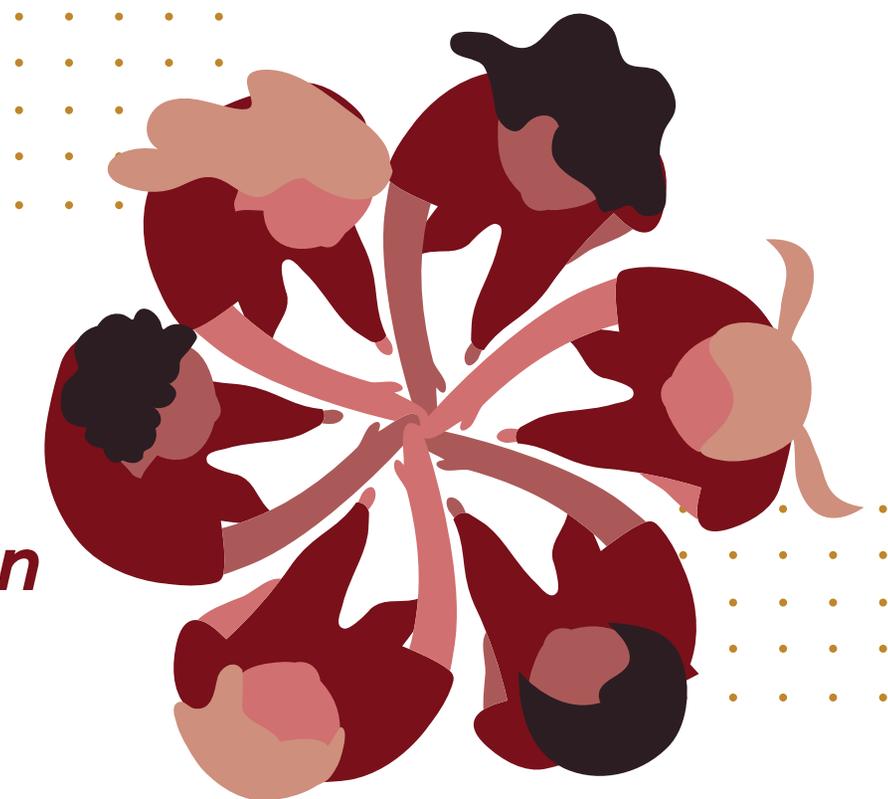


Part II: Public Health Considerations and Models for Cultural Adaptation in Dementia Caregiving

Focusing on African American and Latino Caregivers



Follow the Conversation on Twitter!

Use **#CultureMattersinDementia**
to follow and keep the conversation
going!

 @PHCOE_DC

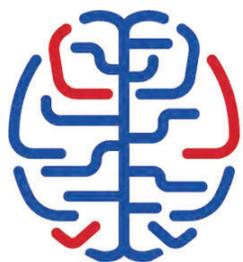


Presented by:



BOLD
PUBLIC HEALTH
CENTER OF EXCELLENCE
ON DEMENTIA
CAREGIVING

In collaboration with:

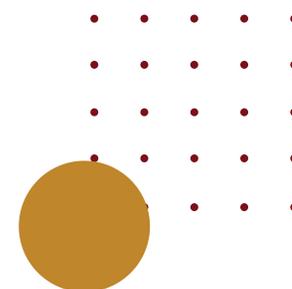


USAGAINSTALZHEIMER'S CENTER *for*
BRAIN HEALTH EQUITY

The Public Health Center of Excellence on Dementia Caregiving

Designed to support state, tribal and local public health agencies nationwide in developing their dementia caregiving-focused programs and initiatives, by...

-  Improving access to evidence-based programs and best practices
-  Facilitating connections and collaboration among public health agencies and a wide range of service organizations
-  Providing technical assistance for identifying, selecting implementing effective public health interventions and strategies



Welcoming our presenters...



Lauren J. Parker, PhD, MPH
Assistant Scientist, Johns Hopkins
School of Public Health



Jason Resendez
Executive Director,
UsAgainstAlzheimer's Center for
Brain Health Equity



Fayron Epps, PhD, RN
Assistant Professor, Emory University
Nell Hodgson Woodruff School of
Nursing



**Judith Susan Rocha, PhD,
LCSW, MSW**
Director of field Education,
Assistant Professor,
Northeastern Illinois University





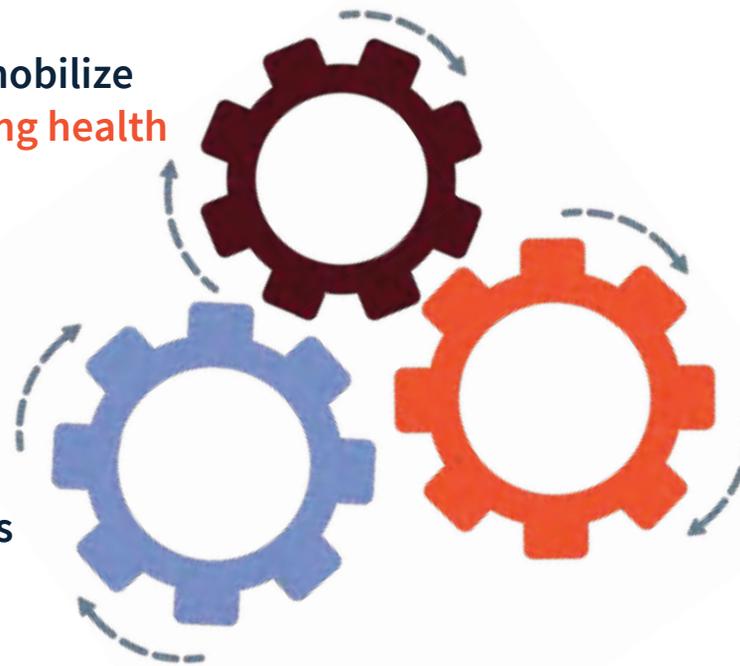
Place and Brain Health Equity

The UsAgainstAlzheimer's Center for Brain Health Equity drives collaboration to develop and disseminate culturally tailored brain health strategies targeting Black and Latino communities.

