



Diversity, Equity, and Inclusion in Alzheimer's and Dementia

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OUR WORK | COMMUNITY AND SCIENCE

The Alzheimer's Association is a global organization working to advance care, support and research across the world

In 1980, our founders united caregivers, researchers and activists to create the Alzheimer's Association.

Our mission symbol pays tribute to their ability to bring people and science together – for the benefit of all.



OUR TIME TODAY

Level Set on Diversity, Equity & Inclusion

Alzheimer's and Dementia
Diversity and Disparities

Opportunities to
Enhance Inclusion

Moving Forward in Pursuit of
Health Equity



DEFINING DIVERSITY, INCLUSION & EQUITY

DEVELOPING OUR UNDERSTANDING

DIVERSITY

- **Numerical** representation of differences
- Different **perspectives, characteristics & beliefs**

INCLUSION

- Achieving an authentic & empowered participation and **true sense of belonging**
- The action or state of including, or being included within a group

EQUITY

- **Everyone gets what they need** to survive, access to opportunity, resources and support
- **Different from “equality”**, where everyone has the same access to & amount of resources



Equality

Equity

A CLOSER LOOK

DEVELOPING OUR UNDERSTANDING

HEALTH EQUITY

Health equity is achieved when every person has the opportunity to attain their full health potential and no one is disadvantaged from achieving this potential because of social position or other socially determined circumstances.

HEALTH INEQUITY

Health inequities are reflected in differences in length of life; quality of life; rates of disease, disability and death; severity of disease; and access to treatment (CDC, 2020).



ALZHEIMER'S  ASSOCIATION®

2022 Alzheimer's Disease Facts and Figures



More than **80%** of Americans
know little or are not familiar with
mild cognitive impairment (MCI), which
can be an early stage of Alzheimer's.

2021 ALZHEIMER'S DISEASE FACTS AND FIGURES

DISCRIMINATION

is a barrier to Alzheimer's and dementia care. These populations reported discrimination when seeking health care:



OVER
11
MILLION

Americans provide unpaid care for people with Alzheimer's or other dementias

Between 2000 and 2019, deaths from heart disease have
DECREASED
7.3%

while deaths from Alzheimer's disease have

INCREASED
145%

Alzheimer's and dementia deaths have increased

16%

during the COVID-19 pandemic



1 IN 3

seniors dies with Alzheimer's or another dementia

It kills more than

BREAST CANCER

+

PROSTATE CANCER

COMBINED

MORE THAN
6
MILLION

Americans are living with Alzheimer's

In 2021, Alzheimer's and other dementias will cost the nation
\$355 BILLION



By 2050, these costs could rise to more than

\$1.1
TRILLION



These caregivers provided an estimated 15.3 billion hours valued at nearly

\$257
BILLION

Why is this important to us?

- Older Black and Hispanic Americans are **disproportionately** more likely to have Alzheimer's or other dementias.
- LGBTQ elders are more likely to **live alone** and have **no caregiving and support** network
- We support **ALL COMMUNITIES** living with Alzheimer's or dementia



2021 Special Report Race, Ethnicity and Alzheimer's in America

To learn more visit
[alz.org/facts](https://www.alz.org/facts)



2021 ALZHEIMER'S DISEASE FACTS AND FIGURES

DISCRIMINATION

is a barrier to Alzheimer's and dementia care. These populations reported discrimination when seeking health care:



of Black
Americans



of Native
Americans



of Asian
Americans



of Hispanic
Americans



What We Learned

- **Discrimination is a barrier** to Alzheimer's and dementia care.
- People of color want health care providers who understand their **unique experiences and backgrounds**, but many doubt they would have access to culturally competent providers.
- Black Americans **lack trust in research** clinical trials, and half doubt that advances in Alzheimer's treatments will be shared.
- **Knowledge, awareness, concern and stigma** about Alzheimer's varies widely across racial and ethnic groups.

