Better Brain Health through Equity:

Addressing Health and Economic Disparities in Dementia for African Americans and Latinos

BY RAJIV AHUJA AND CARA LEVY

MILKEN INSTITUTE

ALLIANCE TO IMPROVE DEMENTIA CARE

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The Alliance to Improve Dementia Care brings together a multi-sector coalition of leaders to advance timely detection, access to treatment and coordinated care, and health equity for people at risk for and living with dementia and their caregivers. Through expert workgroups, convenings, and collaborative initiatives, the Alliance amplifies and promotes the adoption of proven solutions and promising innovations. This report is informed by a consensus-building approach but may not reflect the views of all Alliance members.

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INTRODUCTION

Long-standing health disparities have been brought into sharp focus as the COVID-19 pandemic disproportionately harms racially and ethnically diverse communities. The same underlying health and socioeconomic factors that increase one's risk of contraction and severe outcomes from COVID-19 also hold true for chronic diseases such as hypertension, diabetes, and dementia. The prevalence of dementia in the United States remains high and disproportionately impacts women and racially and ethnically diverse communities.[1] The Milken Institute estimates that more than 7.2 million Americans currently live with Alzheimer's disease or related dementias (ADRD), and this number is expected to reach nearly 13 million by 2040 (two-thirds of whom will be women).[2] Research also predicts that from 2020 to 2060, the number of African Americans and Latinos living with dementia will grow by nearly 200 percent and 440 percent, respectively, while prevalence among non-Hispanic Whites will increase by 69 percent.[3] To respond to these projections, efforts to improve dementia care must put equity front and center.

The Alliance to Improve Dementia Care ("Alliance"), part of the Milken Institute's Center for the Future of Aging, uses a consensus-driven approach to develop recommendations to improve care for individuals and their families across the continuum of dementia care. In October 2020, the Alliance convened a roundtable on "Reducing Health and Economic Disparities in Dementia," bringing together leaders across industry, government, research, advocacy, philanthropy, community-based organizations (CBOs), and health systems for one purpose: to develop recommendations to reduce the inequitable impact of dementia on diverse populations. Informed by the roundtable discussion and the Alliance's expert working group on disparities, this report presents actionable recommendations to build health equity by reducing disparities in dementia prevention, detection, diagnosis, and care. This report centers around two overarching themes: (1) Strengthening the infrastructure among health-care, long-term care, and community-based organizations (CBOs) to achieve greater health equity for people living with dementia and their caregivers and (2) Expanding dementia-friendly networks and workplaces in racially and ethnically diverse communities.
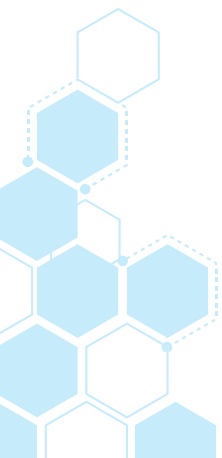
LANDSCAPE: HEALTH AND ECONOMIC DISPARITIES IN DEMENTIA

The World Health Organization defines health equity as the "absence of unfair and avoidable or remediable differences in health among population groups defined socially, economically, demographically, or geographically."[4] Amid demographic trends showing a population growing older and more racially and ethnically diverse, the need to reduce health and economic disparities in dementia care in the US is becoming increasingly urgent. By 2030, Latinos and African Americans will likely make up about 40 percent of the 8.4 million families impacted by Alzheimer's disease, the most common cause of dementia.[5] As the number of individuals living with dementia in these communities grows, so will the economic impacts and costs. While making up only 14 percent of the US population, African Americans bear one-third of the total costs associated with dementia.[6] The occurrence of Alzheimer's disease in African Americans is 64 percent higher than in Whites.[7] Moreover, the total cost for Latinos living with Alzheimer's disease is expected to exceed $100 billion by 2060.[8]

These inequities cannot be addressed without first setting the context in which they exist. Social determinants of health (highlighted in Figure 1) refer to the root causes of health disparities. These are the conditions in which people are born, grow, live, work, and age, including socioeconomic status, education, neighborhood, physical environment, employment, social support networks, and access to health care.[9] These disparities are borne from deep-rooted and long-standing systemic and structural racial inequities, which impact social and economic factors and lead to warranted distrust of the medical system, lack of culturally relevant health communications, fewer treatment options, and reduced access to care. These social and economic factors shape individuals' freedom of choice and ability to engage in healthy behaviors that build brain resilience and help reduce the risk of developing dementia.

Figure 1: Social Determinants of Health

Source: Centers for Disease Control and Prevention (2020)

Emerging evidence indicates that healthy behaviors and lifestyle choices can improve our brains' resilience, decrease our risk of developing dementia, and slow disease progression.[10] The Lancet Commission's 2020 report on dementia prevention, intervention, and care identifies 12 modifiable risk factors, including hearing loss, smoking, diabetes, depression, low social contact, and excessive alcohol consumption, which collectively account for around 40 percent of dementia worldwide.[11] Still, roundtable participant Jennifer Manly, PhD, professor of neuropsychology at Columbia University, explained, "Those lifestyle choices will not eliminate disparities in dementia because [disparities] are caused by fundamental social causes that occur across the life course."

> ## We cannot put the entire onus on the individual. Rather, it is important to consider the role of society, policy, and government support to make a difference if we want to have future positive health outcomes for everyone.

