

# Innovations in ADRD Caregiver Support Programs: Innovative Community Strategies

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December 14, 2022

# Innovations in Alzheimer's Disease and Related Dementias (ADRD) Caregiver Support Programs: Innovative Community Strategies



# Overview

- This session will include presentations, followed by a panel discussion and live Q&A with panelists and participants
- Video replay and slide presentation are available after each session at:  
<https://www.resourcesforintegratedcare.com>

# Support Statement

- This webinar is supported through the Medicare-Medicaid Coordination Office (MMCO) in the Centers for Medicare & Medicaid Services (CMS) to help beneficiaries dually eligible for Medicare and Medicaid have access to seamless, high-quality health care that includes the full range of covered services in both programs. To support providers in their efforts to deliver more integrated, coordinated care to dually eligible beneficiaries, MMCO is developing technical assistance and actionable tools based on successful innovations and care models, such as this webinar.
- To learn more about current efforts and resources, visit Resources for Integrated Care at: <https://www.resourcesforintegratedcare.com> or on Twitter [@Integrate\\_Care](https://twitter.com/Integrate_Care)

# Introductions

## ■ Karen M. Rose, PhD, RN, FGSA, FAAN

Professor, College of Nursing; Vice Dean; Director, Center for Healthy Aging, Self-Management and Complex Care; Chair, Graduate Studies Committee, The Ohio State University



## ■ Katie Scott, MPH

President, CarePartners



## ■ Jo Smith

Caregiver Panelist



# Learning Objectives

- Identify unique challenges and needs for the caregivers of those living with Alzheimer's disease and related dementias (ADRD)
- Deliver innovative strategies and share examples of programs to support caregivers
- Provide community-based strategies that support the unique needs of diverse or underserved communities and address health equity
- Share lessons learned from implementation of community-based caregiver support programs over the past 5-10 years

# Webinar Outline

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- Polls
- Background
- Assessing caregiver burden and supporting the mindfulness of caregivers and families – *Dr. Karen Rose*
- Volunteer-based caregiver support programs - Innovations from Texas – *Katie Scott*
- Panel Discussion
- Audience Q&A
- Evaluation

## Background – ADRD

- Dually eligible population
  - Individuals dually eligible for Medicare and Medicaid are almost three times as likely to have ADRD as people eligible for Medicare only<sup>1</sup>
  - Twenty percent of all dually eligible individuals aged 65 and over are diagnosed with ADRD<sup>2</sup>
  - Dually eligible individuals with ADRD are particularly vulnerable to unplanned hospital admissions<sup>3</sup>
- General population
  - Social determinants of health are an important factor for health plans to consider when supporting individuals with ADRD<sup>4</sup>
  - The general population is aging, and the older population itself is becoming increasingly older<sup>5</sup>
  - Over half of persons aged 65 and older live in nine states, with California having the greatest number in 2019<sup>6</sup>



# Background – Caregivers

- In 2015:
  - 85% of individuals with ADRD lived in community settings.<sup>7</sup>
  - Almost six million people were informal caregivers for community-dwelling older adults with dementia, and it was common for older adults to have more than one caregiver.<sup>7</sup>
  - Most caregivers for community-dwelling older adults with dementia are younger than age 65, and more than half are the child of the person for whom they care.<sup>7</sup>
- Passage of the Recognize, Assist, Include, Support, and Engage (RAISE) Family Caregivers Act in 2017
  - Directed the development of the National Family Caregiving Strategy and the establishment of a council to identify best practices and recommendations.<sup>8</sup>
  - The Council’s August 2019 meeting identified themes emphasizing the recognition of caregivers’ diverse needs, supporting the well-being of caregivers, and integrating and empowering caregivers within the health care system.<sup>8</sup>
  - In September 2022, the Council released the [National Strategy to Support Family Caregivers](#).<sup>9</sup>
- Specific to caregivers for those with ADRD, the national site [Alzheimers.gov](#) shares resources from the National Institute on Aging, the Administration for Community Living, the Centers for Disease Control and Prevention, and others.<sup>10</sup>

