

Resources for Integrated Care
Innovations in Alzheimer's Disease and Related Dementias (ADRD) Caregiver Support
Programs: Innovative Community Strategies
December 14, 2022

Nikki Racelis: Thank you. And hello, everyone. Welcome to the webinar, *Innovations in Alzheimer's disease and related dementia or ADRD Caregiver Support Program, Innovative Community Strategies*. This webinar was rescheduled from its original December 7th airdate. Thank you to those who joined us on the seventh and have joined us here again today. We are looking forward to sharing insights with you all about community-based strategies that support caregivers of individuals with ADRD. My name is Nikki Racelis, and I am with The Lewin Group.

Today's session will include presentations from our esteemed presenters, a panel discussion, and we will close with time for questions and answers. The session will be recorded, the recording and a copy of today's slides will be available at resourcesforintegratedcare.com. The slides are also available to download in the resources pod on your screen. There are two ways to listen to today's presentation. Audio should automatically stream through your computer speakers, make sure that your computer is connected to reliable internet and that the speakers are turned up. If the computer audio option is not working for you, there is a dial-in option. To access this option at any time, click on the black phone widget at the bottom of the screen, a phone number and access code will appear. Calling the number will allow you to listen to the presentation through your phone.

This webinar is supported through the Medicare Medicaid Coordination Office at the centers for Medicare and Medicaid Services. MMCO is helping 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, please visit our website, www.resourcesforintegratedcare.com, or follow us on Twitter. Our handle is @Integrate_Care. You will also find us on LinkedIn.

At this time, I'd like to introduce our presenters. Dr. Karen Rose is the Vice Dean and Professor and Director of the Center for Healthy Aging, Self-Management and Complex Care at The Ohio State University College of Nursing. Her research focuses on meeting the needs of community dwelling persons with Alzheimer's disease and related dementia and their family caregivers. Dr. Rose is active as a fellow in both the American Academy of Nursing expert panel on Aging and in the Gerontological Society of America. She serves on the editorial boards of the Journal of Gerontological Nursing and Research

in Gerontological Nursing and has published extensively in the areas of gerontological nursing and dementia family caregiving.

Katie Scott is the president of CarePartners, a nonprofit organization that provides support, education, resources and respite to family caregivers and older adults. She has worked in health-related nonprofit programs for nearly 15 years. And in her current role, Katie has focused on developing quality programming, incorporating national best practices into innovative intervention for individuals and families to improve their wellness and quality of life.

And Jo Smith is retired with over 30 years' experience in Human Resources. Jo previously cared for her mother-in-law and sister-in-law. She currently cares for her husband, who has Parkinson's disease and Lewy body dementia, and whom she has been married to for almost 38 years. Jo is joining us today as a caregiver panelist during the panel discussion and Q&A portion. Thank you to our presenters for sharing their time with us today.

This event will accomplish the following learning objectives. Identify unique challenges and need for caregivers of those living with 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 that address health equity, and share lessons learned from implementation of community-based Caregiver Support Program over the past 5 to 10 years.

The roadmap for our time to today is as follows. We will start by collecting some information from the audience via two polls. We will then provide some background information about Alzheimer's disease and related dementias, as well as about caregiving. Then, our presenters will share the following presentations, *Assessing caregiver burden and supporting the mindfulness of caregivers and families* and *Volunteer-based caregiver support programs - Innovations from Texas*. After these presentations our panelists will offer their perspective in a guided discussion. Before we engage in Q&A, leveraging questions the audience submit throughout today's event.

If you have questions, please type them into the Q&A box as we go. And we will answer as many as we can. We will close by sharing helpful resources and requesting your feedback on the information shared today.

As noted, we are going to pull the audience before we launch into today's presentation, you should see a pop up on your screen asking *Which of the following options describes your professional area?* The goal of this question is to get a better sense of our audience members today. The options you may select from are Health Plan Case Manager or Care Coordinator, Health Plan Customer Service, Health Plan Administration or Management, Medicine, Nursing, Physician Assistant or other provider, Pharmacy, Social Work and Advocacy. And we'll give folks just another few seconds to respond to the poll.

Great, and it looks like we have representation from all these areas with the majority of you as Health Plan Case Managers or Care Coordinators, and then also Health Plan Administration and Management. So, thank you all for responding to that poll.

Our second poll asks, in which care setting do you work? Again, this information is helpful to our team as we get a better sense of our audience members and can ensure we tailor the information we present today. Response options include Health Plan, Ambulatory Care Setting, Long-term Care Facility, Homecare Agency, Community-based organization, consumer organization, academic or research and other.

And again, we'll wait a moment as folks respond to this poll.

Wonderful, and it looks like a vast majority of those in attendance and who responded are in Health Plan. So, thank you again for participating in those brief polls.

I'd like to take a few minutes to set the stage by providing a bit of background which will ground our time together today. This is a timely discussion as last month we observed National Alzheimer's Disease Awareness Month, as well as National Family Caregivers month. Individuals dually eligible for Medicare and Medicaid are almost three times as likely to have ADRD as people eligible for Medicare only. 20% of all dually eligible individuals aged 65 and over are diagnosed with ADRD. Dually eligible individuals with ADRD are particularly vulnerable to unplanned hospital admissions.

Thinking through the broader impact of ADRD on the general population, social determinants of health are an important factor for health plans to consider when supporting individuals with ADRD. The general population is aging and the older population itself is becoming increasingly older. Over half of persons aged 65 and older live in nine states, with California having the greatest number in 2019.

Moving next to understand unpaid caregivers. In 2015, 85% of individuals with ADRD lived in community settings. Almost 6 million people were informal caregivers for community dwelling older adults with dementia. It is common for older adults to have more than one caregiver. And 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. Passage of the Recognize, Assist, Include, Support and Engage or RAISE family caregivers act in 2017 directed the development of the national family caregiving strategy and established a council to identify best practices and recommendations. The council's August 2019 Meeting identified themes emphasizing the recognition of caregivers' diverse needs, supporting the wellbeing of caregivers, and integrating and empowering caregivers within the health care system.

In September 2022, the council released the National Strategy to Support Family Caregivers. Specific to caregivers for those with ADRD, the national site [alzheimers.gov](https://www.alzheimers.gov) shares resources from the National Institute on Aging, the Administration for Community Living, the Centers for Disease Control and Prevention, and others.

I'm looking forward to some engaging presentations from our speakers. Without further ado, I would like to turn things over to Dr. Karen Rose, Vice Dean and Professor and Director of the Center for Healthy Aging Self-management and Complex Care at The Ohio State University College of Nursing, who will share insights on assessing caregiver burden and supporting the mindfulness of caregivers and families. Dr. Rose, the floor is yours.

