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*UCSF Health Workforce Research Center  
on Long-Term Care*

Research Brief

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# Dementia Care Coordination Workforce and Practices in Seven Duals Demonstration States

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November 20, 2015

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This project is/was supported by the Health Resources and Services Administration (HRSA) of the U.S. Department of Health and Human Services (HHS) under grant number U81HP26494, Cooperative Agreement for a Regional Center for Health Workforce Studies. This information or content and conclusions are those of the authors and should not be construed as the official position or policy of, nor should any endorsements be inferred by HRSA, HHS or the U.S. Government.

Please cite as: Hollister, B. and Chapman, S. (2015). Dementia Care Coordination Workforce and Practices in Seven Duals Demonstration States. San Francisco, CA: UCSF Health Workforce Research Center on Long-Term Care.

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## **Dementia Care Coordination Workforce**

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### Executive Summary

As health systems continue to evolve toward more managed care models, care coordinators are playing an increasingly important role in ensuring that people with Alzheimer's disease or related dementias (ADRD) receive appropriate, well-coordinated, and cost-effective care. Research has shown that effective care coordination and referral to services and supports for patients with ADRD and their informal caregivers (family and/or friends who provide care) can decrease unnecessary medical services utilization, delay institutionalization, and improve the quality of life of both patients with ADRD and their caregivers. However, care coordinators are often unprepared to meet the needs of this challenging population.

This report systematically reviews and analyzes care coordinator policies and practices within health plans participating in the US Centers for Medicare & Medicaid Services' (CMS) demonstration programs for dually-eligible Medicare and Medicaid beneficiaries (referred to as "duals"). The demonstration projects currently under way in 12 states are in the early phases of implementation and evaluation. This research enhances our knowledge of the care coordination workforce and practice requirements in duals demonstrations. It also highlights the need for a workforce of adequate numbers of dementia-capable care coordinators to serve people with ADRD and their caregivers.

### Methods

States were selected for this research based on 4 criteria, including: 1) a capitated financing alignment model; 2) enrollment begun on or before January, 2015; 3) demonstration programs that include older adults; and 4) demonstrations expected to continue beyond January, 2016. Seven states met inclusion requirements for our analysis: CA, IL, MI, NY, OH, SC, and VA. Three-way contracts between CMS, the states, and health plans or other contracted entities were reviewed from each of the 7 states [1-7]. We also interviewed 24 key informants (KIs) selected for their national or state expertise in the care coordination workforce, dementia care coordination, or duals demonstration policy in the individual states or nationally. This study received human subject research exemption from UCSF's Committee on Human Subjects Research.

## **Results**

The review of documents revealed that most state contracts had some language specifying care coordination workforce and practice requirements in duals demonstrations. The 3-way contracts generally defined the workforce conducting care coordination services as “care coordinators” or “care managers,” and many states required a Bachelor’s degree or education or certification in registered nursing or social work. Several KIs noted the lack of adequate and qualified personnel required to meet the needs of the duals demonstration members. For this and other reasons, states tended to opt for more flexibility rather than being too prescriptive in care coordination workforce requirements. Experience and training requirements for care coordinators were often broadly defined. While several state requirements mentioned experience in caring for the aged and persons with ADRD, there was little specificity about the training content or what competencies were required.

## **Conclusions/Recommendations**

The extent to which care coordinator requirements and practices were defined in duals demonstrations is related to several factors: 1) workforce availability and qualifications; 2) existing state policies concerning Medicaid waivers, Medicare Advantage Programs, and Managed Long-Term Services and Supports (MLTSS); and 3) the stakeholder process and strength of advocacy movements surrounding the creation of the duals demonstrations in the state. Several KIs noted an apprehension about making contracts too prescriptive, which would risk negative unintended consequences and prevent the innovation and flexibility necessary to achieve the overall goals of the demonstration.

Promising practices for the utilization of existing workforce resources and dementia-capable training for care coordinators were identified. While the variability of the duals demonstrations makes it difficult to compare across states, all demonstrations will benefit from efforts to evaluate outcomes of policies impacting people with ADRD and their caregivers. The 3-way contracts are often the starting point of a process to more clearly define policies and practices in each state. As the dual demonstrations further develop the requirements related to the care coordination workforce and practice, it will be important to evaluate outcomes and share promising practices.

## Dementia Care Coordination Workforce

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### Introduction

As of 2015, an estimated 5.3 million Americans had Alzheimer's disease, costing the United States \$226 billion in health, long-term care, and hospice care [8]. Medicare and Medicaid are expected to cover approximately 68% of these costs, or \$153 billion [8]. Persons with Alzheimer's disease or related dementias (ADRD) frequently have other serious chronic health conditions: 60% have hypertension, 26% have coronary heart disease, 25% have stroke, and 23% have diabetes. Some have multiple coexisting conditions [9]. Individuals with dementia cost Medicare 3 times more than other beneficiaries in the same age group, mostly due to hospitalizations [9]. Medicaid reimbursements for individuals with cognitive limitations are even higher than for those without dementia, largely due to nursing home utilization [9]. People with serious medical conditions and ADRD are more likely to be hospitalized, and hospital length of stay (LOS) is longer, than people with the same condition without ADRD. They are also more likely to utilize other health care services than their non-ADRD counterparts, costing more per person and resulting in higher costs for Medicare and Medicaid [10-18].

