

Health Disparities in Dementia

SIU Medicine

Dale and Deborah Smith Center for Alzheimer's Research and Treatment

2025 BRAIN AGING CONFERENCE

April 11, 2025

Disclosures


Relevant Financial Relationships

- Salaried Associate Professor at Washington University in St. Louis
- Honorarium for speaking engagements
- Funding from the National Institutes of Health
 - Eunice Kennedy Shriver National Institute of Child Health & Human Development, NCATS, NIA& NIA Standing Study Section Member
- Funding from CDC and PCORI
- Member of Community & Patient Advisory Committees at different academic medical centers
- Health Equity Research Consultant
- Research collaborator with Genentech/Roche
- HypnoLoop Advisory Board

Relevant Non-Financial Relationships

- Visiting Professorship with the University of Puerto Rico
- Research Collaborator with Mayo Clinic
- Board President for Health Literacy Media
- Reviewer for multiple biomedical research journals

Learning Objectives



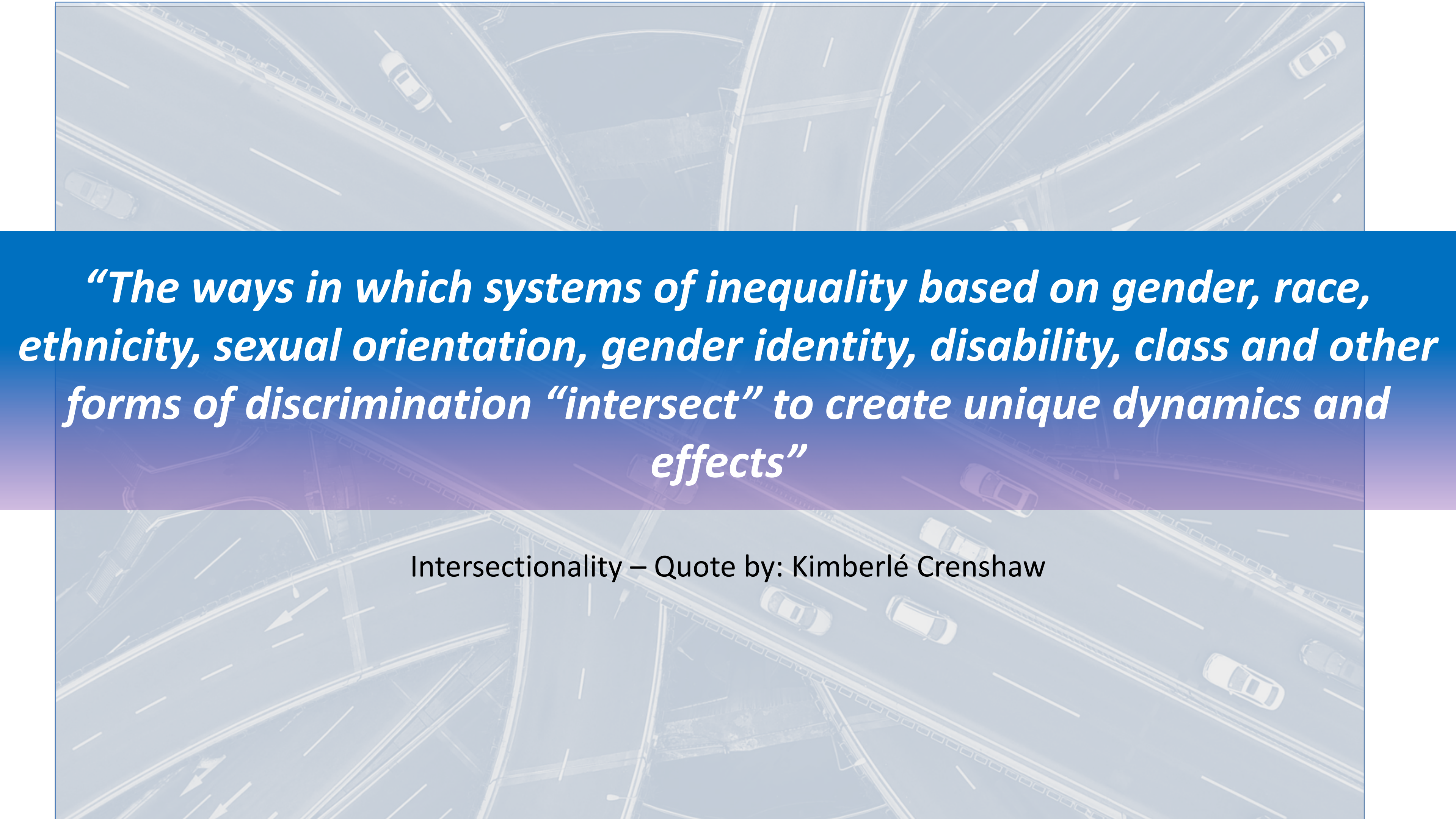
01 | Discuss health disparities in ADRD



02 | Explain current research studies to increase health equity



03 | Discuss the future



“The ways in which systems of inequality based on gender, race, ethnicity, sexual orientation, gender identity, disability, class and other forms of discrimination “intersect” to create unique dynamics and effects”

Intersectionality – Quote by: Kimberlé Crenshaw

Illegal Words

abortion	climate crisis	diversified	gender based	intersex	person-centered	status
accessible	climate science	diversify	gender based violence	issues concerning pending	care	special populations
accessibility	commercial sex worker	diversifying	gender diversity	legislation	polarization	stem cell or fetal tissue research
activism	community	diversity	gender identity	key groups	political	stereotype
activists	community diversity	diversity and inclusion	gender ideology	key people	pollution	stereotypes
advocacy	community equity	diversity/equity	gender-affirming care	key populations	pregnant people	systemic
advocate	confirmation bias	efforts	genders	Latinx	pregnant person	they/them
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Biased toward	ultraprocessed foods	equitableness	inclusive	multicultural	racial inequality	under represented
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Biases towards	disability	ethnicity	inclusiveness	MSI	racially	underrepresented
biologically female	disabled	evidence-based	inclusivity	Native American	racism	underserved
biologically male	discriminated	excluded	Increase diversity	NCI budget	science-based	under served
bipoc	discrimination	exclusion	increase the diversity	non-binary	segregation	understudied
Black	discriminatory	expression	indigenous community/	nonbinary	self-assessed	undervalued
black and latinx	discussion of federal	female	people	obesity	sense of belonging	vaccines
breastfeed + people	policies	females	inequalities	opioids	sex	victim
breastfeed + person	disparity	feminism	inequality	oppression	sexual preferences	victims
Cancer Moonshot	diverse	fetus	inequitable	oppressive	sexuality	vulnerable
chestfeed + people	diverse backgrounds	fluoride	inequities	orientation	social justice	vulnerable populations
chestfeed + person	diverse communities	fostering inclusivity	injustice	peanut allergies	socio cultural	woman
clean energy	diverse community	GBV	institutional	people + uterus	sociocultural	women
	diverse group	gay	intersectional	people-centered care	socio economic	women and underrepresented
	diverse groups	gender	intersectionality	person-centered	socioeconomic	

