Caregiving in the African American and Hmong Communities

Lessons Learned from the Implementation of the Live Well at Home Grant

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Executive summary

Background

The Amherst H. Wilder Foundation Community Services for Aging received a Live Well at Home grant from the Minnesota Department of Human Services (DHS) to develop and test an initiative in the African American and Hmong communities in the East Metro area to:

- Build awareness of caregiving resources within the African American and Hmong communities
- Identify caregiver needs unique to the African American and Hmong communities
- With an effective community engagement process, develop program goals and design a program that results in appropriate and effective caregiving supports in each cultural community
- Implement this program consistent with the community designed plan

Project activities and progress

With the goal of learning from caregivers and community members, as well as sharing information about caregiving resources, project leaders held a wide range of outreach and relationship-building events in the African American and Hmong communities. Events included informational meetings and listening sessions in faith communities, community centers, and schools. Project staff also met with agency staff engaged in similar work, and created culturally relevant leave-behind cards with information about caregiving.

Based on the range of engagement activities with members of these communities, program staff outlined the following four key insights regarding access and engagement:

- An assessment of barriers must address deeper systemic issues
- Outreach must include a culturally responsive approach
- Building relationships takes time and must address cultural and historic contexts
- A family-centered approach is essential

In addition, a review of recent studies and current research about caregivers, combined with information shared by representatives of these communities resulted in the following summary of opportunities for engaging and supporting caregivers in the African American and Hmong communities:

- Provide easy access to information about caregiving services and supports in specific cultural communities, including accurate information in a variety of formats and in multiple languages. Information needs to be responsive to caregivers' specific needs at that time.
- Offer in-home and community-based services that are flexible, trustworthy, and affordable, including those that are available according to a sliding fee scale.
- Provide in-home and community-based services that are provided by staff from the same cultural community, relevant to their cultural norms and practices (e.g., emphasize a family-centered approach), and presented in culturally familiar ways. Expand existing efforts to provide more public funding to agencies delivering culturally specific services.
- Deliver in-home and community-based services that help caregivers put the needs of their care recipients first, and offer practical assistance (such as help with paperwork and translations). Once connected to a service, many use this connection as a pathway for getting information and for links to additional assistance.
- Increase opportunities to connect with health care providers, members of faith communities, friends and family members, and other trusted informal sources to gain culturally relevant support and information. Each potential interaction is an opportunity for information to be exchanged, needs to be assessed, and support to be provided. This would require expanded education to community and health care providers about how caregiver supports can be accessed and who can deliver them in a culturally appropriate way.
- Provide opportunities for connections in intergenerational settings within the Hmong community in order to raise awareness of caregiving within younger generations; provide opportunities for connections in faith communities within the African American community.
- Foster partnerships that strengthen the existing capacity and resources of the cultural communities.

Adaptation of strategies

Prepared with this new understanding, project leaders determined the need for an adaptation of program strategies for the remaining grant period. In consultation with Live Well at Home staff at DHS, Wilder staff developed plans for three guided conversations.

The general purpose of the first two conversations was to share the results of completed work and receive input from members of the African American and Hmong communities, caregivers, and service providers. The purpose of the final conversation was to share the results with policy makers and other agency leaders who may have a broader perspective on this work, and who could support change at the policy or systems levels.

All groups were offered a summary of background information, barriers, and opportunities to engage caregivers, which were identified through project activities, and a review of recent studies and current research about caregivers from communities of color.

Results

While the initial grant objectives changed with a shift in strategies, project team members nonetheless believe that they achieved important progress. Stakeholder meetings to review findings and gather ideas from a diverse range of perspectives yielded dynamic conversations

Observations derived from the third and final convening in the revised strategy yielded the following suggestions for advancing this work:

- Workforce Development get upstream to inform policy, requirements for PCAs, etc.
 - Training in cross-cultural dynamics/approaches.
 - Learn from those who are doing it well.
 - Continue to hear from consumers about what matters to them.
 - Create/develop/adapt services so that services are flexible to meet cultural needs.
 (Example: Senior Linkage Line expand language).
- Health Care Home criteria emphasize the importance of identifying caregivers in these settings and providing a warm hand-off to community resources (caregiver supports) that are culturally sensitive to needs
- Partner and engage with organizations that work with seniors in culturally specific settings.

- Look to partner with faith communities for help messaging and to seek their involvement.
- Use fun events with trusted cultural spokesmen and spokeswomen to engage about caregiver issues. Use comfortable settings with one-on-one opportunities to follow.
- All-white and mostly white agencies need to open the door to allow African
 American and Hmong candidates to enter the work this gets down to how and where the HR departments recruit and review candidates.
- Consider grant proposals differently to be sure that African American and Hmong organizations providing caregiving supports are adequately and equitably engaged.
- Have the African American Caregiver Program at the Volunteers of America provide training and consultation regarding service strategies and approaches.
- Improve the visibility of aging services among and within different cultural communities.
- Social outlets are a good place to go to support Hmong caregivers-work can be inflexible, so churches are good places. Have people floating through the community to provide support. Word of Mouth is important— Hmong Radio is helpful and they are talking a lot about caregiving now.
- Deputize more people to recognize caregivers and educate people about caregiving.
- Need to better clarify what services cost, which ones are free, who is eligible, and how to navigate the payment system for different forms of caregiver support.
- We need to look more closely at where our systems intersect, to see these systems from the vantage point of the caregiver, and ask how they might work better or in a more coordinated way. This includes hospital and clinic care as well as supports at home.
- Continue to expand our caregiver awareness campaigns with more culturally specific messages.

Project leaders believe that they have successfully led efforts to elevate the issues with influential leaders who may guide changes in policy and practice. Key stakeholders and project staff have committed to continuing the conversation and working to develop culturally responsive supports for caregivers in the African American and Hmong communities.

Background and introduction

The needs of family caregivers and importance of this role is gaining attention as caregiving is recognized as the largest source of direct care for the growing population of older adults. Many older adults wish to remain in their homes for as long as possible, and the cost of care for older adults, along with the potential impact on Medicaid and other government resources, requires that family caregivers continue to do the lion's share of this work. But caregiving is stressful and can have a negative impact on caregivers' health and well-being. Supporting caregivers and helping them to continue in their caregiving roles is critically important.

However, supporting caregivers is not a one-size-fits-all proposition. The caregiving experience is complex and dynamic, and depends on a number of factors, including the characteristics and trajectories of diseases or conditions, and the configurations and dynamics of individual family systems. Group identity, family obligations, and additional obstacles related to language and systemic barriers can create unique conditions for caregivers from the non-dominant culture. This is likely to intensify as the population of older adults grows increasingly diverse. The U.S. Census Bureau predicts that in 2060, 44 percent of elders over the age of 65 will be non-White (U.S. Census Bureau, 2012).

