. Holmes facilitated the focus groups.

### **Limitations**

Focus groups, by their very nature, are intended to capture a range of qualitative views, opinions and experiences of the target population and are a good method when in-depth information and explanatory feedback is needed. No attempt is made to quantify or measure the degree to which the opinions are present in the population. Results from focus groups should be applied to the entire population with caution. Participants were recruited on a volunteer basis, rather than being randomly drawn from the total population of Master Trainers who completed the CDSMP

training course through Stanford University Patient Education Research Center. Findings reported from these focus groups represent majority viewpoints that emerged consistently throughout the groups.

### **Study Objectives**

In order to assess the feasibility of a widespread implementation of the CDSMP in the national aging network, the specific research objectives of this study are to:

1. Determine the “after training experiences” of the Master Trainers from the program to better understand the opportunities and barriers encountered in implementing the program in their community settings.
2. Identify the benefits of implementing the program for older Americans, health systems, and organizations that choose to put the program in place.
3. Define the barriers that may be encountered in implementing and running their programs and determine how to overcome them.
4. Define the policy implications of the CDSMP in terms of program design and implementation, partnerships, funding, delivery systems, facility management, staffing, etc.

### **Research Design**

Four focus group discussions with four to six participants each were conducted by teleconference by Dr. Carolyn Holmes of Holmes Research & Consulting, LLC (HR&C) in May 2004. The Moderator’s Guide (Appendix F) was developed by Ms. González and others familiar with the CDSMP, with input from HR&C. A pretest discussion with three participants was conducted to finalize the moderator’s guide. Results from this pretest are included in the report because the Moderator’s Guide did not change significantly after the pretest and the participants’ input added excellent suggestions to the findings.

The sampling frame of 90 Master Trainers was selected from a list of over 600 individuals who had completed the Stanford University Patient Education Research Center’s CDSMP Master Trainer Workshop and returned home to implement the program in their communities. Master Trainers were chosen because they are the critical link between the highly structured Chronic Disease Self-Management Program and local implementation. The roles and functions of the Master Trainers vary according to the needs of the organization. These responsibilities range from securing funding for the program, coordinating the program and staff to recruitment and teaching of lay leaders and course participants. At a minimum, the Master Trainer is expected to facilitate the program workshops initially and then train lay leaders to facilitate future courses.

Since the purpose of this study was to explore a variety of issues related to implementing the CDSMP through community-based organizations, we selected Master Trainers who had some experience working with such organizations. The sample of 90, selected with input from the Stanford Patient Education Research Center staff and NCOA, were initially invited to participate in the study by completing a short web survey. The questionnaire was used to obtain current contact information for the Master Trainer and more background on the

organization, the individual's experience with the CDSMP, their role(s) in implementing the program, the types of communities served, and any collaborations with other community agencies or groups.

The final sample list for the focus groups consisted of the 30 Master Trainers who responded to the request for updated information. The survey responses enabled the research team to select those to invite based on the following set of criteria: 1) Master Trainers who completed training over one year ago so as to have had time to implement the program; 2) Master Trainers who were working with aging network service providers or other community organizations such as public health departments, community health centers, etc.; 3) Master Trainers with experience working with diverse cultural, racial or ethnic communities; and 4) Master Trainers who represent different geographic areas of the country.

### **Characteristics of Participating Master Trainers**

A total of 21 Master Trainers participated in this focus group research, 18 of whom had completed the web survey and three who volunteered or were recommended by others, based on their prior experience with implementing the program. The Master Trainers who participated had offered at least one six-week session and were still involved with the CDSMP. Their length of experience with the program varied from several years to just a few months.

Feedback on the surveys indicated that the most frequently cited partnerships with community organizations were with senior centers, community centers, churches or synagogues, faith-based agencies and area agencies on aging. Most of the Master Trainers listed their role as directly overseeing the implementation of the CDSMP. Other responsibilities of the Master Trainers, listed in rank order, include: training lay leaders, assisting community agencies in implementing CDSMP, monitoring implementation and program fidelity, conducting an evaluation of the program and recruiting lay leaders. Less than half the Master Trainers had the responsibility to secure funding or recruit participants as part of their roles in terms of the CDSMP. These data can be found in Table 1 of Appendix B.



The following sections describe what was learned from the focus groups about motivators for implementing the CDSMP and the six key ingredients for success. Each of the key ingredients is discussed in depth with a summary of both barriers to success and success strategies being followed by quotes from Master Trainers to illustrate the important points.

### **Motivation for Implementing CDSMP**

The decision to enroll in CDSMP training and implement the program was made at the organizational level in some cases and by individual staff members in others. At the organizational level, the motivation to offer the CDSMP stemmed from three factors: 1) organizations saw the CDSMP as another avenue of patient education for those with chronic conditions, 2) the program philosophy was a good match to the organizational mission, and 3) the program was evidence-based with published data to support the outcomes. Selected feedback from study participants included:

*“We wanted our [health plan] members to have more options in terms of ... living with chronic conditions. And we were doing more and more work, not only in diabetes, but with our members with heart failure looking for more and more interventions and systematic approaches that we could take.”*

*“Working for a health plan, we do offer disease management and health management programs to our members and it was just getting more information ... to members to help them participate in the management of their health.”*

*“The directors definitely were encouraging it as an innovative idea ... And of course our executive director supported it for that reason, knowing that it was a program [that was] evidence-based.”*

*“With the Robert Wood Johnson grant, this program had been recommended or listed as a reference and so our committee checked on it in a little more detail and felt that it would really fit into what we wanted to do in the primary care clinics.”*

*“And again, it grew out of the [diabetes] collaborative ... I had to get clearance from my supervisor at the time to participate, but, also wanted to know [if]... we could actually set up some training. Fortunately all of that worked out, and again, it was just a great partnership with one of our stronger medical groups.”*

At the individual level, one or two staff members championed the program within their organization. Often it was their belief in the program that initiated the decision-making process that sent them for training. Their enthusiasm was also extremely important in getting the program implemented upon their return.

*“As a clinic manager and being a community clinic, we serve a multitude of ethnic populations, but, we also understood that diabetes was, of course, affecting these ethnic*

*populations. Being introduced to the model itself and being someone who actually benefited greatly from the workshop as a whole, I was quite excited about having this opportunity to present the workshop to the various members of our populations.”*

*“It became pretty clear to me, both in my own personal experience in my life dealing with illness and other people in my life that I supported over the years, that the strategy just makes sense. And, so what I’ve always loved about it most, is the peer support aspect and that’s what I think makes it really, really special. It’s one of the hardest things about running these programs, is maintaining and managing that, but in my mind, it’s the absolutely most powerful thing about it.”*

The downside for initiating the program based upon the commitment of just one or two staff members is that the organizational support necessary for ongoing success may be lacking. More than one Master Trainer had heard about the program for some time before attending the training. When they saw increasing interest within their organizations or among potential funders, they seized the opportunity to seek support for the training.

*“In the enthusiasm of going through leader training and people get excited about that and want to teach the class, then you get back home to the reality of it all, the sort of infrastructure issues that have to go around that and it dampens things pretty quickly I think.”*

*“I heard Kate Lorig speak at a conference in the early ‘90s, like ‘94, when they were first assembling the research on Chronic Disease Self-Management Program. I was fascinated by it, so I came home and started looking for funding for the program. And it wasn’t until 1998 [we] just kept pursuing it until we finally got funded.”*

The program was most likely to succeed if sponsoring organizations had a belief in the concept of chronic disease self-management, recognized the value of adopting an evidence-based program, and selected project coordinators and Master Trainers who shared these values. All these Master Trainers left the Stanford training with an appreciation for the efficacy of the program; a great deal of respect for the program’s integrity of design and purpose; and a greater understanding of the program benefits for those with chronic conditions.

### **Six Keys to Success**

According to the Master Trainers, successful implementation of the CDSMP is dependent upon several key ingredients, many of which are multidimensional and substantially interrelated with one another. A requirement that emerged as the foundation for program success was the need to develop a program infrastructure and community network to provide the planning and ongoing support to the Master Trainer and the evolving chronic disease self-management program. The steps for building a strong foundation for the program include: obtaining organizational support, fostering partnership development, securing funding, assigning roles and responsibilities, nurturing referral sources, and developing marketing strategies and communications networks to sustain the recruitment and retention of lay leaders and participants.

When the time to build this foundation was not taken, the Master Trainers found themselves continually struggling to keep up. In this case, Master Trainers were often expected to carry the burden of the program alone. As some struggled to keep the program afloat, they slowly lost ground with their marketing, recruitment and fundraising activities. A corollary to not laying a solid foundation in the start-up phase was an underestimation of the amount of work needed to build and sustain a successful program. When the time was not available to plan and organize the activities, satisfaction with the program diminished. The frustrations felt by Master Trainers often arose from low class enrollment, inability to find and train lay leaders, the loss of lay leaders after training, and lack of resources and assistance to do the job right.

