PROJECT: CALIFORNIA PARTNERSHIP TO IMPROVE DEMENTIA CARE AND REDUCE THE USE OF ANTIPSYCHOTICS

Final Narrative Report

March 28, 2016

Service Overview

Under Agreement 13-2055 between California Culture Change Coalition (CCCC) and the California Department of Public Health (CDPH), Phase II of the California Partnership to Improve Dementia Care and Reduce Unnecessary Antipsychotic Medication Drug Use in Nursing Homes (California Partnership) was facilitated by CCCC from March 11, 2014 through February 28, 2016. Through the facilitation, CCCC further refined the targets for action in the Working Together Summary Report (December 2012, published by CDPH) in the following areas:

- "Enforcement" and "Informed Consent" areas by convening the appropriate stakeholders, assisting the development of action plans, and documenting results.
- "Improving Dementia Care" and "Consumer Awareness" areas by serving as the lead agency to implement and coordinate the core strategies identified in this area. "Improving Dementia Care" and "Consumer Awareness" improvements were accomplished through providing education and training, promoting best practices, and providing technical expertise through a variety of avenues.

Overall, the California Partnership worked to improve dementia care and move closer to the goal of ending the unnecessary use of antipsychotic medication in California nursing homes by 30% of the state average based on MDS data using Quarter 4 of 2011 as Baseline.

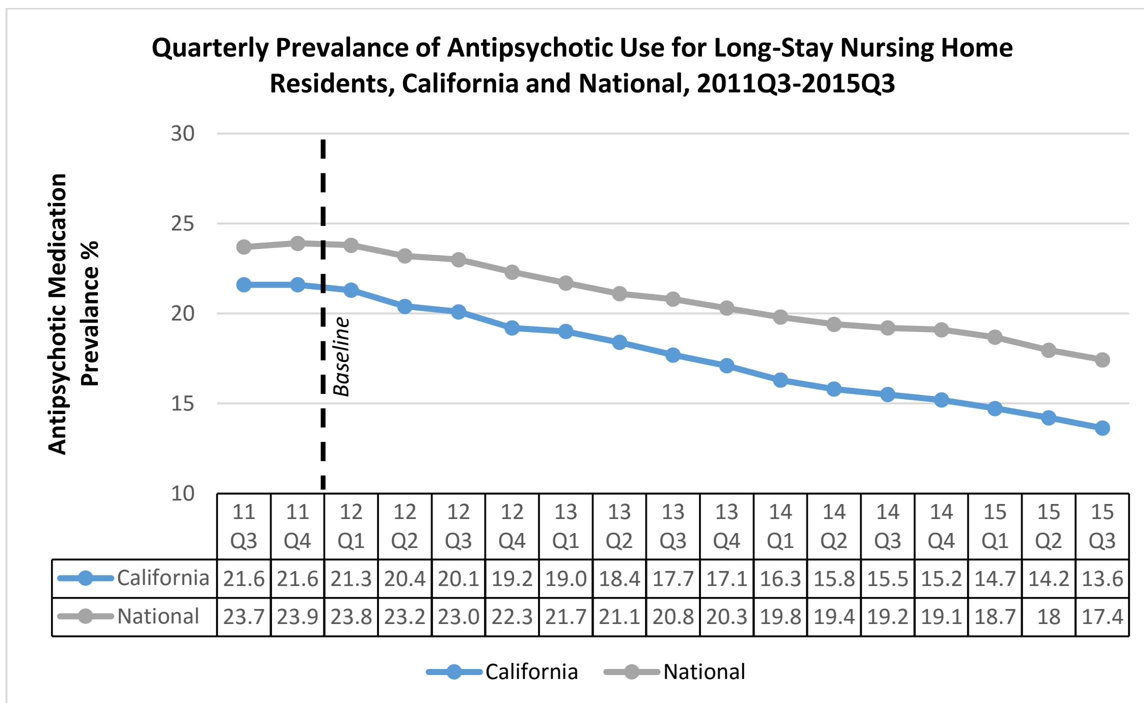
Accomplishments of CA Partnership Goals

Thanks to the support and authorization of funding by the Centers for Medicare and Medicaid Services (CMS) and the California Department of Public Health (CDPH), the California Partnership to Improve Dementia Care has been able to continue the work of reducing the use of antipsychotic medication through education and collaboration. We have appreciated the active participation and involvement of staffs from both these agencies in the CA Partnership.

At the end of this Contract's cycle, we are pleased to note the significant reduction in the inappropriate use of antipsychotic medication in California (Table 1.1). Pre-contract, the CA Partnership set a goal of reducing the use of antipsychotic use for California long-stay nursing home residents by 30% by the end of Quarter 2 of 2013 using Quarter 4 of 2011 as Baseline. ***The goal to reduce the use of antipsychotics by 30% was successfully met in the duration of the Contract at the end of Quarter 1 of 2015*** *(Table 1.2).* Table 1.1 indicates by the end of Quarter 4 of 2011, California's prevalence of antipsychotic use for long-stay nursing home residents was 21.6%. California has seen a 36.8% decrease and is currently at 13.63% prevalence of antipsychotic use for long-stay nursing home residents as of Quarter 3 2015 (Source: CMS Quality Measures, based on MDS 3.0 data). ***California successfully leads the nation as one of the top 10***

states in reducing the use of antipsychotics in nursing homes. Furthermore, since the inception of both the National and California Partnerships to Improve Dementia Care and Reduce the Use of Antipsychotics in Nursing Homes, CMS Region 9, consisting of California, Hawaii, Arizona and Nevada, had a 34.9% reduction of the prevalence of antipsychotic use for long-stay nursing home residents (Table 1.3). The California Partnership to Improve Dementia Care has worked collaboratively with unwavering determination to reduce the use of antipsychotics with a vision to completely eliminate the misuse of antipsychotics in nursing homes. With the determination and leadership of the California Partnership, the past two years has been a success, and we are utmost satisfied of the completed undertakings.

