BOLD PUBLIC HEALTH CENTER OF EXCELLENCE ON DEMENTIA CAREGIVING

# Using Crowdsourcing to Support Dementia Caregivers: *Opportunities for Public Health*

***March 18th, 2024***

# Welcome from...

## Maya Koffski, B.S.

***Center Support,***

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

Center for Healthy Aging and Innovation (CHAI)

University of Minnesota

# Land acknowledgement

*The University of Minnesota Twin Cities is located on traditional, ancestral, and contemporary lands of Indigenous people. We acknowledge with gratitude the Land itself and the People. We take to heart and commit through action to learn and honor the traditional cultural Dakota Values: Courage, Wisdom, Respect and Generosity.*

# 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…

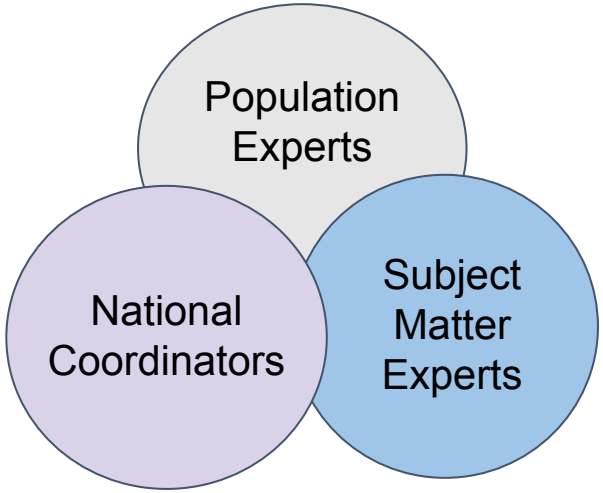
- Improving access to evidence-based programs and best practices.
- Facilitating connections and collaboration among public health agencies and a wide range of service organizations.
- Providing technical assistance for identifying, selecting implementing effective public health interventions and strategies.

Visit our website!

# HBI Collaborative

*Multi-component approach to fully integrate dementia, cognitive health and caregiving into public health practice*

## *HBI Collaborative*




## *Find us online*

- About the HBI Collaborative
- Participating Members
- Contact Information

**hbicollaborative.org**

# We value your feedback!

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

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

# Reminders for the Presentation Session

- **Submit your questions for the speakers into the Q&A feature.**
- Please raise your hand if you wish to speak and **only unmute if you are prompted.**
- Use the **CHAT to share comments, resources, links, and ideas.**
- Feel free to use your reaction buttons!
- The recording, slides and resources will be shared after the event.
- **Please complete the survey at the end of this event** (linked in chat). We greatly appreciate your feedback!

# 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

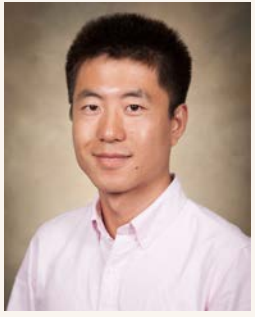
# Welcome our presenters!

## Dr. Nicole Ruggiano, PhD

Professor and Associate Dean of Research, School of Social Work, University of Alabama,
Affiliated Scientist, University of Alabama-Birmingham Alzheimer's Disease Research Center Lead Researcher, Alabama Caregiver Connect Initiative
Email: nruggiano@ua.edu

## Dr. Monica Anderson, PhD

Associate Professor, Department of Computer Science, University of Alabama-Tuscaloosa
Co-Director, Distributed Research Experience for Undergraduates Member of Board of Directors, Computing Research Association
Email: Anderson@cs.ua.edu



## Dr. Zhe Jiang, PhD

Assistant Professor, Department of Computer & Information Science & Engineering, University of Florida
Email: zhe.jiang@ufl.edu

