



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



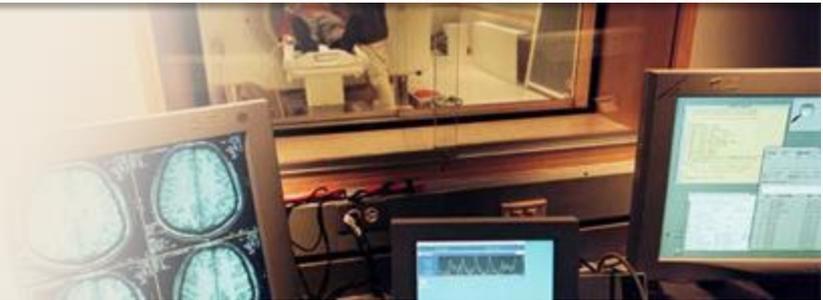
Jane Mahoney, MD
Professor of Medicine
Director, WAI



Cindy Carlsson, MD, MS
Associate Professor of Medicine
Associate Director, WAI



WAI Research



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

*Education, services, research opportunities and resources
for Milwaukee's African-American community*



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



WAI Clinic Network & Clinical Education



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



WAI Public Health



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



WAI Research



Wisconsin Registry for Alzheimer's Prevention (WRAP)

Cindy Carlsson, MD, MS

WAI Associate Director

Associate Professor of Medicine

(on behalf of Sterling Johnson, PhD, WRAP PI)



WAI Research



Wisconsin Registry for Alzheimer's Prevention (WRAP)

- Started by Drs. Mark Sager and Bruce Hermann in 2001
- Adult children of persons with AD, ages 40-65
- Agree to follow-up testing and to participate in clinical, epidemiological and genetic research in AD prevention
- Has evolved into the largest natural history longitudinal cohort of its kind based on family history risk
- Now led by Sterling Johnson, PhD, Professor of Geriatrics at UW-Madison SMPH



WAI Research



WRAP Funding:

National Institute on Aging (NIA) R01 AG27161

Other NIA grants

Holland Research Fund

Helen Bader Foundation

Northwestern Mutual Foundation

Extendicare Foundation

State of Wisconsin





WRAP Goals

Identify AD in its
preclinical phase,
before symptoms develop

Identify **biological,**
health, and **lifestyle**
factors that increase or
decrease risk of AD





What Do We Know About Risk for AD?

Non-Modifiable Risk Factors

- Age:
 - ~10% risk at 65
 - ~40% at 85
- Sex: 2:1 women:men
- *APOE* ϵ 4
 - one copy= 2-3x risk
 - two copies= 6-8x risk
- Parental family history

Modifiable Risk Factors

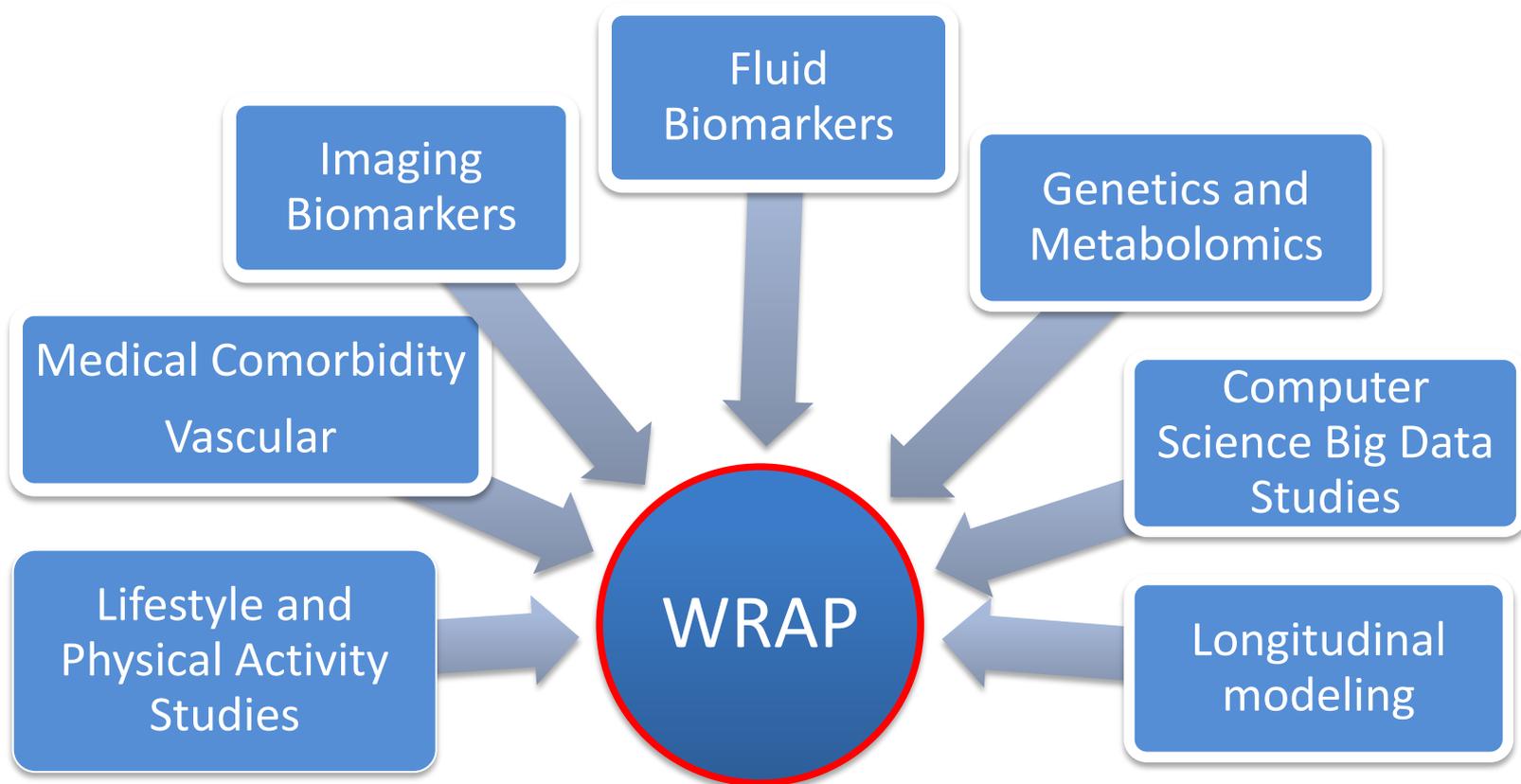
- Exercise*
- Cardiovascular health*
- Diet*
- Sleep*
- Mood*