Katie Brandt, Director of Caregiver Support Services, Massachusetts General Hospital Frontotemporal Disorders Unit, and Co-chair, National Alzheimer's Project Act Non-federal Advisory Council

Manly, who studies the impacts of social structures and exposures to increased risk for dementia for African Americans and Latinos, emphasized that each of us takes our "childhood risk" with us wherever we go. She presented data from several studies that show that social factors such as educational experience, racism, discrimination, neighborhood, and occupational opportunities shape our dementia risk and resilience to cognitive decline.[12] Thus, to reduce the risk of dementia among populations disproportionately impacted, we must increase investment in economic and social policies that alleviate neighborhood inequalities, improve educational quality, and promote economic stability.

To move this effort forward, a life course perspective needs to be used to target socioeconomic factors driving inequities in dementia and their impacts on diverse communities. While the Alliance supports broad-based efforts to address these socioeconomic factors, this report focuses on opportunities to remediate disparities and inequities in health care, long-term care, and communities. Our insights are informed by the October 2020 roundtable, background research, and feedback from the Alliance's expert disparities Working Group (full list of Working Group members is provided in Appendix A).

THEME #1

Strengthening the Infrastructure among Health-Care, Long-Term Care, and Community-Based Organizations to Achieve Greater Health Equity for People Living with Dementia and Their Caregivers

African Americans and Latinos face consistent and adverse disparities in the quality of their dementia care and use of long-term services and supports when compared to non-Hispanic Whites.[13] Research suggests that African Americans and Latinos often receive delayed diagnoses and, as a result, are diagnosed at more advanced stages of dementia than Whites.[14]

Efforts to reduce dementia disparities should be part of a broader effort to transform clinical care, research, and long-term services and supports, and increase collaborations with CBOs. Increasing community outreach and engagement, improving transparency from researchers, and developing mutually beneficial multidirectional relationships among communities, researchers, health care, and long-term care may reduce long-standing mistrust in clinical trials and research studies and facilitate more productive encounters.[15] To move toward a more equitable health- and long-term care system, collaborative dementia-care models must include core elements that reflect diverse cultural norms and preferences, and equity must be integrated into outcome measures to track progress.

To address long-standing disparities in dementia care, the Alliance recommends the following:

RECOMMENDATION #1

Increase community outreach and engagement to improve brain health awareness in racially and ethnically diverse communities.

There is a need to provide education and raise awareness for modifiable risk factors, benefits of early detection, and support services. Over the last five years, the Global Council on Brain Health, an independent collaborative of scientists and health-care professionals, has been convened by AARP for the express purpose of providing outreach and engagement to improve brain health awareness in diverse communities of older adults. By working with collaborators, such as those in the Alliance, and focusing on sharing this information in culturally competent ways in true partnership with communities, risk factors can be modified along with building pathways to support and sustain healthy behaviors. These efforts can help reduce the stigma of Alzheimer's disease, increase participation in clinical trials, facilitate productive provider encounters, and take advantage of available interventions. A study by the National Hispanic Council on Aging found a significant lack of knowledge and awareness about the symptoms and treatment options for Alzheimer's among Latino older adults and caregivers.[16] Findings in the March 2021 Alzheimer's Association special report, "Race, Ethnicity and Alzheimer's in America" show that

"non-White racial/ethnic populations expect and experience more barriers when accessing dementia care, have less trust in medical research, and are less confident that they have access to health professionals who understand their ethnic and racial background and experiences."[17] In addition, African American dementia caregivers report higher rates of unmet basic and health needs.[18]

> **If we provide the funding, if we do the research, unless everyone knows the importance of brain health, it's going to fall on deaf ears. Brain health awareness is vital for not only the community but also for health-care providers.**

Martha Villanigro-Santiago, JD, Advocate/Consultant, Aging and Moving Forward, LLC

An earlier Milken Institute report identified several institutional and cultural barriers that diverse individuals with dementia face when seeking help, participating in research, and engaging with providers. These barriers include a lack of information about dementia, not understanding dementia risks, and a long-standing lack of transparency and discrimination in clinical trials and research.[18] During the roundtable, Lisa Barnes, PhD, a neuropsychologist at the Rush Alzheimer's Disease Center, discussed the need to better represent individuals from diverse communities in clinical trials and research studies. "All of the knowledge we are gathering about detection, diagnosis, and treatment has been driven by research that includes predominantly White populations. Hardly any trials have diverse or low socioeconomic populations because they are often excluded based on criteria to enter the trial. In the areas where the science is moving forward the fastest, diverse populations are not benefiting from that knowledge base."

The first steps to increase that knowledge base are community outreach and engagement. AARP research shows that it is not a matter of interest or willingness to adopt brain healthy behaviors, rather it is a need to overcome barriers and lack of access to information in African American and Latino communities that are the issues.[20] Successful models start with building a trusting and mutually beneficial bidirectional relationship between the community and researchers. Barnes has built successful relationships with community stakeholders using an outreach and engagement model developed at Rush called the NGAGEDD (Network, Give First, Advocate for Research, Give Back, Evaluate, Design & Develop) model. Her colleagues and research team "always give first to the community by providing information, financial support and sponsorship of activities, free health-care screenings, and memory evaluations." She explained that "it's not until we have given first that we then start to advocate for research." An outline of the model is described below.

Building Bidirectional Relationships Builds Trust

The overall goal of research at Rush Alzheimer's Disease Center is to "cultivate inclusive and engaged participation of diverse persons underrepresented and understudied in research on the etiology, pathogenesis, diagnosis, treatment, and prevention of ADRD."[21] Rush created the NGAGEDD model to help reach this goal:

- **Network:** Network with local leaders, stakeholders, and organizations to get buy-in.

