

RACIAL AND ETHNIC MINORITY PARTICIPANTS IN CHRONIC DISEASE SELF-MANAGEMENT PROGRAMS: FINDINGS FROM THE COMMUNITIES PUTTING PREVENTION TO WORK INITIATIVE

Background: The *Communities Putting Prevention to Work: Chronic Disease Self-Management Program (CDSMP)* Initiative funded grantees in 45 states, the District of Columbia and Puerto Rico to implement and expand delivery of CDSMP to older adults. We examine whether there are differences in the enrollment and completion rates of members of racial and ethnic minority groups and what sites have done to enhance their delivery of the CDSMP to such groups.

Method: This study used a multi-method approach including: site visits to 6 states, telephone interviews with the 47 program grantees and delivery sites, review of program reports, and analysis of administrative data on participants, completers, workshops and leaders.

Results: Grantees served 89,861 participants, including 56.3% who self-identified as White, 17.3% as Black, 5.0% as other/multi-racial, 3.2% as Asian/Asian Americans, 1.4% as American Indian/Alaskans, .8% as Native Hawaiian/Pacific Islanders, and 16.0% individuals of unknown race. Overall, completion rates averaged 74.5%, with Native Hawaiian/Pacific Islanders completing workshops at a higher rate (90.6%) than other groups. Completion rates for participants aged ≥ 75 were higher than for younger participants. Senior centers, health care organizations, and residential facilities served 63.1% of the participants.

Conclusions: Grantees have successfully delivered CDSMP to racially and ethnically diverse participants in a range of settings. As the Administration for Community Living/Administration on Aging (ACL/AoA) grantees have demonstrated, CDSMP can be brought to scale by community organizations, partnerships and networks to reach diverse populations in diverse settings. The program can be a significant tool for addressing health disparities and empowering racial/ethnic minorities to take charge, promote better health and self-management of chronic conditions. (*Ethn Dis.* 2013;23[4]:508–517)

Key Words: Chronic Disease Self-Management, Prevention, Wellness, Race, Ethnicity, Minority Populations, Evaluation, Older Adults

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INTRODUCTION

The rising numbers of adults aged >60 in the United States – expected to increase from 57 million to 92 million or nearly 25% of the population in 2030¹ – has directed attention to evidence-based health promotion programs to help reduce the illness burden and costs related with chronic illnesses associated with aging. An estimated 75% of older adults in the United States are reported to have two or more chronic conditions.² Chronic conditions such as heart disease, cancer, stroke, and diabetes are associated with functional disabilities and poor quality of life, and are the major cause of death for older adults.³ According to the Centers for Disease Control and Prevention, more than 75% of US health care costs are due to chronic conditions,⁴ most of which is attributed to aging adults. Racial/ethnic minority groups experience a disproportionate burden of chronic conditions as well as disparities accessing health care and preventive services due to a variety of socioeconomic, behavioral and other factors.⁵

One of the most recognized evidence-based health promotion programs is the Chronic Disease Self-Management Program (CDSMP), a series of 2.5 hour, in-person workshops offered once a week over 6 weeks, to provide education and tools to assist individuals in self-managing their chronic conditions. Randomized controlled trials conducted by researchers at Stanford University showed that individuals participating in

CDSMP, compared to those who did not participate, self-reported significant improvements in exercise, cognitive symptom management, communication with physicians, general health, health distress, fatigue, disability, and social/role activities limitations.^{6,7} Participants also had fewer hospitalizations and spent fewer days in the hospital.⁷ Workshops are typically offered in small groups in community settings such as churches, libraries, YW/MCAs, senior centers, public housing projects, community health centers, and cooperative extension programs. Workshop topics include: 1) techniques to deal with problems such as frustration, fatigue, pain, and isolation; 2) appropriate exercise for maintaining and improving strength, flexibility, and endurance; 3) appropriate use of medications; 4) communicating effectively with family, friends, and health professionals; 5) nutrition; and 6) how to evaluate new treatments. The CDSMP curriculum is not disease-specific and is designed to address the needs of participants with various chronic conditions, including diabetes and arthritis.

Workshop leaders include volunteer lay leaders who are trained by certified master trainers to strictly adhere to specific program requirements and processes in order to attain and maintain fidelity to the program as designed. For example, they are asked to conform to guidelines regarding numbers of workshop participants, workshop content, and duration.

Maintaining fidelity to program standards is important to ensure replication of results found in the original Stanford research. Still, some adaptations may be needed to effectively deliver the program with culturally and ethnically diverse communities. The program has been successfully translated

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for Hispanic/Latino audiences,⁸ resulting in the Spanish language version of CDSMP, *Tomando Control de su Salud*, which includes slight modifications, including an emphasis on nutrition to make the curriculum more culturally relevant. Successful adaptations in the United States have been reported for African Americans,^{9,10} Native Americans,¹¹ and Asian Pacific Islanders¹² that include program name changes, use of a culturally familiar logo, embedding CDSMP within community frameworks to address health care access and communicating with health care providers, incorporating blessings and rituals as part of the program, substituting culturally appropriate foods for examples in the manual, and including a pre-apology to enable younger workshop leaders to direct elder participants in situations where it is not customary to do so.

The US Administration for Community Living (ACL) has supported states in their efforts to develop and implement delivery systems for Chronic Disease Self-Management Education programs since 2003. The ACL's involvement with CDSMP expanded in 2010, when the U.S. Administration on Aging (AoA), a component within ACL, funded the *Communities Putting Prevention to Work: Chronic Disease Self-Management Program*, conducted in collaboration with the Centers for Disease Control and Prevention and the Centers for Medicare & Medicaid Services. Using grant funds authorized by the American Recovery and Reinvestment Act (ARRA) of 2009, ACL/AoA awarded two-year grants totaling \$27 million to 45 states, the District of Columbia, and Puerto Rico in 2010. The ACL/AoA also funded a detailed process evaluation of the initiative to better understand the challenges, opportunities and successful approaches for providing CDSMP, including delivery to minority populations.

