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Improving Brain Health for Populations Disproportionately Affected by Alzheimer’s Disease and Related Dementias

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Introduction

Background

Promoting and maintaining brain health for older adults is one of the greatest challenges facing the public health community in the United States. This will require the public health community to take steps to reduce disparities in brain health across disproportionately impacted communities. Although some levels of change in the brain processes, like slower processing speeds, trouble with multitasking or even increases in knowledge, are expected as people grow older, significant memory loss and other symptoms of dementia are not normal or inevitable (Centers for Disease Control and Prevention, 2021). Dementia is a general term used to describe problems with thinking and memory that are severe enough to interfere with a person’s daily life. Alzheimer’s disease is the most common form of dementia, accounting for about two-thirds of all cases, while other common forms of dementia such as cerebrovascular, Lewy body, frontotemporal or a combination of multiple co-occurring forms together make up a constellation commonly referred to as Alzheimer’s disease and related dementias (ADRD) (Alzheimer’s Association, 2021). Today, it is estimated that over

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6 million people in the United States are living with ADRD (Alzheimer's Association, 2021).

The biological causes of ADRD are not fully known. Certain risk factors can increase a person's likelihood of developing ADRD. Increased age is a strong factor; however, there is emerging evidence for additional risk factors – both modifiable and unmodifiable – such as physical inactivity, cardiovascular health, smoking, social engagement/isolation, educational attainment, obesity, diabetes, nutrition, brain injury, hearing impairment, and genetics (Alzheimer's Association, 2021). No pharmacological treatments currently exist to cure ADRD, but people may be able to reduce their risk for developing ADRD by addressing modifiable risk factors. To stimulate activity in this area, the *National Plan to Address* Alzheimer's Disease: 2021 *Update* added the first new goal to the plan since its formation in 2011, *Accelerate Action to Promote Healthy Aging and Reduce Risk Factors for Alzheimer's Disease and Related Dementias* (Office of the Assistant Secretary for Planning and Evaluation, Department of Health and Human Services, 2021).

Disproportionate impact of Alzheimer's disease and related dementias

ADRD is devastating to all persons living with the disease, their families, and friends. ADRD disproportionately impacts certain traditionally underserved groups. Over the next few decades, disparities in the proportion of people with ADRD among racial and ethnic minorities are expected to increase. By 2060, the total number of people with ADRD is expected to more than double to approximately 14 million; cases of ADRD are expected to increase sevenfold for Hispanic, fourfold for African American—and fivefold for American Indian/Alaska Native (AI/AN)—persons (Matthews et al., 2019). Additionally, ADRD has a unique impact on other underserved populations including people with intellectual and developmental disabilities (IDD). Among people with Down syndrome, about half have Alzheimer's disease in their 60s (Alzheimer's Association, 2021). Each of these disproportionately affected populations are unique. Strategies focusing on improving and tailoring public health messages and actions–including those from Federal, state, and local health agencies, as well as non-governmental organizations–for specific populations is essential to improving outcomes related to ADRD and reducing inequities across the population.

Need for cross-cultural messaging for disproportionately affected populations

Despite an increasing prevalence of ADRD among traditionally underserved populations, there remains a gap in understanding and knowledge of ADRD within these populations. AI/AN, Hispanic, and African American persons are less worried about developing ADRD than White and Asian persons (Alzheimer's Association, 2021). This is in stark contrast to the reality that African American, Hispanic, and American Indian persons are disproportionately impacted by ADRD and will be even more so in the coming decades. There are cross-cutting reasons contributing to both the disparities in ADRD prevalence and the knowledge gap that can be attributed to inequities related to social determinants of health

(SDOH), cultural differences and stigmatization, and a lack of access to culturally competent health care and accurate health information.

Social determinants of health

SDOH affects where and how people live, work, and progress throughout the lifespan and can dramatically shape outcomes into late life. It is important to consider how these SDOH impact brain health but also physical health. Recent advances in knowledge about physical risk factors for cognitive decline like mid-life obesity, hypertension and other lifestyle factors emphasize the outsized role physical health can play on brain health (Centers for Disease Control and Prevention, 2020). As evidence continues to grow, strategies to address ADRD should reflect the longstanding inequities that exist related to physical well-being of disproportionately affected groups. Societal and structural factors that affect physical health, such as educational and economic opportunities, social connectedness, access to culturally competent health-care services, and the built environment can impact brain health. For example, safe options for outdoor physical activity and affordable groceries to maintain a healthy weight and a balanced diet may be limited in some communities (Centers for Disease Control and Prevention, 2020).