# Using Crowdsourcing to Support Dementia Caregivers - Opportunities for Public Health

**Dr. Nicole Ruggiano**
Professor & Associate Dean of Research
School of Social Work
University of Alabama

**Dr. Monica Anderson Herzog**
Associate Professor
College of Engineering
University of Alabama

**Dr. Zhe Jiang**
Assistant Professor
Herbert Wertheim College of Engineering
University of Florida

# Funding Acknowledgement

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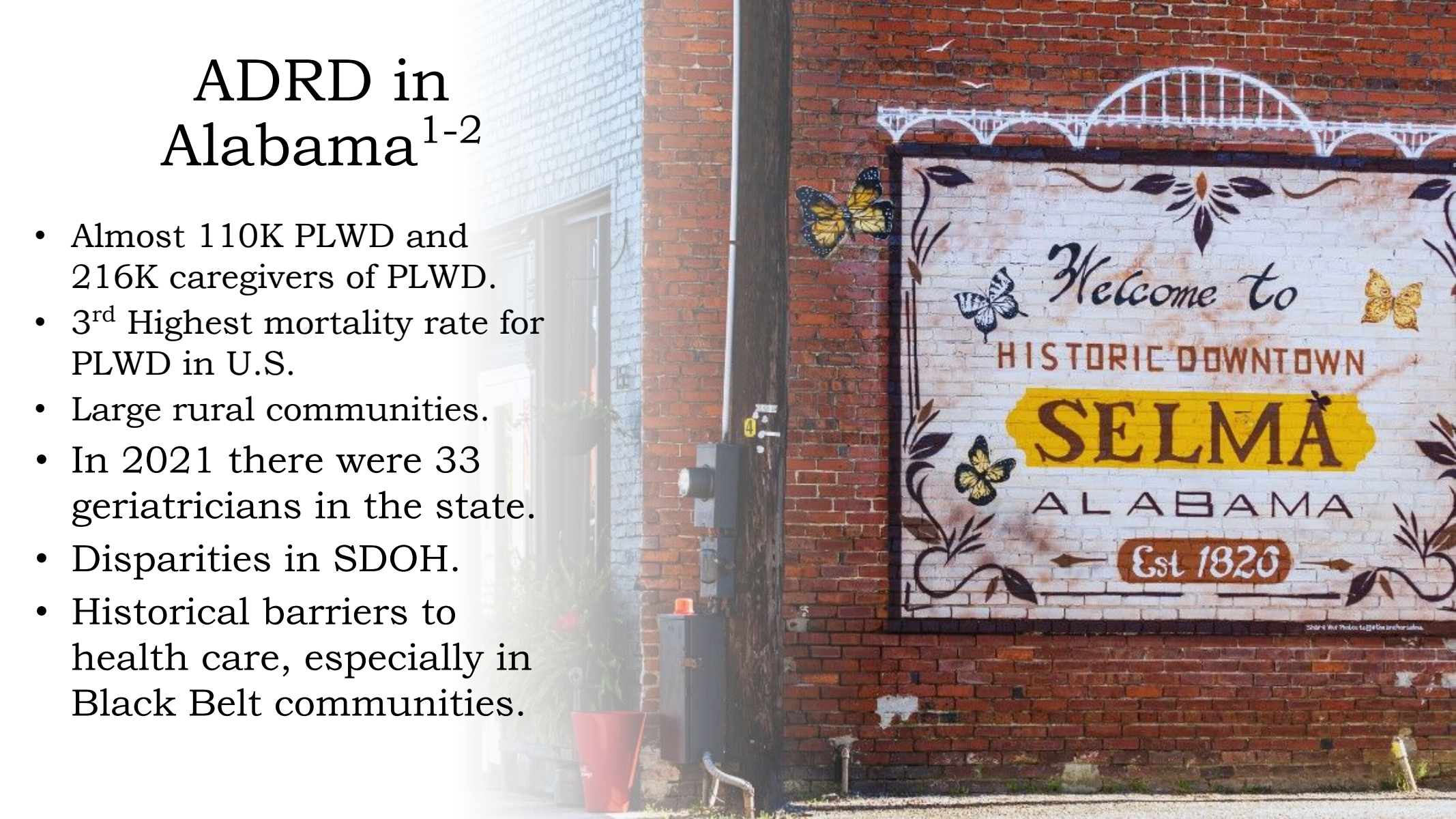
# ADRD in Alabama[1-2]

- Almost 110K PLWD and 216K caregivers of PLWD.
- 3rd Highest mortality rate for PLWD in U.S.
- Large rural communities.
- In 2021 there were 33 geriatricians in the state.
- Disparities in SDOH.
- Historical barriers to health care, especially in Black Belt communities.



