

## Engaging Care Partners in Enhancements to CAPABLE: Findings & Implications

**Deborah Paone**, DrPH, MHSA, Co-Principal Investigator and Director of Implementation & Evaluation – CAPABLE, Johns Hopkins University and the CAPABLE National Center

Sherry Wright, MS, Social Services Project Coordinator, Area Agency on Aging of the Capital Area, Austin, TX

**USAging Conference, Chicago, IL, July 2025** 



## Speaker Information



**Dr. Deborah Paone, DrPH, MHSA** is an independent researcher/consultant and President of *Paone & Associates, LLC*, a firm she founded in 2002 (Minneapolis). Dr. Paone works with providers, health plans, communities, research centers, and government agencies to promote better systems of care, focusing on older adults, people with disabilities, and family caregivers. She is a subject matter expert in health policy, quality measurement, care coordination, integration, health equity, and implementation effectiveness. Deborah has provided technical assistance to organizations implementing the CAPABLE evidence-based program developed by Johns Hopkins University clinician-researchers since 2019. Dr. Paone serves on national technical expert advisory committees such as the MA Stars TEP (CMS/RAND), Person-Centered Outcome Measure Advisory Panel (NCQA), 2028 HCBS Quality Measure Set Workgroup (Mathematica), and is a researcher for the ACL Falls Prevention Innovation Lab. She holds a Doctorate in Public Health, a Masters in Health Services Administration and a Bachelor's in Gerontology and in English Literature. dpaone1@jhu.edu



Sherry Wright, MS, is the Social Services Project Coordinator for the Area Agency on Aging of the Capital Area in Austin Texas. With over twenty-nine years of experience in the aging field, her expertise includes administration and implementation of programs, including the CAPABLE Program. Her roles have spanned various areas such as AAA Aging Care Manager II, AAA Service Coordination, HUD Quality Assurance for Service Coordinators, Service/Program Coordination for Older Adults in HUD Housing Communities, Case Manager, and Manager of a 55+ community. Her experience includes staff/vendor supervision and training, facility and program oversight, community outreach, developing operational and evaluation data elements and workflow of documentation for the CAPABLE Program, project development/implementation, managing a 55+ property/staff and HUD program compliance monitoring for Service Coordinators. She holds a Master of Science degree in Science and Technology Policy Management from the University of Edinburgh in Scotland and Bachelor of Science degree in Gerontology from King's College in Pennsylvania. <a href="mailto:swright@capcog.org">swright@capcog.org</a>

## Focus of this Session

#### Content Covered today . . .

- 2 studies by Johns Hopkins enhancing the evidence-based program CAPABLE
   - what/how done & what learned
- Focus on care partners and adaptations for people with mild cognitive impairment and their care partners
- Pilot partner and CAPABLE service provider - AAA in TX - takeaways & insights

#### Implications - Can be/have. . .

- Part of an evidence-based falls prevention strategy and service to assist "aging in community"
- Synchronicity with Caregiver Counseling Title III E program
- Connection to Alzheimer's Disease services in the community and caregiver support
- Potential for referrals/payment from value-based payers

## What is CAPABLE?





Evidence-based



Home-based



Person-directed



Interprofessional



Long-term impact



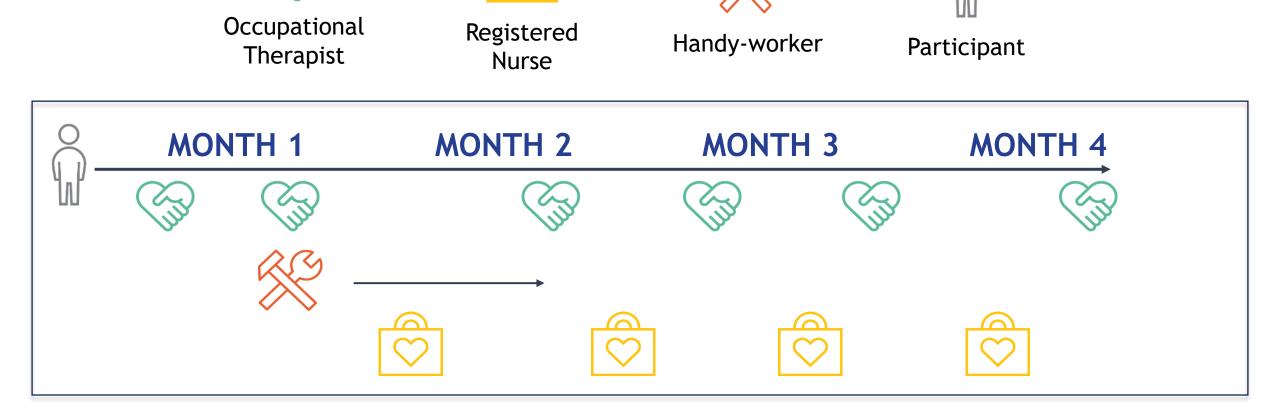
Behavioral change





## CAPABLE at a Glance

CAPABLE is delivered in the home during 10 visits over 4 months through an inter-professional team including the participant:





## How CAPABLE works

An interdisciplinary team uses motivational interviewing, active listening, and coaching communication methods to enable the participant to achieve their self-prioritized goals



