

# **Community Activated Living Well With a Disability**

A Guide for Implementing the Living Well with a Disability Health Promotion Workshop for Community Members who have Disabilities

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## Introduction

Many communities are working on ways to become healthier places to live. Some communities have developed walking and biking paths, others have created community awareness campaigns promoting the benefits of healthy eating and daily exercise. There are many ways that we can make our communities healthier places to live, particularly when we work together with others in our community.

[Healthy People 2020](#) is our nation's blueprint for improving the health of all the people living in the United States. The four overarching goals are: 1) Attain high-quality, longer lives free of preventable disease, disability, injury, and premature death; 2) Achieve health equity, eliminate disparities, and improve the health of all groups; 3) Create social and physical environments that promote good health for all; and 4) Promote quality of life, healthy development, and healthy behaviors across all life stages.

Determinants of health are influenced at multiple levels among many inter-relationships. For instance, a health disparity may be higher rates of asthma among children from low-income homes, or it might be a disparity in access to state of the art treatment following a stroke or other medical emergency.

People with disabilities experience a variety of health disparities, including the occurrence of secondary conditions that may limit normal daily activities. Secondary conditions are related to the disabling condition, but are as diverse as fatigue, depression and pressure sores. While many of these secondary conditions are preventable, many people simply don't know what they can do to manage or prevent them.

The focus of this guide is [Living Well with a Disability](#), a health promotion workshop that helps people manage and prevent secondary conditions so they can continue to do the things they want to do. The Living Well program is a 10-week workshop that introduces a process for setting and clarifying quality of life goals, and teaches skills for generating, implementing, and monitoring a path to reaching those goals. The Living Well program also provides tools for managing one's health and making healthy lifestyle changes, increasing physical activity, developing and maintaining healthy relationships, managing depression and frustration, and improving nutrition.

The Living Well with a Disability program, developed in collaboration with researchers at The University of Montana and Kansas University, demonstrated its usefulness in a national evaluation that included nine Centers for Independent Living (CILs) in eight states. Research showed that participants in the Living Well program reported 20 to 25 percent less limitation due to those preventable health problems and a 10 percent reduction in their use of health care services. The effect of the workshop is maintained for one year or more after its conclusion.

Community Activated Living Well (COALW) is a set of guidelines designed to help plan and implement Living Well with a Disability. It includes ideas, agendas and procedures that community members can use to organize and conduct this health promotion workshop designed specifically for people with disabilities. The activities suggested in this guide may also lead community members to further address health related issues for people with disabilities in their community.

## **Overview of the COALW process**

People with complex health promotion needs often live in communities with few resources to address those needs. Community Activated Living Well (COALW) is a community development framework for helping people with disabilities, service providers and other stakeholders within a community, plan and implement health promotion and wellness services that can help these individuals prevent and manage secondary health conditions.

The framework uses group-oriented methods to bring the consumer and service provider voices together into a service-delivery plan with maximum acceptability, utility and generality for both consumers and other members of the community. Compared to traditional symptom based approaches to healthcare for people with disabilities and other complex health maintenance needs, the COALW process presents a community-based intervention that is cost-effective and links disability and health. Important outcomes include prevention of secondary conditions and reductions in limitation, as well as reduced health care costs.

The COALW process blends the needs and capacities of individuals and their communities to positively impact the long-term health and wellness of community members with disabilities. The process described here is intended to develop stakeholders in health promotion for people with disabilities in your community.

The cornerstone of this process is the formation of a steering committee that can guide implementation of the workshop within your community. The steering committee is typically formed through the actions of a staff member from a community organization (i.e., a Center for Independent Living). The actions of this staff member to form the steering committee constitute Phase I of the process.

Then, in Phase II the COALW process guides the steering committee through a planning process that results in the successful implementation of a Living Well Workshop.

Finally, in Phase III as the workshop is implemented, the steering committee provides problem-solving support and oversees collection of program evaluation data.

As you read through these guidelines, you will find many useful ideas for developing the steering committee and conducting the workshop.

## **Phase I: The Catalyst**

Every effort needs a catalyst. Centers for Independent Living have long been change agents in efforts toward equality and inclusion for people with disabilities and so may be a natural catalyst for bringing together community members and organizations to initiate Community Activated Living Well. However, if your community does not have a Center for Independent Living, don't let that stop you. Contact individuals and representatives of organizations who have a stake in the health of the community and establish a steering committee.

