

Final Report
**Community Input on the Needs of
African American Elders in
Seattle and South King County**



**Prepared for the
Seattle Human Services Department
Aging and Disability Services**

by

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April 2004



Acknowledgements

On behalf of the Mayor's Council on African American Elders, I want to personally thank the City of Seattle Human Services Department, Aging and Disability Services for having the foresight to attempt the collection of this data despite limited resources and time. I also want to acknowledge the members of the Mayor's Council for their support of this effort. A special debt of gratitude is owed to members of the AAEP Transition Steering Committee for their assistance in developing the data collection instruments and especially for their common sense advice on how to do the work.

Finally, I would like to thank the eighty-two elders, caregivers, administrators, community leaders and others who participated in focus groups, key informant interviews and the community survey to find out what our elders need and the perceptions of the services that are available to meet those needs. This study could not have been completed without your participation and feedback.

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I. Introduction/Executive Summary

From December 2003 to March 2004, the Mayor's Council on African American Elders (MCAAE) and a Steering Committee of community representatives and public employees conducted a study of the needs of African American elders in Seattle and South King County. The study had three major goals: to produce recommendations for improving services and assistance for African American frail elders, to determine the level of knowledge about the needs of elders and services to address those needs, and to determine the level of community support for a community-based management and governance structure for providing services for the African American frail elderly.

The study produced the following findings:

- Limited financial resources is one of the most daunting challenges for African American elders in Seattle and South King County. Without adequate income, seniors have a difficult time maintaining their homes, purchasing medicine and accessing health care. African American elders are more likely to be poor with limited income, than their white counterparts. One reason is that many African American elders worked most, and in some cases, all of their work life in low paying jobs with limited or no retirement benefits.
- The African American community does not have significant knowledge about existing services, particularly services that are not provided by governmental agencies. Thus, African American elders often do not get the services and assistance they need.
- The lack of trust of providers and care systems figure prominently in the failure of African American elders to use available services. To win the trust of these elders, providers, caregivers and others must be willing to ask questions, be curious about the life of elders, listen with the intention of learning, act and respond respectfully toward elders and exhibit a high level of patience.
- A successful community-based, community-managed and community-governed African American Elders Project is one that is adequately funded and supported; accessible by elders and the community; trusted by the community; accountable to the community and to funders; and staffed and managed by people who are friendly, flexible and passionate about serving African American elders.
- African Americans do not view Seattle and South King County as "elder friendly" places to live." Nor do they view these areas as "friendly" places for African Americans of any age.
- African American elders are most in need include the following: financial and other resources, health care, assistance in the home, assistance in finding services, transportation and culturally appropriate services.
- The best opportunities for improving services for African American elders in Seattle and South King County are: mobilizing community support for elders, focusing on preventive care, using intergenerational approaches to providing senior services, upgrading outreach services, and improving and expanding communication channels about the needs and services of elders within the African American community.

II. Study Methodology

The study of the needs of African American elders residing in Seattle and South King County included three phases. The first phase was a series of focus groups that sought to determine the level of knowledge of the community about the needs of elders and the availability of services. The focus groups also sought to determine the level of support for community governed and managed services for African American elders. The second phase was the interview of key informant. The interviews were designed to look more deeply as systematic issues that impact needs and services for elders. The third phase, the community survey, was designed to get broader input from members of the community and to confirm the information gathered in the first two phases.

This study was initiated as part of a larger project to develop a plan to transition the African American Elders Project (AAEP) from its current location within local government to a community-based management and governance structure. The AAEP provides services for African American elders in Seattle. The work on this plan led to broader discussions about the need to understand community awareness and perceptions of the needs and services for African American elders in Seattle and South King County and to gauge the level of support for community-based services. It was clear that the group planning the transition need answers to these questions.

Members of the AAEP Transition Steering Committee and the AAEP Transition Design Team identified issues that the study might address. They also assisted in developing questions that might be asked of participants in the study. The knowledge and experience gained by members of the AAEP Partnership contributed to the design of the questionnaire and its format and content. Questions, assumptions and perceptions about the needs of African American elders and services to address those needs were tested via a pilot focus group session that included a select group of individuals. The results informed the development of questions for the remaining focus groups, the key informant interviews and the community survey.

Focus Groups

The convening of focus groups was a key strategy for gathering information about the needs and availability of services for African American elders. Four sessions, including the Pilot Focus Group, were conducted. Each group had a different focus: intergenerational, super seniors (75 years and older) and caregivers. Thirty individuals participated in the four focus groups.

A report on each focus group can be found in Appendix A.

Key Informant Interviews

An important source of information for the study was gathered through interviews of nine local key informants. These individuals were asked to provide their perceptions and ideas on the needs of African American elders and the services currently available to address those needs, including the feasibility of transitioning the African American Elders project from its current location to a community-based governance and management structure. A summary of the feedback from key informants and a list of the key informants can be found in Appendix B.

Community Survey

A survey of the African American community provides a supplemental and supporting approach for gathering information for the study. This approach was selected because it enabled the study to reach a broader cross-section of African Americans across the target area of Seattle and South King County. The survey was sent to over 200 individuals via email. Forty-three respondents from 18 zip code areas completed and returned the survey.

A summary of the community survey can be found at Appendix C.

