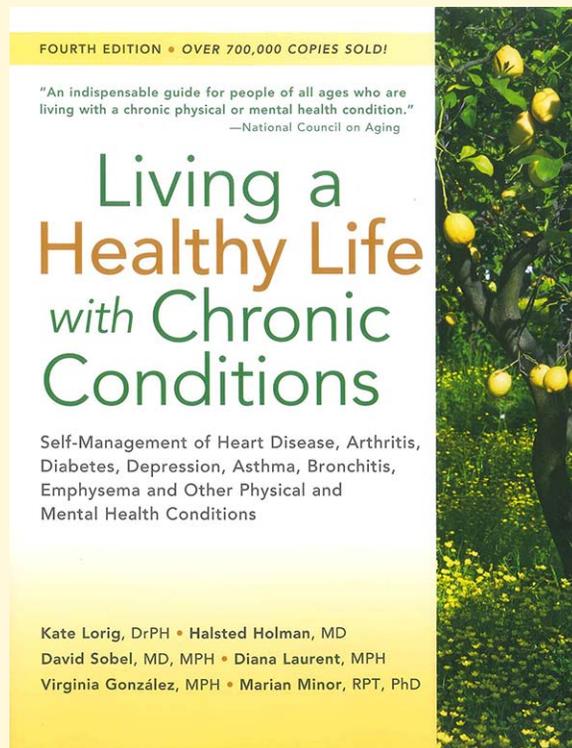


# Living Well with Chronic Conditions

The Stanford University

Chronic Disease Self-Management Program

# COORDINATOR HANDBOOK



Adapted by

Utah CDSMP Coordination Workgroup

This handbook has been developed as a guide for coordinators of the Living Well with Chronic Conditions Program in Utah. Much of the information has been taken from the Stanford Self-Management Programs 2008 Implementation Manual. Please refer to that manual for more detailed program implementation information. You can find it at: [http://patienteducation.stanford.edu/licensing/Implementation\\_Manual2008.pdf](http://patienteducation.stanford.edu/licensing/Implementation_Manual2008.pdf)

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## **I. Program Description**

### **Background**

The Chronic Disease Self-Management Program was developed at Stanford University, Palo Alto, CA. In Utah it is known as the Living Well with Chronic Conditions Program (LWCC).

LWCC is a six week program for people with chronic health problems, their caregivers, and their significant others. The two and a half hour workshop is given once a week, for six weeks, and is held in community settings such as senior centers, churches, libraries, clinics, and hospitals. Workshops are facilitated by two trained leaders, one or both of whom are non-health professionals with at least one chronic condition.

People who attend the workshops come with many chronic conditions, but they all benefit due to the topics: 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 care professionals, 5) nutrition, and, 6) how to evaluate new treatments. Emphasis is placed on three process skills: action planning, disease related problem solving, and decision making.

The program developers have scripted the course content and have specified time frames for each activity conducted during the sessions. The course is to be taught as written. Stanford staff members revise this manual approximately every five years. Their changes take into account suggestions from leaders, Master Trainers, program coordinators and program participants. Sometimes there are special reasons to change the program in small ways. Before these are undertaken, permission from Stanford must be granted by emailing [self-manage@stanford.edu](mailto:self-manage@stanford.edu).

Each participant should receive materials during the course of the workshop. More information about this is addressed in the Materials section.

## **II. Program Needs**

### **Program Coordinator**

Every organization needs a program coordinator. The program coordinator recruits and supervises leaders, arranges for workshop sites, maintains program fidelity, and may conduct program evaluation. This is also the person that leaders turn to in an

emergency. This person may have received leader training and/or training as a Master Trainer, however these are not requirements of being a coordinator.

## **Trained Leaders**

Implementation of the program requires two trained leaders for each six week workshop. Although health care professionals are trained as leaders, lay persons usually make excellent leaders, especially if at least one of them has a chronic health condition. In some cases both leaders are volunteers receiving no pay, but it is suggested that leaders receive a small stipend (\$150 to \$200 for teaching a six-week program). If and how you pay leaders for services rendered depends on your organization and its structure. At a minimum, reimbursement for travel expenses should be given.

