Overcoming Barriers to Diversifying Clinical Trials: 2nd Public Workshop

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Center for Community Engagement and Health Partnerships
Wisconsin Alzheimer's Institute, Regional Milwaukee Office
June 1, 2021

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SCHOOL OF MEDICINE AND PUBLIC HEALTH

WAI Regional Milwaukee Office

Wisconsin Alzheimer's Institute
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- Satellite office opened in 2008: Center for Urban Population Health- Aurora Sinai
  - MAPP: Milwaukee Alzheimer's Prevention Program
  - WRAP: Wisconsin Registry for Alzheimer's Prevention

Vision:

- Committed to working within the African-American community to improve early diagnosis of AD
- Keep elders at home safely
- Provide supportive services
- Build the framework for the community to have available and access appropriate resources
- Increase awareness about AD and participation in research

Leadership Team

Gina Green-Harris, MBA
Director

Nia Norris, Ph.D.
Assistant Director

Stephanie Houston, MBA
MAPP Family Care Manager

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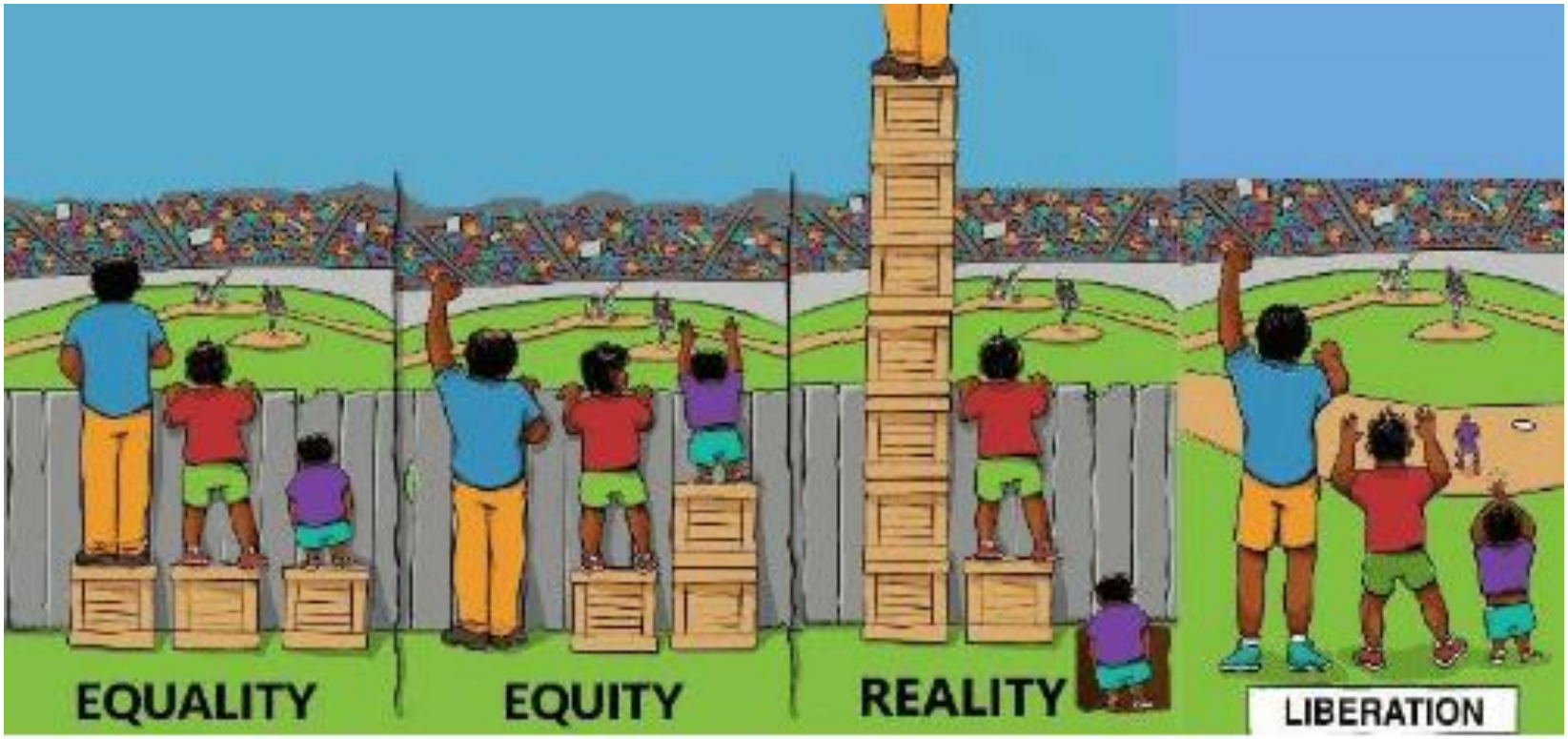
THE WISCONSIN IDEA