III. Recommended Strategies

1. Continue plans to implement the transition of the African American Elders Project to a community-based management and governance structure. However, it is imperative that the agency select demonstrate the following: strong leadership and management capacity, respected by the community, passionate about serving African American elders, flexible organizational structure, capable or developing and providing the services needed by African American elders in Seattle and South King County.
2. Improve the design and distribution of information about services for elders within the African American communities of Seattle and South King County.
3. Expand the service area of the African American Elders Project to include South King County. This strategy recognizes the trend for African Americans to migrate from Seattle to South King County.
4. Develop long-term strategies within the African American community to mobilize community involvement and support for services for African American elders as an issues community-wide issue.
5. Develop, sponsor, promote and incorporate opportunities to get direct feedback from seniors regarding their needs. The use of community forums for hearing from elders was suggested by participants in the survey, interviews and focus groups
6. Develop strategies for improving the delivery of services African American Elders. These strategies should address health care systems and the roles of family, community members and providers. Cultural competence training of providers and systems and training and support for caregivers present opportunities to improve services for African American elders.

Appendix A: Documentation of Needs and Availability of Services

Appendix A-1: Pilot Focus Group - Human Services Department Employees

Background and Objectives

This focus group was conducted to gather information on perceptions and ideas about services for African American elders in Seattle and South King County. This focus group was conducted because the participants represented a cohort of individuals with the following characteristics: employed by the City's Human Services Department (HSD), have experience in human service programs and are knowledgeable about the African American community. In addition, they were all African American. The goals for this focus group session was:

- To better understand ideas and perceptions about services for African American elders in Seattle and South King County
- To determine how much support there is for having these services and/or assistance provided in a community-based setting.
- To test questions for future questionnaires and interviews.

Methodology

An Aging and Disability Services staff member requested African American staff members of HSD to participate in the focus group. They were sent an email that briefly explained the purpose of the focus group and asked them to participate. Following is the demographics of this group:

- Sex (5 women and 2 men)
- Age (40 - 61)
- Ethnicity (African American)
- Level of education (College courses to Masters level)
- Employment (Seattle Human Services Department)
- Knowledge/experience of subject area (human services, elder services, public relations, survival services, youth and family services)

Conclusions

The conclusions drawn from the summary of the proceedings follow:

1. Seattle is not a particularly elder friendly community. A contributing factor to this lack of friendliness is its failure to do a very good job of getting the right information to elders and other about available services.
2. A trusting relationship is a key ingredient for getting African American elders to access and use available services. African American elders are reluctant to invite strangers, even helpers, into their homes. They are also less likely to discuss personal business with strangers. It takes time to develop a relationship with these elders. Churches sometimes act as an agent for connecting elders to services and building a trusting relationship.

3. African American elders, particularly those in South King County, face barriers to accessing needed services including point of service, transportation, costs, red tape and connecting with providers.
4. In considering services for African American elders, you must look at them from an intergenerational perspective and a holistic perspective. If you want to know what elders need, ask them. And, the key informants should be paid for their knowledge.
5. Continuous outreach that focuses on developing trusting relationships with elders is critical for ensuring assistance for African American elders in Seattle and South King County. Also, do not separate elders from others.
6. Quality of service is the most important issues or concern regarding assistance for African American elders. Quality services means holistic services.
7. The nonprofit organization that receives the AAEP project should be independent, respected in the community, flexible in its programming, and accountable to funding sources. They should also have the capacity to raise funds. Finding the right nonprofit organization may be difficult. There are not many that are still successful.

Appendix A-2: Caregivers Focus Group

1. Most expressed that Seattle is not an elder friendly community. Not an African American friendly community.

"The family should be able to decide how to best care for their elders. Some of the people who are supposed to be helping families do not have compassion. Resources are out there, but no one is delivering the message. There is no information and you are at the mercy of the system. Seattle is not Black oriented. It's hard to find culturally appropriate care, including assisted living and nursing homes. Services are not centered on the needs of African Americans."

2. The Group felt that it was difficult to get information about available services. Families don't know how or where to start. They need training on how to care for elders in their home. The general community also needs more education about existing services for seniors. Many elders are without social contact and companionship. Information on home activities is needed and more activities and programs should include music. There is a lack of legal and early long-term care planning information.
3. Barriers to services for African American elders include a lack of access to information about services that support elders and their families. Family members and seniors are often uninformed about the programs that can help and how to qualify for help. When elders ask for help they are not treated with respect and dignity and as a result they may reject help.
4. There is a tremendous need in the Black community for accessible resources and information about resources. Legal and financial planning help are needed. Training is needed for family caregivers and for paid caregivers in homecare agencies and nursing homes.
5. The organization must have the trust of the community and the organization must be accountable to the community for the services it provides. Locating the AAEP in the community would be a great asset. People would know about it and it could provide a single place for

services and information. An African American organization would be more trusted by the community. People would have more confidence in the service. In addition, services would be more accessible if the program was located in the community.

6. When it comes to getting services for our elders, we want equal access to information. A community-based program would provide more equal access to services and information and more support for family caregivers. The organization must understand the needs of caregivers for support such as training, legal assistance and counseling. It must also understand the needs of elders. Elders and their families need to be treated with dignity.
7. The organization and the program must be accessible. People in the community must know about it. There should always be someone in the office to respond to questions, people who walk in. The organization must be trust-worthy and adequately funded.

Appendix A-3: Intergenerational Focus Group

Background and Objectives

The Intergenerational focus group was held February 7, 2003. Georgiana Arnold of Aging and Disability Services, City of Seattle facilitated it.