- **Give First:** Give first to the community by providing information, financial support, sponsorship of activities, free health-care screenings, and memory evaluations.

- **Advocate for Research:** Use culturally and linguistically compatible materials. Give presentations to the community on why research is important in diverse populations, brain-healthy activities, and how ADRD can present in different people.

- **Give Back:** Go back to the community and disseminate the research findings. Provide educational programming heavily focused on prevention, early detection, and early treatment of Alzheimer's disease. Celebrate partnerships and critical milestones.

Community engagement should emphasize bidirectional relationships. Interactions that are mutually beneficial result in informed decision-making about brain health.

Figure 2: NGAGEDD Model
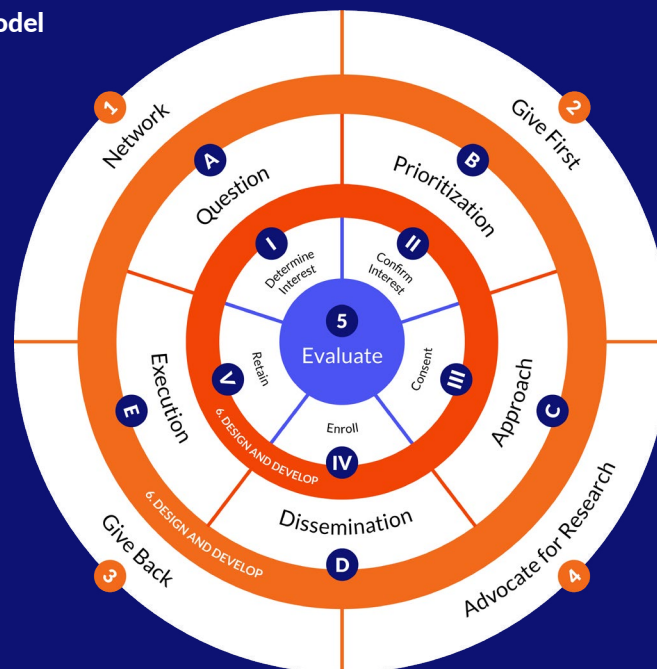
Source: Glover et al., under review

Area Agencies on Aging, local chapters of the Alzheimer's Association, and other CBOs also play a vital role in educating and building community awareness and deliver a broad range of programs and services for individuals living with dementia and their caregivers.[22] CBO leaders often have the reputation and trust necessary to engage diverse communities and can support efforts to improve earlier detection of dementia. For example, Alzheimer's Los Angeles, through its dementia-care network, develops culturally and linguistically tailored brain health awareness campaigns to build trust with local communities, including facts sheets for African Americans and Latinos, educational video series, and a telenovela, a television serial drama or soap opera.

Current fee-for-service payment structures do not incentivize providers to develop community partnerships. To build the infrastructure and collaboration among health-care, long-term care, and CBOs, the Alliance advocates for policies that encourage Medicaid and Medicare managed care plans to contract with and reimburse CBOs for appropriate social services and outreach, engagement, education, assessment, and follow-up services.[23]

Public health initiatives also play a critical role in promoting awareness for dementia through education and dissemination of best practices. The FY21 Omnibus Bill directed $15 million to fund the Building Our Largest Dementia (BOLD) Infrastructure for Alzheimer's Act.[24] This law directs the Centers for Disease Control and Prevention (CDC) to strengthen the country's public health infrastructure by implementing effective Alzheimer's interventions focused on public health issues such as increasing early detection and diagnosis, reducing risk, and preventing avoidable hospitalizations.[25] Reducing health disparities is a crucial priority of the BOLD Act and the newly established Alzheimer's and Related Dementia Public Health Centers of Excellence. The Alliance encourages health- and long-term care systems to tap into these evidence-informed best practices to ensure maximum effect and reach.

Community Conversations Can Improve Outcomes

Eli Lilly developed a community-engagement program in 10 major US cities, including Atlanta. For example, this community-based group in Georgia focused on educating the community, building community support, and ultimately advocating for state funding.

Lilly conducted research and listening forums in Georgia with Alzheimer's disease experts, researchers, advocates, professionals, and persons with Alzheimer's and their care partners on priority issues and community needs. Topics were developed with leading subject matter experts working directly in the field and with communities.

This initiative helped the community develop its community priorities and narrative, which formed the basis for a state-advocacy effort for funding. Georgia is one of the few states with a line item in its budget dedicated to Alzheimer's disease. Stakeholders that participated in these community conversations reported that they were instrumental in implementing successful programs to educate health-care professionals, receive new funds or grants, and implement recommendations, among others. Figure 3 showcases the percentage of participants in the community conversations that reported implementing select programs.

