

# Gaps in the Dementia Care Workforce

## *Research Update and Data Needs*

### *Committee on Population (CPOP) Semi-Annual Meeting*

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# Table of Contents

**Meeting Summary ..... 1**

**Introduction ..... 1**

**Session 1: Overview of Current and Future Dementia Care Workforce..... 1**

    Overview of Current and Future Dementia Care Workforce Gaps and Policy Implications ..... 1

    Creating a Dementia Care Workforce in California: Role, Practice, Training, and Future Demand..... 2

    Discussion ..... 4

**Session 2: Creating High-Quality Jobs for Dementia Care Workers..... 4**

    High-Quality Jobs for Dementia Care: Compensation..... 4

    High-Quality Jobs for Dementia Care: Training, Supervision, and Advanced Roles..... 6

    Discussion ..... 7

**Session 3: Dementia Workforce Issues for At-Risk Populations..... 8**

    Dementia Care in Provider Settings ..... 8

    Dementia Care Workforce Issues for At-Risk Populations ..... 10

    Discussion ..... 11

**Session 4: General Discussion..... 12**

**Appendix 1: Agenda ..... 16**

**Appendix 2: Participant List ..... 19**

## Meeting Summary

### Introduction

On May 23, 2019, the National Academies of Sciences, Engineering, and Medicine's Committee on Population (CPOP) convened a seminar on gaps in the dementia care workforce.

Representatives from CPOP and the National Institute on Aging (NIA) of the National Institutes of Health (NIH) recognize that the nation's health care workforce may not be prepared to meet the health and long-term care needs of the growing number of older adults, particularly those from at-risk populations.

The goal of the half-day seminar was to review recent research on gaps in the dementia care workforce across various settings. Experts provided background in three broad areas: (1) current and future gaps in the paid dementia care workforce; (2) the implications of creating high-quality jobs for direct care and other paid workers; and (3) dementia care workforce issues for at-risk populations (i.e., rural areas, low socioeconomic status, non-English speaking). The agenda and participant list are available in Appendices 1 and 2, respectively.

Following the presentations, seminar participants engaged in a general discussion about research needs and data gaps. Four main themes emerged from the discussion sessions:

- Improving compensation for dementia care workers to increase retention rates
- Understanding and addressing factors in formal and informal caregiving choices
- Improving training for dementia care workers
- Addressing areas of insufficient data

Even if a cure for dementia were found tomorrow, it would require validation and distribution. Therefore, a large population of patients would continue to live with dementia, making these research needs critical for patients and workers in the dementia care field.

### Session 1: Overview of Current and Future Dementia Care Workforce

#### Overview of Current and Future Dementia Care Workforce Gaps and Policy

##### Implications

*Elizabeth Bragg, PhD, RN, Xavier University, Cincinnati, OH*

The U.S. health care system will be challenged as it attempts to care for an aging population with high rates of Alzheimer's disease and related dementias (ADRD) and other chronic illnesses. If nothing is done, it is estimated that, by 2050, more than 16 million adults will be living with ADRD in the United States.<sup>1</sup> Regardless of the level or type of intervention, the demand for health care providers is projected to increase significantly by 2026, for example by 15 percent for nutritionists and dieticians, 16 percent for social workers, 24 percent for

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<sup>1</sup> J. Galvin, "Prevention of Alzheimer's disease lessons learned and applied," *J. Am. Geriatr. Soc.* 65(10), 2128–2133 (2017).

occupational therapists, and 37 percent for physician assistants. Trends suggest that the demand for direct care workers will continue to exceed the supply.

Well-documented weaknesses in the current dementia care workforce include

- inadequate supply of specialists in geriatrics and dementia care who can provide the expert care needed for treating patients and training next-generation practitioners;
- limited availability of training for general health care professionals in the best practices of dementia care and chronic disease management;
- underappreciation of the workforce, leading to insufficient investment in primary care and long-term care services and support; and
- a shortage of well-trained direct care workers.

The American Geriatrics Society (AGS) estimates that as many as 30,000 geriatricians will be needed nationwide by 2030. As of 2018, there were 6,957. Likewise, the Association of American Medical Colleges predicts a shortage of 21,100 to 55,200 primary care physicians nationwide by 2032. These shortages will be particularly felt by older populations in rural settings who have limited means to travel to care settings.

A positive way to consider restructuring the field for treating older populations is to have geriatricians act as researchers and inform other health care professionals how to care for older individuals, therefore creating a larger team of well-trained individuals to treat ADRD patients and older patients with other chronic conditions.<sup>2</sup>

Research suggests that lifestyle modifications could prevent up to 30 percent of ADRD cases. While curing ADRD remains the main goal, the prevention or delay of onset of ADRD could change the face of the disease.

### **Creating a Dementia Care Workforce in California: Role, Practice, Training, and Future Demand**

*Jason Flatt, PhD, MPH, University of California, San Francisco*

At least 5 million people are currently living with ADRD in the United States. Care coordination can delay institutionalization, improve quality of life of patients and their caregivers, and lower long-term health care costs. As a proposed solution for California, Cal MediConnect designed a study to (1) create a formative evaluation of the proposed role, training, and practice of dementia care specialists and (2) describe the implementation of the dementia care coordination program and the ongoing demand in the field. The study was modeled after a clustered randomized controlled trial (RCT) that showed improvement in dementia quality of

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<sup>2</sup> K.E. Callahan, N. Tumosa, M. Leipzig, "Big 'G' and little 'g' geriatrics education for physicians," *J. Am. Geriatr. Soc.* 65, 2313–2317 (2017).

care and quality of life.<sup>3</sup> Cal MediConnect adapted the four main components of the RCT-ACCESS model—that is, care goals and coordination protocols, care managers, targeted provider education, and a web-based communication and decision support system—to develop health plans.