This purpose of this focus group was to gather information on perceptions and ideas about services for African American elders in Seattle and South King County. It was designed as an "intergenerational" session to better understand the roles and relationships of people of all ages in identifying needs and accessing services for African American elders. Freedom Church of Seattle sponsored this session.

Methodology

The AAEP project Design Team identified organizations that might sponsor focus group sessions. Freedom Church was selected as a site. A member of the Design Team worked with a member of the church to set up the meeting.

Following is demographics of this group:

- Sex (11 women, one young adult woman, one man and children of variable ages)
- Ages (Six months to 70+)
- Ethnicity (African American)
- Level of education (variable)
- Employment (variable)
- Knowledge/experience of subject area (the group included people with profession knowledge and experience and people whose life is impacted by the subject area on a daily basis)

Conclusions

1. Seattle and South King County are not elder friendly communities for African American elders. In fact, they are not friendly places for African Americans of any age. More could be done to improve access to services for elders such as improving access to information and establishing a single place for elders to receive services. Two respondents reported that they had tried to access services through the African American Elders Project but were unsuccessful. They stated that no one would return their calls.

2. Important needs of African American elders in Seattle and South King County that are not being met include financial assistance, information, being heard, transportation and support from the African American Community. Many elders need help with paying for food, maintaining housing, legal matters and purchasing medicine. Elder also need to be able to access current information about services in a format that they can easily understand. Elders need to be heard; people do not listen. Elders need and transportation. And finally, elders need the support of the African American community.
3. For those individuals planning the transition of the African American Elders Project to a nonprofit community-based organization, you should: a) locate the services where African Americans live and consider satellite offices; b) make every to reduce the red tape associated with receiving services at the nonprofit; c) prepare for the skepticism that may arise around an African American organization; d) build in real and continuous accountability to the community, community support, community involvement during planning and implementation.

Appendix A-4: Super Seniors Focus Group

Background and Objectives

The "Super Seniors" focus group was held February 5, 2004. It was conducted to gather information and perceptions and ideas about services for African American elders in Seattle and South King County. This specific session was held because all participants represent a cohort of individuals within range of the age qualification for the African American Elders Project. They are all comfortably retired. They are also active elders.

The objectives for this focus group were:

Methodology

A member of the AAEP Transition Steering Committee who is also a staff member of the Human Services Department, Aging and Disability Services identified and convened this group of elders. One member of the group expressed concerned about being "surveyed" by strangers. The convener of the focus group spoke with this individual and subsequently sent a copy of the questions to each participant in the focus group. The session was held in the home of the person that convened the group. The discussion was co-facilitated by this individual and the project consultant. Notes were taken by all. In addition, the session was recorded. Following is the demographics of this group:

- Age: 75 to 83
- Work Background: Railroad, scientist, schoolteacher, health/nursing administrator, US Postal Service.
- Education: High School, some college through advanced degrees
- Employment Status: Retired with annuity and health benefits
- Average Period of Residence in Washington State: Approximately 45 years
- Home States: Louisiana, Alabama, Washington, South Carolina

Conclusions

1. There was a mixed response to this question. Most agreed that Seattle is not an elder friendly community, but felt there had been efforts made. They also agreed that Seattle was not an African American friendly community, but better than 40-50 years ago. They stressed the importance today of reaching the isolated and lonely. Elders recounted many interesting stories of a segregated military, being unable to go places off their military base in Washington State during WWII, etc. Belief that there are some resources, but people don't know about them. Many expressed concern about African American elders being "shut-in" and lonely, and tried to brainstorm ways to help them, and get them connected somehow (e.g., trips to senior centers, visitors/companions/ hot meals delivery, phone trees. Seattle is not Black oriented. The sense of community has been impacted by the costs of living in Seattle, property taxes, and subsequent exodus for many Black families to South King County.
2. This group continued to be concerned about loneliness and isolation, the lack of regular human contact for many Black elders. This group was largely comprised of more middle class African American elders with good retirement benefits and medical coverage. Even so, they worried about "shut-ins nutrition and health care, especially prescription drug costs." Further, they discussed the difficulty of having to move into a nursing home and recommended that residents have an opportunity to interact with young people. Some cited a lack of community support with African Americans leaving the Central Area and moving to South Seattle and South King County. The elders were emphatic about the necessity to ask elders "what they need to have a happy life."
3. The group identified the following barriers to services: isolation, a lack of access to information about resources and services, limited income, a healthy diet, activity and access to health care and affordable prescription drugs. Many elders go without. Shut-ins have the most difficult time. Extra effort is need to help them. *A calling tree, sponsorship program or special donations* could be organized to help this group.
4. People just don't know what's available. Have a community forum to find out what people need and to help them find out about what is available. Provide transportation to those who need it and a meal for them.
5. The group was unsure about where a program with services for African American elders should be. Some mentioned churches and senior centers.
6. The group on the whole had not utilized or known about many services for elders. There was a general consensus that many African American elders needed help. They emphasized the need for involving young people, and involving elders who could contribute to programs that could help. They also emphasized the need to create opportunities to exchange ideas about the needs of elders and care givers. Finally, they were concerned about the cost of health care in generally and particularly the cost of drugs.
7. The organization selected to govern and manage the AAEP must be visible and accessible. People in the community must know about it. It must be available to people and it must be must be trust-worthy. Most of all it must be adequately funded.