The six key ingredients that emerged from the focus groups will be discussed in detail in the following sections. It will include the barriers and successful strategies for addressing those barriers as described by the respondents. The key ingredients include:

- Solid partnerships and collaborations within the community built with shared responsibility for the program in mind;
- Funding for staff time and program costs;
- Staff with designated hours that can be dedicated to the work and a clear division of labor;
- Support from organizational management;
- Strategies for marketing the program to the aging network, medical community and potential participants that begins with partnership building and continues through the life of the program;
- Ongoing recruitment and retention of lay leaders and class participants.

In their efforts to enlist partners and community sponsors, some Master Trainers were surprised by the lack of knowledge about adopting evidence-based programs. Some potential partners or sponsors did not fully understand the self-management philosophy of the CDSMP. Others were reluctant to accept the program as designed. Where the trainers found the most success was with partners, colleagues, lay leaders and staff who believe in the self-sufficiency of people with chronic disease and their ability to make sound decisions for themselves. Although fidelity to the program principles and practices was not the focus of this research, Master Trainers consistently reported a strong sense of commitment to delivering the program as it was designed. Often they experienced circumstances in delivering the program that challenged this commitment. Their stories clearly indicated that there was no question that they would retain the program design, practices and methods as they learned them.

***Partnerships and Collaborations.*** The programs that had longevity and achieved the greatest success are those that understood the value of and invested the resources in developing solid relationships with community organizations. Not only did the partners provide access to potential participants, convenient meeting locations and, in some cases, funding, these collaborative relationships reinforced the value of the CDSMP to the partners' constituent groups. For the Master Trainers, this support was both philosophical and practical – it bolstered their ongoing commitment and belief in the program's value as well as supplied them with people who shared the logistical burden and could reach participants who needed the program.

Time for planning and partnership development was critical to success. When Master Trainers took time to plan for the program and create a collaborative venture prior to being trained, they found that the implementation phase was much smoother. This may have been due, in part, to the fact that Master Trainers needed to effectively communicate the philosophy and substance of the program to potential partners in order to recruit their support and commitment. In doing so, many of the issues related to planning for implementation would be considered and resolved through the process of defining roles and responsibilities, logistical aspects and expected outcomes.

The most successful partners were those that bought into the philosophy and practices of the self-management concept. Physicians, disease-specific support groups, medical centers and systems, senior centers and church leaders proved to be some of the best partners. Partnering with a medical center often ensures a source of professional and lay leaders to teach the classes and provides a continuous stream of potential class participants through physician and staff referrals. The medical center, in return, sees that their patients are better able to manage their conditions and also receives positive publicity. Partnering with organizations within the potential participants' naturally occurring networks, like community centers and churches, is a way to reach out to the less informed, less educated, poor, and ethnically diverse at-risk populations. Success with these typically hard-to-reach populations hinges on the support of a lay leader and participant recruitment by trusted individuals who are respected members of the community.

Barriers to success:

- Lack of knowledge and skills regarding how to identify, develop and nurture partnerships
- Developing collaborations with partners that are dependent on the CDSMP staff to run the program without making contributions of staff time, resources to help recruit potential participants and/or funding to offset the costs of providing the program;
- Large geographic distances to cover, making contact and management of the program difficult.

*“The local agency that I helped to work on this project ran out of money. So they weren’t able to continue. I am also about two and a half to three hours away from the local community. So, I really needed it to work from the local level up and it just kind of fizzled out locally. I personally think the program is wonderful and I would like to see it happen, but trying to find someplace to do it where someone has the money, and to have someone else locally able to keep the program up and running. From my position I am not able to do that.”*

*“I’m a registered dietician and I am in charge of the nutrition program that covers four counties in my state. We have a home delivered meals program. With this program we also have a health education promotion component. ... I decided to implement the program and use leaders from the senior centers. They were trained and we implemented the program in four senior centers. The seniors loved it. Our grant money ran out and I can no longer afford to run the program. Those that went through the program then went on to develop a support group.”*



### Successful strategies:

- Develop strong, ongoing partnerships with a variety of community and health care agencies – detailing what each has to offer (location, participants, lay leaders, etc);
- Network with leaders and educators of disease-specific groups to promote the program through their newsletters, mailing lists, support groups, and networks;
- Find and develop relationships within naturally occurring networks such as established senior and wellness programs in senior centers and churches in order to offer workshops at locations used regularly by seniors;
- Invite partnering staff to participate in the course. This hands-on experience increases their understanding of the program and their ability (and motivation) to help recruit course participants;
- Find ways to help potential partners answer the question: “What’s in it for me?”

*“I had worked with the diabetes educator, she was a colleague ... who was supportive of ... this clinic and ... provided us the space that we needed for all of the things that we needed to actually pull this off.”*

*“There are two kinds of community partnerships that have really worked well for us. One is where we work with a network of community clinics ... and train people and sometimes they partner with yet other organizations ... who are all working together so that the program then can hopefully become a shared community resource for the various people who would access those classes.”*

*“Another kind of partnership I’ve really loved is when we worked with a couple of faith communities that have taken on the program--people who are usually already active in the community and often seen as leaders in the community, the people who get trained as leaders. And, it ends up being this really wonderful thing that the [faith] community can offer for its congregates. Our members live in those communities too so our members go to those classes; it’s a really nice collaboration.”*

*“Several of the areas’ communities have resource centers where they’re conducting all types of classes that are beneficial to the folks in the community. So, partnering with them and getting on their schedule--if we aren’t able to actually conduct a workshop actually at that center--is to utilize their boards or resources there to let the folks know of upcoming classes.”*

**Funding.** Securing funding was the responsibility of only seven of the 18 who responded to the web survey, so dimensions of the funding issues were not known to some of the participants. Related to funding, there were basically three types of respondents – those who had sponsoring agencies that covered program costs so they did not worry about sustainability; those who had successfully secured funding through partnerships and grants; and those whose programs were floundering due to lack of funding.

The most successful programs have either internal funding sources or sponsoring agencies (i.e. county extension services, managed care plans, insurance providers), or have established relationships and shared the costs with medical clinics or other community resources. These

programs seem to be flourishing. The Master Trainers' time could be used for program development and marketing/partnership building, not continually searching for financial resources to sustain the program.

Some programs overcome the long-range funding dilemma by using their start-up funding to successfully secure funding for ongoing programming. The most important dimension of their success is the emphasis they placed on cultivating their constituent groups -- their sponsors, their partners, their professional staff and lay leaders, and even the program participants themselves. Through this networking they obtain both funding and marketing/recruitment support and have been able to build successful, sustainable programs.

Several of the Master Trainers' organizations funded the initial implementation through grants. Some Master Trainers have been unable to find financial support to continue the program beyond their initial grant funding used to start the program. As a result, some programs are on hold while others are functioning at a minimal level with one staff member doing what s/he can with little or no financial support. This group is the one most likely to report that they have not effectively established partnerships or a base of support in the community.

From the Master Trainer's point of view, the greatest need for funding is to cover salaries for staff time, whether it is to cover the costs for the Master Trainer to implement and maintain the program, to compensate the lay leaders for teaching the classes, or to provide administrative support to the Master Trainer and leaders.

#### Barriers to success:

- Lack of seed money to cover the time and costs of implementing the program;
- Inability to sustain the program beyond the initial grant funding for implementation;
- Lack of knowledge about establishing partnerships and obtaining funding;
- Inability to identify and approach potential sources of on-going funding;
- Neglecting the development and nurturing of community-based organization and health care partnerships that could share the costs and the resources required for program success.

*"We needed some seed money in order to get the management of it started and to recruit the leaders and to do the [leader] training and have some kind of an organizational structure to it so that we can do it well."*

*"We didn't have initial funding issues because we were doing this on a grant, but, the program has been going for a number of years now and [our community clinic partners and some of the non-profits we work with] worry from year to year about whether they are going to have the staff time they need and ... about how they're going to afford anything."*

#### Successful strategies:

- Continuously implement a plan of action to secure funding sustainability;
- Establish funding sources to sustain the program beyond implementation particularly if using grant money initially;

- Find partners to share the costs of running the program – enlisting their resources, facilities, and staff to recruit participants, and perform other logistical and administrative aspects of the program;
- Target disease-specific support groups as possible collaborators and funding sources;
- Locate funding sources that believe in self-management as a successful strategy and will support efforts to enhance this among patients with chronic disease.