Educate and mobilize
minority serving health
providers

Empower community partners
and policymakers with data on
brain health inequities

Make culturally tailored brain
health messaging and resources
accessible in hard hit communities





Health Disparities & Comorbidities for Alzheimer's

AMONG BLACK AMERICANS

44% More Likely to have a stroke

23% More Likely to be obese

25% More Likely to die from heart disease

72% More Likely to be diabetic

2X AS LIKELY
TO HAVE ALZHEIMER'S

AMONG LATINOS

10% More Likely to have a stroke

24% More Likely to be obese

22% More Likely to have poorly controlled blood pressure

63% More Likely to be diabetic

1.5X AS LIKELY
TO HAVE ALZHEIMER'S

Why Place Matters to Brain Health?

The New York Times

Living in Poverty May Increase Alzheimer's Risk

People living in the poorest neighborhoods had the highest risk for brain changes typical of Alzheimer's disease.

ScienceDaily®

Your source for the latest research news

Your neighborhood may affect your brain health

Study finds evidence of more brain aging in people living in disadvantaged areas

Date: April 19, 2021

Source: American Academy of Neurology

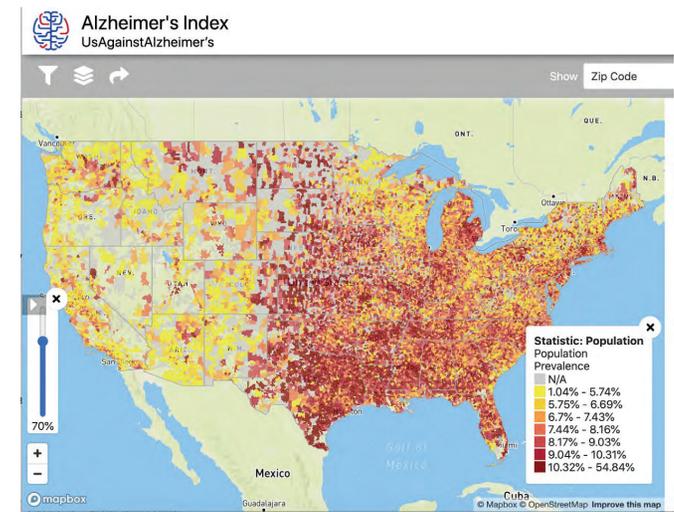
Summary: Middle-age and older people living in more disadvantaged neighborhoods -- areas with higher poverty levels and fewer educational and employment opportunities--had more brain shrinkage on brain scans and showed faster decline on cognitive tests than people living in neighborhoods with fewer disadvantages, according to a new study.

Community Data

UsAgainstAlzheimer's, in partnership with the **National Minority Quality Forum (NMQF)**, launched the **National Alzheimer's Disease Index™ (NADEX)** — a new public health tool that aggregates Medicare data and enables users to visualize ADRD healthcare data to spot disparities.

With the **Urban Institute**, we used the NADEX to:

- 1.) Identify the top 25 counties most impacted by ADRD among Black and Latino Americans in the traditional Medicare program
- 2.) Explore the social determinants of health present in these counties.