Figure 3. Outcomes from Community Conversations on Alzheimer's Disease
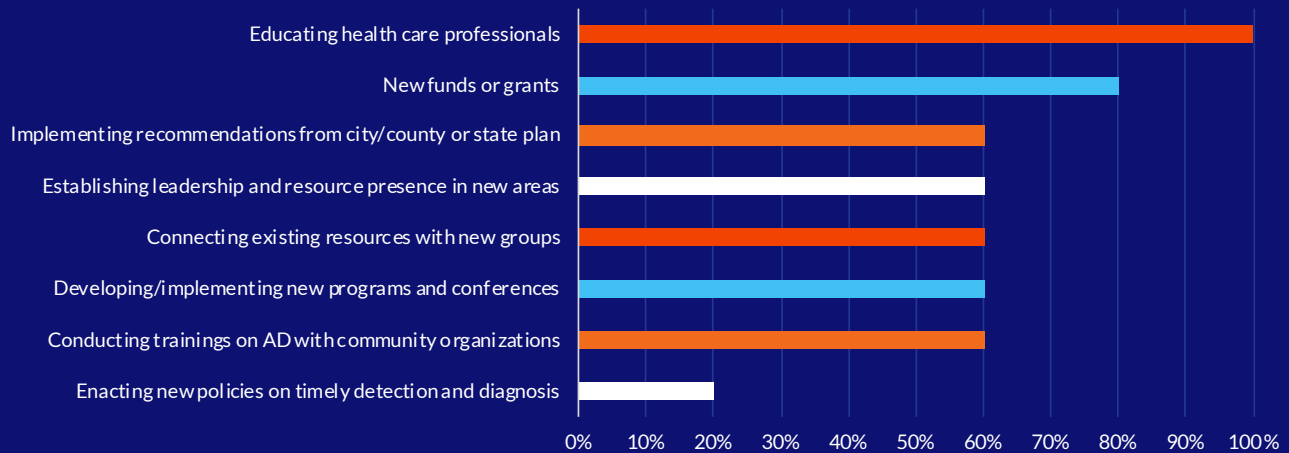
Source: Eli Lilly (2021)

RECOMMENDATION #2

Build a dementia-capable and culturally competent workforce through recruitment, retention, and increased interdisciplinary training.

Given the increasing numbers of individuals with dementia in the US, the health- and long-term care workforce will likely be unprepared to meet the growing demands of dementia care. By 2030, the US will need an estimated 3.4 million direct-care workers to provide long-term services and supports (a 1.1 million increase from 2015).[26] Demand is also projected to increase for social workers (16 percent), occupational therapists (24 percent), and physician assistants (37 percent). In addition, the number of geriatricians in the US must more than double to meet demand. Many practicing geriatricians are not adequately trained to build trusting relationships with the diverse individuals they treat.[27]

> **Just because there isn't a medical treatment doesn't mean that there are not many proactive things doctors can do to help.**
>
> *Terry Montgomery, Advisory Board Member, Dementia Action Alliance; Advocate Living with Dementia*

The Health Resources and Services Administration (HRSA) launched the Geriatric Workforce Enhancement Program (GWEP) in 2015 to better prepare the health-care workforce for an aging population by integrating geriatrics into primary care. As the Milken Institute recommended in our 2019 report, "Reducing the Cost and Risk of Dementia," "a culturally competent, dementia-capable workforce is required to ensure that those living with dementia and their caregivers get the right support and care at the right time."[28] The Coronavirus Aid, Relief, and Economic Security (CARES) Act (HR 748; passed in March 2020) adopts several recommendations detailed in our report.[29] It includes reauthorization of the GWEP and, in the fiscal year 2020, awarded approximately $36 million to build geriatric knowledge across the care system and an additional $4.35 million for COVID-19 workforce development.[30] This significant funding has enabled HRSA to provide grants for training in 35 states and two territories (Guam and Puerto Rico) and includes funding preferences for underserved and rural populations.[31] Additional funding would permit expansion so all states would be able to take advantage of this training, which will help further address health disparities. The Alliance supports increased funding to promote geriatric knowledge and fill workforce shortages through advanced recruitment and retention efforts, especially in racially and ethnically diverse communities.

The Promise of Community Health Workers

The Administration for Community Living (ACL) Alzheimer's Disease Programs Initiative (ADPI) funded the Chicago-based Latino Alzheimer's and Memory Disorders Alliance (LAMDA) in 2018. LAMDA expanded its Promotoras Program, training 60 community health workers (CHWs) to support Latinos with Alzheimer's and related dementias and their caregivers through targeted education and delivery of culturally competent evidence-based caregiver interventions. Outcomes of the Promotoras Program include:

- Reached about 7,000 Hispanic individuals

- Conducted 710 memory screenings during the first year and encouraged individuals to see a physician for diagnosis or treatment if indicated

- Provided a four-week caregiver skills program for 107 Latino family caregivers

- Provided individual care consultant services to 314 persons in the community with possible cognitive impairment who were living alone or at high risk for Alzheimer's or related dementias

- Conducted 12 health fairs in collaboration with key partners in community clinics and schools

Becoming a CHW in the Promotoras program requires significant training—and funding that has not always come easily. ACL is building an evidence base that will enable replication of the program in other parts of the country.[32]

Figure 4. ACL-Funded ADRD Programs Supporting Diverse Communities across the Nation (as of November 2020)

Populations:

- 🔺 African American
- 🔺 Asian Pacific Islander
- 🔺 Latinx
- △ American Indian
- △ Alaska Natives
- 🔺 Native Hawaiian

Grantee Snapshot:

- Health-care systems
- Universities
- AAAs
- States
- Counties
- Tribal entities
- Community-based orgs
- Hospice and palliative care providers
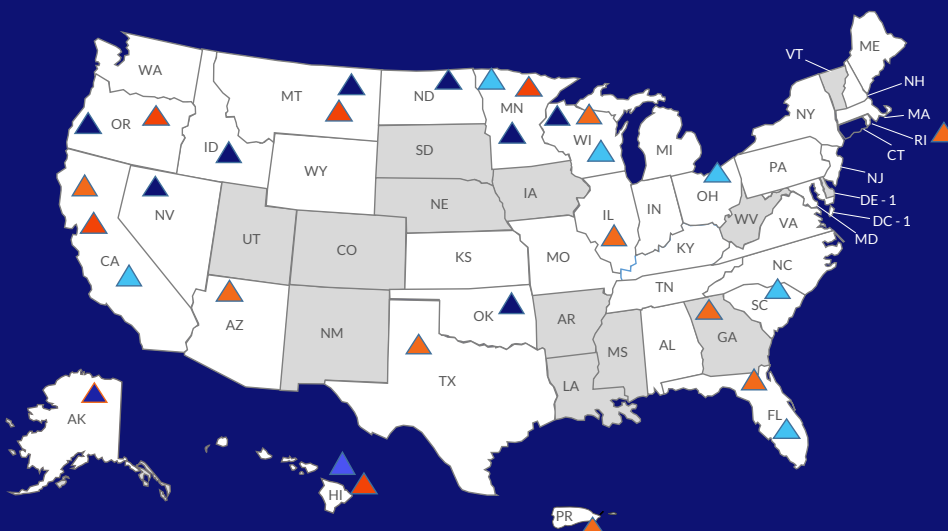
Source: Administration for Community Living (2020)

