



“Meet the People Where they Are”

Addressing Disparities In Alzheimer’s Disease and African American Participation in Research:  
An Asset Based Community Development Approach

Gina Green-Harris  
September 15, 2023



**Wisconsin  
Alzheimer's Institute**  
UNIVERSITY OF WISCONSIN  
SCHOOL OF MEDICINE AND PUBLIC HEALTH



## **Wisconsin Alzheimer's Institute**

UNIVERSITY OF WISCONSIN  
SCHOOL OF MEDICINE AND PUBLIC HEALTH

*Regional Milwaukee Office*

**At the heart of the Regional Milwaukee Office is community engagement  
centered on  
five integrated mission pillars:**

**Community Engagement**

**Professional Education**

**Advocacy**

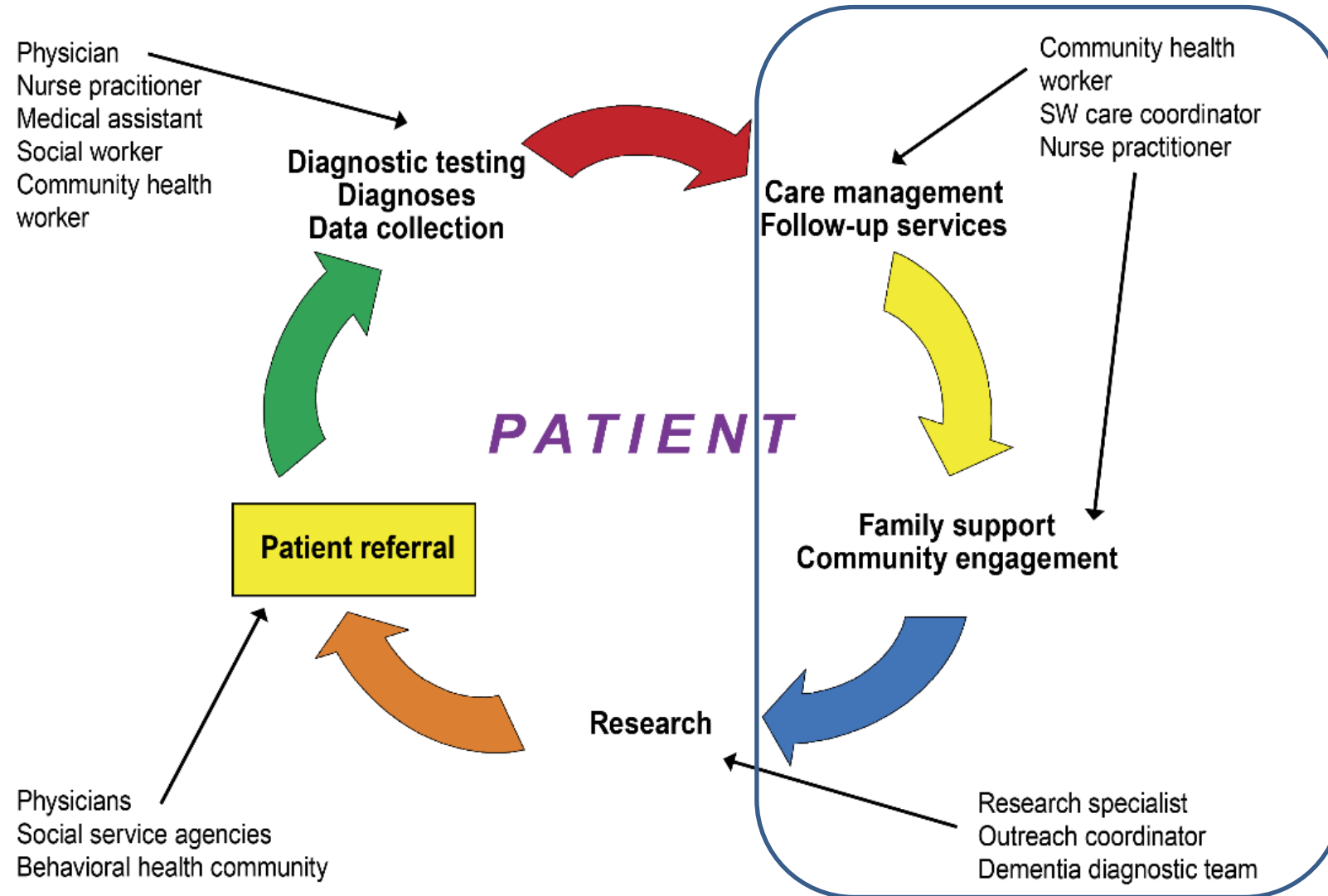
**Service**

**Research**

**This model empowers the Milwaukee and Southeastern Wisconsin communities of color, primarily African Americans, by providing culturally-specific health care services for its aging populations affected by dementia, Alzheimer's disease and other health disparities.**

# Primary Goal: Address the Community's Concerns Related to Diagnosis

## MHSI Memory Clinic Model



Sager, M. A., Hermann, B., and La Rue, A. (2005).



Gina



Nia



Stephanie



Celena



Gail



Ian



Naveena

# Addressing Disparities in Alzheimer's Disease and African-American Participation in Research: An Asset-Based Community Development Approach

*Gina Green-Harris<sup>1,2</sup>, Sheryl L. Coley<sup>3\*</sup>, Rebecca L. Kosciuk<sup>3</sup>, Nia C. Norris<sup>1</sup>, Stephanie L. Houston<sup>1</sup>, Mark A. Sager<sup>3</sup>, Sterling C. Johnson<sup>3,4,5</sup> and Dorothy Farrar Edwards<sup>5,6,7</sup>*

# Our Five Integrated Mission Areas



Community Engagement



Community and  
Professional Education



Service



Advocacy



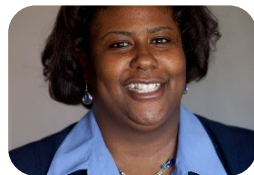
Research



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# Asset Based Community Development(ABCD) Outreach Model





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## Community Engagement

*Motto: Meet the People Where They Are*