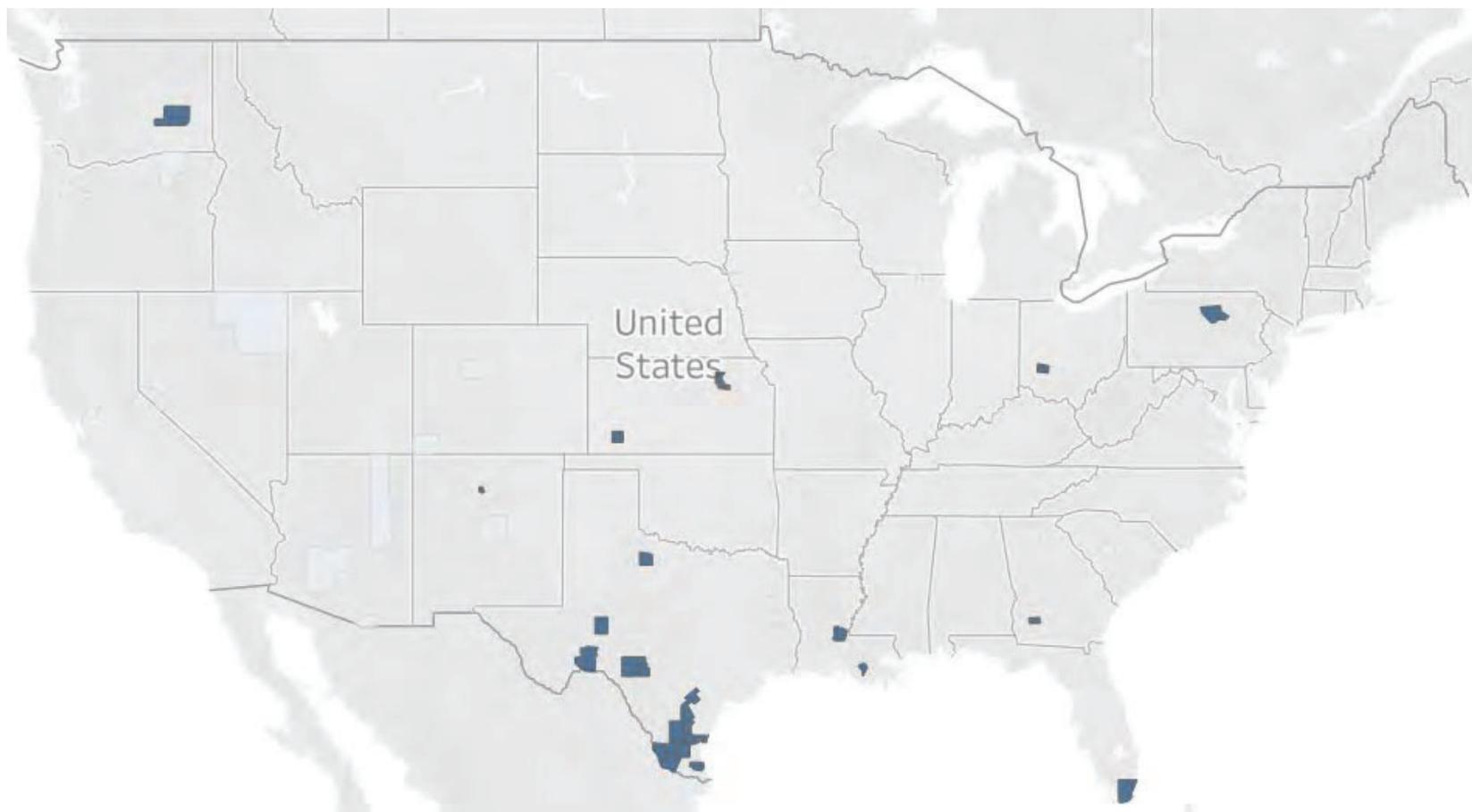
Findings



USAgainstAlzheimer's

The Counties

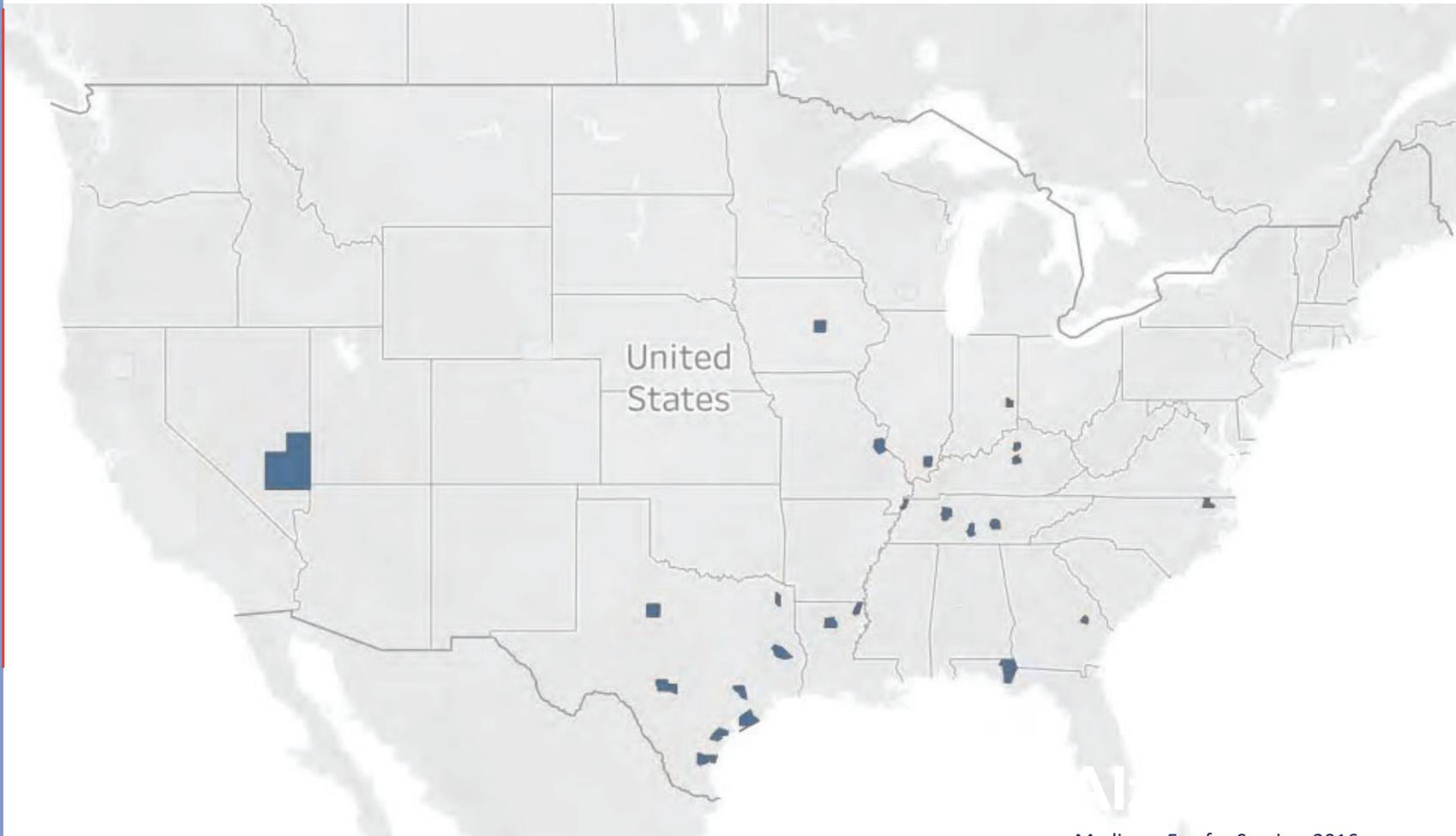
Top 25 Counties Impacted by Alzheimer's among Latinos



Medicare Fee for Service, 2016

The Counties

Top 25 Counties Impacted by Alzheimer's among Black Americans



Medicare Fee for Service, 2016



Systemic Inequities

Deep inequities in the social determinants of health exist in the counties highly impacted by Alzheimer's among Latino and Black communities.

