

# **Program Impact Report: Oregon's Living Well with Chronic Conditions**

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## Summary

This report is the result of an external impact assessment of the Stanford Chronic Disease Self-Management Program (CDSMP), referred to as *Living Well with Chronic Conditions* in Oregon. Living Well is an evidence-based chronic disease self-management program conducted in both English and Spanish (*Tomando Control de su Salud*) throughout the state of Oregon, with an HIV/AIDS-specific program (*Positive Self-Management Program*) also available. The Living Well program has demonstrated both feasibility and popularity by conducting well-received workshops throughout the state. The vast majority of these workshops have been *Living Well*, while *Tomando* and *Positive Self-Management* workshops were increasingly fielded during the past two years. Through December 2009, Living Well programs have enrolled 3,919 participants in 376 workshops, with participation growing from fewer than 100 in 2005 to over 1,300 in both 2008 and 2009.

Based on the best available estimates from scientifically rigorous CDSMP evaluations in other settings, and using Oregon Living Well data from August 2005-December 31, 2009, Living Well is predicted to have resulted in

- 107 quality adjusted life years (QALY) gained
- 557 avoided emergency department (ED) visits, saving \$634,980
- 2,783 avoided hospital days, saving \$6,501,088

In addition, Living Well is likely to have improved participant quality of life through reduced fatigue and increased physical activity, improved emotional and physical well-being, facilitated social functioning, and improved patient-clinician communication.

The goal of the Oregon Living Well program is to make Living Well accessible to all Oregonians with chronic health conditions so they may benefit from the improved health outcomes demonstrated by the original research. The program to date, though successful, has reached approximately 3,900 of 1,566,000 Oregonians living with chronic disease. If Living Well enrolled only 5% (78,300) of eligible Oregonians, its estimated five-year effects could include

- 2,138 quality adjusted life years gained
- 11,119 avoided ED visits, saving \$12,675,660
- 55,593 avoided hospital days, saving \$129,865,248

Living Well has been successful in its statewide implementation, has been well received by participants, and has likely contributed to participants' quality of life while reducing health care costs. To achieve greater impact, Living Well must:

1. identify participant recruitment approaches, workshop venues, and alternate workshop delivery media that promote access to all Oregonians;
2. find a sustainable financial model, one which fully integrates Living Well into Oregon's health reform; and
3. establish an ongoing and comprehensive evaluation.

Expansion of Living Well, as part of local efforts to promote community health and statewide health reform efforts, is likely to help achieve Oregon's goal of improving the lifelong health of Oregonians while containing system-wide costs.

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## Living Well with Chronic Conditions

The Stanford Chronic Disease Self-Management Program,<sup>1</sup> called Living Well with Chronic Conditions in Oregon (*Living Well*, and related programs including Spanish-language *Tomando Control de su Salud* and *Positive Self-Management Program* for people living with HIV/AIDS), is an evidence-based health promotion program for people living with chronic conditions. The Stanford CDSMP has been recommended to states by the Centers for Disease Control and Prevention (CDC) and the Administration on Aging (AoA). CDSMP programs are widely implemented both in the US and internationally, with translation into 17 languages.<sup>2</sup>

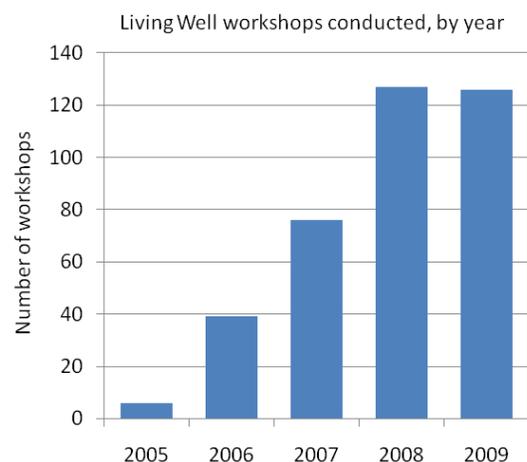
Living Well workshops are delivered in six weekly sessions of two-and-a-half hours each, primarily in community settings: senior centers, churches, libraries, Area Agencies on Aging, clinics, and hospitals. Participants meet in small groups of 10-15 people, and may have any chronic condition, or multiple conditions. Workshops are facilitated by two trained peer leaders, at least one of whom lives with a chronic medical condition. Living Well complements ongoing medical care by providing participants with the skills needed to manage their conditions, including coordination of medical care and medications. To enhance support, family members are encouraged to attend.<sup>3</sup>

