



# **Applications of Health Equity in Dementia Caregiving: Policy and Practice**

***May 15<sup>th</sup>, 2024***



# Welcome from...



## **Lauren Parker, PhD, MPH**

Associate Scientist, Department of Health, Behavior and Society

Johns Hopkins Bloomberg School of Public Health,

Member, PHCOE-DC Health Equity Task Force,

Her research examines how to address the cultural needs of caregivers for people with dementia.



# The BOLD Public Health Center of Excellence on Dementia Caregiving (PHCOE-DC)

Designed to support state, tribal and local public health agencies nationwide in developing their dementia caregiving-focused programs and initiatives, by...

- ✓ Improving access to evidence-based programs and best practices.
- ✓ Facilitating connections and collaboration among public health agencies and a wide range of service organizations.
- ✓ Providing technical assistance for identifying, selecting implementing effective public health interventions and strategies.

Visit our  
website!





# Health Equity Task Force (HETF)

The HETF team works across the Center to ensure health equity is centered in our programming, resources, and leadership.

- ✓ Helps the Center and its partners identify, develop and disseminate culturally tailored and caregiver-centered materials, tools and support to public health interest groups,
- ✓ Provides feedback on the Center's engagement strategies to ensure the inclusion of diverse and minority-serving interest groups, etc.



Robbin Frazier



Lauren Parker, PhD, MPH



Ishan Williams, PhD



Fayron Epps, PhD, RN, FAAN



# We value your feedback!

**\*Please give us your feedback before you leave today's meeting!\***

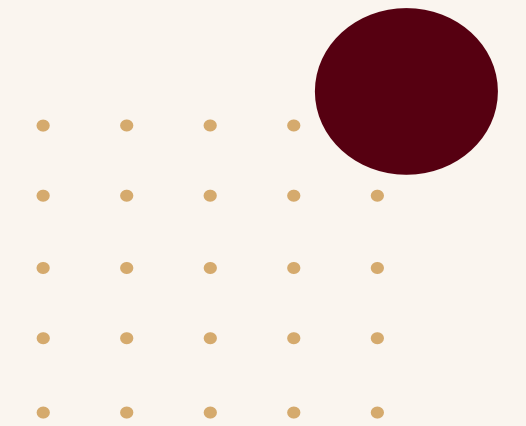
Scan the QR code to open this survey on your phone or click the link in the chat.



# Poll Question

In what capacity are you attending this event?

- BOLD Public Health Agency
- Non-BOLD Public Health Agency
- Community organization/service provider
- Person living with dementia
- Interested caregiver and/or community member
- Care/clinical professional
- Other



# Welcome panelists!



## **Paris "AJ" Adkins-Jackson, PhD, MPH**

Assistant Professor,  
Departments of Epidemiology and Sociomedical Sciences,  
Mailman School of Public Health at Columbia University  
[pa2629@cumc.columbia.edu](mailto:pa2629@cumc.columbia.edu)



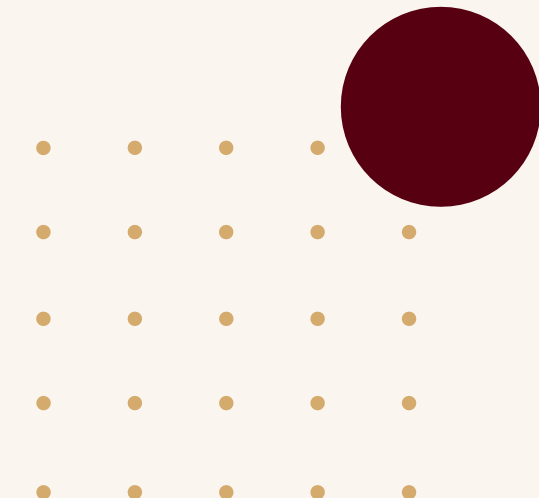
## **Rita Choula, MA**

Senior Director of Caregiving,  
AARP Public Policy Institute  
[rhoula@aarp.org](mailto:rhoula@aarp.org)



## **Edie Yau, MA**

Senior Director,  
Diversity, Equity, Inclusion, and Engagement,  
Alzheimer's Association  
[eyau@alz.org](mailto:eyau@alz.org)