Gender, Racial and Ethnic Disparities in Alzheimer's Prevalence

More than **one-third** of Black Americans, and nearly **one-fifth** of Hispanic and Asian Americans believe **discrimination** would be a barrier to receiving Alzheimer's care

DISCRIMINATION A PERCEIVED BARRIER TO CARE

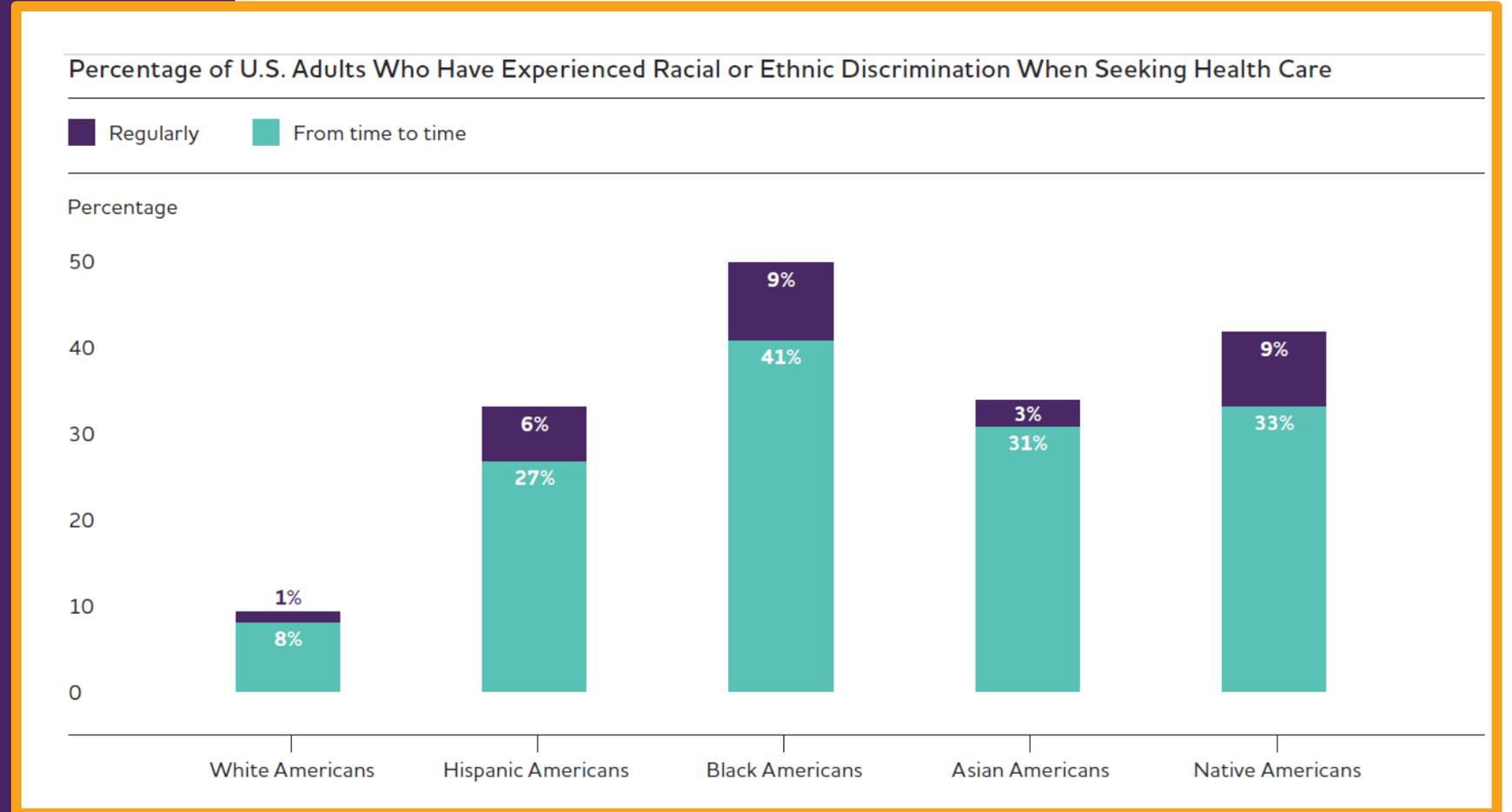
Perceived Barriers to Getting Excellent Health Care and Support for Alzheimer's or Another Dementia Among U.S. Adults