Cal MediConnect created a three-way contract between the Centers for Medicare and Medicaid Services (CMS), the California Department of Health Services, and participating health plans to require all health plans to include dementia care specialists (DCSs). These professionals would be trained in dementia care coordination, become knowledgeable about the systems of care, and involve caregivers and family members in the care plan. To qualify as a DCS, an individual must have a degree in nursing or social work and have 3 years of experience in a public or private agency providing direct service.

The DCS training to increase the dementia-specific capacity of health plan care managers included one 8-hour training (Tier 1), one 2-day, 12-hour training (Tier 2), and monthly “huddle” calls during which certain training topics were reviewed and real-world cases discussed. Tier 1 focused on basic knowledge such as causes and risks of ADRD, disease management guidelines, and challenging behaviors. Tier 2 focused on advanced knowledge such as enhancing cognitive screening skills and identifying the needs of informal caregivers.

### **Results**

The investigators used the RE-AIM framework to evaluate how the research was translated into practice. This framework focuses on five dimensions to determine the public health or population-based impact of the program: reach, effectiveness, adoption, implementation, and maintenance. The RE-AIM framework can identify an evidence-based program’s strengths, weaknesses, barriers, and opportunities for improvement.

All five dimensions of the program were considered to be successful.

- **Reach:** The program was implemented in nine health plans, although participation was mandated by the Cal MediConnect guidelines.
- **Effectiveness:** Over the 3 years of the project, 60 DCSs were trained across the nine sites. They demonstrated high levels of expertise and credibility and were successful in referrals to outside community resources.
- **Adoption:** There was 100 percent adoption across the nine health plans, with high level of agency participation.
- **Implementation:** Measured by real-world fidelity, the results showed that the DCSs became integrated parts of the interdisciplinary care teams.

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<sup>3</sup> B.G. Vickrey, B.S. Mittman, K.I. Connor, M.L. Pearson, R.D. Della Penna, T.G. Ganiats, T. G., ... N. Duan, “The effect of a disease management intervention on quality and outcomes of dementia care: a randomized, controlled trial,” *Ann. Intern. Med.* 145(10), 713–726 (2006); J. Chodosh, E. Berry, M. Lee, K. Connor, R. DeMonte, T. Ganiats, L. Heikoff, L. Rubenstein, B. Mittman, B. Vickrey, “Effect of a dementia care management intervention on primary care provider knowledge, attitudes, and perceptions of quality of Care,” *J. Am. Geriatr. Soc.* 54(2), 311–317 (2006).

- **Maintenance:** The program was extended beyond the 3-year project timeline. The institutions also requested more DCSs. Seven states have since adopted the model.

### ***Lessons learned***

Policy drives health care organization buy-in, and health care organizations are concerned about costs, so institutions or states must see the program's value to encourage its adoption. Challenges to implementation included the slow and difficult process of integrating dementia care coordination into care management systems, a lack of metrics to assess the effectiveness of dementia care coordination for patients and caregivers, and the high turnover rate of DCSs.

The demand for a dementia-capable workforce will continue to increase, and the Cal MediConnect study has created a model for national dementia care coordination. Online training and materials are available for organizations that are interested in the training or in implementation.

### **Discussion**

#### ***Overlap of underdiagnosis and lack of workforce training***

Not enough providers are trained for the large number of patients, and misdiagnosis and mistreatment are also issues in elder care. The major challenge exists in rural communities, where a lack of health care workers leads to underserved portions of the population.

Health care providers who perform their full suite of care services and are paid appropriately have no motivator to seek certification in any area. Certification in fields such as gerontology or dementia care could be encouraged through state-level mandates for key health assessments. There must be some pay structure or pay environment that drives certification and improves the quality of care and services provided.

Geriatric training at the national level is important. However, unlike other fields, geriatrics does not encourage specialization, such as in dementia competency, which is a major factor in the quality of care for ADRD patients. For ADRD care, the ability to perform cognitive screening and utilize similar screening tools to assess caregiver burden is very important.

The field could adopt an integrated philosophy that links different care levels and allows for substitution of roles among caregivers for the elderly and ADRD patients. In this way, care for people diagnosed with dementia could be arranged logically and could span all stages of the disease.

## **Session 2: Creating High-Quality Jobs for Dementia Care Workers**

### **High-Quality Jobs for Dementia Care: Compensation**

*Kezia Scales, PhD, Paraprofessional Healthcare Institute, Inc. (PHI)*

PHI is a nonprofit organization that seeks to ensure quality care for older adults and people with disabilities by creating quality jobs for direct care workers. Direct care workers assist with

activities of daily living (ADLs) for older adults and individuals with disabilities across many care settings, but primarily long-term care settings, and include personal care aides, home health aides, and nursing aides.