Appendix B: Key Informants

Background and Objectives

The African American Elders Project (AAEP) was established in 1997 to identify African American elders who needed services and to assist them in accessing and receiving social and health services through ongoing case management, support and referrals. The AAEP is managed by a "Partnership" that includes the Seattle, Human Services Department, Aging and Disability Services, Public Health: Seattle and King County, Senior Services (a nonprofit community organization) and the Mayor's Council on African American Elders (a community advisory council).

The "Partnership" is currently developing plans to transfer the AAEP to a community-based organization and to update services that will be provided in that setting.

Nine key informants were interviewed to get their perceptions and ideas about the needs of African American elders in Seattle and King County and services to address those needs. There were also asked to comment on a proposal to transfer the AAEP to a community based management and governance structure. The specific purpose of these interviews was to gather information for planning and implementing effective services for African American elders in Seattle and King County and plan a smooth transition of the AAEP to a community-based governance and management structure.

Methodology

African American Elders Project Steering Committee identified individuals to be interviewed by the consultants. Nine individuals were interviewed. Conducted on the telephone, interviews were 35 to 55 minutes in length. All interviews were conducted during the period January 29 through February 12, 2004.

Following is a list of the individuals interview:

1. Patricia Dawson, MD, PhD, FACS, Medical Director, Providence Comprehensive Breast Center, Providence Hospital, Seattle
2. Hubert Locke, PhD, Professor, University of Washington
3. Carol Allen, Outreach Coordinator, Seattle King County Public Health and former director of the Central Area Senior Center
4. Woody Hodge, Senior Researcher, Western States Hospital, and former Chair MCAAE
5. Denise Klein, Executive Director, Senior Services, Seattle
6. George Dicks, BA, GMHS, RCMHP Harborview Medical Center
7. Tony Orange, Acting Director, Central Area Motivation Project
8. Larry Gossett, King County Councilman
9. Karen Lincoln, PhD, Assistant Professor and Researcher, School of Social Work, University of Washington

Findings

1. The most important issues and concerns for African American elders in Seattle and King County are health care, income, housing and health status. Other key issues include racism, geographical distribution, and a community that disconnects from elders, transportation and access to information. Health care is a major issue because African American elders find it difficult to access services. The cost of services and fear and distrust of providers and health

care systems are contributing factors. Health care is also an issue because the quality of services may be lower for African American elder because of an inadequate response to cultural issues, too few African American providers, decreasing numbers of geriatric specialist, fewer physicians that accept Medicaid patients and a fragment system of care. Small or nonexistent retirement annuities is but one of many key factors contributing to financial issues for African American elders. The historically poorer health status of African Americans continues to be a challenge.

2. Several factors make it difficult to get needed services to African American elders. The most prominent appears to be related to issues of trust and access to information. African American elders often do not fully understand systems of care and find it difficult navigating them. They may not trust providers and systems because of racism experienced in the distant or more recent past. They may also resist service approaches and protocols that are foreign or radically different from their life experiences. Other factors that make it difficult to get services to elders include decreasing community support for elders (a societal disengagement), fewer competent providers, inadequate outreach, a fragment, rather than holistic approach to services and ignorance about the real needs of elders.
3. Some of the best opportunities to improve services for African American elders are to a) educate, mobilize and motivate the African American community; b) create culturally sensitive models of care that are flexible, holistic, intergenerational and that involve diverse community institutions; c) locate services nearer communities where African Americans live; and d) develop volunteer programs for people of all ages to help, especially with churches.
4. Some ways to better meet the needs of African American elders are to: a) conduct a comprehensive needs assessment of the needs of African American elders in Seattle and South King County; b) form high quality coalitions and partnerships to mobilize resources; c) develop creative alternatives and strategies to connect with the community; d) understand key policies that impact funding and services for African American elders; and e) Hire the right staff.
5. The transfer of the AAEP to a community-base management and governance structure must be done thoughtfully and carefully. There are advantages and disadvantages to such a transfer, but the advantages outweigh the disadvantages. The selections of the "right" agency must be done with the maximum of objectivity. The selection process must result in an organization that is strong, flexible and respected by the community. The sponsors of the transition must be committed to the success of the venture. Commitment must take the form of providing the required financial support, a willingness to be flexible about ways to provide services absolute clarity about intentions and making every effort to involve and inform the community at all points during the develop and implementation of the transition.

Appendix C: Community Survey

Community Survey Summary African American Elders Project Transition Community Input Initiative

Background and Objectives

The survey was conducted to reach a broader cross section of African Americans living in Seattle and South King County and to reach people who could not or would not participate in a focus group or a key informant interview. The data collected provides an additional cross check to the findings from the focus groups and key informant interviews.

Methodology

Overview. Zoomerang, an online survey package, was used to collect and tabulate the results of the survey. The survey included seventeen questions. Two were basic demographic questions to get information about where responders lived and experience with elders. Seven (7) were open-ended questions about their perceptions about the needs of African American elders and the availability of services to address those needs. The remaining eight (8) were multiple-choice questions focusing on respondents' general knowledge about health and social issues and conditions that impact the needs and services for African American elders.

The Zoomerang software compiles the responses, provided aggregate statistics for the multiple-choice questions and a listing of responses for the open-ended questions. Please refer to Appendix xxx to see the complete results.

