# Meeting the Needs of Diverse Caregivers

## *Applications from the GSA KAER Toolkit for Primary Care Teams*

**GSA Momentum Discussions Podcast from The Gerontological Society of America**

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**Guests:**

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**Debbie Abreu**
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**Host:**

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**Jen Pettis:**
Welcome to this GSA Momentum Discussion podcast episode titled, Meeting the Needs of Diverse Caregivers. Momentum Discussions highlight topics experiencing great momentum in the field of gerontology. We're grateful to Genentech, Lilly, Eisai, and Otsuka for their support of the GSA KAER Toolkit for Primary Care Teams and today's podcast. My name is Jen Pettis and I'm the Director of Strategic Alliances at the Gerontological Society of America, or GSA. I'm pleased to serve as a host for today's Momentum Discussion podcast episode. I'm pleased to be joined by my friends today from the Alzheimer's Association of Northeastern New York, where I'm lucky enough to serve as a board member and volunteer. Beth Smith-Boivin is the Chapter's Executive Director, and Debbie Abreu is the Community Outreach Manager for DEI initiatives. Welcome Beth and Debbie, I'm glad you could join me today.

**Beth Smith-Boivin:**
Thank you, Jen. We're delighted to be here and thank you for all you do for our chapter here at the Alzheimer's Association.

**Jen Pettis:**
My pleasure. According to the Alzheimer's Association, over 11 million Americans provide unpaid care for people with Alzheimer's or other dementias. Family members, friends, or other unpaid caregivers are the focus of this podcast episode. Beth, can you set the stage for the rest of our time together by telling us some information about caregivers in the United States?

**Beth Smith-Boivin:**
Typically, we divide caregivers into two categories. For the purposes of our discussions today we'll be talking about those informal caregivers. Those are generally family members or friends providing unpaid care and support. The unpaid care and support were estimated to be over 18 billion hours, at a numeric value of $339 billion in 2022. Imagine if we didn't have these wonderful unpaid caregivers providing this service to all of us. This would be a monumental expense and burden for the healthcare system. Probably not surprisingly to many people listening today, about two thirds of dementia caregivers are women. In addition to that estimate, one third of those women are adult daughters, and a quarter of them are sandwiched in between taking care of children of their own as well as their parents. The remaining caregivers are typically spouses, and, in that circumstance, they are often older themselves, with their own health conditions to manage as well.

**Jen Pettis:**
Beth, in follow up, it's important to consider that caregivers, just like individuals with Alzheimer's and dementia, come from all races and ethnicities. What does the data tell us about the prevalence of Alzheimer's and dementia, as well as about caregivers in certain racial and ethnic groups?

**Beth Smith-Boivin:**
Alzheimer's disease disproportionately impacts the Black and Brown communities as well as the Hispanic community. People in the Black and Brown community are twice as likely as whites to develop Alzheimer's disease, and in the Hispanic community 1.5 times more likely to develop this disease. We also know that Alzheimer's disease is more prevalent in women than in men. While we wish we had more data on caregiving in diverse communities, we do know a couple of things. We know, for example, that Black, Hispanic, and Asian American caregivers indicate that there are greater demands on them.

They are more at risk for developing depression, and there are fewer resources available to them. In addition, we know that they are more reluctant than their counterparts to accept that help that is available through various agencies, and, as such, they are more likely to develop physical, emotional, and financial burdens because of their caregiving experience.

**Jen Pettis:**
I'd like to hear from you both about a few examples of how the Alzheimer's Association in general as well as how your team locally assists supporting caregivers of certain racial or ethnic communities. Debbie let's start with you. If you could share some work at the local level and how healthcare professionals and others might apply what you're learning in their own work.