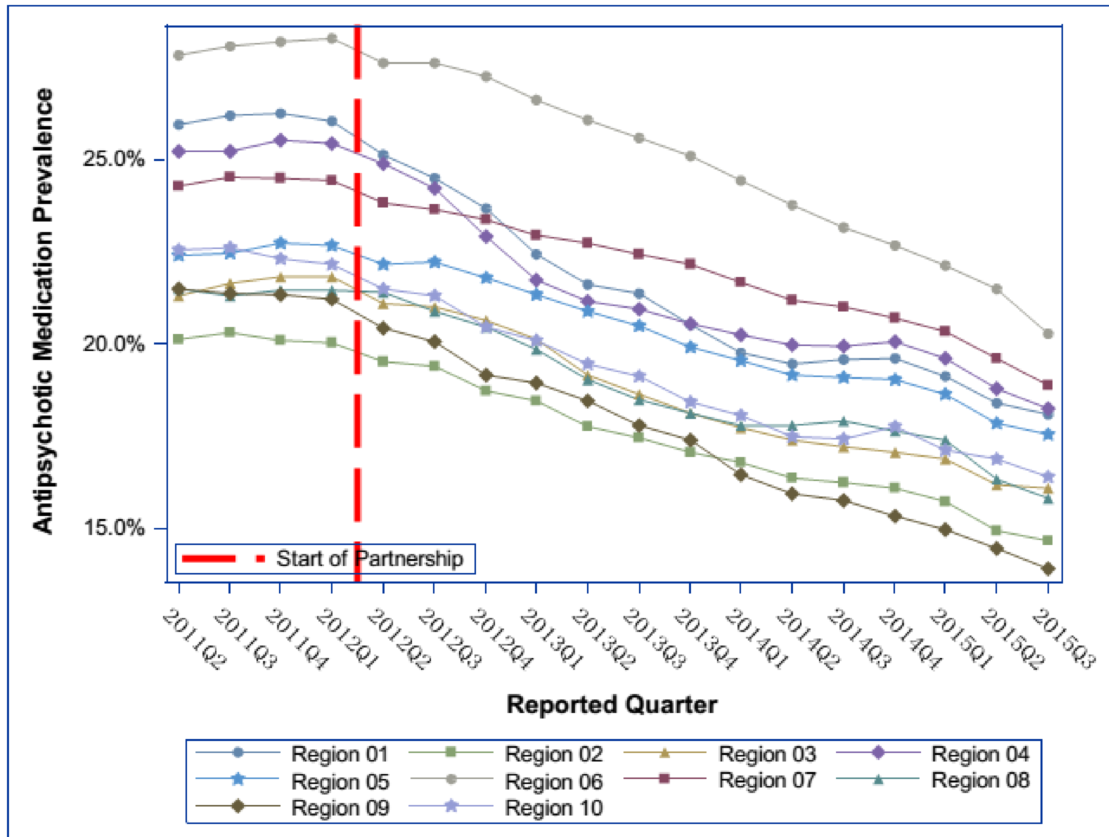
Table 1.1 Quarterly Prevalence of Antipsychotic Use for Long-Stay Nursing Home Residents, California and National 2011Q3 to 2015Q3



	11 Q3	11 Q4	12 Q1	12 Q2	12 Q3	12 Q4	13 Q1	13 Q2	13 Q3	13 Q4	14 Q1	14 Q2	14 Q3	14 Q4	15 Q1	15 Q2	15 Q3
California	21.6	21.6	21.3	20.4	20.1	19.2	19.0	18.4	17.7	17.1	16.3	15.8	15.5	15.2	14.7	14.2	13.6
National	23.7	23.9	23.8	23.2	23.0	22.3	21.7	21.1	20.8	20.3	19.8	19.4	19.2	19.1	18.7	18	17.4

Source: CMS Quality Measures, based on MDS 3.0 data

Table 1.3
Quarterly Prevalence of Antipsychotic Use for Long-Stay Nursing Home Residents, CMS Regions 2011Q2 to 2015Q3



Source: CMS Quality Measures, based on MDS 3.0 data

<u>**Accomplishments of Contract Deliverables**</u>

We wanted to take this opportunity to share with you the accomplishments of the CA Partnership as well as summary thoughts that have emerged from the CA Partnership workgroup and full-Partnership discussions. We hope that these can be considered as you move forward with further reduction efforts.

Through its continued collaborations and leadership, the California Culture Change Coalition achieved all deliverables stated in Contract #13-20555 for and with the California Partnership to Improve Dementia Care by the Contract end date. Table 2.1 outlines the product deliverables and links to the products. Table 2.2 furthermore outlines the goals, objectives and major tasks, the status of those tasks, as well as additional information of the final products, tools and resources.

Table 2.1 Links to Contract 13-20555 Deliverables and Related Products

Goal	Major Functions, Tasks and Activities	Links to Deliverables
Goal 1: Improve Dementia Care	Website, Toolkit, Resources, Best Practices	www.dementiacareresourceCA.org
	Toolkit	Toolkit: Strategies for Success: Dealing with Dementia Behaviors without Drugs
	Webinar/Video, Pre-recorded	Webinar Series: Person Centered Care and Activity Services: Best practice care resources for activity services and residents with dementia related illness.
	Webinar/Video, Pre-recorded	Webinar Series: Antipsychotics and Dementia
	Webinar/Video, Pre-recorded	Webinar Series: For Pharmacists- Tips for Using Antipsychotics in Dementia
	Conference: Statewide conference, *Dementia Care California: Sustaining Momentum and Success,* February 2015	California Health Report conference press coverage article, "Empathy: The Future of Dementia Care"
	Best Practices and Key Strategies, Learning Action Network (LANs); PowerPoint, via HSAG	Change Package: A curation of great ideas and practices to create lasting change in your nursing home (reference only); PowerPoint: Reducing Unnecessary Antipsychotics
	Toolkit: Informed Consent	Toolkit: Verification to Informed Consent and Guide
Goal 2: Raise Consumer Awareness around Dementia Care Best Practices	Handout, Fact Sheet for Consumers	Fact Sheet: Did You Know- Your Right to Informed Consent
	Brochure, Consumer Guide	Consumer Guide: Antipsychotics and Residents, Your Right to be Informed and Give Consent
	Handout, Fact Sheet for Consumers	Fact Sheet: Dementia and Medicines, What You Need to Know
	Postcard	Postcard: Have you or your loved one been prescribed antipsychotics? Learn the Facts
	Website	www.dementiacareresourceCA.org, We Can Help
	Website	www.dementiacareresourceCA.org, We Can Help, Families and Residents
	Training, PowerPoint	PowerPoint: Improving Dementia Care-An Ombudsman Training; Script