Dr. Karen Rose: Thank you so much. It's a pleasure to be with everyone today to discuss one of my favorite topics: how we can further support unpaid or family caregivers for persons living with Alzheimer's disease and related dementia. Next slide, please.

So let me expand a little bit on some of the statistics that you just heard earlier, just to reorient you to how many people really in the United States are living with Alzheimer's disease or related dementia. So, what you heard earlier was that up to 20% of all people who are dually eligible, have a diagnosis of Alzheimer's disease or related dementia. In the general population, that's a little lower 11% over age 65. What we also know is that 13.8 million Americans currently have Alzheimer's disease or related dementia, and that this number is projected to grow. Excuse me, they currently have about 6.5 million, it's projected to grow to 13.8 million, so really a doubling by 2060, which is scary.

So, what you're seeing on the right, then there's a little graph that I pulled together that looks at the age breakdown, if you will, of people living with Alzheimer's disease. And what you'll see then is that the fastest growing segments are really the middle older adults, which I call the 75- to 84-year-old persons. And then certainly the 85 and older are growing at a rate of under expected 2.31 million currently. So really, growth in all segments of persons aged 65 and older, but certainly in the middle and older old seconds. Next slide please.

As we look at caregivers in the United States what I wanted to show you is on the left-hand side, these are data that are encompassed all caregivers across all, all diseases. So, you'll see that about 43.5 million people in the US said that they were caregivers in 2015, this number grew to 53 million in 2020.

We also saw too that this growth from 18% to 21%. That nearly one in five are providing unpaid care to adult with health or functional needs.

Further, we see that more Americans are caring for more than one person needing some assistance, and that number has grown from 18 to 24%. And that more family caregivers have difficulty coordinating care. Again, this number is up from 19% and 2015 to 26% and 2020.

Further, we see that caregivers are caring for more people with Alzheimer's disease up from 22% to 26% in 2020 and then we saw, too, more family caregivers reporting that their health is failing as a result of being a caregiver from 17% up to 21%.

On the right-hand side of the slide, the caregiver statistics there are really very specific for people who are providing care for a family or friend with Alzheimer's disease or a related dementia. And so, in this specific area in this disease 66% of caregivers tell us that they're living with their care recipients. 30% of caregivers are 65 years of age or older. And what that tells me is that many of these people, 30% often deal with their own health needs and chronic disease management. We see that over 50% are caring for a parent or an in-law and that around 10% are caring for a spouse or partner. Next slide, please.

So, we know that Alzheimer's disease and related dementias are progressive, neurodegenerative diseases. So as the disease progresses, we do know increased AD/DR or Alzheimer's disease related dementia symptoms, things like wandering, day night confusion, often becoming more aggressive or paranoid. And so, as these symptoms increase over time, the activities that caregivers need to undertake to keep their care recipient safe and well taken care of increases as well, which can lead to a worsening of caregiver burden and distress. So, the notion behind the work that I've been undertaking is that caregivers really need interventions to reduce their distress in real time. Next slide, please.

So, along this line, we have an ongoing project, titled *Learning and Improving Alzheimer's Patient-Caregiver Relationships via Smart Healthcare Technology*. I provided you information there. If you care to look it up on clinicaltrials.gov, you'll see the identifier there. We do have IRB approval for this certainly from the Ohio State University. And we've received funding for this, four years of funding from the National Science Foundation. Next slide, please.

So, the study purpose and program aims of our study are listed on the [clinical trials.gov](https://clinicaltrials.gov). But I'll repeat them here for you. So, what we have been funded to do from the National Science Foundation is develop a monitoring, modelling, and interactive recommendation solution for caregivers for in-home dementia-patient care, the focus is really on the caregiver and the patient relationship.

And through this, we're going to be monitoring for mood of the caregiver and stress of the caregiver and analyzing the significance of monitoring these for dementia patient care and subsequent behavior dynamics between the patient and the caregiver.

And we're deploying timely behavioral suggestions or recommendations as we call them, with the aim of improving interactions related to caregiving.

So throughout this we have developed, and we have deployed and enhanced smart health technology that uses acoustic monitoring, so vocal recognition, to identify conflict between persons living with Alzheimer's disease and their caregivers. And we aim to provide stress management tips in real time for the caregiver. We're also determining the feasibility and acceptability and efficacy to improve the relationships

using this type of modality. And we're hopeful that we can potentially reduce the stressful effects of the patient's illness and the strain on caregivers. Next slide, please.

So, I mentioned that we're using acoustic monitoring or vocal recognition. And you may ask, how does the voice, how, why don't we use voice as a measure of stress? So let me tell you a little bit about that. So, when we are undergoing stress, you can what we have found out in everyone is that not only stress affects the conversation content, certainly we use potentially different words and grammar. But we can also see other changes speed of the speech, the pitch, the speaking rate. So, you'll see there on the left, when a person experiences higher stress, it activates the HPA. And you'll see hypothalamic pituitary adrenal axis, you may have heard of this, if you remember back to biology. And then what this enacts, then it increases the body's release of cortisol production and release of cortisol, which has two really interactions there. So, to the right, if you follow along, cortisol release, activates the sympathetic nervous system. And this is a system that we often think of as being the fight or flight where we react more rapidly. We have high stress levels we speak quicker we're like more choppy in our behaviors, that sort of thing. And it increases much muscle tension and respiratory rate. Higher cortisol also affects changes in speech production. So, it really is through these changes in voice sound, that we have a proxy for stress. And that's what we're using in our project to measure as a measure of stress. Next slide, please.

So let me overview with you, give you an overview of what our intervention or what our project really looks like. Just start on the right-hand side and move with me from right to left. So, there are three components of the system. And these components are the microphone, the laptop computer, and on the far left, a smartphone. So, when participants speak, the microphone picks up their voices. And when I say participants, that's the caregiver and the person with Alzheimer's disease. So, the microphone picks up their voices. And the voices are uploaded to the cloud for algorithms to identify the emotions that are captured within the caregiver- care-recipient interactions.

When our algorithms detect a mood state, for example, anger, we deliver a mindfulness-based tip through the smartphone to the caregiver as a reminder, to support the caregiver and to help them improve their interactions with their care recipient.

We also use the smartphone to deliver and receive feedback from caregivers regarding whether or not they used our tip, if it worked for them, and to assess their mood states each evening. So, you'll see on the far left, their recommendations or the tips that we give, fall into a couple of different categories. We give them stress management tips, such as taking some deep breaths, doing some deep breathing exercises, taking a timeout, if they're able, doing a quick body scan to see where tension is in their body.

We also have provided them based on their feedback, some pleasure, some ideas for pleasurable activities that they can do by themselves, or with the care recipient at that time. For throughout the day, we provide them with positive affirmations about the

work that they're doing as caregivers, and we provide them too with encouraging words. Next slide, please.