# Application of Health Equity in Dementia Caregiving: Policy and Practice

Rita B. Choula  
AARP Public Policy Institute

May 15, 2024



## Overview

1. Health Equity and Policies Supporting Family Caregivers
2. Key Components to Developing Inclusive Policies
3. Strategies for Engaging Community in Policy Development
4. Promising Policy and Practice Supporting Family Caregivers

**RESEARCH**



**POLICY**



**PRACTICE**

# Health Equity and Policies Supporting Family Caregivers

- Ensuring policies support all families
- Recognizes that certain communities, face barriers in accessing quality healthcare and caregiver supports





# Key Components to Developing Inclusive Policies

- Needs Assessment
- Intentional Inclusive Policy Design
- Allocation of Resources
- Support for Caregivers



# Key Components to Developing Inclusive Policies

- Building Legislative and Regulatory Frameworks
- Evaluation of Utilization



# Strategies for Engaging Community in Policy Development

- Partnerships with Community-Based Caregiving Organizations
- Caregiver Advisory Councils/Workgroups
- Surveys and Focus Groups
- Town Hall Meetings and Workshops
- Utilizing Social Media



# Promising Policy and Practice Supporting Caregivers

## Federal Level

- National Strategy to Support Family Caregivers
- Guiding an Improved Dementia Experience (GUIDE) Model
- Veterans Affairs: Expanded supports for caregivers of veterans in Program of Comprehensive Assistance for Family Caregiver (PCAFC)
- Older Americans Act of 1965 (OAA)
- Lifespan Respite Care Program
- Volunteer Care Corps

# Promising Policy and Practice Supporting Caregivers

## State Level

- Caregiver Advise, Record, and Enable Act (CARE Act)
- Family Caregiver Tax Credits & Grant Programs
- Paid Family Leave laws
- Paid Sick Leave laws