**effect sizes are overlapping and largely unknown*





Scope of WRAP Research



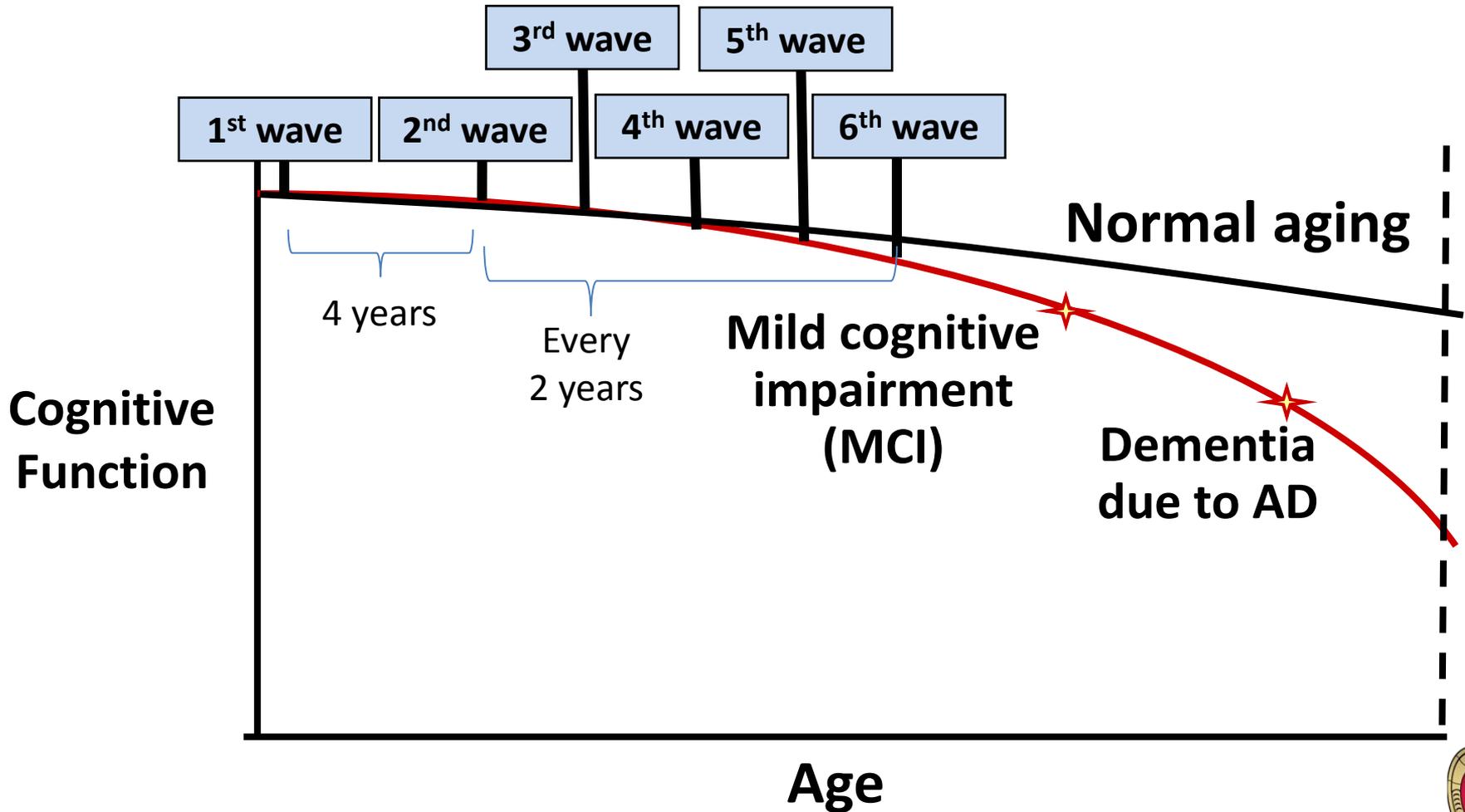


WRAP Participant Characteristics

Sample size	1,550
Age at baseline	54
Age now	65
Avg Years of follow up	10
Sex (% Women)	70%
Parental history of AD %	72%
APOE4+ %	41%
% non-Caucasian	11%
% with diabetes	9%
% with high blood pressure	31%
% with or treated for high cholesterol	50%
% with obesity (BMI > 30)	37%



WAI Research WRAP Design



Start with Assessment of Early Brain Changes

Sperling 2011 criteria for preclinical AD

Stage 0 no pathology

Stage 1 amyloidosis (A+)