So, a bit of an overview of the intervention of our project. So, we certainly screen people for participation. So, they need to be able to understand English, although we are looking at modifications to that make it more accessible for other patient populations, particularly Hispanic patient populations. So, we screen them, we certainly consent them to be a part of this study. And then we have been mailing them the system setup. So that includes the microphone, the laptop, and the smartphone, our original plan, pre-COVID, was to deliver these to individuals and to do some of the training in their homes. COVID had us really pivot that notion because we didn't certainly the older adults were among the most vulnerable during the pandemic. So, we didn't want to interfere or certainly not adhere to guidelines. So, we've been mailing the equipment during the baseline period for up to one month. That really is the time for us. And what I mean us, our system, to understand the different voices of the people. So, for example, if the care recipient and the caregiver are the two people who are a part of this study, we all know that people come to visit right, neighbors, family, all of those things. We don't want to listen, if you will, or play with, interact with, the voices of people, only the caregiver and the care recipient. So, to that end, it's during that really one-month period that we're doing all kinds of background system checks to be sure that we are on that we're understanding exactly, that our computers understanding really, who the caregiver is, they can label them as caregiver and who the care recipient is as well. So that's a lot of what's going on during that one-month period of time. During the three months and implementation period up to three months, that's when we're fully enacting all the recommendations, all the tips, asking them questions throughout the day if they received the tip, if they did it, those kinds of things and really monitoring for mood. And then at the end of the intervention or the study period, that's when we are administering surveys for them. We use a myriad of very reliable, readily available, surveys and then we do an interview really to get their sense of how well the system's met their expectations, how they think we can further refine the systems and just to hear more from your perspective. Next slide, please.

So, while this is an ongoing study, what I can share with you are some interim results. So, we have seen improvements in depressive symptoms, anxiety, and stress in caregivers, we've seen less reactivity to care recipient behaviors, despite there being no reduction in the frequency, if you will, of these behaviors. Caregivers have told us they've gained insights into their own behaviors and ways that they can better interact with their care recipients. We've heard repeatedly that the use of timeout, was very helpful, just a reminder to step away when their stress levels were really high. And we heard too, that the daily affirmations that we send to the caregivers every morning, really help them set the stage for them wanting to have a positive, supportive day. Next slide, please.

So, what we've learned along the way, as well, there are issues certainly with technology. And so, we've had participants who have been very technologically savvy and literate and are so excited and want to give us feedback on software and all kinds of things. And we've had caregivers, I will tell you, the majority, have been caregivers who have not been very tech savvy. So, what we've had to really think through and do some pilot testing was, what are some ways that we can help caregivers understand and not be overwhelmed by the system, because certainly the setup of the system, setting it up to our router, that sort of thing, we've had to really think through best ways to do that, from a distance. We have oftentimes worked with other family members, maybe a daughter, or son-in-law, whomever that might be, who they believe is more tech savvy and can help them with the system set up. Next slide, please.

What we've heard overwhelmingly is that caregivers don't have time. And so, this is not surprising. Certainly, we understand this in the literature. And we've seen this and many other projects. What's been striking is that in the moment, to ask someone to take some deep breaths, they don't have they believe they don't have time to do that. So, it reinforces to us the need for any interventions to be very quick, very easy to understand, and something that they can do without the need for additional equipment, or anything else. So, it's been it's been eye opening. We've understood too, that they've had difficulty answering messages sent in real time, right after the mood detection, which makes sense. So, we've played around a bit with how soon after we send a recommendation, so we send a follow up survey asking: "Did you receive it? Did you enact? Did you enact the mindfulness?" So, it's really been quite interesting for us to understand more fully the time-sensitive nature of the work that the caregivers are undertaking. Next slide, please.

We've also understood and knew this going into it that emotions are really complex. And so even if I were to ask you right now, "how are you feeling?", What you might tell me, and what I might perceive could be different. People have very different insights into their own emotions. And so, asking a computer through machine learning, and algorithms to detect it, we anticipate that they're never going to have a one-to-one match. So, what we've been doing to help with that to help improve our algorithms, we've been going back through it and using, looking at what the algorithm is say we've been manually coding them. And what we've come to come to understand is that oftentimes when people are angry or upset or in conflict, they're not vocalizing, it. They're stepping back, they're stepping away from and certainly if we, if our system that is relying on vocalizations, if people are silent, you know, we have no chance of identifying that mood state. So, these are some questions that we have into and some opportunities for further refining our system. Next slide, please.

So briefly, in summary, consider, I'd ask that technology-based interventions should, could be and should be considered. They provide high flexibility and the potential for scalability as an alternative or complement to traditional in-person services for dementia caregivers. I certainly think that technology is not going to replace interactions

with other people. And that I continue to encourage caregivers to participate in community support groups and support services.

We've heard pretty much 100% of the time that caregivers appreciated hearing compliments on their efforts to support their care recipients. They need some support, [through this pilot program] they're going to hear repeatedly that recognition that they're doing hard work and that it matters. I'd also suggest too that screening for depressive symptoms and referral as warranted, it is certainly needed in this patient population.

Any help we can provide, to assist caregivers with maintaining their own health and well-being is incredibly important. So again, reminding caregivers to maintain their own health maintenance, through regular checkups and vaccinations. Next slide, please.

So, I just wanted to acknowledge our team at the Ohio State, at the University of Virginia, at the University of Tennessee in Knoxville. Thank you. Now I'm going to pass it back to Nikki for her to continue.

Nikki Racelis: Great, thank you so very much, Dr. Rose, for your wonderful presentation on your study. And at this point, I am going to turn it over to Katie Scott, president of CarePartners. Katie, thank you for being with us today. I will turn it over to you.

Katie Scott: Thank you so much, Nikki, and thank you all for joining us today. Today, I will be talking about how we at CarePartners utilize volunteers to expand and strengthen the support system of people with dementia, as well as their caregivers. Next slide, please.

So, CarePartners was founded over 30 years ago, in response to the HIV/AIDS crisis. Our founders had a graduate student who was diagnosed and had little to no support system. And so, our founders asked ourselves, can we utilize the human capital that is widely available in the city to provide the support network that these individuals who are diagnosed need. And from there, they created the volunteer caregiving model. So essentially using volunteers from across the community, to provide the care and support needed for them to continue with their journey. So later on, in our history in 1986, we formalized this concept into what we know as the Care Team. And so, we were able to provide care and support through this care team model, which I'll describe in a bit, to the HIV/AIDS population for a while. And then we asked ourselves, can this apply to other groups?