Responding to the growing number of informal family caregivers and limited uptake of services by members of communities of color,³ Community Services for Aging at the Amherst H. Wilder Foundation received a Live Well at Home grant from the MN Department of Human Services to develop and test an initiative in the African American and Hmong communities in the East Metro area. Live Well at Home grants are intended to stimulate innovation... [and] test new approaches in home and community-based services development, including strengthening services for caregivers.⁴

The initiative proposed by Wilder's Community Services for Aging was initially designed to achieve the following four objectives:

- Build awareness of caregiving resources within the African American and Hmong communities
- Identify caregiver needs unique to the African American and Hmong communities

Scharlach, A., Kellam, R., Ong, N., Baskin, A., Goldstein, C., & Fox, P. (2006)

² Caregivers to Older Adults, Wilder Research, 2013. p. 32

³ Scharlach et al. (2006), p. 152

⁴ https://mn.gov/dhs/assets/Live-Well-at-Home-Grant-RFP-FY-2018 tcm1053-269733.pdf

- With an effective community engagement process, develop program goals and design a program that results in appropriate and effective caregiving supports in each cultural community
- Implement this program consistent with the community designed plan

This report includes six sections, which describe the evaluation plan, original program model, outreach and community engagement methods, adaptation of program strategies, findings from stakeholder convenings, and summary observations.

Evaluation

Community Services for Aging contracted with Wilder Research to complete a process and outcome evaluation of the initiative, to summarize to what extent and in what ways program objectives were met.

Three key questions guided the evaluation:

- 1. Were strategies rolled out as intended and, if adjustments were made during implementation, what form and function did they take?
- 2. Are members of the Hmong and African American cultural communities being engaged and contributing to the design of new programs and/or methods?
- 3. Do the strategies designed through this process show signs of producing benefits for the targeted communities?

Evaluation activities included:

- Review of internal program records, including Aging Services LWAH quarterly reports
- Review of community meeting records created by program staff
- Semi-structured key informant phone interviews with seven Wilder staff involved in the initiative. (See Appendix J for interview form.)

Following the initial evaluation activities, additional activities completed by Wilder Research staff included:

- Consultation on the stakeholder convenings
- Summary of information about caregiving
- Assistance in facilitation of the stakeholder convenings

Overview of the initial program model

The following section outlines the activities included in the original program model proposed by program staff. The model is also represented as a logic model, located in Appendix A.

To build awareness of caregiving, program staff expected to:

- Conduct initial planning meetings with project partners to assess opportunities within each cultural community
- Identify and engage stakeholders to help caregivers self-identify and bring key influencers to the discussion
- Consult with community leadership
- Host culturally-specific kick-off events to convene a broad group of community members
- Use culturally specific publicity

To identify unique caregiver needs, program staff expected to:

- Conduct outreach to engage current caregivers in a discussion of caregiving experiences
- Identify tools and resources currently available to support caregivers
- Identify barriers to accessing services
- Identify and engage with community champions

To design a community engagement process and develop supports, program staff expected to:

- Host sessions to bring stakeholders together to review and prioritize information
- Identify individuals and next steps for community design sessions

To implement a new program, program staff expected to:

- Develop training and coaching to develop caregiver capacity
- Embed programs into existing or new community programs
- Make resources accessible to other cultural groups in MN

Recognizing the importance of community connections, the project team staff included community liaisons within both the African American and Hmong communities. MOUs were also developed with the St. Paul African American Faith Communities Act on Alzheimer's Action Team (SPAAFCAAAT) and North East Neighborhoods Living at Home/Block Nurse Program.

Activities associated with the original program model are discussed in further detail in the following section.

Description of outreach and community events

The primary purpose of the African American and Hmong community events was to gather groups of caregivers, listen to members of the communities, and learn from them about their perceptions and needs as caregivers.

Staff of the Wilder's Community Services for Aging and Center for Communities and Center for Social Healing made contacts within each community, and then arranged and attended those meetings. Methods for outreach and the format of the events themselves varied according to each community. Demographic information about the people who attended the meetings was not collected. Appendix B presents a table that summarizes the community events.

Information in this section describes the outreach efforts, events, and results for the two communities.

Methods for outreach

African American community

The overarching strategy employed by project staff involved making use of existing community connections, in reaching out to providers and organizations who were currently working with caregivers in the African American community, to inform them of the convenings and the work of this initiative.

Outreach to the African American community included the following methods:

- Personal invitations and contacts in-person, and via email and phone
- Leave-behind information card (See Appendix C)
- On air radio interview with KMOJ

Hmong community

Outreach to the Hmong community included the following methods:

- Outreach by a community liaison hired to facilitate connections
- Personal invitations and contacts in-person, and via email and phone
- Leave-behind information card (See Appendix C)

The purpose of hiring the community liaison was to build relationships and network within the Hmong community, including sharing information about the initiative and collecting information about what members of the community know about available supports and resources.

Description and results of events

African American community

In the first six months of the project, several meetings were held with caregivers and stakeholders within the African American community. While the majority of the communication occurred in the East Metro, some work was completed in Minneapolis with African American communities, in order to broaden the reach of the work.

Seven meetings were scheduled with the following groups:

- St. Paul African American Faith Community Act on Alzheimer's Action Team (SPAAFCAAAT)
- Congregants at Holy Trinity and Camphor Memorial United Methodist churches
- Community members at the Wilder Center for Aging
- Community members at Hallie Q. Brown Community Center
- Community members at Sabathani Community Center (Minneapolis)

Additional outreach was initiated at the African American Leadership Forum Fundraiser Dinner, where team members connected informally with key community leaders. Staff were also interviewed on KMOJ radio, which provided an opportunity to discuss the importance of supporting caregivers, as well as the convenings and the desire to listen and understand the needs within the African American community.

At meetings early in the grant period, facilitators used a World Café model⁵ to engage participants. In later meetings, facilitators showed the documentary titled "Caring for Mom and Dad⁶," and then led a discussion that included reflections on the video. Topics covered included participants' experiences as caregivers, unmet needs and concerns that

Productive, small group discussion within a large group setting can be facilitated with the World Café Method. http://www.theworldcafe.com/key-concepts-resources/world-cafe-method/

Retrieved from: http://www.pbs.org/wgbh/caringformomanddad/about/ Documentary film featuring caregivers in the Twin Cities. Premiered May 7, 2015 on PBS.

are unique to the African American community, and awareness of available resources. See Appendix D for a complete list of questions.

Within the African American community, being intentional about taking time to listen carefully, positioning the work in a respectful way, and focusing on building relationships and trust helped form critical connections with key leaders.

Three meetings were held with three people who identified as "champions" and indicated that they would be able to dedicate time to this work. Ultimately, the champions said they had contributed what they could and were not available for additional work.

Staff members described the work with the champions in the following way:

Some of the caregivers who were also champions were not young people and were in need of care themselves. The volume and weight of dealing with the day-to-day responsibilities related to caregiving was a barrier. And for some, the "what's in it for me?" was not strong enough. Coming over to Wilder for the lunch and yet another conversation, when maybe they could use that time to take care of what they needed to get through the day.

The ongoing engagement we were hoping for from champions was not something that easily fit into their lives.

[One of the biggest challenges in engaging champions] was probably a lack of time and clarity about what was in it for them.

We heard loud and clear that they are busy caregiving. They don't have time.

Hmong community

Wilder staff held six events with members of the Hmong community. A list of questions that were asked during events that involved discussion is included in Appendix D.

Outreach, and awareness and relationship building events included:

- MN History Center (We Are Hmong exhibition)
- University of MN Service Learners
- TC Hmong Alliance Church
- Community School of Excellence (twice)

Staff held one listening session with community members at the Wilder Center for Aging.