	White Americans	Hispanic Americans	Black Americans	Asian Americans	Native Americans
Affordability of care	61%	55%	52%	70%	61%
Lack of good health care insurance coverage	31%	41%	31%	39%	36%
Lack of good health care services in my community	20%	24%	27%	27%	24%
Lack of family and social support to help me	20%	21%	20%	25%	20%
Being treated differently because of my race, color or ethnicity	1%	18%	36%	19%	12%
Not being able to communicate easily in English	4%	9%	9%	8%	5%
Other barriers	2%	1%	1%	1%	2%
There would be no barriers	21%	17%	20%	12%	14%

Gender, Racial and Ethnic Disparities in Alzheimer's Prevalence

HALF of Black Americans and at least ONE-THIRD of Native, Asian and Hispanic Americans report experiencing health care discrimination

DISCRIMINATION WHEN SEEKING CARE



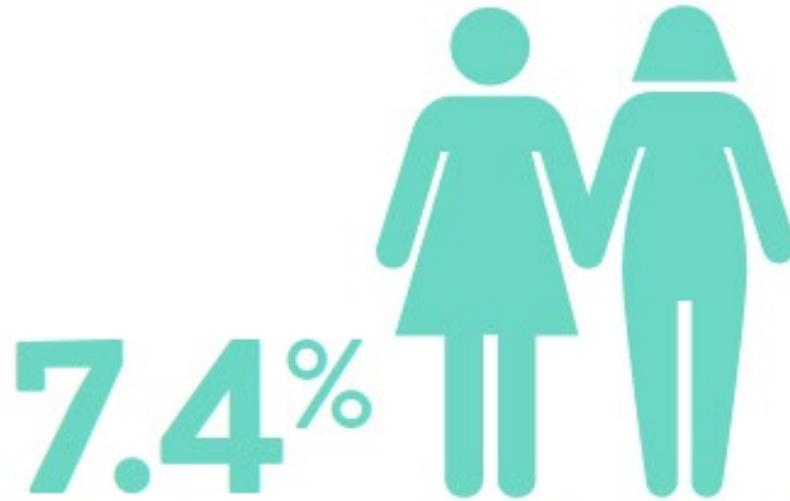
Knowledge, awareness, concern and stigma about Alzheimer's varies widely across racial and ethnic groups

- Concern about developing Alzheimer's is **lower among Native Americans (25%), Black Americans (35%) and Hispanic Americans (41%),** especially when compared with **White Americans (48%).**
- **More than one-third of Native Americans (35%) and nearly 3 in 10 Hispanic Americans (28%) do not believe they will live long enough** to develop Alzheimer's or another dementia.
- **More than half of non-White Americans** believe significant loss of memory or cognitive abilities is **“a normal part of aging.”**

Race, Ethnicity and Caregiving

- Black caregivers more likely to provide more than 40 hours of care per week than White caregivers (54.3% versus 38.6%). Also more likely to care for someone with dementia (31.7% versus 11.9%) than White caregivers.
- Black dementia caregivers — 69% less likely to use respite services compared with White caregivers.
- Hispanic, Black, and Asian American dementia caregivers indicate greater care demands, less outside help/formal service use, and greater depression when compared with White caregivers.
- Black caregivers — more likely than White caregivers to report positive aspects of caregiving.

Gender, Racial and Ethnic Disparities in Alzheimer's Prevalence



of the lesbian, gay and bisexual older adult population is living with dementia

LGBT OLDER ADULTS AND DEMENTIA

Age is the greatest risk factor for Alzheimer's disease

An estimated **2.7million** LGBT people are over age 50

Gender, Racial and Ethnic Disparities in Alzheimer's Prevalence

LGBT adults living with dementia face unique challenges in accessing support

40%  report that their support networks have become smaller over time

34%  live alone

Up to **30%**  experience lower rates of access to care

Alzheimer's is the most expensive disease in the nation

51%  of LGBT older people report being very concerned about having enough money to live on