**We foster partnerships to deliver culturally-appropriate education, training and outreach programs to providers, those living with dementia and family caregivers.**

- *Dispel myths; provide credible information to the community about dementia and other cognitive diseases*
- *Increase public awareness and understanding of health disparities and dementia to reduce the stigma, increase diagnoses and improve access to care.*
- *Increase education about the risk factors associated with AD to improve awareness of the association between chronic illnesses and dementia.*





# COMMUNITY AND PROFESSIONAL EDUCATION

- *Provide health care professionals with recommendations on best care practices of how provide culturally appropriate care to effectively address the patient, family, and community and family needs.*
- *Collaborate with community, faith-based, and grass roots organizations to provide presentations on risks for AD and dementia, inform about resources and assist with navigation through available programs*



**Our keynote speaker:**  
**Sylvia Mackey**

Sylvia Mackey is the wife of Pro Football Hall of Famer, John Mackey, #88 of the Baltimore Colts (1963–1971). John was diagnosed with Frontotemporal dementia (FTD) and passed away in 2011 at the age of 69. As a caregiver, Sylvia became an advocate for John and others with dementia, as well as a renowned speaker on FTD and its impact on patients and their families.

## 2014

Inaugural Minority Health Month  
Community Breakfast  
Breaking the Silence: Facing  
Dementia in Communities of Color

## 2023

9th Annual Minority Health Month  
Community Breakfast  
Breaking the Silence: Addressing  
Dementia in Communities of Color



**2023  
BREAKING  
THE SILENCE**

ADDRESSING DEMENTIA IN  
COMMUNITIES OF COLOR

*Building a Future  
to Remember*

Friday, April 21, 2023  
8:00 AM to 12:00 PM

Join the Wisconsin Alzheimer's Institute  
Regional Milwaukee Office for the 9th  
Annual Minority Health Month Breakfast  
Dialogue!