Within the direct care workforce, 87 percent are female, 57 percent are people of color, 48 percent have a high school education or less, and 25 percent were born outside the United States. Between 2016 and 2026, direct care will have more job openings than any other industry. Direct care workers play an important role in dementia care because, as well as providing ADL support, they are well-positioned to implement non-pharmacologic interventions for behavioral and psychological symptoms, educate and support family members, observe and record changes to clinical team members, and advance into specialist roles.

Nine elements of quality caregiving jobs can be divided into three focus areas:

- **Compensation:** good wages, good benefits, full-time schedule with no mandatory overtime
- **Opportunity:** excellent training, participation in decision making, career advancement
- **Support:** supportive supervisors, resources to resolve barriers to work, organizations who lead quality improvement

Currently direct care workers earn low wages and experience high turnover.<sup>4</sup> Their median income is \$19,100 per year, which means that 25 percent have an income below 138 percent of the federal poverty line and 42 percent rely on public assistance. Studies have shown that increased compensation is “the single most important thing” an employer can do to improve direct care jobs.<sup>5</sup> The evidence also indicates that nonmonetary rewards impact intent to leave, but compensation impacts actual turnover rates.<sup>6</sup> In addition, facility characteristics affect job retention, but income impacts profession retention (meaning whether or not an individual remains in a direct care role).<sup>7</sup> Health insurance and adequate work hours are also associated with reduced intent to leave among those who are employed directly by consumers through Medicaid-funded consumer-direction programs.<sup>8</sup>

Considerations for improving compensation for direct care workers include driving increases in compensation through Medicaid (e.g., wage pass-throughs); increasing total compensation (including increasing the wage floor and addressing benefit cliffs); and linking wages to training,

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<sup>4</sup> PHI, “Workforce Data Center,” <https://phinational.org/policy-research/workforce-data-center/>, (2018).

<sup>5</sup> P. Kemper et al., “What do direct care workers say would improve their jobs. Differences across settings,” *The Gerontologist* 48(Suppl. 1),17–25 (2008).

<sup>6</sup> L. Morris, “Quits and job changes among home care workers in Maine: the role of wages, hours, and benefits,” *The Gerontologist* 49(5),635–650 (2009).

<sup>7</sup> S.C. Stearns, L.P. D’Arcy, “Staying the course: facility and profession retention among nursing assistants in nursing homes,” *J. Gerontol. B Psychol. Sci. Soc. Sci.* 63(3), S113–S121 (2008).

<sup>8</sup> C. Howes, “Love, money, or flexibility: what motivates people to work in consumer-directed home care?” *The Gerontologist* 48(Suppl. 1):46–60 (2008).

experience, and responsibility.<sup>9</sup>At the same time, action must be taken to improve worker competencies and build incentives to invest in training and specialized roles.

## **High-Quality Jobs for Dementia Care: Training, Supervision, and Advanced Roles**

*Natasha Bryant, LeadingAge*

Bryant focused on the training, supervision, and advanced roles needed to improve job quality for direct care workers.

### **Training**

People with dementia experience a mixture of impaired communication, disorientation, confusion, and behavior changes. Therefore, direct care providers need dementia-specific training to develop the necessary skills and knowledge and to learn strategies to address the many presentations of the disorder. Current dementia-specific training programs tend to focus on person-centered principles and communication and are associated with improved knowledge, reduced turnover and increased job satisfaction, and reduced staff burnout. In turn, residents experience positive effects on behavioral and psychological symptoms and improved communications with caregivers.

Yet, training requirements are inconsistent. Federal regulations require basic training for certified nursing assistants and home health aides who provide Medicare- and Medicaid-reimbursed services, but not for in-home personal care aides. In addition, federal regulations require dementia care training for workers who provide care in nursing homes but not in the patient's home. Finally, training requirements for workers in assisted living and community-based settings vary by state.

To improve the training environment, states should establish clear dementia training requirements for all direct care workers from entry level to ongoing. Training should follow not only a competency-based approach (i.e., basic and dementia-specific training at entry, and ongoing training thereafter), but also the Alzheimer's Association Dementia Care Practice Recommendations. Recommended topics for training include (1) understanding the aging process, (2) understanding dementia, (3) creating person-centered care for individuals with dementia, (4) understanding verbal and non-verbal communication, (5) identifying triggers and strategies regarding behavioral and psychological symptoms, (6) learning cultural competency, and (7) establishing care coordination.

### **Supervision**

Supervision is important to the recruitment and retention of direct care workers. When workers believe they have a positive relationship with their supervisor, they are more satisfied with their job and less likely to leave. However, within the direct care workforce, staff are often

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<sup>9</sup> R.A. Baughman, K. Smith, "The effect of Medicaid wage pass-through programs on the wages of direct care workers," *Med. Care* 48(5), 426–435 (2010); A. Cook, *Benefit Cliffs and Benefit Plateaus* (Bronx, NY: PHI, 2017).

promoted based on their clinical skills, rather than their supervisory skills (either innate or acquired via training), which leaves aides to manage on their own.

Enhanced supervision requires training nurses on dementia care and on effective coaching so that they can serve as role models for providing good dementia care and can empower and support direct care staff to be decision makers. Enhanced supervision is much easier to accomplish in the nursing care setting than the home care setting, where workers are usually not supervised.