And so, in the early 90s, we said, let's try this type of volunteer caregiving model with individuals with dementia and their family caregivers. And since then, that has been our primary focus. We're focused on serving older adults, individuals living with dementia, and their family caregivers across Greater Houston. We have our basic Care Team model, but we also added support groups, education and most recently, a dementia day center and care consultation into our service mix. So, before 2020, we utilized

approximately 2000 volunteers to serve about 3500 individuals annually. But like many nonprofits, particularly those serving older adults, COVID-19 really impacted our services. We had many site closures due to insufficient volunteer support and mandated reopening delays. There's a continued fear of COVID-19 spread in congregate settings. And we had reduced capacity at each site related to social distancing and COVID-19 risk reduction protocols. So, in 2022 we project that we will have utilized 1700 volunteers to serve about 2000 individuals this year. Now we work primarily with family caregivers whose care recipients live in the greater community. Some are in personal care homes, but very few are in residential or institutional care. Next slide please.

So, what is the Care Team model? So, its purpose is to create a compassionate service of companionship and practical assistance, utilizing skilled volunteers. Truly, the goal is to expand the support network of a family in a way that makes sense for the community they live in. So, it's a very broad concept, but that is intentional and allows for adaptability. It allows us to provide volunteer caregivers in ways that make sense to the situation. So, there's different models of care teams, and we'll discuss those a little later. But overall, there's really positive impact and similar impact across the different types of care teams we offer. You'll see reduced caregiver stress, improved ability to manage caregiving responsibilities, expanded support networks, for all involved, as well as reduced social isolation. Next slide, please.

So, the Care Team model has different components, depending on the type you're implementing, but there are some basic necessities to make this a successful volunteer caregiving product. And so, the first is partnership and partnering with an entity with a strong volunteer network. So, the Care Team model that we developed originated through partnerships with faith communities, including churches and synagogues. There were many volunteers that had ministries that were focused on care work. However, the model has evolved, and partners need only to have a strong core of volunteers for success.

The next piece is really about management as a volunteer caregiving care team. So, what we provide is professional oversight of all activities. CarePartners assigns a staff person to manage client intake. We are assessing what are the client's needs? What are the caregivers needs? We process volunteer intakes, we provide training, we troubleshoot, and we create policies and procedures to ensure the safety of everyone. At CarePartners, we usually have one CarePartners staff member assigned to 12 or 15 care teams for oversight.

Another key component is volunteer team leaders to provide programmatic oversight. So, they are going to be focusing on what specific care aspects are you providing in this particular care team? What activities are you going to be doing with the person that you're caring for.

And then finally, we need to ensure that there are enough volunteers to care for the needs of the people that you're serving. Typically, in our programs, that looks like a one-

to-one volunteer to client ratio, give or take one or two, depending on the program that we're implementing.

We do require a lot out of our volunteers. First, we want to make sure that they are willing and able to provide basic supervision and companionship, we do not provide any activities of daily living care, that's considered skilled care. All volunteers must participate in required training, including initial training, which is typically multiple days, quarterly continuing education, as well as annual refresher trainings. And all of our volunteers undergo background checks, and report hours and visits at least monthly. Next slide, please.

So, we've had a variety of Care Team models across our history, but currently we have two that are active and running. The first one is our gathering place. And this is a half day activity program for individuals specifically having dementia. We offer the gathering place at 41 different sites across Greater Houston and partner locations will host these programs so there's no charge to CarePartners. The best way to describe it is a mini adult day center, without the skilled care. They run from approximately 10am to 2pm. They include planned social, mental, spiritual, and physical activities, as well as lunch. And volunteers are interacting with members, providing socialization, companionship, and supervision so their caregivers don't have to.

The gathering places are offered once or twice a month at each site. These are very time and resource intensive, as we usually provide care for 15 to 30 people at each offering. And so that is why a lot of our partners are only able to commit to once or twice a month.

In our second family program. This is our in-home companionship program for older adults. It is not dementia specific. Older adults can live either by themselves, or with family members. In fact, about 65% of the older adults enrolled in this program live alone. We have eight care teams across Greater Houston and in these care teams, volunteers create care circles of about 3 or more volunteers to provide various care and support to older adults in their home. Volunteers often trade off responsibilities or days to provide support. They will do things such as companionship and supervision in the home, providing transportation to doctor's appointments, escorting to the grocery store, and things of that nature. The intensity varies depending on the needs and the abilities of the care team. Some individuals may be visited multiple times a week, some only once a week, it just really depends on the care team, as well as the person that they're serving. In both care team types, the caregiver has the option to stay with the individual that they're caring for, or they can leave. So, this is the family caregiver. So, the family member can stay at the gathering place and participate in the activity program. Or they can go engage in some self-care activities, everything from doctor's appointments, grocery shopping, to a little self-care, like naps, or beauty appointments. And same one second family, we really want the caregiver to feel comfortable in whatever way they can to engage in their self-care. Next slide.

So, I outlined why the volunteer-based programs are important from an impact perspective, you see reduced stress, you see reduced isolation. But there are also financial implications. With many of you working at health plans, you understand the cost of long-term care. We know long-term care is expensive, and it's only going to get worse. And if you think of some of our cheapest long-term care options, which are adult day centers, you're still looking at anywhere from \$13 to \$18,000 a year. When you get into nursing home care, you're looking at anywhere from \$70,000 to \$123,000 per year. And most of this is out of pocket.

And so, our care team programs are a potential supplement for long-term care. Long-term care will not be replaced by volunteer caregiving. They're just aspects of skilled care that simply are not quite feasible for the care team model that we developed. But there are opportunities to potentially supplement care to reduce health care costs, not only to the family, but also to the system. For example, if you look at a gathering place, the gathering place cost CarePartners \$10,000 a year to operate. Well, that is one gathering place at one of our sites. At that one site, each month, they can serve 30 individuals. Now it's not always the same individuals each month. But if we're serving 30 individuals and they're getting a half day of care, and that's about four hours, you're looking at providing trained companionship and supervision for approximately \$7 an hour. That's a great asset and a great alternative than some of the more expensive long-term care options. If someone doesn't need that skilled care. You see similar options with second family care team. Think of the transportation costs if you have a client who needs to get to the grocery store or needs to get to a doctor's appointment, utilizing volunteers to bring them to and from can be a cost savings not only from the cost of transportation, but also thinking of the health outcomes later on in life because they are getting the preventative and maintenance care that they need.

A lot of our families utilize these volunteer-based programs to supplement the long-term care that they have. So, our care team programs are offered free of charge to our families. We do have a licensed adult day center that does have a fee. So, some of our families will participate in both the licensed adult day center as well as the gathering place. They may go to the licensed adult day center three times a week and the gathering place twice a week. And that allows them to stretch their dollar a little further. Next slide please.