Sample size and selection. About 200 people were sent email invitations to participate in the survey. We estimate that over 95 percent of persons receiving the email were African Americans. A link to the Zoomerang site was imbedded in the email. The sample selection was a convenience sample composed of members of the AAEP Steering Committee, their contacts and people known to their contacts. Forty-three people responded to and were included in the survey, for a response rate of about 25%. The respondents reported living in various parts of the Puget Sound area.

Finding and Observations

1. In what zip code area do you currently reside?

Most of the respondents live in Central Seattle and South King County but 17% live in North Seattle, Bellingham, Tacoma, Bellevue or Lynnwood. The percentage distribution of respondents by geographic area is as follows: 15% in South King County; 38% in South Seattle; 20% in Central Seattle; 10% in North Seattle; 10% in West Seattle; and 07% in other jurisdictions such as Bellingham, Tacoma, Bellevue and Lynnwood.

2. Which of the following would describe your experience with the elderly?

It appears that most of the respondents have had some experience with the elderly. Those experiences were both familiar and professional. Of 57 responses to the question 25 indicated that the respondent had parents 65 years old or older, 14 indicated that respondent was responsible for

the care of an elderly relative, friend or acquaintance and 6 indicated that the respondent was at least 65 years of age. Under category "Other" nine respondents described themselves as follows: Funder, I volunteer at a Senior Center, My father died at 101 years old, I will be 65 on my next birthday, I have taken care of elderly people as a job, I will soon be 65, I provide financial assistance to a widowed parent, I work with elderly nurses and I am a doctor caring for people at end of life.

3. What are some challenges you face in your role with elderly persons? Please list.

Of the 42 people who took this survey, 39 responded to this question. Their answers can be gathered into about a dozen themes:

<i>Medical and dental needs</i>	<i>Limited resources</i>	<i>Family relationships</i>
<i>The system</i>	<i>Independence for elders</i>	<i>Elders without family nearby</i>
<i>Financial and legal issues</i>	<i>Family caregivers' limited time</i>	<i>Persuading elders to make changes</i>
<i>Communication between elders and those who care for them</i>	<i>The physical and emotional challenges of being elderly</i>	

Almost 16 comments touched on how limited resources increase the challenges of working with or caring for the elderly. These limited resources covered many areas: lack of transportation, few activities, costly services, lack of volunteer chore services, no home health care, lack of financial help for paying bills, etc. Eight other comments mentioned medical or dental care and noted that this costs a lot. To underscore the point, one person wrote:

"High cost medicine, high cost medicine, and high cost medicine, high cost medicine and over & over again."

Among responders who were family members helping to care for elderly relatives, several concerns emerged. One person mentioned wanting to find "a compassionate trustworthy person to care for them in my absence." Another said it was hard to get his or her parents to go to the doctor because they feared they would be experimented on.

Some seemed to feel challenged by the need to respect the needs of elders while trying to persuade them to do things that might help with their well being. One wrote:

"Maintaining a respectful adult/adult relationship without reverting to adult (them) to child (myself) interactions"

On a hopeful note, one responder wrote this message:

"I want to be able to care for elderly people in my home. I think that elders deserve better care and I want to learn how I can help. My mom was in a nursing home for a long time and I felt very sad

that I was too young at the time to do anything about it. Maybe I can do something for other elders?"

4. Following is a partial list of medical conditions that particularly impact the African American elderly. What three conditions is the most critical for the elderly?

Respondents identified diabetes, hypertension, and dementia as the three chronic diseases most critical for African American elders. Respondents were asked to choose three from a list of conditions that included the following: diabetes, hypertension, depression, arthritis, injury from falls, chronic pain, dementia, including Alzheimer's disease, cardiovascular disease. There were 147 responses to the question. Diabetes received 31 responses, closely followed by hypertension with 27, Dementia with 19 and cardiovascular disease with 16. Arthritis, chronic pain and injury from falls received 14 or fewer responses. Under category "Other", three respondents offered the following: a) it's a toss up between hypertension and dementia, b) inability to find a human voice when phoning for help and c) cancer.

5. Following is a list of social and other issues that are often experienced by active and frail elders. What three are the most critical for the African American frail elders?

Survey Respondents identified adequate income as the most critical issue for African American elders closely followed by assistance in the home and lack of knowledge about available services. They were asked to choose three issues from the following list: assistance in the home, safety, home maintenance, social and emotional isolation, limited access to transportation, adequate income, lack of knowledge about available resources and. There were 114 responses to the question. Adequate income received the most responses at 30. Assistance in the home and lack of knowledge about available resources were close behind with 28 and 26 respectively. Social and emotional isolation, home maintenance, limited access to transportation all received at least 11 responses. Under category "Other" four respondents offered the following: a) all seem to apply, hard to limit to three, b) lack of good in-home care facilities, c) making a will, and d) isolation.

6. What other needs of African American elders in Seattle and South King County?

This question was a follow-up to Question 5 that provided a multiple-choice list for social and other issues most critical for African American elders. People were asked to pick three items from the list in question five, so it is unclear whether their responses on Q6 were in addition to the three picked in Q5 or reiterations of previous selections.

Medical care and issues related to it such as access to care, insurance, help finding a physician, assistance and prescriptions received 11 comments. The cultural competence of the providers was commented on frequently. This response is typical: "Culturally competent care with nurturing providers."

