

# **Educating Adults about Chronic Disease Self-Management**

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## Executive Summary

Chronic conditions, such as arthritis, diabetes, and heart, lung, or brain diseases, are a part of most Americans' lives. Older adults and women are most likely to report chronic conditions. In 2010, over half of the non-institutionalized U.S. population had at least one chronic condition, with about one-third of this U.S. population having two or more. When examining data by gender, 35 percent of women and 28 percent of men had at least one condition. About half of people age 45-64, and 80 percent of those age 65 and over have multiple chronic conditions. About 80 percent of Medicare beneficiaries have multiple chronic conditions.

While people with chronic conditions or their caregivers can rely on health care providers for advice, prescriptions, and medical services, the ability to "self-manage" their day-to-day lives and the disease with which they live is very important. Self-management requires knowing about one's conditions, managing appointments with multiple doctors and other health care providers, following sometimes competing treatment recommendations, and making recommended and, often difficult, lifestyle changes.

Valuable programs, which have been demonstrated to be effective through rigorous research, are available to educate people about self-management. Several reviews of research since the 1990s show that self-management education programs of various forms can be effective in helping people with chronic conditions manage their symptoms and engage in healthy behaviors. The results of self-management programs led by peer leaders are as successful as those led by health professionals.

The most prominent peer-led program is the Chronic Disease Self-Management Program (CDSMP), an evidence-based program originally developed at Stanford University in the 1990s. It trains peer leaders to educate people with chronic conditions about how to manage their chronic conditions and improve their health behaviors. Comprehensive reviews of research on the Stanford-developed CDSMP show significant improvements for participants. For example, the Centers for Disease Control and Prevention (CDC) staff analyzed the impact of CDSMP on participants. Their quantitative analysis showed that aerobic exercise, cognitive symptom management, and communication with physician improved at four to six months after baseline. Exercise and cognitive symptom management gains remained significant at nine to 12 months. Stretching and strengthening improved significantly at nine to 12 months. All measures of psychological health were significantly better at four to six months and nine to 12 months. Energy, fatigue, and self-rated health showed significant improvement at four to six months. The significant change in health care use was a small reduction in the hospital use at four to six months.

Given the success of the CDSMP and its adaptations for various groups, the U.S. Administration on Aging (AoA), which is part of the U.S. Administration for Community Living (ACL), has supported this and other health promotion programs since 2003. In 2010, the American Recovery and Reinvestment Act of 2009 enabled ACL/AoA to fund implementation of CDSMP and the Diabetes Self-Management Program (DSMP), among other programs, in 45 states, the District of Columbia, and Puerto Rico. Also part of this expansion was a national process evaluation. Consistent with CDSMP research results, nationwide implementation resulted in similar outcomes for program participants.

Researchers studied whether there were potential cost savings associated with the CDSMP and found that there were due to projected reductions in health care use. The authors found significant reductions in emergency department visits at six months and 12 months, as well as a reduction in hospital use at six months. These results were similar to other studies of health care use among CDSMP participants.

Decades of rigorous research support the effectiveness of peer-led, self-management programs, including the CDSMP, and a national study validated the successful translation of the CDSMP from controlled research settings to community settings across the country. Additionally, research indicates that cost-savings are associated with CDSMP, resulting from decreased emergency department visits and hospital use. Collectively, ACL's grantee network and their partners have reached more than 300,000 participants through the Stanford-developed CDSMPs. While this is an important advance, more needs to be done to sustain these programs and achieve a major population health impact. ACL has several resources available to help states and community-based organizations create and sustain CDSMPs.

# **Educating Adults about Chronic Disease Self-Management**

## **1. Introduction**

Chronic conditions, such as arthritis, diabetes, and heart, lung, or brain diseases, are a part of most Americans' lives. People of all ages may have one or more of these conditions, or may acquire them in the future. Others may provide care for someone who has a condition. Both groups – people with chronic conditions and their caregivers – live with and adapt to the presence of these diseases. The two groups often must manage lifestyle changes, medications, appointments with health care providers, and, sometimes, emergency department and hospital use. They also may contend with the loss of ability to do daily activities, ranging from eating, bathing, or dressing to leisure activities that they enjoy.

While people with chronic conditions or their caregivers can rely on health care providers for advice, prescriptions, and medical services, the ability to “self-manage” their day-to-day lives and the disease with which they live is very important. Self-management requires knowing about one's conditions, managing appointments with multiple doctors and other health care providers, following sometimes competing treatment recommendations, and making recommended and, often difficult, lifestyle changes.