PERCENTAGE OF FAMILIES LIVING IN POVERTY



MEDIAN HOUSEHOLD INCOME



INDIVIDUALS UNDER THE AGE OF 65 WITHOUT HEALTH INSURANCE



INDIVIDUALS WITH ACCESS TO EXERCISE OPPORTUNITIES



■ Highest ADRD Prevalence ■ Lowest Prevalence

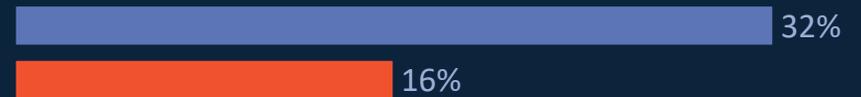


Systemic Inequities

Low levels of educational attainment are uniform across all county groupings highly impacted by ADRD.

PERCENTAGE OF ADULT THAT HAVE A BACHELOR'S DEGREE

Black Counties



Latino Counties



Non-Latino White Counties



■ Highest ADRD Prevalence ■ Lowest Prevalence

The Congressional Districts

CONGRESSIONAL HOT SPOTS BY THE NUMBERS

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

SDOH & DEMENTIA

40%

of dementia cases
could be prevented
by addressing these
lifestyle factors

Keck Medicine
of USC

BEYOND EXCEPTIONAL MEDICINE™

Source: Lancet Commission on Dementia Prevention and Care





USAgainstAlzheimer's

Turning Data into Action

Adapting Educational Materials Using Population Specific Brain Health Data



KNOW SOMEONE WITH MEMORY LOSS?

Subjective Cognitive Decline Among Latino Adults

52% of Latinos with SCD had to give up day-to-day activities such as:

- Cooking
- Cleaning
- Taking Medication

1 in 9 Latino adults aged 45 years and older are experiencing (SCD) Subjective Cognitive Decline

Less than half of Latinos with SCD have discussed their symptoms with a healthcare provider

Talk to a healthcare provider about:

- Possible treatment
- Care planning
- Management of chronic conditions
- Caregiving needs

MEMORY LOSS IS NOT A NORMAL PART OF AGING

USAGAINSTALZHEIMER'S CENTER for BRAIN HEALTH EQUITY

Learn more at usagainstalzhaimers.org

This infographic is supported by Cooperative Agreement N01NS059261, funded by the Centers for Disease Control and Prevention (CDC). Its contents are solely the responsibility of the authors and do not necessarily represent the official position of the CDC or the Department of Health and Human Services.

SOURCE: Behavioral Risk Factor Surveillance System (BRFSS) as published in Taylor, MWRB July 2018, Data from Hispanic Adults in 50 States, Puerto Rico, and the DC: People Aged 45 Years and Older. <https://www.cdc.gov/>



KNOW SOMEONE WITH MEMORY LOSS?

Subjective Cognitive Decline Among Black Adults

54% of Black Adults with SCD had to give up day-to-day activities such as:

- Cooking
- Cleaning
- Taking Medication

1 in 8 Black adults aged 45 years and older are experiencing (SCD) Subjective Cognitive Decline

Less than half of Black adults with SCD have discussed their symptoms with a healthcare provider

Talk to a healthcare provider about:

- Possible treatment
- Care planning
- Management of chronic conditions
- Caregiving needs