The *Communities Putting Prevention to Work: Chronic Disease Self-Management Program* grants offered States the

opportunity to expand availability of CDSMP for older adults and, through the evaluation, to gain a better understanding of program implementation issues and successful practices for providing the self-management program, including understanding program adaptations for members of racial and ethnic minority groups. To date, research on the participation of African American, Latino, Native American and other minority populations in CDSMP and how to effectively reach and deliver the workshops for these populations has been limited and inconclusive.⁸⁻¹⁵

To help address these information gaps, our study examines delivery of CDSMP to racial and ethnic minority adults by ARRA grantees. Our study was conducted to answer the overarching evaluation question of whether there were differences in who took the course, who completed the course, and how courses were implemented based on the racial or ethnic backgrounds of participants. Specifically, our study focuses on: 1) self-reported demographic and chronic conditions among racial and ethnic minority and White CDSMP participants, 2) participation and completion rates of racial and ethnic minorities as compared to Whites, and 3) identification of program adaptations implemented by grantees for CDSMP delivery to members of racial and ethnic minority groups. Identifying characteristics of minority participants and completers, and effective strategies for delivery of CDSMP to these communities can help expand access to delivery of this evidence-based self-management program for these populations, which experience high prevalence of chronic conditions conducive to self-management approaches.

METHODS

Our study reports findings from the national process evaluation of the

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CDSMP participants from racial and ethnic minority groups, and grantees' adaptations to workshop delivery for these populations. The evaluation addressed multiple issues within six domains: 1) CDSMP populations, marketing and recruitment; 2) workshop implementation at grantee sites; 3) CDSMP eligibility, enrollment, and completion; 4) data collection; 5) statewide distribution and delivery systems; and 6) consumer and system-level environments. The ACL/AoA awards focused on CDSMP delivery to adults aged ≥ 60 , although grantees were allowed to serve individuals < 60 including, for example, caregivers, spouses and friends of an older participant with a chronic disease. Following federal program reporting requirements, grantees collected and submitted self-reported data on a total of 89,861 individuals to AoA's technical assistance contractor, the National Council on Aging (NCOA) over the two year grant period. The process evaluation team included individuals with multidisciplinary expertise in aging and health services delivery, program and systems evaluation, health economics, and community and public health. The team designed the evaluation and data collection tools, with input from a Technical Advisory Group (TAG) of state and national experts, and federal and regional ACL/AoA staff.

Data Sources

The evaluation incorporated multiple quantitative and qualitative data sources, described below.

Technical Advisory Group Input

During telephone meetings convened on March 2, 2012, and July 20, 2012, the TAG provided valuable insights that informed development of the process evaluation design. The TAG also advised on the interpretation of findings.

State Survey on Program Sustainability

The ACL/AoA staff provided the evaluation team with data from a 2011 survey of states that examines six elements ACL/AoA identified as central to a sustainable infrastructure and delivery system.¹⁶

Conference Calls with ACL/AoA Regional and Program Staff

The evaluation team conducted two in-depth calls with ACL/AoA regional and central office staff to obtain input regarding their field-based experience with CDSMP in order to inform: a) site selection criteria, site selection, and the interview guide for the site visits; and b) discussion topics, participant selection, and the discussion guide for the telephone discussions conducted with key informants from each of the 47 grantees as part of the grant close-out process.

Site Visits

The evaluation team site visited CDSMP programs in six states in January-February 2012 to observe program implementation on the ground and inform development of the process evaluation. During the two-day visits to Arkansas, California, Kansas, New York, Tennessee, and Vermont, the team met with state lead agency staff, host sites, implementation sites, leaders, program participants, and other stakeholders. To select the six states for site

visits, the team used data from AoA's Sustainable Infrastructure and Delivery System Self-Assessment to develop a system for ranking varying levels of program sustainability based on preliminary data and then selected a characteristic mix of states.

Telephone Discussions with Key Informants

The evaluation team conducted telephone discussions with state grantees, partners, and host sites over the three-month period April-June 2012 as part of AoA's grant close-out activities. The discussions focused on program status, challenges and opportunities, and plans for sustaining the program when ARRA funding comes to an end.

CDSMP Program Data

The NCOA, manages a web-based data collection system that states use to upload data on CDSMP participants, workshops, and leaders each quarter. The NCOA provided the evaluation team with a dataset consisting of self-reported participant demographics and chronic condition status, and data about CDSMP leaders and workshops conducted by the 47 grantees during the ARRA grant period (April 2010 to March 2012). The team designed a data analysis plan that enabled use of these quantitative data to complement the qualitative data and address, to the extent possible, the research questions that examined CDSMP participant characteristics, program completion rates, workshop size and location, and leader experience. In addition to a descriptive analysis, the team designed a series of regression analyses to examine the influence of multiple factors on workshop completion, such as participant characteristics, workshop size and location, and differences in funding history among state grantees.

Grantee Reports

Grantees were required to submit quarterly progress reports and final

reports to AoA. The reports followed a format outlined in ACL/AoA program guidance and document program goals, history, progress in reaching milestones, and other accomplishments. The evaluation team consulted the reports in preparing for site visits and telephone key informant discussions.

Evaluation Approach

The evaluation team used a multi-method approach involving triangulation of data to address study questions and validate responses across multiple data sources, depicted in Figure 1 and described below.

