A Practical Guide:
Communicating Brain Health Messages with Latino and African American Communities
# Table of Contents

4  General Dissemination Tips for Brain Health Messaging in Communities of Color

6  By the Numbers: Latino People and Alzheimer’s

8  Latino Messaging Tips

10 By the Numbers: African American People and Alzheimer’s

12 African American Messaging Tips

14 Case Study – The Power of Community Influencers in Social Media

16 Implementation Tips

18 Terminology Do’s and Don’ts in Message Development

20 About the UsAgainstAlzheimer’s Center for Brain Health Equity

21 Acknowledgments

22 References
Alzheimer’s disease and related dementias are a group of illnesses characterized by progressive cognitive decline, memory loss, and deterioration of other executive functions and activities of daily living. Although advanced age is the most significant risk factor for ADRD, Alzheimer’s is not a normal part of aging. Currently, 6.5 million people in the United States are living with ADRD. This number is expected to reach 12.7 million by 2050.

Latino and African American people are disproportionately affected by ADRD, so the increasing racial and ethnic diversity of older Americans will significantly contribute to the expected increase in ADRD prevalence in the coming decades. Additionally, higher rates of high blood pressure, heart disease, diabetes, and stroke—comorbidities that are disproportionately prevalent in many minority communities—are factors that contribute to an increased risk of ADRD. Between 2020 and 2050, the Black or African American population aged 65 years and older in the United States is expected to double, while the older Hispanic or Latino population is projected to more than triple.

About This Guide

The older American population is becoming more racially and ethnically diverse. Yet, there is limited evidence-based guidance on how to communicate brain health messages to minority communities. Using available research, this guide provides advice on how to culturally tailor Alzheimer’s disease and related dementia messaging for Latino or Hispanic and African American or Black communities to promote brain health. For the purposes of this guide, we will use the terms Latino and African American to describe these populations.

The goal of the guide is to help public health professionals, health providers, researchers, and community service providers incorporate the best available evidence about brain health and cognitive decline risk factors into existing messaging.

About Alzheimer’s Disease and Related Dementias (ADRD)

Alzheimer’s disease and related dementias are a group of illnesses characterized by progressive cognitive decline, memory loss, and deterioration of other executive functions and activities of daily living. Although advanced age is the most significant risk factor for ADRD, Alzheimer’s is not a normal part of aging. Currently, 6.5 million people in the United States are living with ADRD. This number is expected to reach 12.7 million by 2050.

Latino and African American people are disproportionately affected by ADRD, so the increasing racial and ethnic diversity of older Americans will significantly contribute to the expected increase in ADRD prevalence in the coming decades. Additionally, higher rates of high blood pressure, heart disease, diabetes, and stroke—comorbidities that are disproportionately prevalent in many minority communities—are factors that contribute to an increased risk of ADRD. Between 2020 and 2050, the Black or African American population aged 65 years and older in the United States is expected to double, while the older Hispanic or Latino population is projected to more than triple.
This section provides general messaging recommendations for communities of color. Later sections focus specifically on Latino and African American communities. Public health messaging should prioritize using trusted messengers (as defined by the community) to deliver communications and tailoring materials to be as culturally relevant as possible.\(^3\) Remember successful community engagement is a continuous process that builds trust and relationships through two-way communications. It starts with mindfulness and listening and continues with joint decision making and shared responsibility for outcomes.\(^4\) When developing culturally tailored brain health messages, the following are some common values and best practices to keep in mind.

**Values**

✓ African American and Latino communities tend to have a more positive view of caregiving, related to their cultural senses of familial obligation and of greater participation in larger, extended family contexts.\(^5\) Additionally, many may not identify as “caregivers” because they see caregiving as an expected familial role or have different opinions about what the role entails.\(^6\)

✓ Complex family networks\(^7\) are more common in minority communities—beyond the usual duo of spouses or parent and child. When presenting stories and images, it is important to show diverse familial relationships (e.g., grandparents and grandchildren, uncles, aunts, nieces/nephews, cousins).
Best Practices For All Communities

✔ When discussing memory loss, use images that are natural (not overly happy) and balance the use of positive and serious facial expressions. Images should highlight people who are diverse in skin tone, age, body types, range of physical abilities and gender, and use images that depict caregiving at home.