# Caregiver-Reported Challenges[3]

- Lack of information about resources.
- Primary care providers do not refer for non-medical support.
- Lack of support systems.
- Service challenges in rural communities.
- Caregivers are using the internet for information seeking, though tech literacy varies, and search results can be overwhelming.[6]

# Provider-Reported Challenges[3]

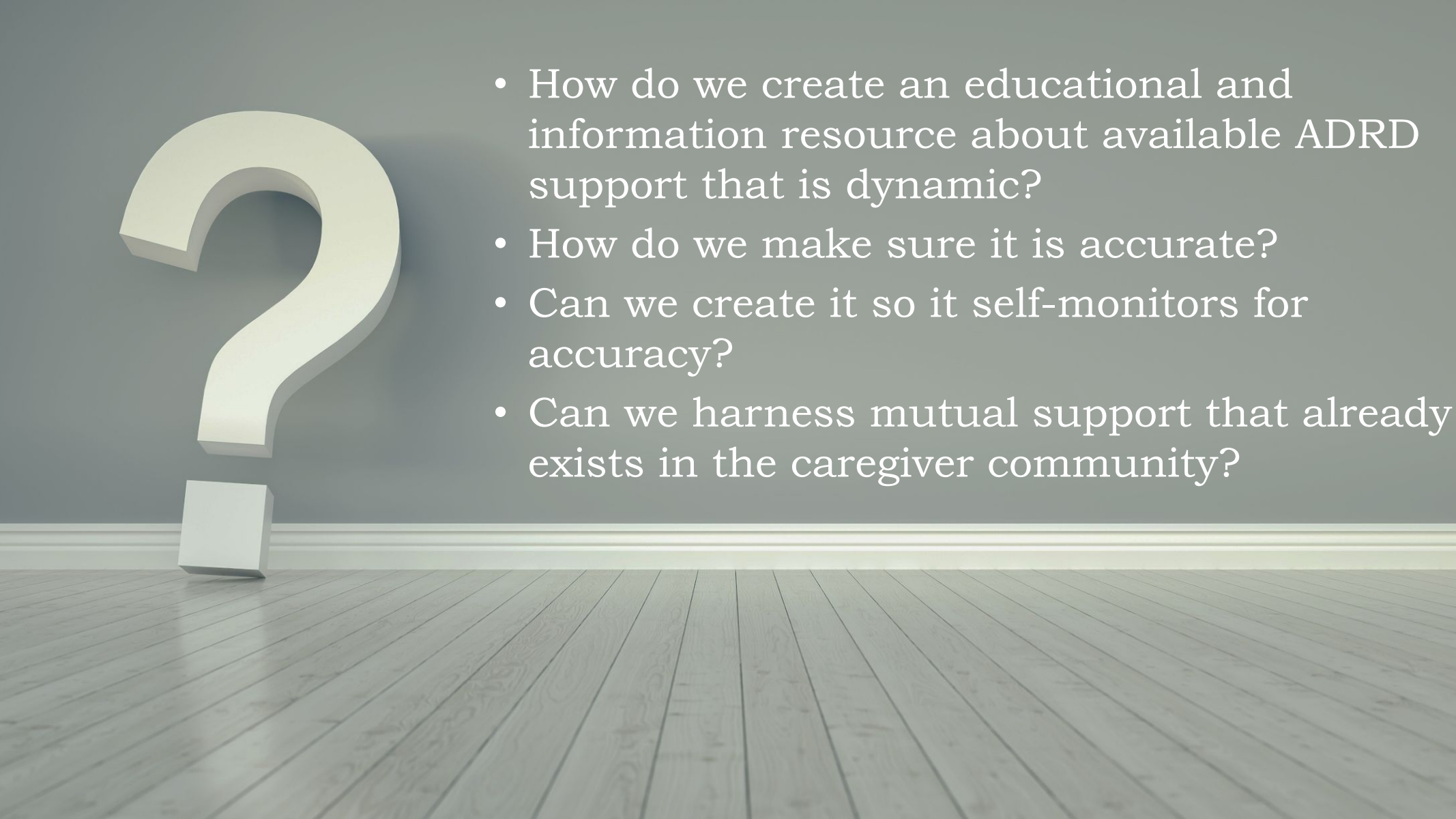
- Lack of awareness about available support services.
- Information is fragmented
- Challenges with Existing Resource lists and directories:
  - They are incomplete.
  - They easily become outdated.
  - They typically do not include less formal sources of support from churches and other organizations.