Valuable programs, which have been demonstrated to be effective through rigorous research, are available to educate people about self-management. Across the nation, state and local aging, public health, and health care organizations have worked together to increase access to chronic disease self-management education programs. Independent researchers have studied the impact of this community-based implementation and found that the results for participants are consistent with those of the original research trials.

This issue brief documents the presence of chronic conditions in the U.S. population, discusses self-management programs generally, and then focuses on those programs that rely on peer leaders who educate small groups about chronic disease self-management. Next, the issue brief describes the research underpinning the successful testing, implementation, and scaling-up of this program in the U.S. Finally, the issue brief offers options for states and localities to consider related to implementing and sustaining chronic disease self-management programs.

## **2. Chronic Conditions among the Non-Institutionalized Population**

A large proportion of Americans has at least one chronic condition<sup>1</sup> and that proportion increases dramatically with age. In addition, the prevalence of chronic conditions is growing over time. Chronic conditions have a major impact on people and their families. Coping with these conditions can require a great deal of effort, as people are often prescribed many medications and see many different doctors and other health care providers. Some chronic conditions, such as arthritis and respiratory difficulties, can force people to limit their activities. As a result, family and friends may end up helping those with chronic conditions remain independent in the community.

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<sup>1</sup> A chronic condition lasts 12 months or longer and results in the need for ongoing medical care or some type of limitation in a person's function.

Older adults and women are most likely to report chronic conditions (Gerteis et al., 2014). In 2010, over half of the U.S. population had at least one chronic condition, with about one-third of the U.S. population having two or more. When examining data by gender, 35 percent of women and 28 percent of men had at least one condition. About half of people age 45-64, and 80 percent of those age 65 and over have multiple chronic conditions. The top five chronic conditions for people of all ages, in order of prevalence, are high blood pressure, high cholesterol, allergies and upper respiratory conditions, arthritis, and mood disorders. About 80 percent of Medicare beneficiaries have multiple chronic conditions.

Chronic conditions can be expensive for society and for the people who have them. Seventy-one percent of health care spending is for people with multiple chronic conditions, with 35 percent of total spending being for those with five or more conditions (Gerteis et al., 2014). Out-of-pocket expenses for people with chronic conditions are high, too. They range from \$216 a year for people of all ages with no chronic conditions to \$1,622 for those with five or more.

Unfortunately, the prevalence of chronic conditions is rising over time. Between 2006 and 2010, the percentage of people with at least one chronic condition rose two percentage points. During the same period, the percentage of people with multiple chronic conditions increased four percentage points.

Educating adults about their chronic conditions and how to better manage them is important because of the physical, emotional, and financial strain on the individual, their family and friends, as well as the financial impact on our health care system.

### **3. Self-Management Education Programs**

Self-management is a person's ability to manage the symptoms, treatment, and physical and emotional aspects of their chronic condition as well as the lifestyle changes that are a part of living with the condition. Effective self-management involves monitoring one's condition and adjusting physical and emotional responses to it so that the person experiences optimal quality of life.

Several reviews of research since the 1990s show that self-management education programs of various forms can be effective in helping people with chronic conditions manage their symptoms and engage in healthy behaviors. Self-management programs may address medication and symptom management, lifestyle, communication, or social support (Barlow, 2002). Educators may be health professionals or peer leaders. Education can occur individually, in groups, or in combination. Program sites include community locations such as senior centers and libraries, as well as clinical settings. Positive results for participants do not vary by educator type, or by group or individual education intervention. A 2005 review (Chodosh et al.) found that chronic disease self-management education programs can have clinically significant impacts on program participants. The authors synthesized studies from the 1980s through the early 2000s. Programs had beneficial effects on certain outcomes, including blood glucose control and blood pressure reduction for programs serving people with diabetes and hypertension. Pain and function for people with arthritis improved somewhat, but the improvements were not clinically significant. The studies in both reviews included many forms of self-management education and most were randomized-controlled trials or trials that had control conditions. Another, more recent review found that participants experience less symptom distress and greater awareness of their own

health, as well as improved self-management strategies, peer support, learning, and hope (Stenberg et al., 2016).