In addition to recruiting a diverse health-care workforce, the Alliance recommends requiring health- and long-term care systems to seek out and include representation from communities of color in governance structures and patient or community advisory boards.[33]

HRSA offers training materials for both the primary care workforce and caregivers to improve competence in dementia care. During the 2017 National Research Summit on Dementia Care, the Workforce Development Workgroup recommended updating training for providers and caregivers to address implicit bias, health inequities, and gender appropriateness.[34] Resources such as the National Consortium on Aging Resources for Seniors' Equity guide address meaningful inclusion in service planning and delivery and can be used as a framework for updating the existing dementia workforce training.[35] The HRSA ADRD curricula, comprised of 16 modules, provides the workforce with skills training to offer high-quality care, ensure timely and accurate detection and diagnosis, and identify high-quality dementia care guidelines and measures across care settings. One example of a topic in the curriculum is Module 3: Role of Diversity in Dementia Care. This module discusses cultural competence, cultural humility, the impact of sex, ethnicity, and race on dementia risk, factors to consider when diagnosing and treating dementia in diverse populations, barriers to optimal care among various groups, and techniques for effective communication with diverse populations.

Community health worker programs are proven mechanisms for trusted community members to deliver culturally competent education and supports and services into diverse communities.

Erin Long, Team Lead, Alzheimer's Disease Programs Initiative, Office of Supportive and Caregiver Services, Administration for Community Living

Lisa McGuire, PhD, lead of the Alzheimer's Disease and Healthy Aging Program at the CDC, asked the roundtable to expand the definition of the dementia-care workforce to include anybody who interacts with individuals at high risk or living with dementia and is either a current or future health-care professional, including nurses, community health workers, and long-term care workers. Enhanced training for a broad interdisciplinary group of care providers, including family members, friends, and other unpaid individuals who care for people living with dementia, can contribute to greater rates of detection, diagnosis, and improved access to services to help treat and manage their condition.[36]

The Alliance recommends leveraging data from HRSA regarding the use and spread of dementia-specific curriculum, tools, information resource centers, and modules to better understand barriers and existing training opportunities and toolkits provided as part of the GWEP. These insights can inform strategies to improve team-based care models that integrate health and social services, greater inclusion of dementia-specific curricula into training, and expansion of federal and state programs to train existing workers.

As efforts increase to train the current workforce, the Alliance supports creating a robust, qualified, and culturally competent workforce across settings through a coordinated interdisciplinary approach that includes scholarships, loan forgiveness, and clinical internships.[37]

RECOMMENDATION #3

Develop the core components of collaborative dementia-care models to encourage providers to increase continuity, build trusting relationships, and follow through with diverse communities.

The current system of dementia care is complex and costly. It is unprepared to treat the growing number of individuals living with dementia who experience cognitive, functional, behavioral, and psychological challenges. More than one-half of primary-care physicians believe that the medical profession is not ready for the growing number of people with ADRD.[38] As a result, many people living with dementia and their caregivers have unmet dementia-related needs for care, services, and supports. Unmet needs for safety, meaningful activities, and prior evaluations and diagnosis are higher in racially and ethnically diverse communities.[39] These are known to increase the risk of adverse health and economic outcomes, including nursing home placement,

> **We need to create collaborative models of care that do not simply replicate or pull people away from their trusted providers but instead find ways to partner and leverage those existing relationships, meeting patients and caregivers where they are, and appropriately resourcing and giving back to the communities they are engaging.**
>
> *Stephanie Monroe, Executive Director, AfricanAmericansAgainstAlzheimer's*

caregiver depression, and lower quality of life.[40] While all groups of people cite affordability as the single greatest barrier to good dementia care, people from diverse racial and ethnic backgrounds perceive discrimination as another significant barrier to receiving quality care. Research from the Alzheimer's Association identified that 36 percent of African Americans say that racial and ethnic discrimination is a barrier, compared to 19 percent of Asians, 18 percent of Hispanics, 12 percent of Native Americans, and just 1 percent of Whites.[41]

Several innovative, collaborative-care dementia models have been developed to support the complex needs of people living with dementia, incentivize providers to deliver high-quality care, and manage the escalating economic impacts associated with dementia care. Effective care models can also reduce caregiver burden and elongate quality of life within the community.[42]

Shari Ling, MD, deputy chief medical officer at the Centers for Medicare & Medicaid Services (CMS), provided roundtable participants with a preliminary list of core building blocks for collaborative dementia care models, based on input from advocates:

- Care coordination based on a person-centered dementia-care plan

- Improved proficiency in dementia diagnosis

- Basic and extended home- and community-based services to avoid institutionalization and prevent or delay enrollment into Medicaid

- A range of caregiver training and supports, including care management, advance care planning, and respite care

Roundtable participants stressed that these dementia-care models should be congruent with cultural norms and address individuals' unique needs. An effective dementia-care model must meet people where they receive care. Traditionally, academic medical centers are the preferred sites for clinical research, treatment, and care. During the roundtable, Stephanie Monroe, executive director of AfricanAmericansAgainstAlzheimer's, emphasized that community health centers are where many people of color receive care and, more often than not, where they have a greater sense of trust in the community. "We need to recognize existing community relationships where patients may be more comfortable and more confident in the care and advice they are receiving. Valuing and building on patient choice is an important strategy to closing equity and access gaps." The Alliance must understand where people prefer to receive health care before before recognizing the significance of expanding the availability of the highest quality treatment from academic medical centers to community health centers.