### ***Advancement***

As with other fields, individuals will be drawn to the care field if they see a meaningful career ladder. Advanced roles will attract and retain direct care workers, thereby stabilizing the workforce. Some potential advanced roles and specializations include peer dementia care mentors and specialized dementia workers. Specialization enables a team-based approach to care and provides opportunities for higher compensation.

To ensure creation of these advanced positions, federal and state policy makers should develop competency-based training standards and existing models should be scaled up to support larger demonstrations and evaluations. This area is not well studied, so evidence of these advanced roles on the impact on consumers and workers is limited.

## **Discussion**

### ***Training and opportunities***

The intent of increasing competency requirements is to bolster the training regimen for workers entering the field (rather than introducing barriers to employment for prospective workers), thereby ensuring that everyone receives the necessary training and no one is excluded from caregiving settings. The goal of training is to professionalize health care workers, who are currently not recognized for the competency and skill levels required to complete their jobs.

The ladder concept is intended to offset the perception that direct care jobs are dead-end jobs. Not all workers will pursue higher-level jobs, and only a portion of workers who climb the ladder will continue training to pursue other career pathways. Career advancement opportunities *within* direct care will help strengthen recruitment and retention. Workers who train up can mentor, support, and supervise workers entering the field, which will increase the retention of direct care workers overall.

If trained to understand and identify dementia symptoms, direct care workers would serve as a good reporting system to get to earlier diagnosis, particularly in the home care setting.

### ***Compensation***

Increasing the minimum wage may not necessarily improve recruitment of direct care workers if jobs in other sectors offer similar pay but better compensation. A higher minimum wage can

help raise the floor for direct care workers' wages, but likely will not impact the overall workforce if not matched by other efforts to make direct care jobs more competitive.

### **Work conditions**

Other in-home workers have reported experiences of working long hours in homes with low pay. Presenters shared anecdotal stories about worker abuse in the home care setting, where direct care workers—mostly foreign born—were asked to stay overnight to provide more care than originally intended.

Both a lack of available hours and choices by workers lead to the prevalence of part-time work in the field. The availability of hours may be limited in some environments. Likewise, some workers also informally care for someone at home (e.g., child or elderly parent) and cannot work full-time. The reasons for part-time work are both economic and non-economic.<sup>10</sup>

### **Turnover**

Participants asked about the frequency of movement between jobs within the same field and the frequency of switching between home care and institutional care settings. Substantial movement occurs between settings. However, although presumed to be high, turnover is not measured in a consistent way, so workforce turnover or movement is poorly understood at the national level.

## **Session 3: Dementia Workforce Issues for At-Risk Populations**

### **Dementia Care in Provider Settings**

*Manisha Sengupta, PhD, Centers for Disease Control and Prevention (CDC) National Center for Health Statistics*

Sengupta presented data from the National Study of Long-Term Care Providers (NSLTCP), which monitors trends in the supply, provision, and use of the major sectors of paid, regulated long-term care services. She noted that these data are presented from a purely statistical standpoint and the CDC does not develop policy or recommendations based on the data gathered.

### **2014 NSLTCP data**

The 2014 NSLTCP wave generated the following data:

- Nationally, 40 percent of residential care community residents were diagnosed with ADRD. The percentage ranged from 18 percent in Iowa to 53 percent in Maryland. For most states, the difference between the state and the national prevalence was not statistically significant.
- The percentage of adult day services center participants diagnosed with ADRD was 30 percent nationally. State percentages ranged from 10 percent in Nebraska to 67 percent in South Dakota. States with prevalence significantly higher than the national prevalence were concentrated in the eastern portion of the country.

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<sup>10</sup> S. Campbell, *The Part-Time Dilemma for Direct Care Workers* (Bronx, NY: PHI, 2018).

- Only 22 percent of residential care communities in the United States had a dementia care unit, defined as a distinct unit, wing, or floor designated for dementia care. State prevalence of dementia care units ranged from 14 percent for Arkansas to 68 percent for New Jersey.
- About 58 percent of residential care communities in the United States offer disease-specific programs for ADRD. State percentage ranged from 22 percent in Iowa to 76 percent in New Jersey. States with percentages significantly lower than the national prevalence were concentrated in the middle of the country.
- Nationally, 69 percent of adult day service centers offer disease-specific programs for ADRD. State percentages ranged from 47 percent in Nebraska to 100 percent in Delaware and Oregon.

### ***2016 NSLTCP data***

The 2016 NSLTCP included two sets of questionnaires to capture data from different sectors. Some questions were included in both questionnaires, and some questions were included in one or the other. The answers to questions in both questionnaires were used to produce state-level estimates; however, the answers to questions in the single questionnaire were used to produce only national-level estimates. Other information not included in the 2012-2016 waves of NSLTCP includes features of dementia special care units, demography data, and costs of care. The questions on a single questionnaire limit the ability to determine an association between socioeconomic status or race-ethnicity and residence of a person with dementia in a special care unit.

Using 2016 NSLTCP data, the investigators determined that the percentage of individuals with dementia in residential care communities was 43 percent in metropolitan statistical areas (MSAs) and 40.4 percent in non-MSAs, when both social work and mental health services were provided. When either type of service was provided, the percentages were 45.4 percent for MSAs and 32.7 percent for non-MSAs. Yet, the percentage was 40 percent regardless of location when neither service was provided. These statistics raise the question as to whether patients without access to these services have needs for these services.