One of the longest and deepest traditions surrounding the University of Wisconsin, the Wisconsin Idea signifies a general principle: that education should influence people's lives beyond the boundaries of the classroom. Synonymous with Wisconsin for more than a century, this "Idea" has become the guiding philosophy of university outreach efforts in Wisconsin and throughout the world.

https://www.wisc.edu/wisconsin-idea/



Liberation

Our Five Integrated Mission Areas

Community Engagement

Community and Professional Education

Service

Advocacy

Research

WAI Milwaukee Program Model

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


Gina


Nia


Stephanie


Celena


Gail


Ian


Naveena

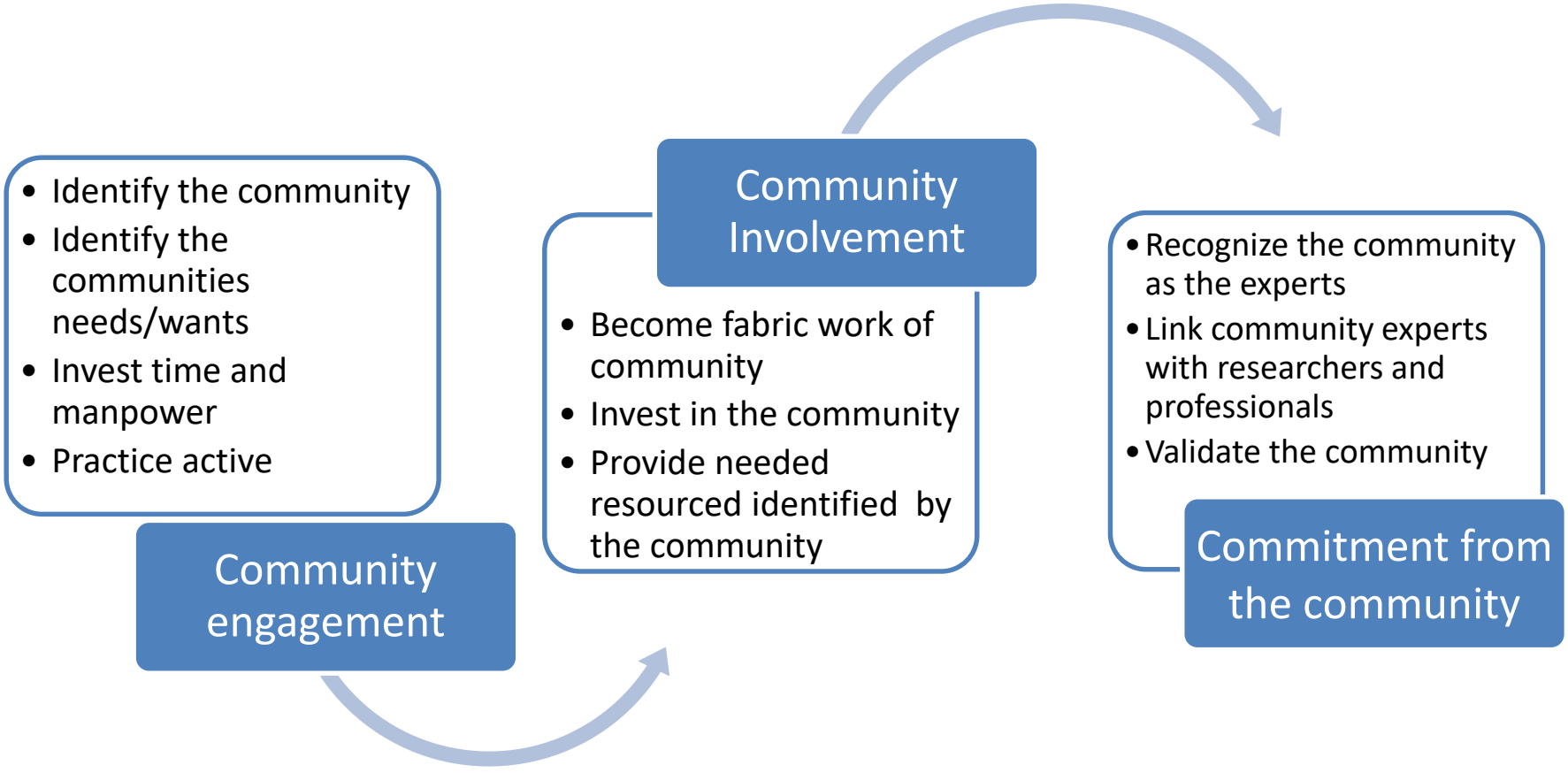
Community Engagement

