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

Building a Future to Remember
The Wisconsin Alzheimer’s Institute: *Future Directions*

Alzheimer’s Association
31st Annual Wisconsin State Conference
May 8, 2017
History of WAI

• An Institute within the UW School of Medicine and Public Health

• Founded in 1998, under the visionary leadership of Dr. Mark Sager

• Created in partnership with UW School of Medicine and Public Health, Department of Health Services, and Bader Philanthropies

• Provide information, education, research, outreach, advocacy and service programs to help improve lives, advance knowledge and inspire hope.
New leadership for WAI: November 2015

Jane Mahoney, MD
Professor of Medicine
Director, WAI

Cindy Carlsson, MD
Associate Professor of Medicine
Associate Director, WAI
Wisconsin Registry for Alzheimer’s Prevention

– Started in 2001 to understand the factors that increase a person’s risk of developing AD by following people over time

– Has received NIH funding since 2006

Presentation by Dr. Cindy Carlsson, Associate Director of WAI, Associate Professor of Medicine, and WRAP Core Faculty
WAI Regional Milwaukee Office

- Initiated in 2008 as a unique minority outreach program
- Improve access to services
- Increase awareness
- Offer supportive services

Presentation by Nia Norris, MA, Assistant Director, Regional Milwaukee Office and Stephanie Houston, MBA, Outreach Specialist, Regional Milwaukee Office
Dementia Diagnostic Clinic Network

– Program initiated in 1998 to train healthcare professionals on the standardized assessment and care of persons with memory complaints
– Modeled on Dr. Sager’s Memory Clinic
– Led to development of a statewide network of WAI-affiliated Dementia Diagnostic Clinics

Presentation by Dr. Cindy Carlsson, Associate Director, WAI, and Clinic Network Director
Public health mission began with WAI’s founding

– Providing education statewide to community partners
– Conducting research with state partners on new ways to increase community awareness and learning
– Helping train Dementia Care Specialists
– Assisting stakeholders to convene new dementia-friendly communities

Presentation by Dr. Jane Mahoney, Director of WAI and Professor of Medicine
Nia Norris, MA
Assistant Director, Regional Milwaukee Office

Stephanie Houston, MBA
Outreach Specialist, Regional Milwaukee Office
Public Health Model
At the heart of the Regional Milwaukee Office is community engagement centered on five integrated mission pillars:

- Community Outreach
- Professional Education
- Advocacy
- Service
- Research

This model empowers the Milwaukee and Southeastern Wisconsin communities of color, primarily African Americans, to actively participate by providing culturally-specific health care services for its aging populations affected by dementia, Alzheimer’s disease and other health disparities.
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.
- 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
Asset Based Community Development (ABCD) Outreach Model

- Community engagement
  - Identify the community
  - Address the communities needs/wants

- Community Involvement
  - Fabric work of community
  - Invest in the community
  - Provide resourced identified by the community

- Commitment from the community
  - Recognize the community as experts
  - Validate the community

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

Annually the WAI Regional Milwaukee Office reaches over 30,000 individuals and households through our programs and activities. Our efforts focus on dementia-related early detection/risk reduction, treatment, psycho-social management, and caregiver interventions.

Professional training offers state-of-the-art education around best practices to provide culturally-sensitive care to patients and effectively address community and family needs.

Excerpt of Activities

- **Annual Minority Health Month Event- Breaking the Silence: Addressing Dementia in Communities of Color (Milwaukee and Racine)**

- **Cultural Inclusion** professional training and educational workshops, at the local, state and national level.

- **Urban Church Wellness Initiative: Roadmaps to Health Faith-based Intervention**

- **Dementia Lunch and Learn** clergy partnership with the State Baptist Convention
At the inception of the WAI Regional Milwaukee Office in 2008, the Community Advisory Board (CAB) was formed to be a voice to, and from, the community. This Board serves 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.
Service: Access to Comprehensive Care

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

WAI Regional Milwaukee Office has connected families to health care services through over 500 in-home care visits and 500 memory and health screenings, resulting in at least 175 individuals obtaining an accurate memory diagnosis.

Over 200 families have been connected to social services, ultimately allowing people living with dementia to remain at home—safer, longer.