# John’s Case

John is an older African American man in Tuskegee who cares for his wife with advanced dementia. John feels isolated and asks their primary care doctor if there are local providers who can stay home with his wife so he can attend church services, but their physician does not know what is available.

# Anne’s Case

Anne’s father has moderate dementia and she recently moved to Birmingham to care for him. Anne is interested in finding a local adult day center for her father while she is at work but isn’t sure what is available. A Google search produces over 12 million results with all different types of daycare centers listed. Anne becomes overwhelmed and puts off selecting a center.



- How do we create an educational and information resource about available ADRD support that is dynamic?
- How do we make sure it is accurate?
- Can we create it so it self-monitors for accuracy?
- Can we harness mutual support that already exists in the caregiver community?

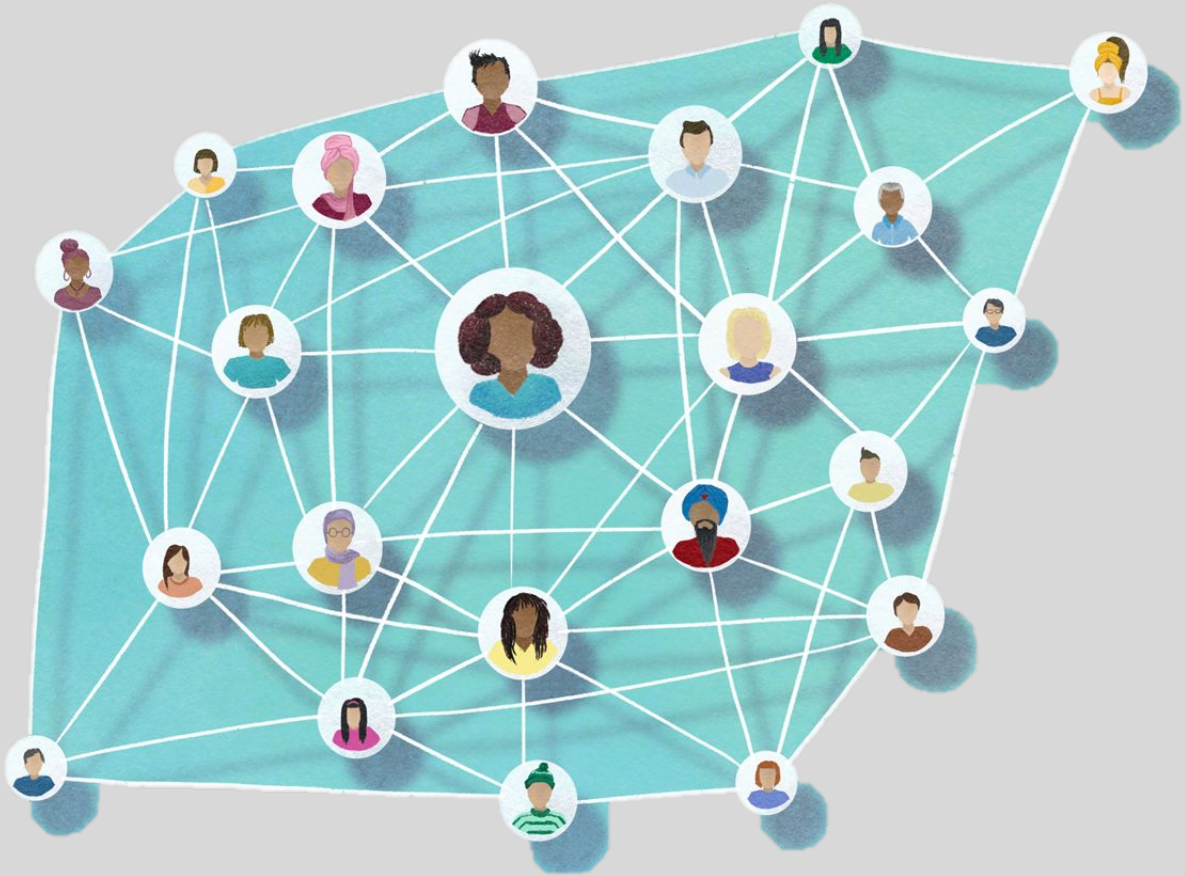
# THE POTENTIAL FOR A COMMUNITY-DRIVEN ASSET MAPPING TECHNOLOGY

# Community Asset Mapping[7]

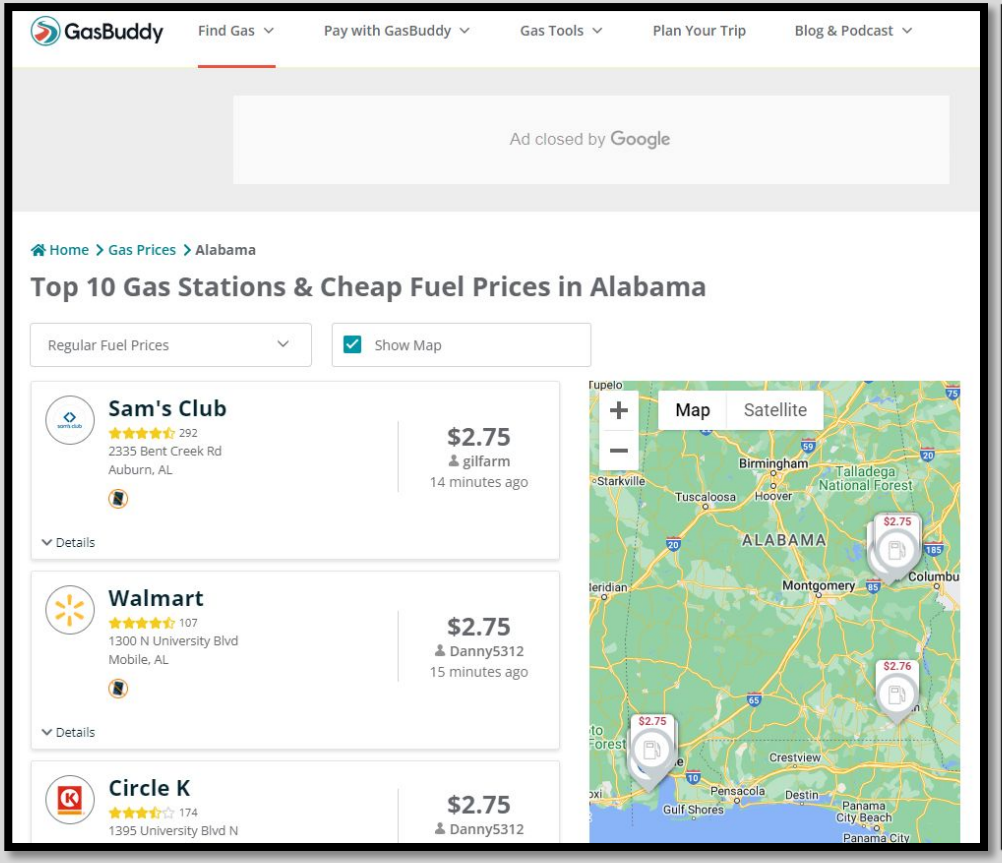
- Community development approach used in many public health areas.
- Documents where tangible and intangible resources or services are in the community.
- Oftentimes, communities are involved with gathering the mapping data.