# Assessing Caregiver Burden and Supporting the Mindfulness of Caregivers and Families



**Karen M. Rose, PhD, RN, FGSA, FAAN**

Vice Dean and Professor, College of Nursing

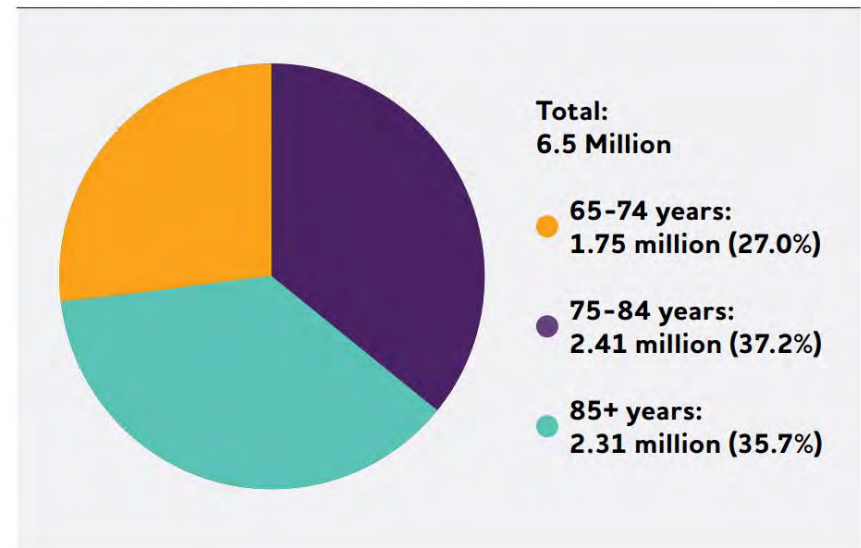
Director, Center for Healthy Aging, Self Management, and Complex Care

The Ohio State University

# Background

- **6.5 million** people aged 65+ in the United States have Alzheimer's Disease (AD)<sup>11</sup>
  - **1 in 9 Americans (11 percent)** aged 65+ have AD<sup>11</sup>
  - **13.8 million** Americans aged 65+ will expect to have AD by 2060<sup>11</sup>

Number and Ages of People 65 or Older with Alzheimer's Dementia, 2022 <sup>11</sup>



# Caregivers in the U.S. in 2020

The number of Americans providing unpaid care has increased over the last five years.\*

**43.5 million**  
2015  **53 million**  
2020



**18%**  
2015  **21%**  
2020

NEARLY ONE IN FIVE (19%) ARE PROVIDING UNPAID CARE TO AN ADULT WITH HEALTH OR FUNCTIONAL NEEDS.\*\*

More Americans are caring for more than one person.

More family caregivers have difficulty coordinating care.

 **18%**  
2015  **24%**  
2020

**19%**  
2015  **26%**  
2020 

More Americans caring for someone with Alzheimer's disease or dementia.

More family caregivers report their own health is fair to poor.

 **22%**  
2015  **26%**  
2020

**17%**  
2015  **21%**  
2020 

**AARP**  
Family Caregiving™

**nac**  
National Alliance for Caregiving

\*Provided care to an adult or child with special needs.

\*\*The remainder of this data is based on the 17% or 43 million caregivers caring for an adult.

URL: [www.aarp.org/uscaregiving](http://www.aarp.org/uscaregiving) DOI: <https://doi.org/10.26419/ppi.00101002>

Caregiving in the U.S. 2020,  
National Alliance for Caregiving and AARP  
For media inquiries, contact [Media@aac.org](mailto:Media@aac.org)

## Caregiver Statistics:<sup>12</sup>

**66%** of caregivers are living with their care recipients

**30%** of caregivers are 65 years of age or older

**Over 50%** are caring for a parent or in law

**Around 10%** are caring for a spouse or partner

# The Issue



Caregivers of persons with ADRD need **interventions** to **reduce distress** caused by **caregiving in real time**.