#### **Participant**

- Self-assessment
- Readiness to change
- Drives own goals and priority settings
- Brainstorms options/solutions;
   Develops Action Plan in own words
- Makes progress between visits;
   Exercises, reads material,
   practices within home
- Practices tips for safe, independent living
- Uses new skills and equipment



## Occupational Therapist

- Functional/Mobility assessment
- Home risk; modifications
   & equipment needs
- Fall prevention, equipment guidance



#### Registered Nurse

- Medical history, current healthcare providers
- Key health issues/risks
- Pain, medication review



#### Handy Worker

- Receives work order; confers with participant
- Obtains and installs equipment
- Makes minor home repairs/modifications

## **Demonstrated Program Benefits**



6 to 7 x return on investment

Roughly \$3,000 in program costs yielded more than \$30,000 in savings in medical costs driven by reductions in both inpatient and outpatient expenditures.\*



Improved physical function

Participants had difficulty with an average of 3.9 out of 8.0 Activities of Daily Living (ADLs) at baseline, compared to 2.0 after five months.



Improved motivation

The change in physical environment further motivates the participant. Addressing both the people and the environment in which they live allows the person to thrive.



Reduced symptoms of depression

Symptoms of depression lessened, and ability to do important tasks, such as grocery shop and manage medications improved.

## Why did we develop the Care Partner Component?

- ➤ Care partners are important helpers in the lives of the older adults Currently, from 25-50% of the CAPABLE participants report having a family or friend who regularly helps them (we call this person a "care partner")
- ➤ Already present CAPABLE clinicians already encounter care partners in their CAPABLE home visit sessions
- ➤ Want to help The care partners want to know and learn alongside the participant to help that person meet goals

## How was the Care Partner Component Developed?

- 1. We conducted a *3-phase study* to explore, develop, and pilot test the Care Partner prototype, materials, and program (2021-2024).
- 2. We reviewed existing care partner programs and literature, consulted with an Advisory Group of nationwide experts in the field, and conducted key informant interviews with CAPABLE participants, care partners, clinicians, administrators and social workers.
- 3. We *pilot tested* the Care Partner Program at 3 CAPABLE sites and obtained feedback and analyzed the effect on Care Partners.

## **CAPABLE Care Partner Study**



#### **Process Timeline**

Phase 1: **Exploratory**  **Review of Existing** Care Partner Programs; mini literature review

Spring 2021

**CAPABLE** Clinician Interviews

Jun 2021

**CAPABLE Participant** Interviews

Jul 2021

Program Outline,

Format Options,

and Prototype

Development

**CAPABLE Care Partner Interviews** 

Aug 2021

Phase 2: Content Development

Round 1 Interviews, Data Coding and **Analysis** 

Sep-Nov 2021

**Advisory Group** Engagement and Feedback

Dec 2021- Apr 2022

**CAPABLE Clinician** and Care Partner Feedback (Round 2 Interviews)

May- Jul 2022

**CAPABLE Care** Partner Prototype Complete; IRB Submitted

Feb-Oct 2022

Phase 3: **Intervention Pilot** 

Training and **Preparation Conduct** & CAPABLE Care Partner Pilot

Oct 2022- Dec 2023

Analysis of Effect on Care Partner, and feedback from Participant, Clinicians, Program Administrators and Sites

Jan - May 2024

Care Partner resources, guides finalized and disseminated to all **CAPABLE** sites

Fall 2024 - Spring 2025

#### **CAPABLE Enhancements – Affects on Care Partners**

**CAPABLE sites can** support the care partner and participant. **The goals** are to:

- To <u>increase knowledge/effectiveness of the care partner around his or her caregiving role</u> and thereby support the older person/participant, by attending CAPABLE home visits with clinicians, when invited and when possible.
- To help the care partner <u>recognize and act on self care</u> through an approach that *mirrors what is done in CAPABLE* with the older adult.
- To provide an opportunity for the care partner & participant to <u>receive</u> support, guidance and resources. This can be a *pathway* to additional help or guidance in the future

## Care Partner Welcome Letter

- 1) Welcomes the Care Partner and explains how to be involved; given to the Care Partner directly or mailed by the CAPABLE Program
- 2) Contains information about the CAPABLE Program, Action Plan, and Helpful Tips and Resources
- 3) Describes options for community supports/where to go next; can be tailored by the local site



#### Dear Family Members and Friends of CAPABLE Participants Welcome to CAPABLE!

Your family member or friend has enrolled in CAPABLE which has been shown to improve well-being and function for older adults. As a "care partner," you are important. You can help that person reach goals that are important to him/her.

This letter describes some resources for you and how you can be involved. We will cover these questions:

- What is the CAPABLE program?
- What is a "care partner"?
- How can I be involved in CAPABLE?
- Where can I get more information and help?

#### What is CAPABLE?

- CAPABLE is a home-based program. It has been shown to improve function in the day-to-day activities of daily living.
- The CAPABLE participant (the older adult) sets goals to work on over the course of 4 months, with the help of a team.
- The team includes: (1) occupational therapist (OT), (2) registered nurse (RN), and (3) handy worker. This team helps the older person make progress toward goals. This will help make daily life easier.
- Each member of the team visits the older person over the course of 4 months.
   There are 10 home visits in total.
- Small changes in the home (to reduce falls hazards, for example) and small changes by the older person can equal big changes in daily life.
- There have been over sixty CAPABLE programs implemented across the U.S.
- CAPABLE does not provide medical care and is not a substitute for home health care or rehabilitation therapy.