The job of the leader is to teach the six-week workshop using the detailed scripted manual provided in their training. Leaders are expected to show up on time for classes prepared to teach throughout the full workshop. It is not expected that leaders will find community sites, order materials, or recruit participants. These duties are the responsibility of the program coordinator. However, they may do all of these things if they wish and should receive additional training.

It is important that the leaders are treated well, and made to feel that they are important to the program.

See the “Fidelity Checklist” (Appendix B) for a broad overview of things to consider for the program.

## **III. Leaders**

### **How to Recruit Leaders**

There are many ways to recruit leaders. Before you recruit, consider what characteristics you want in your leaders:

- Leaders must be literate. They have to be able to read, write, and follow the Leaders Manual.
- Leaders should reflect the make-up of the community you are serving. Middle class areas should have middle class leaders, Hispanic groups - Hispanic leaders, rural farm groups - rural farm leaders, etc. If you have mixed groups, then the leader pairing should be mixed.
- If you serve men, then 30-40% of your leaders should be men. Women are generally happy to attend groups with any gender mix of leaders. Men usually

- feel more comfortable in a group with at least one of the two leaders being male.
- The motivation of leaders to lead should come from wanting to serve and offer help to others, but never to earn money. This is not a job. However, for some leaders the little stipend they get is very important.
  - Be cautious of having the following types of people lead:
    - People whose main focus in their life is their chronic condition.
    - People who are super achievers despite their chronic condition. These are people who have had an amputation and run marathons, etc. They may not be as effective because the participants may not find them relatable.
    - People who are judgmental.
    - People who have “found the answer” to their disease and want to share it with the world.
    - People who are really sick. Sometimes a chronic condition can become all consuming and people are too sick to teach effectively. This requires a judgment call (leaders have successfully taught while on chemotherapy, using supplemental oxygen, and in wheel chairs, etc.).
  - The people you want to be leaders are those successfully living with a chronic condition. They have their good days and bad days but in general lead satisfying and productive lives.

Recruitment of leaders should be an ongoing effort using not one, but many strategies simultaneously.

When talking with people about becoming leaders, do not ask them to call you. Very few of them will ever call. Rather, if they show even a little bit of interest, **always write down their name and contact information** and get back to them with concrete information about the program.

Give those who are potentially interested a call within a few days. You can use this call to inform people about the program and to screen the person to be sure that they are someone you might want as a leader (see Leader Interview Questions, Appendix C). Invite them to an in-person interview.

Do not decide someone is or is not a good candidate to be a leader just because they are not like you. If they meet the criteria discussed above they should be asked to come to training (see Leader Application, Appendix D).

## Recruitment tips:

- Look around you. You probably know people who would make good leaders. Maybe they go to your church, are friends at work or are your neighbors.
- Post the opportunity to become a leader at your local volunteer bureau, senior center, and perhaps online.
- Talk with people in ongoing support groups.
- Post a notice with your community volunteer center.
- Post the opportunity on your agency website.
- Mention this volunteer opportunity when giving talks in the community and take the names of people who might be interested.
- Post a notice in the newsletters of voluntary health organizations such as the Arthritis Foundation, Heart Association, Diabetes Association, etc.
- Utilize local newspapers that run free classified ads for volunteers.
- Ask health professionals to recommend patients who would be good leaders.
- Post notices in neighborhood newsletters and health clubs in the areas that you serve.
- Use local media sources, i.e. radio and newspaper.
- Ask your leaders to watch for people in their classes who they think might make good leaders. Have the leaders approach them for contact information and call them.

It is also a good idea to have several staff people trained to offer programs. They come in handy if you have to find a leader in a hurry.

## How Are Leaders Trained?

Leaders must attend a six hours per day training for four days taught by a Master Trainer to be certified to teach a program. They **must attend ALL of the training**. Before sending a potential leader to training it is best if the workshop(s) they are to teach is/are already planned with dates, sites, and recruitment if possible. If they wait more than six months to teach they will need to be retrained or go through a refresher course (Appendix H). This is at the program coordinator's discretion.

You should plan on between 10 percent and 25 percent of the leaders you send to training never teaching. Some lose interest, others get sick, etc. Generally, you should recruit more leaders than you need to make up for the 10 percent to 25 percent who will never teach.