Table 2.2 California Culture Change Coalition Objectives and Goals for the California Partnership to Improve Dementia Care

Objective	Major Functions, Tasks and Activities	Status	Additional Information
A. Educate and train providers, professional stakeholders, administrators and other healthcare professionals (Physicians/MDs, Registered Nurses/Licensed Vocational Nurses/Certified Nursing Assistants, Social Services Directors, Pharmacists, Occupational Therapists, etc.) in improving dementia care through promoting environmental modifications, person-centered and least medicating interventions as identified	a. Create an on-line tool kit that includes: Train-the-trainer materials for implementing the curriculum of evidence-based materials, such as the modules of the CMS *Hand-in-Hand Dementia Training Program*, Best Practices Resources Listing that includes non-pharmacological interventions and activities specific to enhancing resident care and quality of life with less medication, and a quick reference guide for Best Practices Resources Listing	Completed	Online toolkit live: www.dementiacareresourceCA.org; Train-the-trainer materials for implementing the curriculum of evidence based materials, such as the CMS, "Hand-in-Hand Dementia Training" program, Dr. Susan Wehry's "OASIS" program. Website expanded to include a compendium of dementia care and non-pharmacological tools and resources for health care professionals, including physicians, nursing home leaders and staff, and ombudsmen.
	b. Prepare presentations that can be delivered in person or via a webinar as a series for the following topics: Least Medicating Approaches and Best Practices that identify effective strategies in dementia care that result in antipsychotic medication reduction.	Completed	Three webinars were prepared to meet this deliverable: 1) 3-part pre-recorded webinar aimed for physicians. Part 1: *Dementia,* Part 2: *Agitation: Behavioral Approach,* Part 3: *Agitation: Medications*, 2) 3-part pre-recorded webinar aimed for consultant pharmacists. Part 1: *Tips for Using Antipsychotics in Dementia*, Part 2: *Tips for Treating Insomnia in the Elderly,* Part 3: *Tips for Drug Treatment of Pain and Anxiety in the Elderly,* 3) 3-part pre-recorded webinar aimed for activity professionals titled, *Person Centered Care and Activity Services: Best practice care resources for activity services and residents with dementia related illness*. Part 1: *Person Centered Care,* Part 2: *Dementia Disease Process,* Part 3: *Knowing Our Resident.* *All webinars are currently* accessible at **dementiacareresourceCA.org.**

	c. Identify facilities with antipsychotic medication rate at 30% or above and develop a proposed corrective action plan to promote training in those geographical areas to enhance training opportunities in those areas. This evaluation will be done once in Year 1 and again in Year 2 to allow for targeting the facilities by using the most current antipsychotic medication rate data available	Completed	Facilities identified via CMS MDS data reports; CA Partnership Education Committee Sub-Group met to develop plan. The sub-group drafted and finalized a letter to the nursing homes that provided them with information on free resources to access that will help in AP reduction efforts. HSAG team included materials that support the National Nursing Home Quality Care Collaborative (NNHQCC), a collaborative that focuses on helping nursing homes improve their 13 long-stay measures, including reducing unnecessary antipsychotics.
	d. Identify and promote existing training materials and best practices through key stakeholders, e-mail blasts to providers, residents and their families, Ombudsmen and conferences.	Completed	Training materials and resources identified on an ongoing basis throughout Contract duration; E-mail blasts (e-newsletters) sent at least every other month to CA Partnership partners and affiliations and CCCC contact database for dissemination of training materials, resources and online and in-person training opportunities
	e. Host a statewide conference in northern and southern California that brings all stakeholders together to improve dementia care and stop misuse of antipsychotics.	Completed	*Dementia Care California: Sustaining Momentum and Success, a statewide Continuing Education conference opportunity for nearly 600 providers and leaders in long term care was presented in* Sacramento, February 23, 2015 and in Pasadena, February 25, 2015. The program featured Dr. Al Power, author of *Dementia Beyond Disease,* and facilitated brainstorm sessions related to problem solving issues related to: 1) education resources 2) corrective action planning 3) leadership and 4) staff. The California Health Report featured journalist Matt Perry's press coverage of the event, titled, "Empathy: The Future of Dementia Care".
B. Coordinate with other stakeholders who will provide technical expertise and facilitate training opportunities between	**DELETED** ~~a. Evaluate other measurement tools rather than the CMS quality measures. Prepare a report outlining resources needed, steps involved and associated costs to the recommended measurement tools~~	-	*(Deleted upon agreement between the Contractor, CCCC, and the State Agency, CDPH)*