©2024 Johns Hopkins School of Nursing

## Care Partner Self-Assessment

- Guides discussion and identifies necessary supportive services, self care strategies and resources
- 2) Helps Care Partners "take a look" at their own situation and needs
- 3) Brings awareness to Care Partners in a more concrete way of their situation
- 4) Captures important demographic information and data/measures useful for program evaluation



	_		
Today's	Date:		
I Uuay 3	Date.		

#### CAPABLE Care Partner Self-Assessment

This assessment tool can help care partners look at their own situation, health, and needs. If used with a social worker or other health care professional's guidance, it can help identify and connect to necessary supportive services and resources.

A. Your Information (as a "Care Partner")							
Your Name	::					50	
Address:							
Preferred p	ohone:						
Email Addr	ess:						
What way	do you prefe	er to be conta	cted?				
☐ send	l me a text to	this #:					
□ ema	il me (at ema	ail address ab	ove)				
☐ call a	and leave a r	nessage at thi	s #:				
1. Your	Age Group	(Check one):					
18–39	40-4	40-49 50-59 60-69 70-79 80-89 90+					
			,				
Gender: □Female □Male □Non-Binary □Prefer not to answer     Name of the Person (Senior) who is (was) participating in CAPABLE:							
4. Your	Relationshi	<b>p</b> to this Perso	on: (Check	k one box b	elow)		
Daughter	Son	Grandchild	Niece	Nephew	Sister	Brother	In-law
Spouse/	Other	Friend	Other:				
Partner	Relative						

## **Action Plan Template**

- Is an optional tool for Care Partners interested in setting a goal and working towards it
- May be copied and used multiple times for a variety of goals
- Includes examples for Care Partners and easy to use (without much direction)
- 4) Mirrors the goal setting occurring for the participant in CAPABLE





Questions: Answers:

What is this? This is a tool (form) to help you set a goal, and work towards it.

How do I use it? Think of one thing you want to do for yourself. (That is your GOAL.)

Then what? Use this to write down the "what, when, and how" to work towards your goal. (These are the SPECIFICS on the backside of this form)

What else? Think about what might get in your way of reaching your goal (OBSTACLES) as well as what will help you (RESOURCES)

Can you give some examples?

YOUR SELF-CARE ACTION PLAN			
YOUR GOAL IS:			
YOUR STRATEGY IS:			
YOUR MOTIVATION:			
SPECIFICS ARE:			
OBSTACLES:			
RESOURCES ARE:			
CONFIDENCE LEVEL? Circle one:	Very Confident	Somewhat Confident	Not at all Confident
GOAL STATUS/ATTAINMENT Circle one:	Fully met	Partially met	Not met

©2024 Johns Hopkins University School of Nursing - All Rights Reserved

## Guide to Available Supports for Care Partners

- 1) This form should be adapted for each CAPABLE site by each site
- 2) The CAPABLE site adds information about local Care Partner Support programs available
- 3) When appropriate, this can be used as a guide to make referrals to local programs



#### Guide to Available Care Partner Support Programs

Questions:	Answers:
What is this?	This is a guide for Care Partners looking for more help and support.
How do I use it?	Read through the list of local programs and think about what may be helpful.
Then what?	Contact programs to ask questions about the service, costs/fees and service area.

Service Type	What is it?	Contact Information	Cost/Payment Information
Caregiver Education and Support Groups	Support groups for care partners focus on shared experiences, struggles, humor and coping skills. Members learn & support one another.		
Resource/ Care Partner Consultation	Addresses caregiver concerns about the care receiver: identifying needs, problem solving, and referrals to services.		
Care Partner Coaching	Helps provide care partners with the knowledge, skills, and tools to support their caregiving role while encouraging balance.		
Geriatric Care Management	A geriatric care manager, usually a licensed nurse or social worker can help you and your family to identify needs and find ways to meet your needs.		
Family Meeting Facilitation	Helps families understand their current situation and plan for the future. Meetings help lessen misunderstandings and improve communication.		
Respite for Care Partners	Provides short-term relief for primary caregivers. Care can be provided at home, in a healthcare facility, or at an adult day center.		

Johns Hopkins University © 2024 All Rights Reserved

## Development of the Care Partner Support Specialist Role

Through an introduction of care partner support, the *Care Partner Support Specialist's primary goal/focus is to help the care partner include a focus on his/her own needs*, by:

- 1. Creating a safe and private space for the care partner to explore their own needs which will in turn, sustain their ability to provide care longer.
- 2. Exploring self-care strategies and learning stress management techniques
- **3.** Introducing the Action Plan as a tool for establishing self-care goals.
- 4. Exploring additional resources and supportive services which will expand their helping network.