New collaborative-care models should also address differences in how diverse people living with dementia and their caregivers experience and navigate the health-care system.[43] When individuals receive a dementia diagnosis in any care setting, a checklist of information should be provided to them and their caregivers. These checklists can display clear pathways to clinical and community supports tailored to unique insurance coverage requirements, care preferences, language needs, and cultural preferences. Including and reimbursing staff and professionals such as social workers, care navigators, and care consultants in this process can also help families seek resources on their own. Care models should also include access to nonmedical resources and tools such as legal assistance to navigate complex benefits and complete advance care planning. Area Agencies on Aging offer many of these nonmedical resources, making it essential not to duplicate but to partner and contract with them.

CHWs have a proven track record of improving health outcomes, reducing costs, and addressing health disparities.[44] Incorporating them into new collaborative-care models can help provide a necessary linkage to social and community-based services that help individuals with dementia and their families break down barriers to care. CHWs are trusted members of their communities and provide social and community-based services that focus on nonmedical factors affecting health, including addressing the social determinants of health. CHW services include mental health interventions, smoking cessation advice, nutrition counseling, and connecting people to community-based resources such as housing, transportation, and substance abuse treatment.[45] Collaborative-care models present an opportunity to integrate CHWs into the health-care system and to provide sustainable financing for CHW services. New models should consider adding reimbursement for CHWs and similar community-based care team members for effective services provided within existing payment structures.

Delivery and Payment Models Can Incentivize and Support the Use of Community Health Workers

Blueprint for Health (Blueprint) is Vermont's delivery and payment transformation program. It is designed to improve population health, increase the quality of and access to care, and reduce health-care costs.[46] A key component of the Blueprint is community health teams (CHTs) that receive capitated payments for providing services essential to health but often not addressed in medical care settings.[47] CHTs play an important role in supporting and extending the work of the Patient-Centered Medical Homes (PCMHs) and provide patients with services such as:

- assessing and addressing barriers to health goals,

- developing and documenting patient self-management plans and goals, and

- providing educational resources or referring to educational resources.[48]

The team members who make up CHTs are community-driven. Local workgroups assess the gaps in health, social, and economic resources in a community and design CHTs to best address those gaps, considering community demographics and the capacity of local partners. These teams receive a total payment of $350,000 per 20,000 people,[49] an amount paid by all commercial and public payers, with each payer's contribution dependent on the proportion of the people served by that CHT.

The original Blueprint pilot led to improved outcomes for both providers and consumers.[50] CHTs increased provider satisfaction by helping streamline practices and improving efficiency, and improving people's ability to manage their health.[51] After two encounters with CHTs, consumers reported increased self-sufficiency with health insurance, prescription drugs, housing, and health education. The Blueprint model has also led to short- and long-term health-care cost reductions. The rate of growth in total expenditures was $322 lower over eight years for a Blueprint patient than a person not served by a Blueprint PCMH.[52] Delivery and payment models that utilize trusted community health teams should be scaled to increase access to quality health care in racially and ethnically diverse communities.

Collaborative-care models should also address gaps in care when people transition across settings. McGuire, from the CDC, explained that "we must address the fragmentation that exists in care transition from being diagnosed to being admitted to a health-care or a long-term care facility"—similar to other chronic conditions such as cancer.

Roundtable participants stressed the importance of establishing a collaborative-care framework that inspires trusting relationships that will improve continuity, care coordination, and follow-through with appropriate medical treatments and social supports in diverse communities. Unfortunately, Medicare's reimbursement system does not adequately support these evidence-based, collaborative dementia models.[53] In the coming months, the Alliance will convene a workgroup to advance payment models to support collaborative dementia care. Core elements essential to racially and ethnically diverse communities will be underscored.

RECOMMENDATION #4

Leverage the Age-Friendly Health System framework to develop standardized care pathways and reduce provider bias.

As our population ages and becomes increasingly diverse, the demand for health-care services is projected to rise by greater than 200 percent.[54] African American and Latino older adults consistently exhibit a higher prevalence of chronic conditions and disability than Whites.[55] Moreover, Americans living with Alzheimer's disease have higher emergency department use and inpatient services, with care costing up to $56,000 per year.[56]

> ## An Age-Friendly Health System starts and ends at your kitchen table and creates continuity across care settings.