Upon completion of training, your organization may or may not require Leaders to sign a contract. See the Leader Contract (Appendix E) for a sample template. Leaders should also be supplied a "Leader Guidelines and Responsibilities" sheet (Appendix G).

## How Are Leaders Monitored?

Monitoring the leaders is a key issue in program implementation, especially to preserve program fidelity.

1. Leaders always teach in pairs. This is true even if the leaders have a great deal of experience. There are several reasons for this.
  - This is a complex program and requires two people to be sure that nothing is missed.
  - The leaders act as models for the participants and two leaders provide a varied range of modeling.
  - Leaders support one another. This is especially true if a leader loses their train of thought, goes off track, or is working with a difficult participant.
2. The first opportunity for monitoring leaders is during training. If someone is not appropriate during training, is judgmental, always comes late, talks too much, or is very critical of fellow leader trainees, this same behavior will be seen during actual workshops. Master Trainers should work with program coordinators to address problems during training, including the possibility of dismissing the candidate if necessary. Each potential leader takes part in two practice teaching sessions during training. There are usually several problems during the first practice, but by the second practice, all trainees should be fairly comfortable with what they are supposed to be doing. If major problems still exist at the time of the second practice such as adding material, not following the manual, or being inappropriate with the participants, then the person should not become a leader.
3. New leaders are best paired with experienced leaders. This is not always possible but should be done when possible.
4. After the first session of each new class it is best to check in with each leader by telephone. In this way you can find out if there were any problems with the site, the participants, or the co-leader. If any of these arise, there should be some follow up.
5. Another call can be made to the leaders after the fourth or fifth class. Problems are often uncovered and resolved with these calls.
6. Participants can rate the leaders. Appendix K provides a form to do so.
7. If at all possible, leaders should periodically be directly observed. This is best done at the second or third session so there will be time for leaders to utilize feedback. When observing leaders, use the Leader Evaluation Form (Appendix F).

## **How to Retain Leaders**

People decide to become leaders for their own unique reasons. The more you know about these reasons the more you are able to help them meet their expectations. If someone wants to help people like themselves, then they might be the right person to give talks to disease specific organizations. If they need social contact then they might want to teach more workshops or do some extra work recruiting.

Leaders are special and need to feel special. Thus, when they call you should talk with them or call back right away. When they come into the office, stop and talk with them. Send thank you notes, birthday cards and/or holiday cards.

Your organization is encouraged to hold an annual leader update meeting at which all of your trained leaders are gathered and recognized. At this meeting they can bring up success stories or concerns, and receive a short update training. A sample agenda for this is available in Appendix H.

If people decide they no longer wish to be leaders, find out why. Do not just accept the first answer such as “I am busy”. Probe a little to find out if there is something about the program which has made them decide that it is no longer worth doing. Here is an example of a probe: “I know that all of us are really busy, but I also know that sometimes leaders decide that they want to quit for other reasons such as it being too much work, not getting along with their co-leader, or not being treated well by the staff. We really need to know these things so we can improve. Is there anything else you would like to tell us?”

## **IV. Organizing Workshops**

### **Recruiting Systems**

Before you start your publicity, be very clear about who you want to target. Do you want Spanish speakers, seniors, people living in a certain area, men, or people getting their health care from a specific health care location or system? Once you know who you want to attend, then everything should be focused on getting your target population to attend. This includes the time and place of the workshops as well as how and where you publicize them. What often makes or breaks a program is participant recruitment. This is more difficult than you might suspect.

#### **Time**

Successful recruiting takes advanced planning. Depending on how many people you want to reach this can be a day, a week, or more. For example, recruiting 500 or

more people a year is probably a full time task. From the start of recruiting to the start of a workshop takes real time. You cannot expect to put out publicity and have the workshops full in a week. Stanford starts publicity a full two months before the start of a workshop and this is an ongoing effort.

## Systems

- **Publicity Sources Database:** Every community has hundreds of publicity sources. These include major media such as radio and TV as well as major and local newspapers. Then there are newsletters, church bulletins, advertising from realtors that contain community news, etc.

Do not forget websites and user groups. This is not complicated and you can surely get someone who is web savvy. Voluntary health agencies also have local websites as do organizations such as AARP. More and more neighborhoods have user groups and by contacting the group owner you can often post to these groups.

