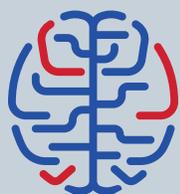




Place & Brain Health Equity

An Data Brief on Congressional  
Districts and Alzheimer's  
Prevalence among  
Communities of Color



USAGAINSTALZHEIMER'S CENTER *for*  
BRAIN HEALTH EQUITY

“We know first-hand the toll Alzheimer’s takes on individuals, families, and communities. This shared experience underscores our call for empathy, unity, and urgent action. The stakes are too high and the wait too long for millions of our families.”



*The Honorable Dr. David Satcher,  
Former United States Surgeon General;*

*Ms. Dolores Huerta, Founder of the Dolores  
Huerta Foundation and Member of the  
UsAgainstAlzheimer's Brain Trust*

- 3 Executive Summary
- 5 The Changing Face of Alzheimer's: Disparities in Alzheimer's Disease
- 7 A Brain Health Equity Agenda for Alzheimer's Disease
- 10 The Congressional Districts
- 13 Sources
- 13 Acknowledgments

# Executive Summary

Social determinants of health (SDOH) have long-term, far-reaching, and not always obvious ramifications in people’s lives—including their risk for Alzheimer’s disease and related dementias (ADRD).<sup>1</sup> This is clear from a close look at the counties most impacted by Alzheimer’s among communities of color.

This data brief identifies the congressional districts that overlap with the 25 counties with the highest prevalence of Alzheimer’s among Black and Latino Americans across the United States. It highlights the systemic inequities prevalent in these counties and makes recommendations for policymakers to advance brain health equity in hard-hit communities.

Whether in an urban area such as Miami-Dade County, Florida, or thousands of miles away in more rural places such as Humphreys County, Tennessee, families living in the counties most impacted by Alzheimer’s among Blacks and Latinos are connected by systemic inequities that deserve urgent action.

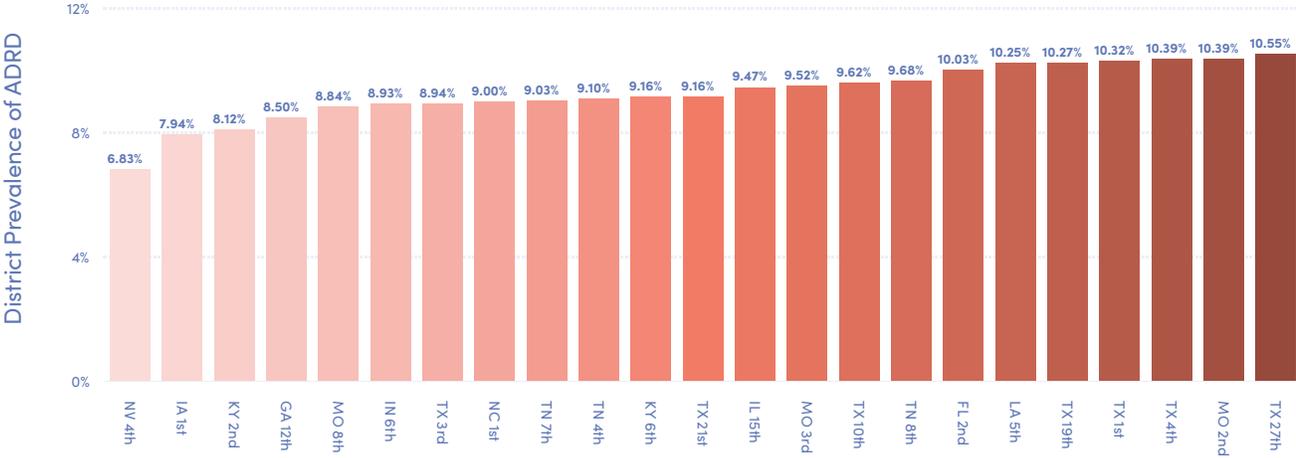
These families are **less likely** to have health insurance, **less likely** to have access to exercise opportunities, and **less likely** to have a bachelor’s degree or higher. At the same time, they are **more likely** to have lower incomes and **more likely** to report poor health than families living in counties with lower levels of Alzheimer’s disease.<sup>2</sup>

Public policy and public health have been slow to address the effects of place on overall health, especially on brain health. Brain health is the ability to clearly think, learn, remember, it also includes your motor and emotional functioning –all important components of performing everyday activities.