*“We look to some of the other areas that we have received funding from before and actually [were] successful a couple of months ago in receiving some additional funds to carry on self-management workshops. So, we are always looking for sustainability.”*

*“The collaborative approach has really been helpful for people--in other words, doing this as a group of organizations in a community takes the financial burden off of any one group. It becomes a shared responsibility.”*

*“Since we do community work and multi-risk screenings ... we’re always trying to either sustain the interventions and also look to expand them ... so we could target and start conducting self-management around that particular setting. So, we were able to kind of tag on to whatever’s the passion of that particular funding source.”*

**Staff Support.** The Master Trainers made it clear that this is not a program that can be implemented and maintained by one person alone. Implementation takes advance planning, on-going management and consistent oversight, and allocation of staff time dedicated to make the program work. In addition to facilitating programs, Master Trainers who are involved in implementation may also have additional responsibilities including marketing the program to medical and community groups, recruitment and training of leaders, and documentation of program outcomes. Those who could call on other staff from their organizations or from their partners’ organizations to share the tasks were able to focus on overall program growth and development, not just on survival.

Once the program has been implemented, successful organizations have divided the labor either internally or among their community partners. There are four distinct labor categories for maintaining this program: logistical/administrative, managerial, program coordination and lay leader responsibilities.

- The administrative tasks include handling the logistics such as determining the locations, dates and times of the classes and updating flyers and brochures.
- Managerial tasks include lay leader recruitment and training; establishing and nurturing relationships with partnering locations; creating a list-serve; and ongoing marketing of the program through many modes including the aging network, health fairs, screenings, and churches.
- Program coordinator responsibilities include recruiting participants, supporting participant retention (including one-on-one communication with participants); assisting lay leaders in setting up their sessions; providing motivational support and feedback to lay leaders; providing refresher training; tracking participation, and documenting outcomes.

- Lay leaders are usually volunteers with chronic diseases who have been recruited and trained to facilitate the CDSMP program workshops. Beyond their main responsibilities of facilitating the workshops, lay leaders are often recruited to help promote the program by giving brief community talks to present the program to prospective participants. Some lay leaders are also helpful with logistical aspects, such as in securing community sites for the programs. The lay leaders are very effective because they may be gatekeepers who have the trust of community members and leaders alike. Because they share a common heritage and values, they engender immediate trust among their cohorts. However, expecting lay leaders to do more than facilitate sessions may lead to burn out.

#### Barriers to success:

- Expecting the same person to manage marketing and recruitment aspects, as well as training and implementation responsibilities;
- Underestimating the hours needed and/or not having dedicated time to manage and market the program;
- Not recognizing that training, managerial and administrative tasks require different skills and some people are not accomplished at all of these skills;
- Lack of a dedicated effort to maintain program;
- Lack of continuous, multi-modal marketing efforts;
- Site coordinators who are not familiar with the program;
- Failure to plan for the support services needed to sustain the program.

*“You have to have a coordinator who has dedicated time to do it. I mean, there is a real assumption that they are going to be spending time on this and that it’s not just another thing that is piled on. It may be piled onto a million other things, but, it has to be understood that time is going to be carved out.... Or it might go for a little while, but it won’t last. That’s been my experience.”*

*“I would like to comment on critical staffing needs for the program. In our case because we were such a small group, it sounds like the others may have had a person, a liaison, but we were trying to do all of it ourselves. So, [we needed] someone that would do particularly just the recruiting, or the phone calls, or the follow-up phone calls...”*

#### Successful strategies:

- Select staff who philosophically believe in self-management concepts;
- Educate staff unfamiliar with program philosophy, concepts and benefits to gain their active support of the program and tasks involved;
- Offer the first course to sponsor’s and partner’s staff members to increase understanding of the program and gain their commitment to program success;
- Delegate the different tasks to people with the appropriate skills and abilities;
- Partner with community organizations that can help with tasks, especially related to recruitment of lay leaders and participants from their communities, and the provision and management of workshop sites and logistics;
- Utilize volunteers, partnering staff, and/or lay leaders to help with administrative and logistical tasks.

*“It’s just an awesome program once you have gotten it implemented and you get people that really believe in it. I think you have to have a lot of people in it, believing in it, and pushing it forward. No one person can do it and the more people that you have the more successful your program is going to be.”*

*“[We] talk about separating those functions ... It really is not only a different skill set, but we all like to do different things and people who are good at teaching aren’t necessarily good at organizing and recruiting and managing and following up and keeping list-serves.”*

*“One of the things that make site coordinators really successful is that they know the program really well and like it a lot. We’ve occasionally had somebody who just doesn’t know the program as well and they don’t dislike it, they just don’t know that much about it ... A successful program [has a] kind of cycle of enthusiasm -- if you have leaders and they’re excited, then they excite the site coordinator and the site coordinator is excited and they excite the staff and it’s a cycle.”*

*“We worked with the Area Agency on Aging and then it was the Wellness Center for the local hospital system. Well since I wasn’t there, they were pretty much doing everything. They were doing the recruiting of the participants, they provided the space, and they did all the advertising. They pretty much did everything, other than teach the class.”*

*“The Parish nurses help, not only to promote the program but have done a lot of work ... things like finding [locations] and the logistical things. They are great partners. I just know that a workshop is going to go very smoothly if there is a Parish nurse involved. I do not have to do so much work on this end, the coordination end. If it is going to be held in their church – they want it to go well too. This is a good partnership.”*

**Organizational Support.** Master Trainers who demonstrated the most success with the program had support from their organizations’ management staff and/or partnering organizations before and after they went for training. In return for improved health of their patients or members and positive community visibility, the parent organizations provided funding, philosophical support, and staffing support for ancillary program functions. Successful programs involved key people from the organization at various levels to enhance the organization’s knowledge and commitment to the program. This provided Master Trainers with multiple avenues for reporting on the outcomes within the organization to help sustain interest and support in the CDSMP. The most supportive organizations had a good understanding of the program philosophy and practices, realistic expectations of the resource requirements, and a willingness to give the Master Trainer the time to do the necessary advanced planning. Planning time allowed Master Trainers to build the program itself, not spend significant portions of their time seeking future funding sources. This enabled them to move from a survival mode to one that fostered growth of the program.

Support was enhanced when parent and partnering organizations allowed their staff with chronic diseases to participate in the program as an employee benefit. These employees became a valuable source of referrals to the program and were committed to its success.

Most Master Trainers agreed that neither they nor their organizational leaders initially understood the time and labor requirements that would be needed to implement and sustain the program. Because of their experience, the Master Trainers made the recommendation that new trainers go into the program with full knowledge of what is required to be successful. Therefore, Master Trainers suggested that a self-assessment readiness tool would be helpful to organizations interested in implementing the program.\*

#### Barriers to success:

- Lack of understanding and commitment to the self-management philosophy and concepts taught in the program;
- Underestimating the resource requirements to implement the program, especially staff time and dedication required to develop, promote and sustain the energy and enthusiasm of the program.

*“I think they need to have a little bit more information of what it is going to take and knowing the community ... needs to be involved from the beginning.”*

*“... when people [Master Trainers] do go home and try to implement the program locally, they are dumbfounded by the amount of time and energy it takes to coordinate the program in terms of advertising, recruiting, and making sure they have enough participants to make a class work.”*

*“I don’t think that we had thought through very carefully about who would do that internally with us; I’ve been trying to do it and it’s gotten way too big for me to manage.”*

*“But I don’t think I’ve got the ... administrative support that I need to do the program. But, I don’t think I’ve made that case very well. So what I’m trying to say is, I think my manager appreciates the evidence-based program and likes having our name behind it in the community ... [but] might be a little clueless about what it takes internally to really pull it together.”*

#### Successful strategies:

- Involve organizational leadership from beginning to gain understanding and appreciation for the program;
- Involve key people at different levels of sponsoring and partner organizations who have stake in the success of the program;
- Offer the first set of program workshops to staff as a covered employee benefit and invite sponsoring and partner organizations to also participate;
- Present the program and provide updates on its successes at meetings with organizational management, boards and with program staff, partners and sponsors;
- Recruit medical providers to support and promote the program to patients;

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\* The Center for Healthy Aging is developing a tool called “Self-Assessing Readiness for Implementing Evidence-based Health Promotion and Self-Management Programs” as well as model program toolkits and trainings.

- Continue to inform organizational leadership of the positive impact of the program, including thank you notes from participants;
- Incorporate processes taught in the program into organization operations.