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 Investment Model




Gina


Nia


Stephanie


Celena


Gail


Ian


Naveena


Dr. Sheryl

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*

2014

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

2019

6th Annual Minority Health Month Community Breakfast
Breaking the Silence: Addressing Dementia in Communities of Color
"The Power of YOU"

SERVICE

Access to Comprehensive Care


Stephanie


Gina


Dr. Sheryl

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.

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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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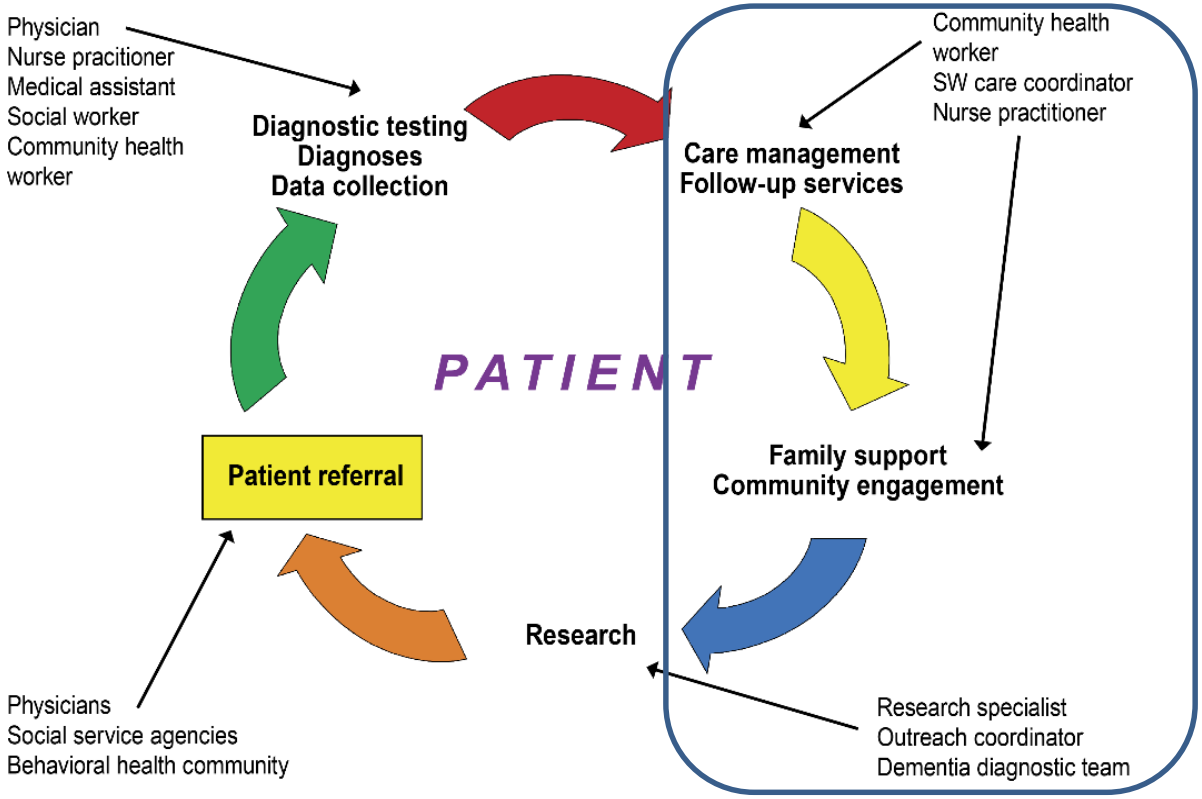
Addressing the Community's Concerns
MHSI Memory Clinic Model –African American Centered