Cultural differences and stigmatization

Strategies to improve brain health and reduce the risk for ADRD need to reflect cultural differences across populations. For example, among AI/AN communities, elders are highly valued for their knowledge, wisdom, and contributions. Because ADRD largely affects people who are older, it is critical that conversations about ADRD within AI/AN communities respect cultural norms while simultaneously balancing health and safety (Heller, Scott, & Janicki, 2018). Moreover, stigma, fear, and lack of knowledge of ADRD can lead to delayed or missed diagnoses. The percentage of African American, Hispanic, and American Indian persons who would not see a provider about problems with thinking or memory is twice as high compared to White Persons (Alzheimer's Association, 2021). Additionally, approximately 20% of African American and Hispanic persons would be insulted if a cognitive assessment was suggested by a provider (Alzheimer's Association, 2021). Much progress is needed to normalize conversations among all populations with providers and in the community about brain health, especially disproportionately affected ones.

Barriers to health care

Nearly all persons with ADRD have one or more comorbid chronic conditions; the successful management of which can be compounded by limitations in cognition (Alzheimer's Association, 2021). For certain groups, discrimination when seeking care for ADRD is a significant problem. Half of African American, 42% of AI/AN, and 33% of Hispanic persons reported experiencing discrimination when seeking health care (Alzheimer's Association, 2021). They were less likely than their White counterparts to feel listened to, treated with courtesy and respect, and receive the same quality of service. Over 85% of individuals in these three disproportionately affected groups feel it is important that providers understand their racial or ethnic background when providing care for a person with ADRD, while only about half have access to a provider who does understand

(Alzheimer's Association, 2021). For people with IDD, receiving adequate health care is often a significant challenge. These persons experience greater unemployment, more complex and poorly managed health conditions, and an over-focus on their intellectual disabilities. Symptoms of ADRD may appear differently and earlier in persons with IDD than among persons without those disabilities (Heller et al., 2018; University of Illinois at Chicago Health Matters Program, n.d.). This can lead to missed diagnoses and delayed interventions resulting in poorer quality of life. It is critical that providers do not discount changes in cognitive functioning in this population and utilize ongoing population-appropriate assessments of brain health (Heller et al., 2018).

National initiatives to improve brain health messages

National healthy brain initiative

The National Healthy Brain Initiative (NHBI), funded through the Centers for Disease Control and Prevention (CDC), promotes brain health by integrating strategies to address cognitive decline, including ADRD, into public health (Centers for Disease Control and Prevention, 2021). The Healthy Brain Initiative's State and Local Public Health Partnerships to Address Dementia, the 2018–2023 Road Map (Road Map) established 25 actions that public health agencies, partners, and other stakeholders can take to advance brain health and improve outcomes related to ADRD in the U.S. (Centers for Disease Control and Prevention, 2021). The actions fall under four of the ten essential services of public health: Educate and Empower the Nation (E), Develop Policies and Mobilize Partnerships (P), Assure a Competent Workforce (W), and Monitor and Evaluate (M). Each of these domains and their corresponding Road Map actions serve as guiding principles for the work funded under CDC's NHBI and Building Our Largest Dementia Infrastructure (BOLD) Act and emphasize health equity.

One of the central goals of the NHBI is to reduce disparities and improve outcomes for populations disproportionately impacted by ADRD by utilizing a public health approach with attention to SDOH. The awardees of Component B of the NHBI have a national reach with one or more sub-populations with a demonstrated disproportionate burden of ADRD (Centers for Disease Control and Prevention, 2021). These awardees are identifying gaps in effective messaging, developing or adapting tailored communications, and implementing tailored Road Map actions for their population of focus. Component B focuses on implementing actions that primarily address domains E, P, and W of the Road Map. Component B awardees focus on public health messaging and actions for African American, Hispanic, AI/AN populations, and people with IDD. There are three NHBI Component B organizations working to address these four disparate populations (Centers for Disease Control and Prevention, 2021).