*“In general because leadership has bought into it as a top-down approach, it’s been easier to implement. And because it is a covered benefit, all health education administrators from all the 12 medical centers have also bought into it. Key people were identified at the different levels and [were] delegated responsibilities. I think that made it easy to integrate into the system.”*

*“When I think about local leadership and how that worked, people whose programs have been really successful often had a lot of buy in from the people running our chronic care management programs, so that they could come to meetings and talk to staff and work out really good systems of referral and that sort of thing.”*

*“[The] clinic that we implemented it in--the administration has been very supportive and has allowed even employees to participate that have chronic disease. Now that we have the employees really gung-ho about the program they’re encouraging the patients to participate.”*

*“Since we have kept the board informed, the community members of the board and board of trustees really relate to the program content, so they have been really instrumental to this program. Also, keeping the good will about funding it and keeping it up [was important], so we just strategically made sure they knew about the program.”*

*“The [medical director of the] clinic [where] we actually presented the trainings had key providers ... and it truly was a team effort. Without his support and the providers that worked in that clinic, I mean, it would not have worked well.”*

*“Again we are just very intentional about explaining the program and showing him successes. When participants ask who they can thank (because we offer the program free and the materials free), I always tell them to write a letter to Dr. So-and-so, the chief executive officer. He gets that feedback on quite a regular basis from our participants.”*

***Marketing the Program, Recruitment and Retention of Participants.*** Master Trainers agree that successful implementation of their programs requires a significant effort in the start-up phase, with marketing and recruitment being core activities. While Master Trainers had varying experiences marketing the program, those with the greatest success have two elements in common. First, they effectively established partnerships in the community or had a sponsoring agency that provided organizational support, other staff to assist them, and funding for program incidentals. Second, they took the time needed to plan for and market their program prior to the first class, thereby laying a solid foundation that increased their chances for success. Several of the items included in the marketing toolkit provided in the Stanford materials were used by implementers to help explain and promote the program. Among the various marketing approaches mentioned, personalized communications work best and radio and newspaper ads were less effective methods.

The marketing activities described by the Master Trainers included:

- Establishing relationships with sponsors, partners, gatekeepers and trusted community members and educating them about the program;
- Developing outreach programs to find and attract potential participants;
- Developing multiple marketing approaches;
- Developing referral sources;
- Customizing approaches to their target audiences, including one-on-one communication when needed.

One marketing challenge Master Trainers faced was in creating a program image that conveyed a positive message that potential participants could identify as a program that would benefit them. Potential participants are more likely to notice information and resources that mention their specific disease (i.e. depression, high blood pressure). Since many people do not think of themselves as having a “chronic condition,” a program promoted for “chronic disease self-management” does not resonate with them. Therefore, many Master Trainers followed Stanford’s recommendation to rename their program.

Some trainers estimated that six months to a year is needed to create the infrastructure and market the program before being able to offer the first class. When the time to build a program foundation and network was not taken, the Master Trainers found themselves continually struggling to keep up.

Recruitment strategies vary by type of organization, available resources and community access but some commonalities emerged. The most effective recruitment results from personal referrals by trusted leaders and staff that are in daily contact with potential participants. Referrals work extremely well, especially when they come from physicians, medical staff, senior center staff, and church staff as well as former participants in the program. Some programs have had success through targeted mailings signed by their physician or attached to a disease specific support group newsletter while others continue to market the program at health fairs, screenings, community events and conferences. Often, the classes are better attended when held at locations familiar to the participants and when transportation is provided to reach those without the resources or means to travel.



A suggested approach to informing key leaders and staff in partnering medical and community organizations is to invite them to participate in the program. This first-hand approach creates a greater understanding of the philosophy and benefits to participants with chronic conditions.

Barriers to success:

- Underestimating the time and resources needed to effectively market the program;
- Lack of knowledge and/or planning regarding where to start, who to approach and how to effectively market the program;
- Lack of partners to share the marketing responsibility;
- Resistance from potential referral sources related to supporting an educational program that is not disease-specific or involving the self-management concept;
- Physicians and educators who question the accuracy or timeliness of the course textbook material;
- The program name Chronic Disease Self-Management Program is imposing and may have a negative connotation for some potential participants;
- Many people do not realize they have a “chronic condition,” so do not see the course as personally relevant;
- Lack of understanding of the target audience and assuming that certain types of people would be interested;
- The concept is difficult to explain in flyers, so additional explanation of the program to potential participants may be necessary;
- Relying on only one or two methods of recruitment, such as brochures and flyers or physician referrals to promote the program;
- Asking participants to go to unfamiliar locations in order to participate;
- Lack of resources to follow-up with inquiries from potential participants to explain the program.

*“I think that our biggest challenge and I don’t know that it really stems from the training, was just how do we get the word out there to get the first group going?”*

*“We had a couple of physicians telling their patients not to come to it. So we worked hard over the years to develop a partnership with that particular group... [The physician] has a fairly controlling practice, so it worried him - self-management worried him. It really was just [convincing him] that we were not doing anything wild and, that [when] he was seeing patients that had better outcomes, they were exercising and seemed to have more interest in taking care of their health... So he saw eventually that that was a good thing.”*

*“[The handbook participants receive] is really geared toward lay people to [help them] gain a better understanding of the disease and what’s out there. It is there as a reference to provide an introduction to information.... [We encouraged the participants] to go to their health professional and get more detailed information or tailored information based on their own health problems because when you write to a general audience, you have to be very general, and many health professionals don’t like that. They want something very specific. They’re very entrenched in something they’re teaching their patients.”*

*“We’re just a community center basically. But we’ve tried several of the things that were mentioned -- giving the participants the books and the tapes--and that hasn’t worked for us and neither has providing food, going out into the community, or going out to the corporations. I really think that what we need to do is listen to the people that we target, or have a focus group or something of that sort to ask them. ‘What would it take to get people interested and to come to a class like this so that you can win them over? And what would it take to get people to come to the first session so that we can win them over?’ So I think we’re missing the boat there.”*

*“When I was actually teaching the workshop, I would ask them what their chronic condition was. They said, ‘I don’t have a chronic disease; I have heart disease, or high blood pressure.’ So we renamed the class Healthier Living: Managing Ongoing Health Conditions ... and I think that people can relate to that more.”*

*“One of the things that was a challenge for me ... [was the] use of flyers around the community or even within the clinical setting. For someone on the outside who’s not really familiar with self-management it was sort of a put off because, you know, no one wants to think that you’re advocating to them that they cannot take care of their condition whatever it might be. So, one of the things that I insisted upon doing was having an opportunity to speak directly with the person who was considering the workshop.”*

*“One way that we are addressing the barrier of proximity to implementation... is to take it to a place that is close in the community and having it taken out to the church has been very, very successful. So again it depends... When it comes to our medical centers I rate [our success] a seven. When it comes to the churches, I rate it close to a nine.”*

*“We had heard from the folks at Stanford not to depend on physician referrals and to make it really open to the community. So that is what we did. We had a couple of physician champions when we came back [from training] and kind of recruited a partnership with a couple, but we never depended on them to do referrals.”*

#### Successful strategies:

- Give the local program a positive, inviting name so as to not focus on negative images, such as “chronic” or “disease.” Program names such as “Help Yourself,” “Take Charge with Health,” “Healthier Living: Managing On-going Health Conditions,” “Action Planning for Health,” and “Living Well” were mentioned.
- Use CDSMP materials to create a toolkit for marketing the program to professionals, community organizations, and community members that might include a video, sample textbook, flyers, a short description of the program, and articles that demonstrate positive outcomes;
- Use a multi-media approach, that might include program announcements through radio, local TV stations, presentations at community organizations and churches, newspaper ads and flyers distributed throughout the community;
- Mail directly to chronic disease registries to invite members, ideally signed by their physicians;

- Approach disease specific group leaders (e.g., diabetes) and promote the program through their support group meetings or newsletters;
- Build a foundation of support among multiple professional and community groups, community leaders, and churches and synagogues to gain their help in promoting the program;
- Invite staff from sponsoring organizations or partnerships to partake in the program workshops so they can personally recommend the program;
- Find partners who will provide opportunities to have “face time” with potential participants; this demonstrates the partner endorses the program and allows the presenter to customize the information to the target audience;
- Use personal contact with interested participants to promote classes;
- Encourage physicians, professional staff, and community members from partner organizations to refer patients;
- Give physicians a prescription pad to refer clients to the program and includes a phone number to call for information;
- Distribute flyers at medical centers, pharmacies, community centers, churches;
- Promote the program to support group leaders and health educators;
- Encourage past participants to ‘spread the word’ and tell others who might benefit;
- Enlist lay leaders to promote the program and register participants;
- Host classes in community locales familiar to participants.