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






Gina Nia Stephanie Celena Gail Ian

ADVOCACY

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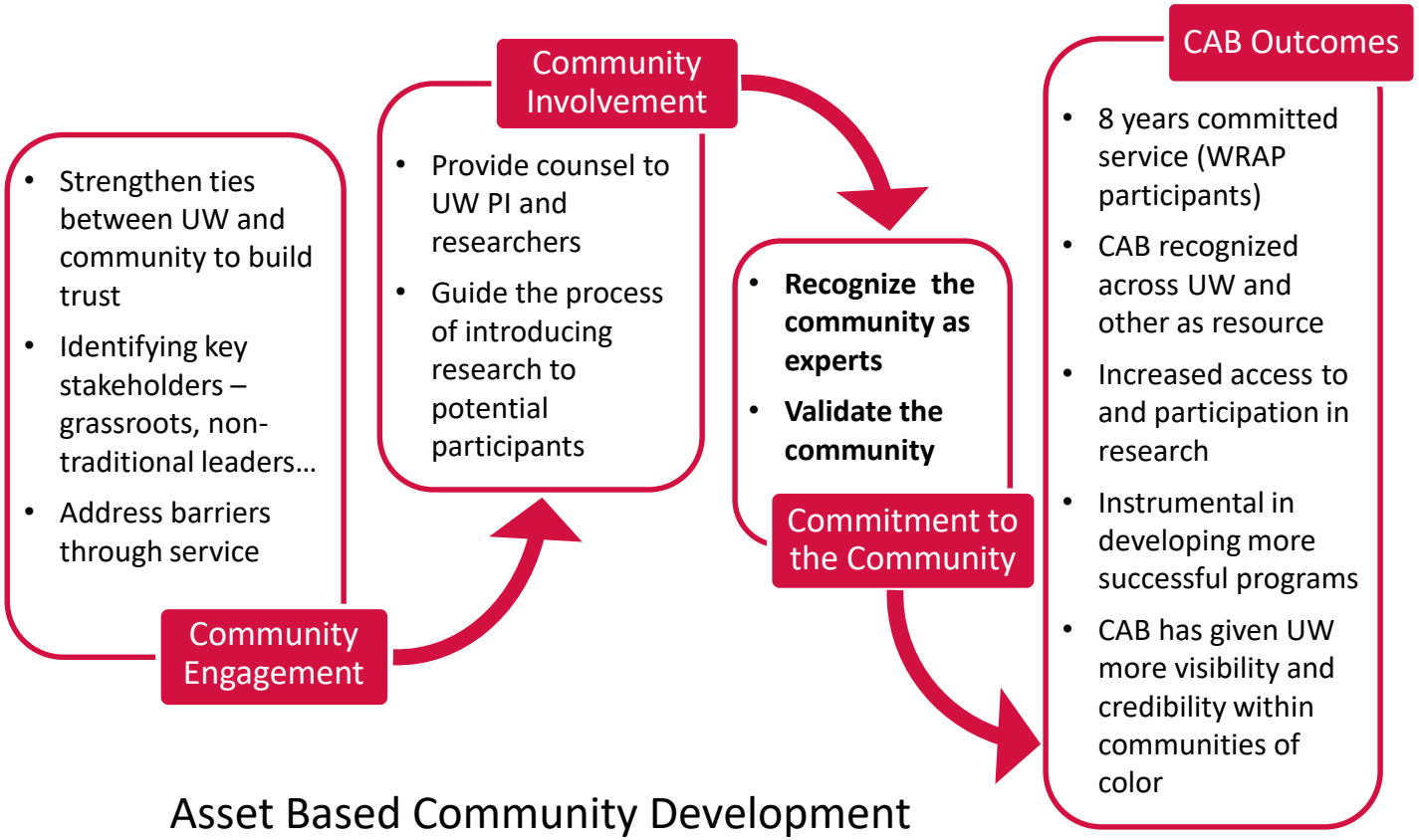
- *Formed in 2009 to serve as counsel to the University of Wisconsin (UW) and WAI Regional Milwaukee Office team on outreach and recruitment strategies that are culturally sensitive*
- *Provide a voice for the community*
- *Identify and address barriers to research participation by underrepresented populations*
- *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.