Two-thirds of people with ADRD live in the community and are cared for by unpaid family or friends, generally referred to as "informal" or "family" caregivers [19]. In 2014, caregivers of people with ADRD provided approximately 17.9 billion hours of caregiving services valued at an estimated \$217.7 billion [8]. Furthermore, caregivers of people with ADRD had \$9.7 billion in additional health care costs of their own (2014 data) as a result of the physical and emotional burden of providing care to someone with ADRD [8].

Research has shown that effective care coordination and referral to services and supports for patients with ADRD and their caregiver can decrease unnecessary medical services utilization, delay institutionalization, and improve the quality of life of both patients with ADRD and their caregivers [20-36]. A lack of knowledge about ADRD and the skills needed to care for an individual with ADRD has been associated with poor patient outcomes, increased caregiver burden, and depression. Many studies revealed that care coordination and service interventions that are more intensive, that are adapted to meet individualized needs, and that target both patients and their caregivers were more successful in reducing caregiver burden, increasing skills and knowledge, enhancing satisfaction, and preventing or delaying institutionalization [36, 37].

## Background

Care coordination is defined in many ways, but after a systematic review of these definitions, the United States Agency for Healthcare Research and Quality (AHRQ) defined care coordination as, "...the deliberate organization of patient care activities between two or more participants (including the patient) involved in a patient's care to facilitate the appropriate delivery of health care services. Organizing care involves the marshaling of personnel and other resources needed to carry out all required patient care activities and is often managed by the exchange of information among participants responsible for different aspects of care." Experts in the field have long provided evidence to support best practices in dementia-capable care coordination and workforce training [38-50]. However, workforce challenges and other barriers remain to implementing these best practices.

### ***The Dementia Care Coordination Workforce***

The current long-term care workforce is neither large enough nor adequately trained to meet the needs of the aging population [51]. It is estimated that by 2030 the United States will need an additional 3.5 million health care providers [52]. The workforce needed to coordinate care for persons with ADRD is part of this overall shortage. These workers include a range of professionals such as physicians, nurses, social workers, and direct care workers (home health care workers and personal health care aides) who provide the bulk of care in the home. The Bureau of Labor Statistics projects an increased need for more than 114,000 social workers by 2022 [53]. In many professions such as medicine, nursing, and social work, few are specialized in the needs of an aging population. A 2005 study showed that only one-third of baccalaureate nursing programs required a course focused on geriatrics [54]. Social worker training is similar in its lack of geriatrics content. As of 2003, only about 29% of social work programs at the Master's level offered an aging concentration/specialization or certificate program [55]. Additionally, just 4% of social workers identify themselves as specializing in geriatrics [56].

### ***CMS' Duals Demonstration Programs***

Over 9.6 million seniors and younger people with significant disabilities are dually eligible for both Medicare and Medicaid and are often among the poorest and sickest beneficiaries in these programs [57]. Recognizing the challenges of coordinating and financing the care for those dually eligible for Medicare and Medicaid, the Centers for Medicare & Medicaid Services' (CMS) launched Financial and Administrative Alignment demonstrations, which seek to improve care and

control costs. As of June 2015, nearly 355,000 beneficiaries in 9 states were enrolled in these demonstrations [57].

In order to improve care and control costs for these beneficiaries, several states are working with CMS to test capitated and/or managed-fee-for-service models, align financing, and integrate care through care coordination. States participating in these “duals demonstration projects” are presented with opportunities to establish and implement best practices related to the care coordination workforce and care coordination activities. In these demonstrations, care coordinators are expected to play an important role in ensuring that people with ADRD receive appropriate, well coordinated, and cost-effective care.

Three-way contracts between CMS, states, and health plans provide an opportunity to define the qualification, experience, and training requirements of care coordinators. These contracts also provide details on models of care, health risk assessments, and care management practices, including the development of an individual care plan and interdisciplinary care teams. These contracts also specify how plans should identify and integrate the caregiver into the care planning process, whether they should assess caregivers’ capacity to provide care, and what supports and services caregivers might be eligible for if needs are identified.

Given the opportunities presented within the duals demonstrations, the evidence supporting best practices in dementia care coordination, and the high costs associated with caring for someone with ADRD and their caregiver, this study provides a summary of the requirements for the care coordination workforce and practices in early implementation across 7 duals demonstration states, especially as they relate to serving people with ADRD and their caregivers.

### ***Dementia Care Coordination and Managed Long-Term Services and Supports***

Many health plans participating in the demonstrations may have experience operating within managed care settings; however, few have experience with providing managed long-term supports and services (MLTSS). Those plans with prior experience in providing MLTSS have previously operated within Medicaid waiver programs or Medicare Advantage Special Needs Plans. Assuming full financial and care coordination responsibilities for member LTSS needs, like those with ADRD, will be new for many of these plans.