Fear of discrimination can delay access to care

40%  say their health care providers don't know their sexual orientation

LGBTQ Caregiving

- Caregivers are more likely to be caring in isolation, which can exacerbate stress and lead to caregiver burnout
- 40% report support networks have become smaller over time
- 2X as likely to live alone; 3-4X less likely to have children
- Health laws and definition of family complicate caregiving

ALZHEIMER'S RESEARCH IN THE LGBTQ COMMUNITY



LEARN THE LATEST IN ALZHEIMER'S & DEMENTIA RESEARCH

Join Jason Flatt, Ph.D., MPH, Assistant Professor, University of Nevada, Las Vegas, and Carl V. Hill, Ph.D., MPH, chief diversity, equity and inclusion officer at the Alzheimer's Association for a discussion of Alzheimer's and Dementia Research in the LGBTQ Community.

Thursday, July 22 | 11 am - 12 pm CT

To register, visit bit.ly/3gzfVx

or call the Alzheimer's Association at
800.272.3900

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sage | Advocacy &
Services for
LGBT Elders
We refuse to be invisible

alzheimer's  association®

African Americans: Alzheimer's and Health Equity

- African Americans are more likely than white Americans to have Alzheimer's and other dementias.
- Deeply impacted by historic and current systemic injustices and inequality.
- Experience additional health disparities.

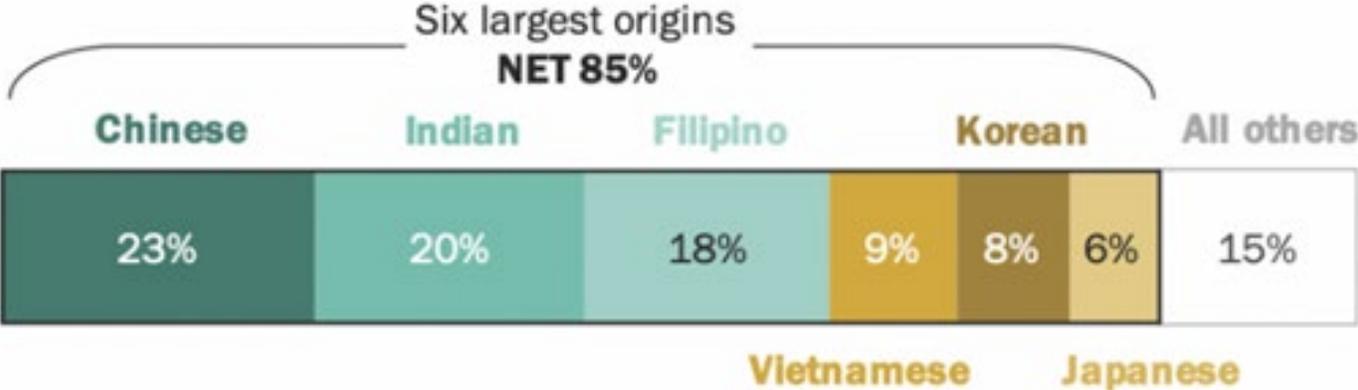


Asian American and Pacific Islanders in the US

- More than 50 ethnic groups and over 100 languages spoken

Six origin groups make up 85% of all Asian Americans

% of the U.S. Asian population that is ...