So, when I first described the care team and the purpose, I was focusing on it being a broad concept and going back to that concept of adaptability being key. We want to be able to use these models and adapt them as we see the changing needs of the people that we serve. So right now, we are trying something new. With seed money from www.elderabuse.org, we have established the Carmel B. Dyer Second Family pilot program. This pilot is designed to address social isolation and older adults at high risk of elder mistreatment and an under-resourced, predominantly African American neighborhood in Houston.

Now, this pilot has all the basic components of our second family program with a few modifications. Typically, in your second family care team, you will have volunteers all from the same partner. In this instance, we are pulling volunteers from multiple outlets. We have volunteers from a local congregation, as well as Rice University students engaging with older adults in their homes. We've also added the option to connect with an older adult via phone at least once a week so that people can remain connected even if they can't physically get there in person.

We're also adding additional training on elder mistreatment and exploitation. So, the volunteers are better equipped to identify concerns and identify potential risk factors before they become a problem. And then volunteers check in more regularly with care partner staff so that we can make sure that we're addressing the needs of those family caregivers, and individuals. Next slide, please.

So, in general, we think about what are the things that we've learned over the years. We started our caregiver care team model back in the 80s, serving the HIV/AIDS population. We've transitioned throughout our history, looking at different opportunities across the board, different populations to serve. And though we've had many different iterations of the care team, there's some key components that we have seen across how we work. So first, you want to identify partners with aligning missions and values. And so that's really key. If your partners are not committed to this work, you're going to see them drop off. The graphic that you see on our screen is a snapshot of our partner locations, excuse me across Harris County. As you see, we go beyond the Greater Houston city limits and out into other counties. And we're able to do that because our partners are strong and strongly aligned with our mission.

The other thing you need to consider is assessing infrastructure needs and resources regularly. COVID was a great teacher for many of us. And it taught us at CarePartners that we need to consistently assess how we serve folks. Because we were constantly assessing and adapting our need, we were able to pivot quickly when COVID hit. Instead of your traditional gathering places and in buildings, we had drive-thru gathering places where volunteers were masked and talking to people in cars. We did porch visits, we provided virtual activity programs online on a regular basis, as well as activity kits. And so, it's really key to see what's happening and what you are able to provide.

Another key component is developing guiding principles. And so, these are principles that I recommend formalizing, in an MOU, a contract or a covenant, so that people understand who is responsible for what and what roles each individual as well as each entity is playing in this partnership. It also ensures that the program can weather any personnel changes.

I also recommend engaging in training support on an ongoing basis. We see the needs of the people we serve changing regularly. And if we continue to make training and support a priority, our volunteers are equipped with the information and resources they need to continue providing the best support for those we serve. It also allows you to

provide opportunities for personal center care. For example, if someone is serving someone with Lewy body dementia, we want to ensure that they know the specific aspects of Lewy Body Dementia versus Alzheimer's disease or another type.

Another key component is collect data. So, if you're hearing from a partner that they want to start a program like this, make sure data collection is part of the planning process. We developed a process to collect outputs and outcomes on a regular basis. And it helps us to tell our story, it helps us to tell the impact. And I would highly recommend considering ways that you can collect data related to health care or health outcome to really impact the story and message to healthcare systems.

And then finally, communication is key. You need to communicate regularly between partners and volunteers. This way the support system and network that you are providing for the families that you're serving is really, really well-connected. We all know what's happening. We know if there's changes in care that need to happen. We also want to communicate regularly with donors and leadership across our community, so that everyone is staying abreast to the needs of the family caregivers, and individuals with dementia. As both Nikki and Dr. Rose brought up, there are a lot of issues and challenges facing both populations, and donors and leadership and partners and volunteers all need to be ready to step up to support.

So, in general, care teams are a great resource, can be a great supplement for long term care programs. And we've learned a lot over time. And the key thing is to make sure that you are able to utilize this wonderful, wonderful resource of volunteers in a way that best serves the needs of family caregivers and people with dementia.

The next slide, and I will pass it back to Nikki for our discussion panel.

Nikki Racelis: Great, thank you so much Katie for sharing your knowledge and so many lessons learned. And also thank you to Dr. Rose, and both of our speakers for sharing your thoughts on community-based support for caregivers and individuals with ADRD. We will now move into our panel discussion.

So, the first question is for all panelists. So, Dr. Rose, Katie and Jo, starting first with Dr. Rose, what top two or three recommendations do you have for unpaid caregivers who are struggling to navigate the complexities of Medicare and Medicaid coverage, and other social programs? For example, SNAP Social Security and guardianship?

Dr. Karen Rose: Great question. Thank you. I think I'd first say, for family caregivers to take good notes. Our memories don't always serve us well. They're dealing with so many things. So, taking, jotting down notes of what you, who you spoke to, and what they said, and I think helps. If there's one spokesperson. You know, oftentimes family members many are involved with if there's really one spokesperson who's taking charge, that can be helpful as well. I'd say to the family caregivers: give yourself grace, you're doing incredibly important work. And there will be times that maybe you drop a

ball or two. But I'd say pick them back up, know who your support systems are, and where you can obtain accurate information.

Nikki Racelis: Thank you, Dr. Rose. Katie, would you like to provide your perspective next?

Katie Scott: Yes, I would simply tell family caregivers: ask for help. You do not have to go it alone. And there are resources available in the community. There are free resources. There are many communities that offer caregiver consultation to local area agencies on aging and other nonprofits. There are also other resources that offer it for a fee. And so, they don't have to do it alone and find the people in your community that are the best and trusted resources.

Nikki Racelis: Excellent, thank you Katie. And Jo, could you please share your thoughts to this question? And Jo, you might be on mute.

Jo Smith: Can you hear me now?

Nikki Racelis: Yes. Loud and clear.

Jo Smith: Okay. Sorry. I was on mute in that. Well, when I first, we were first diagnosed, I, even before that, I had taken care of my mother-in-law and sister-in-law and gotten them through the Medicaid process. And so, I had to educate myself on Medicaid costs driven by income, I did internet research on limitations for and gathered appropriate paperwork, for example bank records, salary limit, EOB, different things that are required for the Medicaid process.

And then in doing that, you have to find the proper insurance, the right insurance that fits them. So, during the advisory group, I reached out for help on, on comparing insurance programs like Medicare Advantage plans, if you will. And you compare four or five of them and see which one best suits your needs. You also have to make sure that your doctors are in the plan that you choose. And that medications are in there as well.

Because not all insurances pay for, you know, the same doctors and or medication. And then, you know, just mainly educate yourself on all you can do. Like in our case, Lewy Body dementia, and Parkinson's feed off of each other. In doing that they affect, hearing and eyes and all different kinds of things. So, I'm a big advocate of learning all that I can, in order to drive what I need to do.