Staff also held the following four meetings with agency staff who work closely with the Hmong community:

- CAPI staff
- Metropolitan Area Agency on Aging staff
- Entira East Side Clinic staff
- Wilder Center for Social Healing

Within the Hmong community, early activities served to raise visibility, but making connections with key stakeholders proved difficult, due to language barriers and cultural constructs surrounding the concept of caregiving. Program staff reached out to other providers and stakeholders in the metro area to seek their input on strategies and best practices for reaching and serving members of the Hmong community with questions about the feasibility of community events to speak with Hmong caregivers. Eventually, the strategy shifted to recruiting bilingual service learners to develop opportunities to engage with the Hmong community. Program staff described the conversations with providers in this way:

What ended up happening was that we didn't engage Hmong caregivers, but we engaged <u>around</u> Hmong caregivers.

We had success getting into some really rich conversations, even though it wasn't at our convenings...but we were talking to people who were actually working with the community.

Program staff also gained further insights into the extent to which caregiving is embedded in cultural expectations. In addition, they learned that younger Hmong have a more practical understanding of the challenges of caregiving. Comments describing these insights in more detail include the following:

We learned that the younger generation in the Hmong community is really interested in these conversations, because they are in family caregiving situations and they see this as their role, but they also see the challenges of balancing their cultural norms and their Americanized living.

Going toward younger, college aged adults in the Hmong community to do the recruiting, convening, and host table conversations...proved to be a good strategy.

To bridge cultural barriers, and engage members in a more culturally competent manner, Wilder contracted with a community member who was well connected in the community and who could function as a liaison. The goal was to have the liaison network and cultivate partnerships. The contract with the Hmong community liaison was terminated after less than twelve months, in order to focus on alternative personal and professional contacts.

Adaptation of program strategies

Background

Six months before the conclusion of the grant period and following a wide range of engagement activities that provided information and insight into caregiving, project leaders determined the need for an adaptation of program strategies. Original program goals no longer seemed attainable, given project leaders' revised understanding of the systemic barriers encountered by members of communities of color, which made caregiving more complex and difficult. Program leaders created a summary document, and met with key staff at the MN Department of Human Services and the Minnesota Board on Aging to share new information and to propose a shift in focus for the remainder of the grant period. The summary document and proposal is located in Appendix E.

Following approval of MN state staff, Wilder project leaders developed detailed plans for three guided conversations with key stakeholders. The general purpose of these conversations was to conduct a thoughtful review of what had been done so far and to seek reactions, observations, and ideas from a diverse range of perspectives. The overall goal was to identify ways to improve future practice and policy efforts in support of Hmong and African American caregivers in Minnesota. Project leaders also hoped to raise general awareness of systemic barriers, in order to benefit caregivers in additional communities of color.

Process of engagement

Wilder staff developed detailed plans for the stakeholder convenings, including schedule, format, and suitable attendees. Appendix F provides further detail about the logistics associated with extending invitations for the three stakeholder convenings.

Key stakeholder conversations

The specific purpose of sessions one and two was to share what had been learned from the project engagement work and to gain feedback on this information from Hmong and African American caregivers, service providers, and others directly involved in the work of caregiving. These two hour sessions were held on May 31 and June 1, 2016.

Session three was specifically designed for policy makers and agency leaders, as well as others who might have a broader perspective on this work, including grant makers, planners, and housing providers. The third session was especially focused on what might

be done from a policy or systems level perspective to improve the quality, use, and value of caregiving resources in both Hmong and African American communities.

All groups were offered the following summary of background information, barriers, and opportunities to engage caregivers, which were identified through project activities and a review of recent studies and current research about caregivers from communities of color.

Summary information offered at each convening

Caregiving background

Key information about caregiving was summarized in the following four points as part of a brief fact sheet distributed at each convening:

- Caregivers experience anxiety and stress from caregiving responsibilities. A gradual
 increase in responsibilities can occur before caregivers realize the toll on their health
 and other aspects of their lives.
- Caregivers feel a deep sense of responsibility for their care recipients' welfare, and frequently make significant personal sacrifices of their own time and resources to ensure that care recipients' needs are met. The use of any service by a caregiver is frequently weighed in terms of how it will benefit their care recipient.
- Help from family, friends, and other individuals is the most important source of social, emotional, and (often) instrumental support for all groups.
- The use of formal supportive services by all caregivers is influenced by unique cultural values, group identity, and service barriers. However, since most services, including caregiver services, are designed and delivered by the majority population, the services may not feel appropriate or comfortable to those who are part of non-majority populations.

Common barriers to service use

The following eight barriers included in the fact sheet were cited by project staff and participants as factors that might keep African American and Hmong communities from accessing caregiving services:

Cultural traditions regarding family obligations for care of elders guide much of the Hmong and African American caregiving experience. Caregiving is not usually seen as a distinct or separate role, and it is often a fundamental expectation that is fulfilled without question. Cultural traditions may be harder to maintain among younger generations. In particular, Hmong caregivers do not typically self-identify as caregivers.

Community members described caregiving in this way:

You need to understand the family dynamic with the African American community. You shouldn't focus just on elder or elder + caregiver. Look at the whole family situation.

Generations are taught to take care of others. Family is family. We take care of each other.

Placement [of an elder in a facility] is considered being selfish or being ashamed of family.

The idea of putting someone in a home is because "you don't love me."

Project team members shared the following observations:

The responsibility of caregiving falls on the oldest son and daughter-in-law.

Caregiving in a Hmong family depends on the strength of the family relationship. If parents and children do not get along, then there will be no one to care for the parent. If parents and children get along, then children will care for their parents.

There is no translation for "caregiver" in Hmong.

Caregiving is not a universal construct.

Supports that meet cultural needs, including native languages for immigrant populations and culturally relevant materials are important. Caregivers are more comfortable with connections that occur within their ethnic communities, and in their native languages.

Community members described their desire for culturally responsive services with the following:

People want to go to clinicians and providers who look like them.

When I hear the answering machine in English, I will just hang up.

I received a packet of information with games and activities you can do. Well, those aren't the things that African Americans do in their homes. Culturally that's not what we do. You can't approach it all in the same way. [From MAAA Caregiver study, 2013.]

A lot of Hmong people tend to stay at home and be taken care of by family members. We hear stories of elders not being taken care of at nursing homes or assisted living.

Hmong people do not want to share their issues or problems with people they don't know.

Rice is important in the Hmong diet. Doctors tell elders with diabetes that they cannot eat rice.

Three project team members described this understanding in the following ways:

Having front line staff who are members of the community you are working to serve is essential. This highlights to me the importance of agencies that are led by and staffed by people of color.

I was distressed to hear in the African American community how alienating the experience is when you are dealing with white mainstream providers. There really is a strong need to be able to work with someone who reflects some of your shared traditions.

The unique social structure within the Hmong community results in family caregiving responsibilities almost being assigned according to birth order and gender. We have so much more to learn about what would be perceived as supportive.

A lack of full information about what services and supports are available, and difficulty finding sources of useful information in the immediate community create barriers. Younger caregivers may be more tech savvy and able to use on-line information sources.

Comments from providers and program team members reflect these complexities in the following ways:

A lot of conversations centered around the concern of how does one benefit, like Social Security or SSI, impact [someone's] waiver benefit or Medical Assistance benefit?

There is concern about how much services cost, and a sliding fee scale is a confusing thing both to explain and to understand.

There is a lot of confusion about public resources and a lot of barriers to even finding out more information about them.

The Hmong community does not perceive that resources for them are plentiful, mostly because of cultural and language barriers.