Four policy actions can better target **research investment, improve access to healthcare, and promote public health** interventions for under-resourced communities.

- 1. Invest in public health, treatment, and research infrastructure** in communities hard-hit by Alzheimer’s and related dementias.
- 2. Invest in educational and economic opportunity** to reduce social inequities.
- 3. Establish an ambitious national goal to prevent** Alzheimer’s disease and related dementias and **address disparities in early intervention and diagnosis.**
- 4. Collect better data to identify and address gaps in access** to Alzheimer’s health services and research for underserved communities.

## Districts that Represent the Top 25 Counties with the Highest ADRD Prevalence Among Black Americans in Medicare Fee for Service



## Districts that Represent the Top 25 Counties with the Highest ADRD Prevalence Among Latinos in Medicare Fee for Service



# The Changing Face of Alzheimer's

## DISPARITIES IN ALZHEIMER'S DISEASE

Black Americans are approximately two times more likely, and Latinos are 1.5 times more likely to develop Alzheimer's than non-Latino Whites.<sup>3</sup> There has never been a more urgent time to reduce Alzheimer's in communities of color. If nothing is done, by 2030 nearly 40 percent of all Americans living with Alzheimer's will be Latino or Black.

Unfortunately, despite higher risk, Black and Latino Americans living with dementia are:



**Less likely** than White patients to receive a timely diagnosis;

In a recent study of Medicare beneficiaries, Black Americans (18.2%) and Latinos (15.8%) were less likely to receive a timely diagnosis when compared to Whites (23.3%).<sup>4</sup>



**More likely** to report experiencing racial discrimination along their patient and caregiver journeys;

Half of Black Americans (50%) and one in three Latino Americans (33%) report they have experienced healthcare discrimination.<sup>5</sup>



**Less likely** to be enrolled in cutting-edge Alzheimer's and brain health research.

Latino and Black Americans make up less than 10% of all clinical trial participants in active ADRD research.<sup>6</sup>

# The Changing Face of Alzheimer's

## DISPARITIES IN ALZHEIMER'S DISEASE

### UNDERSTANDING THE COUNTY-LEVEL IMPACTS OF ALZHEIMER'S DISEASE

The effects of where people live and other SDOH remain under-recognized and under-studied in our national response to effectively target, treat, and prevent Alzheimer's disease. To better understand which SDOH intersect with Alzheimer's in communities, UsAgainstAlzheimer's and the Urban Institute, with support from the National Minority Quality Forum, analyzed Medicare data to identify the counties with the highest and lowest prevalence of Alzheimer's by race and ethnicity and identified trends related

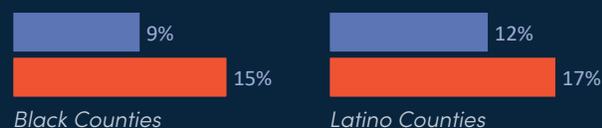
to SDOH among these highly impacted communities.

**The report found significant social inequities in counties highly impacted** by Alzheimer's among Latino and Black Americans compared to counties with the lowest prevalence of the disease among Latino and Black Americans. Counties with the highest prevalence of Alzheimer's among Blacks and Latinos are more likely to have worse SDOH outcomes than counties with the lowest prevalence of Alzheimer's.