✔ Use a variety of communications formats (oral, written, visual, interactive presentations, etc.).

✔ In oral presentations, use simple, common language and conversational expressions. In written materials, use large print and short, clear phrases. For example, instead of using the word “parameters” use the word “limits.”

✔ Use a variety of multimedia approaches, such as a combination of interactive webinars, phone, radio, TV, print materials, and in-person events.

✔ Messengers should be trusted people who have roots in the community, are well-known, have the same or similar background as the intended population, and provide messaging centered on people and families living with ADRD. Common partners can include faith leaders, community organizers, and other trusted community representatives to help with the creation and dissemination of messages.

✔ When using social media for brain health messaging, use animated graphics with text. Animated graphics are in a Graphics Interchange Format (GIF) that contains within the single file a set of images that are presented in a specified order. Animated graphics get 80% more clicks on social media, but most viewers use social media with the sound off, so graphics with text are crucial.

✔ When developing content, evaluate the reading ease and comprehension levels of material to ensure they are appropriate for your intended community. Include simple graphics to accompany written content.
By the Numbers: Latino People and Alzheimer’s
By the year 2050, the Latino older adult population is expected to triple from 4.9 million to 15.9 million.²

Research suggests symptoms of Alzheimer’s appear almost 7 years earlier in Latino people than in non-Latino White people.¹⁵

Latino people are 1.5 times more likely than non-Latino White people to develop ADRD.¹

Although Latino people make up 17% of the US population, they make up less than 2% of the participants currently enrolled in Alzheimer’s research funded by the National Institutes of Health.¹⁶
Tailoring Brain Health Messages for Latino People

Keep in mind that the Latino community in the United States—with a population of approximately 61 million—is not one monolithic group and ranges widely in terms of country of origin, age, race, gender, religion, socioeconomic status, political ideology, and educational attainment. Most are English proficient, although older generations may prefer Spanish-dominant communications, and most were born in the United States.

It is important to leverage available data (e.g., US Census data) to understand the facts about Latino people in your community to inform your messaging and outreach strategies.

Prioritize making materials available in relevant languages (English, Spanish, Portuguese, etc.) simultaneously.

Consider Latino diversity when selecting images and selecting messengers. Ensure that there is Latino ethnic and racial diversity. This means reflecting different skin colors in imagery.

Depict a variety of family members beyond just parents. Health messaging should exhibit important Latino cultural values such as the importance of matriarchs, family togetherness, kindness, and respect.
Considerations for Sharing Brain Health Messages with Latino People

Many Latino people face barriers when navigating health care spaces, including language barriers, not having adequate health insurance, conflicting cultural beliefs (such as the use of holistic medicine), mixed immigration status, and lack of trust in medical professionals. Social media has been shown to be effective in reaching Latino communities, especially when used to ask individuals to act or share their experiences.

Promotoras (lay community members who receive specialized training to provide basic health education in the community) have been successful in recognizing early warning signs and providing charlas (community conversations).

Audio-visual novelas (still photos with audio that tell an engaging story) can be useful for improving attitudes and knowledge about dementia.

Using social media’s real-time monitoring provides organizations with the ability to increase relevant awareness among communities, because organizations can examine and respond to the concerns of the public in real time.

When planning educational activities, it is best to work with trusted partners, such as Spanish-language television, radio stations, newspapers, and community organizations.

Latino people may prefer to speak with medical professionals who share their culture and language, given that many Latino people are worried their concerns could be “lost in translation.”
By the Numbers: African American People and Alzheimer’s
African American people are two times more likely to develop ADRD compared to non-Latino White people.¹

Although African American people make up 13.6% of the US population, they bear 33% of the nation’s total costs of Alzheimer’s and other dementias.¹

By the year 2050, the older African American population will double from 5.4 million to 10.8 million.