The 2012-2016 NSLTCP waves collected no data about turnover in dementia care providers, training or training hours, continuity of care, and continuity of relationships between aides and patients over time.

### ***2018 NSLTCP data***

The 2018 NSLTCP added questions to close gaps in data at the provider and service-user levels. Providers answered questions about the number of beds per AD unit, turnover rates, hours of initial and continued training, and policies about residents leaving the building. Service-users answered questions about the person's residence (i.e., in a care unit) and about monthly charges, comorbidities, demographics, and symptoms.

The 2018 sample was small, supporting only national-level estimates. The statistical team will need to determine what data can be reported reliably. Data about dementia care—services specific to dementia patients, direct care staff training, and racial disparities—remain limited.

The addition of data always needs to be balanced with infrastructure, respondent burden, and available resources.

## **Dementia Care Workforce Issues for At-Risk Populations**

*Nancy Hodgson, PhD, RN, FAAN, University of Pennsylvania School of Nursing*

Hodgson discussed how workforce gaps and related job quality issues differ for workers caring for at-risk populations. More data are needed to determine whether workforce issues of recruitment, retention, and training are more pressing in at-risk communities. Individuals in these communities tend to have more complex care needs and require greater attention to health disparities, social inequities, health literacy, and culturally competent care. This level of care requires a multidisciplinary team with a specific liaison coordinating the workforce.

### ***At-risk populations***

The U.S. Census Bureau projects that the percentage of older adults who are non-white will double by 2050 to 39.1 percent from about 20.7 percent in 2012.<sup>11</sup> There is evidence of disparities in dementia incidence by race and ethnicity, with dementia incidence highest for African Americans and American Indian/Alaska Natives, intermediate for Latinos, Pacific Islanders, and Whites, and lowest among Asian-Americans. Patients from at-risk populations with dementia are more likely to

- live in poverty and in substandard and overcrowded housing;
- rely on informal caregivers, which places additional stressors on the family and may lead to a distrust in non-family caregivers and increased risk for social isolation;
- experience more chronic and comorbid diseases, while having below basic health literacy; and
- have care providers from a different cultural background and with little or no training in culturally competent care.

The dementia workforce faces specific challenges in caring for at-risk populations in rural settings. First, a high concentration of elders in rural settings coincides with the movement of children away from home, leaving fewer family caregivers. Second, patients experience geographic isolation because many caregivers are not located in rural settings, resulting in fewer services and potential staff. Finally, transportation is an inherent issue because patients are dispersed over a wide area.

### ***At-risk caregivers***

One out of six U.S. workers is an immigrant. Immigrants can experience issues entering the dementia care workforce because of problems transferring foreign credentials. In addition, they often work multiple jobs, leaving limited time for specialized training. Limited English

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<sup>11</sup> J.M. Ortolan, V.A., Velkoff, H Hogan, *An Aging Nation: The Older Population in the United States* (Suitland, MD: United States Census Bureau, 2014).

proficiency, which is common in adults who immigrate later in life, may affect their ability to serve on treatment teams (although they can assist with patients who share their first language). Finally, immigrants often suffer from social isolation due to the political climate.

### ***Ways forward***

The care for patients with dementia from at-risk populations can be improved through several changes to health care practice. First, an interprofessional team with dementia care expertise and a family liaison can better meet the complex medical, psychological, and social needs of these patients than a single practitioner working in a silo. Family caregivers should be viewed as an essential member of the caregiving team. Second, cultural competence education will help to overcome barriers to communication and collaboration on treatment. Finally, internet-based and mobile health technologies offer opportunities to provide screening and other treatment that may otherwise be inaccessible due to stigma, lack of transportation, or limited mobility.

An interprofessional team approach to dementia care for at-risk groups offers multiple benefits, including effective use of health care resources, effective assessment of needs, less duplication of efforts, reduced clinical error, increased formal caregiving, better problem solving, and improved care outcomes. In this model, the family and patient are at the center of the team.

Community health workers also add value, particularly for at-risk populations, because of their associations with the health care system, shared ethnicity and language, understanding of community resources, and shared socioeconomic status with community members including dementia patients. However, these roles tend to not be distinguished by the Standard Occupational Classification, and therefore their impact is difficult to measure.

Several research topics related to at-risk populations are ripe for exploration. As a first step, the unmet social and medical needs of diverse populations should be documented. Models to promote recruitment and training of a diverse workforce in interprofessional dementia competencies should be developed and then tested for outcomes and costs. There is a need to test (1) incentives for dementia workforce development and (2) models of community health workers as liaisons in at-risk communities. Finally, technologies that can be used to assist caregivers in at-risk communities should be developed and tested.

## **Discussion**

### ***Care models***

Presenters described how two models of interdisciplinary care relate to at-risk populations. The transitional care model positions a nurse practitioner to assist with patients who are discharged from hospitals to provide additional support and services. That nurse practitioner is part of an interdisciplinary team, and this care model is associated with a reduced likelihood of returning to the hospital with similar injuries. The palliative care model is another interdimensional model that has shown better outcomes for individuals.

In addition, the interdisciplinary model would include therapists, nutritionists, and other providers. Meeting participants asked whether the composition of the interdisciplinary teams

and their coordination would vary based on the different populations' needs. Cultural competence on the interdisciplinary team is especially important for patients from at-risk populations, and social workers will play a key role in providing this perspective.