Stage 2 Amyloid and neurodegeneration

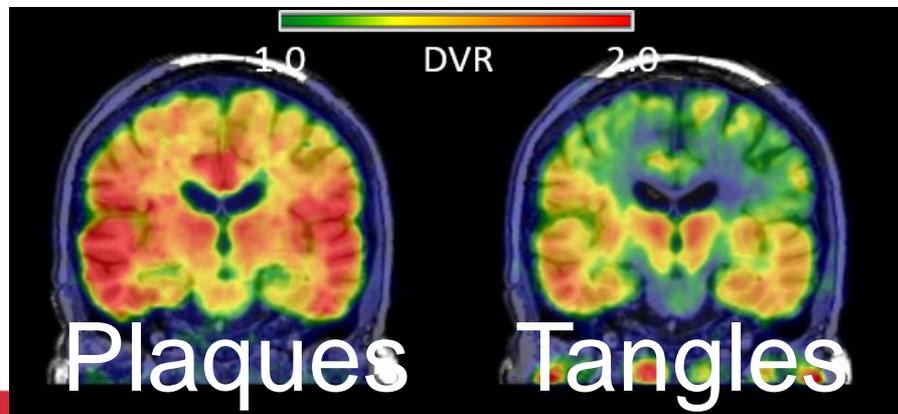
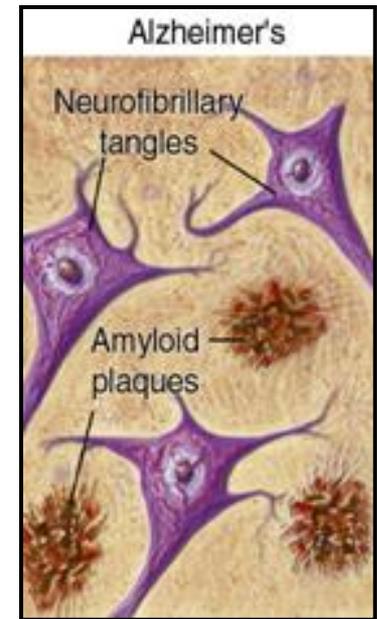
Stage 3 ... + mild cognitive decline

SNAP: suspected non-AD pathology—Neurodegeneration (e.g. tau or atrophy) in absence of amyloid

Dubois 2016 criteria

Asymptomatic at risk: tau (T+) or amyloid (A+) are present

Preclinical AD: tau and amyloid are present



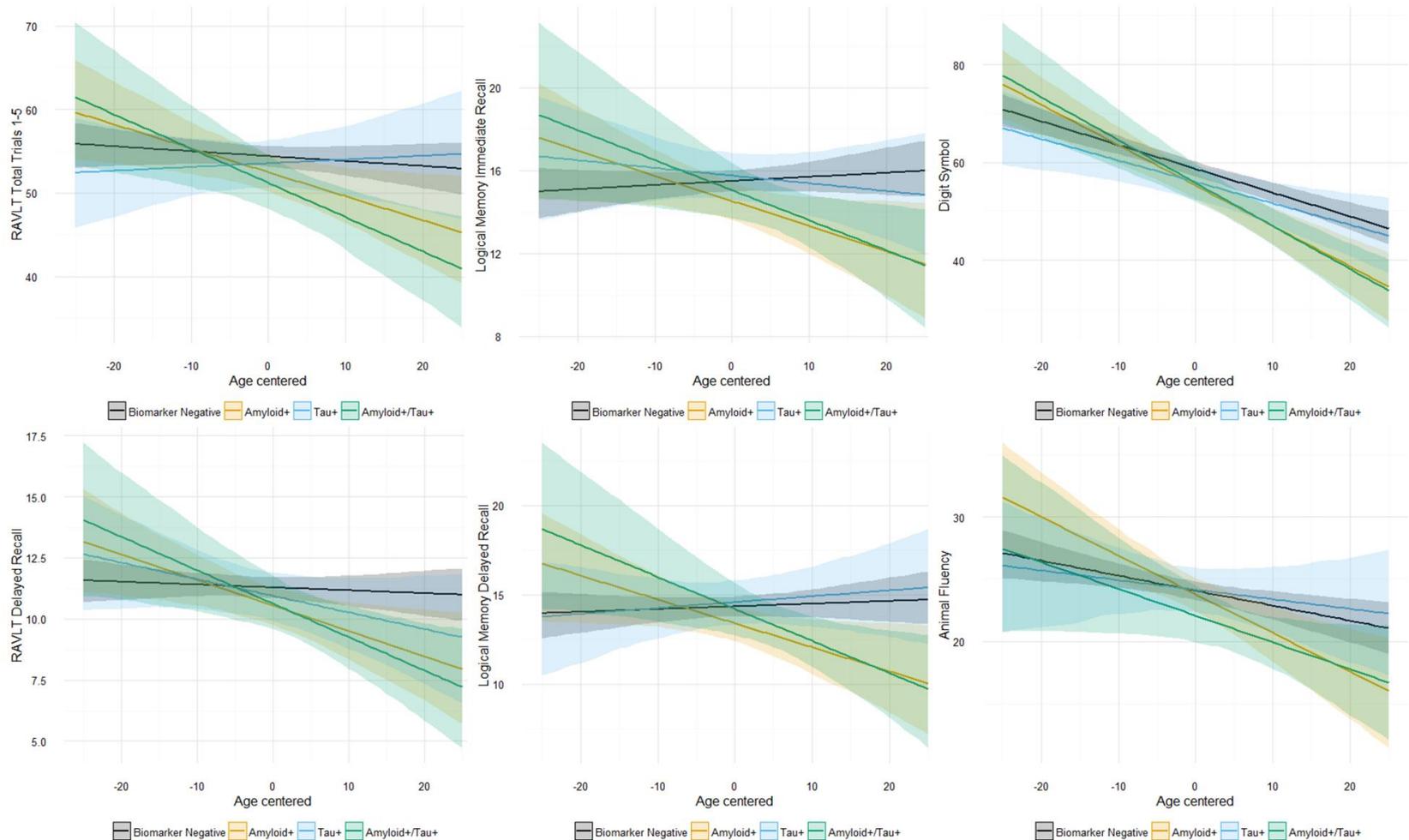
WAI Research WRAP Major Initiatives



- Complete tau and amyloid PET imaging and cerebrospinal fluid (CSF) markers on volunteers
- Increase enrollment in brain donation program
- Identify meaningful cognitive decline that isn't yet MCI using machine learning techniques
- Find health & lifestyle factors that confer risk & resilience
- Increase participation of under-represented groups
- *omics genomics, metabolomics, epi-genetics, risk and resilience genes
- Clinical trial planning