Health Disparities and Health Equity



Alzheimer disease & related dementia (ADRD) by the number

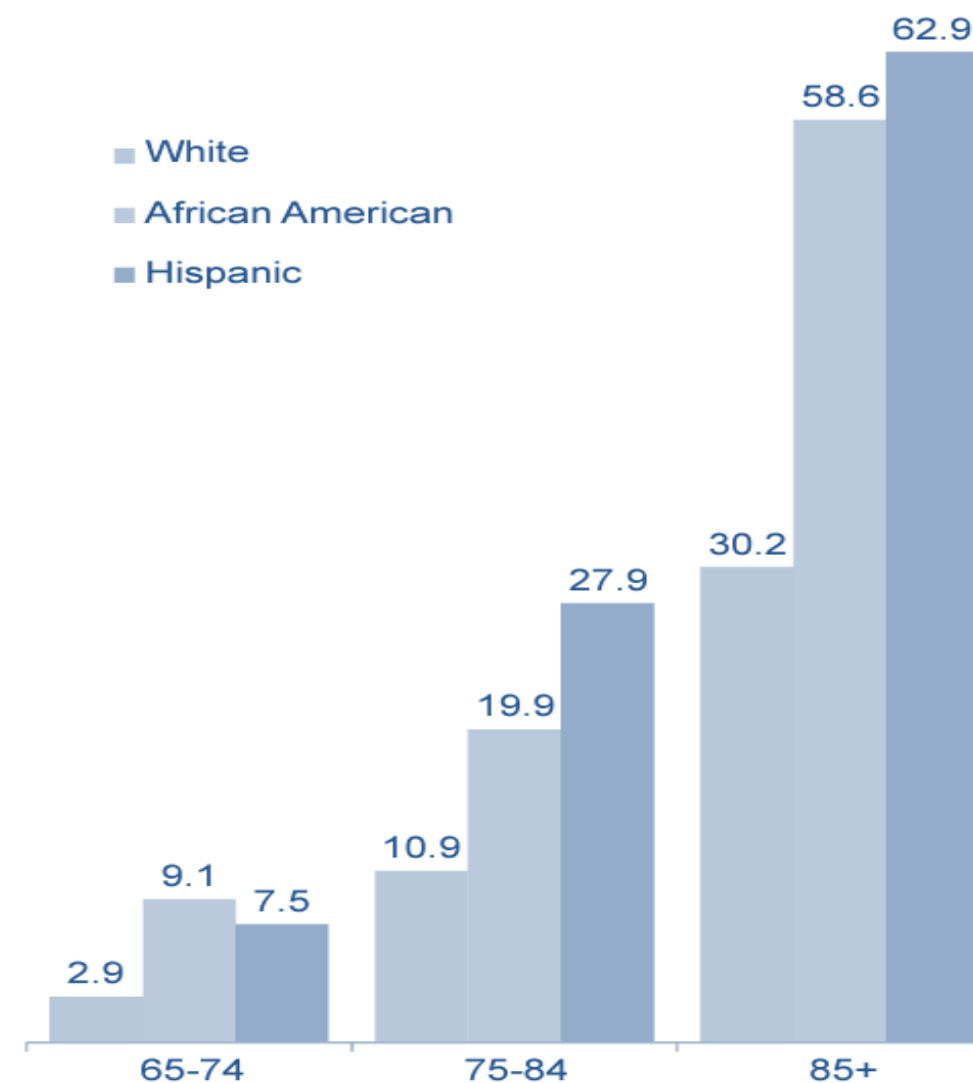
The Epidemiology of ADRD



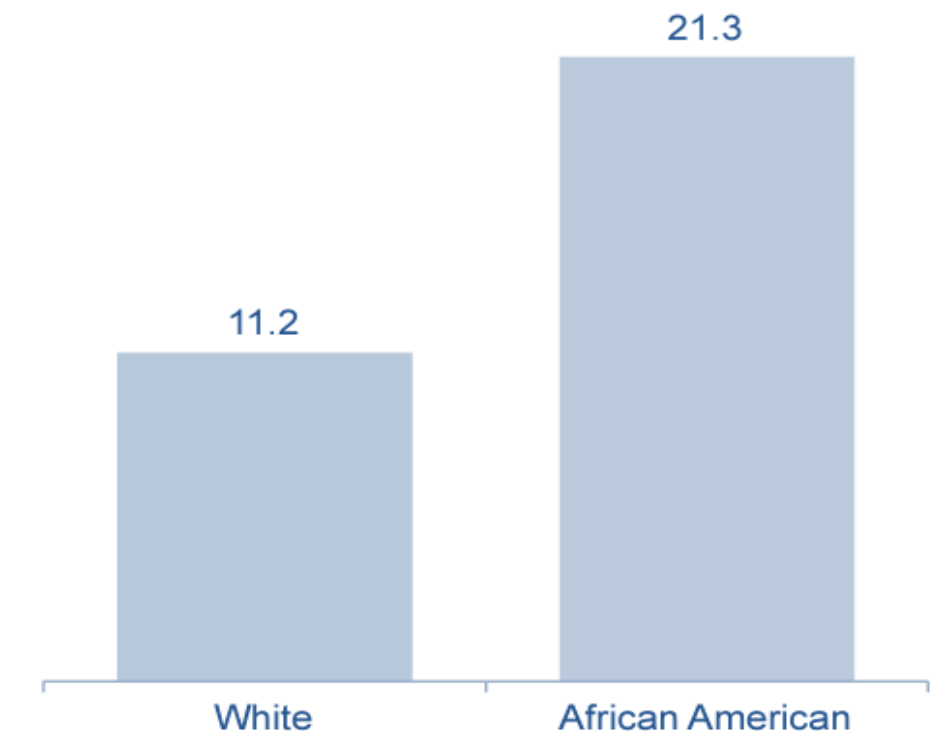
Proportions

- Black/African Americans and Hispanics/Latin/a/o/x experience delay in diagnosis with more advanced disease
- Black/African Americans and Hispanics/Latin/a/o/x use substantially more hospital, physician, and home health services
- Black/African Americans and Hispanics/Latin/a/o/x incur substantially higher costs for those services

Proportion of People Aged 65 and Older with Alzheimer's and Other Dementias
Washington Heights-Inwood Columbia Aging Project



Proportion of Americans Aged 71 and Older with Alzheimer's and Other Dementias
Aging, Demographics, And Memory Study (ADAMS)



The Reality of Health Inequities in Alzheimer's



- Black Americans are about two times more likely than White Americans to have Alzheimer's and other dementias.