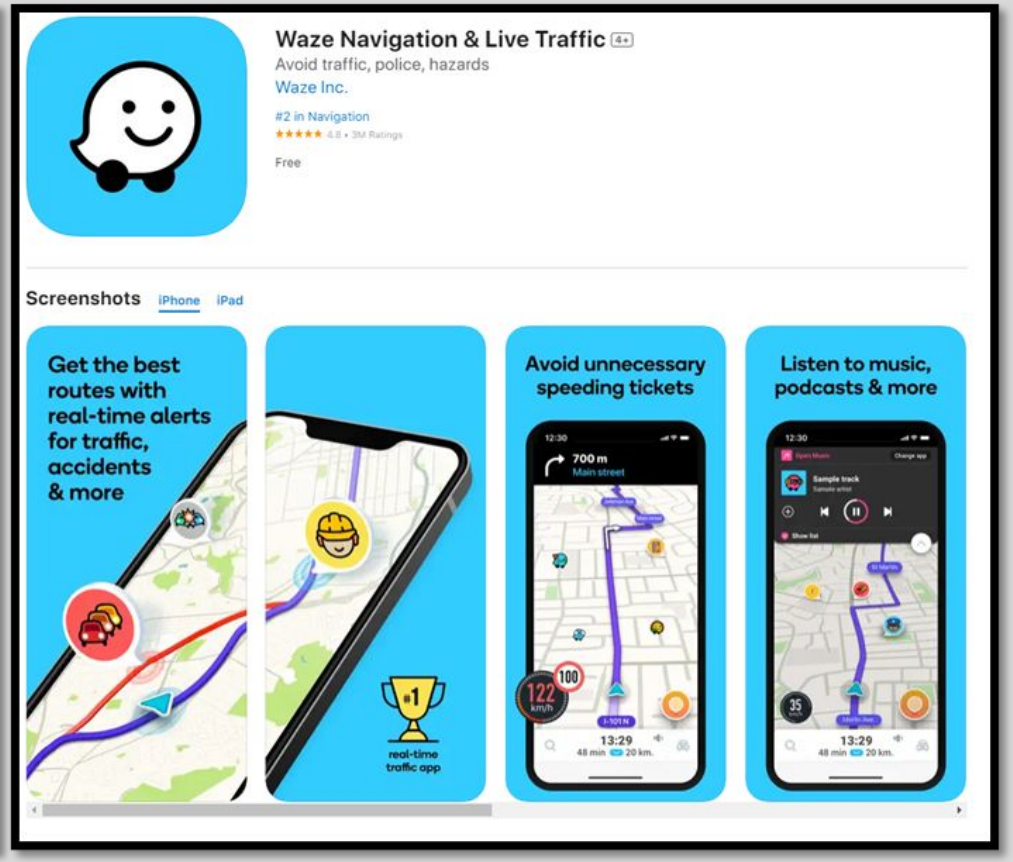
# Crowdsourcing Mapping Data

- Volunteer stakeholders enter data of interest to other app users.
- Harnesses the mutual support already found among caregiver communities.



# Examples of Crowdsourced Asset Mapping



# Long-Term Goals: Alabama Caregiver Connect

- Develop a community asset mapping software for ADRD resources and services.
- Develop a crowdsourcing protocol for populating the map with volunteered geographic information (VGI).
- Test feasibility of local community-members populating the map and using it for information seeking.

# Alabama Caregiver Connect Planning Project

**Early Questions**

- What information would lead people to use the app?
- How do we address data quality?
- How do we create an app that supports varying digital literacy?

**Methods**

- Survey of 78 caregivers across Alabama.
- In-depth interviews/focus group with 16 providers for PLWD and their families.
- In-depth interviews/focus group with 10 caregivers of PLWD.
- Data collection took place during the pandemic.

# What do caregivers say?

- Caregivers want to learn about available resources from other caregivers in real time.
  - 71.5% of survey respondents reported they were likely to use a crowdsourcing mapping program.
  - 73.1% would be willing to add data to the map.
- Biggest information needs:
  - Respite care.
  - Identifying services that insurance covers.
  - Stress relief and support groups for caregivers.
  - Financial Planning and Assistance.

# What do providers and researchers say?

- Potential for helping families make more informed decisions.
- Improve business competition, especially in unregulated markets.
- Support for research recruitment.
- Identify gaps in service delivery.
- Creating a caregiver registry.

# What is the potential for addressing BOLD goals?

- Collecting data to evaluate progress towards Brain Health Road Map goals.
- Educational and training outreach for general public, primary care providers, non-medical professionals.
- Support in tracking “awareness” and “understanding” outcomes.
- As a “hub” for ADRD, can help facilitate clinical-community linkages.

# What do YOU think?

- Questions?
- How do you see this app implemented in your state or local community?
- What cultural or demographic realities in your state would it need to take into account?

# Development Progress

## Working Towards a Dementia-Friendly Alabama

**If you are an Alabamian facing the challenges of dementia, you are not alone!**
**Did you know that...**

- In 2025, more than 110,000 Alabamians will have a diagnosis of Alzheimer's Disease.
- In 2021, there were more than 211,000 Alabamians providing care to someone with Alzheimer's Disease.
- Alabama caregivers provided over 230 million hours of care that year!
- Alabama caregivers report that they need more support and information about dementia and caregiving.