MEMORY LOSS IS NOT A NORMAL PART OF AGING

USAGAINSTALZHEIMER'S CENTER for BRAIN HEALTH EQUITY

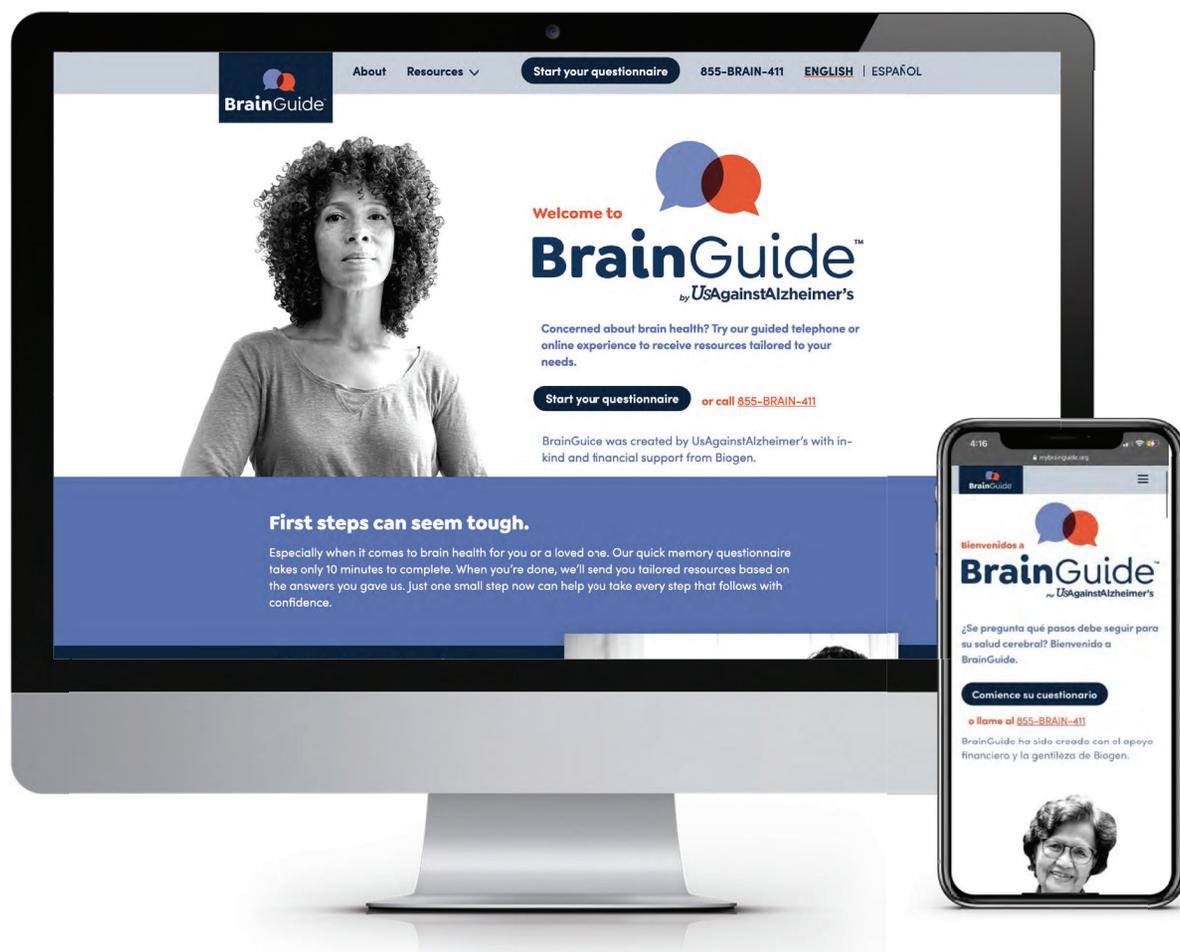
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BrainGuide by UsAgainstAlzheimer's

mybrainguide.org | 855-BRAIN-411



BrainGuide is a first-of-its-kind platform that empowers people with knowledge and resources to take the best next steps in managing their own or a loved one's brain health.

Available in English & Spanish

[Visit the Site at mybrainguide.org](http://mybrainguide.org)



Join Our Movement

Access Data:

<https://brainhealthdata.org/>

Access Resources:

<https://mybrainguide.org/brain-health-for-all-communities/>

Sign Up for Resources:

<https://bit.ly/3s66Bvl>

Thank You

***Us*AgainstAlzheimer's**



ALTERTM
INSPIRING AND EQUIPPING FAITH COMMUNITIES

Fayron Epps, PhD, RN

**Assistant Professor
Nell Hodgson Woodruff School of Nursing
Emory University**

Purpose



- **Faith-based community program (2019)**
 - Why the church?
 - To inspire and equip faith communities.
 - To encourage culture change, shift perceptions of dementia, and strengthen supportive services within African American churches.
 - To establish partnerships with churches to create a supportive environment for African American families affected by dementia.



ALTERTM
INSPIRING AND EQUIPPING FAITH COMMUNITIES

The Problem

Many families living with Alzheimer's disease & other dementias consider not attending church.



Social isolation is a major source of stress for people with dementia.

Alzheimer's is 2x more prevalent among African Americans than whites.

Source: Alzheimer's Association



4th

Alzheimer's is the 4th leading cause of death among older African Americans.

Source: UsAgainstAlzheimer's

While overall membership may be dropping, People over 65 are the fastest-growing group of church members.



Our churches are more than just a place of worship.

They're our safe haven, our community, and our second home.

The spiritual needs of families living with dementia are the same as everyone else.

The impacts of dementia can push members away from their church for all the wrong reasons.

Alter works to preserve access to churches for families living with dementia.



Fayron Epps, PhD, RN
Founder of Alter
Assistant Professor
Emory University

Alter is a faith-based program with the aim to give churches and faith leaders of predominantly African American churches the resources and tools they need to ensure that members affected by dementia are welcome, supported, and accepted—whatever their burdens might be.

Our Solution

Some of the resources and tools we provide include:

- Training sessions, materials, and videos for church leaders
- In-person and virtual support for members with dementia and their families
- Education sessions for all members on becoming more dementia-friendly
- Tools and techniques for addressing the cultural taboos associated with dementia

Are you ready to become a part of our growing, trailblazing dementia-friendly faith community?

**Alter your faith
community today.**



(770)686-7730



www.alterdementia.com



outreach@alterdementia.com

Church Partnerships



- Memorandum of Understanding
- Partnership Checklist
 - 8 required activities
 - 8 additional activities
 - Opportunities to create & customize activities
- Welcome Kit
- Financial Contribution





Checklist & Guidebook

EDUCATION



- Virtual Education
- Memory/Purple Sunday
- Website/Church Bulletin
- Virtual Dementia Experience