Consultations with Stakeholders

The team consulted with ACL/AoA program and regional staff and the TAG to inform the process evaluation design, planning for the site visits, and planning for the key informant telephone discussions.

Site Visits to Six States

The team mapped research questions within each of the six research domains, and developed a series of questions and probes for site visit interviews with state grantee agency staff, representatives, workshop sites, CDSMP participants, and other stakeholders. Site visit findings were used to guide planning for the key informant telephone interviews.

Telephone Interviews with Key Informants

For the one-hour telephone discussions with groups of key informants representing each of the 47 state grantees, the team developed an abbreviated list of questions that mapped to specific research questions that focused on the current landscape for CDSMP versus anticipated changes in the post-ARRA funding environment in order to assess the current status of each program and prospects for sustainability.

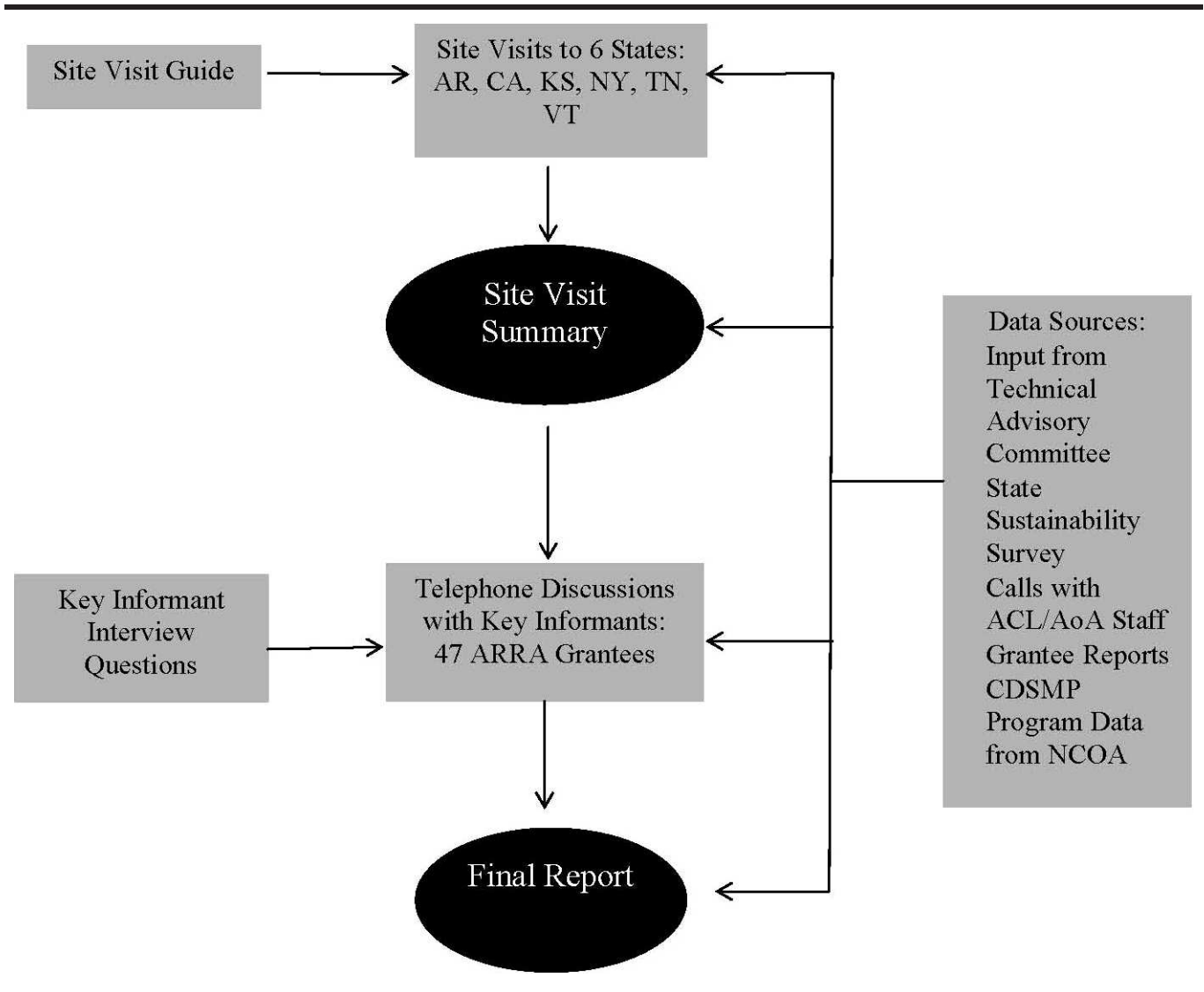


Fig 1. Process evaluation approach and data sources

RESULTS

Grantees of the ACL's Communities Putting Prevention to Work Initiative were asked to target their efforts to individuals aged ≥ 60 years (but were allowed to serve younger adults as well) and to make racial/ethnic minority populations a priority in implementing and delivering CDSMP. Grantees could focus on more than one racial/ethnic minority population and, of the 47 grantees, 20 focused efforts on Native Americans, 10 on Africans/African Americans, 29 on Hispanic/

Latinos and 20 on other racial/ethnic minority groups that were not specifically defined. Notably, some states already served diverse populations so did not change their existing targeting strategies. For example, Puerto Rico serves participants all of whom are considered Hispanic/Latino so did not focus special efforts to this group. Nearly all Native Hawaiian/Pacific Islander participants were from Hawaii and Utah. Other grantees served cultural and linguistic minority populations including Chinese, Vietnamese, Indians, and Somalis.