If you are one of the many people in Alabama impacted by dementia, this website is designed to help you!

# Early Development of AI Tools

Area Agency on Aging for
Tuscaloosa

West Alabama Regional Commission
4200 Highway 69 North Suite 1
Northport, AL 35476
800-432-5030
https://www.westalabamaaging.org

## How can I tell if my loved one with dementia is depressed and what can I do to help them?

5/4/2023 1 Comment

By: Dr. Nicole Ruggiano

**May is mental health awareness month!** One common mental health challenge that people living with dementia face is depression. Depression is a common condition for adults and can range in severity and duration. While depression is common among all adults, older adults with dementia are at greater risk of developing depression. According to the Alzheimer's Association, up to 40% of people with Alzheimer's disease will experience significant depression. This can cause stress for caregivers, who may not understand why their loved one has become depressed, not know what to do, and may even feel guilty that their loved one is suffering. Many often ask how to assess whether their loved one is depressed and what they can do to help them.

Read More

Tweet

1 Comment

## My loved one was recently diagnosed with dementia. How can I help them in the early stages?

1/21/2023 5 Comments

By: Nicole Ruggiano, PhD, MSW

It is never easy for someone to receive a diagnosis of Alzheimer's disease or other type of dementia. In fact, research has shown that older adults are more afraid about dementia than they are afraid of cancer. It is normal for those who are diagnosed with dementia to

## Caregiving 101

**The Caregiving 101 is a resource for caregivers in Alabama who want to learn more about caregiving and dementia.**

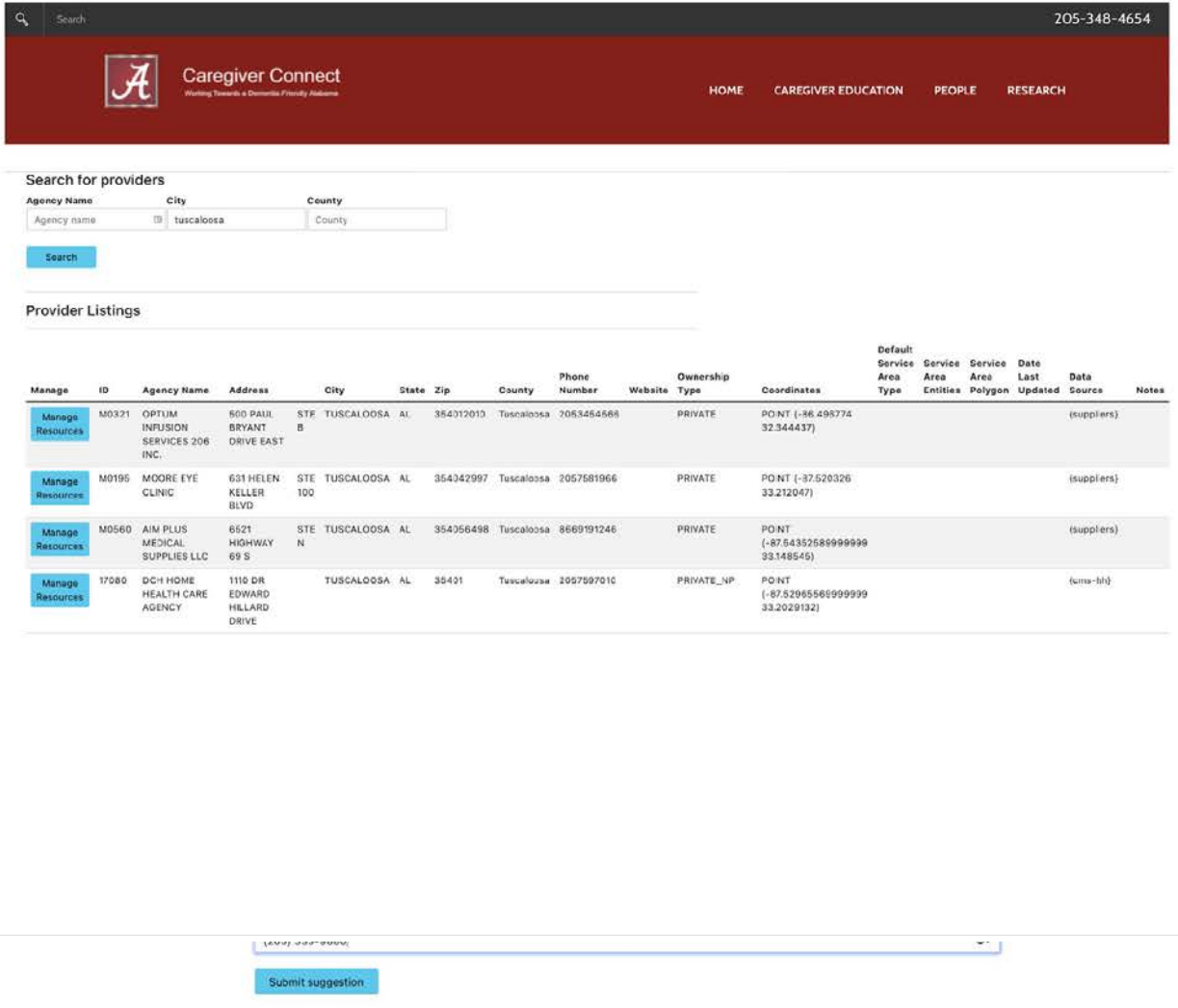
**Ask questions on our Home Page and share your experiences and advice for other caregivers in the comments sections!**