Adult children are helpful for communication. The more education adult caregivers have, the greater the compliance of the older adult.

• Mistrust of established systems in the dominant culture, and reluctance to share personal information and stories keep people from accessing services.

Community members shared the following:

The older generation is private. There was no trust then and not there now.

There are some illnesses that western medicine cannot address.

Some elders don't trust western medicine and seek a shaman for help. This prevents medical care.

One project team member described it in the following way:

They don't have a lot of success in trying to get any kind of public assistance for caregiving, through the county or the state or the bureaucratic resource side. So they do it within their community. There is the whole issue of mistrust of public institutions and having to share all kinds of personal information in order to access any resources from these entities.

• Lower health literacy may make it more difficult for caregivers to navigate complex social service systems and leverage resources in the system. Cultural beliefs about health care may influence connections and access to services.

Two community members shared the following:

Parents do not understand that they need medical check-ups before getting an illness.

Elders think that doctors and hospitals only want to make money.

Concerns about the quality of services such as in-home respite, help with household tasks and personal care services, and misgivings about having unfamiliar people come into their homes keep caregivers from seeking services.

One community member had the following to say:

Mother doesn't want people around the house unless it is spotless. She is leery of strangers. She has become more paranoid. [From MAAA caregiver study, 2013]

Cost of services, especially those associated with respite, home health, housekeeping, and transportation services create obstacles to accessing services. Concerns about how using one service may affect other public assistance may also delay access. The need for providing or arranging for transportation is a burden.

Community members shared the following:

We need services that are affordable, that meet the need.

Basic needs are important!

The hard part is when you can no longer care for someone in the home, and you don't want them to go. The choice is hard, but even harder if you cannot pay for it.

Our communities are experiencing "urban renewal" and people can't afford living there anymore.

Program staff members made the following observations:

There is a lot of misunderstanding and apprehension about the whole benefit structure.

The poorer you are the more transportation issues you have, and the more difficult it is to navigate the system and access resources.

Caregivers may fail to recognize the need for help while managing the daily and pressing responsibilities of caregiving. Many caregivers do not plan to use additional formal supportive services until they see no other option, choosing instead to rely on informal support from family, friends, and non-relatives.

Community members said the following:

We take care of our own.

Family...is more than just birth family, so the circle of care for any older adult is really representing their community...That includes folks form their church, their neighborhood, and their family. That's where they go for services and supports.

Potential opportunities for engaging and supporting caregivers

The fact sheet described seven main opportunities for engaging and supporting caregivers in each community:

- Provide easy access to information about caregiving services and supports in specific cultural communities, including accurate information in a variety of formats and in multiple languages. Information needs to be responsive to caregivers' specific needs at that time
- Offer in-home and community-based services that are flexible, trustworthy, and affordable, including those that are available according to a sliding fee scale.
- Provide in-home and community-based services that are provided by staff from the same cultural community, relevant to their cultural norms and practices (e.g., emphasize a family-centered approach), and presented in culturally familiar ways. Expand existing efforts to provide more public funding to agencies delivering culturally specific services.
- Deliver in-home and community-based services that help caregivers put the needs of their care recipients first, and offer practical assistance (such as help with paperwork and translations). Once connected to a service, many use this connection as a pathway for getting information and for links to additional assistance.

- Increase opportunities to connect with health care providers, members of faith communities, friends and family members, and other trusted informal sources to gain culturally relevant support and information. Each potential interaction is an opportunity for information to be exchanged, needs to be assessed, and support to be provided. This would require expanded education to community and health care providers about how caregiver supports can be accessed and who can deliver them in a culturally appropriate way.
- Provide opportunities for connections in intergenerational settings within the Hmong community in order to raise awareness of caregiving within younger generations; provide opportunities for connections in faith communities within the African American community.
- Foster partnerships that strengthen the existing capacity and resources of the cultural communities. Building relationships takes time and patience.

Key observations from the stakeholder convenings

Key observations from Sessions #1 and #2 (Sessions designed to share what had been learned from the project engagement work and to gain feedback on this information from Hmong and African American caregivers, service providers, and others directly involved in the work of caregiving)

Twenty-seven participants attended the first two sessions, including four specifically representing the Hmong community and nine specifically representing the African American community. Participants responded to the following questions:

- 1. Given the circumstances, experiences, and history of African American and Hmong people within Minnesota, how is caregiving likely to be impacted within this cultural group?
- 2. Besides the demands of caregiving itself, what other issues can make it difficult for African American or Hmong caregivers to obtain needed help? What can be done to overcome these obstacles?
- 3. Given the types of services currently available, what might you suggest to revise them to make them more amenable to the needs of African American or Hmong caregivers? Are there changes needed in how these services are offered or delivered? What else is missing or needed?

The summary of their responses include the following:

- Being a caregiver can be damaging to a caregiver's own health. We need to attend to this, but the terms, "self-care" and "respite" are not well known and sometimes difficult for people to understand.
- Convey information well and often. Use language that is appropriate laymen's terms.
- At our agency, we are trying to make access easier and have moved from a five page information collection form to a one page application.
- People in power like the norm they like the usual ways of doing business. They are not necessarily open to people with differences. They prefer the status quo.
- Need more staff at clinics that are from the cultural communities being served.

- Wages and benefits need to increase for personal care attendants, home health aides, community health workers, and other home service providers to attract more people to these professions.
- There is a lack of complete information and people aren't sure what is available. Complex information needs to be presented in a culturally relevant and accessible way. Brochures are not helpful for everyone.
- Although I have taken mom to clinics and doctors' offices on a regular basis, we've received little or no information about community help or assistance when we visit. More could be done in clinic settings to engage caregivers.
- A volunteer role could be created for doctors' offices that could help persons get resources – a "navigator" of some kind.
- Perhaps churches could create a similar navigator role. Could parish nurses fill this function?
- Provide work force and infrastructure needed to build trust. A lack of trust keeps people from accessing help.
- Build trust in advance, because when you are responding in a crisis, it limits options.
- Focus more engagement efforts on the adult children who are doing much of the caregiving.
- Create plans with regard to the individuals served. No cookie cutter approach no one size fits all. A family wants to know you care, not what you know.
- Transportation is a huge issue. Access to specialized care is hard without transportation.
- It's not just about Hmong and African American caregivers, the bottom line is lack of equity – equality – we could get better service. Providers need to be proactive about addressing these issues.
- Certify competent interpreters. You have to be able to read and write Hmong correctly. Many interpreters are younger people, but there's a lack of understanding. Are these interpreters too young for this population? Interpreters need to know how to use metaphors, examples, etc. Language changes. Hmong and English are mixing.