CDSMP Participation and Completion

Table 1 presents a descriptive profile of CDSMP participants by race and ethnicity. Of the 89,861 total participants in ACL-funded CDSMP workshops, more than half (56.3%) self-identified as White, with Blacks (17.3%), Other/multi-racial (5.0%), Asian/Asian Americans (3.2%), American Indian/Alaskans (1.4%), Native Hawaiian/Pacific Islanders (.8%), and individuals of unknown race (16.0%) comprising the remaining participants. While ACL-funded workshops targeted older adults, participants

Table 1. Descriptive statistics by race and ethnicity

| | <i>n</i> | % | Mean Age ^a | Mean <i>n</i> of CCs ^b | % Female ^c | % Completed ^d |
|------------------------------------|---------------|--------------|-----------------------|-----------------------------------|-----------------------|--------------------------|
| Race | | | | | | |
| American Indian / Alaskan | 1,241 | 1.4 | 60.7 | 2.4 | 71.6% | 73.1% |
| Asian / Asian-American | 2,870 | 3.2 | 68.4 | 1.8 | 73.8% | 77.2% |
| Black | 15,555 | 17.3 | 65.8 | 2.2 | 80.1% | 78.5% |
| Native Hawaiian / Pacific Islander | 720 | .8 | 64.8 | 2.4 | 58.0% | 90.6% |
| White | 50,563 | 56.3 | 68.5 | 2.6 | 78.1% | 75.9% |
| Other / multi-race | 4,525 | 5.0 | 60.9 | 2.3 | 76.9% | 77.3% |
| Unknown | 14,387 | 16.0 | 60.2 | .8 | 76.5% | 63.4% |
| Ethnicity | | | | | | |
| Hispanic / Latino | 11,797 | 13.1 | 59.3 | 1.9 | 78.4% | 76.8% |
| Not Hispanic or Latino | 60,359 | 67.2 | 67.0 | 2.6 | 78.3% | 76.7% |
| Unknown | 17,705 | 19.7 | 68.2 | 1.3 | 75.0% | 65.6% |
| Total | 89,861 | 100.0 | 66.7 | 2.2 | 77.8% | 74.5% |

^a Excludes participants with missing age and age less than 18 and greater than 100.

^b CC, chronic condition. Out of a total of 10 chronic conditions asked during registration.

^c Excludes participants with unknown sex.

^d A participant is assumed to complete the program if he/she is present in at least four of six workshops.

Data Source: Administration on Aging/Administration for Community Living grantee data, Communities Putting Prevention to Work, 2010–2012, from the National Council on Aging.

who self-identified as White or Asian/Asian American were on average older, at 68.5 and 68.4 years, respectively, than participants of other races, with American Indian/Alaskans reporting, on average, the youngest participants (60.7 years) among those who reported race. On average, Hispanic/Latino participants were considerably younger than non-Hispanic or Latino participants, at 59.3 and 67.9 years, respectively. All racial and ethnic groups showed a majority of female participants, with Blacks

reporting the highest percentage (80.1%) followed by Whites (78.1%). Native Hawaiian/Pacific Islanders reported the highest relative participation by men, with females accounting for only 58.0% of workshop participants. Considering ethnicity, Hispanic/Latino and Non-Hispanic Latino participants reported similar majorities of female participants, 78.4% and 78.3%, respectively.

Completion rates (ie, participating in at least four of six workshops) as shown in Table 2 were similar for Hispanic/Latino

and Non-Hispanic or Latino participants, at 76.8% and 76.7%, respectively. Across all groups, completion rates averaged 74.5%. Native Hawaiian/Pacific Islanders completed CDSMP workshops at a much higher rate than other groups, with 90.6% completing the workshops. Completion rates for older participants (aged ≥75) were generally higher than younger participants. Completion rates were generally high, averaging about 75% for the entire program. Participants in Spanish language CDSMP had slightly higher

Table 2. Completion rates by race, ethnicity, and age, %^a

| | <60 | 60–64 | 65–74 | 75–84 | ≥85 | Total |
|------------------------------------|-------------|-------------|-------------|-------------|-------------|-------------|
| Race | | | | | | |
| American Indian / Alaskan | 73.7 | 74.1 | 70.4 | 72.9 | 77.3 | 73.1 |
| Asian / Asian-American | 77.5 | 76.1 | 77.9 | 78.2 | 76.6 | 77.6 |
| Black | 76.4 | 79.1 | 79.3 | 80.3 | 77.5 | 78.6 |
| Native-Hawaiian / Pacific Islander | 82.5 | 96.7 | 93.5 | 84.6 | 93.3 | 90.5 |
| Other / multi-race | 79.4 | 76.7 | 79.5 | 73.3 | 71.9 | 77.8 |
| White | 73.9 | 76.6 | 78.4 | 77.1 | 71.9 | 76.1 |
| Unknown | 70.6 | 73.2 | 79.5 | 68.8 | 70.9 | 71.6 |
| Ethnicity | | | | | | |
| Hispanic / Latino | 77.4 | 77.9 | 79.9 | 76.1 | 74.0 | 77.7 |
| Not Hispanic or Latino | 74.4 | 78.1 | 78.7 | 77.9 | 73.2 | 76.9 |
| Unknown | 69.4 | 70.9 | 75.9 | 72.7 | 71.1 | 72.5 |
| Total | 74.5 | 74.5 | 77.1 | 78.4 | 77.1 | 72.9 |

^a Excludes participants with missing age or age <18 or >100.

Data Source: Administration on Aging/Administration for Community Living grantee data, Communities Putting Prevention to Work, 2010–2012, from the National Council on Aging.