WRAP Participants with Amyloid Changes Are More Likely to Develop Cognitive Decline





Summary

- WRAP is evolving to make biomarker assessment a core feature
 - CSF and/or molecular PET imaging of amyloid and tau
- Brain donation
 - Autopsy to determine what pathology is present in the brain (e.g. AD)
 - Helpful to participants' families to establish what “family history” really means
 - Enables their participation to continue as their brain will be used for decades beyond death





WRAP Future Directions

- Moving rapidly from assessing risk to identifying disease with molecular PET imaging and/or cerebrospinal fluid
- Computational 'Big Data' approaches to identifying subtle decline
- GWAS genetic studies
- Metabolomics
- Health comorbidities
- Increase participation of under-represented groups



WAI Regional Milwaukee Office



Nia Norris, MA

Assistant Director, Regional Milwaukee Office

Stephanie Houston, MBA

Outreach Specialist, Regional Milwaukee Office



WAI Regional Milwaukee Office



Public Health Model



WAI Regional Milwaukee Office



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

Community Outreach

Professional Education

Advocacy

Service

Research



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Regional Milwaukee Office

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.



WAI Regional Milwaukee Office



Motto: *Meet the People Where They Are*

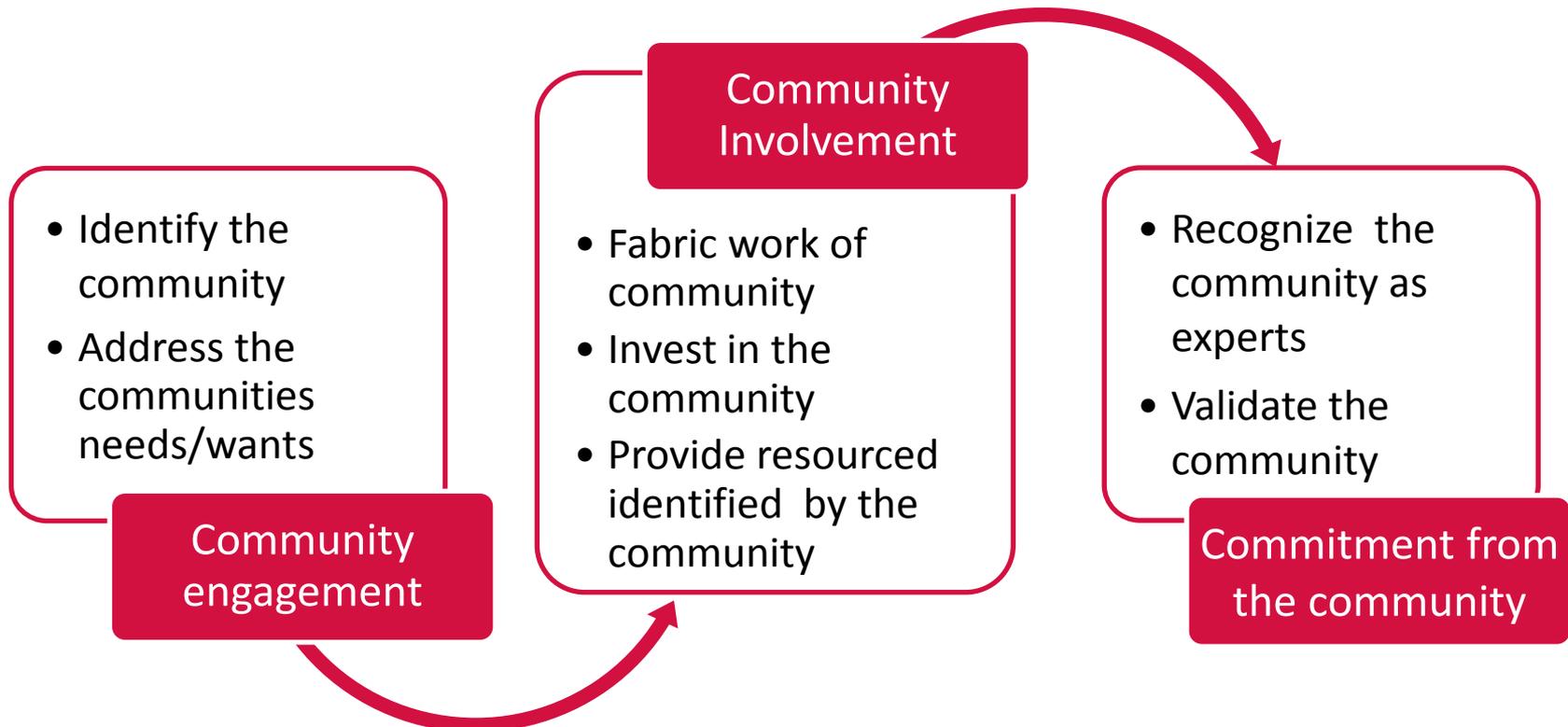
We foster partnerships to deliver culturally-appropriate education, training and outreach programs to providers, those living with dementia, and family caregivers.