## Pilot Launched at 3 Sites

Meals on Wheels Central Texas (TX)

**Area Agency on Aging of the Capitol Area (TX)** 

Lumeris Health (MO)

Pilot sites were chosen based on the following criteria:

- ✓ Current CAPABLE service site with shown leadership.
- ✓ Provided CAPABLE for at least 1 year & served at least 20 people with fidelity to the protocol.
- ✓ Interest in providing a service to care partners/caregivers.
- ✓ Johns Hopkins IRB and research team to do the heavy lifting on the evaluation.
- ✓ Could reasonably reach the target of 6 to 8 dyads served within 9 –12 months
- ✓ Had internal options for a social worker or other trained individual or have options
  for external organization to provide the Care Partner Support Specialist role.

## **CAPABLE- Care Partner – Integrated Approach**





Registered Nurse



Handy-worker



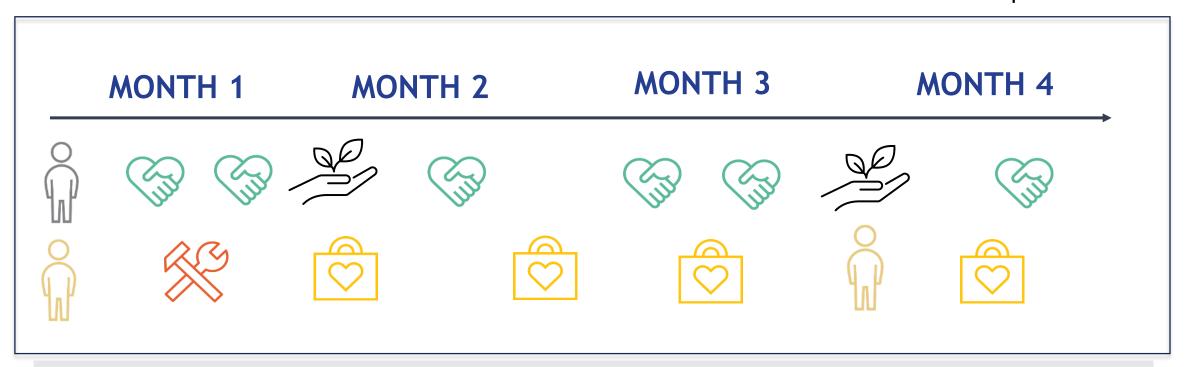
Participant



Care Partner



Social Worker or other trained professional



Visits between the Social Worker & CP/Participant could be in person (preferred), telephonic or virtual. We recommend two visits over the course of 4 months.

## CAPABLE Care Partner Pilot - Pre/Post Data

- 87% of Care Partners responded they learned something that will help them now or in the future during the CAPABLE visits with RN and OT.
- 87% of Care Partners reviewed the Care Partner Resource Folder.
- 81% of Care Partners met with the Care Partner Support Specialist. Of those that met with the CPSS, 92 % rated those meetings helpful.
- 68% of Care Partners reported they learned about additional resources or programs. Examples: counseling, mental health, financial assistance, home/companion care, support groups
- 83% of Care Partners *plan to explore self care practices or caregiver support in the future*.
- 100% of Care Partners rated the program an 8, 9 or 10—using scale from 1 (lowest) to 10 (highest) when asked: How likely is it that you'd recommend this program to a friend or family member?

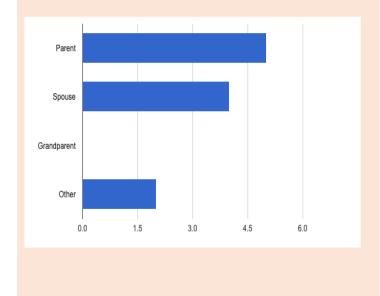
## **Round 2 Interviews Conducted**

A second round of interviews demonstrated strong support for the care partner program across the board. During the key informant interviews, prototype materials (training slide decks & written materials) were reviewed. Interviewees provided suggestions on how to set up in "real world" for feasibility and sustainability. Interviews were conducted with:

- 4 Occupational Therapists
- 4 Registered Nurses
- 4 Program Administrators
- 2 Social Workers (CPSS)
- 4 Care Partners
- 3 CAPABLE Participants

## CAPABLE Participant Interview Data & Themes

11 Participants interviewed had a friend or family member helping with care. They reported their relationship to the Care Partner as a:



Participants liked having their care partner attend some or all of the home visits with the OT/RN:

- "I always like for him to know what is going on. Since he is my caregiver. I just want him to know what is going on."
- "She is my right arm. Learning alongside one another is good."
- "She (wife/care partner) seemed surprised by some of what the clinicians were saying. She was learning things."

#### Overall reaction to the program:

- "It helped both of us. It set us on a path to success... It brought me up a few steps from where I was at. Definitely helped me. And I do think this helped [daughter/care partner] too."
- "Very good program. It was important to have someone he (care partner) could talk too".
- "It is a good idea--having less stress helps"