Terry Fulmer, PhD, President, The John A. Hartford Foundation

Without a change to the way care is currently delivered, health systems will suffer financially, access to services will be limited, and the quality of care received by older adults will deteriorate.[57]

The John A. Hartford Foundation, Institute for Healthcare Improvement (IHI), American Hospital Association, and Catholic Health Association of the United States started the Age-Friendly Health Systems initiative to address many of these issues. The Age-Friendly Health Systems initiative sets a framework for delivering evidence-

based, high-quality care to older adults. As of February 2021, IHI has recognized 1,978 hospitals and health-care practices as Age-Friendly Health Systems participants by IHI.[58] CVS Health MinuteClinic is currently implementing the 4Ms (What Matters, Medication, Mentation, Mobility) framework across all locations.[59]

Figure 5: Age-Friendly Health Systems 4Ms Framework

What Matters
Know and align care with each older adult's specific health outcome goals and care preferences including, but not limited to, end-of-life care, and across settings of care.

Medication
If medication is necessary, use Age-Friendly medication that does not interfere with What Matters to the older adult, Mobility, or Mentation across settings of care.

Mentation
Prevent, identify, treat, and manage dementia, depression, and delirium across settings of care.

Mobility
Ensure that older adults move safely every day in order to maintain function and do What Matters.

Source: The Institute for Healthcare Improvement (2021)

Lenise Cummings-Vaughn, MD, geriatrician, and an associate professor of medicine at Washington University in St. Louis, incorporated the 4Ms Age-Friendly elements into her practice and believes it is a productive framework to reduce dementia disparities. This standardized and structured framework helps reduce provider bias and decrease the complexity associated with dementia care. "Mentation" prioritizes efforts to prevent, identify, and manage depression, dementia, and delirium across settings of care. And the focus on "What Matters" underscores that no two patients are alike; therefore, each patient should be evaluated individually. During the roundtable, Cummings-Vaughn explained that "the Age-Friendly framework helps address factors that affect outcomes for diverse older adults, including consistent assessment, coordinated electronic medical record documentation, and clear interventions for things like mentation, and has great impact."

In 2020, the Age-Friendly Health Systems initiative's advisory group created an equity task force to make racially and ethnically equitable care an explicit part of the 4Ms framework. The task force developed an equity lens that could be integrated into existing outcome measures (e.g., 30-day readmission rates, emergency department utilization, dementia rates). By explicitly linking racial and ethnic data to these outcome measures, Age-Friendly Health Systems will be held accountable for taking action to reduce disparities.[60]

Cummings-Vaughn impressed the importance of "rejecting the propensity to believe that equity in outcomes is not possible for underserved individuals and communities." This mindset creates complacency and a "lack of recognition of factors that can make significant differences in quality of life and outcomes."

The Alliance recommends leveraging the Age-Friendly Health System framework to improve dementia care across settings, focusing on racially and ethnically diverse communities. Working with The John A. Hartford Foundation and its network of Age-Friendly Health Systems, the Alliance aims to utilize best practices from the 4Ms framework to standardize protocols and improve high-quality care for all individuals living with dementia.

THEME #2

Expanding Dementia-Friendly Communities and Workplaces for Racially and Ethnically Diverse Communities

More than 80 percent of people with dementia live in their homes, with an estimated one-quarter or more living alone.[61] This trend is particularly evident in racially and ethnically diverse communities. People of color are 40 percent less likely than Whites to enter a long-term care facility and more likely to live alone or in multigenerational households.[62] Dementia-friendly community and workplace initiatives are critical sources of support for the growing population of people of color living with dementia and their caregivers. Dementia-friendly models such as Dementia Friendly America foster community awareness of dementia and provide supportive options to maintain quality of life for people with dementia and their caregivers.

During the roundtable, many participants agreed that supporting caregivers is an essential function of any dementia-friendly community. Caregivers help loved ones prepare meals, pay bills, attend appointments, and assist with work. Female caregivers in racially and ethnically diverse communities often experience significant health and financial impacts. Female caregivers (who comprise two-thirds of all unpaid caregivers) report higher levels of depression and lower levels of life satisfaction and physical health.[63] African American caregivers generally spend a higher proportion of their household incomes on caregiving than White caregivers.[64] And Latino family caregivers report experiencing more intensive caregiving situations than others.[65]

As increased funding is approved for Alzheimer's disease research, the Alliance recommends allocating additional funding to support community-based services. The Alliance joins organizations such as the Alzheimer's Foundation of America to advocate for increased funding for the Administration for Community Living, which supports home and community-based services and caregiving training, both of which strengthen dementia-friendly communities and improve quality of life for families affected by Alzheimer's disease.[66] The Alliance strongly supports the additional $300 million that Congress approved for the US Department of Health and Human Services' (HHS') 2021 fiscal year budget, designated for Alzheimer's disease research at the National Institutes of Health.[67] But this budget falls short in funding services that support individuals living with dementia to continue to live in their communities.

The Alliance supports efforts to strengthen cultural competence and awareness and expand dementia-friendly initiatives into communities of color and recommends focusing on strategies to support family caregivers:

RECOMMENDATION #5

Support and promote bipartisan federal and state policy efforts to expand financial support and paid family and medical leave for elder care and encourage employers to provide caregiving benefits.

The US is one of the few developed countries without guaranteed paid leave to care for children or older relatives. In other countries, time off to care for children is more common and more generous than for older family members. In 2019, more than 16 million unpaid caregivers provide 18.6 billion hours of care for people with Alzheimer's or related dementias valued at $244 billion.[68] Without government or employer-based support systems, the health and economic well-being of both the caregiver and the person receiving care may be negatively affected. Given the projected numbers of individuals who will need care in the future, the public and private sector should develop more guaranteed protections and benefits for unpaid family caregivers who are also employed.

Less than one-half of employed dementia caregivers report having access to paid leave benefits, although those who can utilize paid leave benefits report improved health and emotional well-being.[69] The Alliance supports paid family leave for family caregivers. UsAgainstAlzheimer's recently convened the Paid Leave Alliance for Dementia Caregivers to advance the passage of federal paid family leave policies that include family care for adults with serious medical conditions, such as dementia.