Key findings on SDOH indicators include:

■ Highest ADRD Prevalence ■ Lowest Prevalence

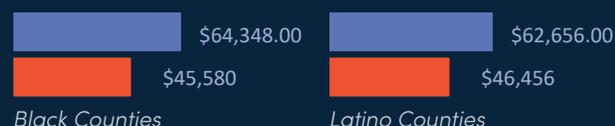
#### PERCENTAGE OF FAMILIES LIVING IN POVERTY



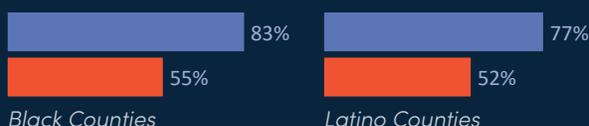
#### INDIVIDUALS UNDER THE AGE OF 65 WITHOUT HEALTH INSURANCE



#### MEDIAN HOUSEHOLD INCOME



#### INDIVIDUALS WITH ACCESS TO EXERCISE OPPORTUNITIES



### WHY SOCIAL DETERMINANTS OF HEALTH MATTER TO BRAIN HEALTH

Growing evidence suggests that dementia risk can be modified by brain healthy behaviors, including effective management of hypertension, diabetes, and obesity. In fact, the Lancet Commission released new research showing that managing a dozen risk factors could prevent or delay approximately [40 percent](#) of worldwide dementia cases.<sup>7</sup>

Under-resourced communities are at a disadvantage in managing these risk factors, however, due to systemic inequities in education, access to exercise opportunities, and access to nutritious food. SDOH—and policies that address them—must be part of the solution to ensuring better brain health for all American families.

# A Brain Health Equity Agenda for Alzheimer's Disease

A greater understanding of Alzheimer's and the ways to treat, delay or prevent the disease is creating new hope for millions of individuals and families. But ensuring that hope reaches **all families** regardless of **zip code, income, race, or ethnicity** will take greater commitment, investment, and policy change centered in health equity and social change.

## POLICY RECOMMENDATIONS

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### 1 Invest in Public Health, Treatment, and Research Infrastructure in Communities Hard-Hit by Alzheimer's and Related Dementias

There is limited public health and research infrastructure in underserved communities aimed at improving early detection of ADRD and broadening access to treatments, care, and cutting-edge research for high-risk communities. In fact, an analysis conducted by UsAgainstAlzheimer's found extremely limited access to federally funded Alzheimer's Research Centers in the U.S. counties most impacted by ADRD among patients of color.<sup>8</sup>

**ACTION STEP:** Dedicate funding, through the FY 2022 appropriations process, for increasing the capacity of safety-net providers, including Federally Qualified Health Centers (FQHCs), to train staff to address disparities in access to ADRD diagnosis, treatments, prevention, and care for underrepresented communities. Funding of safety-net providers should be dedicated to evaluating and increasing access to low-cost diagnostics for ADRD, including blood-based and electronic biomarkers, and increasing access to available treatments and care services.

**ACTION STEP:** For FY 2022, triple funding to \$60 million for public health infrastructure for responding to ADRD in communities through the Centers for Disease Control and Prevention's Healthy Brain Initiative, BOLD National Center of Public Health Excellence, and BOLD Public Health Programs. These programs should be fully funded as part of efforts to disseminate best-practices and translate research into communities and public health systems. Specific funding should be dedicated to support programs and strategies in communities and geographies with a high burden of ADRD.

**ACTION STEP:** For FY 2022, support a \$289 million in additional Alzheimer's research funding for the National Institute on Aging.

**ACTION STEP:** Require an assessment of the National Institute on Aging's internal infrastructure needs related to research operations, recruitment, and engagement, with an emphasis on underrepresented communities. This review should (a) assess gaps related to the infrastructure needed to ensure its federally funded clinical trials are successful and accessible to underrepresented communities at greatest risk of ADRD and (b) outline the resources needed to address identified gaps, including the appropriate staffing levels needed to support research optimization, grant oversight, and compliance with federal regulations on diversity and inclusion.

# A Brain Health Equity Agenda for Alzheimer's Disease

## POLICY RECOMMENDATIONS

### 2 Invest in Educational and Economic Opportunity to Promote Brain Health Equity

Advancing coordinated policies to overcome SDOH barriers to brain health could improve outcomes in later life for high-risk communities. SDOH affects multiple health issues, including brain health, and policy solutions that target these factors—from economic opportunity to educational quality—can improve health overall simultaneously

**ACTION STEP:** Establish a paid family and medical leave policy that covers family caregivers of older adults and of people living with serious medical conditions such as ADRD. Expanding paid family and medical leave policies for dementia caregivers will have an outsized impact on people of color, who are more likely to provide care while working and are less likely to utilize formal care supports when compared to White Americans.