- 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

Excerpt of Activities

- In-Home Memory Assessments
- 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
Memory Diagnostic Clinic Model

Patient referral

Physicians
Social service agencies
Behavioral health community

Diagnostic testing
Diagnoses
Data collection

Care management
Follow-up services

Family support
Community engagement

Research

Research specialist
Outreach coordinator
Dementia diagnostic team

Community health worker
SW care coordinator
Nurse practitioner

Physician
Nurse practitioner
Medical assistant
Social worker
Community health worker
Service: Access to Comprehensive Care
Reducing barriers that impede access to information and services by building trust, credibility and partnerships

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.

Excerpt of Additional Activities through our Service Pillar

• Dementia Care Service and Resource Connectors
• Connect African American families and others to services that address their health and social needs
• Community-Based Dementia Care and Programming
Research

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

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. Of those, 196 participate from the Milwaukee community; 109 are African-Americans, and 34 Hispanics.

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

Excerpt of Activities
• Cognitive testing every 2 to 4 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
• Biennial information sessions on research findings and new studies for participants and guests throughout Wisconsin

Upcoming 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 2 informational sessions annually focusing on research findings from African American participation in WRAP
Jane Mahoney, MD
Director of WAI and Professor of Medicine
In 2016, Kathleen Smith, Senior Outreach Specialist, conducted interviews with 20 dementia professionals in 61 Wisconsin Counties.

– Many areas of Wisconsin have developed promising practices to enhance their dementia-friendly communities and help build dementia-capable organizations.

– Dementia best practices, resources and information are not easily accessed and shared in all communities around the state.
In 2017, WAI convened stakeholders to discuss this gap and how to address it.

- Alzheimer’s Association Chapters
- Alzheimer’s and Dementia Alliance of Wisconsin
- DCS’s
- State of Wisconsin Office on Aging
- Dementia-friendly community coalitions

This became the founding task force for the Wisconsin Dementia Resource Network
Wisconsin Dementia Resource Network (WDRN)

- A collaboration of statewide partners
- WAI as convener
- Goal: share best practices in community-based programming for people with dementia and their families
- Mission: Enhance the ability of Wisconsin communities to create supportive and inclusive environments for all people living with dementia
Ultimate Goals of the WDRN:

- Increase the number of dementia-friendly communities in WI
- Increase the number and variety of programs that communities offer for individuals with dementia and their families
- Increase the number of dementia-capable organizations, particularly health care organizations, in WI
- Increase linkages between dementia-friendly communities and dementia-capable organizations, particularly health care organizations
WAI as convener for WDRN:

– Investigate and discover best practices in community programs from around the State
– Convene, host, and share innovative best practices through teleconferences and in-person meetings, in collaboration with statewide partners
– Serve as clearinghouse for “how-to guides” so communities can adopt best practices
Developing and Testing New Community Programs

2016 three-year grant from Administration for Community Living to help meet needs in four areas:

– People with dementia who live alone
– Medical concerns of people with moderate to severe dementia
– People with intellectual and developmental disabilities who develop dementia
– Caregivers of people with dementia who have behavioral concerns
Rationale for four target areas:

– Older adults with dementia who live alone often have poor access to services.

– Older adults with moderate to severe dementia may have multiple medical problems related to their dementia and caregivers are often unprepared.

– People with intellectual and developmental disabilities are at very high risk for development of dementia

– Behavioral symptoms associated with AD may increase caregiver burden and lead to early nursing home placement.
### Grant interventions and goals:

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<tr>
<th>Interventions</th>
<th>What we hope to achieve</th>
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| EMS visits to older adults with dementia who live alone                      | ✓ Decreased emergency transports  
✓ Increased connections to community resources                                      |
| Home health training for caregivers to help them prevent and manage medical concerns of loved ones with moderate to severe dementia | ✓ Decreased caregiver burden  
✓ Increased caregiver self-efficacy  
✓ Decreased unplanned medical services (hospital, ED, urgent care)              |
| Training dementia care specialists to help implement DICE with caregivers to manage behavioral concerns of loved ones |                                                                                       |
Wisconsin Alzheimer’s Institute

Advancing research, clinical care, and service for the residents of Wisconsin and beyond
Thank you!

www.wai.wisc.edu