- The African American community is family-oriented. Hmong families are part of a clan system. There are benefits to being part of a community including the help you can get from family and friends.
- It may be useful to review a recent article in Minnesota Medicine on mistrust in Medicine called "Equity Rx" about provider biases
 http://pubs.royle.com/publication/index.php?i=274367&m=&l=&p=4&pre=&ver=html5#">http://pubs.royle.com/publication/index.php?i=274367&m=&l=&p=4&pre=&ver=html5#">http://pubs.royle.com/publication/index.php?i=274367&m=&l=&p=4&pre=&ver=html5#

Key observations from Session #3 (A session designed for policy makers and agency leaders, as well as others who might have a broader perspective on this work, including grant makers, planners, and housing providers. The third session was especially focused on what might be done from a policy or systems level perspective to improve the quality, use, and value of caregiving resources in both Hmong and African American communities)

Twenty-eight participants attended the final session, including four specifically representing the Hmong community and four specifically representing the African American community. Participants responded to the following question:

1. Where do you see an opportunity to better engage and support African American and Hmong caregivers?

The summary of their responses includes the following:

- Workforce Development get upstream to inform policy, requirements for PCA's, etc.
 - Training in cross-cultural dynamics/approaches.
 - Learn from those who are doing it well.
 - Continue to hear from consumers about what matters to them.
 - Create/develop/adapt services so that services are flexible to meet cultural needs.
 (Example: Senior Linkage Line expand language).
- Health Care Home criteria emphasize the importance of identifying caregivers in these settings and providing a warm hand-off to community resources (caregiver supports) that are culturally sensitive to needs
- Partner and engage with organizations that work with seniors in culturally specific settings.
- Look to partner with faith communities for help messaging and to seek their involvement.

- Use fun events with trusted cultural spokesmen and spokeswomen to engage about caregiver issues. Use comfortable settings with one-on-one opportunities to follow.
- All-white and mostly white agencies need to open the door to allow African
 American and Hmong candidates to enter the work this gets down to how and where the HR departments recruit and review candidates.
- Consider grant proposals differently to be sure that African American and Hmong organizations providing caregiving supports are adequately and equitably engaged.
- Have the African American Caregiver Program at the Volunteers of America provide training and consultation regarding service strategies and approaches.
- Improve the visibility of aging services among and within different cultural communities
- Social outlets are a good place to go to support Hmong caregivers-work can be inflexible, so churches are good places. Have people floating through the community to provide support. Word of Mouth is important— Hmong Radio is helpful and they are talking a lot about caregiving now.
- Deputize more people to recognize caregivers and educate people about caregiving.
- Need to better clarify what services cost, which ones are free, who is eligible, and how to navigate the payment system for different forms of caregiver support.
- We need to look more closely at where our systems intersect, to see these systems from the vantage point of the caregiver, and ask how they might work better or in a more coordinated way. This includes hospital and clinic care as well as supports at home.
- Continue to expand our caregiver awareness campaigns with more culturally specific messages.

The session concluded with the distribution of an action card, and asking participants to consider two things they could commit to as a follow-up on the discussion about African American and Hmong caregivers. Specifically, participants were encouraged to follow up with someone they met at the event or knew in another professional capacity. They were also challenged to determine other ways in which they might use the outcomes of the conversation to inform strategies and policies, and generate new approaches to supporting African American and Hmong caregivers. The sample action card is included in Appendix G.

Conclusion

The following section summarizes progress on the initiative funded by the MN Department of Human Services through the Live Well at Home grant, based on three main evaluation questions.

1. Were strategies rolled out as intended and, if adjustments were made during implementation, what form and function did they take?

The final project objective remained the same—co-creating a culturally responsive caregiving support model that would exist within each community⁷, and program staff believe that they made important progress even as final results of the initiative did not entirely meet original expectations.

With the understanding that caregiving is defined by the unique culture and expectations of each community, one project team member described the complexities related to the topic of caregiving and this work in the following way:

There is still a lot of guardedness among community members about what we are trying to do. The conversation about family caregiving is so simple and normal that there is an element of, "Why are we still talking about this? It is what it is". We just need resources. We are finding in these communities that people are doing caregiving, and that they are doing it well. They need more services and supports. But these are not accessed evenly by all the cultural groups in the Twin Cities. So the expectations of just linking those communities with resources doesn't make much sense. It's not the need for awareness-building. The family caregiver piece is there. It's really understanding what are the most needed resources. We are finding it is around finances and health disparities and access to health care. Some of that access is related to trust issues. It's complicated.

Staff members had this to say about their revised focus:

I think what we uncovered along the way is actually a critically important set of findings, which may not have gotten us to our original outcomes. The project brought to light how complicated the concept of caregiving is in various cultural communities.

Probably it's the right step that we are pausing and sharing some of these observations at the state. For anyone to make any inroads in developing, or even discerning, what is happening in these communities in terms of family caregiving has got to be considered in the context of a lot of other structural barriers related to basic services access. You can't do one without the other.

Aging Network Extranet

Another staff member summarized the process and opportunity in this way:

This is not at all what we envisioned at the start of writing the proposal for this project. We thought we were going to engage the community, get their insights and ideas, and work with them to organically grow something within the community. When we were doing that, we heard barrier after barrier that we, as Wilder and the community, could not change. So the idea was—what if we don't wait until the end of the grant report to share that? What if we have a different convening, and share that information while we are still working on the grant?... I hope that if we can deliver on this, it will have incremental real impact on change. It's that broader group that are doing the service delivery, making the decisions, making assumptions, perpetuating some of these barriers. If we can impact that, I think that will be real and impactful support for these communities.

A revised version of the logic model representing the adapted model is located in Appendix H. Table below outlines efforts and outcomes on this initiative.

Efforts and outcomes of LWAH initiative

Activity	Status in African American community	Status in Hmong community
Conduct initial planning meetings with project partners to assess opportunities within each cultural community	Completed	Completed
Identify and engage stakeholders to help caregivers self-identify and bring key influencers to the discussion	Completed	Completed
Consult with community leadership	Completed	Completed
Host culturally-specific kick-off events to convene a broad group of community members	Completed	Completed
Use culturally specific publicity	Completed	Completed
Conduct outreach to engage current caregivers in a discussion of caregiving experiences	Completed	Completed
Identify tools and resources currently available to support caregivers	Completed	Completed
Identify barriers to accessing services	Completed	Completed
Identify and engage with community champions	Completed	Not completed
>>Objectives and activities assessed. Project direction revised<<		
Host sessions to bring stakeholders together to review and prioritize information	Completed	Completed
Identify individuals and next steps for community design sessions	In process following stakeholder convenings	In process following stakeholder convenings
Develop training and coaching to develop caregiver capacity	Now part of the larger community initiative launched by this project	Now part of the larger community initiative launched by this project
Embed programs into existing or new community programs	Community efforts TBD	Community efforts TBD
Make resources accessible to other cultural groups in MN	Report available upon request	Report available upon request

2. Are members of the Hmong and African American cultural communities being engaged and contributing to the design of new programs and/or methods?

The project team originally expected that the initial community events and key learnings about caregiving would contribute to broader efforts to engage community members and address the complexities of caregiving in cultural communities.

Following early efforts, team members concluded that foundational work surrounding cultural responsiveness and family-centered approaches, and networking and relationship building was critical for developing collaborative efforts with members of cultural communities.

In particular, team members identified the importance of a unique approach that is both respectful and sensitive to the language and norms of the people in those cultures. Family systems may differ from those of dominant culture communities and not everyone approaches caregiving from the same perspective. Support for caregivers must be family-centered and include everyone to be relevant and acceptable.

Project team members also highlighted the importance of relationships, including understanding the culture of the communities and the ways in which people form connections, allowing adequate time to form personal connections, and responding to mistrust in the systems. Efforts to build relationships must include culturally sensitive practices.

Team members captured these concepts especially well with the following:

In a project like this with a community engagement component, if you don't have a relationship with the community, you have to build time into the grant to build the relationship before you can get the information you need.