Recently, the AARP Public Policy Institute (PPI) contracted with Truven Health Analytics to conduct an evaluation of care coordination in MLTSS systems [58]. The report presents information about the care coordination workforce requirements and practices as defined in 18 managed MLTSS state contracts with health plans,

including both Medicaid-only programs and Medicare-Medicaid demonstration programs. The report also describes who care coordinators are, what they do, whom they help, and if they involve caregivers. Although the AARP PPI report is not focused on duals demonstrations in particular, or the care coordination needs of people with dementia and their caregivers, relevant findings are reported below alongside findings from this study in order to link the findings of each of these significant efforts. We refer to the AARP PPI report frequently in this report and use some of their terminology, models, and frameworks.

## Methods

States were selected for this research based upon the following criteria: 1) duals demonstrations included a capitated financing alignment model; 2) duals demonstrations began enrollment on or before January 2015; and 3) duals demonstrations included older adults (age  $\geq 65$  years). Fee-for-service (FFS) financing models were excluded as the financial incentives in these models vary significantly from those of capitated models. Duals demonstrations with a later enrollment date were thought to have too little experience in implementation to be analyzed at this time. Lastly, although ADRD impacts adults under age 65, the greater proportion of the affected population is over age 65 years, and thus programs including those over 65 years of age were most relevant to our inquiry.

As of July 2014, 12 states had signed memoranda of understanding (MOUs) or 3-way contracts with CMS, 10 of which utilized capitated payment models [57]. The Massachusetts demonstration serves only non-elderly adults and was excluded. Texas' demonstration was excluded from analysis due to a late start date. Additionally, although Washington originally included a capitated payment demonstration, it is unlikely to be continued past 2015 and was therefore excluded. For these reasons, our analyses included 7 states: California, Illinois, Michigan, New York, Ohio, South Carolina, and Virginia.

While the duals demonstrations will be evaluated nationally by Research Triangle International (RTI), many state-specific evaluations are now under way. Those evaluations will focus on overall outcomes of the program, rather than on the process of workforce development and training required to reach those outcomes.

## **Document Reviews**

The documents reviewed included 3-way contracts between CMS, each of the 7 states, and participating managed care plans. The contract documents were reviewed first for sections relevant to the care coordinator workforce, dementia and caregiver assessments, and care coordination practices. Following the initial review, we conducted key word searches in each of the 3-way contracts to ensure that nothing of relevance to the study objectives was overlooked. In addition, several other reports were helpful in guiding our study design, developing our interview instruments, and informing our analyses [38, 41, 57-60].

## **Key Informant Interviews**

Key informants (KIs) were identified based upon their national or state expertise in care coordination workforce, dementia care coordination, or duals demonstration policy in the individual states or nationally.

Twenty-four KIs were interviewed. Thirteen of the KIs are considered national experts, but may have also had expertise in one or more of the demonstration states. Another 11 KIs represented specific states, including California (2), Illinois (1), New York (3), Ohio (2), and South Carolina (3). We were unable to secure KI interviews for 2 states. We attempted to interview KIs representing a variety of stakeholders engaged in duals demonstrations, including: CBOs and advocacy organizations (8), academic researchers (6), federal government (5), state government (4), and health plans (1). Only 3 of the invited participants failed to respond or refused to participate, and 5 referred the study team to someone else that they deemed knowledgeable on the topic.

Interviews utilized a semi-structured protocol and lasted between 45 and 90 minutes. Most of the interviews were recorded and transcribed verbatim prior to analysis; in 2 interviews, notes were taken by separate interviewers and combined for analysis. This study received human subject research exemption from UCSF's Committee on Human Subjects Research. KI participants were reassured that their identity would be kept confidential, data would be de-identified, and participant identification keys would be securely stored. Notes and transcribed interviews were analyzed by the study using qualitative data analysis software (ATLAS.ti).

## Results

### ***Care Coordinator Semantics***

The review of documents revealed that most state contracts defined the workforce conducting care coordination services as “care coordinators” or “care managers.” Michigan’s contract includes workforce specifications for both a “care manager” and a “LTSS service coordinator.” Similarly, Ohio’s contract details the qualification requirements of a “care management director” and a “HCBS/LTSS director” that each health plan is required to hire.

Despite this variability, some trends emerged from our KI interviews. Often, “care managers” and “care coordinators” were understood to require a higher level of education or certification, such as registered nurses or social workers. Occasionally, health plans and Area Agencies on Aging (AAAs) used the term “case manager” to describe the workforce that coordinated the care of their clients. The term “care navigator” was also used occasionally to imply a workforce that was embedded within a community to improve outreach into difficult to reach populations, such as non-English speaking populations or transient populations. Overall, it was generally agreed that these terms are often used interchangeably and inconsistently both across and within states by health plans, community-based organizations, or state representatives. When we asked the interviewees explicitly about the difference between these terms and roles, many admitted that they did not know.

For the purposes of this report, we utilize the term “care coordinator” to refer to an employee or delegated subcontractor of the duals demonstration health plan who coordinates the care of members, conducts health risk assessments, develops person-centered care plans, convenes interdisciplinary care teams, and ensures that members receive necessary services. As was defined in the AARP PPI report, care coordinators are responsible for the coordination of all health and social service care needs, including medical, LTSS, and behavioral health [58].