# Interventional Study

## Learning and Improving Alzheimer's Patient-Caregiver Relationships via Smart Healthcare Technology

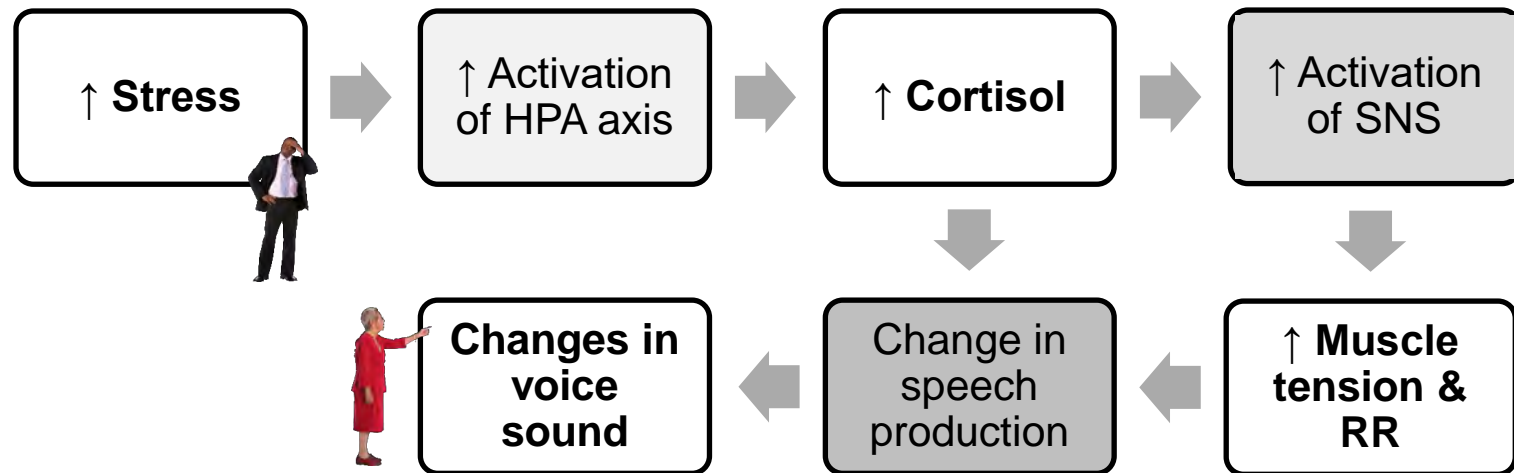
- IRB: #2019B0406 | ClinicalTrials.gov identifier: NCT04536701
- Funding from the National Science Foundation (NSF)  
#1838589, #1838615

# Study Purpose and Program Aims

- Purpose:
  - Develop a monitoring, modeling, and interactive recommendation solution for caregivers for in-home dementia patient care that focuses on caregiver-patient relationships
  - Monitor for mood and stress and analyze the significance of monitoring those attributes to dementia patient care and subsequent behavior dynamics between the patient and caregiver
  - Deploy timely behavioral suggestions with the aim of improving interactions related to caregiving
- Aims:
  - Develop and deploy an in-home Smarthealth Technology acoustic monitoring system to identify patient–caregiver conflict and provide stress management tips in real time
  - Determine feasibility, acceptability, and efficacy to improve relationships and emotional health in caregivers
  - Potentially reduce the stressful effects of the patient's illness and strain on caregivers

# Study Overview: Stress and Voice Change

- Monitor caregiver voice
  - **Changes in voice** can be a biological marker of stress
  - Stress can affect not only **conversation contents** (wording, grammar) but also **other changes** (speed of speech, pitch, jitter, speaking rate)



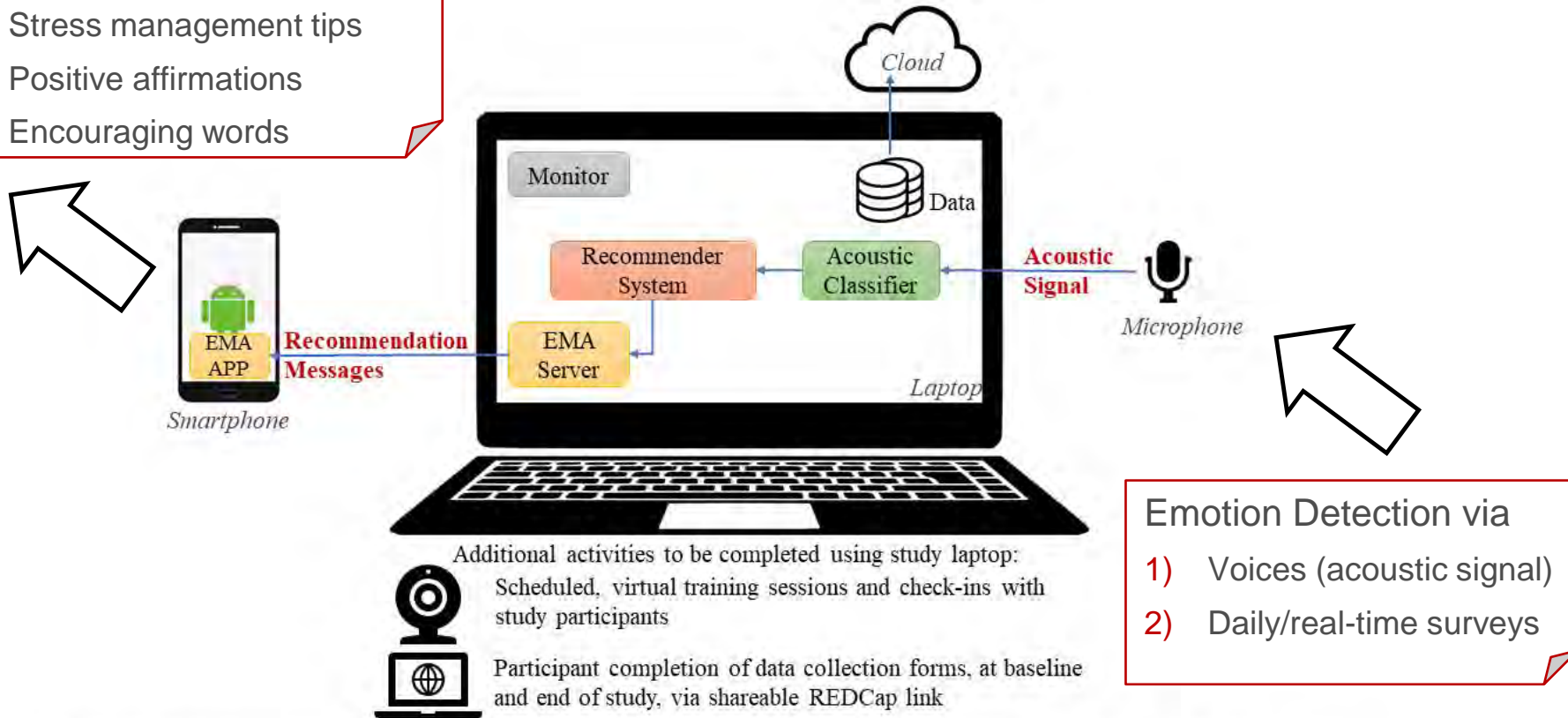
HPA = hypothalamic-pituitary-adrenal axis  
 SNS = sympathetic nervous system  
 RR = respiration rate