Although African American people make up 13% of the US population, they make up just 6% of the participants currently enrolled in Alzheimer’s research funded by the National Institutes of Health.¹⁶
| Use images that show an adult accompanying their parent(s) or loved one at a doctor visit.  
| Common barriers to health care engagement include lack of knowledge and understanding about dementia, racial discrimination, lack of trust in the medical system, poor communication, and other barriers, such as transportation or proximity to quality health care.  
| Take important African American values into account, including the understanding that:  
| Information should not include medical lingo; use everyday terms and approachable content that is culturally sensitive.  
| • Caregiving can be perceived as a welcomed responsibility.  
| • Many may not identify as “caregivers” because they may see caregiving as an expected familial role.  
| • Some African American caregivers rely on their faith and church to cope with the difficulties associated with caregiving and family responsibilities.  
| Acknowledge daily stressors, such as racial discrimination, when appropriate. |
Considerations for Sharing Brain Health Messages with African American People

Public health professionals must prioritize gaining trust, increasing visibility, thoughtfully following up, and engaging in purposeful community activities (e.g., community health fairs, back to school supply drives). African American patients may be less receptive to their provider’s opinion if they perceive the provider has not presented all treatment options.

When an African American patient feels their voice is not heard by their provider, it may decrease the likelihood of them adhering to their treatment plan.

Community-building:

Regular communication, such as birthday and holiday cards, have been shown to increase retention in public health programs.

African American patients tend to face multiple stereotypes at the same time—such as stereotypes about aging and memory impairment plus racist stereotypes that downgrade their intellect. African American communities should substantively provide input to ensure that materials are relevant and respectful.

Work with trusted partners, such as faith-based organizations, local service organizations including fraternities and sororities, and African American-serving media.

For African American people influenced by Southern culture, messaging should especially reflect values of discretion and privacy as well as highlight support from family, religious communities, and other social communities.
In social media, an “influencer” is someone who has a group of followers with whom they actively engage for the purpose of affecting others’ decisions or habits. Influencers are often trusted sources of information. For work directed by a team from the University of Wisconsin–Madison led by Dr. Maria Mora Pinzon, Melissa Metoxen, and Dr. Carey Gleason, the term was reframed as “community influencer” to refer to local leaders who leverage social media (Twitter, Facebook, Instagram, TikTok, etc.) to educate communities on current health events. Community influencers know their audience incredibly well. They know how to craft narratives so that stories and messages that address common beliefs (or misconceptions) can spread farther and deeper on social media. Influencers also tend to emphasize quality over quantity in their posts.14

The role of community influencers in the dissemination of accurate information about COVID-19 among communities of color was explored in Wisconsin with funding from the Wisconsin Partnership Program and led by the University of Wisconsin–Madison team. The team partnered with the Latino Health Council of Dane County and two community members from the Black Community in Dane County and the Oneida Nation, a federally recognized tribe in Wisconsin. As the project progressed, influencers decided to rename their role as “community advocates,” to avoid the perception that they were trying to manipulate their audiences.

The advocates met weekly with a communications specialist, a graphic designer and media expert, and a team of scientists and physicians. These meetings supported the advocates in (1) identifying topics and questions relevant to their community, (2) crafting messages that were medically accurate, and (3) developing content that was culturally appropriate and engaging with their audience. Advocate-driven, medically-accurate information was shared on Facebook, Instagram, and Twitter. Information from a variety of sources, such as CDC, national organizations, and local images and videos created by the community advocates, were used.
Case Study – The Power of Community Influencers in Social Media

Across all the communities, short informative videos from the community advocates performed better than other types of posts. The effect of the messenger in dissemination of messages is reflected in the table below, which compares different types of posts about the COVID-19 vaccine published by the Latino Health Council of Dane County on their Facebook page.

<table>
<thead>
<tr>
<th>POST EXAMPLE</th>
<th>IMPRESSIONS</th>
<th>ENGAGEMENTS</th>
</tr>
</thead>
<tbody>
<tr>
<td>Generic material on where to get a vaccine (from local or federal government)</td>
<td>77</td>
<td>9</td>
</tr>
<tr>
<td>Post from a physician (with no community ties) receiving the vaccine</td>
<td>138</td>
<td>24</td>
</tr>
<tr>
<td>Post from a national influencer (famous physician) sharing how he was feeling after receiving the vaccine</td>
<td>163</td>
<td>47</td>
</tr>
<tr>
<td>Post from a local leader/community member receiving the first dose of her vaccine</td>
<td>2011</td>
<td>222</td>
</tr>
</tbody>
</table>