### ***Care Coordination Workforce Requirements***

#### *Care Coordinator Qualifications*

Similar to what was reported in the AARP PPI report [58], we found that care coordinator qualifications varied by state. Of the 7 state contracts examined, 3 require care coordinators to have at least a Bachelor’s degree (MI, SC, VA) while 3 do not (CA, NY, OH) (Appendix Table 1). Illinois’ 3-way contract requires that care coordinators serving older adults through their “persons who are elderly HCBS

waiver” have either a Bachelor’s degree or at least 4 years of program experience. Nursing and social work were the most common types of degrees cited; others mentioned include sociology and psychology.

Although California’s MOU defined a “clinical care coordinator” as a licensed registered nurse (RN) or other individual licensed to provide clinical care management, this designation and the degree requirement do not appear in the final contract. California’s contract states that care coordination is to be performed by “nurses, social workers, primary care providers, if appropriate, other medical, behavioral health, or LTSS professionals, and health plan care coordinators as applicable” [5]. While New York has required care coordinators to be health nurses, social workers, and therapists in previous MLTSS contracts, their contract states that “care managers must have the experience, qualifications, and training appropriate to the individual needs of the participant, and the [health plan] must establish policies for appropriate assignment of care managers” [3].

CMS was consistent across contracts in its expectation that health plans will match more highly qualified care coordinators, such as nurses or social workers, with members diagnosed with more complex conditions, requiring higher levels of care coordination and other health and social services. From our KI interviews, this expectation appears to have been upheld and some innovations were shared: *“One of the plans was talking about [how] one of their care managers was a breast cancer survivor and she had not only the clinical expertise [of] being a nurse but actually went through chemo and treatment for it, so she took more of the cancer patients. It wasn’t that it was a requirement but some plans... try to group the beneficiaries with the same conditions with them” (CA KI).*

### Care Coordinator Experience

Beyond workforce qualifications, state requirements for care coordinator experience also varied. One concern expressed in the KI interviews was that even with a degree, some care coordinators might lack the expertise required to coordinate care for highly complex members, especially those with dementia. For example, RNs may be qualified to coordinate the medical care of their members, but may be less proficient at evaluating and addressing their members’ psychosocial needs.

Some state contracts dealt with this challenge by requiring care coordinators to be familiar with LTSS, psychosocial services and supports, and/or working with older adults. For example, the MI, NY, and SC contracts require that care coordinators must have knowledge in several areas important for people with ADRD and their caregivers, including: aging and loss; appropriate support services in the

community; depression; challenging behaviors; Alzheimer's disease and other disease-related dementias; available community services and public benefits; quality ratings and information about available options such as nursing facilities; and elder abuse and neglect. The AARP PPI report presented a similar finding, with about half of the MLTSS systems requiring care coordinators to have experience in LTSS or disability [58].

### Care Coordinator Training

Duals demonstration contracts also presented an opportunity to advance workforce training requirements, especially for care coordinators serving members with complex needs, such as those with ADRD, and their caregivers. As was found in the AARP PPI report on MLTSS system training requirements, all contracts required some level of initial or ongoing training for care coordinators. Occasionally training requirements were not defined in contracts for care coordinators specifically, but rather for interdisciplinary care team (ICT) members, which include care coordinators, as well as providers, members, and caregivers. Several important areas of training for care coordinators were mentioned in most contracts: person-centered care planning processes; cultural and disability competence; communication, accessibility and accommodations; Americans with Disabilities Act (ADA)/Olmstead requirements; independent living; and recovery and wellness principles. Examples of training requirements spelled out in states' contracts are presented in the Box.

Illinois' contract: Care coordinators must be trained on topics specific to the type of HCBS waiver enrollee they are serving. Care coordinators who serve enrollees of the Persons who are Elderly Waiver must be trained in related subjects.

California's contract: Health Plans designate and train a "dementia care coordination specialist" who receives training in: understanding dementia symptoms and progression, understanding and managing behaviors and communication problems caused by dementia, caregiver stress and its management, and community resources for enrollees and caregivers.

- Illinois' contract: Care coordinators must be trained on topics specific to the type of HCBS waiver enrollee they are serving. Care coordinators who serve enrollees of the Persons who are Elderly Waiver must be trained in related subjects.
- California's contract: Health Plans designate and train a "dementia care coordination specialist" who receives training in: understanding dementia symptoms and progression, understanding and managing behaviors and communication problems caused by dementia, caregiver stress and its management, and community resources for enrollees and caregivers.

In most cases, however, the specific content of trainings were largely undefined, leading to concerns about the consistency of content and the quality of training programs. In addition, with the confusion over the various care coordinator roles, it remains unclear in our analysis as to which roles will require training, and in which competencies.