African American and Hispanic populations

Through the NHBI, UsAgainstAlzheimer's Center for Brain Health Equity has employed two culturally centered strategies to support brain health among African American and Hispanic populations (UsAgainstAlzheimer's, n.d.). The first is to leverage expertise of African American and Hispanic providers and community leaders by centering project work through focus groups and regular engagement with target communities. The second is to design community outreach and education strategies to enhance knowledge about disparities experienced by African American and Hispanic communities due to structural racism and SDOH. In practice, UsAgainstAlzheimer's is working to develop effective and tailored public health strategies for African American and Hispanic communities through collaborations with impactful and relevant groups, such as nursing professionals and community-based organizations. The content of the messages developed meet the intended audiences where they are, accounting for the wideranging levels of health literacy in target populations. Supporting the Road Map domain W, the project is intended to improve competency among providers who serve African American and Hispanic patients and families (UsAgainstAlzheimer's, n.d.).

American Indian and Alaska native populations

The International Association for Indigenous Aging (IA^2) serves as a national hub for informational resources for Indian Country and focuses on brain health messaging for AI/AN (International Association for Indigenous Aging, n.d.). IA^2 is addressing ADRD in tribal communities by working to fulfill eight actions outlined in the Road Map for Indian Country (Centers for Disease Control and Prevention, 2020; International Association for Indigenous Aging, n.d.). IA^2 is building capacity among tribes and tribal member-serving organizations, promoting brain health strategies across the lifespan, and fostering dementia-capable tribal communities. They created a resource library to educate and empower tribal communities to better understand the impact of ADRD on tribal communities, caregivers, and elders and to normalize conversations around brain health. Efforts are framed exclusively on AI/AN populations and communities and support values of tribal sovereignty, respect cultural traditions and knowledge, while encouraging innovation. In its work, IA^2 recognizes the importance of mutually beneficial collaborations and strives to promote thoughtful and effective partnerships (International Association for Indigenous Aging, n.d.)

Persons with intellectual and developmental disabilities

The University of Illinois at Chicago's (UIC) Healthy Brain Community of Practice promotes brain health and well-being among people with IDD (University of Illinois at Chicago Health Matters Program, n.d.). It is a central resource with strategies to improve brain health across the lifespan. One critical aspect is to diminish the myth that ADRD is an expected and natural outcome of growing older with IDD. The overarching goals of the program are to achieve health equity for people with IDD and to support health and wellness of their caregivers. UIC works to develop culturally tailored messages, resources, and trainings to empower people with IDD, families, caregivers, community partners, and professionals consistent with Road Map E domain. The primary strategies for achieving these goals are to develop health messages, resources, and trainings that are accessible to people with IDD, their families, caregivers, and community partners and to empower public health and healthcare professionals, direct support personnel, families, and caregivers to be brain health ambassadors. UIC emphasizes framing resources and messages for providers and other partners in a positive way to catalyze system change and illuminate the steps that can be taken to improve brain health and awareness for people with IDD (University of Illinois at Chicago Health Matters Program, n.d.).

Remaining challenges and the way forward

NHBI awardees are making progress toward reducing ADRD disparities by tailoring messages and materials to the four populations they serve. It is a start. The challenge is that there are numerous other populations who would benefit from brain health messages and actions tailored to them. The way forward should include content reflective of the needs of the community by utilizing members' input to ensure that messages are culturally appropriate and will be the most effective. Additionally, there needs to be an emphasis on SDOH that contribute to health or behavior outcomes in the community that are key to improving brain health outcomes. For example, maintaining social connections and reducing social isolation have a large impact on risk for poor outcomes and are associated with risk for ADRD and other contributing factors like heart disease, stroke, depression, and anxiety. Finally, identifying cross-cutting themes or approaches are an opportunity to harmonize chronic disease initiatives with those focused on brain health. For example, reducing risk of dementia across the lifespan in connection with physical health can have synergistic effects on targeted areas such as cardiovascular disease, smoking, and diabetes by adding a new and compelling dimension to existing messaging. The challenges to improve brain health for populations disproportionately affected by ADRD are daunting but not insurmountable if intentional action is taken that does not rely on a one-size-fits-all approach.

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