# ***Creating Equitable Supports for Family Caregivers who Face the Cost of Care***

- **Opportunity**
- **Financial**
- **Health and Well-Being**







**X: @rchoula**

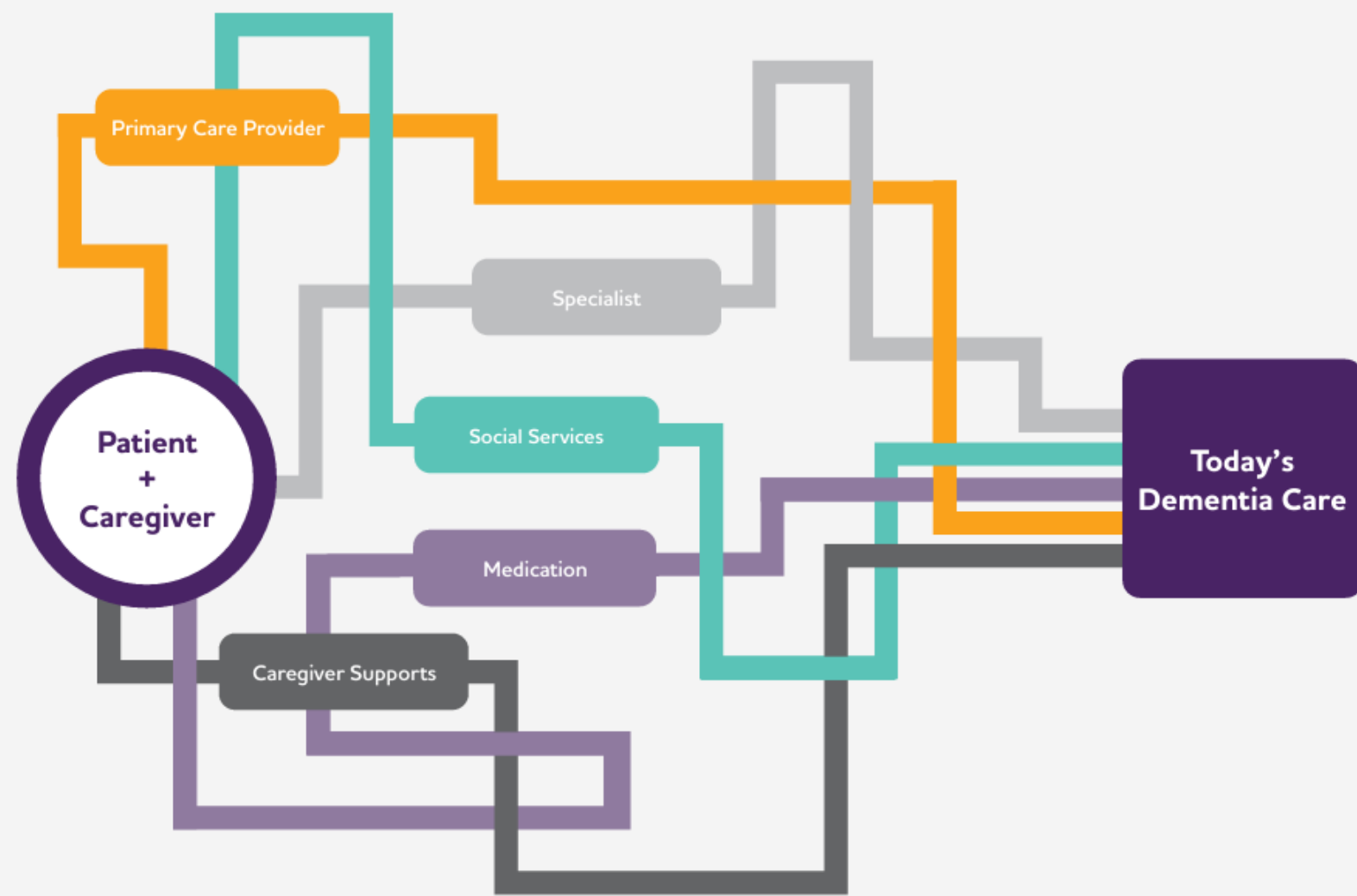
**THANK YOU!**

# Health Equity in Dementia Programs

Edie Yau

Senior Director, DEI Engagement

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## What is GUIDE?<sup>986</sup>

The Guiding an Improved Dementia Experience (GUIDE) Model is an eight-year pilot program in dementia care management designed to help dementia patients and caregivers better navigate health care and social support systems to improve dementia care.

Three primary aims of GUIDE are to:

- Improve quality of life for people living with dementia.
- Reduce strain on their unpaid caregivers.
- Enable people living with dementia to remain in their homes and communities.



# Special Report

## Mapping a Better Future for Dementia Care Navigation

- Conducted two nationwide surveys of U.S. dementia caregivers (1,500+) and health care workers (1,200+) most likely to provide care navigation services, largely nurses, social/community health workers.
- Survey of dementia CGs included responses from Asian, Black, Hispanic, Native and White Americans.
- Surveys examined several issues, including:
  - ✓ CGs/HCWs experience, exposure and attitudes on dementia care navigation (DCN).
  - ✓ DCN services and supports provided/needed.
  - ✓ Perceived benefits of DCN for both people living with dementia and their caregivers.
  - ✓ Barriers to dementia care navigation.

# Key Takeaways: Dementia Caregiver Survey

Dementia caregivers want and need help navigating the current health care system. **70% say care coordination is stressful.**