# Intervention Process

## Recommendation Messages

- 1) Stress management tips
- 2) Positive affirmations
- 3) Encouraging words

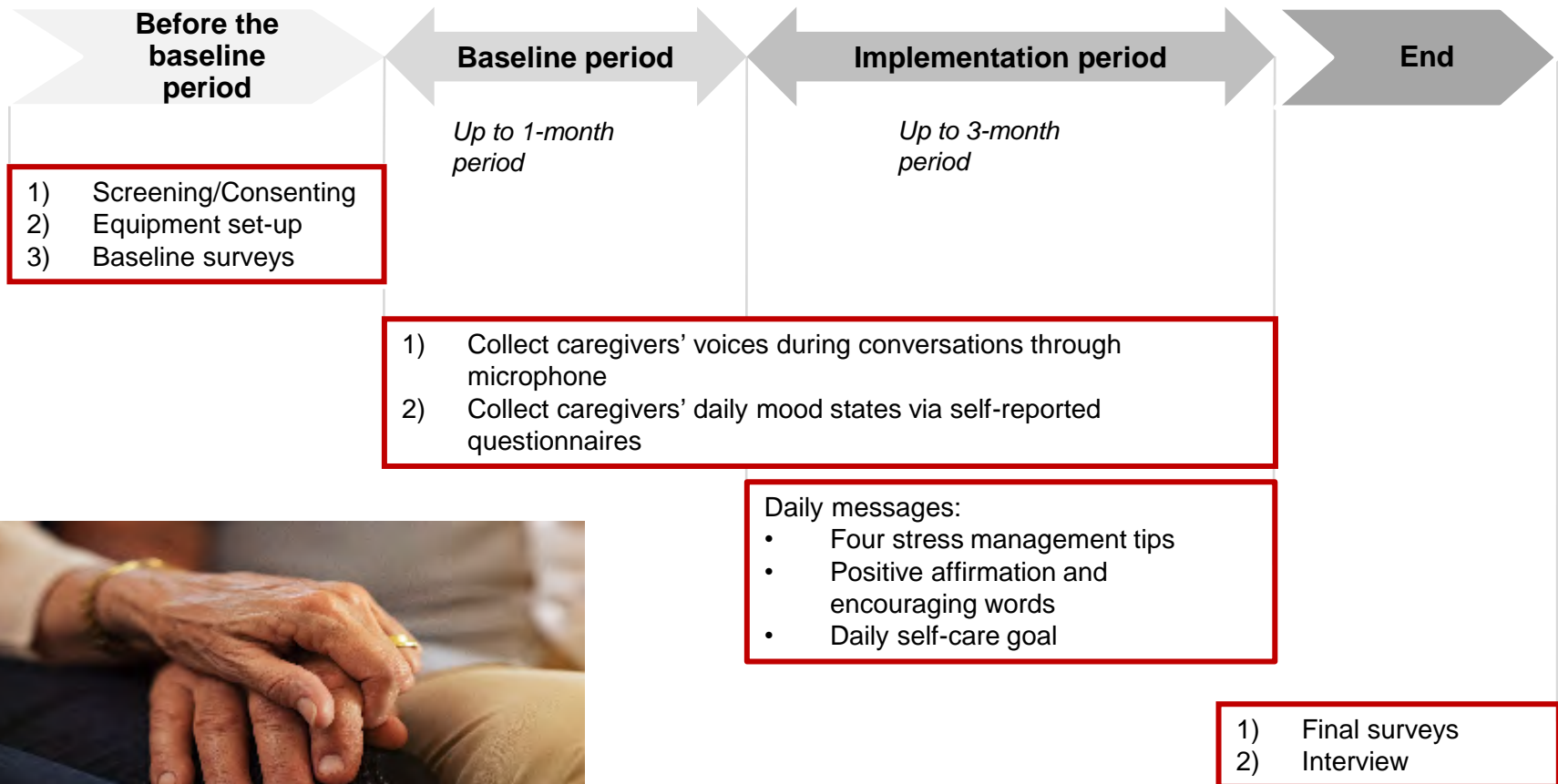


## Emotion Detection via

- 1) Voices (acoustic signal)
- 2) Daily/real-time surveys

Figure 1. Study Equipment Function and Procedural Use. This figure provides an overview of the smarthealth technology system.  
Legend: EMA=Ecological Momentary Assessment<sup>13</sup>

# Intervention Timeline



# Outcomes

- Interim results:
  - Improvements in depressive symptoms, anxiety, and stress
  - Less reactivity to care recipient behaviors, despite no reduction in these behaviors
  - Insights gained into their own behaviors
  - Use of “time out” was helpful
  - Daily affirmations were appreciated

## Considerations: Technology

- Participant technological literacy
- Majority of participants are older adults (average age of active participants = 62.9 years)
  - Perceived challenges in deploying study system
  - Difficulty installing study equipment; engaging other family members

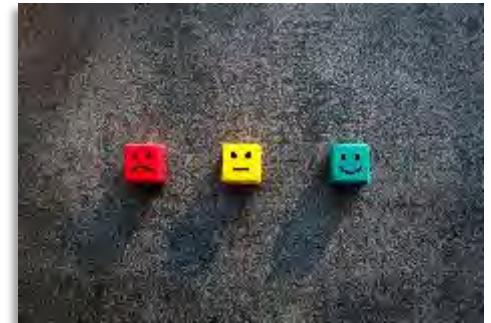
# Considerations: Caregiving Role Workload

- Caregiving role workload
  - Effort required to participate in the study while providing care
    - ✓ Juggling work and caregiving
    - ✓ Managing unanticipated behaviors of care recipients (e.g., unplugging the system)
  - Difficulty answering messages sent in real-time right after mood detection



# Considerations: Emotional Expression and Communication

- Emotions are complex
  - Discrepancy between self-reported emotions and those detected by system
- Manual labeling with the system-generated labeling
  - Use of both manual labeling and system-induced labeling can improve the functional accuracy of emotional detection
- Difficulty capturing non-verbal communication
  - Open-ended interview at the end of study



## Summary

- Consider technology-based interventions, which provide high flexibility and the potential for scalability, as an alternative or complement to traditional in-person services for dementia caregivers
- Encourage caregivers to participate in community support groups and support services
- Compliment caregivers on their efforts to support their care recipients
  - Screen for depressive symptoms and refer as warranted
- Assist caregivers with maintaining their own health and well-being
  - For example, through routine appointments with their healthcare provider

# Our Team



Dr. Karen Rose, Dr. Kathy Wright  
Eunjung Ko, Sooyoung Kim, Lorene Kelley



Dr. Jack Stankovic, Dr. Hongning Wang  
Ashley Gao, Lahiru Wijayasingha, Peng Wang  
Jason Jabbour, Zetao Wang, Chuanhao Li