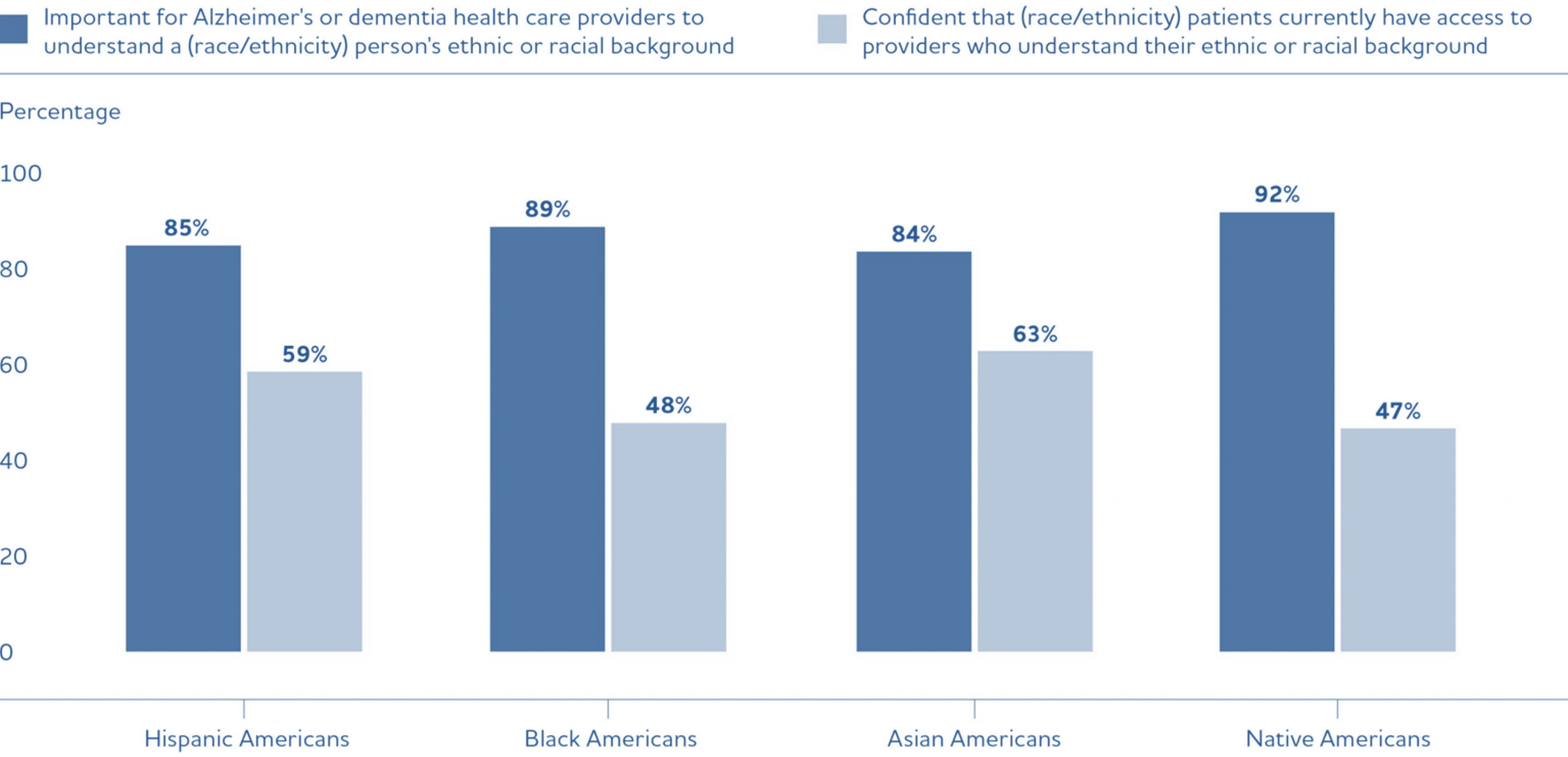


- Hispanic Americans are about one and one-half times more likely than White Americans to have Alzheimer's and other dementias.

Yet, these communities make up less than 10% of participants in Alzheimer's research.

FIGURE 19

Access to Health Care Providers Who Understand Racial and Ethnic Backgrounds Among U.S. Adults



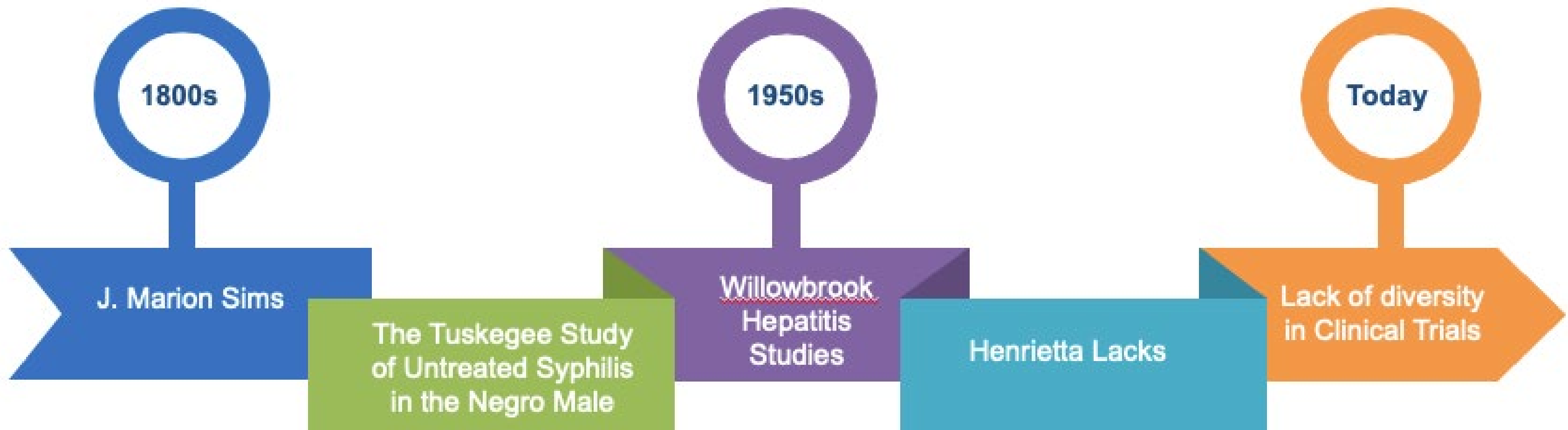
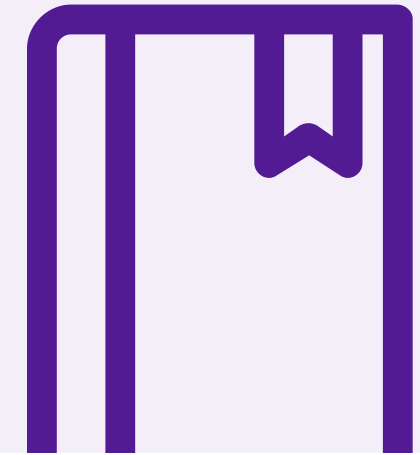
Source: Alzheimer's Association 2021 Alzheimer's Disease Facts and Figures.