### ***Understanding the Variability in Workforce Requirements***

Several themes arose within the KI interviews that may help explain some of the variability across states as to specifications for care coordinator qualifications and requirements. First, much of the variability can be traced to previous Medicaid waiver legislation or existing state terms and definitions. This is evidence of the path dependency of relying on previous policies, systems of care, and terminology already used by the states [61]. "*The state-specific demonstrations flowed from any foundation the state already had for duals or for their Medicaid-only people with disabilities programs*" (National KI). For example, most states retained the standing terminology related to care coordinators and care coordination. While using consistent terminology might be convenient, it was not a priority for CMS, and states preferred to perpetuate existing terminology. Similarly, the models of care presented in the contracts often built upon existing programs, resources, and strengths in each state. States with a history of strong Medicaid Waivers often adopted or integrated models of care from those waivers into their duals demonstration. Despite this path dependency, these duals demonstrations also allowed some states to explore new and innovative systems of care.

Second, several KIs noted the lack of qualified personnel required to meet the care coordination demands. Given the national shortage of geriatric-trained social workers, nurses, and non-clinical care coordination staff, imposing strict experience requirements would be problematic for many states. States with requirements that health risk assessments (HRAs) be conducted by care coordinators with a clinical degree imposed challenges to hiring sufficient internal staff to meet the HRA timeline requirements imposed by CMS. (Most HRAs,

especially for high-risk members, had to be completed within 30 days of enrollment.) This resulted in some health plans contracting with outside agencies specifically to meet their HRA completion requirements. The workforce shortage has also forced competition for qualified care coordinators throughout the health and social service systems in some states. *"The state care managers are being hired by the MCOs [managed care organizations] and it's becoming more and more of a challenge for the states to keep anybody at the state level that can do that job well, because all of the good people went to the higher pay employer which is always the MCO versus the state"* (National KI).

### ***Promising Practices***

Our analyses revealed several promising policies, care coordination workforce requirements, dementia-capable training, and care coordination practices. As duals demonstrations are still in their relative infancy, further evaluation of these practices is needed to determine outcomes related to member and caregiver satisfaction; utilization, costs, and returns on investment (ROI); and feasibility and scalability.

### ***Building on Existing Resources***

Some states' contracts required health plans (at least for the initial phases of the demonstration) to utilize the existing LTSS systems to coordinate the care of members requiring those services (CA, OH, VA). While this approach ensured that existing resources and expertise were being utilized and that members had continuity of care through their existing care coordination services, it also forced contracts to perpetuate the existing workforce requirements of these programs and agencies.

In Ohio, the contract required that health plans contract with AAAs to coordinate the home- and community-based waiver services for members over 60 years old [2]. AAAs were highly involved in advocating for the inclusion of this provision in the contract, arguing that plans didn't have the expertise to provide these services and that without this provision, members would experience a significant disruption in their care and the relationships they have built with AAA care coordinators. Health plans resisted the provision, believing that delegating a function as important as care coordination in a capitated managed care program would diminish their capacity to control costs. Despite this resistance from health plans, the contract ultimately required that plans contract with AAAs for at least the first phase of the demonstration. KIs noted that this was working well in regions with strong AAAs, but AAA capacity varies significantly throughout the state of

Ohio. The AARP PPI report includes a case study of Ohio's demonstration that describes these nuances more thoroughly [58].

In California, health plans are required to establish MOUs with county social services agencies to coordinate In Home Supportive Services (IHSS) [5, 57]. Although not mandated, some health plans have established contracts directly with IHSS. The AARP PPI report also described a trend in MLTSS systems toward what they referred to as a "Shared Functions" model, even when there was no specific requirement to establish partnerships with community-based organizations (CBOs) [58]. Whether through an MOU or a direct contract, key informants believed that effective collaboration between health plans and IHSS agencies was necessary to ensure effective care coordination for people receiving IHSS or other LTSS.

In South Carolina, the Department of Health and Human Services (DHHS) utilized a phased implementation model, delaying the transfer of several care coordination activities from the DHHS to their health plans until later in the demonstration [1]. A Key Informant argued that this ensured that plans had time to build their capacity to serve complex members and reassured advocates in the state that were concerned about health plans' capacity to serve members requiring LTSS.

#### Caregiver Identification, Assessment, and Supports and Services

A caregiver can be a valuable informant and resource for health plans seeking to better coordinate the care of a member with ADRD. As the AARP PPI report found in their review of MLTSS contracts, "The most common mention of family caregivers is in the context of assessment, usually as a source of information that should be sought out by the care coordinator with consent of the member" [58]. Most contracts stipulated that caregivers be identified and involved in the care planning process, and that their qualifications or capacity to provide care be assessed (IL, MI, NY, OH, SC, VA) (Table 1). The South Carolina contract was among the most prescriptive, noting that caregiver status and capabilities should be assessed using the state's comprehensive assessment tool, Phoenix, and should include the caregiver's status, capacity, and qualifications, and risks associated with burnout or the ability to no longer perform duties [1].

**Table 1. Caregiver Assessment Requirements in 3-way Contracts**

<b>California</b> [5]	None specified
<b>Illinois</b> [6]	Health plans must identify and evaluate risks associated with the member’s care. Factors considered include caregiver qualifications.
<b>Michigan</b> [4]	Assessments must include natural supports, including family and community caregiver capacity, and social strengths and needs.
<b>New York</b> [3]	Assessment domains will include caregiver status and capabilities. Health plans must identify and evaluate risks associated with the member’s care. Factors considered include caregiver qualifications.
<b>Ohio</b> [2]	Assessments must include caregiver status and capabilities and informal and formal supports.
<b>South Carolina</b> [1]	Assessment domains will include caregiver status and capabilities. Health plans must identify and evaluate risks associated with the member’s care. Factors considered include caregiver qualifications and risks associated with burnout or the ability to no longer perform duties.
<b>Virginia</b> [7]	The plan of care will contain the member’s informal support network and services.