Subjects covered in Living Well workshops include but are not limited to:

1. Goal setting, problem solving and action planning to achieve self-management goals
2. Techniques to deal with frustration, fatigue, pain, and depression
3. Appropriate exercise for improving strength, flexibility, and endurance
4. Appropriate use of medications
5. Communicating effectively with family, friends, and health professionals
6. Healthy eating
7. How to evaluate new treatments

### Statewide implementation

The Oregon Department of Human Services (DHS) – Public Health and Seniors and People with Disabilities Divisions have supported implementation of Living Well in Oregon using a variety of federal grant funds since 2003. DHS provides leader training, technical assistance, and participant books to local organizations that are licensed by Stanford. DHS also coordinates the Oregon Living Well Network, comprised of local program representatives around the state, oriented around workgroups that provide resources and guidance to further the Oregon Living Well Program in its goal of being accessible to all Oregonians with a chronic health



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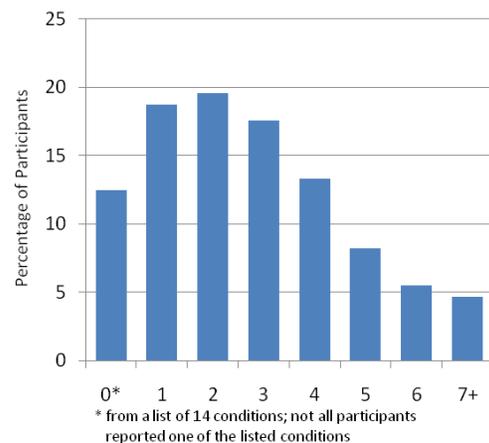
condition. Local organizations offering Living Well in Oregon include hospital systems, local health departments, faith communities, aging services providers, Oregon State University Extension services, and social service agencies.

The number of workshops per year has expanded considerably since 2005, when state-wide data collection was initiated.<sup>3</sup> To date, Living Well has conducted 376 workshops: 334 (88.8%) have been *Living Well*, 33 (8.8%) *Tomando*, and 9 (2.4%) *Positive Self-Management* (on which formal data collection began in November 2008). Workshops have been geographically dispersed, having been conducted in 27 of Oregon's 36 counties. There is substantial variation in the number conducted by county, however, with ten counties conducting 10 or more workshops since 2005, and 14 counties conducting five or fewer.

A total of 3,919 participants enrolled in the workshops during 2005-2009, and program effect estimates are based on these participants. Of the 3,919 participants, 3,916 provided individual level data: 3,571 chronic disease participants and 345 support people, most with chronic diseases of their own. Workshop size averaged 10.4 participants, and average participant age was 62 years. Living Well is one of few evidence-based approaches to self-management which is not disease-specific, and is therefore not only efficient to administer, but is uniquely suited to people with multiple conditions. The average number of chronic conditions was 2.7, with approximately 20% reporting four or more chronic health conditions, suggesting that Living Well is attracting an appropriate audience for chronic disease self-management.

The workshops have attracted participants from diverse groups, including 437 participants of Hispanic background (11.2% of participants), roughly the same rate as their representation in the Oregon population, and 118 Native Americans (3.0%), roughly twice the rate as their representation in Oregon. African Americans, however, were underrepresented at 1.3% of participants. Three-fourths of participants (76%) were women. During 2005-2009, approximately 71% of participants who signed up for Living Well completed four or more of the six sessions.