Table 3. Prevalence of chronic conditions by race and ethnicity, %

| | None | AR | CA | DE | DI | HD | HT | LD | OS | OT | ST |
|------------------------------------|------|------|------|------|------|------|------|------|------|------|-----|
| Race | | | | | | | | | | | |
| American Indian / Alaskan | 11.8 | 45.0 | 8.3 | 27.9 | 31.1 | 17.2 | 43.7 | 23.5 | 10.0 | 29.9 | 6.3 |
| Asian / Asian-American | 17.3 | 32.7 | 5.3 | 9.8 | 25.8 | 12.3 | 44.6 | 8.6 | 18.3 | 19.4 | 4.1 |
| Black | 10.9 | 46.7 | 6.8 | 14.1 | 34.1 | 15.5 | 58.8 | 17.5 | 8.9 | 14.4 | 7.0 |
| Native-Hawaiian / Pacific Islander | 12.6 | 32.9 | 9.2 | 18.5 | 46.9 | 14.9 | 45.8 | 16.7 | 4.7 | 45.6 | 7.2 |
| Other / multi-race | 15.7 | 40.0 | 7.7 | 27.3 | 30.2 | 14.7 | 42.9 | 19.6 | 12.6 | 30.7 | 5.5 |
| White | 8.9 | 50.1 | 12.4 | 26.9 | 26.6 | 20.1 | 46.6 | 20.5 | 16.6 | 34.5 | 5.5 |
| Unknown | 64.1 | 13.6 | 2.1 | 6.6 | 14.1 | 4.9 | 16.3 | 5.0 | 2.7 | 12.4 | 0.9 |
| Ethnicity | | | | | | | | | | | |
| Hispanic / Latino | 19.0 | 31.6 | 4.3 | 18.4 | 32.2 | 10.5 | 38.9 | 12.4 | 8.8 | 27.1 | 2.3 |
| Not Hispanic or Latino | 9.1 | 49.5 | 11.4 | 24.0 | 28.1 | 19.2 | 49.4 | 20.4 | 15.5 | 29.9 | 6.2 |
| Unknown | 51.4 | 25.3 | 5.2 | 8.8 | 15.8 | 10.2 | 26.7 | 8.6 | 5.8 | 16.3 | 2.4 |
| Total | 18.7 | 42.4 | 9.2 | 20.9 | 26.2 | 16.3 | 43.6 | 17.0 | 12.7 | 26.9 | 5.0 |

AR, Arthritis; CA, Cancer; DE, Depression; DI, Diabetes; HD, Heart Disease; HT, Hypertension; LD, Lung Disease; ST, Stroke; OT, Other; OS, Osteoporosis.

Data Source: Administration on Aging/Administration for Community Living grantee data, Communities Putting Prevention to Work, 2010–2012, from the National Council on Aging.

completion rates than participants in English language CDSMP (76.4% compared to 74.3%).

Prevalence of Chronic Conditions

At enrollment participants self-reported diagnoses of 10 categories of chronic conditions: arthritis, cancer, depression, diabetes, heart disease, hypertension, lung disease, stroke, osteoporosis, or other. (Table 3)

Whites had the highest average number of chronic conditions (2.6) but were also the oldest (68.5) among all races. Asian/Asian Americans had the lowest average number of chronic conditions even though the average age for this category was nearly as high as Whites (68.4). The remaining race categories had about 2.3–2.4 average number of chronic conditions.

Hypertension followed by arthritis were most the most frequently reported conditions across all participants, and are reported by 43.6% and 42.4%, respectively. Approximately half (50.1%) of White participants reported having arthritis, while far fewer Asian/Asian Americans (32.7%) and Native Hawaiian/Pacific Islanders (32.9%) reported this condition. Black participants were more likely than other groups to report

having hypertension, with 58.8% reporting being hypertensive.

Program Delivery Sites

Table 4 shows the settings where CDSMP workshops were held. Overall, senior centers, health care organizations, and residential facilities served nearly two-thirds (63.1%) of participants. Faith-based organizations and Area Agencies on Aging served an additional 8.7% and 4.7% of the participants, respectively. The majority of the Hispanic or Latino population attended workshops at health care organizations (33%). Approximately one quarter of Asian/Asian Americans participated in workshops at multi-purpose social settings (24.3%).

Table 5 summarizes the completion rates by type of site for each race and ethnicity. A few findings are worth emphasizing: Asian/Asian Americans were not as likely to complete the CDSMP at faith-based organizations as were other groups, and the Native Hawaiian/Pacific Islanders were most likely to complete workshops offered at senior centers. Completion rates for Blacks were very high at many types of sites, but lower than the average at health care organizations and residential facilities. Whites were less likely to

complete workshops offered at county health departments than other groups.

Program Adaptations

State grantees and sites were expected to follow Stanford's fidelity standards for implementing and delivering CDSMP. Grantees and sites understood the importance of this directive; however, grantees reported making adaptations and accommodations for cultural, ethnic and linguistic minorities and other special populations. Stanford requests that adaptations be submitted for comment, and a small number of grantees reported working together with Stanford's program developer on modifications. The most common adaptation reported across all workshops was allowing smaller class sizes in rural areas due to challenges enrolling a sufficient number of participants in sparsely populated areas. The CDSMP adaptations reported on site visits and telephone discussions with grantees for racial/ethnic populations included: program name changes to increase interest or cultural relevance. For example, one grantee changed the program's name to "Help Yourself;" some faith-based groups used opening and/or closing prayer; voluntary 6-month participant reunion meetings provided opportunities for participants