**ITALIAN COMMUNITY CENTER**  
**631 EAST CHICAGO STREET**  
**MILWAUKEE, WI 53202**

BREAKFAST & NETWORKING

RESOURCES & INFORMATION

PERFORMANCE BY  
THE AMAZING GRACE CHORUS®

This event is jointly provided by:

 **WISCONSIN ALZHEIMER'S INSTITUTE**  
UNIVERSITY OF WISCONSIN  
SCHOOL OF MEDICINE AND PUBLIC HEALTH  
Regional Milwaukee Office

 **BADER  
PHILANTHROPIES, INC.**  
CELEBRATING COMPASSION

**KEYNOTE SPEAKERS**

**Dr. Mark Sager**  
Founder- Wisconsin Alzheimer's  
Institute and Wisconsin Registry  
for Alzheimer's Prevention

**Dr. Art Walaszek**  
Public Health and Education  
Leader- Wisconsin Alzheimer's  
Institute

**Antonio Freeman**  
Former NFL Green Bay Packer

**NO COST TO ATTEND**  
**REGISTER BY APRIL 14**  
<https://wai.wisc.edu/breakthesilence/>

More information  
414-219-5124





# SERVICE

*Access to Comprehensive Care*

**Reducing barriers that impede access to information  
and services by building trust, credibility and partnerships**

## Excerpt of Activities

In-Home Memory Assessments  
Dementia Wellness Program

Provide information and education of  
local resources and healthcare delivery  
systems to help patients and families  
navigate their dementia journey

Diagnostic Memory Clinic  
(Professional partnership between  
UW/WAI and Milwaukee Health Services  
Inc.)

Community-Based Dementia Screening  
and Cognitive Testing

Personalized Care and Treatment Planning

- *Provide culturally-sensitive care, improve quality of life for persons with dementia, and support family caregivers*

- *Deliver culturally-appropriate Alzheimer's-related and related disorders resources and services*

- *Foster partnerships with faith-based groups, medical and social service providers, and community organizations to enhance effective service delivery for those living with dementia and family caregivers*



As a service model of care our signature program, the Amazing Grace Chorus®, improves the quality of life of its participants and caregivers through socialization and music while integrating the pillars of education and service.

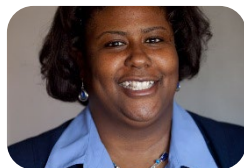
Mittelman, M. S., and Papayannopoulou, P. M. (2018). The Unforgettables: a chorus for people with dementia with their family members and friends.



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Naveena



Dr. Sheryl

# ADVOCACY



- *Formed in 2009 to serve as counsel to the University of Wisconsin (UW) and WAI Regional Milwaukee Office team on outreach and recruitment strategies that are culturally sensitive*

- *Provide a voice for the community*

- *Identify and address barriers to research participation by underrepresented populations*

- *Support the recruitment and retention of research subjects*

- *Become a conduit for supporting Community-Based Participatory Research (CBPR) in the community*

## Excerpt of Activities

- Provides meaningful insight and support to UW investigators on research projects; resulting in funding for those projects provided by the National Institutes of Health (NIH) and other funding agencies

- Recognized by scientists, researcher across Wisconsin's institutions for its expertise and recommendations on how to successfully implement innovative research proposals for engaging communities of color, especially African Americans.

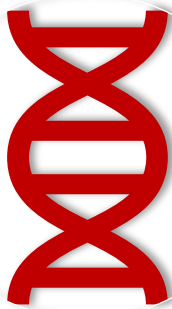
- Instrumental in helping address the lack of diverse scientist and other staff to lead the work for research in African American communities.



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# RESEARCH

Advancing dementia and health disparities research by actively engaging under-represented populations in cutting-edge scientific studies



Celena



Ian



Nia



Gina



## Excerpt of Activities

- Cognitive testing every 2 years
- Provide WRAP Updates and Newsletters to research participants
- Present the latest news and resources on research strategies, results and dissemination

## Recruitment and Retention Activities

- Community Outreach and Recruitment Events
- Biennial information sessions on research findings and new studies for participants and guests throughout Wisconsin

## Plans to Increase African American Participation

- Provide and increase public awareness and understanding of the importance of health disparities and Alzheimer's research utilizing media outlets and community outreach
- Host multiple informational sessions annually focusing on research findings from African American participation in WRAP

By implementing a public health community investment approach to research that focuses on transparency, community engagement, and reducing the stigma and fear often associated with Alzheimer's disease and research, we have grown the number of African Americans participating in research from 2% to 10%.