One advantage to forming a steering committee is that it gives you the opportunity to extend the reach of the Living Well program beyond what any single agency can achieve. You may try to form a committee of diverse members to add a variety of perspectives and resources to your committee. However, getting people to volunteer for the steering committee can be tricky. We have put together three resources to help you. First, we have included information you can use to describe the Living Well with a Disability program. Second, we have defined the scope of the steering committee in such a way that it will be able to achieve its mission in five meetings or less. Third, we have provided a list of potential contacts you might use for selecting members for the steering committee.

### **Describing Living Well with a Disability**

For the general population, participation in health promotion and wellness programs has been shown to improve quality of life and overall health, reduce medical care costs, and lower mortality rates. Living Well with a Disability is a health promotion and wellness workshop designed specifically for anyone with a disability or physical limitation.

The Living Well workshop is a ten-week course that teaches tools for helping people continue or begin to do the things they enjoy. The healthier a person is, the more they are able to do, so Living Well begins with participants developing a goal that is meaningful to them, and then making connections between healthier behaviors and reaching their goal. For example, if a person's goal is to spend more time with their children, they may need to address fatigue in order to reach their goal. That may lead them to begin an exercise program, or to examine their eating habits. The better the person begins to feel, the more time they are able to spend with their children.

The topics in the ten, two-hour workshop sessions are:

- Goal setting
- Problem solving
- Having healthy reactions
- Managing discouragement
- Healthy communication
- Information seeking
- Nutrition
- Physical activity
- Advocacy
- Maintaining healthy lifestyle changes

Potential health benefits include fewer health complications, increased physical activity, decreased stress levels and improvements in outlook. Participants have made a great variety of changes in daily

living, including transportation solutions for community access, changes in living arrangements, new jobs, new social and recreational activities and educational pursuits.

Here are a few quotes from past participants that might be helpful.

“The best part of Living Well was classmates asking what I did over the past week to meet my goal. I feel more personal satisfaction. Setting goals gave me some motivation to hope, work, think towards a future—a positive, worthwhile, much needed experience.”

“The Living Well Program has taught me to be more assertive, more self-assured, and happier in my life. It has taught me to praise others for their accomplishments as well, no matter how small.”

“After participating in Living Well, I now know that I can solve problems. I am not so overwhelmed when life just happens.”

People practice and develop skills for living well when they have important meaningful goals they are pursuing. Living Well with a Disability helps people to think about those goals and develop a plan to reach them, emphasizing healthy lifestyle behavior changes as a way of removing barriers and increasing opportunities.

This Living Well description has content that can go into brochures or flyers. Brochures and other outreach materials can be downloaded from the [Living Well with a Disability program website](#).

### **Potential Timeline for COALW**

- Weeks 1 – 3
  - Catalyst organization develops outreach plan and a list of potential stakeholders for
  - Steering Committee formation
  - Begin contacting and recruiting for Steering Committee
  - Review the steps for obtaining a program license
- Week 4
  - 1st Steering Committee meeting
  - Establish initial budget & timeline
  - Develop template of topics to be checked each meeting
- Week 6
  - 2nd Steering Committee meeting
  - Recruit and confirm facilitators
  - Choose workshop location and set tentative schedule for workshop series
  - Begin outreach and participant recruitment
- Week 8
  - 3rd Steering Committee meeting
  - Participant recruitment and outreach continues
  - Online facilitator training begins
- Week 9
  - Online facilitator training continues
  - Confirm workshop location and schedule
  - Confirm participants and identify any needed accommodations
  - Facilitators organize materials, order or print participant manuals

- Week 10
  - 4th Steering Committee meeting
  - Plan program evaluation
- Week 11
  - Workshop begins
- Week 13
  - 5th Steering Committee meeting and celebration

### **The mission and role of the steering committee**

The mission of the steering committee is to get the Living Well program implemented and evaluated in their community. To accomplish this, we suggest a series of five meetings with specific activities for each meeting. You can use the following example meeting schedule to describe and plan the activities of the steering committee.

### **Example Steering Committee Meeting Schedule**

- Meeting 1
  - Purpose:
    - Introductions/Icebreaker
    - Living Well overview & purpose of the steering committee
    - ID other stakeholders
    - Establish initial budget & timeline
    - Develop template of topics to be checked each meeting
  - Duration: 60 minutes
- Meeting 2
  - Purpose:
    - ID potential facilitators
    - Participant outreach and recruitment plan
    - Find accessible meeting place
    - Transportation plan
  - Duration: 90 minutes
- Meeting 3
  - Purpose:
    - Confirm facilitators
    - Schedule workshop
    - Confirm meeting place & transportation plan
    - Progress on participant recruitment
  - Duration: 90 minutes
- Meeting 4
  - Purpose:
    - Program evaluation
    - Follow-up
    - Other community health resources
    - Plan refreshments
  - Duration: 60 minutes
- Meeting 5