Table 4. Participation by type of site, %

| Type of Site | American Indian / Alaskan | Asian / Asian-American | Black | Native Hawaiian / Pacific Islander | Other / Multi-race | White | Hispanic / Latino | Not Hispanic or Latino | Total ^a |
|---------------------------|---------------------------|------------------------|-------|------------------------------------|--------------------|-------|-------------------|------------------------|--------------------|
| Senior center | 19.0 | 22.8 | 25.8 | 18.9 | 21.6 | 24.4 | 18.2 | 25.1 | 23.4 |
| Health care organization | 22.2 | 15.3 | 12.8 | 5.1 | 20.9 | 21.5 | 33.2 | 16.8 | 21.7 |
| Residential facility | 11.2 | 15.6 | 20.1 | 5.7 | 15.1 | 18.6 | 10.8 | 19.2 | 18.0 |
| Other | 20.7 | 9.1 | 10.6 | 9.3 | 12.3 | 9.2 | 12.8 | 9.6 | 9.6 |
| Faith-based organization | 4.7 | 3.8 | 14.2 | 51.8 | 9.0 | 7.2 | 7.2 | 9.2 | 8.7 |
| Multi-purpose social | 3.7 | 24.3 | 6.1 | 1.9 | 7.9 | 4.2 | 8.0 | 5.5 | 5.7 |
| Area Agency on Aging | 3.4 | 1.3 | 5.1 | 1.4 | 3.2 | 5.7 | 1.4 | 6.0 | 4.7 |
| Recreational organization | 1.9 | 2.6 | 2.1 | 1.4 | 1.7 | 2.5 | 1.4 | 2.5 | 2.2 |
| Educational institution | .8 | 1.6 | 1.2 | .4 | 3.0 | 2.5 | 3.6 | 2.0 | 2.1 |
| Library | .6 | 2.1 | 1.3 | 1.4 | 2.3 | 2.3 | 1.8 | 2.1 | 2.0 |
| County health department | 1.0 | .3 | .5 | 1.7 | 1.4 | 1.3 | 1.1 | 1.1 | 1.2 |
| Workplace | .8 | 1.1 | .3 | 1.0 | .9 | .5 | .2 | .6 | .5 |
| Tribal center | 10.1 | 0 | 0 | 0 | .6 | .1 | .1 | .3 | .2 |
| Unknown | 0 | 0 | .1 | 0 | 0 | 0 | .2 | 0 | .1 |
| Total | 100.0 | 100.0 | 100.0 | 100.0 | 100.0 | 100.0 | 100.0 | 100.0 | 100.0 |

^a Includes unknown race and ethnicity.

Data Source: Administration on Aging/Administration for Community Living grantee data, Communities Putting Prevention to Work, 2010–2012, from the National Council on Aging.

to reconnect, socialize, and compare progress since workshop completion; tracking stick to designate speakers/discussants used for Navajo populations; starting classes late if transportation issues arose; postponing class when there was a death in a tribe (cultural sensitivity); separating classes of men and women for Muslim populations.

In addition to program adaptations to improve cultural appropriateness, grantees relied on partnerships with community organizations such as churches, cultural clubs and service groups to conduct CDSMP outreach and recruitment, and to support minorities' participation in workshops. Many grantees partnered with community-

and faith-based organizations to reach Latinos, particularly to increase awareness of CDSMP and recruit participants. Grantees focused on training Spanish/English bilingual lay leaders and master trainers to help expand their reach into the Latino community, as they believed this led to better success in recruiting participants and sustaining

Table 5. Completion rates by participation by type of site and race and ethnicity, %^a

| Type of Site | American Indian / Alaskan | Asian / Asian-American | Black | Native-Hawaiian / Pacific Islander | Other / multi-race | White | Hispanic / Latino | Not Hispanic or Latino | Total ^b |
|---------------------------|---------------------------|------------------------|-------------------|------------------------------------|--------------------|-------------------|-------------------|------------------------|--------------------|
| Senior center | 74.6 | 80.9 ^c | 80.4 ^c | 91.2 ^c | 77.0 | 77.4 | 77.9 | 78.6 | 76.3 |
| Health care organization | 66.3 | 77.0 | 73.0 | | 71.6 | 74.5 | 72.7 | 74.4 | 71.5 |
| Residential facility | 68.3 | 74.4 | 72.2 | | 71.8 | 72.0 | 74.6 | 71.7 | 69.8 |
| Other | 88.3 ^c | 72.3 | 83.1 ^c | 92.5 ^c | 83.2 ^c | 80.4 ^c | 84.1 ^c | 80.3 ^c | 80.0 ^c |
| Faith-based organization | 72.4 | 69.4 | 83.2 ^c | 95.4 ^c | 87.4 ^c | 78.9 | 81.0 ^c | 81.8 ^c | 79.4 |
| Multi-purpose social | | 79.3 | 79.1 | | 78.4 | 75.8 | 77.7 | 76.7 | 75.3 |
| Area Agency on Aging | | | 81.2 ^c | | 78.1 | 79.0 | 83.6 ^c | 79.3 | 78.0 |
| Recreational organization | | 78.9 | 76.3 | | 75.6 | 73.6 | 70.6 | 75.2 | 73.0 |
| Educational institution | | | 83.4 ^c | | 82.6 ^c | 77.0 | 78.5 | 77.6 | 76.6 |
| Library | | 70.0 | 83.8 ^c | | 88.3 ^c | 72.8 | 81.2 ^c | 74.5 | 74.0 |
| County health department | | | 73.8 | | 67.7 | 68.8 | 72.5 | 70.7 | 67.0 |
| Workplace | | | | | | 84.0 ^c | | 85.6 ^c | 82.7 ^c |
| Tribal center | 66.4 | | | | | | | 70.8 | 69.7 |
| Unknown | | | | | | | | | 84.1 ^c |
| Total | 73.1 | 77.2 | 78.5 | 90.6 ^c | 77.3 | 75.9 | 76.8 | 74.2 | 74.5 |

^a Rates based on <50 participants are not presented.