Dr. Kristina C. Gordon  
Matthew McCall



# Volunteer-Based Caregiver Support Programs – Innovations from Texas



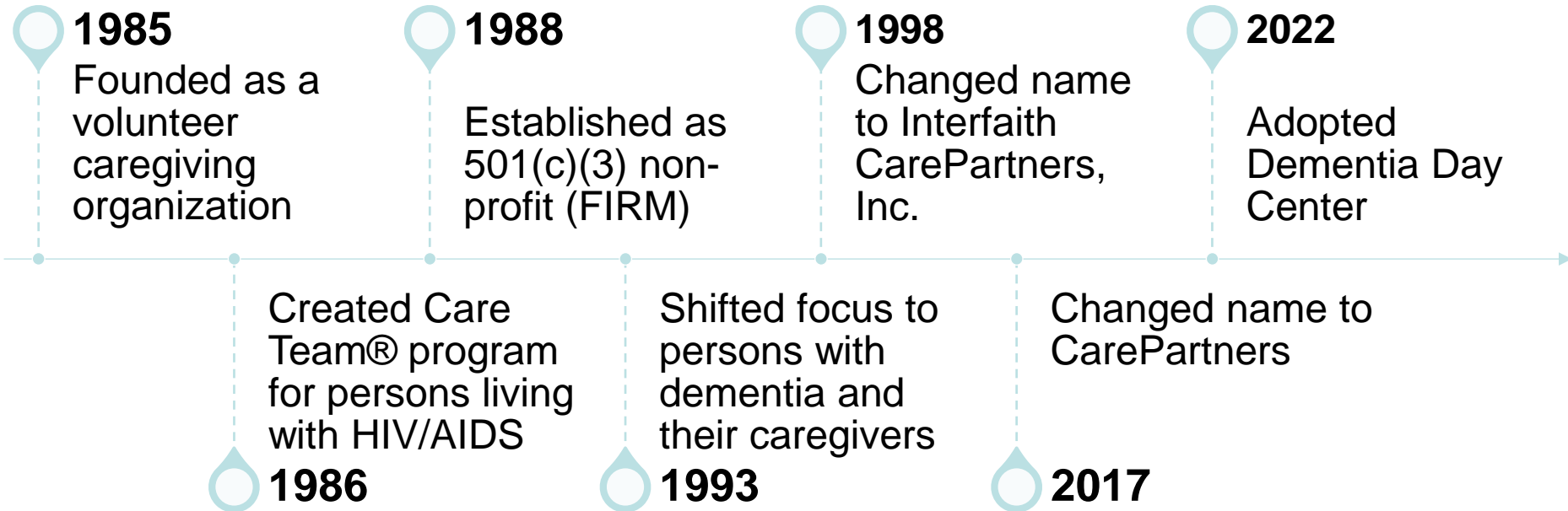
**Katie Scott, MPH**

President

CarePartners



# CarePartners



Location: Greater Houston, Texas

Before 2020: Utilized 2,000 volunteers to serve 3,500 individuals

Projected 2022: Utilize 1,700 volunteers to serve 2,000 individuals

FIRM = Foundation for Interfaith Research and Ministry

## The Care Team® Model

- Purpose: To create a compassionate service of companionship and practical assistance utilizing skilled volunteers
  
- Impact:
  - Reduced caregiver stress
  - Improved ability to manage caregiving responsibilities
  - Expanded support network for caregiver and older adult or individual with dementia
  - Reduced isolation for caregiver and older adult or individual with dementia

# The Care Team® Model

- Basic components:
  - Partnership with entity with a strong volunteer network
  - CarePartners provides professional oversight of all activities
  - Volunteer team leaders provide programmatic oversight
  - 1:1 volunteer to client ratio (typical)
- Volunteer requirements:
  - Provide basic supervision; No Activities of Daily Living (ADL) Care
  - Participate in multi-day training, quarterly continuing education, and annual refresher trainings
  - Undergo background checks
  - Report volunteer hours and visits



# Care Team® Model in Practice

## **The Gathering Place:**

Half-day activity program for individuals with dementia

Includes:

- Planned social, mental, spiritual, and physical activities
- Lunch
- Activities offered once or twice a month