#### **4. Group, Peer-Led, Self-Management Programs**

As noted above, the results of self-management programs led by peer leaders are as successful as those led by health professionals. Meta-analyses that focus on peer-led programs found positive results too. For example, a meta-analysis of 17 randomized-controlled trials with 7,442 participants in peer-led, self-management programs found that pain, disability, depression, and fatigue decreased (Foster et al., 2007). Self-reported health status improved, along with health behaviors, cognitive symptom management, and self-efficacy. A review of peer-led self-management programs for participants with arthritis showed marginal improvements in depression, disability, and pain. However, improvements in self-efficacy were larger (Nolte et al., 2013). Both of these analyses included many studies of a specific set of programs developed at Stanford University.

The most prominent peer-led program is the Chronic Disease Self-Management Program (CDSMP), an evidence-based program originally developed at Stanford University in the 1990s. It trains peer leaders to educate people with chronic conditions about how to manage their chronic conditions and improve their health behaviors (Ahn et al, 2015). This program involves two peer leaders teaching classes for 8-12 participants using a standard curriculum. The curriculum covers coping skills and symptom control. Coping strategies include action planning and feedback, problem-solving techniques, and decision-making. Symptom management techniques include relaxation, healthy eating, sleep and fatigue monitoring, medication management, exercise, and improved communication with providers.

CDSMP is an interactive program that engages participants for six weekly sessions for two and a half hours per session. This program is one of the most popular self-management programs in the U.S. and is ideal for the Aging and Public Health Networks to implement because peer leaders facilitate the classes, training is widely available, and it has demonstrated positive outcomes among middle-aged and older adults. In addition to the standard CDSMP, there are also disease-specific variations available in both English and Spanish for diabetes, chronic pain, cancer, and HIV/AIDs. The intervention has also been adapted for caregivers. Online versions are available for some programs, as well as a mailed toolkit.

#### **5. Evidence on CDSMP Results**

Comprehensive reviews of research on the Stanford-developed CDSMP show significant improvements for participants. For example:

- Centers for Disease Control and Prevention (CDC) staff conducted a meta-analysis of the impact of CDSMP on participants (Brady et al., 2013). They included articles from 1999 through 2009. Their quantitative analysis showed that aerobic exercise, cognitive symptom management, and communication with physician improved at four to six months after baseline. Exercise and cognitive symptom management gains remained significant at nine to 12 months. Stretching and strengthening improved significantly at nine to 12 months. All measures of psychological health were significantly better at four to six months and nine to 12 months. Energy, fatigue, and self-rated health showed significant improvement at four to six months only. The only

significant change in health care use was a small reduction in the hospital use at four to six months.

- A Health Ontario peer-reviewed report on nine randomized-controlled CDSMP trials between 2000 and 2012 found improvement for participants related to pain, disability, fatigue, depression, health distress, self-rated health, and health-related quality of life over six months (Franek et al., 2013). Healthy behavior outcomes improved related to aerobic exercise, cognitive symptom management, and communication with health care professionals. Self-efficacy also improved.

Many of these CDSMP results rely on self-reported data, so researchers compared this type of data to Medicare administrative claims data (Jiang et al., 2015). The data came from Medicare beneficiaries who were part of the [National Study of the Chronic Disease Self-Management Program](#). Self-report and Medicare claims data largely agreed for health services use among people with diabetes and chronic obstructive pulmonary disease, cancer, and heart disease. There was substantial agreement between the two data sources for number of hospitalizations and use of emergency departments. Agreement was low for number of physician visits.

## 6. CDSMP Adaptations

Given the long-term success of peer-led, chronic disease self-management programs, a number of adaptations have been developed, in which participants experience positive outcomes akin to those in the earlier programs. The program has been adapted for frail older adults, cancer survivors, people with mental health conditions, and for rural populations who used telehealth mechanisms for teaching and attending classes.