In cultural communities, the natural ways of making connections aren't the same as in dominant culture communities...You have to work the natural, normal ways of communicating that these communities actually recognize. Sending out 100 fliers or 100 emails is practically a waste of time. But to identify cultural leaders from target communities, and to have them be the leverage point, is a good use of your time.

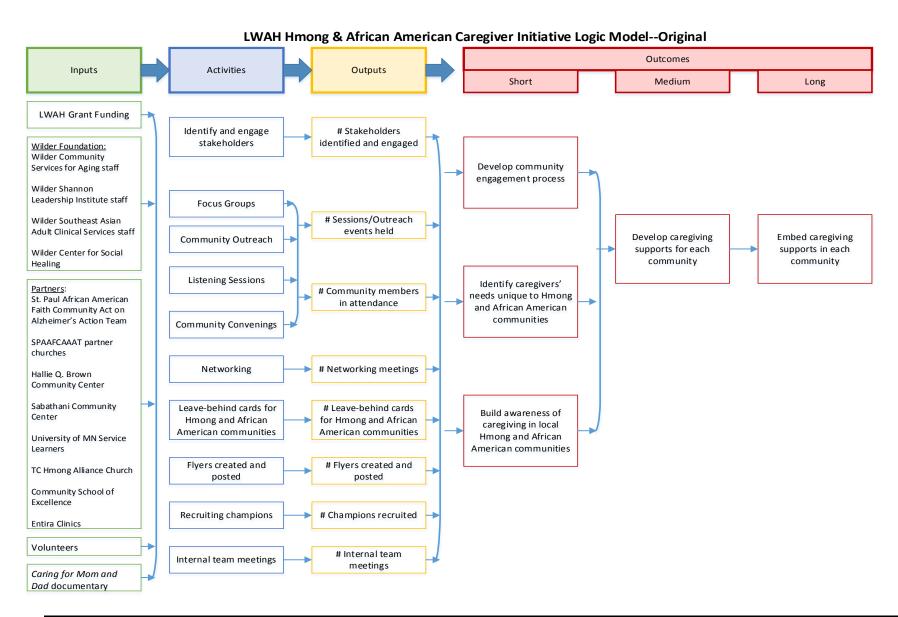
...By asking these questions [about needs of caregivers] it almost invites the recipient to think, so what are you going to do about it? I think this is an unspoken expectation...We may be looking at it from a research or service development lens, but what it looks like from the other side is You are coming in to extract information from us, and what is the quid pro quo?

3. Do the strategies designed through this process show signs of producing benefits for the targeted communities?

Project team members believe that the process of producing benefits for the targeted communities is underway. Early efforts to engage leaders from the African American and Hmong cultural communities resulted in a shift in strategies. Stakeholder meetings to review findings and gather ideas from a diverse range of perspectives yielded dynamic conversations. In addition, many key stakeholders in attendance have committed to continuing the conversation and working to develop supports for caregivers in the African American and Hmong communities that are culturally responsive.

Project team leaders believe they have also made contributions to elevating the conversation beyond service providers to leaders who may influence policy and practice. Additionally, project team leaders are committed to continue supporting and facilitating culturally responsive efforts to address disparities in the African American and Hmong cultural communities, which can come from the communities themselves.

Appendix A: Original program logic model



Appendix B: Community events

Community events

B1. African American community and outreach events

Date	Group	Type of event	Attendance
11/19/2015	SPAAFCAAAT	Community outreach	12
12/11/2015	KMOJ-Interview with Brother Milford Johnson on the Seniors Perspective show	Publicity	NA
12/15/2015	Community Gathering (CSA)	Listening session	5
12/17/2015	Community Gathering (CSA)	Listening session	8
3/6/2016	Holy Trinity Church	Listening session	20
4/9/2016	Hallie Q. Brown Community Center	Listening session	4
6/5/2016	Camphor Memorial United Methodist Church	Listening session	13
6/9/2016	Sabathani Senior Center	Listening session	6
7/15/2016	African American Leadership Forum Fundraiser Dinner	Networking	NA
9/7/2016	Champions meeting	Champions meeting	1
9/14/2016	Champions meeting	Champions meeting	2
10/5/2016	Champions meeting	Champions meeting	2

B2. Hmong community and outreach events

	Group	Type of event	Attendance
12/22/2015	We Are Hmong Minnesota Seniors Tour at MN History Center	Community outreach	35
3/11/2016	University of MN Service Learners	Networking	2
3/28/2016	CAPI staff	Networking	NA
5/1/2016	TC Hmong Alliance Church	Listening session	14
5/20/2016	International Culture Celebration at Community School of Excellence	Community outreach	NA
6/2/2016	Metropolitan Area Agency on Aging staff	Networking	NA
6/9/2016	International Culture Celebration at Community School of Excellence	Community outreach	NA
7/13/2016	Entira East Side Clinic	Networking	NA
11/9/2016	Wilder Center for Social Healing	Listening session	NA
12/7/2016	Hmong Caregiver Café at Wilder Center for Aging	Listening session	53

Appendix C: Marketing materials

Leave-behind publicity cards





Appendix D: Questions asked at community events

African American events

Questions asked at the African American events include:

- What needs and concerns are unique to the African American community that aren't being met?
- What is your experience in providing care to someone in the African American community? What stories are you aware of that relate to this?
- What resources are you aware of for taking care of an older adult? Are there alternative resources that caregivers are accessing?
- What caregiving issues are raised in the movie that are consistent with your experiences and what we've learned so far? What did you see or feel of your experience?
- What new caregiving issues or opportunities are raised in the movie? Is anything else missing in the priorities identified?

Hmong events

Questions covered at the Hmong community events include:

- What does caregiving look like in your family?
- What would be helpful for caregivers you know?
- What resources are you aware of for taking care of an older adult? (Respite, adult day, coaching, classes, etc.)
- How do you navigate services for elders and caregivers?
- What is your experience in providing care to someone in the Hmong community? What stories are you aware of that relate to this?
- What needs/concerns are unique to the Hmong community that aren't being met?

Questions asked at the meetings with providers included:

- What can you tell us about caregiving in the Hmong community?
- What are the challenges you see Hmong families struggling with?
- What are some of the strategies you have tried to engage Hmong families? Why have or haven't they been successful?
- What ideas do you have for locations/connections to host a conversation?
- Is there anything else you think we should know, but we didn't ask the right question?

Appendix E: Proposal for program adaptation

The challenges that go beyond caregiving

The story we're hearing from the African-American community:

It is so difficult to find out about and get access to resources. When I do finally get access, the system is confusing and confining, and I don't trust the people, agencies, institutions, or policies that are "helping" me.

- Much of the feedback we've heard is around the pervasive lack of trust in social service agencies, the state, service providers, and researchers who tap the knowledge of the community and then do nothing.
- There is a desire for service providers who are members of the African-American community that was expressed multiple times by multiple individuals.
- Finances are a concern-there is frustration over the changing housing costs in neighborhoods where families have lived for many years, means-tested services, lack of money to provide for basic needs like nutritious food and transportation, and a lack of money to use the services that are touted as helpful.

The story we're hearing from the Hmong community:

My family doesn't have enough money to pay for what we need, so we try to do it all ourselves. Even if we wanted help, who can we go to who speaks the same language and understands our family?