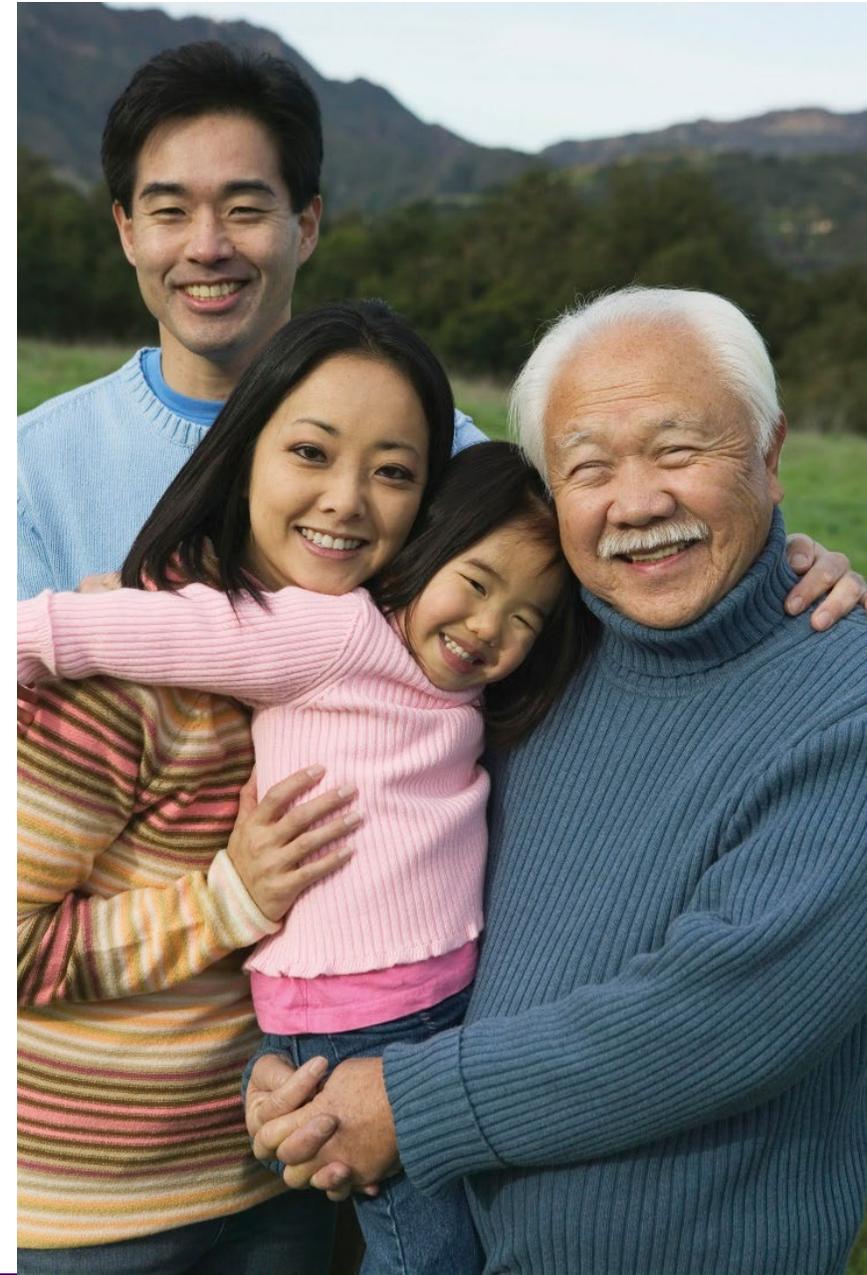
Note: "Chinese" includes those identifying as Taiwanese. "All others" includes the 3% of U.S. Asians in the category "Other Asian, not specified." Figures may not add up to 100% due to rounding. Figure for all origin groups include mixed-race and mixed-group populations, regardless of Hispanic origin.

Source: Pew Research Center analysis of 2019 American Community Survey 1-year estimates (Census Data).

PEW RESEARCH CENTER

Cultural Barriers

- Misconception about dementia/normalization of illness
- Language barrier
- Acculturation continuum (not only immigrants)
- Anticipation of not being understood
- Perception of Western biomedical model of treatment



Native Americans

- 1 in 3 Native American Elders age 65+ will receive a dementia diagnosis over the next 25 years.
- Prevalence of diabetes, heart disease, cigarette smoking and traumatic brain injury are high among American Indian and Alaska Native populations.



Road Map for Indian Country



Native Americans' Perceptions of Alzheimer's and dementia

- About two-thirds (65%) of Native Americans say that they know somebody with Alzheimer's.
- Only 25% of Native Americans say that they are worried about developing Alzheimer's disease.
- More than one-third of Native Americans (35%) say that they do not expect to live long enough to develop Alzheimer's.
- More than half (53%) of Native Americans believe that significant memory or cognitive losses are a normal part of aging.