Asset Based Community Development Model
Community Advisory Board

McKnight & Kretzmann (1993). *Building Communities From the Inside Out: A Path Toward Finding and Mobilizing a Community's Assets*

Building Trust with our Stakeholders
WAI-Milwaukee Community Advisory Board

- Composed of interested residents and healthcare providers in the Milwaukee African-American community.
- Purpose: To strengthen the ties between research and lay communities in the Milwaukee metropolitan area.
- The CAB is an essential component of the WAI Milwaukee Project.

Goals:

–Provide a voice for the Community

–Counsel the UW and WAI team on outreach and recruitment strategies that are culturally sensitive.

–Identify and address barriers to research participation by minority persons.

–Support the recruitment and retention of research subjects.

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

RESEARCH

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



Celena Jan Nia

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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Using Asset-Based Community Involvement to Address Health Disparities and Increase African American Participation in AD Research: Experiences from the Wisconsin Alzheimer's Institute

Gina Green-Harris, MBA
Wisconsin Alzheimer's Institute

AAIC 2017 Presentation

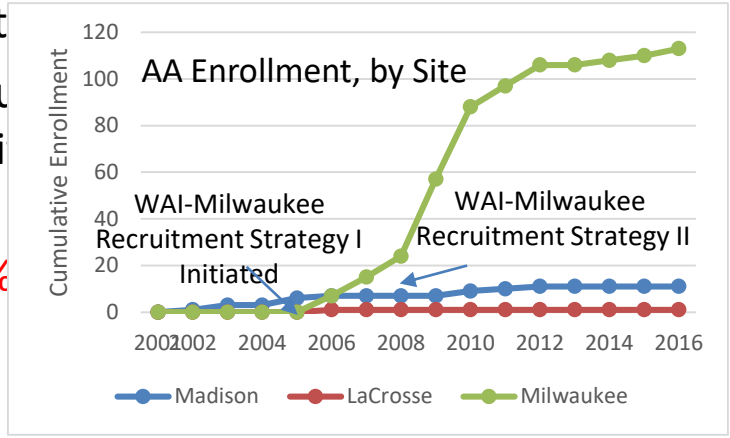
Co-authors: R. Koscik[1], S. Houston[1], N. Norris[1], J. Mahoney[1], M. Sager[1], S. Johnson[1,2], D. Farrar Edwards[1,2]