*“The publicity that we did said it was for people of various types of diseases. And we didn’t use the word chronic disease either, you know. We said, ‘Do you have diabetes? Do you have asthma? Do you have heart disease? Then this program may help you.’ So that we promoted it as something that [would benefit people suffering from various diseases ...]”*

*“We did a lot of leg work. We contacted hospitals, other health care centers; we actually contacted some physicians, personally, one on one. We went into the churches, because that is a predominant area for African Americans, so we went to the churches, made presentations to those pastors, then they would either allow us a certain time of the week or on a Sunday morning after their announcements allow us to present the program and to solicit participants for recruiting.”*

*“She developed a tool kit that she distributed to different professionals so they would find out about the program and whenever they attend meetings, or it’s something to carry around with you and have it to share and to show ... We developed a video that we can show to providers or members. We have flyers, a short description of the program [and] a couple articles.”*

*“That is what is working in the primary care clinic ... the staff that work there ... has participated, including the front office staff that makes the next doctor’s appointment. They can ask that person, ‘Hey, my doctor recommended this program, what do you think?’ ‘Oh, yeah. I participated in that - that’s a great program.’ ”*

*“So, we are trying to keep the employees also participating so that they can then encourage folks to go. We have a prescription pad that we give to the physicians if they want to refer someone. It has a short description of the program and then a telephone number to call to register.”*

*“We emphasize promoting in multiple ways. Sending mass emails to providers--not only flyers in waiting areas, but also promoting the class ... in other chronic disease classes that patients attend.”*

*“[The] patient support services coordinator [had] me present at provider meetings where I could then communicate with the health care providers of both of the clinics on a regular basis, and then actually promoting the workshops themselves ... reminding them to refer clients, especially folks who were in dire straits and could definitely benefit from this. [She] actively supported me when I moved to invite family members to the sessions ... to help them understand exactly what was taking place and then to offer another invite to them, to be there to act as support for their family member.”*

*“We promote [the program] in our support groups and on bulletin boards here at the senior center; but again it’s that person to person contact that we’re making as it really does fill the class as a thread of our health enhancement program.”*

*“We also have found in some of our medical centers where we get the doctors involved, the doctor’s referral helps with getting members to the classes.”*

*“Our most successful strategy by far has been mailings to people who are on one of our chronic disease registries ... and sending a letter to 300-500 people for each class, that’s signed usually by their physicians, has by far been our most successful strategy for recruiting people to these classes.”*

*“When I think about success in recruiting ... I would say [the] partnerships we formed with community leaders and health leaders and Parish nursing [have] been integral. We have a great Parish nursing network in our area and they are very credible people at the community level. So we partner with Parish nurses a lot to recruit and also for sites to hold classes. We never hold them on our health care property. We always hold it in community settings.”*

*“And, I think that is so important to have lay leaders because that has really helped our recruitment. I use lay leaders to do community talks at support groups and they are just so credible.”*

**Program Retention.** Organizations with successful programs encourage initial attendance through personal contact with the potential participant to explain the program, the nature of the course, reconfirming the dates and times and, if needed, encouraging them to bring a family member or friend for support. Once participants are registered, successful programs address retention problems by making reminder calls; utilizing the buddy system so that participants encourage each other to attend; building a rapport with the leaders; providing transportation; and

providing snacks. They applaud the buddy system for establishing lasting relationships among participants as well as the skill building activities and eventual empowerment of participants.

The lack of ability to retain participants is most often related to factors outside of the program itself (e.g., weather, deteriorating health, transportation issues, etc.). To offset this factor, programs often “over-recruit” by registering more potential participants for a given course, expecting that some will drop out. While most participants are highly engaged in the process, especially when they have a buddy for support and ongoing encouragement, a few participants decide not to continue past the first couple of sessions because the course is not what they expected. This misalignment of expectations results because participants believe that they will receive a lot of factual information in a content-based program. What they discover is that they are asked to create personal action plans and commit to making personal behavioral changes based on activities aimed to help them develop an enhanced sense of self-efficacy. Most Master Trainers have learned to manage the expectations of potential participants by explaining the nature of the course before the first class.

#### Barriers to success:

- Participants’ misunderstanding the nature of the class and that it requires their participation;
- The cost of providing materials to participants;
- Outside circumstances such as illness, lack of transportation and bad weather.

*“Some people have these expectations and we have just written a little introduction that leaders can use ... and we have a video that leaders can use at the beginning of the class to just give people a sense, this is what this is and this is what this isn’t. So they’re not coming in expecting a series of lectures from experts.”*

*“Our participants need to know that it is a participatory program. It’s not where you sit and listen to someone and that’s what they are wanting and they’re not getting what they need. So we’re advertising it as a workshop and not a class, emphasizing that you have to participate.”*

*“The way that we count people who have been successful in completing the class ... it’s not necessarily sessions 1, 2 and 3; it’s three out of six sessions. And we have something like about 80% completion with that. We’re actually very happy with that because of the circumstances of people’s lives.”*

#### Successful Strategies:

- Hold classes in familiar locales, with several transportation options;
- Explain the participatory nature of the program to the registrants before the course starts to manage their expectations;
- Choose lay leaders that participants can relate to in terms of age, ethnicity, chronic condition, or who have participated in program previously;
- Build rapport between the lay leaders and participants at the beginning by having them make reminder calls to participants before the course starts;
- Support lay leaders to continue personal contact and follow-up during course term;

- Invite participants to bring a supportive family member or friend if necessary;
- Emphasize the buddy system in the course; buddies make participants accountable to each other and offer peer support through phone contact between classes;
- Offer a book and material lending program each week if participants cannot afford to purchase the book;
- Offer the books and materials at completion of course as a gift;
- Provide healthy snacks;
- Provide incentives appropriate to each session, such as gift certificates, pedometers, cookbooks (look for donations from community businesses, supermarkets, etc.)

*“We’re a very rural state and where this clinic is very rural as well as low income. We found that really incorporating it right there at the clinic helped because it was someplace that they could usually get to. And the other thing that we’re working on now is with the different businesses and wellness councils and try to incorporate it into something that we could do right there at their business so that there again, people could participate during their lunch hour.”*

*“We register up to 16 people in a class, and we won’t hold it unless there are eight to ten registered in a class. We call everyone a couple of days before on our registration list, because people just call in to register on a central 1-800 number. The [lay] leaders call folks the night before and confirm people coming, which helps and I think the buddy calls really help in between [classes].”*

*“The other thing I think the [lay] leaders like about [doing the reminder calls] is they get a chance to hear the voices of the participants ahead of time, and so they start their connection with the participants with that call.”*

*“What we do to try to retain the individuals that we do have is to rely on that buddy system concept that we implement as far as working with their goals and things. We encourage them to remind each other when the next session is and that seems to work very well, especially in our rural area.”*

*“Because a lot of the folks that attend don’t have the finances to purchase the book, we lend it out until the next week. So we get their name, and their phone number, and there again the clinic already knows a lot about the individual and we let them take it home for a week and bring it back.”*

*“Our retention rates are quite high and I think it really has a lot to do with the fact that, as I mentioned earlier, we have the incentives that go throughout the workshop that’s appropriate to each session if at all possible.”*

**Lay Leader Approach.** The CDSMP is based on a team-leading approach, usually pairing a volunteer lay leader who has a chronic disease with a health professional. Master Trainers agree that the recruitment and retention of lay leaders who maintain a commitment and active involvement to the program is one of the greatest challenges they face. The lay leader candidate must commit to receive training and then to facilitate the program which consists of six

workshops. Oftentimes, lay leaders are enlisted to help with other tasks such as recruiting participants. Some programs ask for a commitment to teaching two courses. Ideally, Master Trainers can identify likely candidates for becoming lay leaders among previous program participants.

Several organizations have found that ongoing recruitment for more lay leaders after the first few courses is necessary. Most agree that they must train more lay leaders than needed because fewer end up following through on their commitment to teach the course. Successful and established programs have become better at identifying potential leaders, explaining the commitment before investing in training and pairing newly trained lay leaders with experienced leaders to help keep them in the program.

In terms of effectiveness, the leader's age is less of a factor than her/his approach to class facilitation. The average age of lay leaders in a program often reflects the demographics of the population more than any other factor. For example, leaders in Florida are more likely to be 60 or older because there are more people in older age brackets to draw on in the Florida population.

Former educators with preconceived ideas for how a course leader functions in the classroom do not seem to be good lay leaders. The program's structured protocol is based on a group process facilitation model, not a content-laden didactic model. This does not allow leaders to "teach" in the traditional sense nor can they expand on the subject matter of that week's session.

Using lay leaders proved to be an obstacle in rural communities and among certain ethnic populations. In settings where "everyone knows everyone else" some participants do not want to open up to the lay leader (whom they often know personally) or to their fellow community members. In other ethnic communities, however, the opposite is true – some groups wanted to stay together after the official end of the sessions.

Another cultural difference that may help or hinder program success is the need for translation of the program materials. If participants do not have English as their first language, the program materials may not be easily understood and examples given in the manual may not be culturally sensitive and relevant. Ideally, if one of the leaders is of the same ethnic or cultural background and can help to modify and/or translate the materials for that particular audience, the acceptability of the program will be enhanced.