advocacy groups and facilities on least medication alternatives and person-centered interventions	b. Identify partners and their interest in participation for learning and action networks (LANs)	Completed	It was been identified that the Health Services Advisory Group (HSAG) will serve as a primary partner with their LAN efforts with individual nursing homes. Namely, HSAG developed and produced day-long learning sessions throughout the state with the objective to employ best practices to avoid unnecessary antipsychotic medications in nursing home residents living with dementia.
	c. Collaborate and convene workgroups with LANs to identify key strategies	Completed	The CA Partnership sought the expertise and collaboration with HSAG, California's Medicare Quality Improvement Organization (QIO), to provide key strategies and resources utilizing the National Nursing Home Quality Care Collaborative (NNHQCC) Change Package. The information was used to produce the LANs series.
	d. Provide continued process and outcome improvement through LANs	Completed	
C. Support the ongoing collaborative efforts through the facilitation and organization of the Partnership Stakeholders Executive Committee	a. Facilitate workgroup meetings of the collaborative stakeholder group	Completed	The Partnership Executive Committee identified as the facilitators of each workgroup: Improving Dementia Care (Education), Consumer Awareness, Enforcement and Informed Consent. Facilitation of meetings completed as needed and as requested. The California Partnership convened as a whole every six months, in addition to the workgroups that would meet quarterly. As goals and deliverables were processed and completed, the workgroups (and subgroups) would meet as needed, with ongoing communications conducted via phone conference or e-mail.
	b. In conjunction with key stakeholders, identify and refine key strategies for improving dementia care and reducing antipsychotic medication use in the nursing home.	Completed	*(Please refer to the Findings and Recommendations and Additional Findings and Recommendations: Future Leadership of the CA Partnership sections of the Final Report)*
	c. Ensure that there continues to be a vehicle for interagency communication, coordination, and leadership related to the initiative to improve dementia care and reduce the use of antipsychotic medication used in skilled nursing facilities including related issues related to enforcement and informed consent.	Completed	*(Please refer to the Findings and Recommendations and Additional Findings and Recommendations: Future Leadership of the CA Partnership sections of the Final Report)*

	d. Collaborate with key stakeholders to include this topic area in statewide meetings, trainings and conferences	Completed	Trainings included, but not limited to the CA Partnership Statewide Conference, Dementia Care California: Sustaining Momentum and Success, statewide conference opportunity with Plum HealthCare, "I Already Told You…Don't You Remember?" A Guide to Excellence in Dementia Communication and Behavior Prevention without Antipsychotic Medications", statewide Ombudsman Trainings, California Association of Long Term Care Medicine webinar, Health Services Advisory Group statewide learning sessions and representation at Alzheimer's Association regional conferences
	e. Make arrangements for teleconference option as an alternative to in-person meetings	Completed	Teleconference options were always provided as an option to attending in person
	f. Prepare and distribute the meetings notes within one week of the meeting	Completed	Completed as assigned
	g. Finalize and distribute the meeting notes within two weeks of the meeting to all attendees	Completed	Completed as assigned
	h. Coordinate the dissemination of all announcements/updates providing copies to all stakeholders including CDPH	Completed	All announcements, materials and updates provided to all CA Partnership members, including CDPH, and included in all quarterly reports
D. Create and facilitate work groups/committees comprised of CCCC/key stakeholders. The work groups/committees will report to the CA Partnership any progress, outcomes, issues or concerns with appropriate actions directed and taken for project completion and success in meeting goals and targets.	a. Coordinate and schedule workgroup meetings via telephone or in person, depending on the preference of the workgroup members	Completed	Four workgroups sustained the CA Partnership: Enhanced Enforcement, Informed Consent, Improving Dementia Care (Education), and Consumer Awareness. A CCCC Board member was represented on each of the four CA Partnership workgroups and serves as an advisory committee at CCCC Board of Director meetings and ongoing communications. Additionally, the facilitators of each workgroup also served on the CA Partnership Executive Committee. All goals, tasks and deliverables of the workgroups were reported quarterly at the CA Partnership meetings
	b. Make arrangements for teleconference option for the workgroup members if that is their choice, or for those members that cannot travel to the in-person meeting.	Completed	Completed as assigned

	c. Prepare and distribute draft meeting notes within one week of the meeting.	Completed	Completed as assigned
	d. Distribute the finalized meeting notes within two weeks of the meetings to all attendees	Completed	Completed as assigned
	e. Coordinate the dissemination of all announcements/updates providing copies to all stakeholders including CDPH	Completed	All announcements, materials and updates provided to all CA Partnership members, including CDPH, and included in all quarterly reports
A. Identify and train providers and professional stakeholders in improving dementia care through promoting environmental modifications, person-centered least medicating interventions.	a. Collaborate with key stakeholders to create a broad based education campaign plan for families and consumers to increase awareness of positive practices in management of dementia related behaviors and the consumers' right to informed consent	Completed	Throughout the duration of the contract, CCCC, the CA Partnership Education and Consumer Awareness workgroups identified resource and educational needs for consumers including nursing home residents, families and advocates
	b. Conduct a literature search to find existing appropriate materials (brochures, tool kits, articles, and non-technical resources) to incorporate into the educational campaign. Prepare a report of findings with recommendations for inclusion in the educational campaign.	Completed	All resource list findings and appropriate materials can be found at dementiacareresourceCA.org
	c. Work with key stakeholders and potentially a public relations consultant to develop new educational materials as needed. Materials to include brochures, flyers, and articles suitable for posting to websites as well as to collect a rich compendium of tools/resources that will guide their non-pharmacological dementia care practices, making them readily available to the care teams. The "tools" necessary are to be developed while working in collaboration with the key stakeholders.	Completed	CCCC worked with a Creative Services Specialist to develop consumer friendly information guides for residents, families and advocates. The resource materials will be available at dementiacareresource.org. The resources include: **Fact Sheet:** *Did You Know, Your Right to be Informed* **Handout:** *Dementia and Medicines: What You Need to Know* **Brochure:** *Consumer Guide: Antipsychotics and Residents, Your Right to be Informed and Give Consent*