- **Frail older adults.** The authors conducted a randomized-controlled trial of the CDSMP with frail older adults who attended an adult day service center (Jonker et al., 2015). Six months after the trial, participants experienced a stable valuation of their lives while that measure decreased in the control group. Participants with low education levels experienced significant improvements to their sense of mastery. Dropout rates for this group were low despite the participants' frailty.
- **Cancer survivors.** One study examined outcomes for cancer survivors who participated in standard CDSMP during the previously referenced National Study (Salvatore et al., 2014). These participants experienced improvements in general health, depression, and sleep at six and 12 months. At 12 months, communication with physicians, medication compliance, pain, days in poor physical health, days in poor mental health, and days kept from usual activities and physical activity also improved. A second study examined an adaptation of the CDSMP – *Cancer: Thriving and Surviving*. Participants in this study experienced positive outcomes in a randomized-controlled trial. They experienced improvements over six months in communication with providers, depression, energy, sleep, and stress (Risendal et al., 2015).
- **Mental health conditions.** The Health and Recovery Program (HARP) for people with mental health conditions showed beneficial effects in a randomized-controlled trial (Druss et al., 2010). At six months, participants showed improvements in patient activation, having at least one primary care visit, physical quality of life, physical activity, and taking medications appropriately compared to people in usual care. HARP appeared to have more benefits for those with medical and social disadvantages. In a separate study of the standard CDSMP for participants with serious mental illness, researchers found the program improved fatigue, quality of life, sleep, depression, health distress, and days of bad health, medical adherence, and communication with doctors (Lorig et al., 2014).

- **Telehealth.** Two Northern Ontario telehealth versions of CDSMP for rural areas found improvements at four months for participants related to self-efficacy, exercise, cognitive symptom management, communication with physicians, role function, psychological well-being, energy, health distress, and self-rated health (Jaglal et al., 2013). Also, 70 percent of participants completed at least four sessions, a rate similar that of in-person classes. A second telehealth study in South Australia found improvements in a convenience sample of participants at six months for four health status measures, six health behaviors, self-efficacy, and visits to emergency departments. At 12 months, most improvements remained significant (Lorig et al., 2012).

## **7. Participant Outcomes in the Nationwide Implementation of CDSMP**

Given the success of the CDSMP and its variants, the U.S. Administration on Aging (AoA), which is part of the U.S. Administration for Community Living (ACL), has supported this and other health promotion programs since 2003. In 2010, the American Recovery and Reinvestment Act of 2009 enabled ACL/AoA to fund implementation of CDSMP and the Diabetes Self-Management Program (DSMP), among other programs, in 45 states, the District of Columbia, and Puerto Rico through the Communities Putting Prevention to Work Initiative. Also part of this expansion was a national process evaluation.

Consistent with CDSMP research results, nationwide implementation resulted in similar outcomes for program participants. Numerous studies document this result.

- Using self-report data, researchers compared baseline scores for 1,170 program participants to their scores at six and 12 months (Ory et al., 2013). Participants experienced improvements in self-reported health, pain, fatigue, depression, communication with physician, medication compliance, and reductions in emergency room visits and hospitalizations. Similar results occurred at 12 months, with the exception of reductions in hospital use (Ory et al., 2014).
- Researchers compared results for middle-aged versus older participants at baseline and a 12 month follow-up while controlling for socio-demographic factors and the number of chronic conditions (Ory et al., 2014). All primary outcomes, including participation in activities, limitations, depression, and communication with doctors improved in both populations. Both groups' illness symptoms improved, such as fatigue and pain. Only participants who were middle-aged realized improved quality of life and reduced unhealthy mental health days. The outcomes' effect sizes generally were larger among the middle-aged population, who were more likely to have started out in poorer health and to be minorities.
- Nationwide implementation of CDSMP occurred in Canada, as well the U.S. Researchers examined changes in depression levels among participants in small group (U.S.) and internet (Canada) CDSMP (Ritter et al., 2014). They found that participants experienced less depression at 12 months after baseline and that depressed and non-depressed participants experienced improvements in pain, fatigue, activity limitations, and medication adherence.

## **8. Hospital Use and Potential Cost Savings**

Researchers studied whether there were potential cost-savings associated with the CDSMP and found that there were due to projected reductions in health care use. The authors collected self-report data from 1,170 community-dwelling CDSMP participants at baseline, six months, and 12 months from 22 organizations in 17 states (Ahn et al, 2013). They found significant reductions in emergency department visits (five percent) at six months and 12 months, as well as a three percent

reduction in hospital use at six months. These results were similar to other studies of health care use among CDSMP participants. The authors estimated potential cost savings using data from the 2010 Medical Expenditure Panel Survey by calculating savings from lower health care use and subtracting estimated participant program costs. They found that a potential net savings of \$364 per participant would result in a national savings of \$3.3 billion if five percent of adults with one or more chronic conditions participated in CDSMP.

The same researchers created a cost estimator tool for implementing CDSMP using data from the 2010-2012 National Study of CDSMP, the 2010 Medical Expenditures Panel Survey, and the 2010 U.S. Census (Ahn et al, 2015). Sites can input their data into the [tool](#) and project cost savings over time as a way of marketing their programs to health plans and providers. The tool has a complete set of step-by-step instructions for entering site-specific data and receiving tailored estimates of cost savings.