Number of chronic diseases among Living Well participants



Though a statewide participant post-intervention satisfaction survey has not been conducted, most organizations collect some type of feedback from participants completing workshops. The Living Well program in Jackson and Josephine counties has conducted several post-intervention participant surveys in which participants were asked to describe how they were using the skills they learned in workshops, and their self-confidence in managing their chronic conditions.

“I am able to tackle and accomplish projects I thought were undoable!”  
- Living Well Participant

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While those surveyed may not have been entirely representative, they were nearly unanimous in their positive evaluations. Participants valued learning action planning and problem solving skills and reported greater confidence in their ability to manage their conditions. Of 49 participants responding to the survey, 20 (41%) reported that “action planning”—making concrete plans to manage chronic conditions—was the most useful activity they learned, while 38 (78%) said their confidence in managing their condition had increased, versus only 2 (4%) who reported their confidence had not increased. Many reported that their physicians had either referred them or were enthusiastic about their participation. One-fifth of Living Well participants reported hearing about the program from a clinician or in a clinical setting,<sup>3</sup> and 22 of 49 survey participants (45%) reported that they had discussed Living Well with their physicians. Improved patient-clinician communication may in turn improve both quality of care and patient satisfaction.

“[My doctor] had heard about the program and recommended I attend”  
- Living Well Participant

Although the workshop content, leadership, and execution are standardized, Living Well has been implemented across Oregon with variations in time of day, locations, and funding models. The Oregon Living Well program estimated a per participant cost of \$375, based on a 2009 statewide cost survey of Living Well programs. These costs are currently supported in a variety of ways by local organizations, including a mix of grant funding, in kind support, and organizational support. While most workshops have been supported by external funding, 68 workshops (18.1%) required participants to pay an average of \$25, with 25% of those charging \$10 or less, and 20% charging \$40 or more. In some workshops, these fees were paid by participants’ health plans, while in others they were borne out-of-pocket. The vast majority of these workshops (62 of 68 which required payment, 91.1%) were English language programs, and concentrated in five counties (59 of 68, 86.8%).

### **Living Well Impact to Date**

Grants from the CDC and AoA have supported statewide training and technical assistance to implement Living Well with fidelity to the CDSMP model, but have not provided support for comprehensive evaluation. Several well-done evaluations of CDSMP in other participant populations allow estimation of the likely impact of Oregon’s Living Well to date. Most evaluations of CDSMP have reported short-term effects (6-12 months), and studies reported so far have not been large enough to estimate changes in healthcare utilization with high levels of precision. Previous studies have consistently shown improvements among CDSMP participants in health related quality of life and well being: improvements in subjective health status, greater vitality and reduced fatigue, fewer role limitations, improved psychological well-being, increased physical activity, and improved ability to manage chronic conditions (greater disease-specific self-efficacy and improved communication with physicians).<sup>4</sup> Findings for healthcare utilization have not been as consistent, partly due to the manner in which healthcare utilization results have been reported,

The program adopted by Living Well has strong evidence for improving quality of life, and moderate evidence for healthcare cost savings.

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and partly due to the substantial variability typically seen in healthcare utilization. Studies to date have not followed participants in sufficient number or duration to determine utilization effects beyond two years.

We estimated the impact of Living Well by applying findings from similar settings and populations to the participants who have successfully completed Oregon Living Well workshops (i.e. the 71% who attended at least 4 of 6 sessions) during 2005-2009. Since there have been no truly long term studies of Living Well, we assumed that the effects of the program did not last longer than the longest study done to date—2 years.<sup>5,6</sup> As longer-term outcomes studies are reported from a wider range of locations, revised impact estimates may well paint a somewhat different picture of Living Well effects. (An appendix to this report describes the studies relied upon and details the methodology used to generate the estimates which follow.)