	d. Share best practices resources and resource list with nursing homes, and key stakeholders that have training capability with the goal of the stakeholders with training capability to incorporate these best practices in their programs, literature, websites, and conferences.	Completed	Ongoing direct mailings, electronic communications via CCCC and CA Partnership contacts were completed. Mailings also included outreach to all California nursing home facilities.
B. Develop a website with public information aimed at the lay person that provides non-technical information regarding person centered approach behaviors management of dementia related behaviors	a. Expand the existing CCCC website to include pages dedicated to consumer education about person centered care that contains the following information that has been vetted through key stakeholders: A Frequently Asked Questions section that addresses the questions family members should ask when their loved ones are having behavioral challenges in a long term care setting, Provides balanced information regarding the pros and cons of pharmaceutical interventions for dementia related behaviors, and a simple guide for consumers on their right to informed consent related to the use of psychotropic medications in skilled nursing facilities.	Completed	The www.dementiacareresourceCA.org has been expanded to include a consumer section titled, "We Can Help", and is available on the CCCC website. The section includes guides and information to help individuals and families further understand why the use of antipsychotic medications to treat a person's symptoms of dementia is most likely not the safest first choice for care, and includes important information on what you should do to advocate for the best treatment options.

	b. Train Ombudsmen to conduct outreach to resident and family councils on improving dementia as follows: Develop and present a session at the Ombudsman conference and develop at a minimum of one webinar on the topic of how Ombudsman can help to raise consumer awareness regarding person centered care and non-pharmacological techniques for treating people with dementia related behavior, and Identify and utilize exert Ombudsman to assist with the development of strategies to raise awareness about the resources and guidance materials available regarding how Ombudsman can assist with the dissemination of information about the positive dementia management resources available throughout the CCCC website.	Completed	At the statewide Ombudsman training during the Fall of 2014, an all-day training session was conducted by the National Consumer Voice for Quality Long-Term Care. In part, the session was dedicated to reviewing a strategy chart that would develop an outreach plan to attain the vision: *Every prescriber of an antipsychotic medication to a resident of a Long Term Care facility will obtain informed consent from the recipient or legal representative.* An Informed Consent package was created by the Informed Consent workgroup of the CA Partnership, which included the *Verification to Informed Consent Form, Guide to Using the Informed Consent Form,* and a sample letter that encourages prescribers to use the form. Tools of the Informed Consent package were used at the Ombudsman training and can be found a**t dementiacareresourceCA.org**
		Completed	Antipsychotics: What You Need to Know webinar conducted on 3/29/14 was transcribed to create a script for future Ombudsman training sessions and community education opportunities for consumers.

The California Culture Change Coalition has been honored to work with the CA Partnership and its stakeholders. Without the collaborations and partnerships, CCCC would not have been successful at surpassing its goals. Table 3.1 lists the affiliations of which the CA Partnership is comprised. Namely, the following affiliations were significantly involved in reaching the goals outlined in the Contract, and we would like to acknowledge them for their contributions and dedication to the CA Partnership:

- Alzheimer's Association
- California Advocates for Nursing Home Reform
- California Association of Health Care Facilities
- California Association of Long Term Care Medicine
- California Department of Aging/Office of the State Long Term Care Ombudsman
- California Department of Public Health
- Center for Medicare and Medicaid Services
- Chaparral House
- ElderConsult
- Health Services Advisory Group

Table 3.1 CA Partnership to Improve Dementia Care Organization Affiliations

CA Partnership to Improve Dementia Care, Organization Affiliations	
Alzheimer's Association	ElderConsult
American Society of Consultant Pharmacists, CA Chapter	Foundation Aiding the Elderly
Board of Registered Nursing	Health Services Advisory Group
California Advocates for Nursing Home Reform	Kaiser Permanente
California Association of Health Facilities	LeadingAge California
California Association of Long Term Care Medicine	Long Term Care Services of Ventura County, Ombudsman Program
California Culture Change Coalition	Mother Lode LTC Ombudsman
California Department of Aging/Office of the State LTC Ombudsman	Occupational Therapy Association of California
California Department of Public Health	OmniCare
California Hospital Association	San Joaquin County LTC Ombudsman
California Long-Term Care Ombudsman Association	Stanford Geriatric Education Center (SGEC)
California Medical Association	Trisel Eldercare Consulting, Inc.
Chaparral House	U.S. Department of Health and Human Services
Council on Aging - Orange County	UC Davis, Dept. of Psychiatry & Behavioral Sci
Creekside Rehabilitation & Behavioral Health	WISE & Healthy Aging
Disability Rights California	

Findings and Recommendations

There are currently four active workgroups identified in the CA Partnership: *Enhanced Enforcement, Informed Consent, Consumer Awareness, and Improving Dementia Care (Education).* This section identifies findings and recommendations among the workgroups of the CA Partnership moving forward.

Enhanced Enforcement Workgroup

Of the four workgroups, the Enhanced Enforcement workgroup found that they were tasked with objectives that were more philosophical and principled in nature. It was identified that while enforcement practices could be developed and recommended, they did not have the power of implementation of such practices. However, the Enhanced Enforcement workgroup outlined the following findings and recommendations:

1) Next Steps from Dementia Care Pilot Projects

We were very pleased that California volunteered to participate in the Focused Dementia Care Survey Pilots conducted in 2014. We note that Survey and Certification Letter 15-31-NH provided very general information about the next steps for states to engage in "… more intensive, targeted efforts to improve surveyor effectiveness when citing poor dementia care and the overutilization of antipsychotics, and broaden the opportunities for quality improvement among providers". The S&C Letter also states that further discussions between state survey agencies and CMS on the implications for continuing this focused effort sometime this summer. We strongly support the continuation of the focused surveys in California for those facilities with higher rates of antipsychotic use and/or pattern of deficient practices in this area.

We fully recognize that the focused surveys require significant staff resources so that it is unlikely that CDPH would be able to conduct the full, focused surveys in a significant number of facilities at the current time. However, we would advocate for CDPH's further potential partnership and recommendations and support the incorporation of selected elements of the focused pilot survey protocol into the routine, periodic certification surveys for those facilities that have a rate of antipsychotic use using the new CMS target of a 30 percent reduction by the close of 2016, using the prior baseline rate (fourth quarter of 2011).