## 9. Implementation Factors

During the CDSMP nationwide implementation, most participants attended workshops at senior centers or area agencies on aging, followed by health care organizations (Smith et al., 2014). The average workshop had about 13 participants. After reaching the first 25,000 participants, serving additional groups of 25,000 took shorter periods of time and more people in zip codes with higher poverty levels participated.

As a result of the nationwide implementation of CDSMP, researchers were able to study who was most likely to attend and complete the program, as well as factors that affected these outcomes. CDSMP programs served a higher proportion of minorities than exist in the general U.S. population and these minorities were more likely to complete the program than their White counterparts. Disease mattered in that those with diabetes were more likely to complete the program than those with depression. Introductory classes led to more completion of the program. Location mattered too; rural areas and Aging Network sites experienced the highest completion rates. For example:

- ACL/AoA grantees successfully engaged ethnic and minority populations during the national roll out of CDSMP. Researchers found that CDSMPs disproportionately serve minorities (Korda et al., 2013 and Towne et al., 2014). At the time of the study, grantees served 89,861 participants. Fifty-six percent were White, 17 percent African American, five percent were multi-racial, and three percent were Asian Americans, whereas roughly 80 percent of the U.S. population is White (Korda et al., 2013). Not only were minorities more likely to participate in CDSMP, they were more likely to complete it too. Erdem and Korda (2014) found that those most likely to complete CDSMP were women, Native Hawaiian/Pacific Islanders, African Americans, and Asian Americans.
- Those who had an introductory class explaining CDSMP and expectations (i.e., Session 0) were more likely to complete the program (Smith et al., 2017).
- The age group most likely to complete CDSMP and DSMP were those age 65 to 74 years (Smith et al., 2017).
- Completion rates were highest among faith-based organizations for CDSMP and area agencies on aging for DSMP. Participants living in rural areas had better attendance at CDSMP and its variants.

The CDC analyzed whether any particular program implementation factors had an impact on CDSMP participant outcomes (Brady et al., 2016). The authors found that, generally,

implementation factors did not have a strong impact on participant outcomes. In addition, payment of participants and peer leaders did not affect outcomes.

## **10. Conclusions and Efforts to Sustain CDSMP and Related Programs**

Decades of rigorous research support the effectiveness of peer-led, self-management programs, including the CDSMP, and a national study validated the successful translation of the CDSMP from controlled research settings to community settings across the country. Additionally, research indicates that cost-savings are associated with CDSMP, resulting from decreased emergency department visits and hospital use. Collectively, ACL's grantee network and their partners have reached more than 300,000 participants through the Stanford-developed CDSMPs. While this is an important advance, more needs to be done to sustain these programs and achieve a major population health impact.

Funding for ACL's Chronic Disease Self-Management Education initiative comes from the Prevention and Public Health Fund. In fiscal year 2017, ACL supported state and local, organizations via competitive grants which have two primary goals: (1) to significantly increase the number of older adults and adults with disabilities in underserved populations and areas who participate in evidence-based self-management education programs; and (2) to implement innovative funding arrangements to sustain these programs during and beyond the grant period.

ACL's Business Acumen Initiative supports the second goal of program sustainability. This Initiative, which involves collaboration with private foundations and other national partners, helps states and community-based organizations market their services, ensure funding for services, and achieve quality goals and cost savings. Evidence-based programs, including CDSMP, are a popular service package that states and community-based organizations can offer health care payers.

Specific to CDSMP, the ACL-funded [National Chronic Disease Self-Management Education Resource Center](#) supports the business acumen of organizations implementing CDSMP and other self-management programs throughout the country. In addition to technical assistance, the Resource Center also operates two learning collaboratives focused on Medicare reimbursement and network development. The 2017 cohort of the [Medicare Reimbursement Learning Collaborative](#) includes 10 organizations that are working to achieve Medicare payment for their chronic disease self-management education programs through three existing benefits: Diabetes Self-Management Training, Medical Nutrition Therapy, and Health and Behavior Assessment and Intervention. The 10 organizations participating in the [Network Development Learning Collaborative](#) are aiming to partner with a health care payer.

These efforts will help promote sustainability of CDSMP and other proven self-management education programs. Given the health care system's emphasis on value and outcomes, these programs will be a beneficial addition to improving outcomes for adults with chronic conditions.

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