Several KIs expressed a concern that just identifying a caregiver was inadequate without also mandating assessments of the caregiver’s capacity or the provision of education, respite, or other services to meet their needs. One KI stated that it would be important *“to include assessment of the caregivers involved and how they’re doing because very often how the caregiver is doing often drives how well the participant does”* (National KI).

Another KI, who is also a caregiver for someone with ADRD, argued that caregivers shouldn’t be assessed if health plans don’t also have services and support to offer to them. *“In all honesty it’s not helpful to pretend to do an assessment of the caregiver if you can’t offer them anything. You’re better off to not do it, and that’s God’s honest truth... If you get to the end of it, and they say we can’t offer you anything, they just wasted the your time. Just don’t bother”* (National KI). Most of the contracts required that health plans provide health

promotion and wellness activities for caregivers (IL, MI, NY, OH, SC, VA), with several states using the same contract language. Health plans "...must provide a range of health promotion and wellness informational activities for enrollees, their family members, and other informal caregivers." Unfortunately, contracts rarely mandated that health plans provide caregiver supports and service to meet the non-educational needs identified through assessments.

South Carolina was, again, the exception, with one key informant describing their efforts to *"...identify caregiving as a topic that we want our health plans to address.... each of the plans has to come up with at least one quality improvement project that centers on caregiving.... we think that that's another nuance that they're not necessarily thinking about that as they should especially as their members over time will age in place. They need to think ahead, of the role of the caregiver in helping to support the member and helping them to maintain that high quality of life"* (SC KI). While other contracts didn't mandate the provision of supports and services to caregivers in need, those services may be offered through existing LTSS programs. As mentioned in the AARP PPI report, caregiver training and support are available services under the Community-Based Adult Services (CBAS) program in California, which is a required LTSS benefit offered by health plans. Health plans can also offer optional supports and services when a unique member need is identified, which could open the door to caregiver supports and services. Additionally, benefits available to the member may also be beneficial to the caregiver, such as care coordination and IHSS.

Unfortunately, most duals demonstration evaluations have limited capacity to home in on outcomes specific to best practices in caregiver identification, involvement, and supports and services. Innovative programs such as South Carolina's could help other states argue persuasively for similar caregiver-friendly provisions. One SC KI believes that, *"...the data from our caregiver assessment will help us... build an argument for why we should perhaps consider adding this as one of the services under the waiver. That's one of the things that we're seriously looking at for our waiver renewal next year, adding a caregiver-related service"* (SC KI).

By simply identifying a caregiver, KIs questioned whether the health plans might rely too heavily on the care provided by the caregivers, lower the member's risk level, or provide fewer services to the member than if they didn't have a caregiver. One KI noted that *"There's certainly the accusation that managed care models are going to push more of the caregiving burden back on family members in order to increase profits of the health plans. I have not seen any evidence of that. But that's certainly one of the hypotheses"* (National KI). While any examples of this have been anecdotal, another KI explained that, *"Often there is a negotiation*

*between the health plan and the family caregiver around meeting the total care needs of the member.... So, if they say, 'well, we can only give you 4 hours a day or 6 hours a day,' then somebody else is going to have to be there at other times"* (National KI). Additional research is needed to ensure that plans are not shifting the costs of care to overburdened and unsupported caregivers.

### *Dementia-capable Care Coordination Training*

South Carolina's DHHS has contracted with the University of South Carolina Office for the Study of Aging to provide the dementia care coordination training for all health plan care coordinators as required in their contract. Future training needs will be fulfilled in partnership with the South Carolina Alzheimer's Association. Caregiver trainings are also being provided to caregivers of people with dementia whose assessments reveal a need for such training. South Carolina's model of integrating dementia-capable trainings and education into their duals demonstration, with specially designated funds to deliver these services, could serve to inform future replication in other states.

In 2013, California's Alzheimer's Association and the California Department of Aging received funds from the United States Administration for Community Living to provide dementia care coordination training to care coordinators within California's duals demonstration health plans. To date, 255 care coordinators have been trained with project funds, and additional trainings have been hosted and funded by health plans. Preliminary results from the Cal MediConnect Dementia Project have shown that satisfaction among care coordinators participating in the dementia care coordination training has been high, and promising systems changes continue to be made [62]. To meet the requirement in the California contract to provide a "dementia care coordination specialist," several health plans have contracted with the Alzheimer's Association in California to provide a "dementia care coordination specialist" training for these specially designated staff. By early September of 2015, approximately 19 dementia care coordination specialists had been trained, representing 8 health plans or medical groups.