Specifically, we would suggest that the following be adopted, if approved by CMS:

- *Consider a facility's rate of antipsychotic use for residents with dementia when extracting the resident sample during standard certification surveys:*

As part of Task 1 of the offsite preparation for, and Phase 1 of the survey, first identify those facilities that have a higher prevalence of antipsychotic use. This is consistent with the guidance to surveyors in Appendix P, in that a higher prevalence of antipsychotic use would be considered to be, "concerns based on other sources of information listed below and note other potential residents who could be selected for the sample; and determine if the areas of potential concerns or special features of the facility require the addition to the team of any specialty surveyors". In addition, selecting long-term stay residents with a diagnosis of dementia who are also prescribed antipsychotics would seem to be the best way to identify potential deficient practices.

- *Incorporate a short step into the supervisorial review of the CMS Form 2567 survey document:*

  When district office supervisors review the CMS Form 2567, reviewing the document for deficiencies related to unnecessary use of antipsychotics should be conducted. If no deficiency was written, a query to the team leader would identify whether a deficiency should have been written, and would further emphasize to the survey teams the importance of scrutinizing this practice.

We believe that relying on a random sample of residents and not identifying facilities with a high rate of antipsychotic use prescribed for residents, leaves too much to chance. These short steps could provide for a more focused approach to standard surveys, and emphasize to both surveyors and providers that California is making a concerted effort to further reduce the rate of antipsychotic use through all available mechanisms.

In addition, we would suggest that this sort of focused look be incorporated into abbreviated (complaint) surveys. If the resident who is a subject of the complaint (and an expanded resident sample, if triggered) has a diagnosis of dementia, we suggest that the surveyors identify whether the resident has been prescribed an antipsychotic, and the extent to which this might have contributed to the incident involved in the complaint.

Of additional importance is to ensure that facilities who have Special Treatment Programs (STPs) are viewed somewhat differently to the extent that their residents do not have a primary diagnosis of dementia, and/or have a primary or secondary diagnosis of a mental illness for which antipsychotics are appropriate. This would be very important when selecting the resident sample in these facilities and drawing conclusions about deficient practices.

There have also been increases in residents with mental illnesses residing in nursing facilities that are not STPs, due to a shortage of mental health facilities. This needs to be taken into consideration when viewing a facilities rate of antipsychotic use.

2) Definition of "Actual Harm"

The final report of the Focused Dementia Survey Pilot noted that surveyors were challenged when assigning the scope and severity to deficiencies written; in particular, what constitutes actual harm when it involves unnecessary use of antipsychotics. While we understand the difference between a potential risk to patients and proving actual harm, a similar situation existed in the past, related to the imposition of physical restraints. CMS provided clear guidance to state survey agencies and providers on assigning the scope and severity of deficiencies related to the use of physical restraints. We believe that similar guidance needs to be developed for the unnecessary use of "chemical" restraints, for both surveyors and providers.

3) Use of State vs. Federal Requirements when Citing Deficiencies

One of the tools available to CMS and CDPH in reducing inappropriate use of antipsychotics involves the use of state and federal enforcement remedies. We understand that the construct of federal enforcement remedies almost always provides the opportunity to come back into compliance before a federal remedy is actually imposed, unless the deficiency is a "repeat" violation. A repeat deficiency can only be considered if a violation of federal regulatory requirements is cited, rather than a violation of state regulations. This results in an occasionally "parallel" and seldom intersecting system of accountability.

One facility that was involved in the pilot survey had previously received a state citation related to the use of antipsychotics. However, because this deficiency was written for a violation of a state regulatory requirement rather than for a violation of federal requirements, the deficiency was not considered to be a "repeat" deficiency and therefore did not trigger a federal enforcement remedy.

We also know that CDPH has the discretion to either recommend the imposition of a federal enforcement remedy (for violations of federal requirements) or issue a state citation for a violation of state or federal requirements and may also recommend the imposition of a federal enforcement remedy (for violations of federal requirements).

> *Health and Safety Code §1423: If the department determines that the violation warrants the issuing of a citation and an exit conference has been completed it shall either:*
>
> > *(1) Recommend the imposition of a federal enforcement remedy or remedies on a nursing facility in accordance with federal law; or*
> > *(2) Issue a citation pursuant to state licensing laws, and if the facility is a nursing facility, may recommend the imposition of a federal enforcement remedy.*

We also know that you cannot direct surveyors to always issue a state citation as this would be considered to be underground regulations. However, we would like to suggest that consideration be given to reminding district offices of the array of enforcement options, and consider always writing deficiencies for violations of federal requirements when issuing state citations, unless state requirements are different than, or significantly more stringent than federal requirements. The state statutory informed consent requirements would be an example of a violation that would warrant a deficiency under state requirements. In addition, we would like to suggest that the department consider the consistent imposition, when appropriate, of a state citation for violations of federal deficiencies related to unnecessary use of antipsychotics, in which no federal enforcement remedy is likely to be imposed.

4) Referrals to Other Licensing Boards

The Partnership has invited the participation of representatives from health care professional licensing boards; and some representatives continue to participate in workgroup efforts. However, it is important to hold accountable, not only the facilities that are being surveyed, but the health care professionals who may have engaged in egregious violations of their own practice acts, and contributed to the inappropriate use of antipsychotics. CDPH should continue its efforts to make referrals to appropriate licensing boards for individuals that violate their licensure standards.

5) Surveyor Training

The successful completion of surveyor training on the surveyor tool for all California surveyors last summer represented a tremendous effort to enhance surveyor skills related to improved dementia care and detecting the inappropriate use of antipsychotics. As stated above, and if CMS approves or changes the survey protocol, consideration is recommended for additional surveyor training, based on the "lessons learned" in the Focused Dementia Pilot Surveys, incorporating some of the key elements of the focused surveys, to the extent those can be incorporated into standard surveys and abbreviated (complaint) surveys.