^b Includes unknown race and ethnicity.

^c Rate ≥80%, indicating settings where each racial and ethnic group participated significantly more often than the average mean, 74.5%.

Data Source: Administration on Aging/Administration for Community Living grantee data, Communities Putting Prevention to Work, 2010–2012, from the National Council on Aging.

high completion rates. New Mexico's Southern Area Health Education Center (SAHEC), near the Texas border, used promotoras, community health workers who advise residents about health and community health resources, to deliver CDSMP to Hispanic/Latino residents. The promotoras are respected as lay health leaders on diverse topics, and CDSMP has been a natural fit with their activities. The SAHEC director reported that fidelity is very high, as the promotoras are proud of and take their role in delivery of CDSMP very seriously.

Using strategies similar to those developed to reach the Latino community, grantees targeted Asians and African immigrants and Native Americans by partnering with community- and faith-based organizations and residential facilities to increase awareness of CDSMP and recruit participants. Illinois, for example, targeted immigrants and limited English speakers, particularly those aged ≥ 60 years, through a community wellness center. Implementation sites worked with the center to recruit participants through their established outreach program and network. New Jersey, with funding from the Office of Minority and Cultural Health, has been able to offer CDSMP in seven languages and has targeted Latinos, Koreans, and members of other ethnic minority groups. The Office of Minority and Cultural Health has partnered successfully with the New Jersey Sickle Cell Association to offer CDSMP to African Americans affected by the condition.

Several states have made translations of the CDSMP curriculum to facilitate participation by linguistic minorities: Pennsylvania provided two Chinese language workshops; Illinois delivered CDSMP in Hindi; Maryland offered CDSMP to South Americans as part of a breast cancer initiative; Georgia offered workshops in Korean and Vietnamese. For many languages, translations of CDSMP program materials are available through the Stanford website.

Working with Stanford's CDSMP developer, an Area Agency on Aging in Maine translated and adapted CDSMP for Somali women including reducing class size to accommodate cultural norms allowing participants to fully express their needs. A Hawaiian site reported having modified the program for Asian and Pacific Islanders, providing supplemental books in Hawaiian, Ilocano, and Chinese, and providing additional support to participants outside class. Other adaptations in Hawaii included program name changes, use of an opening prayer, and six-month participant reunions.

DISCUSSION

The CDSMP has an impressive evidence base showing its value as a health promotion approach to help individuals with chronic illness better manage their conditions; it was widely disseminated by grantees of the ACL/AoA Communities Putting Prevention to Work Initiative. While White females comprised the majority of workshop participants, ACL/AoA grantees have successfully delivered CDSMP to a range of racial, ethnic and other populations, in some cases making program adaptations, and have increased the numbers of minority CDSMP participants. Grantees reported that many minorities enrolled in CDSMP faced additional challenges relating to socioeconomic status, education, and access to health care, but once enrolled, they were likely to stay with the program as shown by their high completion rates.

Self-reports by participants from different racial/ethnic groups in this study revealed varied rates of prevalence and types of chronic conditions. Across all groups, hypertension and arthritis were reported most frequently. Hypertension was especially prevalent among Blacks, consistent with trends relating to chronic conditions among diverse aging populations.³ While food preparation,

ACL/AoA grantees have successfully delivered CDSMP to a range of racial, ethnic and other populations, in some cases making program adaptations, and have increased the numbers of minority CDSMP participants.

use of sugar and salt in the diet have been reported as approved program adaptations for Hispanic/Latino and African Americans,^{8,10} workshop leaders in this study held mixed opinions about whether such adaptations addressing common health issues are needed given CDSMP's general applicability to chronic conditions.

Grantees reported adaptations such as adding opening prayers or adjusting workshop schedules or format to meet cultural norms, but adaptations were typically modest, implemented to improve cultural acceptance while maintaining fidelity to the Stanford program. Research with Hispanic/Latinos, Asian Pacific Islanders, and others suggests that CDSMP can be modified for cultural appropriateness while maintaining the program design and content, and achieving positive behavior changes.^{8-10,12} How the program is introduced to the community, the context of community support and involvement have also been named as key determinants of successful delivery of CDSMP to minority populations.¹¹ Further study is needed to determine which elements of the evidence-based program are most important, and the extent to which modifications can be made without compromising critical program elements.

In our study workshop settings appeared to be important in delivery of CDSMP to diverse racial/ethnic populations. For example, our findings showed that Asian Americans were less likely to complete CDSMP when offered in faith-based environments, and that Whites had high completion in worksites, settings not widely utilized in this initiative with other populations. The evaluation team received conflicting anecdotal reports about whether and how setting may impact participation and completion.

Many grantees acknowledged that reaching out to include diverse populations requires resources, especially for participants who may have additional issues with transportation, and access to health care and insurance coverage. One grantee described the need to provide one-on-one assistance to non-English proficient individuals in completing forms for program participation, others identified lack of familiarity with health and health care in the United States as challenges for some new arrivals. Efforts to further expand and scale the program must keep an eye to the larger context of participants' experience, and the extent to which the adaptations sites developed are replicable with similar populations in other settings.