SUPPORT

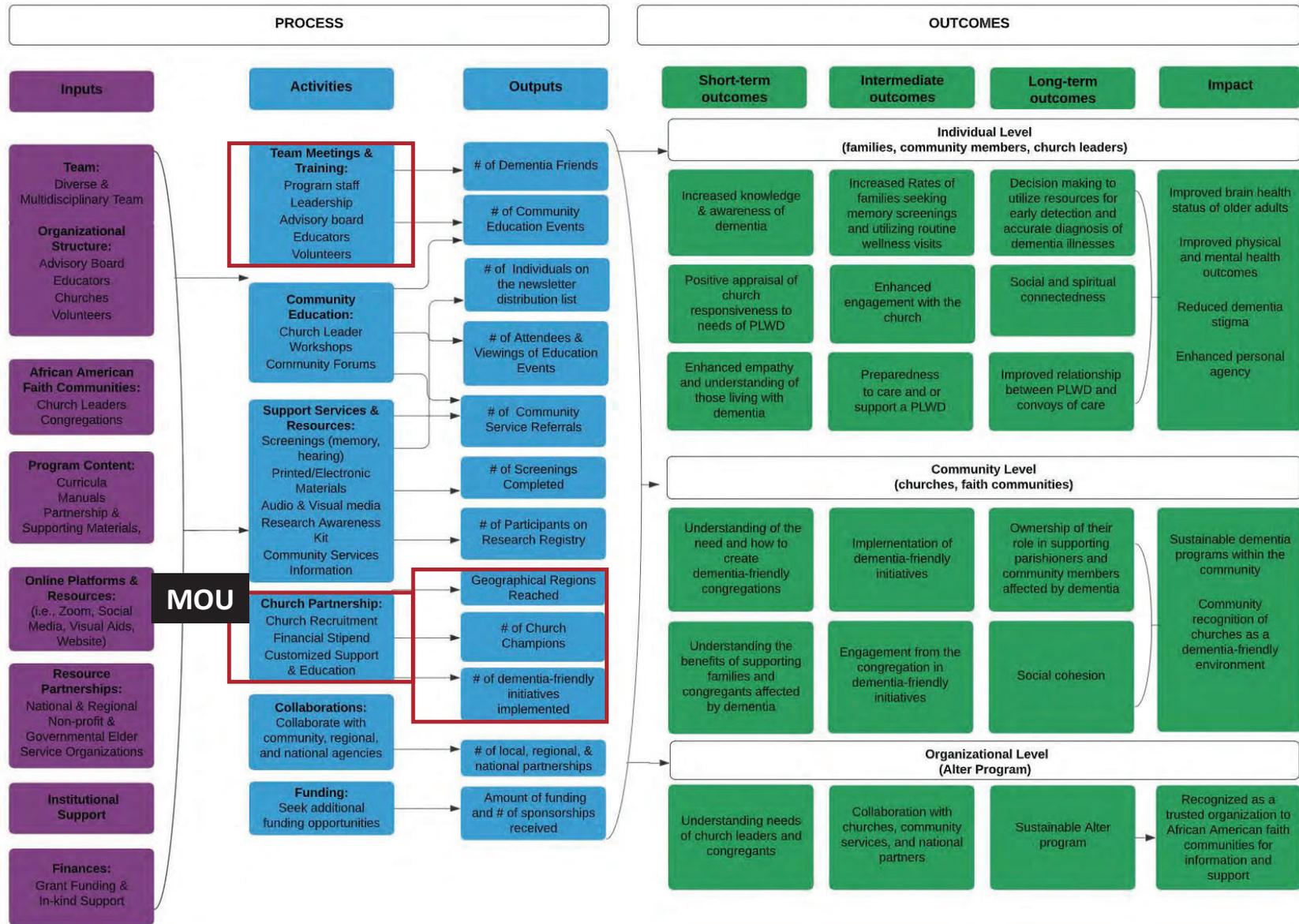


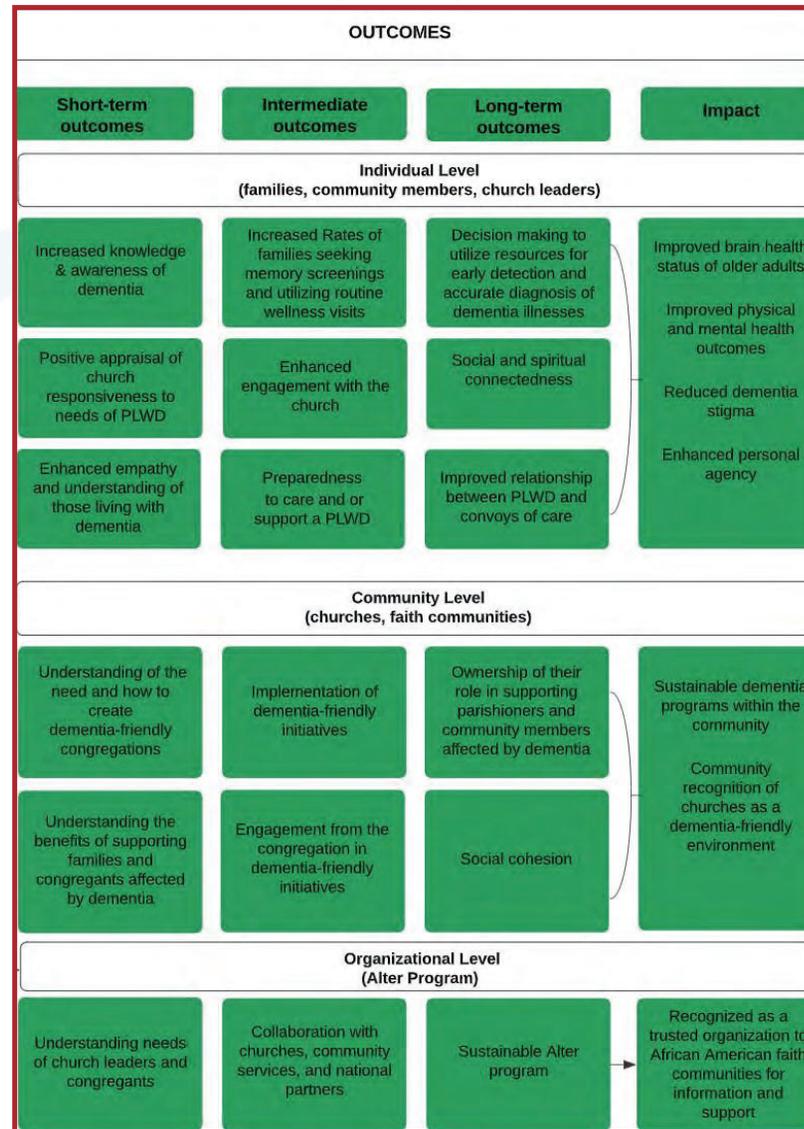
- Memory Cafe
- Dementia Support Group
- Resource Library
- Respite Program