**Cost of care** and **care coordination** are top stressors

**97%** – say **having navigation support would be helpful.**

**85%** – say having access to a care navigator would influence their choice of provider.

**Special Report**  
Mapping a Better Future for  
Dementia Care Navigation

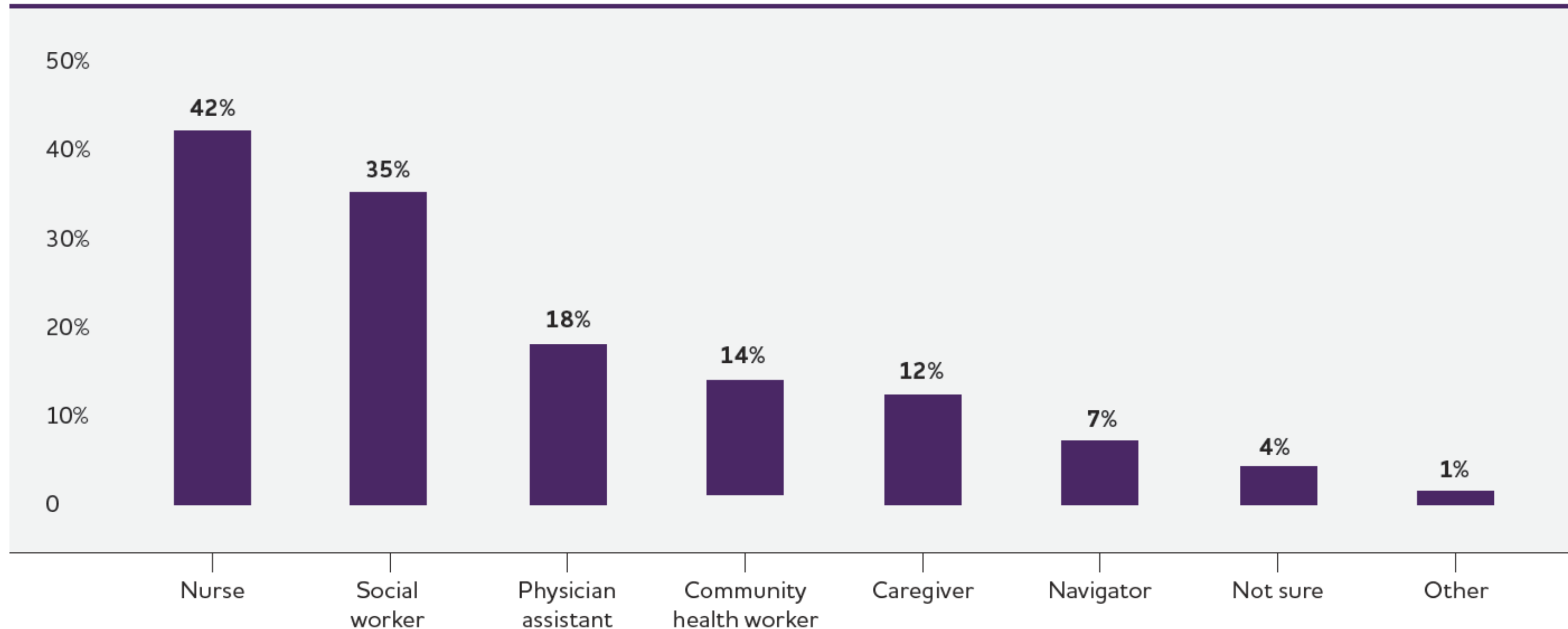
# Key Takeaways: Health Care Worker Survey

- **60%** of workers surveyed say the current health care system is **not effectively helping people living with dementia** and their caregivers navigate dementia care.
- Nearly half of these health care workers (**46%**) say their employers' practices and hospitals do not have a clearly defined process **for care coordination and clinical pathways** for people with MCI, Alzheimer's disease or related dementias.
- While many of these workers are helping dementia caregivers address current challenges -- **75%** of health care workers assisting dementia caregivers say they **have no formal dementia care training**.