#### Barriers to success:

- Finding and recruiting lay leaders who can commit to facilitating the program;
- Investing in the training of lay leaders with very few following through to run a program;
- Inability to compensate or acknowledge leaders in some way for their time and commitment to the program;
- Resistance to personal sharing in some small, rural or close ethnic communities.

*"Whenever we have a medical center or a clinic or a church identify someone, it is very clear what the expectation is and lay leaders are questioned whether they will be able to commit. So some of those kinds of issues are addressed or beginning to be addressed up front."*

### Successful strategies:

- Recruit previous program participants to be trained as lay leaders;
- Use word-of-mouth promotion by leaders and prior participants to recruit lay leaders;
- Set clear expectations regarding the commitment to conduct a course after training;
- Match newly trained leaders with experienced leaders to provide support and motivation;
- Pre-schedule courses so new trainees can facilitate a series of sessions immediately after the training; this sets expectations and allows little time for self-doubt to prevent trainees from leading a course;
- Provide on-going support to maintain interest and involvement in program;
- Offer incentives or stipends for their commitment to leading the course;
- Provide ways to acknowledge leaders' contribution and to celebrate the success of the program.

*“Usually if the person is leading, they have a chronic condition. It’s really buy-in or bonding that goes on regardless of the age.”*

*“We have identified our leaders from participants that really benefited from the class and were engaged in the program and people that we thought would be able to transfer that to others.”*

*“We send out flyers to organizations that want the program. They want the program so they are vested in identifying volunteers. So whoever they think would be a good volunteer or someone who has attended a class and they give the flyers to those individuals.”*

*“We have a standing line in our brochure that we are always recruiting lay leaders, and that, I think, has helped. I think in most areas we pay them a stipend for facilitating a class. I think that’s been helpful.”*

*“One of the things that we’re doing with the primary care clinics is that the clinics are usually associated with a support group of some kind, whether it be for diabetes, cardiovascular, asthma, arthritis or whatever. And we’ve contacted the leader of the support group and informed them about the program. And we’ve had some of them interested in becoming lay leaders. First they want to attend the sessions to see what it is all about and then when they have gone through the program they say, ‘Yeah. I want to take this back to my support group so I’d like to be a leader.’”*

*“What we do is we have workshops scheduled to start in about three weeks after the lay leader training. So with an experienced leader, we have one experienced leader signed up so I can partner a new person with an experienced person rather than them going right off the bat. This has been key in keeping the retention, they have a chance to do it pretty soon after they have taken the lay leader training.”*

*“To sustain it [the program] over time, we’ve had to come up with a way to really mentor the lay leaders and really support them in a way that made sense so that they didn’t drop away.”*



*“We do a yearly appreciation and an update for our leaders. It really is a revitalizing and energizing experience to get together and hear what everybody is doing and hear about the successes. And talk about what didn’t work and how they are changing things. And so I think for us it is really like a homecoming to get together with these people every year and talk.”*

### **Why the CDSMP is Successful**

Master Trainers were asked to briefly list the benefits of the CDSMP to its many stakeholders. Their responses reiterated the points made during the discussions.

#### ***Participants***

- Learning new skills to better manage their health;
- Becoming active participants in their own care and treatment;
- Empowering, especially for those with serious conditions;
- Improving their outlook on life and they even “complain less;”
- Learning new problem-solving skills they can apply to their lives (e.g., brainstorming an issue with the group).

*“But really it’s how to make or set goals and them leaving knowing and understanding that they can apply that concept to [anything,] even when the program is over. But I think that the program is very comprehensive. It’s good, which is a major benefit because it doesn’t just address how to set goals, it touches on other issues that people are going through who have a chronic condition, not just dealing with the disease itself but how the disease relates to these other aspects of their lives.”*

#### ***Sponsor Organizations***

- Increasing community recognition;
- Broadening scope of the organization’s services to community;
- Creating healthier and happier members who, in turn, with new communications skills and enthusiasm, influence providers;
- Lowering medical costs associated with their care;
- Incorporating goal-setting and action-planning strategies at the operational level;
- Encouraging professionals in primary care to embrace self-care concepts in their practice;
- Enhancing the skill base of existing staff members;
- Exposing non-members to the organization in a positive way;
- Gaining new members because of the positive good will engendered by the program

*“It has really helped us to get away from the idea that [our organization] is really here for swimming lessons and aerobics classes. That we are a community health initiative, at least in this area, it’s helped to support that and show the community that we have programs and staff, professional staff, here at the facility that go beyond what [we] have traditionally been.”*

*“Well for us it’s getting our project better known in the community... community recognition.”*

*“It has been healthier, happier members. Members who are getting appropriate care - seeing a physician less but they are seeing them when they need to, and maybe not waiting as long. [Also it is our course participants] who will make a list and be prepared when they go in to see the physician. We’ve had stories of members who were very non-compliant, took the course and became very compliant and healthy.”*

*“One of the things I would look at is the cost savings for keeping people independent and happy in their home. With the self-management theme I think there could be a dollar sign that is placed on the advantage of implementing this program.”*

*“We have incorporated self-efficacy into the philosophy of our health education and the strategies and I think that has been very helpful in just doing programming and evaluating it.”*

*“An expected benefit that the sponsoring organizations realized was that the self-management program philosophy has influenced their staff’s approach to other programs in their organization. They found their staff has implemented the sound principles of problem-solving and goal-setting skills taught in the program to many other settings and patient situations.”*

*“Actually, in our own organization what happened is that a lot of other classes and approaches to things that we developed later used all of the things that we learned, used all of the tools and techniques that we learned from the self management program. So, you know, it had a bigger impact on our system as a whole in that way.”*

*“At the clinic where we are working, we are incorporating the whole self-management concept into what the nurses do, what the doctors do, how they communicate with their patients and that type of thing. So we’re trying to make an actual systems change with the whole process.”*

*“There’s a strategic advantage for us as a health care plan in terms of all of our health education program. It’s one of the ways that we are able to set ourselves apart ... One of the things that is appreciated is that we have these wonderful people facilitating these workshops and we don’t have to spend a lot of money on staff time.”*

*“[They] like the fact that it’s a tested evidence-based product. Those are the words now that everybody wants to hear. I think that there are researched and published articles on this and they pretty much know they’re not funding something that’s an experiment in that sense for us.”*

### **Partners and Funders**

- Delivering better-informed patients and staff members;
- Providing opportunity to foster good will for the organization within the community;
- Providing organizations that adhere to the self-management philosophy an opportunity to support a program that matches their mission;

- Providing a tangible method to help members of the partners' organizations who are suffering from chronic diseases;
- Engendering a positive sense of community-building for private organizations;
- Enabling community-based organizations to expand their services;
- Helping incorporate self-management concepts into the organization through exemplary activities and staff involvement.

*"It has served as a banner program that has helped to develop many partnerships with churches and clinics. So that is a benefit."*

*"For the primary care clinics, [the benefit has been] to get the self-management concept to the physicians, to the staff in the offices, through the program itself as well as now through the patients coming in and saying, 'Well, I learned this in this class and can we do this together' type issues."*

*"Our primary partner is a local private foundation which was developed out of the sale of a hospital. And the foundation was created to further health and education in this community. So I think that basically the program sums up what their primary goal is and it just reinforces the fact that they are committed to doing just what they set out to do when they created the foundation."*

*"In terms of our community partnerships, it has created a great deal of good will with our partners and within our community."*

*"In our case, with us being a community-based organization, it has allowed other community-based organizations or our partnering organizations to expand their services to their clients, i.e. patients."*

*"They like that they have another option that they can provide to people who have chronic conditions."*

*"In terms of the participants and also the leaders and representatives in the senior center, they found that the seniors were just a lot less complaining. I don't know if you can put that in as an overall reaction, but they just found them much more gracious"*

*"[For a hospital] I think that they feel grateful that it's adding to the value of their services to a community that they serve."*

*"[With our partners'] employees, and retirees -- that particular relationship helps with the employees' productivity."*

*"Prevention is of the utmost importance and if the insurance companies can embrace this program, they are going to save money in the long run. But more importantly, they are going to save people's quality of life. I really think the insurance companies need to fully understand... that something like this can truly change someone's quality of life and well-being."*



## **APPENDICES**



## Appendix A

### Chronic Disease Self-Management Program Overview

The Chronic Disease Self-Management Program is a workshop given two and a half hours, once a week, for six weeks, in community settings such as senior centers, churches, libraries and hospitals. People with different chronic health problems attend together. Workshops are facilitated by two trained leaders, one or both of whom are non-health professionals (referred to as lay leaders) with a chronic disease themselves.

Topics covered 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) how to evaluate new treatments.

Each participant in the workshop receives a copy of the companion book, *Living a Healthy Life With Chronic Conditions, 2nd Edition*, and an audio relaxation tape, *Time for Healing*.