- Purpose:
  - Review implementation progress and issues
  - Next steps?
- Duration: 60 minutes

## **Putting together a steering committee**

### Disability-Specific Stakeholders

- Disability leaders—government, business, civic, political
- Disability organizations
- Community members with a disability
- Center for Independent Living staff/volunteers

### Service Providers

- Vocational Rehabilitation staff
- Medicaid Waiver case management
- Home health providers
- Counselors/mental health workers
- Hospital—medical social workers,
- rehabilitation personnel
- Outpatient clinics
- Physical and occupational therapists
- Developmental disability case managers or service providers
- Family practice/internist physicians or nurses
- Medicab/ transportation services
- Durable medical equipment suppliers
- Personal assistants
- CMT/fire department personnel

### Community Organizations (in addition to disability specific organizations)

- Senior Citizen Centers
- Houses of Worship/Clergy
- Caregiver networks
- Librarians
- Public Health
- County Health department staff
- Community Health Center staff
- Office of Public Assistance
- Indian Health
- Community health workers
- Women Infant and Children staff
- Fitness or Wellness Partners
- Fitness centers and YMCAs
- Malls (walking programs)
- Yoga, aerobics, dance, martial arts, etc.

- City/County Parks Department
- Community centers
- Ski and recreation Areas
- Aquatic parks
- Private resorts
- Industry wellness programs

#### Schools

- Special education teachers/transition staff
- Universities or colleges

Include representatives from different ethnic groups, socio-economic groups and genders. The steering committee will be most effective if it is representative of the population in your community. You and those you work with will come up with other good stakeholder ideas and every community offers its own unique possibilities. This list is just a starting place.

## **Phase II: Planning for the Workshop**

Once the steering committee has been recruited, they will meet approximately five times to plan and oversee the Living Well workshop. We have identified a variety of activities that the steering committee may address in each of these meetings and list them here with suggestions for accomplishing each one.

### **Steering Committee Meeting 1**

At the first meeting, it is important to help the committee form its purpose and mission for meeting. This includes two important parts. First, the committee must quickly learn who the members are and what they “bring to the table” for the COALW process. This can be done with brief introductions that may include an icebreaker and important information about each member. For example, you might ask each person to introduce themselves, describe any work or other activities they do and share where they were born, and one of their favorite ways to spend a day.

The second part of helping the committee “find its feet” is to provide a good overview of the Living Well program itself. You may use the information from the introduction of this manual, the program website, as well as your own ideas from your knowledge of the program and materials.

Once the introductions to each other and to the program have been made, there are a few other topics you may choose to address in the first meeting. These include identifying other stakeholders, forming the project budget, and establishing an initial timeline for program activities.

#### ***Identifying other stakeholders***

When you formed the steering committee, you looked for individuals who you thought would participate and could contribute to the COALW process. One of the first activities of the steering committee might be to identify other community members who might be interested in health promotion for people with disabilities. The steering committee might write a letter or email to them and/or might wish to contact some personally. The important outcome is that the steering committee feels everyone who should know about the program does know about the program.

#### ***Establishing an initial budget***

The plans for conducting the workshop that are developed by the steering committee will depend largely on the funds available to support the program. The committee will need to know how much money can be spent and be aware of any guidelines for using available funding. Budget categories for the committee to consider include: training and paying facilitators, purchasing the license, meeting space rental fees, transportation and refreshments. Much of the planning the steering committee does will depend on the funds available and needs of people in the community.

#### ***Establishing an initial timeline***

If time remains in the first meeting, you might try to develop an initial timeline for conducting the workshop. This might include the timing of steering committee meetings, recruiting and training of facilitators, marketing and recruiting participants and lastly a start date for the workshop itself. The timeline will help the steering committee know when activities should be accomplished and will specify the duration of their work on the steering committee.

#### ***Developing a template of topics to be checked at each meeting***

The first meeting can feel a bit chaotic as people are getting to know each other and one topic will lead to questions regarding another. Developing a template and an initial timeline relieves the pressure of feeling like everything must get done in the first meeting. In addition, checking the list of topics at each

meeting ensures that those topics will be completed. As in any organizing effort, asking for specific commitments from individual steering committee members also improves follow through.

## **Steering Committee Meeting 2**

### ***Facilitator recruitment***

Much of the success of the Living Well program is related to the qualities and abilities of the workshop facilitators. We recommend two facilitators, with at least one of the facilitators being a person with a disability or chronic health condition. We have listed some of the facilitator qualities below that you might consider when choosing people for the program.