# Health care workers most likely to provide navigator-type support and services

Navigator's Professional Role

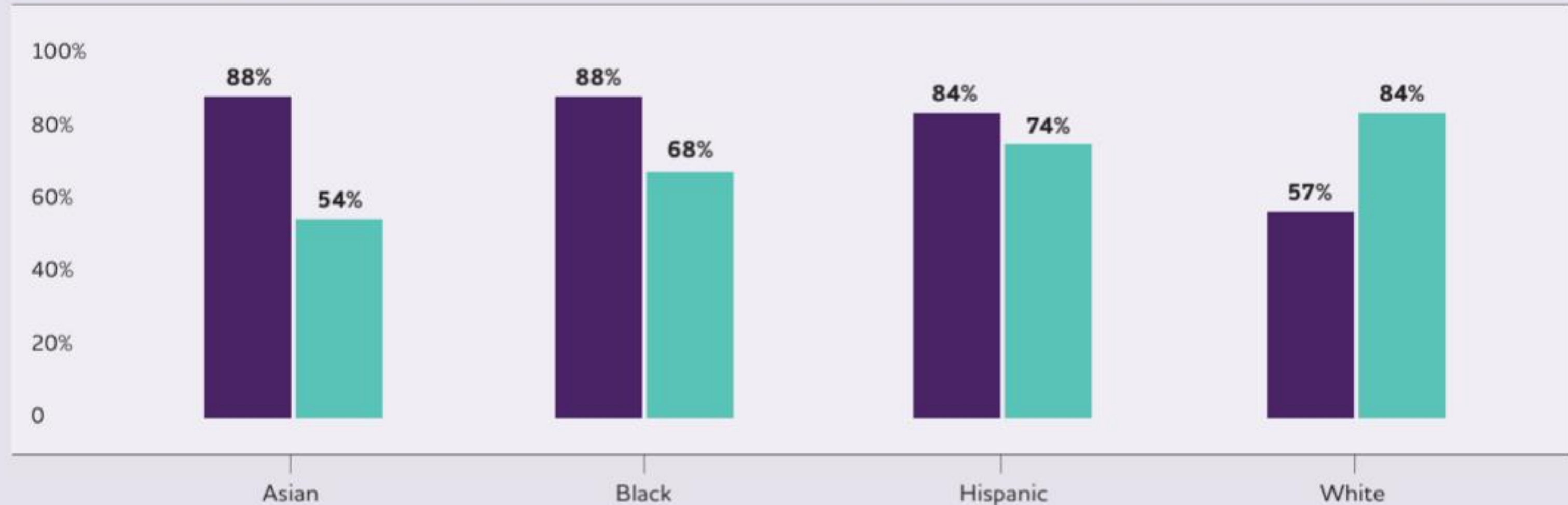


# Cultural Competency is Fundamental for Dementia Care Navigation

Figure 22

Access to Care Navigators With Cultural Competency by Race/Ethnicity of Care Recipient



- Important for care navigator to understand the ethnic or racial background of the person being cared for
- Provider of navigator-type service rated "good" or "excellent" on understanding the ethnic or racial background of the person being cared for



<https://www.alz.org/alzheimers-dementia/facts-figures>

# Most Valuable Services in Supporting Dementia Care for Patients and Their Families

 Seen as especially important by medical professionals

|   |   |
|---|---|
| Referrals to community support services and resources             | 68%   |
| Training on how to care for someone with dementia                 | 63%   |
| Help managing behavioral symptoms                                 | 62%   |
| Helping with emotional and cultural support                       | 59%   |
| Coordinating care and communication between different specialists | 59%   |
| Help finding services to take a temporary break from caregiving   | 57%   |
| Help understanding the health care system                         | 57%   |
| Screening for safety needs  |  54% |
| Help understanding mild cognitive impairment or dementia          | 50%   |
| Help monitoring medications                                       |  50% |



# Dementia Care Navigation Service

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For more information please  
visit [rippicare.com/alz](https://rippicare.com/alz) or  
email [dcns@alz.org](mailto:dcns@alz.org).



**ALZHEIMER'S ASSOCIATION**

# ALZHEIMER'S AND DEMENTIA CONVERSATIONS

Addressing Alzheimer's in Tribal Communities

Presented by the Alzheimer's Association®

## Addressing Alzheimer's in Indian Communities

Tuesday, November 15 | 2 p.m. MST | 3 p.m. PST

The Alzheimer's Association in partnership with Indian Health Service will discuss progress in addressing Alzheimer's disease and dementia in tribal communities.

» Learn about specific tribal dementia programs in development as well as pilot initiatives underway.

Wednesday, November 8, 2023  
4 p.m. ET | 3 p.m. CT

Register today at [bit.ly/3PU6lvW](https://bit.ly/3PU6lvW)

Hosted in partnership with:



# DEI National Partners

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NAHN  
National Association  
of Hispanic Nurses



NHCOA  
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CENTER ON AGING



# GARRETT DAVIS' **Unforgettable**

Presented by



## New cities announced in 2024 for Unforgettable!

Since the launch of Unforgettable in July 2022, the Association has reached **10,000 new constituents**, made 700,000 media impressions, and worked with **150 local and national partners**.