**Debbie Abreu:**
From the community level, we target underserved communities by building a presence in the community. We work with grassroots organizations to bring awareness to diverse populations. These communities are unaware of the impact of Alzheimer's and other dementias and are also unfamiliar with the warning signs. We find that professionals tend to focus or have an expertise in their own field, yet they're lacking the knowledge of the impact of the disease. I would like to highlight that professionals are our community members as well. I try to bring in a prevention approach, to the communities and caregivers on how to take care of their brain in addition to disease education.

**Jen Pettis:**
Beth, can you add a couple of examples of work at the national level and, like Debbie, share some learnings that others might apply while they're supporting caregivers?

**Beth Smith-Boivin:**
Absolutely. I'm very proud of the Alzheimer's Association and their leadership in Diversity, Equity, and Inclusion (DEI). In 2019, we revised our last national strategic plan to add a goal that specifically stated no longer can it simply be a value of this organization that we respect diverse communities, and we are an inclusive organization. Instead, we must do the work to ensure that the people in these communities have access to the resources they need. As part of that goal, we created the outreach manager position. We are so fortunate to have Debbie, who is bilingual, here in Northeastern New York as our person who is, as she said, out there providing that grassroots support. However, that's only one step that the organization took with this new strategic plan. In addition, we have a 24-hour helpline, and that is staffed by either master’s-prepared or PhD-prepared clinicians, dementia experts, to provide care and support 365 days a year, around the clock.

We can translate that service into as many as 200 different languages. In addition, 30 members of our helpline staff at the home office call center are now bilingual members of our team. We provide an education program to dementia providers in communities, called Project ECHO. It's an educational outreach program available to primary care doctors and mid-level providers who are trying to do their best to learn more about making this diagnosis. Forty percent of the Project ECHO programs that we've delivered in the past year have been in either rural communities or federally funded healthcare centers. It means that this education is getting to providers who are seeing these diverse audiences. Lastly, Debbie spoke about the warning signs and how few people know about those warning signs. We just launched a new campaign in multiple languages to teach Americans about the warning signs of Alzheimer's disease and dementia.

**Jen Pettis:**
Beth, what's the website where people can find information?

**Beth Smith-Boivin:**
Alz.org. Not only can care partners find resources, but professionals can access information specific to their work as well.

**Jen Pettis:**
You have alluded that there's diversity in many areas that we need to consider when we think of caregivers. We need to think of things like ages, incomes, education levels, sexualities, gender identities. Beth, what are the unique strengths and needs of caregivers from the LGBTQIA community? What advice do you have for healthcare professionals and others to support these caregivers? Think about the strengths and needs of caregivers from that community.

**Beth Smith-Boivin:**
In terms of needs for the LGBTQ community, we see some similarities between this community and our other diverse communities. They complained of finding discrimination when they reach out for care and support services, not unlike the discrimination that perhaps they find without a dementia diagnosis attached. That's really something we're trying to mitigate through education. At a national level, we are partnered with SAGE, and they provide education on a variety of issues to staff around the nation. Our local chapter has partnered with staff from the Pride Center, who provided us with an amazing, two-hour education program from the director of the Pride Center to increase sensitivity and awareness about the issues faced in this population. In terms of strength, I think partnerships with the Alzheimer's Association are a strength because they know that they can find a trusted resource among our team here, as well as trusted information and the loyalty that the community has in each other. There is an enormous amount of support from the LGBTQ community. We often find that care partners come from within their own community.

**Jen Pettis:**
Where one lives is really an important issue as well. For example, you shared with me that here in upstate New York some of your priority areas for the chapter include rural communities, native American reservations, and Amish communities. Debbie, if you could reflect on those communities a bit, what are some unique strengths and challenges for caregivers in these three groups that I mentioned? How are you and your colleagues working to support caregivers in those communities?

**Debbie Abreu:**
These communities you mentioned face barriers to access due to location, cultural, or religious beliefs. We identify the need and find a supportive way to support and serve these communities. We have hired a new rural outreach manager to address these rural communities and identify those barriers. In the North Country, we have identified an indigenous population and have a designated North Country program manager to work with this community. We recognize that a lack of internet access and transportation also affects services including care. We find that caregivers are unfamiliar with the disease, which is why the Alzheimer's Association's free services are vital to support and educate caregivers and families with the tools throughout this journey. We want to make sure you don't feel alone by offering an inclusive approach to assist everyone.