Nikki Racelis: Wonderful, thank you so much, Jo. And for your recommendation, regarding finding the best coverage for you, folks may also be able to leverage their State Health Insurance Assistance program or SHIP, which aims to support Medicare eligible, excuse me, individuals when making benefits or care decisions.

So, this next question is for Dr. Karen Rose, for caregiver support programs that would like to offer and implement technology for the people they serve, what are next steps?

Dr. Karen Rose: Sure, so that's, that can be challenging, I think that probably the first big step is to understand access to technology and whether or not your audience you're trying to reach has good access to broadband, you know, that sort of thing, because I still maintain that a telephone can be high tech. So, I think that, you know, understanding that piece is something that's really important.

I think being prepared to support people with computer and technology literacy challenges. Not everyone, even if they have access to broadband, understands really how to use it. So, I think you need to be prepared to support people. And what I mean by that is, is that if there's a helpline that they actually speak to a real person in real time versus been being put in a queue to or to an automated call, because people get frustrated quickly, and then just give up on it.

Nikki Racelis: Thank you, Dr. Rose. Our next question is for Jo. Jo, what are two or three services or supports that has been most helpful to you as a caregiver?

Jo Smith: Well, at the very onset of my husband's diagnosis, I knew that I needed help. So, I sought out a counselor for myself. And it was a lifesaver. She's the one who introduced me to CarePartners. I started out going to the seminars that were held at one of the local churches and attended breakout sessions and through her and you know, of course me, we chose the ones that we thought would be more, the most beneficial to my situation. I sure, I attend all the caregiver seminars and breakout panels that I can, I learned about many resources from who I was, what help I needed, doctors that I might be needed or wanted to see. And through this counsellor, is how I learned about seminars and I, you know, connected with CarePartners.

Here, we attend caregiver groups, we have five in a month's time with four attended and we haven't gotten on the second one yet. My husband is having some medical problems, but we will. Those have always also been lifesavers for us because it's the other people that we can relate to and that we can feed off or I find myself, you know, looking around the room when we go to our CarePartners function, and, you know, it helps you realize that you're not alone, you know, there are people. And two of the facilities have breakout sessions called common ground. And that puts you in a setting where you are with other caregivers, and you're able to talk about different situations that affect each of you differently. And, and, you know, for me, that's been wonderful. You know, they just act as support groups for us.

We have volunteers who have taken care of my husband when you know, and they become volunteers. For instance, I'm a person who stays at caregivers' functions, because I've learned to love it, and I get a lot out of it. But should I need to go out and get pedicure, or shop or go to the doctor, they take care of my husband, and I would not hesitate to leave him there without me.

And then my counsellor moved away, I will find a new counsellor. And should I need her I know I could call her, but I need always to talk to somebody, I need to have an outlet where you know, I can get some feedback and know that I'm doing the right thing.

My husband, even on his worst day, once we get to caregiver to do the gathering, he changes. It's given him an outlet, his attitude changes. I honestly don't know where I would be without CarePartners and the relationships that we have formed through this organization.

Nikki Racelis: Thank you so very much, Jo.

Our next question has two parts and is for Dr. Rose and Katie. According to the Alzheimer's Association, Alzheimer's and other dementias disproportionately affect Black Americans, Hispanic Americans, Asian Americans, American Indian and Alaska Native, members of the LGBTQ community and women. Starting with Katie, what specific challenges do people living with ADRD and their caregivers who belong to diverse or underserved communities face? Also, what recommendations? Do you have a health plan to implement culturally sensitive strategies for people with dementia and their caregivers?

Katie Scott: I think one of the biggest challenges that these communities face is that as service provider, we often try to provide cookie cutter solutions that don't necessarily fit with our cultural or community norms around caregiving, around Alzheimer's disease and other dementias. As service providers, we really need to understand and appreciate that different communities have different views, responses, and reactions to the diagnosis of dementia, as well as the role of caregiving. And so, it's really important that service providers engage in cultural competency training. So, there are many training programs out there. There are also opportunities to connect with community leaders to understand what are the most pressing needs.

Often, we will come at a problem and say, well, that's caregiver stress. So why don't you take a caregiver stress reduction class? Well, the stress may be due to lack of access to transportation to get respite. And you only know these things when you ask the question for the people experiencing them. So, I think it's really important that health plans get into the communities that they're serving, ask the questions about what they need, and then think about the solutions that might be best for them, and consider the community views and the differences they have in their responses to dementia, as well as the role of caregiving. Really just boil it down to listen to those people that you're serving.

Nikki Racelis: Thank you, Katie. And, Dr. Rose, do you mind providing your perspective next?

Dr. Karen Rose: Sure. So, I think some of the challenges, particularly in underserved areas, certainly a lack of support services can be incredibly challenging - and challenges

accessing them. If they do exist, how do people access them? Because we know in under-resourced areas, transportation issues can prevent people from accessing resources. Do they have adequate mental health resources that they can access? And I get too, that some things that maybe many of us take for granted, you know, like when we often advise caregivers to go out and get more exercise and eat more healthy, do they have access to safe places, to exercise? Do they have access to the healthy food options? So, I think context is very important and understanding where people are. Recommendations. I just echo what Katie said, listen to people, people know what they need. People know what their questions are, and what challenges they're having. So again, meeting people where they are, and trying to build on people's strengths. I think it's really important. Everyone has as many strengths so building on those, it's a great approach to build trust and to support people.

Nikki Racelis: Wonderful, thank you so much, Dr. Rose. This next question is for Jo.

Jo, from your perspective, as a caregiver, what improvements should be prioritized by support programs, to better address caregivers' most pressing needs or to fill gaps?

Jo Smith: Well, once again, go back to your resources. And oftentimes, we don't get the right equipment that we need. Like for me, when my husband became challenged in his walking, in getting in and out of the car. There should be resources, or recommendations on where you could get equipment. And, you know, for instance, my daughter went out and bought us a wheelchair, lightweight wheelchairs that I could get in and out of the car, when we needed to go get our COVID shots. So, but just, you know, it comes back to education and learning all you can about the disease. A next step for me is coming up, I've been advised to start looking for a place to transition my husband.

And I will tell you, I'm not ready for that yet. But I have to be, we have to be smart about it and have to look for resources and how they're funded. What it would take from us to have him there. And that's not possible right now, because we are outside of most that financially that any help is provided for. So, you know, and, and I've said, educate yourself and be ready for what, what you when that time comes, be ready for what you need. It's kind of like going back and when I educated myself on the Medicaid process and gathered all of the resources and requirements that they needed. So that's what we're facing right now. And you know, my church is a great, great, great support group for me, but CarePartners, without CarePartners, I would be lost and it's so beneficial to him, though. We'll soon have to face the next step.