## Common Themes Clinician, Program Admin, CPSS Interviews

Value of Care Partner Participation in Home Visits	"We hear it from the OTs and the RNs. One of the biggest benefits of having the care partners included, is then those clinicians, have another tool, another person, more information, to better serve the CAPABLE participant."—Program Administrator
Support for Integrating Social Worker into Home Visits	"The social worker is a critical element. And getting them connected. You know, sometimes there are just things that they can do, and especially face to face. I really think that was important". —Program Administrator
Social Worker Needs to be Part of the CAPABLE team	"Need more open communication with CPSS. They should be part of the team."— Clinician "The CPSS/Social Worker needs be part of the team—it is an important part of CAPABLE. And have the [SW and clinicians] interact with each other "—Program Administrator
Resource Folder needs to be tailored to individual needs and local resources	"Care partners need person centered care. One size does not fit all"—CPSS The Care Partner Resource Folder is helpful when it is tailored to individual needs and local resources. "I recommend a simple introduction—timing is important. Need to be flexible and open to care partner"Clinician

## Care Partner Key Informant Interview Quotes

#### Value of CPSS meetings:

"I like the setting of the goals. Because basically that is...how do I put this? I needed a push and for someone to be accountable to"

"They (the CPSS) were valuable in the sense that they gave me someone to talk to...very freely. I felt very comfortable and could say what I was really feeling.

"The CPSS was very helpful. I was at my wits end dealing with a health crisis and was anticipating needing many additional resources"

#### Overall Impact of the Program:

"My relationship with my mom is improving because I am not feeling as much stress"

"Focus on myself, using meditation, and getting a break"

"Self-care is important. That was always a back burner for me and now it is becoming a priority"

# Area Agency on Aging of the Capital Area











#### Area Agency on Aging of the Capital Area

The Area Agency on Aging of the Capital Area (AAACAP) serves older adults, people with disabilities, and their caregivers through a variety evidence-based programs and support services. AAACAP direct services: Access and Assistance program, Benefits Counseling, Long-term care and Assisted Living Facilities Ombudsman services, Care Coordination and Information, Referral and Assistance services. It also contracts with other agencies to ensure the availability of services such as transportation, nutrition, homemaker, and senior center operations. The 10-county service area of the AAA: Bastrop, Bianco, Burnet, Caldwell, Fayette, Hays, Lee, Llano, Travis and Williamson).

https://www.capcog.org

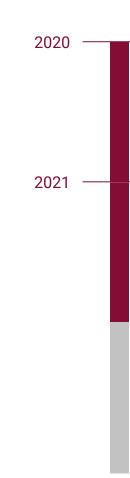


### Implementation of the AAA CAPABLE Program

2020 St David's Foundation awarded AAA CAPCOG a grant for the CAPABLE Program

St David's

**FOUNDATION** 



#### St David's Foundation Grant

Received Grant, but CAPABLE was placed on HOLD due to COVID

## Implementation of the AAA CAPABLE Program

Implementation restarted in 2021 and by July 2021 three Occupational Therapists and two Registered Nurses were trained. AAACAP contracted Occupational Therapist, Registered Nurses and Handyman who worked remotely.

#### **August: Enrolled first two participants.**

By the end of December 2021 AAA CAPABLE Program had enrolled 8 participants. During the first year AAA CAPABLE Program was only in one Rural county of the ten counties AAA CAPCOG served. This was per grant requirements.





St. David's Foundation renewed grant for 2022 -2025

Care Partner Pilot Launch

2026 St David's Foundation is funding 50% of the previous grant for CAPABLE Program

2022 — 33 Participants Enrolled

2023

2024

2025

In 2022, AAA CAPABLE in two rural counties (per grant) of the ten AAA CAPCOG serves

**35 Participants Enrolled** 

In 2023, AAA CAPABLE in four counties of the ten counties counties (per grant) AAA CAPCOG serves.

St David's Foundation did a two year grant for 2024 & 2025

In 2024 enrolled **29 Participants**. Hired a CAPABLE Program Specialist to assist with referrals, Intakes and Screening.

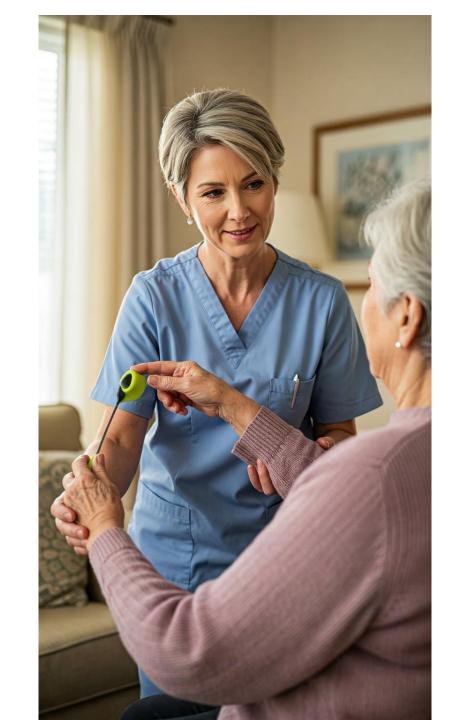
January - April enrolled

Each participant enrolled does the following surveys: Pre-Baseline (Intake), Participant Satisfaction Survey (given at last OT Session), Post-Baseline (completion of CAPABLE), Six Month Survey (Mailed 1 year after starting CAPABLE).

### **CAPABLE Fidelity and Evidence**

## AAA CAPABLE follows the fidelity of the JHU School of Nursing CAPABLE Program.

- The Occupational Therapist makes 6 home visits and the Registered Nurse makes 4 home visits - total of 10 home visits.
  - Minimum of 8 home visits (5 OT, 3 RN).
- Does not replace home care visits ordered by a provider.
- JHU provides comprehensive training and ongoing support.
- JHU provides annual check-in ensures ongoing alignment.