### *Facilitators and Challenges to Replicating Promising Practices*

Through KI interviews, a couple of important factors related to the feasibility and replication of promising practices were revealed. First, stakeholder processes and individual champions often influenced the integration of best practices into the duals demonstrations. In South Carolina, a handful of strong state level champions are credited with leading the state's efforts to pursue more advanced identification, assessment, and inclusion of caregivers of people with dementia. One KI noted that, "*...from a design perspective, our team just understood the importance of*

*recognizing dementia and then providing dementia support to not only the members but also the caregiver as it relates to helping people stay out of the long-term care system, so it was just having that big picture understanding” (SC KI).* In California, the Alzheimer’s Association and other advocates were highly involved in the stakeholder process. Similarly, the Alzheimer’s Association’s partnership with the California Department of Aging through their Cal MediConnect Dementia Project allowed advocates a “seat at the table” and opportunities to raise awareness and pursue systems change at a state level. As duals demonstrations continue to be implemented across the country, advocates should learn from efforts in other states.

A second factor influencing the possibility of establishing or replicating promising practices seems to be the history and entrenchment of managed care organizations in each state. As mentioned earlier, demonstrations may be limited by the path dependence of previous policies and practices, including those of an established managed care industry. One possible explanation for the progressive nature of South Carolina’s contract is that MCO activity in South Carolina, especially in LTSS prior to the demonstration, was minimal, allowing the state to start from scratch in building their model of care. *“We researched other states and tried to learn from their mistakes and from the opportunities that they ran into with their different approaches” (SC KI).* However, the presence of an established managed care industry also implies established collaborations and partnerships that are crucial to effectively coordinating care across the health and social sectors. Replication of promising practices should consider any variation in managed care organization entrenchment, capacity, and practices.

## Conclusions

Care coordination is an important component in the implementation of duals demonstrations projects. The 3-way contracts between CMS, the states, and health plans include language defining, to some extent, the care coordinator workforce and care coordination practices. The extent to which care coordinator requirements and practices were defined in duals demonstrations is related to several factors: 1) workforce availability and qualifications; 2) existing state policies around Medicaid waivers, Medicare Advantage Programs, and MLTSS; and 3) the stakeholder process and strength of advocacy movements around the creation of the duals demonstrations in the state.

The most common professions identified as care coordinator were social workers and nurses. However, labor market projections indicate a shortage of social workers in the future [54]. Training requirements for care coordinators were defined in some of the agreements but there was little specification of the training

content or identified curriculum. Previous research indicated that geriatrics content is absent or minimal in many professional training curricula [55]. In states like California and South Carolina, promising practices could be traced back to particular advocacy efforts or the work of dementia champions within the state. KIs noted concerns about making contracts too prescriptive, thus risking negative unintended consequences and preventing innovation and necessary flexibility to achieve the overall goals of the demonstration.

### **Recommendations / Future Directions / Implications**

While variability across duals demonstration programs makes cross-state comparisons challenging, future evaluations of demonstration outcomes may highlight promising practices. However, implementing promising practices from one state to another will require some flexibility to account for state differences. State-specific evaluations of duals demonstrations will be helpful to understand the impact of care coordination models on duals demonstration members and their caregivers [63].

National movements to better understand MLTSS systems will also help advance our understanding of care coordinator workforce and practice policies. Organizations like the AARP PPI, American Society on Aging, the Gerontological Society of America, The Hartford Foundation, the SCAN foundation, the National Care Coordination Consortium (N3C) and the Dementia Caregiving Network are all interested in better understanding the intersection of MLTSS, care coordination, dementia care coordination, and the care coordination workforce. This research helps shine a light on some of the issues to date, but further research and evaluation is needed on the impact of duals demonstration policies on care coordination workforce and practices for people with ADRD and their caregivers.

## **Acronyms Used in this Report**

AAA	Area Agency on Aging
AARP PPI	AARP Public Policy Institute
ADRD	Alzheimer’s disease and related dementias
CMS	Centers for Medicare and Medicaid Services
FFS	Fee for Service
HCBS	Home and Community-Based Services
HHS	U.S. Department of Health and Human Services
HRA	Health Risk Assessment
HRSA	Health Resources and Services Administration
ICT	Interdisciplinary Care Team
KI	Key Informant
MCO	Managed Care Organization
MLTSS	Managed Long-Term Services and Supports
MOU	Memorandum of Understanding
MSSP	Multi-Purpose Senior Service Program
LTC	Long-Term Care
LTSS	Long-Term Services and Supports
SLUMS	Saint Louis University Mental Status Examination