**Impressions** are how many times a post has been shown in users’ feeds.

**Engagements** are times that people have interacted with a post—such as sharing, commenting, and liking.

Overall, it is clear that the messenger matters as much as the message.
We hope that you will use this tool as much as possible. Printing out this guide and putting it on a shelf is not the same as putting into action evidence-based communications. What follows are specific tips and best practices that may help you systematically implement effective messaging to Latino and African American people.
MESSAGE AND RESOURCE DEVELOPMENT

This tool is meant to be used by a national audience working with Latino and African American communities, but you know your specific community best. The terminology used in this guide may or may not be what the participants are familiar or comfortable with using.

- Feel free to “translate” the information, answer questions, troubleshoot, and help guide participants.32
- Use local examples and language. Use scenarios that will engage intended audiences. To your best ability, try to ensure that the information is culturally appropriate and tailored.
- Consult community members on concept and message development to ensure that messages and their dissemination resonate with intended audiences.4
- Complete an environmental scan to identify messages and resources tailored for your intended audiences and subject. Think of this guide as advice for further tailoring those messages and resources.
- Use clear and plain language when developing educational resources and messages. Consider literacy levels. For example, avoid using five sentences when one will do. It is also important to avoid jargon and acronyms and to include definitions for key terms. For example, if your resource is focused on risk reduction, be sure to define what risk reduction means. The same is true for terms like prevention. Consider adding a glossary of key terms to all resources.
- When designing resources, break up long sections of text into subsections, with headers and images when possible. Keep in mind the recommendations for the intended populations when selecting images.

DISSEMINATION

Use the implementation tips outlined above and consider creating a toolkit to help disseminate your messages to local partners.

- Set deadlines for when relevant materials should be updated to reflect the evidence presented in this guide.
- If you are collecting any process or outcome measures with your current materials, assess whether those measures should change to reflect updated materials.

- Develop a communications brief to share with partners that includes:
  - Summary of your objectives, resources, and messages.
  - Different types of social media post samples that partners can easily use or adapt.
**When Describing Older Adults**

<table>
<thead>
<tr>
<th>INSTEAD OF USING…</th>
<th>Elderly</th>
<th>Frail</th>
<th>Fragile</th>
<th>Seniors</th>
</tr>
</thead>
<tbody>
<tr>
<td>TRY…</td>
<td>Older adults</td>
<td>Elders</td>
<td>Numeric age groups (e.g., persons aged 65-74 years)</td>
<td></td>
</tr>
</tbody>
</table>

**When Describing Race and/or Ethnicity**

<table>
<thead>
<tr>
<th>INSTEAD OF USING…</th>
<th>Referring to people as their race/ethnicity (e.g., Blacks, Hispanics, Latinos, Whites, American Indians, Alaska Natives)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Referring to people as colored people, colored Indian (to refer to American Indian)</td>
</tr>
<tr>
<td></td>
<td>Native American (for federal publications)  Eskimo</td>
</tr>
<tr>
<td></td>
<td>Oriental  Afro-American  Negro  Caucasian</td>
</tr>
<tr>
<td>TRY…</td>
<td>RACIAL GROUPS</td>
</tr>
<tr>
<td></td>
<td>Hispanic or Latino people  Black or African American people; Black people</td>
</tr>
<tr>
<td></td>
<td>American Indian or Alaska Native people/communities/populations  Asian people</td>
</tr>
<tr>
<td></td>
<td>Native Hawaiian people  Pacific Islander people  White people</td>
</tr>
</tbody>
</table>

**Notes:**
- When feasible, be as specific as possible about the group you are referring to (e.g., Caribbean people, Mexican people).
- Consider racial/ethnic groups as proper nouns and capitalize (e.g., Black, White).
- Latinx has been proposed as a gender-neutral English term, but there is debate around its usage. Its use may be considered on an audience-specific basis.