**Beth Smith-Boivin:**
One of the things that Debbie understands and does best is going into these communities. She is meeting with families where they live and where they work, which is the critical part of this. We can't serve these populations sitting in an office. We must meet with them in their local faith-based community centers where they're most comfortable. Debbie has learned how to make those inroads, bringing culturally appropriate food with her everywhere she goes to attract an audience and make sure that she's connected to the people. It has worked! Our numbers have exploded in terms of serving these populations. I will also add that a big barrier to the work that we try to do is the technology deserts that are here in New York State throughout our 17-county footprint and beyond. We have several of our North Country counties that simply can't get our programs by internet, and we have several of them in the Southwest part of our territory as well. We look forward to our politicians addressing this challenge for all of us in New York State. Particularly, if we ever face another pandemic like we did during 2020 and 2021, where really being virtual with people was our only means to deliver the service.

**Jen Pettis:**
This was a great discussion, and I appreciate your time and insights and all that you do for people in our area and their care partners. A few key points that I heard: One was about trust. I heard the theme of trust throughout, whether it's trusted resources, trusted information, and trusted people. The idea of coming to a community, but also staying in the community and engaging with people to build that trust and how important that is to really to be able to serve people that need assistance. I also heard the issue of technology certainly loud and clear that technology's great when it works and when it's available. But in rural communities and other locations, it's just not available to some of our neighbors here in New York State.

I also heard about warning signs, and it's wonderful to hear that your warning signs resources are going to be coming out in multiple languages. But really elevating how important it is to elevate the idea of brain health overall. Not just focusing on early detection but talking about it as we age. Brain health across the lifespan in diverse and underserved communities is such an important message as well. What are some things that I didn't mention that you really would like to leave our listeners with? Beth, I'll start with you.

**Beth Smith-Boivin:**
First, as the Executive Director here at the Alzheimer's Association, I want to make sure that your listeners understand that we are here for all those informal caregivers and to meet their needs. But we're also here for professional caregivers. If there are care partners out there that want to learn more about the warning signs or want to learn more about how we can help the people that they are helping, we are happy to do that. We're happy to connect them to Project ECHO or offer private education for any of those care partners as well. We are the resource. We are here 24 hours a day, seven days a week, and we have a robust website full of information for anybody that needs it.

**Jen Pettis:**
Debbie, how about you? Some final thoughts?

**Debbie Abreu:**
I wanted to reiterate that in the BIPOC (Black, Indigenous, and people of color) communities, they're more affected by this disease, but they're less than likely to receive a diagnosis. Another thing is kind of busting some of the myths. A lot of people think that this disease is affecting only people over 65, and we want to let everyone know that you can be diagnosed as early as your 40s. Brain health is vital because it's affecting people even younger than 65.

**Jen Pettis:**
Beth, any last words from you?

**Beth Smith-Boivin:**
I think ending with brain health is terrific because there are all things that we can do. Get a good night's sleep; follow all those heart healthy habits; stay active and engaged on both a cognitive, social, and spiritual level. You may indeed reduce your risk of developing Alzheimer's disease or other forms of dementia, and that's in all communities.

**Jen Pettis:**
Thank you for joining me and for all that you and your colleagues are doing at the Association to reach and to support diverse caregivers. Thanks to everyone who's listening to this episode of the GSA Momentum Discussion podcast. We hope you found it informative and enjoyable.

**Announcement:**
To learn more about the Gerontological Society of America, visit geron.org. The Gerontological Society of America was founded in 1945 to promote the scientific study of aging, cultivate excellence in interdisciplinary aging research, and education to advance innovations in practice and policy. For more information about GSA, visit geron.org.