Nikki Racelis: Thank you, Jo. Our next question is for Katie, regarding CarePartners' Carmel B. Dyer Second Family pilot program in Houston. What specific challenges have you observed that people living with ADRD and their caregivers in this neighborhood face? Also, what successes have you identified?

Katie Scott: We started this project actually having community conversations. And so, we went out to community leaders just as I was advising you all to do, you know, I put my money where my mouth is. And that's how we started this project. And the things that we really heard were access to services in general, accesses to good, really well-rounded healthcare needs. But then also access to things like technology and transportation, that impact isolation, particularly post COVID. And then we also heard a lot of associated neglect and elder mistreatment concerns, simply because of the lack of support system, and a lot of it was stemming, after COVID and the isolation that so many older adults felt and experienced because of their restrictions in movement simply because they were so vulnerable.

So, our success thus far has been our ability to build on the strengths of the neighborhood and their sense of community and connection. You know, though individuals might be isolated, the community, particularly in this neighborhood, comes together and try to create a wraparound alternative support system for folks when they don't have families. And so, we were able to build on this existing community system and build with the communities of faith and students and neighbors to really create an additional support system for these individuals.

Nikki Racelis: Wonderful, thank you, Katie.

This next question has two parts and is for Dr. Rose and Katie, starting with Dr. Rose, what recommendations do you have for health plan in improving outreach and access to community-based ADRD or care navigation services, other steps that health plans can take to ensure that outreach is culturally and linguistically appropriate?

Dr. Karen Rose: Great question. So, I think, most importantly, is know your audience. So how, you know, think of ways that you can personalize the message, because there's, as Katie said earlier, a cookie cutter approach and a one size fits all really doesn't work. So, I think that that's incredibly important. Having said that, in, for example, in Ohio, knowing that we have a large population of Somalians. And so, we need to have on board people who speak their language. We need materials in their language, and awareness of family dynamics and cultural norms, so that you're speaking to the appropriate people, and you're not turning them off in ways just because you are unfamiliar with their cultural norms.

Nikki Racelis: Thank you, Dr. Rose. Katie, could you provide your perspective next?

Katie Scott: Yes, to piggyback on that, the next step is to become a trusted resource for the community leaders and the populations that you're trying to serve. So, if you are unable to say, provide the translations that you need for the different populations you're working for, find people in the community that can and once the community leaders trust you, they know that you are there for the right reasons, they will then make sure that you are also a trusted resource.

Another thing to consider is make formal connections to the community organizations in the communities you're trying to reach out to, to minimize the burden on family caregivers trying to navigate these systems. For example, CarePartners has been successful recently in creating formal partnerships with healthcare systems. And in these partnerships, the healthcare system simply presses a button, sends an email for a referral for someone who needs additional assistance. And then we as a community organization follows up and that takes the burden off the family caregiver, then this caregiver is then connected to community, pardon me, to resources in their communities where they live, and they can get the support they need as soon as they need it.

Nikki Racelis: Great. Thank you, Katie. And our final question is for Jo. Jo, what advice do you have for other caregivers who want to find a caregiver support program, connect with peers or make other meaningful relationships that can be supportive?

Jo Smith: Well, I would say first of all, find the group like CarePartners and become very involved. I've attended activities, I mean, they have exercises and lunch and entertainment, bingo and they concentrate, for instance, like on my husband, in a, you know, although I'm there with him, because the concentration comes from them and, and it just makes him feel important.

And have to get myself out of the home and connect with other people or go back, my church, I sing in a choir and that is so important to me my faith. But right now, I'm locked in, you know, there are days when my husband and I barely talk and you've got to have some kind of connection, you know, and I don't leave him a lot. But I do need to find somebody, like for instance, I recently had hip replacement, so I'm recovering from that and taking care of him. But, you know, the day of surgery, one of the deacons from the church came and sat with him, took him out to lunch. Those things are important. I have people calling all the time. What can we do for you?

My spiritual support groups are really, really important friends, friends that we've been friends for 50 years and, you know, so it's important, I don't do it nearly enough. I don't get out of the house I, but of course I'm recuperating, as I said right now, but when that's over, you know, I, I'd like to take him on drives. And we used to after church, we just hop into the car and we just drive out in the country and, you know, spend the rest of the day together. And we don't do that anymore. Because it scares me that I might get him out there. And then I think something would happen and I won't be able to take care, so there's a lot of things that go on with this disease that you just have to accept, and, and work on changes and try to fit it in. And it's like, you're in a new relationship. So, honor that relationship. Like I had to learn or relearn, when I speak to him and never say things to him like, "well, don't you remember that? We just talked about that." Okay, do that. And I'm better. But I've got ways to go.

Nikki Racelis: Thank you so very much, Jo.

And a big thank you for the presentations from Dr. Rose, and Katie, and also our speakers and Jo for that engaging panel discussion. With that we now have a few minutes for questions from the audience. If you have questions for our speakers, please submit them using the Q&A box on the lower left of the presentation, type your comment at the bottom of the Q&A box and press Submit to send.

So, our first question is for Dr. Rose. There are unique caregiver and care community challenges in rural settings, where many older adults may live and face ADRD alone. Do you have suggestions for innovative community strategies to support caregivers in rural or non-urban setting?

Dr. Karen Rose: It's a great question. So, I too my parents live in a rural setting. So, I understand this challenge. I think that it's really again, if there's broadband access, I think that opens a whole world up for people. I know oftentimes in community settings, they're incredibly close-knit relationships, through religious groups, potentially, through other civic groups. I'm thinking, like here in Virginia, where my parents are there are rooted groups, there are other rotary groups that can provide transportation assistance, errand assistance, that sort of thing. So certainly, reaching out to those. And I always recommend too certainly Area Agencies on Aging, and that kind of support that they can provide in the resources that they have as well. It is challenging, there's no question. but there are resources, you may have to look a little harder.

Nikki Racelis: Thank you, Dr. Rose. Our next question is for Katie. Katie, how do you incorporate program, volunteer and caregiver feedback to inform your offerings?

Katie Scott: Yes, so we have ongoing volunteer and client and caregiver, informal feedback, every opportunity, I frequently visit some of the sites. We have a staff member at all of our gathering places, so we have those conversations. But then we have an annual survey that we solicit feedback from everyone who is a part of our agency, everyone from the volunteers to the clients, and the caregivers. And we ask them about the impact of the program, how it has helped them and what improvements they can see going forward. We also offer that kind of open forum and dialogue to our partners as well.

Nikki Racelis: Wonderful, thank you, Katie.

Dr. Rose, we have a few questions regarding your study. So, the first couple of questions, what is the scale of the study? How many participants are currently enrolled?