Some interdisciplinary models of care, such as the Programs of all-Inclusive Care for the Elderly (PACE) model, allow teams to bill for dementia care. The palliative care model may work in the acute care setting, where hours are billed based on consultative services provided by the team, which develops the plan of care.

### ***National plan***

Cross-country comparisons of health care techniques and systems for treating individuals with ADRD are difficult because of differing financial models. However, some countries with national ADRD plans have dedicated funds for workforce development. Many of these countries are smaller, with significantly different demographics from the United States, such as Scotland.

The National Plan to Address Alzheimer's Disease (born from the National Alzheimer's Project Act enacted in 2011) lays out the U.S. plan to address ADRD. Although the plan focuses on efforts to find a cure, discussions about care and services that align with the plan are ongoing. The plan consists of five key components: research, better care, better awareness, quality clinical care, and tracking and monitoring data.

### ***Limitations of CMS partnership***

The potential for a better partnership with CMS exists. It is difficult to disentangle direct care and reimbursement for that care from CMS. There is also a shared cost between Medicare and Medicaid. If the field wants to move care to the community, which would mean Medicaid covers the costs, then Medicare may save money directly as the cost of acute care decreases. However, the cost-sharing aspect has not been modeled, so the return on investment from investing in direct care workers to help keep patients in the community settings is unknown.

### ***Proportion of population at-risk***

Social determinants are important when assessing risk factors. For example, a stressful life course increases an individual's risk of developing dementia. These factors are also in play after diagnosis. Individuals from at-risk populations are often diagnosed later and experience rapid development of symptoms. In addition, the environments in which they live and are served, which are often under-resourced with high crime rates and pollution levels, play a role. The ability for families to assist in care for these populations also has an impact on their disease course.

## **Session 4: General Discussion**

The above sessions identified multiple overarching themes. These included the need for increased compensation for dementia care workers to increase retention and decrease poverty among workers, the factors that lead to the use of formal versus informal care, the need for increased training in the workforce, and the need to fill data gaps. During the final session of

the seminar, the attendees discussed these areas in more detail with a goal of informing the direction of future research.

### **Compensation**

Several presenters addressed the issue of low compensation across all forms of direct care workers. The demand for high-quality health care workers will exceed the supply. With one-half of health care paid for by the government, federal reimbursement policies can affect this gap. Low pay and turnover are connected. With a workforce largely comprised of women of color receiving less than a livable wage, increased reimbursement could lead to increased workforce empowerment. Improved educational opportunities will also empower the workforce. For example, a grantee in Tennessee devotes funding to training individuals from impoverished and underserved communities, particularly women, to become certified nursing assistants, which includes training in dementia. This opportunity has motivated these individuals to continue their education and training to become medical assistants.

This issue applies to in-home caregiving across the board. This workforce largely consists of underpaid and undertrained women, many of whom rely on public assistance. Research into the conditions and compensation for in-home caregivers would be a win-win scenario to increase the quality of care for patients while increasing the quality of life for caregivers.

The concept of supply and demand can help to illustrate this issue. The workers entering the field tend to be immigrants, have lower education levels, and are willing to work for lower wages. Conversely, families caring for relatives with AD/DRD, particularly those that are simultaneously caring for children, struggle to pay for the care needed. Researchers must understand these economic dynamics when evaluating potential solutions.

### **Family vs. Formal Caregiving**

Economic status may influence a family's decision to utilize informal, unpaid family care rather than direct care. Meeting participants expressed interest in the relationship between family caregivers and paid caregivers. Consumer-direction programs such as California's In-Home Supportive Services (IHSS) enable a family caregiver to be a paid caregiver. Even unpaid, a family caregiver may be the preference, especially if, due to different reimbursement programs, the family will need to pay a caregiver's wages for up to 3 months before the caregiver receives paychecks from the agency. If paid, a family caregiver may accept a lower salary because they are already in the home. Little is known about the implications of paying family members to provide direct care, compared to hiring workers through agencies (i.e., the traditional model). In addition, the differences in the quality of care provided by a family caregiver versus a direct caregiver have not been adequately studied.

Paid and unpaid leave for family caregivers is another topic of interest. The United States does not have national-level requirements for paid leave. Only seven states and the District of Columbia currently require paid leave for employees.<sup>12</sup> An expansion of paid leave could allow

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<sup>12</sup> See National Partnership for Women & Families at <http://www.nationalpartnership.org/our-work/resources/workplace/paid-leave/state-paid-family-leave-laws.pdf>.

for more family caregiver hours, reducing the stress related to the financial burden of paying for care or losing pay. This could in turn reduce the burden on paid caregivers. Blanc noted that the current workplace environment may discourage extended absences. Workers may believe that they have missed opportunities or supervisors may perceive that employees have been absent from the team for too long.

At the global level, there has been a recent surge in interest in the economic cost to women of unpaid work to care for any family member, child or elder. Expecting caregiving to be inexpensive is different from expecting caregiving to be free. At the macro level, the absence of capable women in the labor force because they must stay home and care for others creates an opportunity cost.

The lack of specialized training in dementia care may cause families to choose a family caregiver rather than a formal caregiver. This lack of training also makes it more difficult to find—and retain—a capable caregiver, creating additional stress for families with relatives living with ADRD. Therefore, there is a huge appeal to understand how to make the in-home care system work.