- *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



WAI Regional Milwaukee Office



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*



2015 Breaking the Silence
Minority Health Month Event



WAI Regional Milwaukee Office



Advocacy

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.*



WAI Regional Milwaukee Office



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

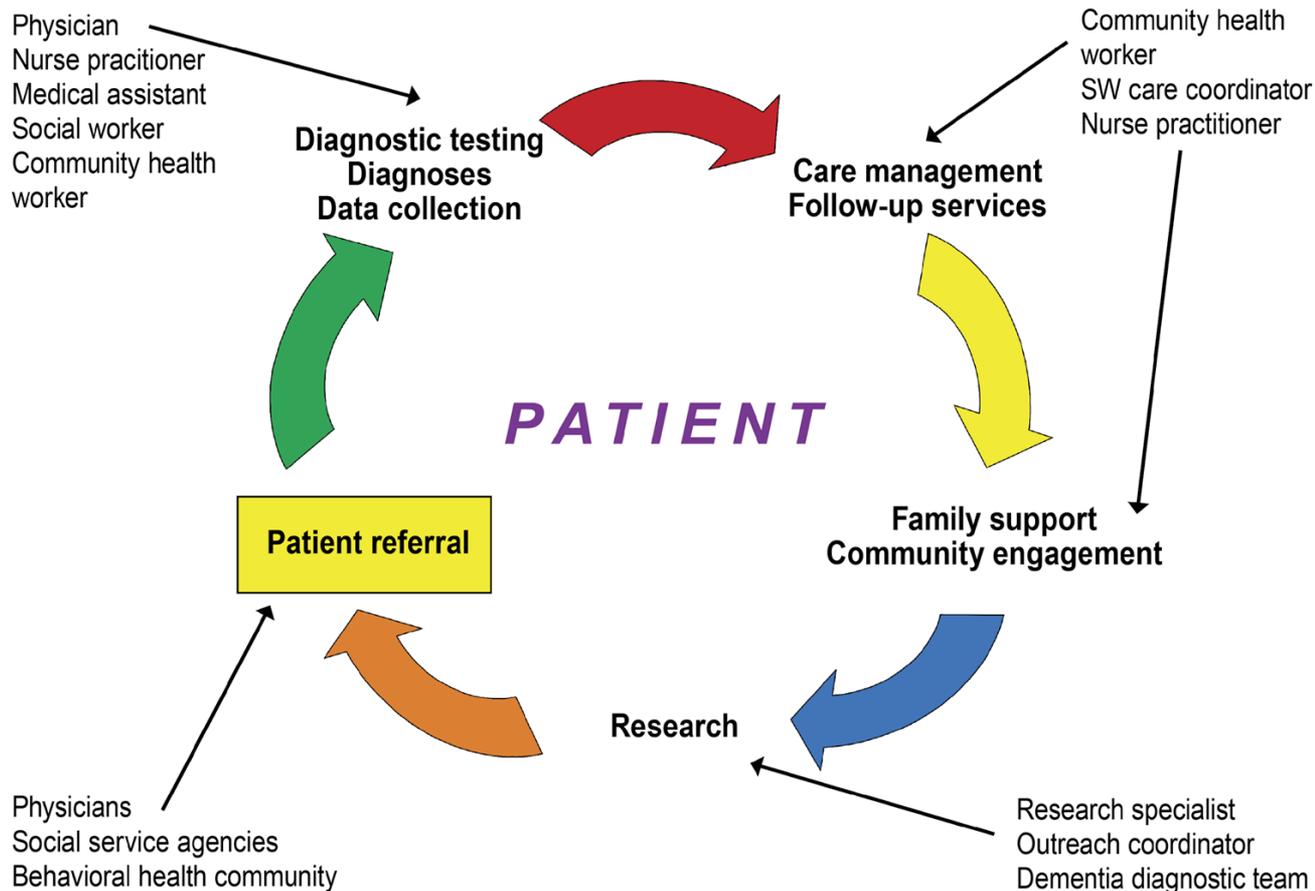
- *In-Home Memory Assessments*
- *Provide information and education of local resources and healthcare delivery systems to help patients and families navigate their dementia journey*
- *Diagnostic Memory Clinic*
- *(Professional partnership between UW/WAI and Milwaukee Health Services Inc.)*
- *Community-Based Dementia Screening and Cognitive Testing*
- *Personalized Care and Treatment Planning*



WAI Regional Milwaukee Office



Memory Diagnostic Clinic Model



WAI Regional Milwaukee Office



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.



Amazing Grace Chorus

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*



WAI Regional Milwaukee Office



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*



WAI Clinic Network & Clinical Education



Cindy Carlsson, MD, MS
WAI Associate Director
Associate Professor of
Medicine



WAI Clinic Network & Clinical Education



Provide care to the people of Wisconsin through state-of-the-art memory clinics

- 50% of people with dementia are undiagnosed
- Persons in rural and ethnic minority communities are diagnosed at later stages of dementia
- Earlier diagnosis improves access to resources and reduces caregiver burden