## Pilot Launched - 2023



The AAA Director and CAPABLE Program
Administrator (Social Services Project
Coordinator) were strongly supportive of
the purpose and believed including



AAA already had a seasoned Social Worker who already provided caregiver services through the AAA



Screening question was added to Intake process: ask if they had a family member or a friend who helped them out regularly



For this pilot that SW would serve as the Care Partner Support Specialist



This SW had the flexibility to meet with the care partners in-person, virtually, or by telephone



## Two Case Studies

- Includes Participant in the CAPABLE Program
- Care Partner of the Participant



#### Participant Summary #1 "Paul"

• **Age**: 71

Gender: Male

 Health Conditions: TIA (stroke), neuropathy, diabetes, Parkinson's disease.

#### **Equipment and Support:**

- OT Items: 2 threshold risers/ramps, elevated toilet seat, shower chair with back (installed by a handyman).
- **RN Items**: Non-slip roll dycem, fat-weight pen, writing board/large folding paper, lap desk, ergonomic ballpoint pen.

#### **OT Goals and Progress:**

- Mobility: Improve safety getting on/off the toilet –
   Achieved.
- Mobility: Improve safety and support getting in/out of the shower – Achieved.
- Mobility: Improve safety and independence entering/exiting home Achieved.

#### **RN Goals and Progress:**

- 1. **Fall Prevention**: Improve strength to be more active
  - Partially met (using exercise peddler).
- Mood: Enjoy writing despite Parkinson's Disease –
   Partially met (using a new pen and slant boards).

#### Care Partner Summary #1 "Alice"

• **Age**: 60-69

Gender: Female

- Care Partner's Role: Cares for her husband (Participant ID: AAA002P) who has a TIA (stroke), neuropathy, diabetes, Parkinson's disease, and has undergone three back surgeries (fused disk).
- Caregiving Hours: 40+ hours a week, with increased time due to her husband's worsening balance

#### **Final Assessment:**

• No change in caregiving tasks: The Care Partner continues to provide the same 40+ hours of support per week.

#### Goals:

- Primary Goals: Obtain respite care, reduce caregiver stress.
- Progress: The Care Partner reported being "somewhat successful" in achieving her goals. Care Partner has had a live-in companion for the participant since December, but the companion does not provide direct care. The Care Partner is checking her long-term care insurance for additional assistance options.

#### **Care Partner's Support Tasks:**

 Provided Tasks: Meal preparation, grocery shopping, yard work, transportation, doctor visits, medication management, bill paying, emotional support, clutter reduction, cleaning, and general caregiving.

## Participant Summary # 2 "Peter"

• **Age**: 67

Gender: Male

 Health Conditions: Neuropathy, muscle spasms (pain), Cervical & Thoracic surgery - 2022. HX; brain aneurysm and paralyzed right side. Bed bound, housebound – uses a wheelchair, needs assistance with transfers, mobility issues, difficulty holding items.

#### **Equipment and Support:**

#### **OT Goals and Progress:**

- Improving ADL's: Improve safety and independence with bathing Achieved.
- Improving ADL's: Improve safety and independence with toileting Partially met.
- Mobility: Improve safety and independence entering/exiting home and car transfers –
   Achieved.

#### **RN Goals and Progress:**

- Medication: Understanding all medications he is taking – Achieved
- 2. Fall Prevention: Inability to walk on his own— Partially met
- **OT Items**: sliding chair transfer bench, shower wand w/Cutoff, leg lift w/2 hand loops, toilet safety frame, bidet, gel U seat/foam cushion, bottom buddy, car door handle, aerobic riser, 2 threshold ramps, safety toilet rail
- RN Items: Blood pressure monitor

## Care Partner Summary #2 "Martha"

• **Age**: 60-69

• **Gender**: Female

- Care Partner's Role: Care partner had to quit her full time job to care for her husband (Participant ID AAA004P) who recently had neck & spine surgery. He needed assistance with transferring to wheelchair, toileting, dressing, bathing. She also is caregiver to her three Great grandchildren (ages 5,4 & 3)
- Caregiving Hours: 40+ hours a week, with increased time due to her husband's recent surgery and caregiving.

#### **Final Assessment:**

• No change in caregiving tasks: The Care Partner continues to provide the same 40+ hours of support per week.

#### Goals:

- Initial Goals: Return to work, address spouse's health and health insurance issues, improve health and obtain utility assistance.
- Progress: The Care Partner reported being "Very successful" in achieving her goals. Care Partner brother-in-law is looking into voucher program to provide respite

#### **Care Partner's Support Tasks:**

• Provided Tasks: Bathing/showering, dressing or getting ready for the day, Meal preparation, grocery shopping,laundry, yard work, driving/transportation, doctor visits, medication management, bill paying/managing finances, emotional support, clutter reduction, cleaning, and social visits.

## Care Partner Pilot Wrap-Up for AAA CAPCOG

Difficult fitting in 2-3 visits due to caregiving responsibilities

Needed more Services and resources: AAA Caregiver program



## **AAA Care Partner Adjustments**



AAA CAPABLE now refers Care Partners to the Caregiver Support Program for Caregiver services and additional services.