How does Alzheimer's affect Hispanic Americans and Latinos?



Gender, Racial and Ethnic Disparities in Alzheimer's Prevalence

FACT: LESS THAN 5% of trial participants are

- Black/African American
- Latino/Hispanic
- Asian American/Pacific Islander
- American Indian/Alaskan Native

UNDERSTANDING THE WHY

- Less likely to be recruited for clinical trials
- Higher drop-out rates in AD trials
- Awareness/Education/Bioethics

INCLUSION IN DEMENTIA RESEARCH



PURSUING EQUITY IN ALZHEIMER'S & ALL OTHER DEMENTIA

CHANGING
THE COURSE

1

Conduct, Promote and Support Multi-Level Health Disparities Research

2

Increase Diversity in Health Systems and Health-Related Institutions

3

Enhancing Cultural Competence in Dementia Research and Care

4

Compliance/Accountabilities

5

Participatory Engagement to Build Trust and Agency

What is the Association doing?

→ ENACT Legislation

Equity in Neuroscience and Alzheimer's Clinical Trials (ENACT) Act, legislation introduced to **increase clinical trial participation** among underrepresented populations.

→ Community Forums

Over 500 **listening sessions**, almost 15,000 attendees

→ Health Equity

Focusing on future treatments

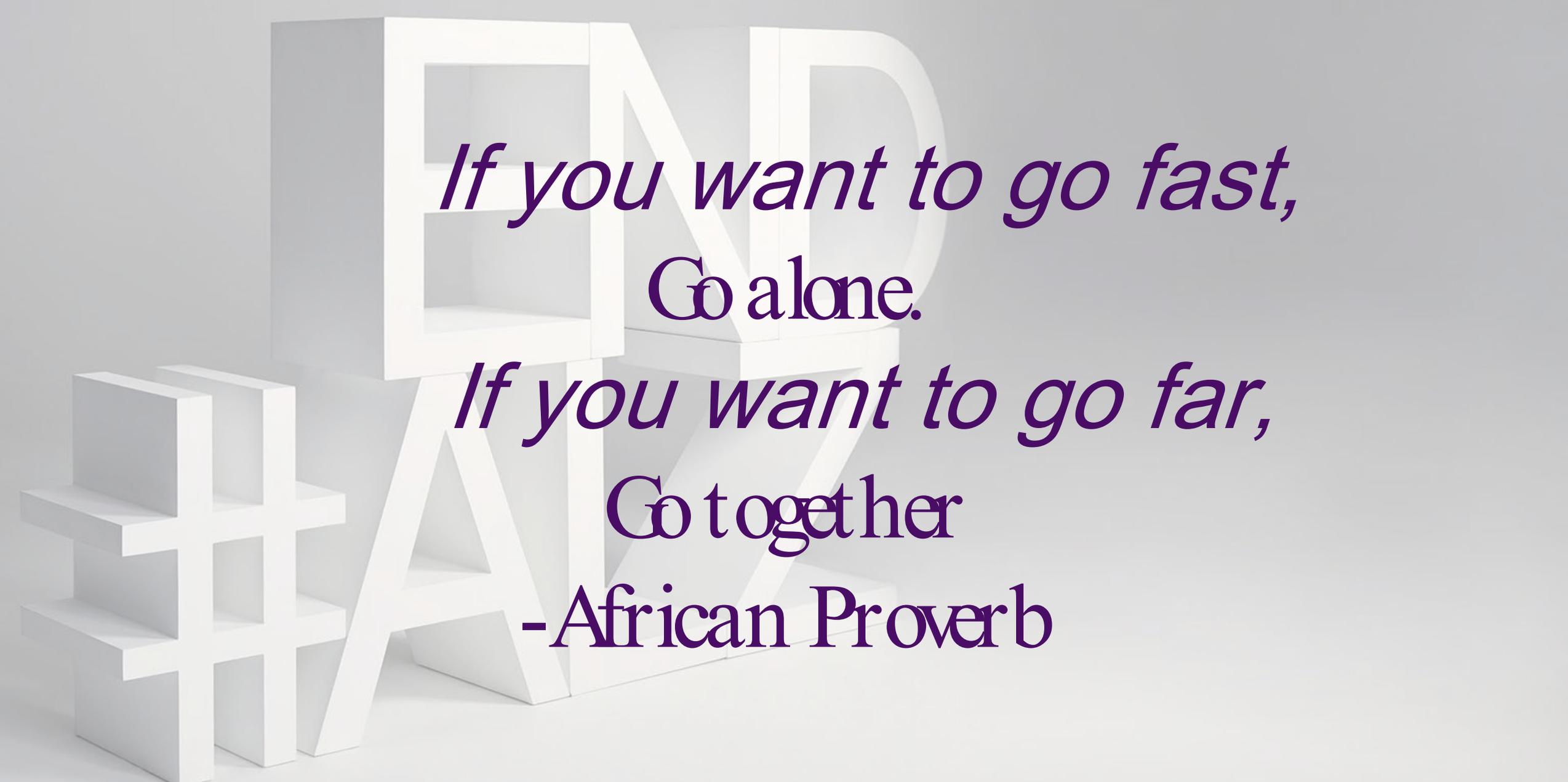
What is the Association doing?