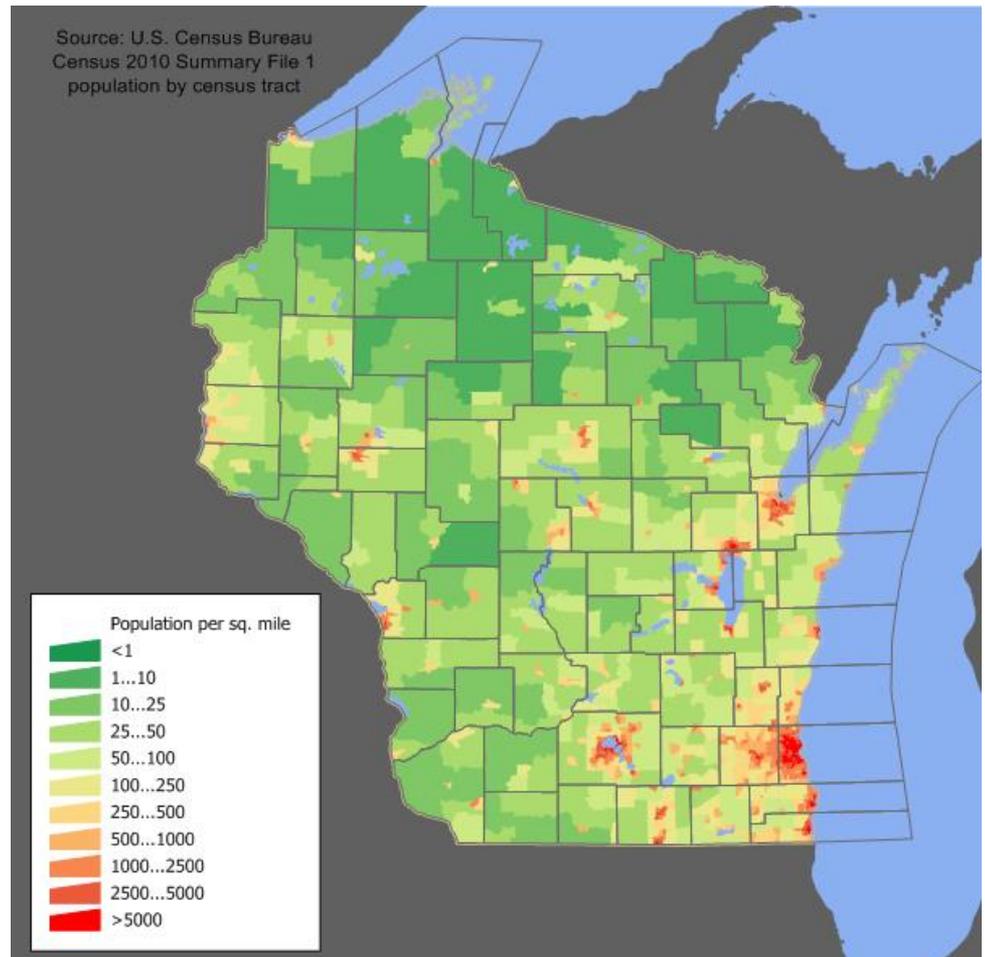


WAI Clinic Network & Clinical Education



Wisconsin Facts

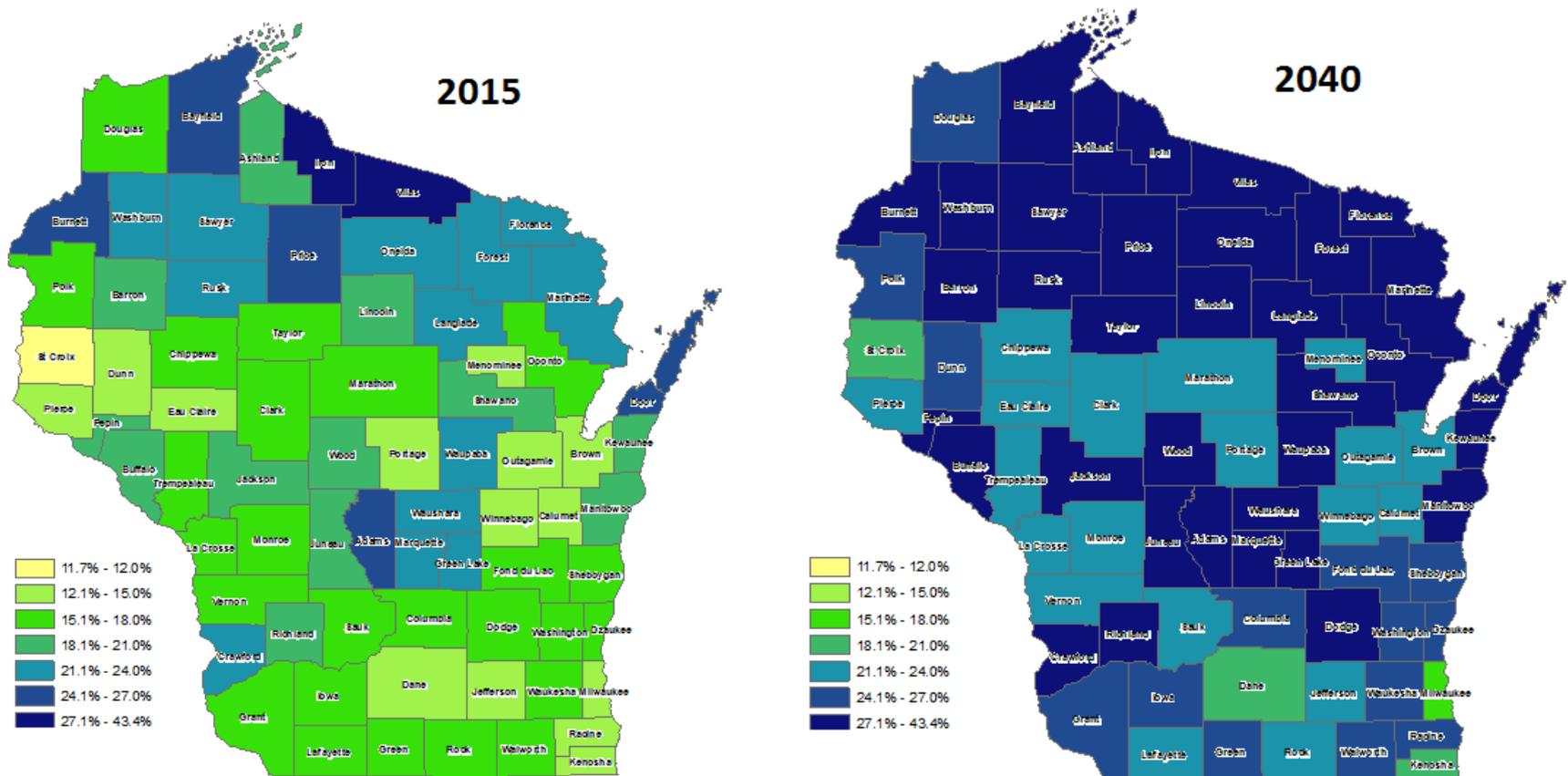
- WI population:
 - 5.7 million people
 - 15% >65 years
 - 110,000 adults >65 years with AD