The daily needs of elders drew suggestions for senior advisors, housing, good day care centers, and the need to have elders' social met by having someone to talk with and assist them with their lives. One person suggested that homebound elders be helped to connect to their faith communities of choice. In home assistance drew comments with one-person notice a need to locate people elders can trust in their homes.

Long-term needs of elders were mentioned, especially the need for long-term care planning, hospice care, palliative and end of life care.

Two comments pointed to the need for “lobbyist that truly have the elderly in mind” and “advocacy for health concerns.”

The issue of families appeared in comments related to the emergence of elders as caretakers for their grandchildren and the need for more assistance. Another responder wrote “Show Love & Keep including elders in family affairs.”

One responder had a lot of ideas and motivation to help elders. This person wrote:

[There needs to be] a really good day care center_where they can do crafts, exercise, and do other things that they like doing. They need contact. They could learn to surf the web, read books/be read to. I have many great ideals and want to be able to create a business doing these things.

7. In your opinion, what needs of African American elders in Seattle and south King County are NOT being met?

The 31 people, who provided responses to this question, collectively, provided list of 28 needs of African American elders not currently being met. Some concerns clustered around the need for advocacy, assistance, counseling or advice. Two people suggested that families needed more support or help sustaining family support networks. There was one mention of the need for counseling for families with elders and adult children living together.

When non-family members step in to help the task can be challenging. One person wrote: “it is very difficult to arrange for long-term or hospice care when there are no relatives to help.”

Five people mentioned that the need for culturally competent care is not being met. One person went even further and suggested a need for a “culturally focused” social service agency focused on African American elders comparable to Jewish Family Services.

The inadequacy of a variety of services drew comments. Included among these services were: health care, home care, home repair, legal assistance, transportation, affordable housing, and volunteer chore service programs.

Several comments did not fall easily into the other categories. One person mentioned the need for community, adding, “This is true for most people but it is worse for the young and the old who would normally spend a larger amount of time in the community.”

Another mentioned a need for medical and social services in Skyway.

One responder drew attention to the lack of governmental monitoring for elder’s safety while in respite care.

8. How familiar are you with services and assistance for the elderly?

Approximately 20% of respondents were very familiar with services and assistance for the elderly. Since a large percentage of the survey respondents had close contact and involvement with the elderly, this number might be considered relatively low. Forty-one responses were recorded to this question. Of the total, 22 respondents were somewhat familiar with services and assistance for the elderly, 11 were very familiar and 8 were not very familiar.

9. How would you find out about services and assistance for elders?

Survey respondents offered 74 responses to this question. The responses could be grouped into the following seven categories: Government; Senior/Elderly Service Providers; Family/Friends; Nonprofits (no senior or elderly services provided); Media; Medical and Social Service Providers; and Other. Senior/Elderly organizations were mentioned most often, followed by the media local and state government, friends and family. Medical and social service organizations and nonprofit service organizations were mentioned the least.

The *Senior/Elderly Service Provider* category includes four types of organizations: Senior Services, Senior Information and Assistance, Senior Centers, the AARP, the AAEP and Hospice Care. The first three were mentioned 4 time each. The AAEP, AARP and Hospice Care were mentioned once each.

The *Media* category includes newspapers, radio, TV, the Web and Directories. These outlets were mentioned 11 times. Respondents mentioned the directory "Where to Turn" twice.

The *Government* category includes City of Seattle, King County and the State's DSHS. The Mayor's Office on Aging was mentioned most often, six times compared to 2 each for DSHS and Human Services Department and 1 for the Public Health Seattle and King County.

Friend and family were identified 11 times as a source of information about services and assistance.

The *Nonprofits* service category includes 7 organizations including Urban League, Crisis Line, United Way, Red Cross, Salvation Army, and Catholic Community Services.

The *Other* category includes the workplace, churches, seniors and other contacts for information about services and assistance. Seniors themselves were mentioned 4 times. Churches were mentioned 4 times. The workplace and other locations were mentioned 2 times each.

The *Medical and Social Service Providers* category includes doctors, hospitals, nurses, and social workers. Respondents mentioned these providers four times.

10. Following is a list of programs/services that provide assistance for elders to continue living in their own homes. Which of the following are you, at least, somewhat familiar with?

Respondents appear reasonably familiar with the set of program and services listed in the survey. In order of ranking, they were most familiar with Meals on Wheels, the Mayor's Office for Senior Citizens the Central Area Senior Center and Access Transportation Service. The response rates for this group ranged from a high of 85% for Meals on Wheels to a low of 71% for Access Transportation service. The response rate for the remaining four ranged from 27% to 56%.

Respondents were asked to select all that apply from a list that included the following: Mayor's office for Senior Services, Catholic Community Services, Alzheimer's Association, Respite Services, Central Area Senior Center, Access Transportation Service, Meals on Wheels and Senior Information & Assistance. Of 195 responses, 35 respondents were, at least, somewhat familiar with Meals on Wheels, the largest vote getter. Meals on Wheels was followed the Mayor's Office for Senior Citizens and the Central Area Senior Center with

30 each, Access Transportation Service 29 and Catholic Community Services with 23. Respite Services and the Alzheimer's Association were mentioned the least.

11. In your experience, which of the following keeps African American elders from participating in programs and services they need?

For the programs and services listed, respondents indicated that *transportation, costs and not comfortable with providers* as the top three reasons African American elders do not participate in programs and services they need. The response rate for each was 86%, 74% and 60%, respectively. The response rate for the bottom three ranged from a low of 21% to a high of 51%.