### 3 Establish an Ambitious National Goal to Prevent Alzheimer's Disease and Related Dementias and Address Disparities in Early Intervention and Diagnosis

The U.S. should set a national prevention goal for Alzheimer's and related dementias that is ambitious and achievable and ensures access to an early and timely diagnosis for high-risk communities. This goal must include dates to strive for, a roadmap to guide the efforts, metrics to measure progress along the way, and a focus on healthcare equity that recognizes the disproportionate impact of this disease on communities of color and women.

**ACTION STEP:** Promote policies to address the social determinants of health and increase opportunities for brain health across the life span, including the following areas:

**Education:** Invest in a better understanding of how different education pathways (e.g., school quality) affect brain health and how these impacts vary across race and ethnicity. Invest in programs and policies that promote access to high-quality early childhood education.

**The Built Environment:** Improve access to well-maintained parks and recreation facilities and catalyze community partnerships to improve neighborhood walkability and livability.

**Food Security and Quality:** Incentivize healthy food purchases among low-income Supplemental Nutrition Assistance Program (SNAP) beneficiaries. For example, explore public-private partnerships to bring healthy foods to low-income neighborhoods.

**ACTION STEP:** Update the National Alzheimer's Project Act to articulate a prevention goal and identify the strategies for ensuring this goal is achieved equitably.

**ACTION STEP:** Incentivize and equip providers with the tools they need to accurately detect and diagnose Alzheimer's at its earliest stages by directing the Centers for Medicare and Medicaid Services (CMS) to require the use of culturally sensitive cognitive detection tools identified by the National Institutes of Health.

# A Brain Health Equity Agenda for Alzheimer's Disease

## POLICY RECOMMENDATIONS

### 4 Collect Better Data to Identify and Address Gaps in Access to Alzheimer's Health Services and Research for Underserved Communities

To address disparities and promote equity, we must ensure that health systems, researchers, and advocates have access to accurate and representative data on Alzheimer's and related dementias. For example, federally qualified health centers (FQHCs) are bedrock healthcare institutions serving an extremely diverse, vulnerable, and rapidly aging population. However, these health centers collect limited data on Alzheimer's and brain health-related services. Moreover, despite deep disparities in ADRD risk and clinical trial participation among communities of color, disaggregated clinical trial data are not regularly made accessible to the public.

**ACTION STEP:** *The Health Resources and Services Administration (HRSA) should develop measures and data collection strategies as part of the Uniform Data System (UDS) to improve access to Alzheimer's and brain health-related services provided by federally qualified health centers.*

**ACTION STEP:** *Require the National Institute of Aging to report the recruitment and retention levels of underrepresented communities across federally funded ADRD research trials and sites, releasing disaggregated recruitment data in real time. Funding decisions should consider the plans of each applicant to engage, recruit, and retain underrepresented communities that reflect the diversity of the site's local community.*

# The Congressional Districts

UsAgainstAlzheimer's, with support from the National Minority Quality Forum, identified the congressional districts that overlap with the 25 counties with the highest ADRD prevalence among Black and Latino Americans.

## Congressional Hot Spots by the Numbers

Number of Districts*	41
Total Number of People Living with ADRD**	347,610
Total Medicare FFS Costs Spent on Beneficiaries living with ADRD in 2016**	\$8.5 billion
Average ADRD District Prevalence in 2016**	9.50%
Average Percentage of District Medicare FFS Dollars Medicare Dollars Spent on ADRD in 2016**	26%

*\*Number of Districts That Represent the 25 Counties with the Highest Rates of ADRD Among Blacks and Latinos, Medicare Fee for Service, 2016*

*\*\*Medicare Fee for Service, 2016*

**District Calculation Methodology:** The alignment of beneficiaries to Congressional Districts is not directly defined in the Medicare data set. Because of this, the National Minority Quality Forum – our platform developer – developed a crosswalk methodology to allow the NADEX to make the best association based on known information about the beneficiary and zip codes associated with U.S. Congressional Districts. A document detailing the crosswalk methodology is available from NMQF upon request.