Initial and Final Assessments are still sent to the Care Partners through the AAA CAPABLE Program.

#### Care Partner Pilot - Additional Services & Referrals



- AAA Care Coordination Program
- AAA Caregiver Support Services

   (includes grandparents or non parent relative age
   55 or older with formal or informal custody of a child age 18 or younger)
- AAA Benefits Counseling
- Texas Ramps
- Aging in Place with Habitat for Humanity
- Legal Aid

- Habitt for Humanity & Easter Seals for home repairs and accessibility modifications
- Transportation
- Caregiving resources
- Food Pantry
- Meals on Wheels
- Food Bank
- Lending closets
- Caregiver Grandparent program
- Utility assistance

# Care Partner AAA CAPABLE Program Referral Process

- At Intake question is still asked if they have a family member or friend who helps them out regularly
- Referred to Caregiver Support Program
- Care Partner's Initial Assessments are mailed to Care Partner
- Care Partners additional needs being met through AAA Caregiver Support Program
- Final Care Partner Assessment mailed to Care Partner





# AAA CAPABLE Program Summary

- The CAPABLE program assists older adults to age 'gracefully' in .their own home.
- It is a free, 4-month program that includes an occupational therapist, registered nurse, and handyman.
- Participants must be 55 or older, live in Bastrop,
   Caldwell, Hays, or Williamson Counties, and be able to set their own goals.
- Caregiver support services are also available for Care Partners that adds additional services and resources for the participant and the Care Partner.

#### CAPABLE Enhancement Study #2 - Doctoral Dissertation Research

Adapting CAPABLE for the Caregiver Care-Recipient Dyad with Alzheimer's Disease and Related Dementias (ADRD) and Disability



Emerald Jenkins, PhDc, DNP Student, MSN, RN

**PURPOSE:** To adapt CAPABLE to meet the needs of older adults with co-occurring MCI/early ADRD and physical disabilities and their care partners and to evaluate initial acceptability and **feasibility** of CAPABLE-Family.

## Aim 1 - Results (OT, RN)



Sample Themes	Sample Codes	Sample Quote
Challenges of CAPABLE for Persons with Dementia (PWD) and Care Partners (CP)	Older adults [persons with dementia] lacking support Connection to PCP/care team Lack of Motivation Acceptance of Declining Function/Cognition	"The moment we identify there's an issue, and there's no caregiver or no support, we have to take safety measures in place for this person to be at home, safe"
External supports used by PWD and CP	Alzheimer's Association Transportation Caregiver Support/Respite Educational programs, services, materials, etc,	"Many people don't access the Alzheimer's Association, and they don't just do caregiver programs. They have wonderful support programs."

## Aim 2 - Results: Dyadic Primary Outcomes



Follow-up Characteristics	Older Adult Assessments (n = 7) Mean (SD)	Care Partner Assessments (n=6) Mean (SD)	
Older Adult ADLs	2.4 (2.94)	2.6 (2.36)	
Older Adult IADLs	2.6 (0.8)	5.3 (1.70)	
Pain Interference	11 (3.6)	8 (0)	
Depression Symptoms	4.6 (5.46)	3 (2.94)	

### Aim 2 - Results: Clinician Feedback Questionnaires

"Client is easily distracted by environment, i.e., people coming in and out of house, conversations can have tangents." (RN) (Theme: Session Differences for Persons with Dementia)

"Yes, include the CP [care partner] but don't let them overshadow what the client really wants if it is a safe option" (OT) (Theme: Care Partner Participation)

#### CAPABLE MCI and Early-Stage Dementia - Materials and Adaptations

CAPABLE Team Contact Information Sheet This contact sheet is a resource for the participant and care partner so they know who is coming to the home. It is helpful to have the teams' photos to assist participants with recognizing their CAPABLE team members.

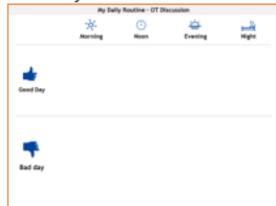


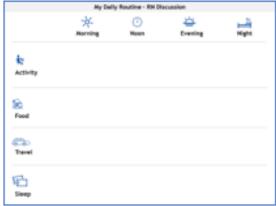
CAPABLE Program Calendar

This calendar included in the participant folder is used to keep track of CAPABLE team member appointments. The Reminder section has various uses, like to record a 'To Do' item or what goal will be discussed next.

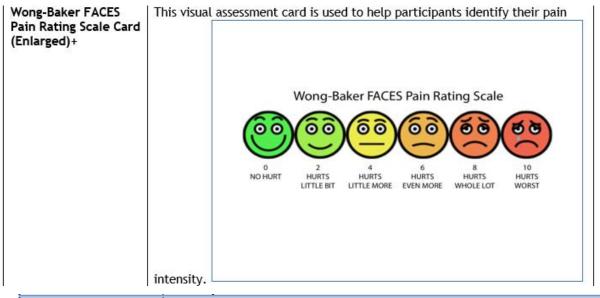


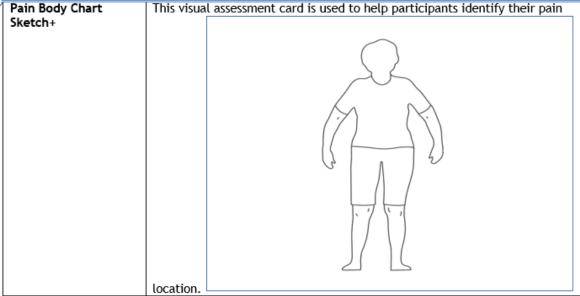
My Daily routine OT and RN Discussion Cards+ This card is shown to participants to help them think about how they spend their days. It is used to discuss good vs bad days and routines.