Limitations

Our study has several limitations. The evaluation from which these findings are derived was designed to address a range of administrative and field-based delivery system issues relating to CDSMP implementation and dissemination by ARRA grantees, not as a rigorous examination of racial and ethnic participation in the program. As such, study findings are based on administrative and self-reported data on participants, workshops and leaders submitted by grantees to ACL's technical assistance contractor, NCOA, as required by the grant. These real world data do not include information on socioeconomic status, education, behav-

ioral or health status indicators or other characteristics likely to influence program participation and delivery, and have not been verified for accuracy. Further, whether and to what extent missing data may be disproportionately attributed to specific racial and ethnic groups is unknown. While the team sought representative respondents and discussants for telephone interviews and site visits, this qualitative approach and the data collected by the evaluators, while internally verified by two- and three-person site teams, is also subject to bias. Additionally, the CDSMP participants in this study are not scientifically representative of racial/ethnic older adult populations, but reflect the populations and settings selected by grantees for program outreach and dissemination, limiting generalizability of findings.

Finally, the study data do not support examination of outcomes. While it is important that increased numbers of minorities are being enrolled and completing CDSMP, it is also crucial to understand health care utilization and cost outcomes across participant groups and to understand whether and how these outcomes may differ and can be improved. Another area important to examine is participant experience and outcomes in general CDSMP, proven to benefit participants with diverse chronic conditions together, compared with condition-specific self-management, for example, the Diabetes Self-Management Program and the Arthritis Self-Management Program.

The evaluators, TAG and ACL/ AOA considered several evaluation frameworks, approaches and methods that might have offered more rigorous and systematic information about the program. However, funding and time limitations, federal data collection restrictions, conduct of other ongoing studies of CDSMP and other evidence-based programs, and concern with maintaining and encouraging widespread access to CDSMP for older

adults were considerations shaping the evaluation approach.

CONCLUSION

Our descriptive profiles show that ACL/AOA grantees have successfully delivered CDSMP to racially and ethnically diverse participants in a range of settings. Some grantees have made adaptations, though these modifications appear to be minor and maintain fidelity to the Stanford curriculum. Further research is needed to assess health care utilization and cost outcomes. Also, study findings do not identify generalizable directives for delivery of CDSMP to populations on the basis of race and ethnicity alone. Other participant, program and community characteristics, for example, cultural and socioeconomic features of local communities, including presence of local leaders and champions, appeared to provide significant influence on program participation, completion and dissemination. That is, it appears that adaptation may be needed to encourage high levels of participation in and completion of the CDSMP among members of racial and ethnic minority groups, but given the diversity of these populations nationwide, the nature and extent of adaptation is likely to be locally determined. Still, as the ACL/AOA grantees have demonstrated, it is clear that CDSMP can be brought to scale by community organizations, partnerships and networks to reach diverse populations in diverse settings.

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REFERENCES

1. U.S. Census Bureau. *Projections of the Population by Age Sex for the United States: 2010 to 2050* (NP2008-T12), August 14, 2008.
2. Anderson G. *Chronic Care: Making the Case for Ongoing Care*. Princeton, NJ: Robert Wood Johnson Foundation; 2010.
3. Centers for Disease Control and Prevention. Chronic Diseases and Health Promotion. www.cdc.gov/chronicdisease/overview/index.htm. accessed March 1, 2013.
4. Centers for Disease Control and Prevention. Chronic Diseases. The Power to Prevent, The Call to Control. www.cdc.gov/chronicdisease/resources/publications/aag/chronic.htm. Accessed June 3, 2013.
5. Mead H, Cartwright-Smith L, Jones K, Ramos C, Woods K, Seigal B. Racial and Ethnic Disparities in U.S. Health Care: A Chartbook. The Commonwealth Fund. www.commonwealthfund.org/usr_doc/Mead_raceethnicdisparities_chartbook_1111.pdf. Accessed March 1, 2013.
6. Lorig K, Ritter P, Stewart A, et al. Chronic disease self-management program: 2-year health status and health care utilization outcomes. *Med Care*. 2001;39(11):1217–1223.
7. Lorig K, Sobel D, Stewart A, et al. Evidence suggesting that a chronic disease self-management program can improve health status while reducing hospitalization: A randomized trial. *Med Care*. 1999;37(1):5–14.
8. Lorig K, Ritter P, Gonzalez V. Hispanic chronic disease self-management: A randomized community-based outcome trial. *Nurs Res*. 2003;526:361–369.
9. Gitlin L, Chernett N, Harris L, Palmer D, Hopkins P, Dennis M. Harvest Health: Translation of the Chronic Disease Self-Management Program for older African Americans in a senior setting. *Gerontologist*. 2008;485:698–705.
10. Rose M, Arenson C, Harrod P, Slakey R, Santana A, Diamond J. Evaluation of the Chronic Disease Self-Management Program with low-income, urban, African American older adults. *J Community Health Nurs*. 2008;254:193–202.
11. Jernigan V. Community-based participatory research with Native American communities: the chronic disease self-management program. *Health Promot Pract*. 2010;116:888–899.
12. Tomioka M, Braun KL, Compton M, Tanoue L. Adapting Stanford's chronic disease self-management program to Hawaii's multicultural population. *Gerontologist*. 2012;521: 121–132.
13. Dongbo F, Ding Y, McGowan P, Fu H. Evaluation of chronic disease self-management program (CDSMP) in Shanghai. *Patient Educ Couns*. 2006;613:389–396.
14. Griffiths C, Motlib J, Azad A, et al. Randomised controlled trial of a lay-led self-management programme for Bangladeshi patients with chronic disease. *Br J Gen Pract*. 2005;55520:831–837.
15. Swerissen H, Belfrage J, Weeks A, et al. A randomized control trial of a self-management program for people with a chronic illness from Vietnamese, Chinese, Italian, and Greek backgrounds. *Patient Educ Couns*. 2006; 64(1–3):360–368.
16. Administration on Aging. *Sustainable Infrastructure and Delivery System Self-Assessment*. <http://www.ncoa.org/chamodules/documents/AOASustainabilityAssessmentTool.pdf>. Accessed September 9, 2013.

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