It is the process in which the program is taught that makes it effective. Classes are highly participative, where mutual support and success build the participants' confidence in their ability to manage their health and maintain active and fulfilling lives.

The program does not conflict with existing programs or treatment. It is designed to enhance regular treatment and disease-specific education such as Better Breathers, cardiac rehabilitation, or diabetes instruction. This program is especially helpful for those people who have more than one chronic condition, as it gives them the skills to coordinate all the things needed to manage their health, as well as to help them keep active in their lives.

#### **How was the Program developed?**

The Division of Family and Community Medicine in the School of Medicine at Stanford University received a five year research grant from the federal Agency for Health Care Research and Policy and the State of California Tobacco-Related Diseases office. The purpose of the research was to develop and evaluate, through a randomized controlled trial, a community-based self-management program that assists people with chronic illness. The study was completed in 1996. The investigators included Halsted Holman, M.D., Stanford Professor of Medicine; Kate Lorig, Dr.P.H., Stanford Professor of Medicine; David Sobel, M.D., Regional Director of Patient Education for the Northern California Kaiser Permanente Medical Care Program; Albert Bandura, Ph.D., Stanford Professor of Psychology; and Byron Brown, Jr., Ph.D., Stanford Professor of Health Research and Policy. The Program was written by Dr. Lorig, Virginia González, M.P.H., and Diana Laurent, M.P.H., all of the Stanford Patient Education Research Center. Ms. González and Ms. Laurent also served as integral members of the research team.

The process of the program was based on the experience of the investigators and others with self-efficacy theory, the confidence one has that he or she can master a new skill or affect one's own

health. The content of the workshop was the result of focus groups with people with chronic disease, in which the participants discussed which content areas were the most important for them.

## **How was the Program evaluated?**

Over 1,000 people with heart disease, lung disease, stroke or arthritis participated in a randomized, controlled test of the Program, and were followed for up to three years. We looked for changes in many areas: health status (disability, social/role limitations, pain and physical discomfort, energy/fatigue, shortness of breath, psychological well-being/distress, depression, health distress, self-rated general health), health care utilization (visits to physicians, visits to emergency department, hospital stays, and nights in hospital), self-efficacy (confidence to perform self-management behaviors, confidence to manage disease in general, confidence to achieve outcomes), and self-management behaviors (exercise, cognitive symptom management, mental stress management/relaxation, use of community resources, communication with physician, and advance directives).

## **What were the results?**

Subjects who took the Program, when compared to those who did not, demonstrated significant improvements in exercise, cognitive symptom management, communication with physicians, self-reported general health, health distress, fatigue, disability, and social/role activities limitations. They also spent fewer days in the hospital, and there was also a trend toward fewer outpatient visits and hospitalizations. These data yield a cost to savings ratio of approximately 1:10. Many of these results persist for as long as three years.

## **How can a facility offer the Program?**

The Stanford Patient Education Research Center offers training for the Chronic Disease Self-Management Program and Tomando Control de su Salud (the Spanish CDSMP).

Facilitator trainings for representatives of health care and other interested organizations are 4½ days. It is **strongly** suggested that health professionals bring a lay person with chronic disease with them. All workshops and trainings are designed to be facilitated by 2 people. Each trainee receives a detailed leader's manual, and a copy of the workshop's textbook and audiotapes. Those being trained as Master Trainers (trainers of lay leaders) also receive a trainer's manual and a program implementation tool kit. Spanish-language program trainings at Stanford are done in Spanish, and all materials are in Spanish.

To enable an organization to sustain the program locally, Stanford trains and authorizes Master Trainers for a facility, who in turn, serve as that organization's on-site trainers for the future. A license to give the program(s), issued to the trainee's organization, is included with the training.

Adapted from the Stanford Patient Education Research Center website with permission from Dr. Kate Lorig:  
<http://patienteducation.stanford.edu/>



## Appendix B

### Screening Survey Responses of Master Trainers in Focus Groups (N=18)

<b>Involved in Effort to Offer CDSMP</b>	94% n=17
Still Involved with CDSMP	89 % n=16
Offered at Least One 6-week session of CDSMP	89 % n=16
<b>Master Trainers Roles Relative to the CDSMP (Rank Order of Multiple Responses)</b>	
Directly oversee implementation of the CDSMP	67 % n=12
Train lay leaders	61 % n=11
Monitor implementation and program fidelity	56 % n=10
Assist community agencies in implementing CDSMP	56 % n=10
Conduct an evaluation of the program	56 % n=10
Recruit lay leaders	50 % n=9
Recruit participants	39 % n=7
Secure funding	39 % n=7
Convince my organization to reach out to community agencies	28 % n=5
<b>Types of Community Agencies Involved When Implementing CDSMP (Rank Order of Multiple Responses)</b>	
Senior center	33 % n=6
Community health center	28 % n=5
Community center	22 % n=4
Church or synagogue	22 % n=4
Faith-based agency	22 % n=4
Area agency on aging	22 % n=4
County/city agency	17 % n=3
Health coalition or council	11 % n=2
Housing facility	11 % n=2
Aging services agency	11 % n=2
Extension service	11 % n=2
Health promotion/ wellness agency	11 % n=2
Tribal community	11 % n=2
Other Mention – Community clinics	11 % n=2
Community action agency	6 % n=1
State health department	6 % n=1
Multi-purpose social service agency	6 % n=1
Other Mention -- YMCA	6 % n=1
Other Mention – Community-based organizations	6 % n=1
Other Mention -- Schools	6 % n=1
Other Mention – Medical centers	6 % n=1
Other Mention – Support groups	6 % n=1



## Appendix C

### Focus Group Participant List

Karla Beardsley, MS RD LD  
Nutrition Project Director  
MAC Inc. Area Agency on Aging  
Salisbury, Maryland

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Robert Wood Johnson Diabetes Initiative  
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Master Trainer  
Taking Care of You, Powerful Tools for  
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Martha Valencia, MPH, CHES  
Regional Health Education, Health Promotion and Prevention Unit  
Department of Education Services  
Kaiser Permanente  
Pasadena, CA

Rietta Williams  
WA State Diabetes Control Program, Washington

Roberta J. Young  
Coordinator of Consumer Health Education  
MeritCare Health system  
Fargo, North Dakota

## Appendix D

### Letter to Introduce Survey to Master Trainers

Dear Self-Management Friends,

We have a really exciting opportunity. As you know, we now have training down pretty well but many folks continue to struggle with self-management program implementation. We hope to be much more helpful with this in the future. Thus, The Stanford Patient Education Research Center is collaborating with the U.S. Department of Health and Human Services' Administration on Aging and the National Council on the Aging (NCOA) to learn more about the experiences of CDSMP Master Trainers who have tried to reach older adults (aged 60+) through community service agencies. Our definition of a community service agency is quite broad. Our goal is find Master Trainers who have helped get classes launched outside of hospitals and medical groups.

We know that implementing the CDSMP is not easy. Some of you have tried with success, while others of you have encountered considerable barriers. Regardless of the success of your efforts, however, we want to uncover these different barriers, challenges, successes, and lessons learned from trainers throughout the country.

Our plan is to convene several telephone focus groups in which you will be invited to share your experiences. Before organizing these focus groups, however, we need to know more about you and the organization you represent. Therefore, we are asking you to please answer the questions on the attached survey (just scroll down to see attachment) and return the survey as an email attachment to [healthyliving@med.stanford.edu](mailto:healthyliving@med.stanford.edu) (**NOT THE LIST SERVE**) by **March 5<sup>th</sup>**. To send back the survey, open the attached document in word and fill out the survey, click "save as" to save the document and send as an attachment from your email program. If you prefer, you can also print off the survey and fax to 650-725-9422. After we review these surveys we will be contacting some of you to participate in the telephone focus groups. The information obtained from the focus groups will be compiled and presented at a meeting with key national leaders. Most important of all, I promise that all of you will get copies of everything we learn.

In advance, we would like to thank you for helping us make the Chronic Disease Self-Management Program more widely available to older adults with chronic conditions.