WAI Clinic Network & Clinical Education



Prevalence of Older Adults in Wisconsin Counties

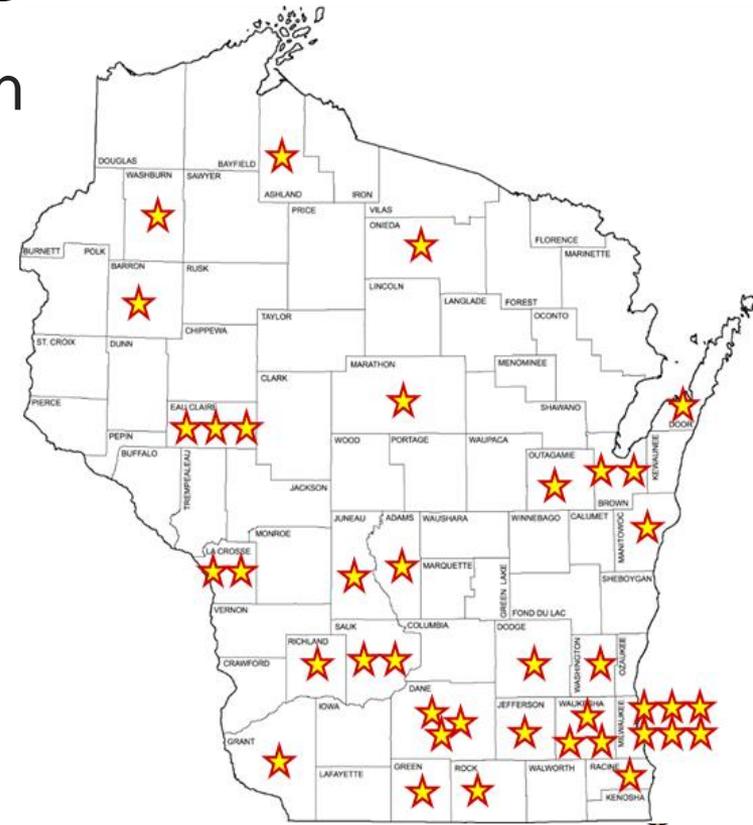


WAI Clinic Network & Clinical Education



Provide care to the people of Wisconsin through state-of-the-art memory clinics

- 32 memory clinics across Wisconsin serving >3000 patients annually
- Clinic teams receive training on high-quality dementia diagnosis and management
- Improved access in rural and underserved communities
- Facilitate access to community resources



WAI Clinic Network & Clinical Education



To become a clinic, teams agreed to:

- Support an interdisciplinary team to conduct medical, cognitive, and psychosocial evaluations
- Be affiliated with a healthcare organization that can provide assistance with scheduling, labs, imaging, referrals, etc.
- Have a relationship with local Alzheimer's support groups
- Undergo training in cognitive assessment and participate in twice annual clinic network meetings
- Use standardized diagnostic criteria for dementia and related cognitive disorders
- Assess patient mood, functional status and caregiver burden
- Collect a 1-page de-identified data information form



WAI Clinic Network & Clinical Education



2016 WAI Clinic Survey assessed:

- Clinic structures and models
- Disciplines included in each interdisciplinary team
- Frequency of clinics, average waiting times
- Types of cognitive batteries, mood and functional questionnaires, caregiver assessments used
- Relationships with local community Alzheimer's support networks and resources
- Unique aspects of each clinic
- Barriers to clinic function and sustainability
- Reasons for affiliation with WAI Dementia Diagnostic Clinic Network