# The Congressional Districts

## Congressional Districts that Represent the Top 25 Counties with the Highest ADRD Prevalence Among Black Americans (Medicare Fee for Service, 2016)

State	Congressional District	Total ADRD patient population in District	District Total AD Prevalence	All Medicare FFS Costs Spent on ADRD Beneficiaries in District	Percentage of All Medicare FFS Costs Spent on ADRD Beneficiaries in District
TX	27th	8,862	10.55%	\$246,792,772	30%
MO	2nd	10,239	10.39%	\$213,058,930	27%
TX	4th	12,122	10.39%	\$344,299,941	29%
TX	1st	10,634	10.32%	\$278,056,622	28%
TX	19th	8,803	10.27%	\$219,127,927	27%
LA	5th	11,612	10.25%	\$345,387,551	30%
FL	2nd	8,742	10.03%	\$201,645,769	26%
TN	8th	11,378	9.68%	\$246,407,722	25%
TX	10th	7,478	9.62%	\$211,663,005	29%
MO	3rd	9,616	9.52%	\$197,941,385	24%
IL	15th	12,120	9.47%	\$255,962,631	23%
TX	21st	9,419	9.16%	\$234,362,061	29%
KY	6th	8,387	9.16%	187,889,421	26%
TN	4th	9,004	9.10%	\$198,849,695	24%
TN	7th	9,476	9.03%	\$207,567,222	24%
NC	1st	8,761	9.00%	\$194,371,689	22%
TX	3rd	6,120	8.94%	\$175,671,164	28%
IN	6th	11,176	8.93%	\$260,545,244	24%
MO	8th	12,686	8.84%	\$262,669,349	22%
GA	12th	7,167	8.50%	\$157,189,485	22%
KY	2nd	9,431	8.12%	\$199,589,874	21%
IA	1st	8,958	7.94%	\$143,209,905	17%
NV	4th	5,135	6.83%	\$197,198,148	27%

# The Congressional Districts

## Congressional Districts that Represent the Top 25 Counties with the Highest ADRD Prevalence Among Latinos (Medicare Fee for Service, 2016)

State	Congressional District	Total ADRD patient population in District	District Total AD Prevalence	All Medicare FFS Costs Spent on ADRD Beneficiaries in District	Percentage of All Medicare FFS Costs Spent on ADRD Beneficiaries in District
FL	27th	8,146	14.95%	\$248,038,515	36%
FL	26th	6,194	12.07%	\$183,608,784	33%
TX	34th	7,694	11.91%	\$204,905,937	31%
FL	25th	7,004	11.57%	\$193,476,893	30%
TX	15th	6,769	11.40%	\$183,267,851	30%
TX	28th	8,075	10.78%	\$228,499,488	32%
FL	24th	4,561	10.64%	\$159,632,401	29%
FL	23rd	5,896	10.51%	\$180,777,987	30%
LA	5th	11,612	10.25%	\$345,387,551	30%
TX	13th	10,535	10.20%	\$273,856,644	27%
KS	1st	12,661	9.95%	\$249,798,543	22%
GA	2nd	7,849	9.38%	\$169,734,333	24%
TX	21st	9,419	9.16%	\$234,362,061	29%
LA	6th	7,036	8.81%	\$173,875,996	25%
TX	23rd	7,163	8.74%	\$187,415,524	27%
PA	12th	5,553	7.92%	\$139,520,136	27%
OH	10th	6,385	7.78%	\$162,138,851	23%
WA	4th	7,901	7.68%	\$149,124,936	19%
LA	2nd	4,454	7.44%	\$119,464,347	22%
NM	3rd	6,408	6.28%	\$130,515,132	18%

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## Acknowledgments

UsAgainstAlzheimer's exists to conquer Alzheimer's disease. We take on the toughest problems; bring all of "Us" together to break down barriers; advocate for research that will speed treatments to market; and drive changes that matter most to people living with the disease. We will not rest until brain-span equals lifespan – for everyone.

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