Today over 1,500 participants are enrolled in the WAI's Wisconsin Registry for Alzheimer's Prevention (WRAP), the world's largest study of its kind.

## High priorities of our program:

- *Retention of research participants in WRAP*
- *Increasing participation by African Americans*
- *Unlocking the answers of why communities of color are at a higher risk of developing the disease*



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# Recommendations

- Rethink funding mechanisms
- Improve evaluation tools
- Community Stakeholder engagement
- Integrated research strategies that are developed with people living with dementia and their caretakers
- Rethinking Equity and Inclusion
- Rethink funding for intervention and prevention models for high-risk communities

Thank you



# Participants

- **96** enrolled at **8 sites** between July 2015 - September 2016
  - **Predominately African-American (80%) women (81%)**
  - Widespread **chronic conditions** including Hypertension (77%), High Cholesterol (56%), and Type II Diabetes (34%)
  - High rates of **comorbidity** - 56% w/ 2+, 26% w/ 3
  - 73% BMI of “**obese**”
  - 71% Waist/Hip Ratio est. **health risk of “high”**
  - 27% positive **depression** screen
  - 58% **abnormal cognitive** screen





*Connecting the Dots Part 2 –  
The Dementia Wellness Project: A Culturally Appropriate Lifestyle  
Intervention for African American Elders at Risk for Dementia*

Gina Green-Harris MBA, Michelle Corbett MPH CHES,  
Stephanie Houston MBA, Teresa Skora NP, Carrie Stehman MA,  
Carla Wright MD, Nia Norris MA, Dorothy Edwards PhD



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## UW/WAI /MHSI

### Moving Upstream- Dementia Wellness Project

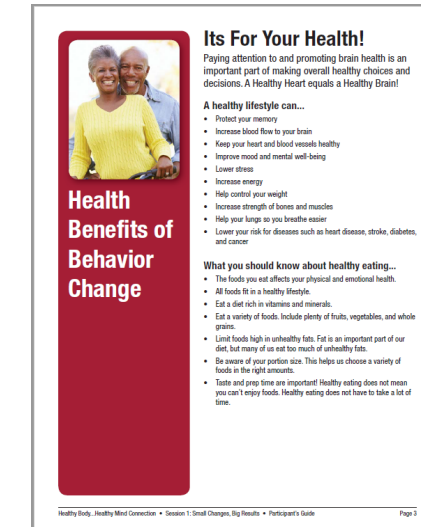
- **Milwaukee Health Services Multidisciplinary Memory Clinic**
  - Physician, Nurse Practitioner, Case Manager
  - Medical Home Model
- **Community Screening Events**
  - Screening for memory loss and common chronic illnesses
  - Referrals to Memory Clinic and other health services
  - Individual Family/caregiver education
  - Pathway to lifestyle intervention program
- **Health Body-Healthy Mind Connection Wellness Program**
  - 5 weekly two-hour group sessions
  - Focus on: brain health, diet and nutrition, physical activity, chronic disease management, social support, goal setting
  - One-on-one health coaching to support goal attainment

# Intervention

- 8 cycles held in **7 housing sites** and **1 senior center**
- Half of enrollees **attended 4 or more** sessions
- Half focused on **increasing physical activity** levels
- **Satisfaction** with the program was high:
  - 96% were **glad they participated**
  - 98% would **recommend to a friend**

*“The class made you more mindful and more aware of your own health conditions and that your health could be better.”*

*“I liked the support from the group that helps you believe that you will achieve your health goal.”*





# Outcomes

59 participants completed 3-Month Follow-Up visit

- 34% had **achieved SMART goal**, 59% were in progress
- **Positive behavior changes reported** in diet and physical activity
- Statically significant positive change in **quality of life measure\***
- **Decreases** in mean BMI, systolic BP, and total cholesterol
- Statically significant decrease in **A1C\*\***

*“I push to fit in exercise every day.”*

*“The way I shop, the way I eat . More vegetables, more fruit,  
reading labels.”*

*“I learned how to rest and I feel better. Less stress and anxiety.”*

*“Getting up out of bed every day.”*

\*.004 “mean # of days in last month that physical/ mental health interfered with daily activities”

\*\* .012