6) Provider Training

As CMS and CDPH continue efforts to train surveyors and continue the initiatives to reduce inappropriate antipsychotic use, we would like to ensure that providers are afforded the opportunity to be aware of changes in regulations, and formal guidance to state survey agencies.

Education Workgroup

The findings and recommendations of the Education Workgroup moving forward post-contract are as follows:

1) Develop Outreach Protocol

   Training tools for nursing home staff and leaders, activity professionals, physicians and pharmacists were created over the course of the contract period. A few contributors namely the California Culture Change Coalition's Program Director and Administrative Assistant participated in outreach and distribution of such tools. It would be highly beneficial for the CA Partnership to develop outreach protocol, or perhaps an outreach subcommittee, to make sure these valuable tools and resources are routinely distributed to the necessary parties.

2) Utilize HSAG's Performance Improvement Plan Tools and Resources

   As California nursing homes collectively decline in the use and misuse of antipsychotics, statistics reveal that the use of antipsychotics in specific nursing homes continues to remain the same and show no decline. It is recommended that such nursing homes that are not experiencing a decline of antipsychotics, particularly if the rate of antipsychotic usage for long-stay residents is over 15%, work with the necessary training personnel to develop a specific Performance Improvement Plan (PIP) that is tailored to the nursing home's needs. For example, California's Quality Insurance Organization (QIO) is the Health Services Advisory Group (HSAG).

   HSAG as an integral part of the CA Partnership, has previously partnered with CCCC on education trainings specifically on topics related to developing Performance Improvement Plans (PIPs) to decrease the use of antipsychotics in nursing homes. It is recommended that HSAG work directly with CA Partnership partners, contractors, trainers and with nursing homes who have not shown a decline in antipsychotic use for long-stay residents utilizing PIP tools approved by HSAG.

3) Seek Continuing Education Unit (CEU) Approval for CA Partnership Courses

   Currently the webinars that are offered through the created online dementia care toolkit (dementiacareresourceCA.org) are not approved to offer continuing education units. It is advised that the CA Partnership work with its partners and the Administrator Certification Section (ACS) of the Community Care Licensing Division to offer continuing education units for the training webinars offered. Under ACS regulations, Nursing Home Administrators are required to take training specifically in the topic of "medication management, including the use, misuse and interaction of drugs commonly used by the elderly, including antipsychotics, and the

adverse effects of psychotropic drugs for use in controlling the behavior of persons with dementia."

4) Establish Co-Facilitators for Combined CA Partnership Workgroups

While it was recommended that the Education and Consumer Awareness workgroups combine efforts under one workgroup moving forward, the intention and expectation is to place equal attention and deliberate planning for projects and deliverables that are tailored for all audiences, including professionals and families. The concern is that the education efforts will primarily be placed for professionals and the workgroup will experience a diminution in education efforts for residents and families. It is recommended that the combined Education and Consumer Awareness Workgroup establish co-facilitators from each of the former workgroups.

5) Establish Focus Groups for Proposed Tools and Resources

As additional tools and resources are developed and perhaps current tools and resources are re-evaluated, a focus group prior to distribution of the products should be utilized to ensure that they are tailored and standardized for the intended audience. The workgroup should develop a focus group, for example, consisting of nursing home staff and leaders, should tools be developed and disseminated for that particular audience.

6) Meet Cultural Competence Standards

It is the expectation and hope that the valuable training tools and resources that have been developed and will be developed to be evaluated to meet cultural competence standards. In addition, it is recommended that training tools are translated and made available in additional languages. For example, Dr. Gallagher-Thompson and her team at the Alzheimer's Research Center at Stanford are exemplary representatives of forming standards of cultural competence and are open to working with the CA Partnership to meet cultural competence standards.

Consumer Awareness Workgroup

The Consumer Awareness Workgroup findings and recommendations post-contract are as follows:

1) Develop Outreach Protocol

Similar to the resources developed through the Education Workgroup, it is highly recommended for the Consumer Awareness workgroup participants that resources and information guides that were developed for lay audiences such as residents and families, are routinely distributed, and

an outreach protocol plan is developed and maintained for further informative tools and resources for families.

2) Place Equal Efforts and Importance to Combined Workgroups

As mentioned in the previous section above, as the Education and Consumer Awareness workgroups combine, the expectation is to place equal efforts in assuring both families and residents receive model information regarding the use of antipsychotics and the right to informed consent and equally health care professionals receive the valuable training and education tools on antipsychotic use and dementia care.

3) Meet Cultural Competence Standards for Families

Addressing the participants of the Consumer Awareness workgroup, it is the expectation and hope that the information and resources that have been developed and will be developed for families are evaluated to meet cultural competence standards. In addition, it is recommended that all resources for families and residents are translated and made available in additional languages. Again, Dr. Gallagher-Thompson and her team at the Alzheimer's Research Center at Stanford are exemplary representatives of forming standards (and trainings) of cultural competence, and could be a potential go-to resource.

4) Establish Focus Groups

To assure all resources and tools meet the needs of families and residents, a focus group of lay persons is recommended to review all resources and tools prior to public distribution.

Informed Consent Workgroup

Lastly, below are findings and recommendations of the Informed Consent Workgroup post-contract:

1) Create Campaign to Disseminate Informed Consent Form Toolkit

One of the praiseworthy accomplishments of the CA Partnership is the development of the *Verification of Informed Consent Form for Antipsychotic Medication in Nursing Facilities* and the *Guide to Using the Informed Consent Verification Form.* The Informed Consent "Toolkit" also includes a Consumer Guide and an Example Letter to a Prescriber. While there was an initial promotion of the toolkit to all nursing home and stakeholders, it is essential that this valuable toolkit is distributed on an ongoing basis. The dissemination, implementation and follow-up of use of the form needs to continue in the next phase of the CA Partnership.