WAI Clinic Network & Clinical Education

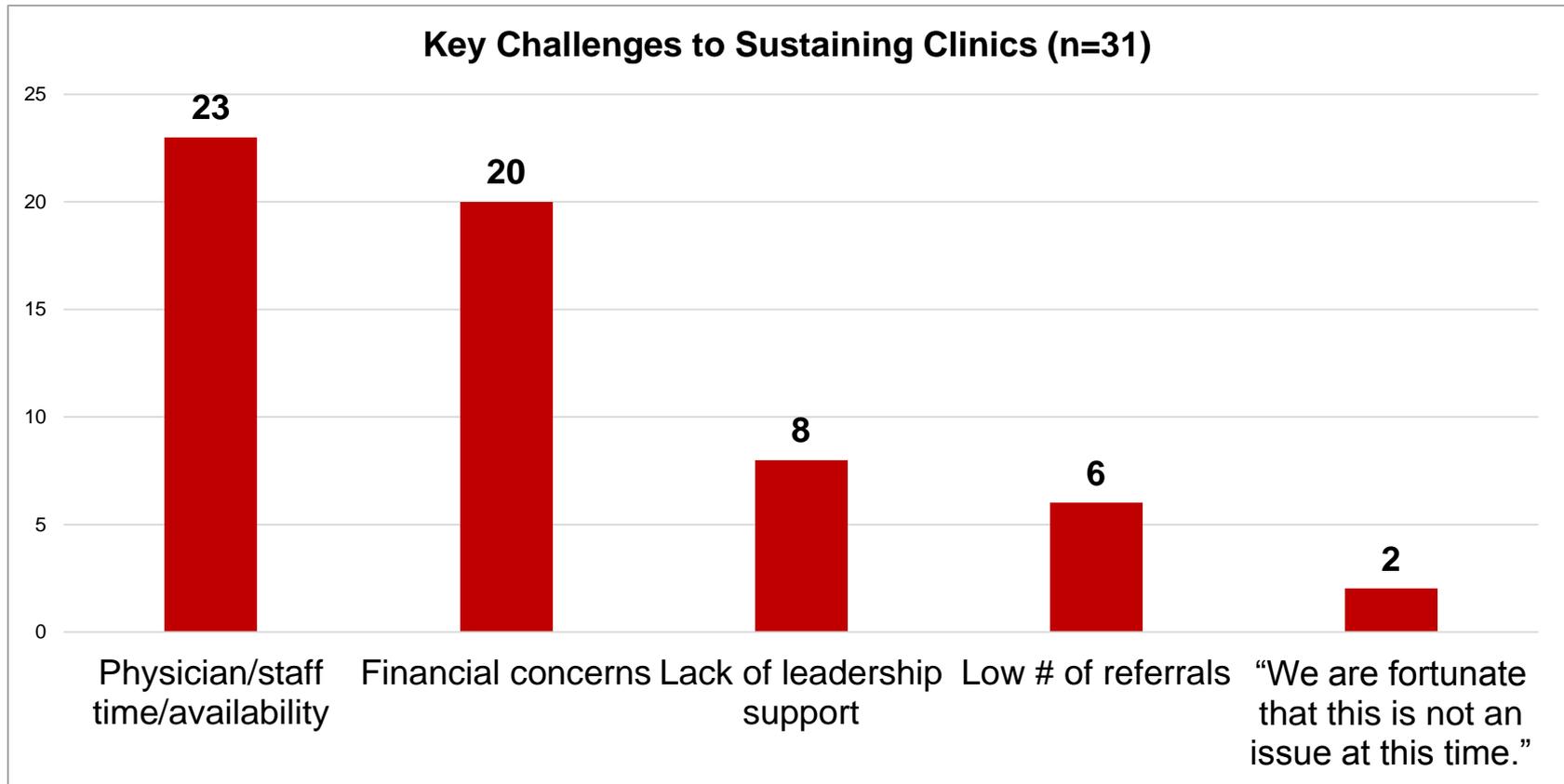


2016 WAI Clinic Survey showed:

- Great variability in clinic operational procedures
- Many sites struggled to maintain an interdisciplinary team
- Clinic meeting frequency ranged from daily to once a month
- The types of cognitive batteries, mood and functional questionnaires, caregiver assessments had drifted over time
- Relationships with local community Alzheimer's support networks and resources were variable
- Clinics had developed unique areas of focus
- Clinics partnered with WAI because they valued opportunities to network and learn from other dementia clinicians and teams



Key Challenges in Sustaining Clinics



WAI Clinic Network & Clinical Education



Clinical Education:

- Annual AD Update Conference
- Twice annual WAI Dementia Diagnostic Clinic Network meetings
- Partnering students with patients with dementia (“New Friends” program)
- Medical student summer externship
- Dementia care specialist training sessions
- Additional lectures and hands-on experience to learners at different stages of training



WAI Clinic Network & Clinical Education



Future Directions:

- Evaluate clinic team member roles to optimize flexibility while maintaining quality of care
- Explore options for regional resources for neuropsychology, geriatric psychiatry, and other limited specialties using telehealth, video-assisted clinics, e-consults, etc.
- Investigate which team structures and clinic models may lead to greatest sustainability
- Provide teams with practical guidebook built upon original WAI guidelines



WAI Clinic Network & Clinical Education



Future Directions:

- Utilize data registry information forms to evaluate quality of care and provide feedback to care teams
- Expand the number of WAI Dementia Diagnostic Clinics to all counties in Wisconsin
- Partner with diverse communities to develop clinics meeting their community members' needs
- Work with teams from other states to aid their developing statewide dementia clinic networks
- Expand use of these clinics as training resources for healthcare professionals and students
- Increase partnership with other student training programs



WAI Public Health



Jane Mahoney, MD
Director of WAI and
Professor of Medicine



WAI Public Health



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.



WAI Public Health



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.



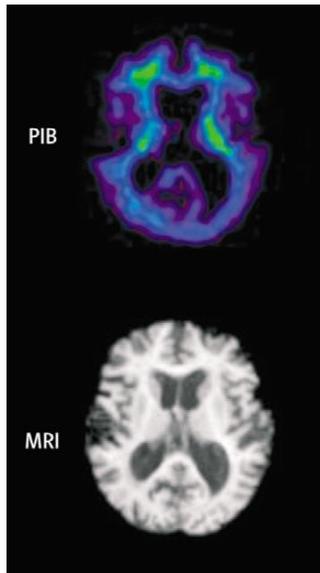


Grant interventions and goals:

Interventions	What we hope to achieve
EMS visits to older adults with dementia who live alone	<ul style="list-style-type: none">✓ 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 Training dementia care specialists to help implement DICE with caregivers to manage behavioral concerns of loved ones	<ul style="list-style-type: none">✓ Decreased caregiver burden✓ Increased caregiver self-efficacy✓ Decreased unplanned medical services (hospital, ED, urgent care)



Wisconsin Alzheimer's Institute



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



Thank you!
www.wai.wisc.edu