Systemic Barriers

01	Mistrust in research (historical abuses from unethical research)
02	Healthcare access & bias (Black patients are less likely to be diagnosed early) which might lead to misdiagnosis or late diagnosis
03	Financial & logistical challenges (cost of care, lack of transportation)
04	Cultural stigma (denial, fear or burdening family, lack of awareness)

Historical Marginalization & Mistreatment

Examples from history to today





Spot the Disparity

- A Black woman experiences memory problems. Her doctor says, 'It's just stress,' with no follow-up testing
 - What's the disparity here?
- A hospital offers a free Alzheimer's screening event is held on a weekday morning in a mostly white, wealthy neighborhood
 - Who is excluded?
- A research study on Alzheimer's prevention is advertised online but requires participants to complete all forms in English
 - What's the inequity here?

Moving from Awareness to Action

Research & policy impact:

Diverse participation in research leads to more inclusive and effective treatments. Advocating for equitable healthcare policies ensures systemic change that benefits all populations.

Talk about these issues with family and friends.

Economic impact:

Reducing health disparities leads to lower healthcare costs, as early intervention can prevent expensive long-term care. Additionally, a healthier workforce contributes to stronger local economies.

Challenge bias in healthcare by seeking second opinions and speaking up.

Education & awareness impact:

Increasing knowledge about disparities helps families, caregivers, and communities make informed decisions, reducing stigma and promoting proactive brain health strategies.

Demand inclusivity in research—ask researchers about diversity in their studies.

Advocate for policies that improve healthcare access.

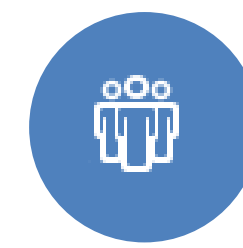
Health impact:

Improving early detection, diagnosis, and treatment options for marginalized communities can lead to better health outcomes, longer life expectancy, and a higher quality of life.

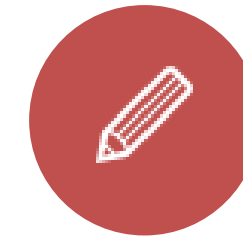
*Be the Change.
Ways to take
action.*



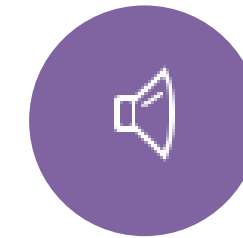
“Health inequities in Alzheimer’s care and research don’t just happen—they are the result of systemic barriers. But when we recognize them, we can push for change. The more we see the gaps, the better we can fight to close them.”



Trust, fatalism, fear & risks



Access, time & resources



Awareness, comfort & misinformation



Misdeeds

Historical Marginalization & Mistreatment

Leading to under-representation in research participation

High-Risk Dementia Engagement Core

Balls-Berry Lab



True Partnership



Strafing works
across lab and Core



GROWTH

**Inaugural Lead HDE Core
&
PI Balls-Berry Lab**



Joy Balls-Berry, PhD

Clinical Research Specialists



Marilyn Wilson, MSW



Dotti McDowell, MA

Research Coordinators



David Bradford



Makalah Coleman-Viser



Yvonne Hughes

Main Objective

Create sustainable partnerships that focused on increasing research participants among the ADRD high-risk populations



Participation

Utilize and expand the registry as a recruitment source for ADRD research by automating the referral and enrollment processes.



Education & Training

Develop a tailored educational and consultative services for Knight ADRC-affiliated investigators to increase engagement and participation by high-risk populations in Knight ADRC studies.



Engagement

To increase knowledge about ADRD in high-risk populations to encourage engagement in Knight ADRC research.

HDE CORE Timeline

The diagram features a horizontal timeline bar with a blue-to-purple gradient. Four circular markers are placed along the bar at regular intervals, each connected by a vertical line to a text label below. The labels are in a purple font. The years 2021, 2022, 2023, and 2025 are positioned directly above their respective labels.

2021

Est. the Core

2022

Implementation of
R24 & CDC Grant

2023

Referrals Process from
COEQUAL

2025

Reimaged

Engagement

Increase community -engaged research opportunities to address AD/ ADRD health disparities and to facilitate recruitment of persons under-represented in research



Partnering with ORE Core, WashU Institute for Clinical and Translational Science, and the Greater Plains Collaborative to engage and identify new partners



NIA R24 funding allowed for the expansion of the COEQUAL Governance Board



Partnering with the Knight ADRC operational leadership area to create a referral process for COEQUAL

Engaged

Use community and patient engaged research approach



Facilitate Recruitment

COEQUAL registry established

Governance Board

Created a community, patient, provider, and scientist advisory board



Community Engagement



Traditional Outreach

Community outreach at health focused events



New & Old Partnerships

Engaging local social and civic organizations



Cultivating Student Engagement

Provided opportunities for the next generation to learn community outreach and engagement

Governance Board

COMMUNITY, PATIENT, AND PROVIDER BOARD

Important to create an opportunity for deeper levels of engagement locally and nationally through board members

MEMBERS

Meets quarterly in the community to show a deeper commitment to our partners

GROWTH

Members have life happening but remained on the board



A photograph of a desk setup. On the left, a small potted plant with green leaves sits in a white pot. Next to it is a round analog clock showing approximately 10:10. In the center, a stack of four books with pink, yellow, and blue covers is visible. To the right of the books is a glass jar filled with colorful pencils and a pair of red-handled scissors. In the foreground, a tablet computer lies flat, reflecting the scene above it.

Education & Training on ADRD Health Disparities

Provide education & training on health disparities & health equity to learners internally and externally.