*Quality of life, health and functional status, disability, and confidence*

It is very likely that Living Well has resulted in quality of life improvements for Oregonians. Studies on individual outcomes as a result of participating in Living Well consistently show improvement in both physical and emotional well-being.<sup>4</sup> On average, Oregonians in Living Well can expect one additional week of “perfect” health per year more than they might have had without the program (i.e. the time *equivalent* to one week of disease- and limitation-free life, though by definition Living Well participants have one or more chronic diseases at the start of their participation).<sup>7</sup> If Living Well costs \$375 per participant, the estimated cost for all 3,919 participants is \$1,468,500, for a gain of 5,566 weeks (107 years) of “perfect” health, or \$13,734 per year gained. This figure is substantially more cost effective than other approaches to chronic care management, such as telephone disease management support with nurse care management, which can cost \$30,000 per year gained.<sup>8</sup>

Living Well is also likely to have had important effects on physical and social functioning. Some of the most consistent results from CDSMP evaluations are that participants have increased vigor and energy, improved self-confidence around disease self-management, lower health distress, improved social role functioning, and improved psychological well-being.<sup>4</sup> For an older participant, Living Well may allow continued independent living. As one participant said, “I’m still walking. I can’t do too much, but I am still trying.” For younger participants, Living Well may allow them to take control of their own care, and relieve some burden from informal caregivers. One participant said, “I go to the doctor and don’t rely on my parents. I’m eating better and making better choices.” When asked on a 0-10 scale about their ability to control their chronic conditions several months after going through Living Well workshops, 38 of 42 participants (90%) responding to a survey rated their ability a “7” or better, and only 2 rated themselves at “5” or lower.

“[I] always wanted to do a running race and the [Living Well program] sparked my confidence. I’ve run 2 races. I will run the “Aloha 8 mile Run” even if I have to walk.”  
- Living Well Participant

Other evaluations of CDSMP have reported reductions or slowing of disability, fewer social and physical limitations, and improvements in mobility<sup>4</sup>—suggesting that Living Well is highly likely to be improving Oregonians’ ability to live independently, be engaged in their social and community lives, and avoiding placements in care facilities. Unfortunately, none of the metrics used in the studies to date can be mapped onto well-documented predictors of primary (i.e. not following hospitalization) nursing home placement, so it is impossible to estimate the effect of improved functional status on this important personal and healthcare utilization outcome.

*Healthcare utilization and costs*

Healthcare utilization, particularly for acute care, is very likely to be reduced in Living Well participants who complete at least four of the six workshop sessions. The best estimates, from patient populations in the west coast of the United States demographically similar to Oregon Living Well participants, suggests that participants, on average, reduced emergency department visits from 0.8 to 0.7 visits per year, hospitalizations from 0.4 to 0.3 visits per year, and hospital days from 2.4 to 1.9 days per year.<sup>5</sup> For the participants who have completed Living Well to date, this translates to 557 fewer emergency department (ED) visits, 557 fewer hospitalizations, and 2,783 fewer hospital days. In 2007, the average cost of hospitalization in Oregon was \$2,336 per day.<sup>9</sup> Thus, Living Well is estimated to have saved Oregon health plans and Oregonians \$6,501,088 in hospital costs. Similarly, the average cost in 2007 for an ED visit in the western US was \$1,140,<sup>10</sup> yielding an estimated savings of \$634,980 in ED costs among Living Well participants. If program costs are \$1,469,625 (based on \$375 per participant), Living Well is estimated to have saved a net of \$5,666,443, or \$1,446 per participant.