### **Training**

Flatt's presentation highlighted the effectiveness of training to improve the quality of care. However, workforce training might have unexpected consequences. For example, specialized training may empower some workers to leave the field altogether to advance their careers. Some direct care workers do seek to advance their careers, but most workers are happy in their current position and seek only a living wage and recognition of their value.

The need for improved training is a well-understood area that requires attention from the dementia research community. A paper prepared after the 2017 dementia care summit highlighted dementia care and workforce gaps and identified four main research focus areas: "(1) evaluate the cost savings/cost benefits of providing dementia-related training to paid caregivers, health care system, individuals, and public programs; (2) study the costs associated with dementia certification versus a learning certificate in dementia care; (3) identify the financial implications and health impacts to person living with dementia, their families and caregivers, and accountable entities ... in expanding options for paid caregiving in Medicaid and for self-directed service delivery; and (4) investigate the cost saving/cost benefits of updating existing health professions curricula, providing additional health professions dementia training, and having a specialty certification..."<sup>13</sup>

### **Insufficient Data**

Common across all topics discussed was the issue of insufficient or incomplete data. Researchers should further investigate what direct care job quality looks like in the home care setting, the interface between paid and unpaid caregivers, and the relationship between household economic stability and caregiving. It is important to compare the workplace

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<sup>13</sup> See J. Weiss et al., "Workforce Gaps in Dementia Education and Training," <https://aspe.hhs.gov/system/files/pdf/257826/WorkforceGaps.pdf> (September 2017, p. 10).

conditions of in-home versus nursing home caregivers. The former may be asked to provide services outside their scope of work or work for longer hours without compensation.

To close the gaps in the direct care workforce in dementia care, research efforts should be directed toward measuring the return on investment from training and other job quality improvements. Direct care workers are perceived as unskilled, which drives the low-wage issue. Until the public and private sectors perceive the direct care workforce as more highly skilled, any improvements to job quality will be slight. RCTs or natural experiments, as well as sufficient data (including baseline) to assess their effectiveness, can move the field toward achieving that goal.

**Next Steps**

A suggestion was made to hold a separate meeting around the time of the second Dementia Care Summit, to be held on March 24-25, 2020. In addition, several topics discussed during this meeting might inform the agenda for the summit.

## Appendix 1: Agenda

### ***SEMINAR: Gaps in the Dementia Care Workforce: Research Update and Data Needs***

The National Academies of Sciences, Engineering, and Medicine  
Keck Center – 500 5<sup>th</sup> St NW – Room 105

May 23, 2019

- 1:00-1:20 pm**            **Welcome and Introductions; Goals for the Seminar**  
*Vicki Freedman, University of Michigan*  
*Marie Bernard, Deputy Director, National Institute on Aging*
- 1:20-2:10 pm**            **Session 1: Overview of Current and Future Dementia Care Workforce**

Questions to be addressed include:

- What are the most important dementia care workforce gaps – in terms of numbers, locations, and competencies?
- How do these gaps vary across stage of disease and setting (e.g. residential care, home-based care, as well as primary care, hospital and post-acute settings)?
- How are shortages projected to change in the near future as the Baby Boom generation reaches ages at much higher risks of cognitive impairment?
- If more workers are needed, what options are there to increase the workforce (e.g. postpone retirement, recruit younger workers, train and pay family members, change care models to require fewer workers)?

Presenters:

- *Elizabeth J. Bragg, Xavier University, Cincinnati, OH*
- *Jason Flatt, University of California, San Francisco*

Background Readings:

- ✓ Warshaw, G.A., and Bragg, E.J. (2014). Preparing the health care workforce to care for adults with Alzheimer's disease and related dementias. *Health Affairs*, 33(4), 633-641. Available: <https://www.healthaffairs.org/doi/full/10.1377/hlthaff.2013.1232>.
- ✓ Spetz, J., Trupin, L., Bates, T., and Coffman, J.M. (2015). Future demands for long-term care workers will be influenced by demographic and utilization changes. *Health Affairs*, 34(6), 936-945. Available: <https://www.healthaffairs.org/doi/10.1377/hlthaff.2015.0005>.

**2:10-3:00 pm                      Session 2: Creating High Quality Jobs for Dementia Care Workers**

Questions to be addressed include:

- How is the quality of direct care worker jobs assessed? What is the role, for example, of compensation, promotion ladders, benefits, flexible scheduling?
- How does quality of job relate to training and certification? To retention and turnover?
- Are there examples of high quality direct care worker jobs? What are the barriers to exporting these models to other settings or geographic locations?