1. Wisconsin Alzheimer's Institute 2. Wisconsin Alzheimer's Disease Research Center

Milwaukee WRAP Research Participation Highlights

- 189 people are enrolled in WRAP in the Milwaukee area:
  - African-American/ black (110)
  - Caucasian/white (41), Hispanic/Latino (35)
- Currently in 4th wave of ret
- Primary focus in the Milwau African-American communi

By 2012, AA's comprised ~8% of WRAP sample



Conclusions

- African Americans bear a disproportionate burden of AD and other dementias
- Structural and social barriers affect access to diagnosis, treatment and family support
- Culturally tailored community based services are needed to reduce inequities and improve access to education, diagnosis, treatment and prevention programs
- Asset Based Community Engagement programs have the potential to improve quality of care, reduce costs, decrease burden and improve quality of life
- Use of this model has resulted in increased participation in research of African Americans.

Acknowledgements

Funding:

- University of Wisconsin School of Medicine and Public Health Wisconsin Partnership Program (WPP2782)
- Bader Philanthropies (formerly Helen Bader Foundation)

Collaborators:

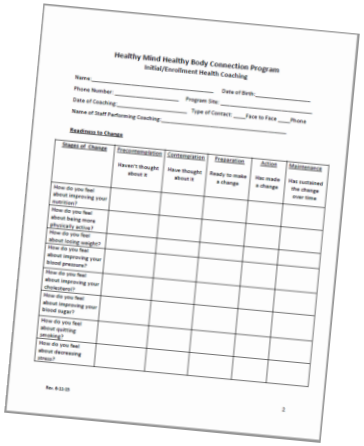
- Milwaukee Health Services Inc.
- SET Ministries
- Center for Urban Population Health
- Wisconsin Alzheimer's Disease Research Center
- Alzheimer's Association of South Eastern Wisconsin

Thank You!

Data Collection

- **At Enrollment and 3-Month Follow-Up:**
  - Brief medical history
  - Lifestyle Survey
  - Biometrics: BMI, Waist/Hip, A1C, Cholesterol, BP
  - Strength/Flexibility/Balance Assessment
  - Behavior Change Readiness Assessment/ Status Review

SMART Goal



Healthy Mind Healthy Body Connection Program
Initial/Enrollment Health Coaching

- **At Post Intervention:**
  - Knowledge and Satisfaction Survey

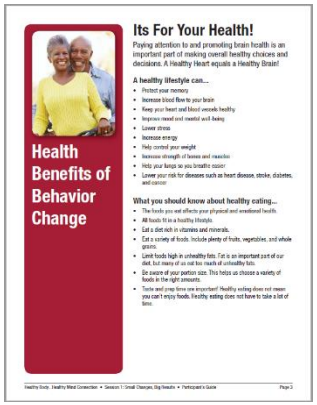
- **At 3-Month Follow-Up:**
  - Brief qualitative interview