<b>Estimated Impact of Living Well in Participants to Date</b>		
<b>Living Well impact on</b>	<b>Estimated impact</b>	
Quality adjusted life years	107 years gained	
Healthcare utilization		Costs avoided
Emergency department visits	557 avoided ED visits	\$634,980
Hospitalizations	557 avoided hospitalizations	
Hospital days	2,783 avoided hospital days	\$6,501,088

While older individuals generally use healthcare more frequently and incur more healthcare costs, a substantial proportion of chronic conditions and associated healthcare occurs in patients under 65 years of age. Among Living Well participants to date, 57.3% were under 65. This means that the estimated healthcare utilization savings likely benefit both public and private payors in Oregon, as well as federal programs.

**Potential Living Well Impact**

Through 2009, approximately 3,900 Oregonians have participated in Living Well workshops—roughly 0.3% of the 1,566,000 Oregonians living with chronic disease. If Living

Well enrolled even 5% of eligible Oregonians—78,300 participants— over the next five years as part of comprehensive health reform, its estimated effects would be impressive.

At a cost of \$375 per participant, Living Well would cost an estimated \$29,362,500 for five years, or approximately \$5,872,500 per year. However, these costs would be more than offset by savings in healthcare utilization, averaging \$1,445 per participant.

For this investment in Living Well, participants would gain an additional 2,138 years of “perfect” health, at a cost of \$13,733.63 per quality adjusted life year. At the same time, they would avoid an estimated 11,119 emergency department visits, 11,119 hospital admissions, and 55,593 hospital days. In addition to the healthcare costs avoided, this represents a substantial savings to participants in terms of lost income, both from co-insurance/co-pays and from lost days of work.

It is very likely that participants will experience improvements or prevent further disability, and improvements in physical and mental health described in the previous section; also, the avoidance of hospitalizations and nursing facility stays represents a substantial improvement in quality of life for participants. In turn, these improvements in patient-centered outcomes will have direct but difficult-to-quantify influences on community health and productivity. Finally, Living Well represents a community level resource, and has benefits for local hospitals, clinics, public health departments, and service organizations, which can refer patients and clients to Living Well programs.

Aside from any potential cost savings, Living Well is very likely to improve participants’ quality of life and well-being.

Potential Impact of Enrolling 5% (78,300) of Eligible Oregonians		
Living Well impact on	Estimated impact	
Quality adjusted life years	2,138 years gained	
Healthcare utilization		Costs avoided
Emergency department visits	11,119 avoided ED visits	\$12,675,660
Hospitalizations	11,119 avoided hospitalizations	
Hospital days	55,593 avoided hospital days	\$129,865,248

### Limitations of the Impact Estimates

Though several well-conducted studies have provided the results which underpin this impact report, they are limited in several ways:

1. Most CDSMP follow-up studies have lasted no more than one year, and only one has followed participants for two or more years. Because benefits in the first two years have been reported, we assumed no benefit for participants after two years. It is not yet possible to estimate the longer-term effects of the chronic disease self-management program; however, if the effect of the program extends beyond two years, the cost savings will be *greater* than that estimated for this report. Studies to

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date have not examined the crucial question of avoiding long-term care placement or nursing facility use.

2. There are relatively few findings from Oregon’s experience or from experiences in other locations about effectiveness of the chronic disease self-management program in minority populations. The Living Well programs have attracted Hispanic participants, and there are indications that the Tomando program yields short-term benefits.<sup>11</sup> The program has not been extensively studied in other traditionally underserved US minority populations, however, and an initial study in an African-American population has found no influence of the program on utilization.<sup>12</sup>
3. The studies used to provide estimates for this report were conducted in “real world” research settings; while they remain the best source for estimates of effect, they may not necessarily reflect the experience of Oregon or other states when implementing the program in non-research settings. In the future, findings combining results from several studies in community settings may provide better estimates of what can be expected in practice; results of thorough evaluation of Oregon’s Living Well outcomes would be the most informative for statewide policy decisions.