## **Second Family:**

In-home companionship program for older adults

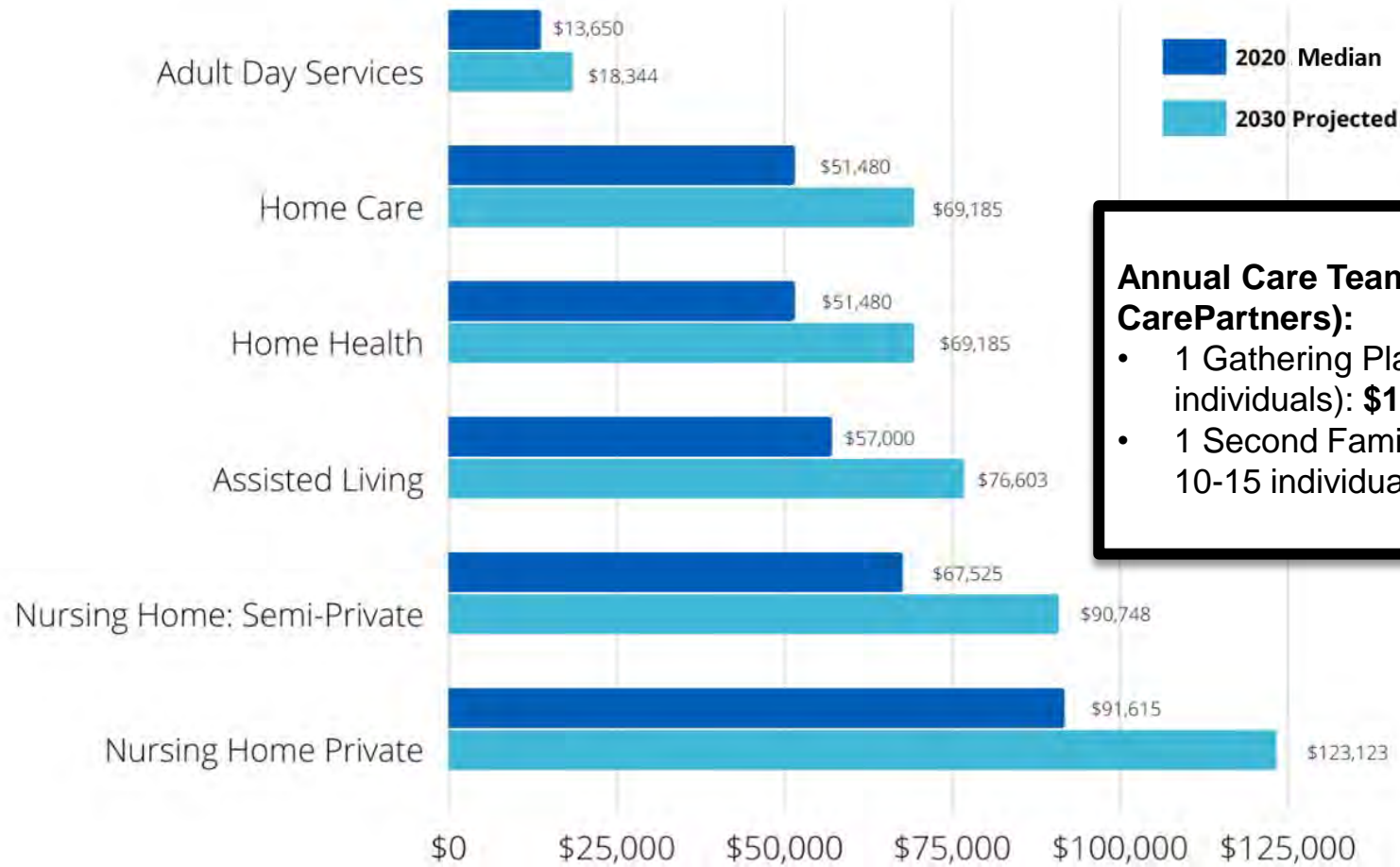
Includes:

- Socialization and basic supervision
- Transportation

Length and number of visits vary based on capacity and need

# Houston Annual Long-term Care Costs

Cost of Care by Care Setting per Recipient



**Annual Care Team® Costs (from CarePartners):**

- 1 Gathering Place (serves 30 individuals): **\$10,696**
- 1 Second Family team (serves 10-15 individuals): **\$2,074**