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

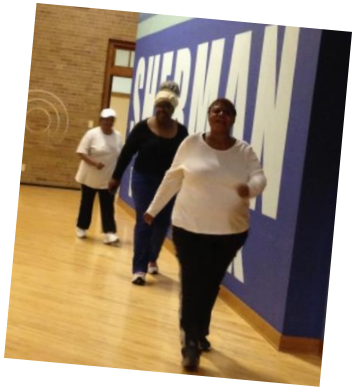
Intervention

- 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**

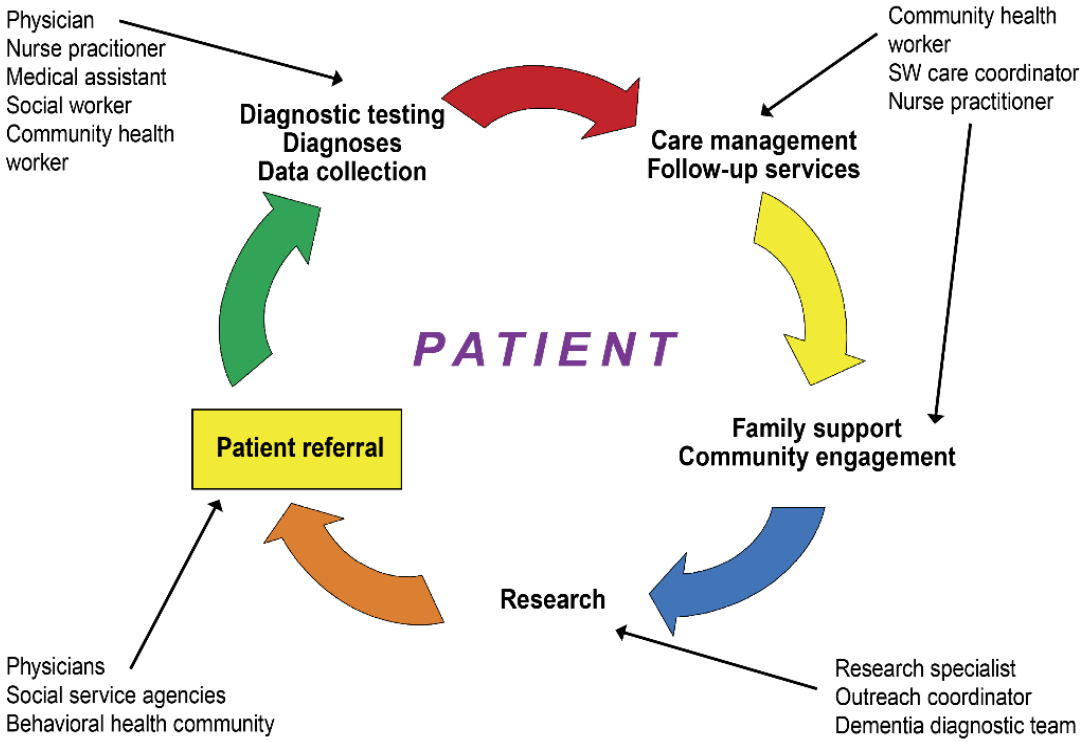


"The class made you more mindful and more aware of your own health conditions and that your health could be better."

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



Addressing the Community's Concerns
MHSI Memory Clinic Model



Supports for Participation	Barriers to Participation
Intrapersonal Factors	Intrapersonal Factors
- Feeling comfortable, welcomed, and accepted - Feeling proud or honoured for sharing cultural knowledge or making a contribution - Feeling grateful for programs and services - Having a sense of shared identity	- Feeling uncomfortable, shy, judged, intimidated, embarrassed, or overwhelmed - Feeling mistrustful of others - Past experiences of trauma, bullying racism - Feeling self-conscious of differences c stigma related to income, race/ethnicit age, marital status or spiritual beliefs
Interpersonal Factors	Interpersonal Factors
- Welcoming behaviours of others - Respectful interactions—getting to know people and making friends - Receiving and giving support—sharing parenting strategies, encouragement, and childcare Maintaining confidentiality Interacting across groups - Attending with a friend or as a family	- Negative action of others—gossiping making negative comments, asking intrusive questions, leaving people ou and lack of welcoming behaviour - Closed social networks—cliques, difficulty making friends, insular cultural and religious groups and raci barriers - Experiences of loss, conflict, bullying or racism
Organizational Factors	Structural Factors
- Program design—free, accessible programs - Staff approach—making personal contact, linking community programs, engaging low-income, Aboriginal parents and youth and inviting volunteers Staff competencies—building trusting relationships, and being knowledgeable about parenting, First Nations language and culture - Program focus—promoting group diversity, cultural appreciation and First Nations cultural activities	- Geographic— rural location and add travel costs - Financial—lack of transportation, program fees, low-paying jobs and fo insecurity - Lack of access—services and post-secondary education - Community attitudes and racism