## *Unforgettable* 2024 Tour

- ★ Miami, FL
- ★ St. Louis, MO
- ★ Indianapolis, IN
- ★ Oakland, CA
- ★ Detroit, MI
- ★ Cleveland, OH
- ★ Pittsburgh, PA
- ★ Milwaukee, WI
- ★ Baltimore, MD
- ★ Atlanta, GA



# Road Map Approach

- Conversation starter
- Prompt local planning
- Public health strategies



Road Map for Indian Country



# Resources and Support

- Helpline, available around the clock, 365 days a year
- Education Programs
- Support Groups
- Care Consultations
- Early Stage Programs



24/7 Helpline

**800.272.3900**

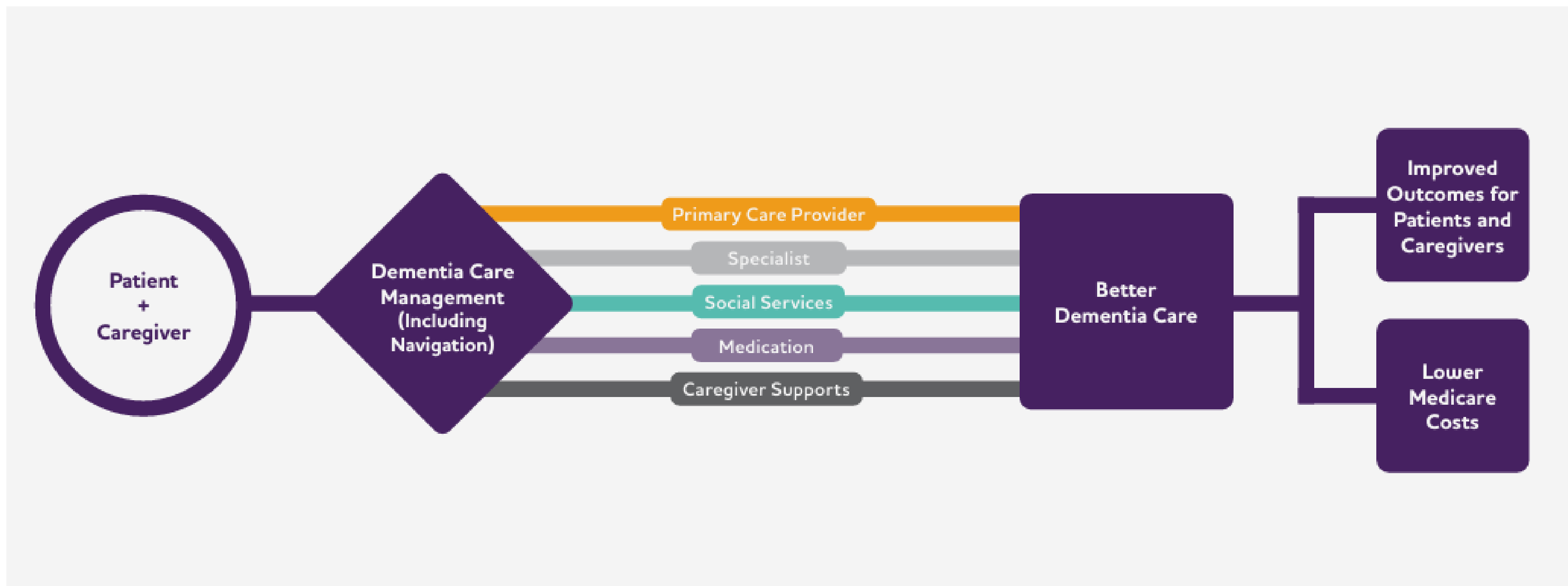
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Live Chat



# Future State of Dementia Care



# Resources

- <https://www.alz.org/alzheimers-dementia/facts-figures>
- [Special Report: Mapping a Better Future for Dementia Care Navigation](#)
- Dementia Care Navigation Service:  
visit [rippicare.com/alz](http://rippicare.com/alz) or email [dcns@alz.org](mailto:dcns@alz.org)
- [alz.org](http://alz.org)

# Q&A

Please, submit your questions in the Q&A Zoom feature!





# Connect with us!

Visit us online at <https://bolddementiacaregiving.org> to....

- ✓ Find today's slides and recording.
- ✓ Request Technical Assistance to support your public health work in dementia caregiving.
- ✓ Access resources and materials.
- ✓ Stay up to date with PHCOE-DC activities.

Follow us on X  @PHCOE\_DC



# Thank you for joining us today!

Please take a moment to complete a brief survey. Scan the QR code or click the link in the chat.

We appreciate your feedback!