Each new publicity source should go in the database. Be sure to note when they publish, who to contact for public service announcements, the fax number, and or email for that person, and how far in advance of publication he/she needs information. This may be days, weeks or even a month or two. You will also want to include in your database what the coverage is for that media source. If you can enter this by ZIP code, neighborhood, or town, you can then sort your publicity sources when you want to target a specific area. Keep your database current. Thus the collective recruitment wisdom will not rest in the hands of one person who might not be around the next time you want to recruit.

- **Potential Participants Database:** Most organizations recruit on a workshop to workshop basis. If someone is not interested now or does not show up at the class he/she is lost as a potential future participant. To avoid this problem and add efficiency to recruiting, set up a potential participant database. The purpose of this database is to keep track of all the people who may have indicated any interest at any time. This way they can be invited to programs in their area over time. Capture the contact information for as many potential participants as possible.

Once someone has given you his/her name, address, phone, and email contact information, enter it into a database. In the same database, keep information on whether the person actually registered for a program, showed

up for a program, and how many sessions he/she attended. You can also keep track of how many times the person was invited to attend a program before actually attending.

It has been Stanford's practice to keep people in the database for two to three years and inviting them to every available program in their area before taking them out of the data base. Anyone who requests it should be taken out of the database immediately.

## **V. Scheduling**

### **Timing of programs**

#### **1. Time of day/day of week**

Be aware of time of day when scheduling classes to meet the needs of the particular populations that you are targeting. Stanford noted that Saturday mornings from 9:30 to 12:00 works very well for large segments of the community.

If BINGO is going on at the same site at the same time you probably will not get much attendance. Think outside of the normal Monday to Friday 9 to 5 box!

#### **2. Time of year**

It is best to schedule programs so that they will end by the second week in December and not start again until the second week of January. Avoid, when possible, other holidays that will interrupt class schedules, i.e. Thanksgiving, 4<sup>th</sup> of July, Labor Day, etc.

Weather can also be a problem. Have a contingency plan in case you get snowed out, etc. Schedule a site for seven weeks instead of six during bad weather months. This allows for the option of making up a missed week if necessary.

### **Place**

Hold workshops where people usually go. Familiar sites are more successful than unfamiliar ones. See community sites on pages 12-13.

## **Leader Availability**

In planning, you must have two leaders committed to teach for the full six weeks. Having a large pool of leaders allows flexibility to schedule workshops in advance.

In rural or other areas where you may have only two or three leaders, you should first ask your leaders when they can/would teach and then schedule as best you can around them. Consider having two to three leader trainings each year if possible to grow the leader pool.

For areas with large leader pools, the Workshop Sign-Up Sheet (Appendix I) may be a helpful template for assigning available leaders to facilitate upcoming workshops.

If a leader might have a difficult time coming to all six sessions, a substitute leader is a must. Check with other program coordinators in your area to find a substitute leader.

## **VI. Finding Participants**

Be sure that your publicity tells people what to expect. They tend to get upset when they think they are going to a lecture by a professional and end up in an interactive workshop.

Many organizations use a publicity kit containing a simple fact sheet about the program along with any or all of the following:

- Public service announcement (print, radio, TV)
- Flyer
- Referral Card
- Letter to potential participants
- Website link
- Blog announcement
- User group announcement
- Newsletter announcement

Brand your program and all associated publicity so that it is recognizable over time. Produce all materials electronically. This way only names, dates, and maybe the graphics change as you publicize each site.

**NOTE:** Your sources database is a great tool to reach your target participants.

#### Other tips:

- Talks to community groups, announcements made by leaders at church, talks at community lunch sites, etc.
- Use your sites to recruit. Many churches, senior centers etc. have their own newspapers and/or websites. Be sure your publicity is included. Get buy-in from the staff at your sites. Attend a staff meeting, tell them about your program and answer questions
- Use mass media such as newspapers, TV and radio – radio talk shows can be especially helpful in some areas
- Flyers in grocery or pharmacy bags
- Information in utility bills
- Standing in front of big box stores like Wal-Mart and talking to people
- Announcements at senior lunch programs
- Emails to employees at their workplace
- Flyers under doors of housing projects or large apartment complexes
- Flyers in the windows of neighborhood stores
- Flyers on community bulletin boards
- Letters with information about the program sent from the physician, health center or clinic. (Stanford has found that the uptake on a first letter is about 10% so you will need to send about 150 letters to fill a program)
- A reminder in the electronic medical record to health professionals to refer people to the program, or better, a link where they can download information and hand it to their patient
- Past participants are a great recruiting resource. Use your database to mail flyers to past participants (if a class will be in their area) and ask that they post them or give them to friends
- Recruitment at health fairs