WORSHIP



- Length of Service
- Visual Aids
- Memory Support Staff
- Order of Worship







Amanda
Flipper AME
Church

Journey to the
Cross Ministries

Big Bethel
AME Church

Saint Philip
AME Church

Turner Monumental
AME Church

House of Hope
Atlanta

South Fulton
Ministerial Alliance

Tranquil AME
Church

Pan African
Orthodox Christian
Church

New Tabernacle of
Faith Baptist
Church

Light of the World
Church International

Allen Temple AME
Church

In His Great Name
Worship Center

Conspired Destiny

Greater Turner
Chapel AME Church

Destiny Christian
Center International



An Alter Champion

Accepts and values people regardless of cognitive abilities.

Ensures that people living with dementia and their care partners are supported through their journey.

Makes sure that people living with dementia and their care partners are spiritually and pastorally supported and nurtured.

Is supportive to what people living with dementia have to offer so that they may participate in their faith community.

Publications



Received: 4 May 2020 | Revised: 20 May 2020 | Accepted: 21 May 2020
DOI: 10.1111/ghn.12759

POPULATIONS AT RISK ACROSS THE
LIFESPAN – PROGRAM EVALUATIONS



Promoting dementia awareness in African-American faith communities

Fayron Epps PhD, RN, Assistant Professor¹ | Karah Alexander MPH, Research Assistant¹ | Glenna S. Brewster PhD, RN, FNP-BC, Assistant Professor¹ | Lauren J. Parker PhD, MPH, Assistant Scientist² | Mia Chester MA, Project Coordinator³ | Audrey Tomlinson BS(c), Research Assistant³ | Aisha Adkins MPA(c), Research Assistant⁴ | Sabrina Zingg BSN, Research Assistant¹ | Jacque Thornton MSA, CEHA, Population Health Director⁵

Article

tia

A dementia-friendly church: How can the African American church support families affected by dementia?

Fayron Epps¹
Emory University, Atlanta, USA

Dementia
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DOI: 10.1177/1471301219900416
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Author manuscript
J Appl Gerontol. Author manuscript.

Perceptions and Attitudes Toward Dementia in Predominantly African American Congregants

Fayron Epps,
Emory University, Nell Hodgson Woodruff School of Nursing
Kimberly Foster,
Georgia State University, School of Nursing

<https://doi.org/10.1007/s10943-020-00993-x>

ORIGINAL PAPER



Designing Worship Services to Support African-American Persons Living with Dementia

Fayron Epps¹ · Jenny Choe¹ · Karah Alexander¹ · Glenna Brewster¹

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AlterDementia
Faith Village Connections



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ALTERTM
INSPIRING AND EQUIPPING FAITH COMMUNITIES

Thank you.

Contact us:

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alterdementia.com

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LA BROCHA

Latinas/os Buscando Refugio y
Optimismo Cuando Hacen Aрте
(La BROCHA)

Latinas/os seeking refuge & optimism
when doing art
(The Paintbrush)

Presented by: Judith Susan Rocha,
Ph.D., LCSW



LA BROCHA Collective



Judith Susan Rocha, PhD, LCSW

- Master's Social Work Program
Field Education Director,
Northeastern Illinois University
- Research interests include Latino-relevant social issues with a focus on the family caregiving of older Latinas/os with Alzheimer's disease or related dementia



Yadira Montoya, MSPH

- Research Scientist, NORC,
University of Chicago
- Committed to research and community strategies that address the intersection of immigration, Alzheimer's disease, and caregiving.



Susan Aguiñaga, PhD

- Assistant Professor, University of Illinois at Urbana-Champaign
- Research focuses on the design and implementation of community-based physical activity and sedentary behavior interventions in older Latinos with cognitive impairment

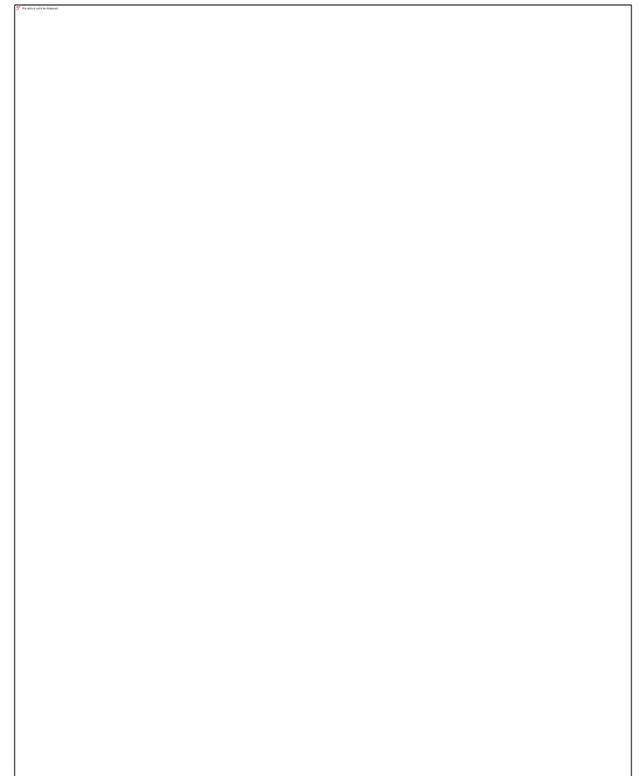
What is LA BROCHA?