**When Describing People Living with Dementia**

| INSTEAD OF USING… | Suffering from…  A victim of…  Dementing  Demented |
|-------------------|-------------|--------|----------|----------|
|                    | Affliction  Senile Dementia  Senility |
| TRY…              | A person living with dementia  A person living with Alzheimer’s |
|                    | Alzheimer’s disease and other types of dementia |
|                    | A form of dementia  A type of dementia |
### When Describing People Living with Disabilities 33

<table>
<thead>
<tr>
<th>INSTEAD OF USING…</th>
<th>Disabled</th>
<th>Differently abled</th>
<th>Afflicted</th>
<th>Handicapped</th>
<th>Confined to a wheelchair or wheelchair-bound</th>
</tr>
</thead>
<tbody>
<tr>
<td>TRY…</td>
<td>People living with disabilities or a disability</td>
<td>People who are deaf, hard of hearing, blind, or have low vision</td>
<td>People with an intellectual or developmental disability</td>
<td>People who use a wheelchair or mobility device</td>
<td></td>
</tr>
</tbody>
</table>

**Notes:**
- Avoid using vulnerable when describing people with disabilities.
- Some individuals with disabilities prefer to use identity-first terminology, which means a disability or disability status is referred to first; for the purposes of these guidelines, we promote person-first language, in line with CDC standards.

### When Describing Healthcare Access and Access to Services and Resources 33

<table>
<thead>
<tr>
<th>INSTEAD OF USING…</th>
<th>Underserved people, underserved communities, or the underserved</th>
<th>The uninsured</th>
<th>Hard-to-reach populations</th>
</tr>
</thead>
<tbody>
<tr>
<td>TRY…</td>
<td>People who are underserved by [specific service/resource]</td>
<td>People who are medically underserved</td>
<td>People who do not have health insurance</td>
</tr>
<tr>
<td></td>
<td>People who are uninsured</td>
<td>People who are underinsured</td>
<td></td>
</tr>
</tbody>
</table>

**Note:** Underserved relates to limited access to services that are accessible, acceptable, and affordable, including healthcare. Do not use underserved when you really mean disproportionally affected.

### When Describing People with Lower Socioeconomic Status (SES) 33

<table>
<thead>
<tr>
<th>INSTEAD OF USING…</th>
<th>Poverty-stricken</th>
<th>The poor</th>
<th>Poor people</th>
</tr>
</thead>
<tbody>
<tr>
<td>TRY…</td>
<td>People with lower incomes</td>
<td>People or households with self-reported income in the lowest income bracket (if income brackets are defined)</td>
<td>People experiencing poverty (do not use “underserved” when meaning low SES)</td>
</tr>
</tbody>
</table>

**Note:** “People with lower socioeconomic status (SES)” should only be used when income, education, parental education, and occupation are used as a measure of SES.
The UsAgainstAlzheimer's Center for Brain Health Equity is a hub for collaboration in our nation’s efforts to address brain health inequities affecting people of color and women. The Center’s key strategies include mobilizing minority serving health providers, making culturally tailored brain health messaging and resources accessible, and empowering community partners and policymakers with public health data on brain health inequities.

For more information, visit https://www.usagainstalzheimers.org/center-brain-health-equity
We are grateful for the contributions and efforts of the following external reviewers who helped shape this guide (listed alphabetically): Alzheimer’s Los Angeles; Fayron Epps, PhD, RN, assistant professor, Nell Hodgson Woodruff School of Nursing, Emory University; Michelle Jaldin, MPH, student, Kinesiology and Nutrition, University of Illinois Chicago; David Marquez, PhD, professor, Kinesiology and Nutrition, University of Illinois Chicago; Lauren J. Parker, PhD, MPH, assistant scientist, Department of Health, Behavior, and Society, Johns Hopkins Bloomberg School of Public Health; and Maria Mora Pinzon, MD, MS, family medicine fellow and scientist, Wisconsin Alzheimer’s Institute, University of Wisconsin–Madison.

This resource is supported by the Centers for Disease Control and Prevention of the US Department of Health and Human Services (HHS) as part of a financial assistance award (1NU58DP006781) totaling $600,000 with 100% funded by CDC/HHS. The contents are those of UsAgainstAlzheimer’s and do not necessarily represent the official views of, nor an endorsement by, CDC, HHS or the US Government.