#### Here are some rules of thumb:

- The more personal your publicity and contact, the more effective.
- Use multiple modes of publicity and usually the more the better. Have too many people? Conduct more programs and show your funding source that you have a high demand.
- Be courteous to callers. This sounds simple but what does it mean? Have your phone answered by a real person. When someone leaves a message call them back quickly. Be sure that the person on the phone is well trained to answer questions about the program. Again, the more personal the better.

- Once you have someone's contact information, he/she should be invited multiple times to the program. Sometimes all it takes is a personal phone call to get someone to attend.

NOTE: Don't rely too heavily on newsletters. They may go to lots of people but never get read.

Do not rely on referrals from health professionals. They are extremely busy and it takes time to tell patients about your program. They may not remember even if they have the information right in the examination room. A minute of professional time may be 10% of a clinic visit. The electronic medical record system may be useful to send a referral to you. Use a dot-phrase like ".self management" or ".chronic". Make it as easy as you can on your providers. Use the support staff to educate patients about LWCC. Lab techs, X-ray techs and medical assistants have more time with patients than providers do.

If a participant attends a workshop and does not come back, call them and ask for information about why they did not continue attending the other sessions. This information will help you to improve the program if necessary. Appendix J provides a script for contacting a participant who has dropped out.

## **VII. Emergencies**

A clearly defined plan of action is needed in the case of any emergency that could happen during class. Leaders need to follow a course of action predetermined by the program staff and/or coordinator, i.e. calling 911, crisis center or other.

## **VIII. Community Sites**

Program sites must meet several criteria:

- Handicap accessible (this includes not requiring the use of stairs)
- Safe
- Be able to accommodate up to 20 people in a circle or U configuration
- Have safe, ample parking
- Have well lighted exteriors if the program is held after dark
- Be open to having anyone from the community attend
- Have a room that provides privacy and enough space for the leaders, participants, flip charts, white board and room to move around. Comfortable

chairs help, and extra space if any of the participants or leaders uses a wheelchair or scooter

- Have liability insurance

Be aware that some people may have allergies to chalk. In the case of having to use a chalkboard, seat those people as far away as possible. Remind participants not to wear strong fragrances in consideration of others who may have respiratory illnesses.

The site should also be in the same community you want to serve for easy accessibility for participants.

Finally, the site should be someplace where participants will feel comfortable. This is not always obvious. For example, a church setting may seem perfect, but not everyone may feel comfortable there. Also be aware that sometimes perception is more important than distance. You may have an excellent site near the community you want to serve but people from that community may feel uncomfortable crossing the road or tracks on the way to this site.

The following is a list of some sites that many groups have found useful:

- Senior centers
- Public libraries
- Churches
- Retirement communities
- Community centers
- Community rooms in apartment or condominium complexes
- Community rooms in banks
- Public schools after hours (be aware of small desks)
- Meeting rooms in the offices of voluntary organizations
- Union halls
- VFW halls

There are also some sites that may seem perfect but may also cause problems. You will have to make the decision for your own community.

- Hospitals – these may seem perfect but people have reasons for avoiding them.
- Clinics – these are less problematic than hospitals but people have reasons for avoiding them as well.
- Mental health facilities – unless you are offering a program for people who use these facilities, the non-users have reasons for avoiding them.
- Shared spaces – these are often not private enough for the confidential information shared during the workshop.

If possible, coordinators should do a site visit before workshops are started to ensure readiness of the site. Are white boards/chalk boards available? Do chairs need to be set up before the workshop? Workshop set up should be made easy for leaders, especially those with chronic conditions that would have a difficult time, for example, arranging or setting up chairs before the workshop.

Leaders who are capable of hauling workshop supplies and snacks (provided by the coordinator) to the workshop sites may have no problem and be willing to do that. However, it should be assumed that the program coordinator will do whatever is necessary for the leaders to have as easy a time as possible in setting up workshops.