Data source: Genworth Cost of Care Calculator<sup>14</sup>

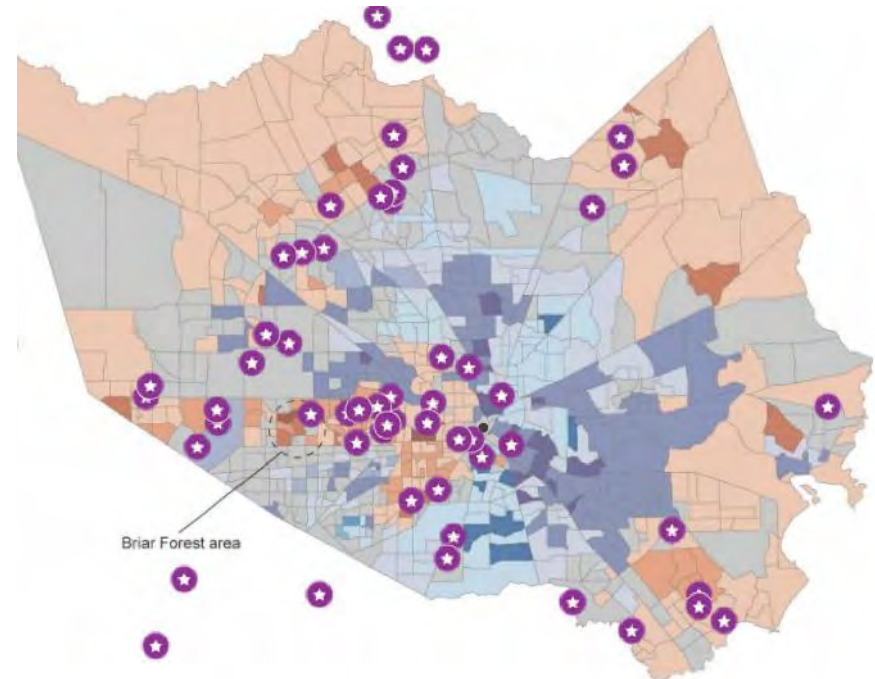
## Carmel B. Dyer Second Family

Pilot designed to address social isolation in older adults at high risk of elder mistreatment in an under-resourced, predominantly African American neighborhood in Houston.

- Volunteers from a local congregation and Rice University engage with older adults in their homes and via phone at least once a week.
- Volunteers receive additional training on signs of elder mistreatment and exploitation.
- Volunteers check in with CarePartners staff members for regular case reviews.

# Lessons Learned

- Identify a partner with aligning mission and values
- Assess infrastructure needs and resources regularly
- Develop guiding principles (MOUs, contracts, or covenants)
- Engage in training and support
- Collect data
- Communicate regularly with partners, volunteers, donors, and leadership



MOUs = Memorandums of Understanding

Partner locations across Harris County, Texas



# Discussion Panel



## Panel Discussion



**Dr. Karen Rose**

Center for Healthy Aging, Self-  
Management and Complex Care,  
College of Nursing, The Ohio State  
University



**Katie Scott**

CarePartners



**Jo Smith**

Caregiver



# Questions and Answers



**Dr. Karen Rose**

Center for Healthy Aging, Self-  
Management and Complex Care,  
College of Nursing, The Ohio State  
University



**Katie Scott**

CarePartners



**Jo Smith**

Caregiver

# Thank You for Attending!

- The video replay and slide presentation will be available at: <https://www.resourcesforintegratedcare.com>
- Questions? Please email [RIC@lewin.com](mailto:RIC@lewin.com)
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## Webinar Evaluation Form

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- Your feedback is very important! Please take a moment to complete a brief evaluation on the quality of the webinar. The survey will automatically appear on the screen approximately a minute after the conclusion of the presentation.

# Resources

- The Ohio State University College of Nursing [Center for Healthy Aging, Self-Management and Complex Care \*Managing Shame: A Grounded Theory of How Stigma Manifests in Families Living With Dementia\*](#) – An article co-authored by Dr. Karen Rose, published in the Journal of the American Psychiatric Nurses Association in 2020
- [Smarthealth technology study protocol to improve relationships between older adults with dementia and family caregivers](#) – An article co-authored by Dr. Karen Rose, published by the Journal of Advanced Nursing in 2021
- Information on the ongoing study, *Learning and Improving Alzheimer's Patient-Caregiver Relationships Via Smart Healthcare Technology*, sponsored by The Ohio State University: <https://www.clinicaltrials.gov/ct2/show/NCT04536701>
- Programs and educational resources provided by CarePartners: <https://carepartnerstexas.org/>
- 'What is elder abuse?' page on the Administration for Community Living website: <https://acl.gov/programs/elder-justice/what-elder-abuse#:~:text=In%20general%2C%20elder%20abuse%20is,of%20elder%20abuse%20prevention%20laWS>
- Genworth Cost of Care Calculator: <https://www.genworth.com/aging-and-you/finances/cost-of-care.html>
- [RIC Event: Innovations In Alzheimer's Disease And Related Dementias \(ADRD\) Caregiver Support Programs: Building And Leveraging Support Systems Webinar](#), including the webinar recording and slides
- Reports and infographics from AARP: <https://www.aarp.org/ppi/info-2020/caregiving-in-the-united-states.html?CMP=RDRCT-PPI-CAREGIVING-042920>
- State Health Insurance Assistance Program (SHIP): <https://acl.gov/programs/connecting-people-services/state-health-insurance-assistance-program-ship>

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