2) Create Education Component for Informed Consent Form

In addition to routine distribution, it is recommended that there be an educational component, such as a webinar or video, to both filling out the form and a train-the-trainer training. The education component also needs to include information on the right to be informed and give consent. The educational components are to meet cultural competent standards and available in additional languages. In a previous CA Partnership discussion, it was suggested that Dr. Karl Steinberg or a representative at the California Association for Long Term Care Medicine (CALTCM) prepare a video that addresses the above, which can be posted on the online toolkit and distributed publicly.

3) Establish Informed Consent Representatives to Serve on New CA Partnership Workgroups

It is recommended, and previously discussed by the CA Partnership, that the Informed Consent workgroup does not need to have an ongoing workgroup, but have Informed Consent "representatives" participating in the other CA Partnership workgroups.

Additional Findings and Recommendations: Future Leadership of the CA Partnership

The California Culture Change Coalition facilitated the CA Partnership and its members to derive an action plan to transition leadership successfully as to not disrupt the pulse and continuance of the work of the CA Partnership. Recommendations are discussed below. The final CA Partnership meeting under Contract 13-20555, which included extensive discussion of future goal setting and transition protocol, was held on February 23, 2016 at CDPH in Sacramento. The minutes of the meeting are referenced here.

1) Identifying New Leaders to Facilitate the CA Partnership

Nearly midway into the Contract, it was noted that the CA Partnership will need to identify new leaders to facilitate the CA Partnership once the Contract with CCCC came to a close in order to avoid a breach in momentum in achieving the mission to improve dementia care and reduce the use of antipsychotics in nursing homes. Continuity in both leadership and support staff is not only a recommendation, but a necessity.

In preparation of the next phase of the CA Partnership, CCCC identified the following contributors to lead the CA Partnership beginning March 1, 2016:

- Dolores Gallagher Thompson, Stanford Geriatric Education Center
- Elizabeth Landsverk, ElderConsult
- Jedd Hampton, LeadingAge California
- Karl Steinberg, California Association of Long Term Care Medicine
- KJ Page, CCCC Board, Chaparral House

- Lisa Hall, California Association of Health Care Facilities
- Michael Wasserman, Health Services Advisory Group

It should also be noted that the *Health Services Advisory Group* has been championed to lead and facilitate the CA Partnership and its Executive Committee. Workgroup facilitation at the CA Partnership meetings will be done by HSAG staff. The workgroups will work with HSAG staff to determine if this is the preferable way to proceed with the workgroups, or if they want to suggest someone within the workgroup to facilitate.

2) Suggested CA Partnership Goals

Participants need to further develop a consensus as to the continued purpose of the CA Partnership efforts. The CA Partnership will need to further discuss: Does the purpose of the CA Partnership remain the same, or do new goals need to be set?

- The suggested goal discussed at the CA Partnership meeting held on February 23, 2016: *The ultimate goal is to continue the reduction movement of .5% per quarter and get every facility below 5%.*

In general, the future work of the CA Partnership and the results of that work, needs to be measurable, and tied to specific deliverables that support the purpose of the CA Partnership.

3) Suggested CA Partnership Guiding Principles and General Discussion Points

Moving the Partnership forward into the next phase will require a consensus of why and how we are to move forward. The following are offered for discussion, to develop a consensus and common understanding about the CA Partnership's focus and responsibilities:

- Each participant brings important perspectives, experiences and priorities to the table. The CA Partnership values all participants.

- Participants of the CA Partnership shall be invited to involve organizations, such as nursing home providers, that are conducive to achieving its goals. However, to avoid discontinuity and setbacks, it is recommended that the CA Partnership work as a closed group by a certain cutoff date, with the exception of collaborating with consultants and advisers.

- While reaching 100% consensus is desirable for workgroup decisions, sometimes that is not possible. In those few instances, decisions about workgroup goals and deliverables will be established by a majority of workgroup members.

- The CA Partnership's work will be completed through the establishment of workgroups. The previous workgroups were: Education; Consumer Awareness; Informed Consent and Enhanced

- Enforcement. Consensus for the following was identified: combining the Education and Consumer Awareness workgroups into one; discontinuing the Informed Consent workgroup but having representatives on the other work groups; and changing the focus (and the name) of the Enhanced Enforcement workgroup. Subject to a name change requested by the workgroups, this would mean that the two workgroups would be:

    - Education and Consumer Awareness
    - Quality Care and Compliance

Conclusion

There is continued work to be done to ensure that no resident is prescribed unnecessary antipsychotics. The Partnership participants pledge to work closely with CDPH and CMS in efforts to further reduce the use of antipsychotics, as the Partnership transitions to a post-funding level of activity. There are several changes that have taken place over the past two years, that have the potential to continue the push toward antipsychotic reduction, and we will use the experiences and accomplishments of the past two years to guide our future activities and initiatives.

The California Culture Change Coalition is honored to have been an integral part of the campaign to improve dementia care through our leadership and collaborative efforts with the California Partnership to Improve Dementia Care. CCCC and the CA Partnership could not have done it without the support of the Centers for Medicaid and Medicare Services and the California Department of Public Health. ***CMS and CDPH not only served as authorized funding and contract entities, but served and continue to serve as dedicated participants and advisers committed to establishing our state's nursing homes to be model standards of care.*** By Contract's end, we invite you to visit dementiacareresourceCA.org, where all of the training tools, resources, and best practice guidelines for both professionals and families will be located. For your reference, please refer to Table 2.1 of completed California Partnership to Improve Dementia Care projects and resources during the Contract duration, and a direct link to access them.

Thank you to the California Department of Public Health for your time and the opportunity.

California Culture Change Coalition
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Below is a list of those who served on the CCCC Board during the term of Contract 13-20555

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