Respondents were asked to select all programs and services that apply from a list that included the following: transportation, time of day when services are available, location of service(s), not comfortable with providers, cost and other. Of 141 responses, respondents mentioned transportation 37 times, cost 32 times, location of service(s) 26 times, location of service(s) 22 times, other 15 times and time of day when services are available 9 times. Under category other respondents mentioned the following that keeps African American elders from participating in the services they need:

- a. Services from trusted sources
- b. They do not know about them
- c. Not knowing about them
- d. Not knowing and understanding what's available
- e. Privacy issues
- f. Not culturally relevant
- g. Depression
- h. Lack of information
- i. Someone to help the connect with the services
- j. Activities are not that interesting
- k. Don't want anyone to know how bad off they are.
- l. Most Senior Day Care Centers are depressing
- m. Financial risks-intrusiveness of disclosure
- n. Maybe they don't know about the services

12. What would you like to see improved in programs and services for African American elders in Seattle and South King County? Please be specific.

More money was the most frequently mentioned improvement among the 33 people who responded to this question. People suggested the money could be used for a variety of purposes, including: free services, help with utility bills, culturally appropriate care, in home care, medical bills, prescriptions, and to fund existing programs. One person listed the state or federal government as the source of these funds.

Outreach, advertising and more visibility for current services could be improved according to respondents. Two people wanted a broader distribution of information to promote services and another suggested a need for an approach focused on African American elders.

Several people mentioned a need for an African American focused culturally appropriate approach to providing services. As one person wrote:

Overall, a more flexible, client-centered, culture-based approach to providing services that affirms the individual and never demeans.

Other possible areas for improvements included: health care, housing, activities and simpler applications. Renton and Skyway were named as areas lacking services.

Someone pointed out that some elders "feel their assets are jeopardized by disclosing financial data to public agencies."

Though only one person wrote it in as an improvement, no doubt elders and the people who help and support them can recognize the need for change:

Many seniors will not make medical appointments, business call, etc. because they can't get a human voice and don't know how to manage the electronic steps through which they must go in order to express a concern. Even I have that problem, especially when the programmed instructions don't work or can't be remembered. When that happens, I end up resorting to e-mail, if I can, or to a fax, asking for a phone call.

13. What would you say to those who are planning to improve services for the African American elderly in the future? Please comment below:

This question drew 34 responses. Almost a dozen people responded that planners should ask and listen to those directly affected by the services. Who should be asked? Responders said, "the community," "especially the homebound, not the highly functioning senior," family members, and "people who will need and use the services." One responder provide detailed guidance on how to listen:

Listen! Don't just ask questions and write the first response that is offered. Listen, be sensitive to generational differences, communication styles and, above all, if a person is speaking slower than you would like, don't try to complete their sentences. Be patient!!!!!!

Accountability was mentioned in two different senses. First, someone wrote that planners had to be accountable to the African American Community. At the same time, another person noted that policy makers had to be held accountable to provide "the level of support necessary to make a difference." Two people suggested a variant on the Golden Rule: that planners should "remember that one day you would be elderly, too. So plan something that would be good for yourself." One person pointed out the value of spending time in a senior center and trying to find ongoing medical services for an elder who is not a relative.

A composite profile of the suggestions from persons who see a program that: focused on keeping people at home as long as possible, whenever possible, be persistent and patient in order to let trust develop, have transportation available in the early evening or events before afternoon, not require a lot of paperwork, follows nutrition guidelines, connect African American elders to their own core culture, and have friendly and flexible staff.

One person went so far as to invite a job offer. She provided her phone number and said she had a "heart for the elderly" and would "love to work in some capacity helping them."

14. Have you heard of the “African American Elders Project” before?

Forty-two respondents answered this questions; 24 yes and 18 no. Fifty-seven percent (57%) of respondents had not heard of the African American Elders Project before. It’s difficult to analyze the significant of the responses to this question. It is related to question 15. The analysis might also be done best in the context of other questions important to the project, such as, “How well are we reaching the African American community about the services we provide.”

15. If you have heard of the AAEP before, how did you learn about it?

The response rates for the set of possible responses were generally low, ranging from a low of 0% to a high of 58%. This likely indicates that respondents, as a group, were not very familiar with the AAEP. However, the respondents that provided responses under “Other” appear to be more familiar with the AAEP. Four hear about the program through work and two were involved in the creation of the project. The others hear about the project through community events or by word of mouth or worked for the program. In summary, it appears that, as a group, respondents were only somewhat familiar with the project.

Respondents were given five options for responding to the question including: knew someone that received services through the program, heard about the program from a friend of family member, read or heard about the program through media, referred someone to the program for services or assistance, received services through the program and other. Respondents identified 11 other ways they learned about the program. The list includes the following:

- a. Through work
- b. Professional contacts
- c. Helped create program
- d. Through work
- e. Worked for program
- f. Involved when it was started
- g. Attended community event
- h. Attended program to introduce it to the community
- i. Work for public health
- j. Word of mouth

Of a total of 48 responses, 15 mentioned that respondents heard about the program from a friend or family member, 9 referred someone to the program for services or assistance, 7 read or heard about the program though media and 6 knew someone that received services through the program. There was no response to the items named Received, services through the program.

16. What advice would you give to those who are planning the transition of the AAEP to a community-based organization? Please make specific comments below.