## **IX. Materials**

Books and CDs are available from Bull Publishing. All other materials are purchased locally.

1-800-676-2855

<http://www.bullpub.com>

P.O. Box 1377, Boulder, Colorado 80306

Each participant in the English program will need:

- A copy of the book *Living a Health Life with Chronic Conditions*. (Please note that this is available in several languages and there are also English editions for the United States, Canada and the United Kingdom.) For those who cannot read or see this is also available on CD.
- A relaxation CD (this is optional but many participants find it useful)

Each participant in the Spanish program (*Tomando Control de Su Salud*) will need:

- A copy of the book *Tomando Control de Su Salud*
- An exercise CD (audio) in Spanish
- A relaxation CD in Spanish (this is optional but many participants find it useful)

**Over the phone is the easiest way to obtain discount information and place an order.**

Every leader will need a set of charts for the program. Flip charts or poster board and markers should be provided to leaders who do not already have them. They learn in leader training how to make their own charts.

## **Assure participants have all needed materials**

Materials for the workshops are an important part of the program. Ideally, each participant is given a book and/or a CD to keep for on-going use. The following are options to consider:

- Purchase of training materials by a sponsoring organization. Organizations, in turn, donate them to the program for use by participants.
- Some organizations charge the participant a small fee that covers the cost of the books or CDs and/or the cost of attending the workshop series. Ideally, however, the workshops should be free.
- Other organizations establish a “lending library” that allows materials to be borrowed and returned.
- Some programs loan the books to participants for use during the workshops, giving them the option to purchase the book at the end of the series.
- Materials are much less expensive if they are bought in large quantities. Bull publishing has discount information. Call them for pricing.

Your organization should discuss the method you would like to use to ensure that workshop materials are available to participants.

## **X. Costs**

It is too difficult to estimate exactly how much it costs to implement the program. There are many factors that depend mostly on how many programs you will give. Some cost considerations include but are not limited to:

- Program License (no cost if under state-wide license)
- Leaders stipend (if offered and accepted)
- Leaders training
- Publicity
- Sites for programs (usually donated but you may have to consider rent)
- Materials for participants, such as books (\$15-20 each) and optional cd's (\$10 each) should be factored in before implementation.
- Flip charts (\$30-100 each) can be hand-drawn or printed and can be used for more than 1 workshop
- Two easels for the charts
- Dry-erase markers
- Light snacks, bottled water, napkins, paper plates, etc.

- Carrying device large enough to enable carrying of materials to site in one trip (see Appendix L for a list of things to include)

## **XI. Program License**

Before an organization can offer programs it must have a license. The programs are all owned by Stanford University.

1. The license establishes the legal obligations of the organizations offering the program.
2. The license protects Stanford's intellectual property.
3. The license lets Stanford keep track of who is offering the program and thus form a network of all licensed organizations.
4. The license allows Stanford to easily notify organizations when there are program changes.

The cost of a license is determined by how many programs your organization plans to offer each year. As of fall 2008, a basic license for 10 programs per year for three years costs \$500. You can find full information about current license fees and a form to apply for a license at <http://patienteducation.stanford.edu/licensing>.

If at any time an organization cannot afford the licensing fee, it should contact Stanford for a fee reduction. This can be done by email: [self-manage-licensing@stanford.edu](mailto:self-manage-licensing@stanford.edu).

The license holder, in most cases the Utah Arthritis Program, will send each coordinator a copy of Utah's Stanford license for implementing CDSMP/LWCC. The coordinator should give paper copies to their leaders to place in their binder after they have completed leading their first workshop. Please note: Do not e-mail the license to leaders.

## **XII. Special Considerations for Working with Different Cultures**

The Stanford self-management programs are designed to be as culturally neutral as possible. However, there is a diverse cultural population in Utah and cultural traditions and beliefs should be respected. If participants wish to not participate in certain parts of the workshop that is acceptable (for example, some Hispanic Seventh Day Adventists have asked that the relaxation exercises be taken out of their workshop). Leaders should be made aware of any situations that may arise according to the population who

will be attending the workshop. Here are a few principles from Stanford to think about when working in a culture with which you are unfamiliar.