- Finances come first. Much of the feedback we heard is about how obtaining one benefit (like adult day) impacts another benefit (like SSI). There is a lot of concern over how services impact monthly income.
- Families are utilizing MA and CDCS for PCA services so that caregivers can have some income while providing for the needs of older adults. There is worry about how utilizing other services (like adult day) impacts the income of the family caregiver who is dependent on their PCA work for income.
- Families have a difficult time working with non-Hmong service providers largely because of the language barrier. There is also a reported desire Hmong families have to work with Hmong service providers as it creates an immediate bond and enhances trust. This is reflected in the difficulties families experience with Western medicine.

Proposed model

Sessions 1 & 2 Audience:

- People who have knowledge about what service looks like on the ground
- Voices from the African-American and Hmong communities

Wilder will present what we've learned and additional research to tell a fuller story

Key opportunities and questions that lead to positive and helpful actions addressing the systemic barriers that make caregiving all the more difficult

Session 3 Audience:

- Decision-makers
- Policymakers

Wilder will present the key opportunities and questions identified in Sessions 1 & 2

ANSWERS & SOLUTIONS

Appendix F: LWAH convenings logistics

1. Brainstorm names of people to include

Sample email for inviting people to session 1/2:

Dear

2. Reach out with personal invitations via brief in-person conversation or phone call Sample script:

Wilder is working on some of the challenging issues around supporting African-American and Hmong caregivers. We're planning 2 sets of conversations to share some common challenges and

	talk through some possible ideas to address those challenges. It would be great to have yo perspective at one of those conversations. Can I send you an email with dates and more deabout what we're planning?	
3.	Send follow-up email	

Thanks for taking my call today. As I mentioned on the phone, we have been doing some work as part of a State of Minnesota Live Well grant (these were formerly called Community Service/ Service Development grants). Our grant has focused on the development of strategies to engage and strengthen supports for caregivers in the African-American and Hmong community. As we have proceeded with the work, we have learned that a focus on caregiving by itself is not enough. There are also other issues that must be addressed including the cultural competence of the service providers, strategies for building trust, how best to engage those caregivers who could benefit from additional support, income inequality and service eligibility, health disparities, and transportation problems, just to name a few.

So, as we near the end of the project, Wilder is going to conduct two key discussion groups. For the first, we will gather people who have knowledge about what services look like on the ground including voices from both of these communities to better understand the challenges and opportunities ahead of us.

For the second, we will gather policy makers, funders, and agency leaders to respond to our learnings to date and work on developing solutions based on what we have learned from this project. Our goal is to come away with one or two policy and practice recommendations that can help set the course for strengthening caregiver supports and resources in both communities. I think you'd have a lot to contribute to the first discussion group.

There are two opportunities for you to weigh in on these issues: Wednesday, May 31st from 11:00 to 1:00 or Thursday, June 1st from 6:00 to 8:00 PM. **LOCATION**

Also, do you have any recommendations regarding others we might invite to either of these groups?

Thanks, [name], for your interest and potential involvement.

I look forward to hearing from you.

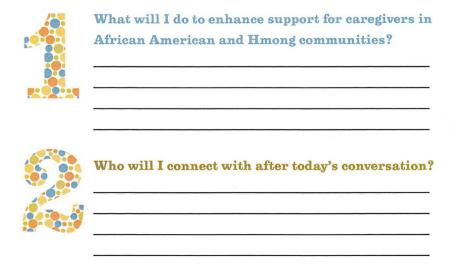
<i>Dear</i>
Thanks for taking my call today. As I mentioned on the phone, we have been doing some work as part of a State of Minnesota Live Well grant (these were formerly called Community Service/Service Development grants). Our grant has focused on the development of strategies to engage and strengthen supports for caregivers in the African-American and Hmong community. As we have proceeded with the work, we have learned that a focus on caregiving by itself is not enough. There are also other issues that must be addressed including the cultural competence of the service providers, strategies for building trust, how best to engage those caregivers who could benefit from additional support, income inequality and service eligibility, health disparities, and transportation problems, just to name a few.
So, as we near the end of the project, Wilder is going to conduct two key discussion groups. For the first, we will gather people who have knowledge about what services look like on the ground including voices from both of these communities to better understand the challenges and opportunities ahead of us.
For the second, we will gather policy makers, funders, and agency leaders to respond to our learnings to date and work on developing solutions based on what we have learned from this project. Our goal is to come away with one or two policy and practice recommendations that can help set the course for strengthening caregiver supports and resources in both communities. This second discussion group is the one we would like to you and potentially others at [organization] to be part of.
We haven't selected specific dates yet. We are thinking of June 6, 7, or 8, or June 13, 14, or 15 for the second group.
Are there specific dates we should avoid if we want to be sure you can be involved?
And do you have any specific recommendations regarding others we might invite to either of these groups?
Thanks, [name], for your interest and potential involvement.
I look forward to hearing from you.

4. Follow-up with invitation.

Sample email for inviting people to session 3:

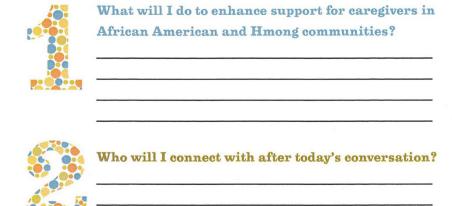
Appendix G: Action cards





Funded in part by a LWAH grant from the MN Department of Human Services





Funded in part by a LWAH grant from the MN Department of Human Services

Appendix H: Revised logic model

LWAH Hmong & African American Caregiver Initiative Logic Model--REVISED Outcomes Outputs Inputs Activities Short Long LWAH Grant Funding MN DHS Identify and engage # Stakeholders stakeholders identified and engaged Wilder Foundation: Wilder Community Services for Aging staff Wilder Shannon With support of DHS hold Leadership Institute staff convenings with providers **Focus Groups** Wilder Southeast Asian and community leaders to Adult Clinical Services staff # Sessions/Outreach discuss community needs events held Wilder Center for Social Community Outreach Healing <u>Partners</u>: St. Paul African American Build awareness of caregiving **Listening Sessions** Faith Community Act on in local Hmong and African Alzheimer's Action Team # Community members American communities in attendance SPAAFCAAAT partner Identify caregivers' needs churches unique to Hmong and African **Community Convenings** American communities Hallie Q. Brown Community Center Sabathani Community Networking # Networking meetings Center University of MN Service Learners With community input, Leave-behind cards for # Leave-behind cards develop caregiving supports TC Hmong Alliance Church Engage with leaders and **Hmong and African** for Hmong and African for Hmong and African stakeholders to develop policy American communities American communities Community School of American communities or practice recommentations Excellence to strengthen resources for Flyers created and # Flyers created and caregivers and communities Networking contacts: posted posted Entira Clinics CAPIstaff MAAA staff African American Recruiting champions # Champions recruited Leadership Forum KMOJ Radio # Internal team Internal team meetings Volunteers meetings Caring for Mom and Dad documentary

Appendix I: Replication basics

Based on the key lessons learned in the process of implementing the work for the LWAH grant, team members offered the following additional higher level advice for agencies that may seek to replicate or design similar work.