As always many many thanks,

**Kate**



## Appendix E

### Screening Survey of Master Trainers

**Name:**

**Preferred email address:**

**Current employer:**

**Are you willing to participate in a telephone focus group?**     \_\_\_ Yes     \_\_\_ No

If you do not want to participate or are not the appropriate person to ask, please provide us with the contact information for the person in your organization who might be helpful with our project:

---

Name

Email

Phone Number we can contact you/ or above person at:

Current Mailing Address:

**Have you been involved in an effort to offer CDSMP to older adults through community service agencies/organizations?**     \_\_\_ Yes     \_\_\_ No

**Are you still involved with CDSMP?**     \_\_\_ Yes     \_\_\_ No

**Did you offer at least one 6-week session of CDSMP?**     \_\_\_ Yes     \_\_\_ No

**If yes, please answer the following:**

**Who was your employer during that effort?**

**What was your position/title?**

**What is/was your role relative to the CDSMP? (*Check all that apply*)**

- \_\_\_ Directly oversee implementation of the CDSMP
- \_\_\_ Assist community agencies in implementing CDSMP
- \_\_\_ Secure funding
- \_\_\_ Recruit lay leaders
- \_\_\_ Train lay leaders

- Convince my organization to reach out to community agencies
- Recruit participants
- Monitor implementation and program fidelity
- Conduct an evaluation of the program
- Other, please specify:

**What types of community agencies do or did you work with or for when implementing CDSMP? (*check all that apply*)**

- |  |  |
|--|--|
| <input type="checkbox"/> Tribal community                    | <input type="checkbox"/> Church or synagogue               |
| <input type="checkbox"/> Community action agency             | <input type="checkbox"/> Faith-based agency                |
| <input type="checkbox"/> Health coalition or council         | <input type="checkbox"/> Extension service                 |
| <input type="checkbox"/> Housing facility                    | <input type="checkbox"/> Aging services agency             |
| <input type="checkbox"/> Area agency on aging                | <input type="checkbox"/> Mental health agency              |
| <input type="checkbox"/> State health department             | <input type="checkbox"/> Health promotion/ wellness agency |
| <input type="checkbox"/> State unit on aging                 | <input type="checkbox"/> Community health center           |
| <input type="checkbox"/> County/city agency                  | <input type="checkbox"/> Community center                  |
| <input type="checkbox"/> Multi-purpose social service agency | <input type="checkbox"/> Senior center                     |
| <input type="checkbox"/> Other, please specify:              |  |

**Which cultural or ethnic groups do or did this agency work with?**

Thanks for taking the time to fill out the survey! Please email this document to [healthyliving@med.stanford.edu](mailto:healthyliving@med.stanford.edu) or fax to 650-725-9422



## Appendix F

### CDSMP Master Trainer Moderator's Guide

#### **BACKGROUND**

The purpose of this study is to assess the opportunities and barriers that exist in implementing the Chronic Disease Self Management Program (CDSMP) in the aging network in the United States. The study will be used to inform the discussions at a meeting of national leaders convened to prepare policy recommendations related to making the CDSMP more widely available through community aging service providers.

#### **RESEARCH OBJECTIVES**

In order to assess the feasibility of a widespread implementation of the CDSMP in the Aging Network in America, the specific research objectives of this study are to:

5. Determine the “after training experiences” of the Master Trainers from the program to understand the opportunities and barriers encountered in attempting to implement the program in their community settings.
6. Identify the benefits of implementing the program for older Americans, health systems, and the organizations that choose to put the program in place.
7. Define the barriers that may be encountered in implementing and running these programs and how to overcome them.
8. Define the policy implications of the CDSMP re: program design and implementation, partnerships, funding, delivery systems, facility management, staffing, etc.

**PRETEST: TUESDAY, MAY 4<sup>th</sup> 11:30-1 EST**  
**GROUP 1: WEDNESDAY, MAY 5<sup>th</sup> 11:30-1 EST**  
**GROUP 2: WEDNESDAY, MAY 5<sup>th</sup> 2-3:30 EST**  
**GROUP 3: TUESDAY, MAY 18<sup>th</sup> 4-5:30 EST**  
**GROUP 4: WEDNESDAY, MAY 19<sup>th</sup> 9-10:30 EST**

---

#### **INTRODUCTION TO RESEARCH**

**Brief introduction of moderator and research.**

**Participant introduction (*ask them to be brief*) – name, position, organization and the roles they play in implementing the CDSMP in their organization.**

#### **PROGRAM IMPLEMENTATION IN COMMUNITY**

1. Why was your organization interested in participating in (Stanford's) Chronic Disease Self-Management Program? PROBE: How did you get involved? (Was the decision to do this part of an overall organizational plan/strategy or was it motivated by the interest of one or more individuals (champions) within the organization?)

## **ORGANIZATIONAL ISSUES:**

2. Would like to know how successful do you feel your organization has been in implementing the CDSMP in your community and what do you attribute this to? Did things like collaborations or partnerships/leadership's commitment/ staffing/funding strongly influence your agency's degree of success (of lack of success) with the program?

## **PARTNERSHIPS**

3. Who were your partners? What type of support did they offer?
4. How did you approach potential partners to join you in this effort? Why did they join your effort?

## **LEADERSHIP/ORGANIZATIONAL STRUCTURE**

6. Which leaders within your organization supported your efforts and how strong was their commitment?
7. What part of your organization housed the oversight of the CDSMP? What organizational structure have you put in place to manage the program?

## **STAFFING**

8. Which staff roles are critical to successful implementation and maintenance of the program?
9. Are any special management skills needed to administer this program – vs. other types of programs?

## **FUNDING**

10. What major problems or obstacles have you experienced in funding the program?
11. What type of funding did you seek for the program and from whom?  
PROBE: Which was hardest to get funded -- supervision, training, lay lead stipends, materials, space, etc.?
12. What lessons did you learn about securing adequate funding? [Refer to sustainability issues such as charges/fee scales/voluntary contributions.]

## **MARKETING**

13. What were your greatest challenges (greatest successes) regarding marketing? What did you do? What worked? What did not work?
14. What makes the CDSMP attractive to older adults?
15. What about location – what type of location is best for this type of program?  
PROBE: Are clinical settings and community settings both good locations? Are there any settings that are not good locations?

## **LAY LEADERS**

**Next, I'd like to know more about the process of recruiting, retaining and working with Lay Leaders.**

16. Do you use lay leaders, and if so, what percent of leaders in the program are lay leaders?
17. What percent of your lay leaders are older adults – say over age 60? Do you think that older adults make good lay leaders and why?  
    PROBE: What are the barriers to having more of older adults serve as lay leaders?
18. How did you recruit lay leaders? Which methods were most/ least effective in recruiting lay leaders?  
    PROBE: What worked and what did not? (Any strategy for recruiting leaders?)
  - Advertising
  - Flyers in public venues
  - Word of mouth
  - From classes or client base within your organization
19. Other than recruitment, what other problems have you encountered with lay leaders, if any?  
    PROBE: What have you done to deal with these problems?
20. Was retention of lay leaders a problem or not? What methods did you try and how did they work?

## **COURSE PARTICIPANTS**

**Let's focus now on the process of recruiting, retaining and working with participants for the CDSMP courses.**

21. Which methods were most effective in recruiting program participants?
  - If collaborations/partnerships within your organization or with other agencies in community – How did you do this? What was the nature of the partnership?
  - If outreach programs -- how did they work?
22. Which methods were least effective and with which groups? Why?
23. How were your methods different for recruiting participants of different ethnic/cultural groups, if at all?
24. What other problems, if any, have you encountered with course participants?  
    PROBE: What have you done to deal with these problems?
25. What has your experience been in retaining participants, once they begin the program? What strategies did you use that worked and what did not work?
26. [IF TIME:] Are health literacy disparities an impediment to effective training with this program? If so, how do trainers deal with that?

### **BENEFITS OF THE PROGRAM BY STAKEHOLDER TYPE**

**Let's turn to another topic – benefits of the CDSMP for its various stakeholders. What I would like to do now is to “go around the table” and make some lists with your help. Our goal is to generate a list of potential benefits, not produce an in-depth understanding of each at this point.**

27. First, thinking about your **organization**, what benefits have you experienced as a result of the program?
28. Your **partners** (define who they said these were)?
29. Your **funders**?
30. Other **stakeholders**?

### **CLOSING**

31. In closing, what other things about your experience do you think are relevant to this conversation as we prepare policy recommendations for making the CDSMP more widely available?

**THANK YOU ALL VERY MUCH FOR TAKING THE TIME TO PROVIDE SOME INSIGHT INTO THE EXPERIENCES YOU HAVE HAD SINCE RETURNING TO YOUR COMMUNITY TO USE THE CDSMP.**

## Acknowledgments

NCOA, Center for Healthy Aging would like to thank the Master Trainers for volunteering to participate in this important study. They spent considerable time describing their programs and the essential elements of their successes and failures. Their candid responses were keys to the completion of this study.

This study was conducted in collaboration with The Stanford University Patient Education Research Center, Stanford, CA. The research was conducted by Carolyn Holmes, Holmes Research & Consulting, LLC, Phoenix, AZ who was also responsible for this final report.

In addition, NCOA appreciates those staff who have worked on and guided this effort and who are similarly available as resources including: Nancy Whitelaw, PhD, Director, Center for Healthy Aging and Alixe McNeill, Vice President, Program Development.

Cover quote: Lorig, K. (1993). Self-management for chronic illness: A model for the future. *Generations*, 17: 11-14.

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