1. Cultural competence is a development process. It is impossible for anyone to be aware of all facets of a culture – even in one’s own culture. For this reason, we prefer the concept of cultural humility. This means that we approach cultural issues from a humble position without making judgments, and with a curious mind and an open heart.
2. One needs to be very careful about cultural stereotypes such as “all African Americans...” or “my people...” One size seldom fits all.
3. Ask the people who know about the culture. We suggest that before you make any adaptations, you find a group of people and offer the program as it is written. Then at the end of the program have a focus group and ask the participants what they would change. They will appreciate being part of an effort to improve the program and may refer others!

\*Note: Currently workshops can be taught in English, Spanish, Tongan, Samoan, and Navajo in Utah. Workshops must be taught by two trained leaders in the language of the workshop being offered.

### **XIII. Evaluation**

The RE-AIM (reach, efficacy, adoption, implementation and maintenance) model provides one very useful way of considering how to evaluate LWCC. There is also an excellent website at [www.rea-aim.org](http://www.rea-aim.org).

The following are just a few examples of possible evaluations you may want to consider for each element of the model:

#### **Reach**

You may want to find out who your program is reaching and how representative this is of your area or of who you are trying to reach. You may also want to know what proportion of a total population you are reaching. Record keeping is valuable and often data submission is required to fulfill contract and/or grant obligations.

1. The most basic reach question is how many people are attending your programs. In Utah, demographic data such as gender, age, ethnicity, etc. is gathered.
2. As your program grows you might have a goal of reaching 10% of the seniors who attend a specific senior center. Keeping data allows you to check on your goal periodically.
3. You may want to know which types of publicity bring in which kind of people.

## **Effectiveness**

In evaluating effectiveness, evaluate positive and negative impacts of the program on such things as behaviors, symptoms, health status and health care utilization.

For information about effectiveness studies and sample questionnaires you can go to the following websites:

<http://patienteducation.stanford.edu/research/index.html>

<http://patienteducation.stanford.edu/research/primer.html>

## **Adoption**

Adoption evaluations look at the settings and organizations that are offering a program and how successful each is. Here is one example that could possibly happen:

- You offer leader training to 20 community organizations; ten send people to training. How do those that send people differ from those that do not? After a year, six organizations have offered a program but four have not. Why is this? At the end of two years, only four organizations are offering programs. Two of these offer several programs a year while two only offer one program a year. Can you learn anything by talking to these programs and finding out what makes the difference?

## **Implementation**

At the agency level, implementation fidelity refers to how closely staff members follow the program that the developers provide. This includes consistency of delivery and following of the formatted workshop timeline as outlined by Stanford.

At the individual level, implementation refers to clients' use of the intervention strategies.

## **Maintenance**

Maintenance refers to the extent in which a program or policy becomes institutionalized or part of the routine practices and policies of an organization. Within the RE-AIM framework, maintenance also applies at the individual level.

At the individual (participant) level, maintenance has been defined as long-term effects of a program on outcomes six or more months after the most recent intervention contact.

Funding agencies require specific information be provided to them. Appendices i and ii are forms that leaders provide to participants and give to program coordinators at the end of each workshop.

#### **XIV. Reporting to Utah Department of Health, Arthritis Program**

The Utah Arthritis Program requires that the following forms are completed and returned for each workshop:

- Conditions Summary Report
- Attendance Form

The Conditions Summary Report – Individual Form should be filled out by each participant after they listen to the Confidentiality Statement, which should be read by the leader at the beginning of the first class. Leaders should then transfer participant’s information onto the Conditions Summary Report and give it to their program coordinator within one week of the last class.

All of these forms are found in Appendix A.

#### **XV. Need Additional Support?**

If you have questions that your agency manager does not have answers to, contact Rebecca Castleton, Christine Weiss or Randy Tanner at the Utah Department of Health Arthritis Program:

[rcastlet@utah.gov](mailto:rcastlet@utah.gov) or (801) 538-9340

[cweiss@utah.gov](mailto:cweiss@utah.gov) or (801) 538-9458

[rtanner@utah.gov](mailto:rtanner@utah.gov) or (801) 538- 9193

[www.health.utah.gov/arthritis](http://www.health.utah.gov/arthritis)