## Archives


May 2023
January 2023
November 2022
August 2022
July 2022
June 2022
April 2022
March 2022
February 2022


**What would you**

# Development Progress



# Community Engagement Since February 2022:

- Community outreach:
  - Sponsorships for two public radio stations.
  - Coverage in print and television news.
- More than 1,600 individual users from 10 countries.
- More than 2,700 page views.
  - Most Popular Page: Caregiver 101.
  - 39 Contact Form Submissions.
  - Several for- and non-profit agencies have reached out.

# POTENTIAL CHALLENGES AND POSSIBLE SOLUTIONS

# Identified Challenges and Potential Solutions

- Crowdsourced data can be noisy.
  - *Develop algorithms that assess for accuracy in data.*
- Information needs vary across cases.
  - *Developing protocols with clear categories of caregiver needs.*
- Preventing predatory, misleading, and false information.
  - *Use the citizen scientist model.*
- Staying relevant for rural communities.
  - *End user testing in remote communities.*

# What do YOU think?

- Questions?
- How can departments of public health get involved?

# References


1. Alzheimer's Association. 2023 Alzheimer's Disease Facts and Figures. Alzheimers Dement 2023;19(4). DOI 10.1002/alz.13016.
2. Christine Snead, M., & Cockerham, W. C. (2002). Health lifestyles and social class in the deep South. In Social Inequalities, Health and Health Care Delivery (pp. 107-122). Emerald Group Publishing Limited.
3. Ruggiano N, Brown EL, Shaw S, Geldmacher D, Clarke P, Hristidis V, Bertram J. The potential of information technology to navigate caregiving systems: perspectives from dementia caregivers. Journal of gerontological social work. 2019 May 19;62(4):432-50.
4. Bangerter, L. R., Griffin, J., Harden, K., & Rutten, L. J. (2019). Health information–seeking behaviors of family caregivers: analysis of the health information national trends survey. JMIR aging, 2(1), e11237. https://aging.jmir.org/2019/1/e11237
5. Nguyen, H., Phan, H. T., Terry, D., Doherty, K., & McInerney, F. (2022). Impact of dementia literacy interventions for non-health-professionals: systematic review and meta-analysis. Aging & Mental Health, 26(3), 442–456. https://doi-org.libdata.lib.ua.edu/10.1080/13607863.2021.1884843.
6. Winton, T., Ruggiano, N., Daquin, J, Anderson Herzog, M, Jiang, Z, & Gray, J. (under review). Health Information Seeking Using Tech and Non-tech Sources among Caregivers in the Deep South
7. Luo Y, Ruggiano N, Bolt D, Witt JP, Anderson M, Gray J, Jiang Z. Community asset mapping in public health: a review of applications and approaches. Social Work in Public Health. 2023 Apr 3;38(3):171-81.

# 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!