“The goal of education is
the advancement of
knowledge and the
dissemination of truth.” —
John F. Kennedy





Empowering others through education

- Lectures and seminars at WashU
- Community needs assessments, educational events, and dissemination of findings

Workforce



- Development of a workforce plan
- Staffing of the HDE Core has changed overtime
- Ability to be agile
- Consider what is best for the community
- Success and failures

NIA Health Disparities Research Framework

Lifecourse perspective using a socioecological model to address environmental, sociocultural, behavioral, and biological as priorities areas for health disparities research

Health Belief Model

Foundation is psychological and behavioral theory to examine one's desire to avoid illness and specific behaviors will prevent, treat, or cure an illness

Increasing Health Equity Through Research: Theory

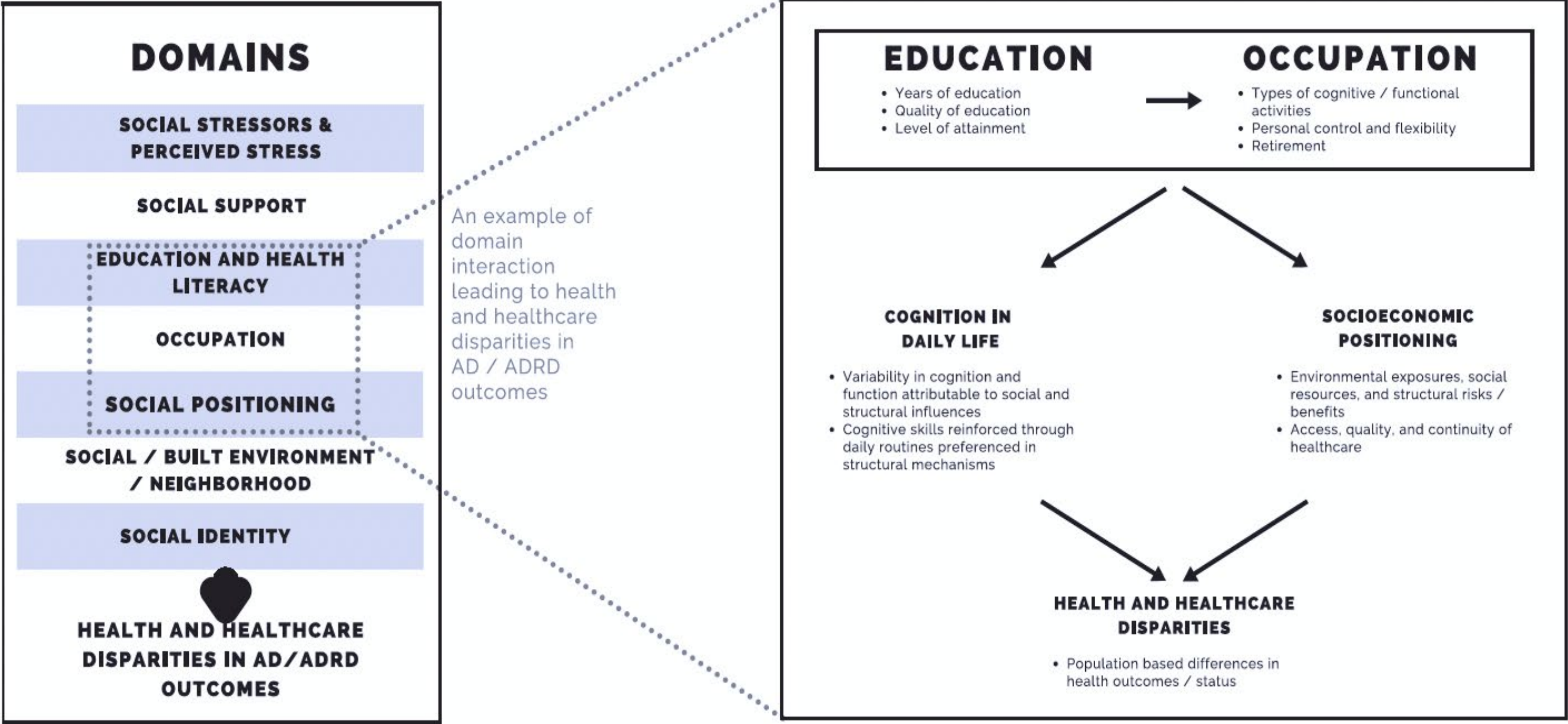
Social Cognitive Theory

Examines the self-efficacy and outcome expectations

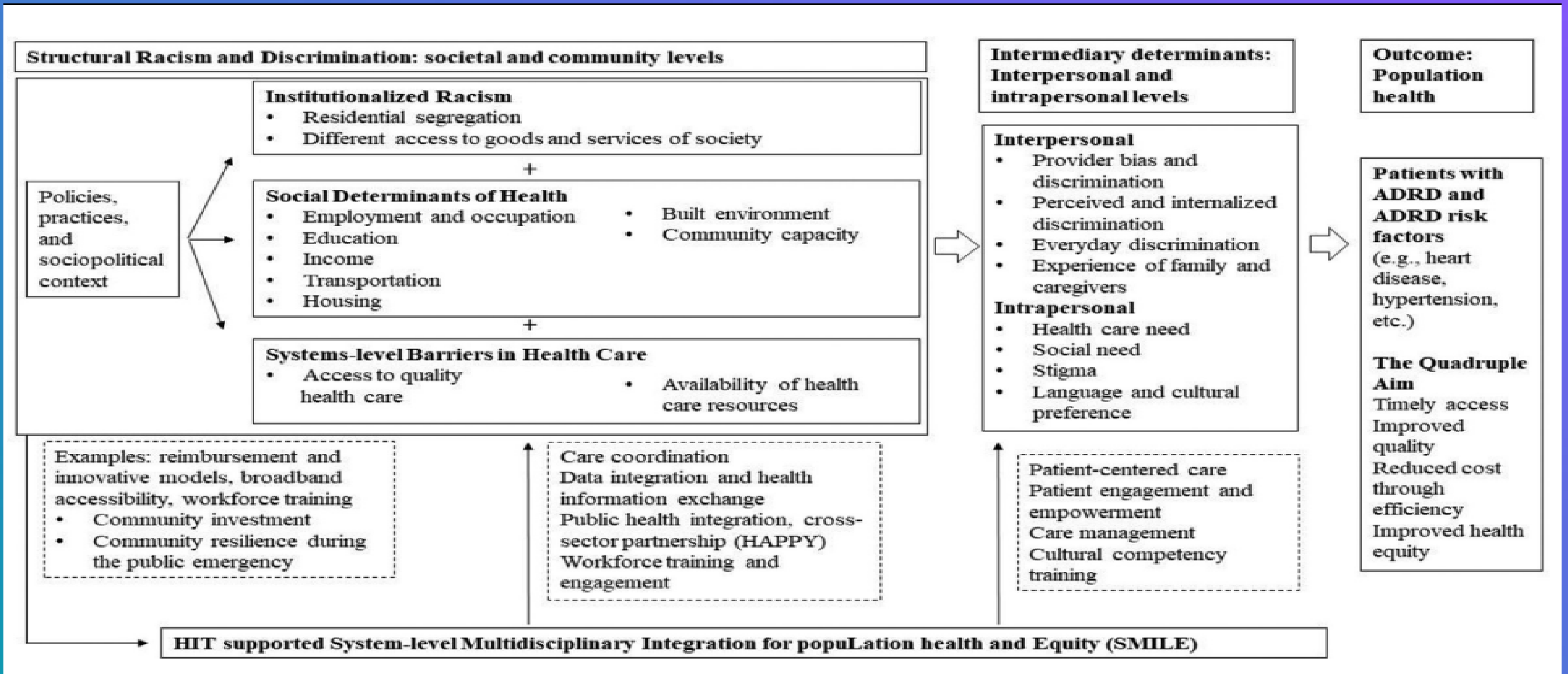
Motivation Theory

Considers if we are empowered and motivated for health

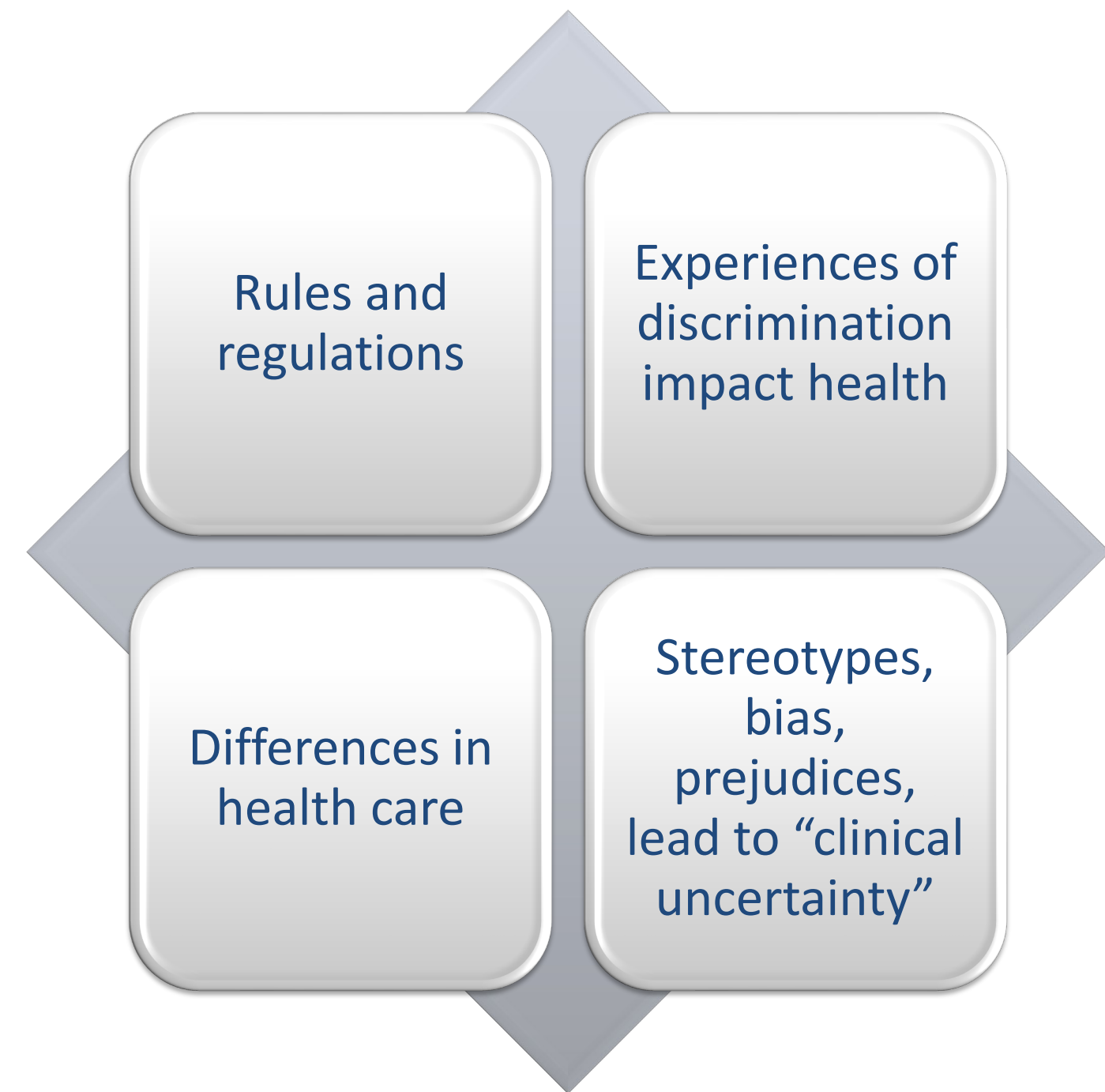
Intersection of Identify & Health



Framework Of Structural Racism and Discrimination in ADRD: HAPPY + HIT



Why measure SSDoH factors?