## **Recommendations**

Program reach. While the current Living Well program has been successful, it is not without limitations. Most chronic disease self-management programs have difficulty reaching minority populations effectively, and while Living Well appears to have been successful in large measure, greater efforts to recruit and retain participants currently under-represented in Living Well (e.g. African Americans, men) should be implemented. Living Well must reach and retain members of traditionally underserved groups in Oregon, and evaluate the effectiveness of the program in those groups.

While the program has been offered in nearly all Oregon counties, it is not offered with sufficient frequency to be accessible to the majority of Oregonians with chronic diseases. Only 10 counties have offered any version of Living Well more than 10 times since 2005. To reach enough Oregonians to have public health impact, substantially more workshops must be offered. Since Living Well is conducted face-to-face in group settings, it must be offered in geographically diverse sites even within counties—particularly in rural counties. Workshops must also be offered at varying times of day, in order to reach the widest possible audience. Oregon’s population density is roughly half that of the US as a whole, with the vast majority of counties without any metropolitan areas. Therefore, alternatives to “traditional” (in-person, small group) Living Well workshops will also be required to reach all Oregonians. As evidence from online and other distance versions of the chronic disease self-management program become available, they should be demonstrated in Oregon and, if successful, adopted as statewide alternatives for participants unable to travel to a “traditional” on-site workshop.

Similarly, retention of participants, once recruited, is crucial to achieving both individual and public health impact. While 71% retention is comparable or superior to rates in many similar programs,<sup>13</sup> it nonetheless represents a missed opportunity. In the future,

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Living Well staff should attempt to identify predictors of program drop-out, and consider modifications to the program to enhance retention.

Sustainability and integration. If Living Well is to be maintained, and even expanded, a sustainable business model must be developed, which balances needed program resources with achieving the widest possible access to chronic disease self-management programs. The current focus on population health and health reform at the federal and state levels offers an opportunity to build just such a model for support of comprehensive disease management, including chronic disease self-management.

Achieving substantially greater coverage for Living Well will necessitate commensurately greater resources, which evidence to date suggests will be recouped through decreased healthcare utilization. If Living Well is to be fully integrated into health care reform, specifically into the Chronic Care Model<sup>14,15</sup> and “medical home” concepts central to effective chronic disease control, Living Well must be accepted and actively promoted by clinicians, and patients and clinicians must discuss the goals of the program in the context of ongoing medical management. As part of medical management, Living Well can complement effective medical and pharmaceutical approaches to care. In such a setting, it may be possible that costs associated with Living Well can be weighed against healthcare utilization savings, justifying clinician and staff effort involved in referring patients to Living Well workshops, as well as community organizations’ efforts to ensure availability of community-based workshops for people with chronic conditions.

Evaluation. Living Well staff in both local organizations and at the state level have done an admirable job of collecting implementation data. Living Well participants report leaving the program confident of their improved ability to manage their conditions. The program on which Living Well is based has been extensively evaluated in other settings—the results of the best evaluations were used to generate the estimates in this report. However, there is no substitute for directly measuring the health and healthcare outcomes of the program with Oregon participants. As Living Well is incorporated into Oregon’s health reform agenda, an ongoing, comprehensive evaluation program should be put in place to determine whether Living Well is the best alternative for chronic disease self-management. Such an evaluation should assess important outcomes described in this report (e.g. quality of life, hospital days) as well as outcomes not yet evaluated in other settings (e.g. nursing home placements), and should also evaluate the extent to which Living Well is successfully integrated into patients’ primary care medical homes.

Living Well is the best documented currently available opportunity to achieve the disease self-management goals crucial to comprehensive chronic disease control. In Oregon, disease control is embodied in the “medical home” concept at the center of state health reform efforts, in public health’s efforts to prevent and manage chronic conditions of the population, and in aging and social services’ efforts to maintain the health and independence of clients they serve. If *Living Well with Chronic Conditions* is fully integrated into Oregon’s health and healthcare reform, it will help achieve the goals of improving lifelong health of all Oregonians and promoting more appropriate healthcare utilization.

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