Survey participants provided 23 responses to this item. Participants were eager for planners to understand the importance of asking for help, input, and providing culturally competent services. Some of the themes that emerged from the analysis of responses to other survey questions also emerged in answer to this question:

- a. Make sure the program is solidly funded and continuously supported.
- b. Make services truly accessible and easy to use (walk-in appointments, no red tape, and all resources one-stop.)

- c. Look at working models from other communities such as the ACRS.
- d. The staff and facility needs to be flexible and friendly, supported well enough that they do not burn out, and passionate about working with African American elders.

One person cautioned that personal preferences play a role and even though it "is geared for African Americans doesn't mean that it's a good fit."

One person felt the transition should be completed in 2004. And another reminded the planners not to compete with other programs but instead to "partner, partner, partner with existing programs."

17. Please share any other perceptions, idea, opinions or concerns you have regarding the needs and services for African American elders in Seattle and South King County?

Respondents offered the following additional comments:

- a. Think out of the box. We need to think differently and stop using the same prescription for all people. Give up the notion that we already know what they need. African Americans have fallen thru the cracks, because of an ethnocentric view that we should accept what's offered. This thinking creates barriers, psychologically, and racist barriers. There must be an understanding of respect, therefore staff or providers of care must have training around cultural competence.
- b. Thank you for caring about elders.
- c. I am not for sure as of now the elders I have are not in Seattle. This has lead me to do some investigating on the issue.
- d. It would be more effective if the emphasis were on "preventive medicine". In other words, it would help the African American Seniors, if the medical community would collaborate with AAEP to teach the above to our seniors before they become to ill, a crisis erupts and they become to incapacitated to help themselves. Thank you, from a concerned staff member as part of the AAEP project.
- e. Use a holistic approach to providing services that understands and respects African American cultural norms and values. Hold funders and policy makers accountable in providing adequate resources to support your program. Involve the community, and provide the very best in customer services. Maintain accountability to the African American community, and stay in touch with the needs identified by the community.
- f. Need more seminars on topics: COPEs, Medicaid/Medicare, Health, Transportation given regularly
- g. Existing programs and facilities should be given adequate levels of funding and support to continue to provide services in the central area community.
- h. It would be nice to have some youth involved.
- i. Be sure to think outside the box. One model does not fit all people; make the case management program more relevant to the people, and not so bureaucratic.
- j. Plan, organize, lobby with the knowledge that you one day too will live to get old and will need more personal CARE...
- k. I am glad that you are doing this survey. It is a start.
- l. Elders will need lots of info about the new viting procedures; if a person is on Medicaid they will need help understanding the new estate recovery law changes.
- m. The mindset of the elderly does not lend them to allow for help unless they feel comfortable with the providers.
- n. All elders need better avenues for expressing their concerns. There is little advocacy in the medical field to assist with making informed decisions about their care. Family members need to be involved in care giving decisions.

- o. There is the perception that people other than the African American Elders decide what is needed and when and how it is delivered. Grass roots surveys such as these are absolutely mandatory on a regular basis.
- p. I'm glad you are doing this survey and I hope the results will guide you in your next steps.

Appendix D: AAEP Transition Steering Committee

MCAAE Members

- **Rowena Rye, Chair, MCAAE**
- **Margaret Boddie, Vice Chair, MCAAE**
- **Gloria Leonard**

AAEP Partner Agencies

- **Pamela Boring, Public Health: Seattle/KC**
- **MaryPat O'Leary, Supervisor, ADS Case Management Program**
- **Dick Sugiyama, Director, ADS Case Management Program**

Community Representatives

- **Raleigh Bowden, Seattle African American Comfort Project**
- **Gayle Johnson, Alliance for Education**
- **Norm Johnson, Executive Director, Therapeutic Health Services**
- **George E. Parker, Jr., Therapeutic Health Services**

ADS Staff

- **Rosemary Cunningham, ADS Planning Unit**
- **Karen Winston, ADS Planning Unit**

AAEP Consultant

- **Neal Adams, Global Consulting**

Appendix E: Mayor's Council on African American Elders & AAEP Project Staff

Council Members

- 1. Rowena Rye, Chair**
- 2. Gloria J. Leonard**
- 3. Karen D. Lincoln, Treasurer, MSW, MA, PhD**
- 4. Adrienne E. Caver-Hall**
- 5. Margaret Boddie, Vice Chair**
- 6. Merlin Rainwater, ARNP**
- 7. George Dicks, BA, GMHS, RCMHP**
- 8. Vincent Latimore**
- 9. Juana R. Royster, PhD, CFCS**

AAEP Partners & AAEP Project Staff

- 1. Pamela Boring, Public Health: Seattle/King County**
- 2. MaryPat O'Leary, Supervisor, ADS Case Management Program**
- 3. Dick Sugiyama, Director, ADS Case Management Program**
- 4. Wanda Harper, ADS Case Management Program**
- 5. Eileen Murphy, Assistant Director, Senior Services of Seattle & King County**
- 6. Mattie Taplin, Program Manager, Central Area Senior Center**
- 7. Mildred Dade, ADS Case Management Program**
- 8. Wyvonne Ray, ADS Case Management Program**

ADS Staff

- Rosemary Cunningham, ADS Planning Unit**
- Karen Winston, ADS Planning Unit**

AAEP Consultant

- Neal Adams, Global Consulting**