## Appendix

**Appendix Table 1. Care Coordinator Degree/Certification and Expertise Requirements in 3-way Contracts**

	<b>Degree/Certification Requirements</b>	<b>Expertise Requirements</b>
<b>California</b> [5]	Care coordinators are nurses, social workers, primary care providers, and, if appropriate, other medical or long-term services and supports professionals, and health plan care coordinators.	Health Plans will have a process for assigning a care coordinator to each member needing or requesting one. Assignments made to a care coordinator with the appropriate experience and qualifications based on a member’s assigned risk level and individual needs.
<b>Illinois</b> [6]	<p>Care coordinators who serve members assigned to higher risk levels must have a clinical degree. Care coordinators who serve members assigned to lower risk levels may have non-clinical backgrounds.</p> <p>Care coordinators who serve members within the Persons who are Elderly HCBS Waiver must meet 1 of 4 requirements: (1) RN licensed in Illinois; (2) Bachelor’s degree in nursing, social sciences, social work, or related field; (3) LPN with 1 year of experience in conducting comprehensive assessments and provision of formal service for the elderly; or 1 year of satisfactory program experience may replace 1 year of college education, at least 4 years of experience replacing Baccalaureate degree.</p>	<p>Care coordinators must have the qualifications and training appropriate to the needs of the member, and the health plan must establish policies for appropriate assignment of care coordinators.</p> <p>Care coordinators who serve members assigned to higher risk levels may have community-based experience working with the elderly, persons with disabilities, including developmental disabilities, and person-centered planning approaches.</p>
<b>Michigan</b> [4]	Care coordinators must be a Michigan-licensed registered nurse, nurse practitioner, physician’s assistant, or Bachelor’s or Master’s prepared social worker.	Care coordinators must have the experience, qualifications and training including Michigan Department of Community Health required training appropriate to the needs of the member, and the health plan must establish policies for appropriate assignment of care coordinators.

Degree/Certification Requirements	Expertise Requirements
<p>LTSS Supports Coordinators must be a Michigan- licensed registered nurse; licensed nurse practitioner; licensed physician’s assistant; licensed Bachelor’s prepared social worker; limited license Master’s prepared social worker; or licensed Master’s prepared social worker</p>	<p>Care coordinators must have knowledge of physical health, aging and loss, appropriate support services in the community, frequently used medications and their potential negative side-effects, depression, challenging behaviors, Alzheimer’s disease and other disease-related dementias, behavioral health, substance use disorder, physical and developmental disabilities, issues related to accessing and using durable medical equipment as appropriate, available community services and public benefits, quality ratings and information about available options such as nursing facilities, applicable legal non-discrimination requirements such as the Americans with Disabilities Act, person centered planning, cultural competency, and elder abuse and neglect.</p> <p>The LTSS Supports Coordinator must: Have knowledge of HCBS; be culturally competent; be able to provide information regarding the quality ratings and licensure status, if applicable, of available options; be knowledgeable about risk factors and indicators of and resources to respond to abuse and neglect; be familiar with applicable long-term care facility licensing requirements and resources such as the long-term care ombudsman program; and have experience conducting LTSS needs assessments</p>
<p><b>New York [3]</b></p>	<p>Care managers must have the experience, qualifications and training appropriate to the individual needs of the member, and the health plan must establish policies for appropriate assignment of care managers</p> <p>Care managers must have the experience, qualifications and training appropriate to the individual needs of the member, and the health plan must establish policies for appropriate assignment of care managers.</p> <p>The health plan shall assign every member to a care manager with the appropriate experience and qualifications based on a Participant’s assigned risk level and individual needs (e.g., communication, cognitive, or other barriers).</p> <p>Care managers must have knowledge of physical health, aging</p>

	<b>Degree/Certification Requirements</b>	<b>Expertise Requirements</b>
		and loss, appropriate support services in the community, frequently used medications and their potential negative side-effects, depression, challenging behaviors, Alzheimer’s disease and other disease-related dementias, behavioral health, and issues related to accessing and using durable medical equipment as appropriate.
<b>Ohio [2]</b>	<p>Care manager must be an appropriately qualified professional.</p> <p>The health plan is responsible for ensuring that staff who are completing care management functions are operating within their professional scope of practice, are appropriate for responding to the member’s needs, and follow the state's licensure/credentialing requirements.</p>	The care manager must have the appropriate experience and qualifications based upon the member’s assigned risk level and needs.
<b>South Carolina [1]</b>	<p>At minimum, care coordinators must have a Bachelor’s degree, preferably in a health or social services related area. Care coordinators who serve members assigned to moderate to high risk levels must have a clinical background. Care coordinators who serve members assigned to lower risk levels are not required to have a clinical background.</p>	<p>Care coordinator must have experience, qualifications and training appropriate to the needs of the member, and the health plan must establish policies for appropriate assignment of care coordinators</p> <p>Care coordinators who serve members assigned to moderate to high risk levels may also have community-based experience working with the elderly, persons with disabilities, including developmental disabilities, and person-centered planning approaches.</p> <p>Care coordinators must have competency to communicate with members who have complex medical needs and may have communication challenges; experience in navigating resources and computer systems to access information; knowledge of physical health, the aging process and associated losses, appropriate support services in the community, frequently used medications and their potential negative side-effects,</p>

	<b>Degree/Certification Requirements</b>	<b>Expertise Requirements</b>
<b>Virginia</b> [7]	The health plan must establish its own written qualifications for a care manager that at a minimum meets the following criteria: have a Bachelor’s degree, or be a Registered Nurse licensed in Virginia with at least 1 year of experience working as a RN.	depression, challenging behaviors, Alzheimer’s disease and other disease-related dementias, behavioral health, and issues related to accessing and using durable medical equipment as appropriate. The care manager must have demonstrated ability to communicate with members who have complex medical needs and may have communication barriers. The care managers also must have experience navigating resources and computer systems to access information.

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