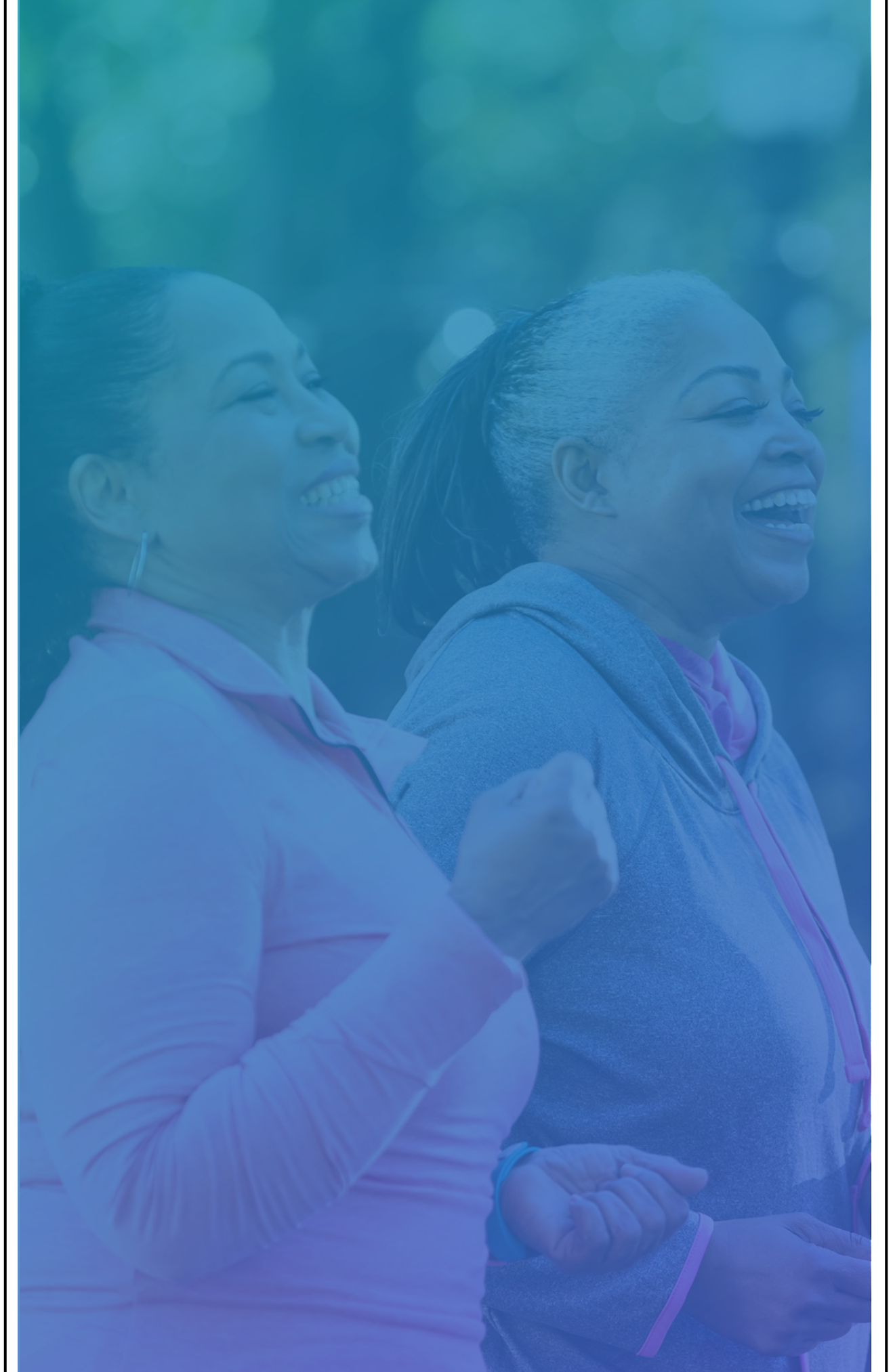
Racialization

Human Genome Project recognized that genetics characterize only geographic origins of ancestors – this is not race

But there is a predisposition for many groups based on the social construct of race to experience more disparities in health

For instance, we are often categorized by how we look, our hair texture, facial features, or our skin tone

Racialized groups have different experiences and transgenerational histories of slavery, immigration, genocide, and acculturation with population-level health outcomes being altered across generations because of racialization



Interpersonal & Institutional Racism Was Associated With Lower Memory Scores Among Multiracial Groups

Multiple Studies

- Evaluated experiences with interpersonal and institutional racism

Structural Racism

- Blacks noted more experiences
- Yet, all groups reported lower episodic memory

Lifetime experiences with Racism

- Persons 90+ lower semantic memory

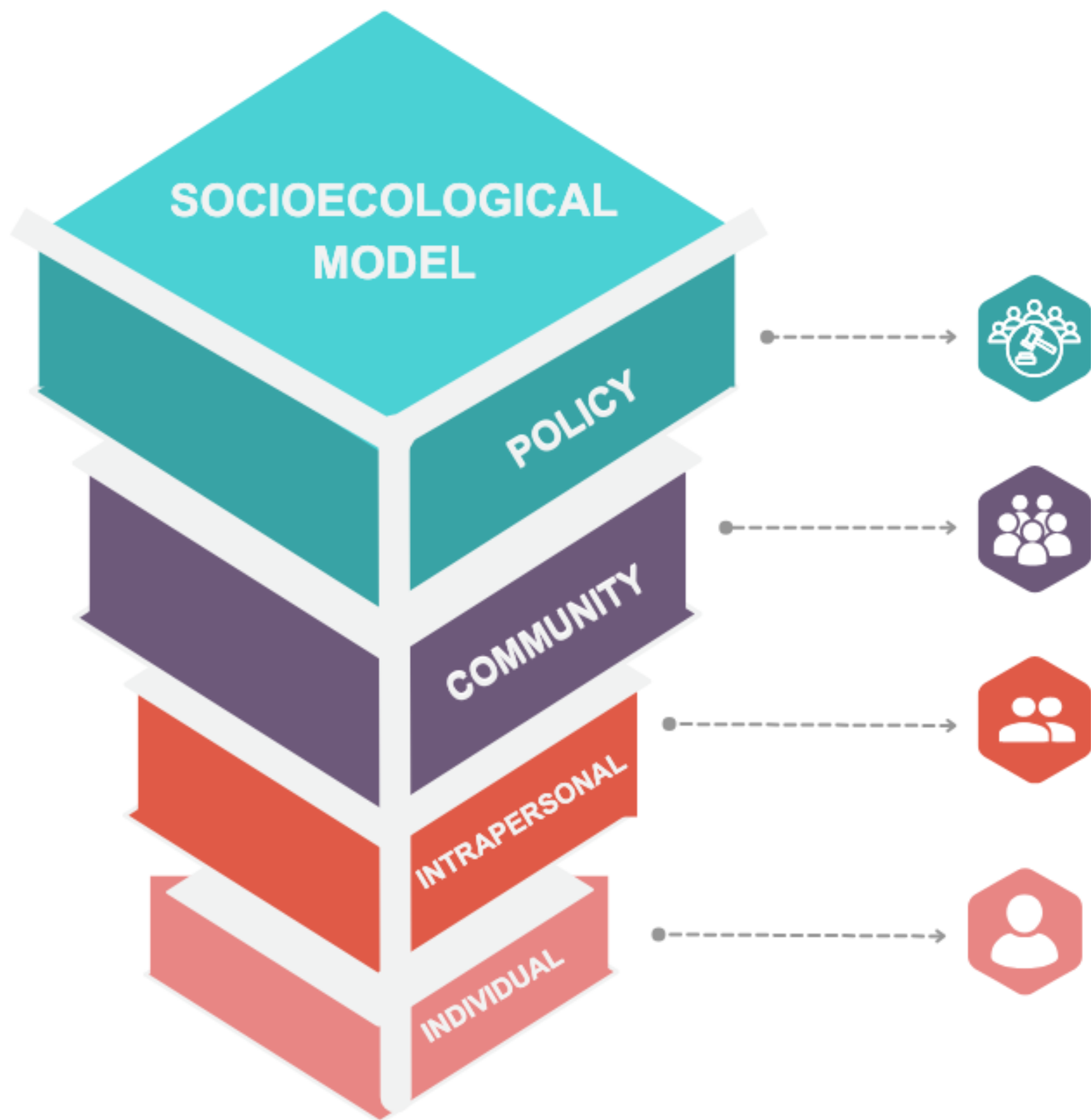


What about STL?

- More delays in diagnosis
- The lower usage of memory
- Black patients diagnosed with more advanced dementia
- Most approved drugs are limited (clinical trial diversity plus stage of disease)

Community-Patient Engaged Research





CPER

- National Institute of Neurological Disorders and Stroke (NINDS) SDOH framework
- Healing Accelerated Aging for All (HA3Quity)
- Social Cognitive Theory
- Adult Learning Theory
- Learner's Readiness to Engage in Research
- AI Prompt Engineering
- Traditional Content Analysis



Connection to the Lab

—
The HDE Core is directly connected to much of the work in the Balls-Berry Lab.