- Enthusiastic and passionate about health and disability
- Communicates effectively and nonjudgmentally
- Organized—able to coordinate materials, schedules, special needs, etc.
- Personable and flexible

There are many ideas for recruiting facilitators. Centers for Independent Living often have peer advocates or peer mentors—people with disabilities who provide peer support to people with disabilities. Peer advocates can be strong facilitators, bringing with them their own life experiences and expertise. Facilitator training can be mutually beneficial for the peer advocate, providing training and potential income. A second model is to recruit people who are currently involved with Vocational Rehabilitation Services. Again, this model provides job experience and resume building for the new facilitator, and benefits the program by providing leadership from a person with a disability.

### ***Outreach for recruiting participants***

As plans for implementing the workshop begin to take shape, the committee can begin to consider how they will recruit individuals to participate in the workshop. It is useful to think about two avenues or pathways to outreach. We call the first passive outreach. Passive outreach includes all advertising including print, radio, television, and social media. It is passive because the outreach recipient is simply exposed to your message and then he or she must respond to it. This approach is good for reaching many people and getting the word out. For example, it is relatively inexpensive to mail letters, post flyers, or post online. The problem with passive marketing is that it may not be enough to motivate many people who would both enjoy and benefit from attending the workshop. Passive outreach fails when people don't understand the message, they don't believe it would be useful for them or simply are not ready to respond to flyers or a web post. Passive outreach typically is effective in recruiting 2% to 8% of the total number of people reached. That means, for every 200 letters mailed, four to 16 people respond.

To review, passive outreach requires people to understand the message and then respond to it. If they either misunderstand the message or misjudge the likelihood they will enjoy and benefit from the offering, it is unlikely they will participate. Hence, passive outreach is effective for only a small proportion of the people Living Well could serve.

The second avenue to outreach is called active outreach. Like passive outreach, active outreach puts the message out, however the message is followed by a telephone call, email or personal contact.

Active outreach is good for reaching those who are not ready to respond to a passive message, but with personal contact, may choose to participate. Of course, active outreach is not so good for reaching large

numbers of people because it takes time to talk with people. However, engaging a small number of people rather than lightly touching a large number may be more effective in recruiting for Living Well. Using active outreach methods, between 22% and 47% of those contacted respond (i.e. talking with 20 people generates 4 to 10 responses).

In reality, having skills for both passive and active outreach is important to the success of many human services. Even more, passive and active outreach methods work well together. First you mail out information and then you follow-up with personal contacts.

The steering committee may begin with recruiting case managers or other folks who already have a relationship with potential participants so that they can encourage participation in Living Well to people with whom they have working or personal relationships.

### ***Accessible meeting place***

A critical feature of organizing Living Well programs is locating an accessible meeting space for the sessions. Accessible generally means that people with any type of disability can get to, in, around, and out of a building. It also means that it is easy to get into, out of, and around the room you will be using for the session. Remember, the restrooms need to be accessible too!

Some buildings are more likely to be accessible than others. Under the Americans with Disabilities Act (ADA) all public and government buildings are required by law to be accessible. These might include the post office, social service offices, hospitals, public libraries, and other such facilities. Newer buildings are generally more accessible than older ones and many hotels comply with the ADA and have accessible meeting spaces. In general, you should look to see if there are: 1) designated accessible parking places, 2) curbs or other obstacles from a parking area to the building allowing wheelchair users easy access, 3) stairs into the building or to the meeting room (there should be a ramp or elevator), and 4) entry ways wide enough for a large wheelchair. Inside the building: 1) carpet should not be so thick that it presents undue resistance to a wheelchair user, 2) hallways should be wide enough to allow a wheelchair to turn completely about, 3) the meeting room should be large enough to allow those who use wheelchairs or walkers to move about easily, and similarly, 4) the bathrooms should be large enough to allow a wheelchair to enter (wide door with open swing), large enough to allow the door to close, offer grab bars for transferring, and a toilet seat that is between 17 to 19 inches from the floor.

A word of caution, it is very easy to overlook obstacles or barriers. You may want to have a friend or colleague who uses a wheelchair or other mobility device check out the facility. Another alternative is to seek advice and recommendation from an independent living center or other disability service provider. For more detailed information about accessibility standards, visit the [United States Access Board's ADA Accessibility Guidelines](#).

There are many possibilities for accessible meeting space, such as hotels, hospitals or businesses. One community found a free accessible meeting space in their Senior Center where accessible transportation was readily available, as well as affordable meals and snacks.

### ***Transportation***

There will be few problems if the location for the workshop is serviced by local accessible transportation systems, however, public transportation or transportation that is accessible may not be available in rural areas. Therefore, it may be necessary to coordinate or provide transportation to help consumers attend.