- 1. Have something of value to return to the community. There is an unspoken expectation of quid pro quo, especially with communities that have historically been over researched.
- 2. Be sensitive to the time constraints of people you are asking for time.
- 3. Build relationships through trusted community members. Do the pre-work to respect and understand the community you seek to enter.
- 4. Allow plenty of time for the work. Building relationships and trust takes time. The process cannot be rushed. Develop relationships with one community at a time.
- 5. Identify champions at the outset of the project so you have people with experience who can also help to expand the reach of the work.
- 6. Support the agencies currently successfully doing this work within cultural communities, and enhance their resources.
- 7. Language is important. Be sensitive to the cultural appropriateness of using certain terms and be aware of the way terms translate.
- 8 Miscellaneous:
 - Smaller convenings work best.
 - Provide food for convenings. Culturally familiar food is best.
 - Flyers are impersonal and an ineffective recruiting technique.

Appendix J: Key informant interview

Name:			
Date:			

Hmong and African American Caregiver Project Key Informant Interview (#71994)

Thanks so much for talking to me today about the Hmong and African American LWAH caregiver project. I am interested in hearing your perspective about work on this project, including things that have gone particularly well, and aspects of the program that may have been challenging. The interview is voluntary and I will not share any identifying information about your responses with others unless you give me permission to do so when we conclude the interview. The interview will take about 30 minutes, depending on what you have to tell me.

- 1. In your view, what did this program start out to accomplish? [Probe: What did you see as the primary objectives of the program?]
- 2. What did you hope would be different when the grant work was completed?
- 3. To what extent do you believe the program was successful? In what areas do you count your work as a success?
- 4. In what areas do you feel you may have come up short regarding your original goals? What did you hope to achieve that may have been more difficult than you thought?
- 5. Did you adjust the goals of the project while you were working on it? If so, what changed?

Now I'd like to ask you about specific aspects of the work.

- 6. First of all, please tell me about the process of building awareness of caregiving in the African American community.
 - [Issues to cover: Did you gain a better understanding of opportunities to develop connections? Did caregivers self-identify? How did you publicize this information?]
 - a. What aspects have gone especially well? (What contributed to these successes?)
 - b. Where were the biggest challenges?
 - c. What did you do to address those challenges? (What happened when you addressed the challenges in that way?)

- 7. How about the process of building awareness of caregiving in the Hmong community. [Issues to cover: Did you gain a better understanding of opportunities to develop connections? Did caregivers self-identify? How did you publicize this information?]
 - a. What aspects have gone especially well? (What contributed to these successes?)
 - b. Where were the biggest challenges?
 - c. What did you do to address those challenges? (What happened when you addressed the challenges in that way?)
- 8. Now I would like to ask you about the process of identifying caregiver needs that are unique to the African American community.
 - a. How did the outreach work? Were you successful in engaging caregivers?
 - b. What did you learn about the tools and resources that are available within these communities?
 - c. What, if anything, do you think keeps caregivers from accessing services?
- 9. How about the process of identifying caregiver needs that are unique to the Hmong community?
 - a. How did the outreach work? Were you successful in engaging caregivers?
 - b. What did you learn about the tools and resources that are available within these communities?
 - c. What, if anything, do you think keeps caregivers from accessing services?
- 10. Now I would like to ask you about the process of engaging with champions in these two communities.
 - a. In what way(s) were champions identified or engaged? (How many?)
 - b. What were the biggest challenges you experienced in engaging with the champions?
 - c. What successes did you experience in engaging with champions?

Now I have some general questions about this work.

- 11. We know this project has evolved since its beginning. What would you say are the most critical elements you need now, given these changes, in order to continue to move forward on this project?
- 12. [If not already covered] What do you think your greatest successes have been with this project?
- 13. [If not already covered] What have been your greatest frustrations with this project?
- 14. Has anything surprised you about this work? [Probe: Process and/or outcomes?] Please explain.
- 15. If you were advising someone from another agency or organization who was trying to develop a similar program, what would you tell them? [Probe: Top (5) recommendations/ things to consider, critical elements to put in place?]

or your thoughts on implementation at this stage?
As I said at the beginning of the interview, the information you have provided will be very helpful in our efforts to describe this program to others. Will it be okay if I attribute your observations and comments about the program to you, or would you prefer to remain anonymous?
Okay to attribute
Prefer to remain anonymous
Thank you for taking the time to talk to me today!

Appendix K: References

- Alzheimer's Association. Serving African American families: Home and community based services for people with dementia and their caregivers. Retrieved from http://www.alz.org/national/documents/aoagrant_kts_aa.pdf
- Brookman, C., Holyoke, P., Toscan, J., Bender, D., & Tapping, E. (2011). *Promising practices and indicators* for caregiver education and support programs. Markham, ON: Saint Elizabeth Research Department.
- Casado, B. L., van Vulpen, K. S., & Davis, S. L. (2011). Unmet needs for home and community-based services among frail older Americans and their caregivers. *Journal of Aging and Health*, *23*(3), 529–553.
- Friedemann, M-L, Newman, F.L., Buckwalter, K.C. & Montgomery, R.J.V. (2014). Resource need and use of multiethnic caregivers of elders in their homes. *Journal of Advanced Nursing*, 70(3), 662-673.
- Herrera, A. P., George, R., Angel, J. L., Markides, K., & Torres-Gil, F. (2013). Variation in Older Americans Act caregiver service use, unmet hours of care, and independence among Hispanics, African Americans, and Whites. *Home Health Care Services Quarterly*, 32(1), 35–56.
- Hong, S.-I. (2010). Understanding patterns of service utilization among informal caregivers of community older adults. *Gerontologist*, *50*(1), 87–99.
- Mather, M., Jacobsen, L.A. & Pollard, K.M. (2015). Aging in the United States. *Population Bulletin*, 70 (2).
- Montoro-Rodriguez, J., Kosloski, K., & Montgomery, R.J.V. (2003). Evaluating a practice-oriented model to increase the use of respite services among minorities and rural caregivers. *The Gerontologist*, 43(6), 916-924.
- Nápoles, A. M., Chadiha, L., Eversley, R., & Moreno-John, G. (2010). Developing culturally sensitive dementia caregiver interventions: Are we there yet? *American Journal of Alzheimer's Disease and Other Dementias*, 25(5), 389–406. http://doi.org/10.1177/1533317510370957
- National Academy of Sciences. (2016). *Families caring for an aging America*. Retrieved from http://nationalacademies.org/hmd/reports/2016/families-caring-for-an-aging-america.aspx
- Pinquart, M. & Sörensen, S. (2005). Ethnic differences in stressors, resources, and psychological outcomes of family caregiving: A meta-analysis. *Gerontologist*, 45(1): 90-106.
- Reinhard, S.C. & Choula, R. (2012). *Meeting the needs of diverse family caregivers* (Insight on the Issues No.69). AARP Public Policy Institute.
- Scharlach, A., Kellam, R., Ong, N., Goldstein, C. & Fox, P. (2006). Cultural attitudes and caregiver service use: Lessons from focus groups with racially and ethnically diverse family caregivers. *Journal of Gerontological Social Work, 47(1-2),* 133-156.
- Wennberg, A., Dye, C., Streetman-Loy, B., & Hiep Pham. (2015). Alzheimer's patient familial caregivers: A review of burden and interventions. *Health & Social Work*, 40(4), e162–e169.
- Wilder Research. (2012) Caregiving in context: Understanding caregivers' networks of support. St. Paul, MN.
- Wilder Research. (2013). Caregivers to older adults: How they connect to services and how connections can be encouraged and strengthened. St. Paul, MN.
- Wilder Research. (2017). A study of Title III-E Caregiver Services in Minnesota: Where are we now and where could we go next? St. Paul, MN.