Dr. Karen Rose: The scale? I'm not sure exactly. Maybe the scales that we use the instruments that we use to identify maybe some of the mood states if that's, if I'm understanding that correctly. So, we do use the depression anxiety and stress scale to measure depression, anxiety, and stress. And then we do use the revised memory and behave problematic behavior checklist and that gives us a sense of care of how frequent some of the problematic behaviors are occurring in the person, in the care recipient,

and the reactivity, how distressing these behaviors are for the caregivers. So, I hope I've answered that if that's correct, in terms of how many people have we enrolled, it's a small pilot, we were looking to enroll up to 30 number a little over halfway there. I'd say at this point, it's still an ongoing project, as I've described. So, we're getting there. But I think that all of us in in, in many facets of life, things slowed down in COVID, and rightfully so. So, we're, we're still actively recruiting for the study.

Nikki Racelis: Great. And another question, regarding your study, how many hours a day is the tech system working, and I think picking up on the caregiver and care recipient voices.

Dr. Karen Rose: Sure. So, the caregivers really tell us, they're in charge of that. So, they tell us that they don't want it to start, you know, maybe till eight in the morning, eight in the morning, 10 in the morning, or whatever, and they wanted to stop it 5,6,7,8,9, 10 whatever time they tell us that they're, they're in charge of that. There's also a way that they can turn it off, if they want to, at any time. For example, if they're having, you know, I know over the Thanksgiving holiday, they're having multiple people and this one care recipient, and they just wanted to turn it off, they didn't want to receive any messages. They didn't want anything. And they were able to do that. So, we really, that's part of the system too. We want to give as much control as possible to the caregivers.

Nikki Racelis: Great. Thank you, Dr. Rose. This next question is for Dr. Rose, and Katie. So, starting with Katie, what are some ways to engage caregivers early and to support them throughout the progression of ADRD?

Katie Scott: That's great. And I'm going to particularly speak out to those of you and your care management and as service provider roles. You know, once someone is diagnosed with some type of dementia, encouraging that connection for that caregiver to reach out for help then. I hear on multiple occasions; I wish I had known about you XYZ years ago. And I think the challenge that many caregivers are facing is that they get a diagnosis, I get 10 minutes, and then they just don't know where to look. And so, some sort of warm handoff. And the same way that I described connecting health plans with community leaders to create this kind of trust network, it would be the same thing. Find the trusted resource in your community that can help guide a caregiver through the next steps of the process. And make sure they're directly connected to that, whether that's a formal referral system, like we've established with health care entities, or it's a more informal system. Just let them know that they're not alone as soon as possible and get them connected to those resources as soon as possible.

Nikki Racelis: Thank you, Katie. Dr. Rose, would you like to share your perspective next?

Dr. Karen Rose: I ditto everything that Katie said, I think you're right on target with that. I'd also offer to that; I think that the Alzheimer's disease and being a caregiver for can be stigmatizing. And so, I think that we all need to check ourselves in terms of the words

that we use. So, for example, you know, we now know that people live with Alzheimer's disease, versus people suffer from Alzheimer's disease, you notice the difference there, living with, suffering from and so I think that the words that we use, really do impart some notion of what the disease trajectory is. We all know, people who've been diagnosed early, you know, or wherever they are in the spectrum, still can lead incredibly meaningful lives, maybe different lives than they had anticipated and have expectations for but incredibly meaningful lives. And so, I think that that too matters, the words that we use in the way in which we address caregivers and people living with Alzheimer's disease really matters.

Nikki Racelis: Thank you both. Another question for both of you. Dr. Rose and Katie, what is the best place to start with providing caregiver resources? What do you recommend we address first and let's start with Dr. Rose this time?

Dr. Karen Rose: That's a great question. I think you start first with what people tell you they need. And so, I will tell you that you know, there have been times devised thoughts in my head. I will start here and actually when you talk to people you realize that's wrong. Before we can solve you know, problem C, we need to address problem A first. So, it's I think it's incredibly meaningful to understand some of their questions, you know, what they need right now is maybe assistance with, with transportation, that sort of thing, versus something else that we might think is important in their lives they might need right now, access to free and reduced medications. Maybe that's not something we readily address, that would be important. So again, I just come back to this notion of ask people what they want and what they need, because they're the ones who know best.

Nikki Racelis: Thank you, Dr. Rose. And Katie?

Katie Scott: I second everything that Dr. Rose just said, I had a caregiver, tell me once in a focus group said, we need the right information at the right time. And she was describing situations where at early diagnosis of her husband's Alzheimer's disease, people were giving her information on nursing homes. And she said that simply wasn't helpful. So as Dr. Rose said, ask the questions, and then you'll know where to go from there. But outside of that, I think the first thing they need to know is who, again, going back to who are the trusted sources of information, both online and locally? And so, if you can work out in your community, where are the resources that you want to send people to get the most accurate information on diagnosis, on stages, and on next steps, I think that's also a good generic answer. But I'd prefer to go with Dr. Rose and ask the question, because they know what they need first.

Nikki Racelis: Great, thank you. This next question is for Dr. Rose, could there be an opportunity depending on the real time feedback you get from your study, that support resources can be linked to the caregiver and patient. In other words, for instance, if a particular family is experiencing high stress for a long period of time, as per the

information collected, for this somehow trigger the opportunity to send out counselling or social services support to that family.

Dr. Karen Rose: Love that. And we've considered that, that's great. Right now, that's beyond really our capability. But I think that's a great next step. The challenge for us to them will be to be sure because you all know, resources change. Phone numbers change, contact people, you know, numbers change. And so right now, because we're doing this really across the US, we've been unable to do that. And I think that that's an incredible next step for this system to undertake. Yes, I love that. Thank you.

Nikki Racelis: Wonderful, thank you. And we have run out of time for our Q&A, but thank you to our speakers and panelists for your responses. And thank you to all the audience members who submitted those questions.

At this time, if you have any additional questions or comments, please email us at RIC@lewin.com. The slides for today's presentation are recording and a transcript will be available on the resources for Integrated Care website shortly. Additional Resources referenced during today's presentation are included on the end of this presentation and these references are available to you upon downloading the slides.

Please complete our brief evaluation of our webinars so that we can continue to deliver high quality presentations. This evaluation should only take a moment to complete. Thank you in advance for completing that. Our speakers wanted to highlight a few key resources for you all today. And you can find those on the slide. And then this slide and the next contain references from this presentation.

So, thank you again to our speakers, Dr. Karen Rose and Katie Scott for sharing your engaging and informative presentations and also to Jo Smith for sharing your experience and perspective as a caregiver. Thank you to our audience members for your participation as well. So, thanks and have a wonderful afternoon.