A project whose goal is to offer art workshops to Latina and Latino elders (60+) and individuals with with memory loss, dementia, or Parkinson's disease



Why is LA BROCHA important?

- By 2060, the number of Latinos with Alzheimer's disease (AD) is expected to increase by 832%
- Latinas/os are 1.5 more likely to develop AD than non-Latino whites
- Yet, the number of linguistically and culturally appropriate community programs for Latinas/os elders and those with AD and their caregivers is limited



Where did this idea originate?

- Judith Rocha and her mother, Ms. Socorro, attended an art workshop led by Robert Valadez
- In July 2016, we submitted our idea, to pilot La BROCHA, for an Acting Up Chicago Community Trust Award



La BROCHA's Model

- Community Artist creating images with participants that are culturally relevant
- Art Therapist
- Event held in a community space
- Healthy lunch
- Educational resources



During the Pandemic

LA BROCHA

CALMA Y VERSATILIDAD

(en los tiempos del coronavirus)

¡Saludos!

Durante este momento no solo es importante tomar precauciones para mantenerse saludable y quedarse en casa, también le animamos a hacer actividades que le ayuden a mantener su cerebro saludable. Colorear es una manera divertida y relajante para ejercitar su cerebro. Al igual que pintar, colorear ayuda a mejorar la concentración y coordinación psicomotriz ya que uno se enfoca en "no salirse de la raya". Es por esta razón que le enviamos estas hojas de colorear que fueron especialmente diseñadas por artistas latinos para los participantes de La BROCHA. También le enviamos una hoja con varios ejemplos de ejercicios para que se pueda mantener activo desde la seguridad de su casa.





Artwork by Ricardo Gonzalez

PASTEL DE ZANAHORIA

Cecilia Gonzalez

Age: 73

Cecilia learned this recipe from her mom. Her mom would make her this cake when the weather got cold. The smell of cinnamon still reminds her of her mom.

CHILE PASADO

Socorro Rocha

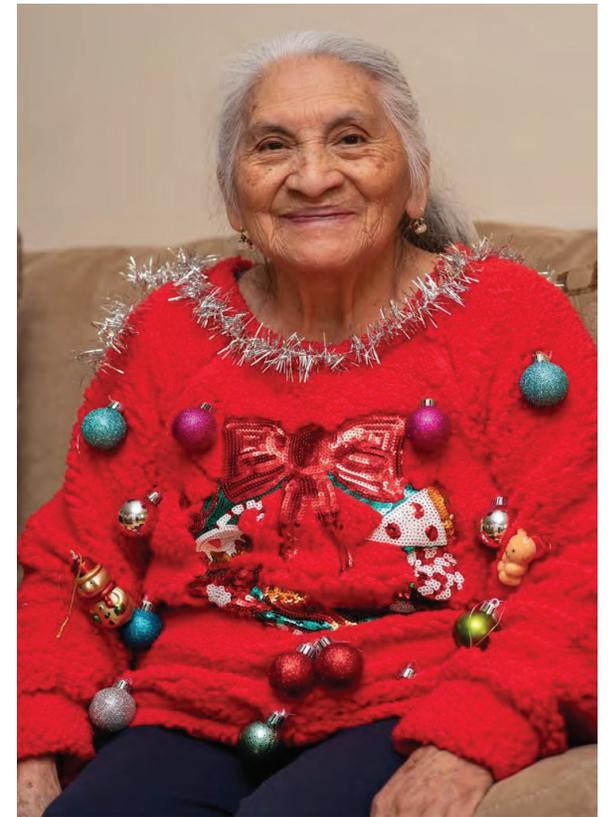
Age: 83

This type of pepper (pasado) is typically only used in the Mexican state of Durango and it reminds Socorrito of her hometown.

Social Distancing Portraits



Photos by: Hex Hernandez



Contact Information

Telephone: 708-858-1323

Email: LaBrochaChicago@gmail.com

Facebook: [@LaBrochaChicago](#)

Caring of Caregivers Organically (CoCO)

Health intervention for Latinas that are caring for a family member with Alzheimer's disease or other related dementia (ADRD)

- Piloted in 2018-2019 with funding from the University of Illinois at Chicago (UIC) Midwest Roybal Center for Health Promotion and Translation
 - 8-week in-person group model
 - Conducted with two facilitators called Acompañantes (translates to English as companions)
- Currently being revised to CoCO 2.0 with funding from the RRF Foundation for Aging for 2021-2022
 - 10-week virtual model
 - Facilitation of pre-recorded videos and synchronous Zoom weekly sessions by two Acompañantes and one technical aide
- Any inquiries can be directed to Dr. Judith Susan Rocha, J-Rocha5@neiu.edu or via phone 773-580-3302



Cuidando Cuidadoras Orgánicamente (CoCO)

Un programa de educación de la salud para mujeres latinas que cuidan de un familiar/ser querido con Alzheimer o demencia

**Manual para las
Acompañantes**



Q&A

Please use the Q&A feature to submit your questions!



Connect with us!

Visit us online at <https://bolddementiacaregiving.org> to....

- ✓ Find today's slides and recording
- ✓ Request Technical Assistance to support your public health work in dementia caregiving
- ✓ Access resources and materials
- ✓ Stay up to date with PHCOE-DC activities!

Follow us on Twitter!



@PHCOE_DC



Thank you for joining us today!

Please take a moment to complete our evaluation form
at the end of this presentation.