When arranging transportation, the various needs of people with disabilities must be considered. There are three general approaches to arranging transportation:

- rely on consumers to make their own transportation arrangements
- offer to arrange or provide transportation for consumers who have no clear transportation options
- provide transportation for all participants to the workshop

It is important to get workshop notices to consumers and participants in a timely manner. This gives participants adequate time to arrange their own transportation through traditional transportation systems or other transportation options, such as family, friends, ride share or Personal Assistive Services.

If participants are unable to find transportation to the workshops, the facilitator or a steering committee member may need to help them make necessary transportation arrangements. It is important to keep in mind that standardized transportation providers need adequate notice, sometimes as much as two weeks to schedule transportation for your workshop. Community organizations might also provide accessible transportation, including Centers for Independent Living, medical clinics, senior citizen centers, hotels, and faith-based organizations.

Once the date, location, and specific consumer needs have been established, potential transportation providers can be contacted to confirm availability of transportation. Finally, transportation costs need to be included as a budget item if individuals are unable to afford the cost.

### **Steering Committee Meeting 3**

#### ***Facilitator training***

The Research and Training Center at the Rural Institute offers an online, self-guided training platform for facilitators. Once the Steering Committee has reviewed and agreed to the Living Well program [license agreement](#), you may purchase a license via the [online training portal](#) and then register individuals for the self-guided facilitator training site. The license cost is \$300.

Once you have signed up for organizational access, you will receive instructions for registering individuals for the facilitator training website. Living Well trainees can access all training materials through the specialized training website. Individuals learn to facilitate the workshop material by going through the curriculum as if they were participating in a consumer workshop themselves. During the course of the training, trainees watch videos, learn facilitation tips, and complete exercises.

#### ***Workshop scheduling***

When scheduling a Living Well workshop, it is important to consider public transportation schedules and what time of day might be best for the majority of potential participants. Some people with disabilities may find it easier to attend an afternoon workshop. Others may need to attend after work hours, necessitating an evening offering. This means that identifying who will be recruited may affect the time that the workshop will be offered.

### **Steering Committee Meeting 4**

#### ***Program Evaluation***

Program evaluation is a vital component of any program. Evaluation helps determine program effectiveness in terms of stated outcomes and provides a framework for future support of the project. If

you are interested in evaluation materials, contact Meg Ann Traci, PhD, Montana Disability & Health Program, at [Meg.Traci@mso.umt.edu](mailto:Meg.Traci@mso.umt.edu) or (406) 243-4956.

### ***Other health resources in the community***

A further role that Living Well may play is connecting people with disabilities with other health resources in the community. For example, tours of local fitness facilities might be arranged. Health care providers, dieticians, counselors, or yoga instructors might be invited in to help lead a particular session, or brochures might be handed out at workshops informing participants of available health resources within their community.

### ***Planning refreshments***

Refreshments are an important part of workshop meetings. They provide an opportunity for participants to stretch and change their physical positions and to network informally with others in the workshop. If planning refreshments, the workshop facilitator or steering committee member must keep in mind the varied needs and special requirements of people with disabilities. If any participants have special dietary needs (e.g., people with diabetes), the workshop facilitator would want to consider this when ordering food, to allow alternative choices.

### ***Certificates***

Participants that go through Living Well work hard and are often proud of their achievements. A certificate of participation or a similar acknowledgement is a nice reward for all of their efforts and contributions to the group.

### ***Follow-up***

Many Living Well workshop participants may want to continue meeting after the workshop is over. Some participants continue to support one another by meeting together periodically to discuss goal progress or other activities, while others evolve into advocacy groups or more formal mutual aid organizations. Participation in Living Well also provides facilitators the opportunity to connect consumers with helpful supports or available programs.

The steering committee may also wish to continue meeting, perhaps undertaking additional tasks, such as meeting with local fitness facilities to encourage accessible equipment and class offerings.

## **Phase III: Implementing the Workshop**

### **Steering Committee Meeting 5**

#### ***Review implementation progress and issues***

This meeting may be used to confirm that all is in place and ready to roll, or may be held after the first session or two have been conducted to make sure that all is going according to plan. It is also a good time to critically reflect on process, progress, and other issues. At this point, the steering committee may decide to continue by beginning to plan a second Living Well implementation or health promotion activity.

#### ***Celebrate***

Finally, and of great importance, CELEBRATE all of your hard work! Perhaps your celebration can include a small token of appreciation for each steering committee member or someone could host a potluck or dessert. Your community has joined the hundreds of others around the nation who are working to include all community members in health and wellness activities.

Congratulations and keep up the good work!

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## **Photos**

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## **For Additional Information**

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