> **African American and Latino caregivers are more likely to leave the workplace to take on caregiving responsibilities, which significantly impacts the ability to build generational wealth. There needs to be a greater public awareness for caregiving and the impacts on caregivers' personal aging and finances.**

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Paid Family Leave Programs Have Helped Millions of Families across Select States

Eight states and the District of Columbia have enacted paid family and medical leave programs, charting the way forward. Evidence from state programs demonstrates that paid family and medical leave programs are affordable and sustainable with benefits for working families, public health, and businesses.[70]

Figure 6 shows that over the past 15 years, since 2004, over 13 million paid leave claims have been provided in select states that implemented paid family leave. Notably, in California, 12.3 million claims have been paid since 2004. Recently, nearly one-third of claims were for family caregiving, while the other two-thirds were for personal medical reasons. About 5 percent of covered workers use the program each year. Men have filed a growing share of caregiving claims.

Since its implementation, California has expanded the range of family members for whom caregiving leave can be taken, increased benefit levels for lower-wage workers, and made more workers eligible for job protection.

Figure 6. Paid Family Leave Claims Provided in Select States

State	Program Years	Paid Leave Claims
California	15	12,300,000
New Jersey	10	1,100,000
Rhode Island	5	189,000
New York	0	128,000

*Source: National Partnership for Women & Families (2019)*

Financial circumstances may force many families to spend down their assets to qualify for Medicaid to receive long-term care. Patricia Jones, DrPH, director of the Office of Special Populations at the National Institute on Aging, expressed the need for "policies that create appropriate pay reimbursement for care from a family member, who that individual is more trusting of and willing to receive support in the first place." The Alliance supports financial assistance for caregivers that provide care and receive training, counseling, and information, including tax credits or deductions and direct payment for caregiving services. The enactment of the Recognize, Assist, Include, Support, and Engage (RAISE) Family Caregivers Act in 2018 requires HHS to create a national family caregiver strategy, which includes identifying ways to increase financial security and develop workplace policies to help family caregivers keep working while meeting the needs of the diverse caregiving population.[71]

During his 2020 presidential campaign, President Joe Biden put forth a comprehensive plan to address caregivers' health and financial needs by including paid family leave for child and elder care, funding to cover caregiving at home, creating tax credits to reimburse families for expenses associated with unpaid caregiving, and expanding Social Security credits for the time that family caregivers spend out of the workforce caring for loved ones.[72] Biden's plan also aims to improve caregiving and health outcomes in underserved communities by adding 150,000 CHWs and adding CHW services as an optional benefit for states under Medicaid. These measures are urgently needed to support family caregivers who may be forced to choose between their careers and leaving their work to care for a loved one.

Government-driven policies alone may not be enough to support family caregivers adequately. Kevin Crain, head of workplace solutions integration at Bank of America, explained to the roundtable participants that he considers caregiving to be an employee benefit as significant as retirement savings. Crain noted the role of private companies in filling this gap. "We know that companies and employers must work to provide broad-based financial wellness support for their employees. In addition to financial benefits, employers can create new caregiving benefits that include legal assistance, paid leave, and assistance with selecting care facilities." The Milken Institute's report on "Reducing the Cost and Risk of Dementia" recommended creating a National Employer Task Force on Eldercare to explore innovative caregiving support strategies.[73] The Alliance recommends building the business case to recognize the value of these employee benefits for recruitment, retention, and productivity among employees fulfilling this caregiving role.

As more individuals living with dementia choose to remain in their homes, communities must work across sectors to build supportive networks that foster engagement and improve quality of life. Caregivers play a critical role in dementia-friendly communities and need inclusive policies to support them. Investing in
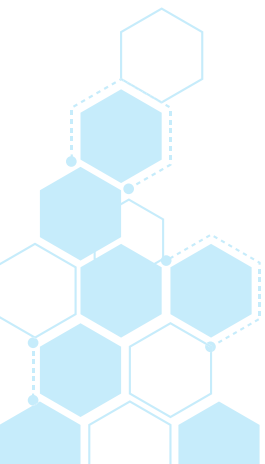
social and economic policies such as paid family and medical leave, respite care, and care-related reimbursement can begin to address systemic racial and gender discrimination and can improve health outcomes and wealth accumulation.

CONCLUSION

The convergence of the COVID-19 global pandemic, racial justice movements, and economic instability have shined a light on long-standing health inequities in the US. Whether it is heart disease, diabetes, stroke, or dementia, long-standing systemic issues have disproportionately impacted racially and ethnically diverse communities. The global pandemic has created a nationwide focus on understanding and addressing these health inequities.

The Alliance is hopeful that, after years of investment and research in ADRD, the groundwork is now being laid for future therapies and treatments. However, we need to work harder to build awareness for brain health and increase access to evidence-based interventions for everyone, especially women and individuals from racially and ethnically diverse communities who are at greater risk of developing dementia and disproportionately bear the financial and health-related impacts of dementia caregiving.

In this report, the Alliance puts forth a series of recommendations to address disparities within the health- and long-term care systems and communities and workplaces. These recommendations focus on strengthening the infrastructure among health-care, long-term care, and CBOs and expanding dementia-friendly networks and workplaces in racially and ethnically diverse communities. We are encouraged that these recommendations will build momentum as innovative strategies emerge to increase access to high-quality dementia care and make inclusive policies to improve the lives of all people living with dementia and their families.

APPENDIX A

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