➔ **New IDEAS** recruitment

Enrolling 7,000 participants, including 2,000 Hispanics/Latinos and 2,000 Blacks/African Americans.

➔ **Grow national and local DEI partnerships**

Partnerships with National Hispanic Medical Association, National Hispanic Council on Aging, National Indian Council on Aging, National Black Nurses Association, National Asian Pacific Center on Aging, Services and Advocacy for Gay, Lesbian, Bisexual and Transgender Elders (SAGE) and others



If you want to go fast,

Go alone.

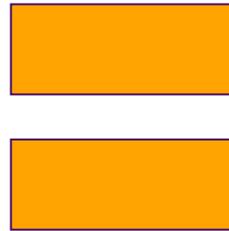
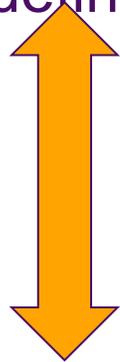
If you want to go far,

Go together

-African Proverb

The Power of Collaborative Partnerships

Each community has its own needs and assets, as well as its own culture and social structure -- a unique web of relationships, history, strengths, and conflicts that defines it.

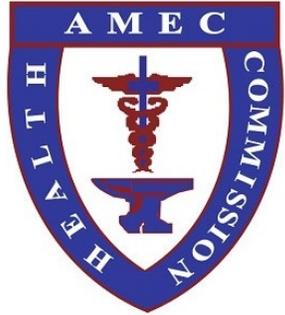


Include community members from the very beginning of the building process. Encourages both trust in the process and community buy-in and support.

Community-based Participatory Research Principles (CBPR)



Our National Partners



PURSuing EQUITY THROUGH NATIONAL PARTNERSHIPS

LOCAL ACTIVATION
NATIONAL SCOPE

PARTNERS ENGAGE THEIR MEMBERS AND COMMUNITIES THROUGH:

- Training
- Volunteers
- Community Engagement
- The Longest Day[®]
- Walk to End Alzheimer's[®]
- Conferences and Events
- Purple Sunday
- Advocacy Efforts
- Research
- Concern & Awareness
- Education Programs
- Referrals
- AAIC[®]



In Summary

- The *2021 Facts and Figures* special report **shines a bright light on barriers** facing non-White racial/ethnic population in accessing dementia care.
- The data suggest that **discrimination and lack of diversity** in the healthcare profession are **significant barriers** that demand attention.
- The already devastating burden of Alzheimer's **must not be made worse** by discrimination and health inequities in the current system.
- The Alzheimer's Association **is committed to reducing health inequities and health care disparities**, particularly as they impact older adults and their ability to access high quality dementia care.

THANK YOU.



www.alz.org
24 Hour Helpline (800) 272-3900

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Alzheimer's Disease Facts and Figures

Go to www.ALZ.org/facts to view the most recent facts & figures.