 COEQUAL

 RETAIN

The COEQUAL Registry: Creating Opportunities to Increase Health Equity and Equality (COEQUAL) for Persons at Risk for Alzheimer Disease and Related Dementias

PI: Balls-Berry 5R24AG074915

COEQUAL

Knight ADRC Engagement

ORE & HDE Cores Outreach Efforts, African American Advisory Board, COEQUAL Governance Board, and COEQUAL Brain Aging Cafes



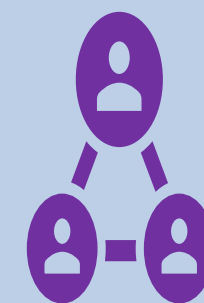
WashU & BJH Internal Resources

ICTS Community Engagement and Precision Health Programs, Prevention Research Center, Institute of Public Health, Harvey A. Friedman Center for Aging, and MyChart



External Resources

Medical societies, faith-based groups, philanthropic societies, private practices, FQHC, social clubs, and service providing agencies



Opportunities

Expansion on community engaged research efforts to engage new communities within a 100 miles of WashU

Reduce Silos

Determine engagement opportunities with other internal WashU teams across the campuses

Cultural Appropriate

Acknowledgement of historical underpinnings of unethical science and lack of access, triangulate data from Brain Aging Cafes to develop a robust engagement plan for COEQUAL

Brain Aging Café

Selected Demographics

n=306



	%
Number of BAC	14
Race	
Black/African American	90%
White	5%
Ethnicity n (%)	
Hispanic/Latin/a/o/x	8%
Average Age (Range)	68 (46-96)
Female Gender Identity	78%



A priori themes



Unique cultural needs regarding health, wellness, research engagement



Impact of Alzheimer disease on community



Barriers and facilitators to accessing care, services and resources



Availability and accessibility of educational resources



Barriers and facilitators to research participation and building partnerships



How to effectively recruit and retain research registry participants

- “I’m always drawn to participating in some way because Black people don’t participate in disproportionate rates due to previous events in history that broke trust. I always like to be a part of it because I want to help give back to the Black community. They don’t have as much data on us since we don’t participate as much.”
- “Due to past experiments that took advantage of Black people, people are weary of participating in research”

COEQUAL

Brain Aging Café

Selected Quotes

Selected Demographics

Self Reported Characteristic	n=1015 (%)
Age in Years Median (IQR)	64 (58-71)
Black/African American	79%
Hispanic/Latin(e/a/o/x)	4.6%
Female	72%
Less than College Graduate	61%
Earns Less than \$35,000 Annually	46%
Retired	49%
Study Partner	43%

Note: Percentages are rounded to the nearest whole number

COEQUAL Referrals



Affiliated Studies

Developing processes to refer and test the feasibility of COEQUAL to serve as the point of entry for MAP and COMPASS

Balls-Berry Lab

Recruitment into RETAIN is occurring now for the interview project

Other Projects

Contact us about your studies

RETAIN: Recruiting and Engaging with Technology Older Adults to Increase Neurocognition

The goal is to create a culturally tailored ADRD exercise intervention to aid in the prevention of symptomatic ADRD

PI: Balls-Berry (PI) and Brownson (PI WashU CDC Prevention Center)
6 U48DP006395 Supplement
Funding Period 9/2022 to 9/2024



Selected Demographics

Self Reported Characteristic	n=20 (%)
Age in Years Mean (Range)	61 (41-82)
Black/African American	100%
Female	65%
Less than College Graduate	55%



Literature Reviews

- Culturally tailored exercise programs for African Americans to reduce Cognitive Decline
- Diagnosis of asymptomatic and symptomatic Alzheimer disease in diverse populations

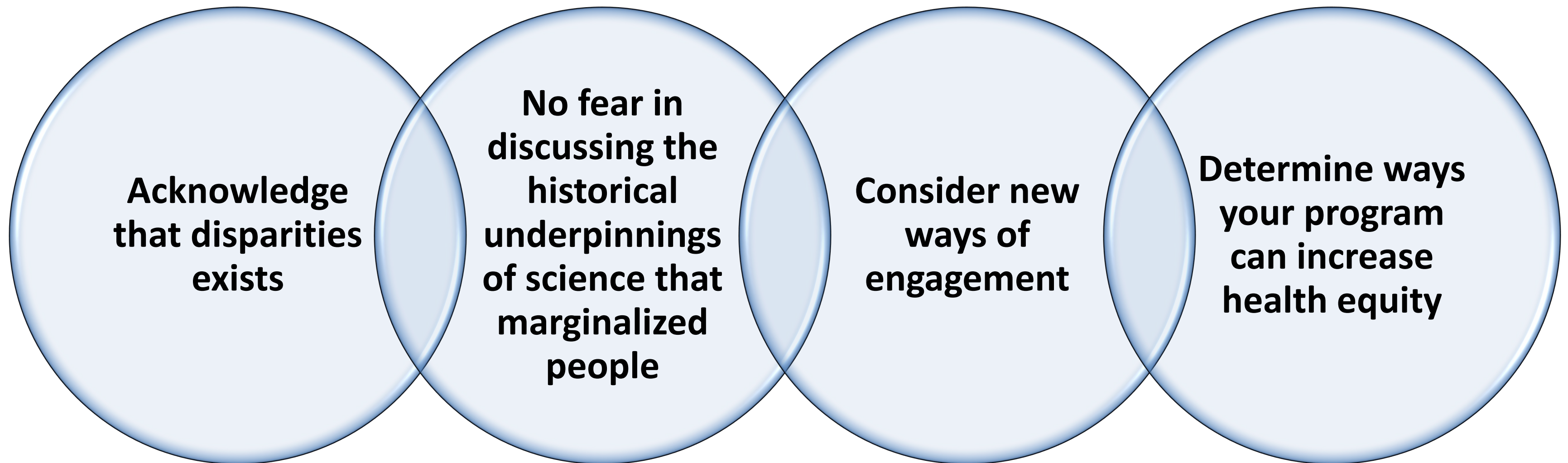
RETAIN Interviews

Barriers	Benefits	Robot Trainer
<ul style="list-style-type: none">• Motivation• Physical Location• Health concerns	<ul style="list-style-type: none">• Physical health• Cognitive health• Social aspect	<ul style="list-style-type: none">• Most agreed exercise improved cognitive health• Interested in engaging with the robot

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clean energy	diverse group	gay	intersectional	people-centered care	socio economic	women and underrepresented
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The time is now!





Thank you for working on the goal of increase health equity in
ADRD research

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