#### CAPABLE MCI and Early-Stage Dementia - Materials and Adaptations





'Yes/No' and 'A little/A Lot' Cards+	This OT answer card is an alternative to the 4-5-point Likert scales which may be too difficult to process for some participants.				
	Yes		A Little		
	No		A Lot		

#### Care Partner & MCI Enhancements Disseminated:

- 1. Including Care Partner and MCI training modules for clinicians and social worker/support specialists for all licensed CAPABLE sites.
- 2. Disseminating the Care Partner and MCI materials (welcome letter, assessment forms, OT & RN and SW tools, new participant resources, care partner satisfaction survey, and other materials) to all the CAPABLE sites.
- 3. New CAPABLE Social Worker/Support Specialist Manual.
- 4. Encouraging CAPABLE sites to connect to community resources, especially locate and make a warm handoff to caregiver support services and to Alzheimer's disease and related services and education.

#### AAA CAPABLE Participant Memory Issues Case Study

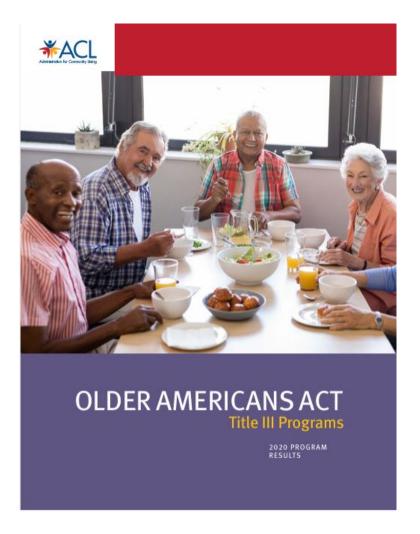
- 81-year-old male, caregiver wife also caring for daughter with cancer
- Health Issues: Dialysis 3x/week, recent double UTI, difficulty concentrating, sleepy
- OT/RN visits scheduled around dialysis, participant hospitalized twice, sessions were shorter
- Last admission, admitted to rehab,
   OT noted cognitive decline
   (5th/final OT visit)
- Total visits: 5 OT, 3 RN



This is an example of how the program had to adapt.
Less visit content per

session, clinicians attentive to fatigue (Dialysis affected him greatly), wife as care partner with health issues

### Implications - CAPABLE Can be/have . . .



- Part of an evidence-based falls prevention strategy and service to assist "aging in community"
- Synchronicity with Caregiver Counseling Title III E program
- Connection to Alzheimer's Disease services in the community and caregiver support

ALZHEIMER'S Call Our 24/7 Helpline 800.272.3900 https://www.alz.org/help-support/caregiving

Potential for referrals/payment from value-based payers



# Q&A & Discussion:

# Let's Hear from You

#### **ACKNOWLEDGEMENTS & DECLARATIONS – CARE PARTNER Study**

**Participants & Experts** – We are grateful for the interest and willingness of the CAPABLE participants, their care partners, and the occupational therapists, nurses and social workers who served them, to provide insights and feedback through individual interviews. We also extend our thanks to the Advisory Group of national experts in caregiving and in the CAPABLE model.

*Pilot Study Sites* – The CAPABLE Care Partner Study Team and Johns Hopkins acknowledge and thank the three organizations that piloted the Care Partner enhancement— including the Area Agency on Aging of the Capital Area (TX), Lumeris/Essence Health (MO), and Meals on Wheels Central Texas (TX). All three organizations implemented CAPABLE starting in 2021 and are seasoned providers of this evidence-based service.

**Funding** – Funding for the **CAPABLE Care Partner Study** and this presentation development was provided through a grant from the National Institute on Disability, Independent Living, and Rehabilitation Research(NIDILRR) to Johns Hopkins School of Nursing [90RTGE0003). NIDILRR is a Center within the Administration for Community Living (ACL), Department of Health and Human Services (HHS). The contents of this presentation do not necessarily represent the policy of NIDILRR, ACL, or HHS, nor endorsement by the Federal Government.

**Study Team** – The study team included: Dr. Sarah Szanton, Dr. Deborah Paone, Jeanne Schuller, and Tiffany Riser, with support from Samantha Curriero.

IRB: This study was reviewed and approved by the Institutional Review Board of Johns Hopkins, #IRB00308713

ABOUT CAPABLE V

WS, EVENTS & PUBLICATION

TRAINING OVERVIEW

CONTACT US V









Community Aging in Place – Advancing Better Living for Elders

www.capablenationalcenter.org (888) 352-9062 CAPABLEinfoscapablenationalcenter.org