Presenters:

- *Kezia Scales*, PHI International
- *Natasha Bryant*, LeadingAge

Background Readings:

- ✓ Weiss, J., Tumosa, N., Perweiler, E., Bailey, D., Blackwell, E., Forceia, M.A., Miles, T., Tebb, S., Trudeau, S., and Worstell, M. (2017). Workforce gaps in dementia education and training. Stakeholder group paper. Washington, DC: Assistant Secretary for Planning and Evaluation, U.S. Department of Health and Human Services. Available: <https://aspe.hhs.gov/system/files/pdf/257826/WorkforceGaps.pdf>.
- ✓ Campbell, S. (2017). U.S. Home Care Workers: Key Facts. Bronx, NY: PHI. Available: <https://phinational.org/resource/u-s-home-care-workers-key-facts/>.
- ✓ Flatt, J.D., Hollister, B.A., and Chapman, S.A. (2017). Dementia Care Specialist Workforce in California: Role, Practice, Training, Demand. San Francisco, CA: UCSF Health Workforce Research Center on Long-Term Care. Available: [https://healthworkforce.ucsf.edu/sites/healthworkforce.ucsf.edu/files/REPORT\\_DCS\\_Re port\\_FINAL2.1.18.pdf](https://healthworkforce.ucsf.edu/sites/healthworkforce.ucsf.edu/files/REPORT_DCS_Re port_FINAL2.1.18.pdf).
- ✓ Gilster, S.D., Boltz, M., and Dalessandro, J.L. (2018). Long-term Care workforce issues: Practice principles for quality dementia care. *The Gerontologist*, 58(S1), S103-S113. Available: [https://academic.oup.com/gerontologist/article/58/suppl\\_1/S103/4816757](https://academic.oup.com/gerontologist/article/58/suppl_1/S103/4816757).

**3:00-3:20 pm                      BREAK****3:20-4:10 pm                      Session 3: Dementia Workforce Issues for At-Risk Populations**

Questions to be addressed include:

- Are there other at-risk places or populations likely to be affected sooner or more acutely by paid dementia care workforce shortages? For instance in rural areas, in areas serving groups dually eligible (Medicaid/Medicare) or with low socioeconomic status, or in transitional settings (for individuals moving from inpatient to post-acute to home (residential care or community) setting)? Is the anticipated increase in the population of older adults with dementia who are

immigrants and have limited English fluency likely to cause a shortage of the workforce who are adequately trained to care for them?

- How do the workforce gaps and related job quality issues differ for those caring for at-risk populations?

Presenters:

- *Manisha Sengupta*, Centers for Disease Control and Prevention
- *Nancy Hodgson*, University of Pennsylvania

Background Readings:

- ✓ Harris-Kojetin, L., Sengupta, M., Lendon, J.P., Rome, V., Valverde, R., Caffrey, C. (2019). Long-term care providers and services users in the United States, 2015-2016. *Vital and Health Statistics*, 3(43). Available: [https://www.cdc.gov/nchs/data/series/sr\\_03/sr03\\_43-508.pdf](https://www.cdc.gov/nchs/data/series/sr_03/sr03_43-508.pdf).
- ✓ Hirschman, K.B., and Hodgson, N.A. (2018). Evidence-based interventions for transitions in care for individuals living with dementia. *The Gerontologist*, 58(1), S129-S140. Available: [https://academic.oup.com/gerontologist/article/58/suppl\\_1/S129/4816738](https://academic.oup.com/gerontologist/article/58/suppl_1/S129/4816738).

**4:10-5:00 pm                      Session 4: General Discussion: Research needs and data gaps**

Questions to be addressed include:

- With respect to paid dementia care workforce gaps, what overarching research questions need more attention?
- Are there particular populations that need special attention?
- What data would be helpful to address such issues?

**5:00 pm                              Adjournment**

## Appendix 2: Participant List

### ***SEMINAR: Gaps in the Dementia Care Workforce: Research Update and Data Needs***

The National Academies of Sciences, Engineering, and Medicine  
Keck Center – 500 5<sup>th</sup> St NW – Room 105

May 23, 2019

Ann K. Blanc, Population Council  
Elizabeth Bragg, Xavier University  
Natasha S. Bryant, LeadingAge  
Jason D. Flatt, University of California, San Francisco  
Vicki A. Freedman, University of Michigan (*via Zoom*)  
Dana A. Glej, Georgetown University  
Kathleen Mullan Harris, University of North Carolina at Chapel Hill  
Nancy A. Hodgson, University of Pennsylvania  
Hillard Kaplan, Chapman University  
Hedwig Lee, Washington University in St. Louis  
Jennifer J. Manly, Columbia University  
Isabel V. Sawhill, Brookings Institution  
Kezia Scales, PHI  
Manisha Sengupta, Centers for Disease Control and Prevention (CDC)  
John R. Wilmoth, United Nations  
Joan Weiss, Health Resources and Services Administration (HRSA)

#### **National Institute on Aging**

Marie Bernard, Deputy Director  
Elena Fazio, Health Scientist Administrator, Division of Behavioral and Social Research (BSR)  
John Phillips, Chief, Population and Social Processes, BSR  
Rebecca Lazeration, Rose Li and Associates, Inc. (Contractor)

#### **National Academies of Sciences, Engineering, and Medicine**

Tara Becker, Program Officer, Committee on National Statistics (CNSTAT) and Committee on Population (CPOP)  
Molly Checksfield, Program Officer, Board of Behavioral, Cognitive, and Sensory Sciences (BBCSS)  
Mary Ghitelman, Senior Program Assistant, CNSTAT and CPOP  
Ellie Grimes, Senior Program Assistant, CNSTAT and CPOP  
Tracy Lustig, Senior Program Officer, Health and Medicine Division  
Malay Majmundar, Director, CPOP and Senior program Officer, CNSTAT  
Sharyl Nass, Director, Board on Health Care Services and Director, National Cancer Policy Forum  
Adrienne Stith Butler, Associate Board Director, BBCSS  
Jordyn White, Program Officer, CNSTAT and Board on Environmental Change and Society