LOCAL CAREGIVER NEEDS ASSESSMENT UNDER
CALIFORNIA’S FAMILY CAREGIVER SUPPORT PROGRAM

June 28, 2002

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I. EXECUTIVE SUMMARY

Conducting community needs assessments of the 60+ population has been at the core of the Area Agency on Aging planning process since 1980. With the passage of the National Family Caregiver Support Program, both the definition of the service population, as well as the type of needs that AAA services and programs are intended to target have been significantly altered. This report aims to identify some of the central issues that have arisen with the introduction of this new caregiver client population to the AAAs as it specifically impacts the needs assessment process.

The purpose of this report is to identify the process, method, and practice by which the AAAs may most effectively and accurately identify the needs of caregivers in their Planning and Service Area (PSA). For the purpose of this analysis, we have adapted and integrated three distinct models of need analysis (McKillip, 1987). In developing this model, consideration was given to both the minimum requirements put forth by California Code of Regulations §7300, and to the guidelines provided by the California Department of Aging Program Memo (PM) 01-10. Our intent is to incorporate these regulations and guidelines into a comprehensive and practical framework of caregiver needs assessment.

Within this framework, we examine the following six general steps in the needs assessment process: 1) describe the current population of caregivers; 2) determine existing and unmet needs of caregivers; 3) inventory existing caregiver resources and services; 4) identify service gaps, including existing barriers to equitable access to caregiver resources and services; 5) prioritize the identified service needs of caregivers; and 6) design a plan for the delivery of caregiver services that reduces identified barriers to access, supplements existing services, and creates new services where none exist, in
the most effective and efficient manner possible. We also provide a brief description and critique of some of the most commonly used methods to identifying needs, including surveys, secondary data analysis, focus groups, key informant interview and public meetings.

In accordance with the interagency agreement between the California Department of Aging and the Center for the Advanced Study of Aging Services, this report samples, and makes recommendations related to local needs assessment methods including, but not limited to, the local profiling of caregivers, the determination of caregiver needs, and the determination of unmet caregiver needs. This analysis of the local family caregiver needs assessment process is based primarily on two sources of information: (1) a review of Title IIIE Area Plan addenda, which describe the initial proposed plan for the delivery of caregiver services in each of the Planning and Service Areas (PSAs); and (2) the responses of 24 of the 33 California AAAs to a survey designed to enhance the information gathered from the area plan addenda.

Our review and analysis of the content of the Title IIIE Area Plan Addenda addressed the following areas: (1) the needs assessment methodology used by the AAAs; (2) the needs identified through these assessments; (3) the types of activities that define the program plans resulting from these assessments; and (4) the extent to which program plans actually reflect identified needs.

In general, our review of AAA Title IIIE Area Plan Addenda suggests that most AAAs utilize a variety of methods in identifying the needs of caregivers in their communities. The method used most often, and considered most effective, was a basic description of the local caregiver population. However, only 3 of the 33 AAAs reportedly used a caregiver-specific survey to obtain this information. In total, 48% of AAAs described the caregiver population in their PSA using a combination of regional,
state, or national survey data. The majority of AAAs, 61%, reported reviewing the findings from a sample community survey that was conducted for the purpose of the general 4-year Area Plan.

The majority of AAAs (91%) included a list of identified caregiver needs in their Title IIE Area Plan Addenda. In total, 277 needs were independently cited. While some AAAs cited as few as 2 needs, others identified more than 40 needs. Most AAAs did not present the list of needs in order of priority. Moreover, the 3 AAAs (10%) that did prioritize the list of itemized needs did not specify how the order of priority was determined.

Nearly all of the AAA service plans (93%) included general goal statements; 48% included process objectives; and 69% included at least some specific programmatic objectives. It should be noted here that the absence of more specific programmatic objectives might very well reflect the time constraints experienced in the start-up phase of this program.

AAAs varied considerably in their apparent utilization of information about caregiver needs to develop service plans. Six AAAs (18%) provided a program description that addressed all of the caregiver needs they had identified through their needs assessment activities; however, 14 (42%) of the program descriptions included fewer than one-half of the identified needs.

The results of the AAA survey provide more information about the barriers to obtaining accurate information about caregivers. The barrier mentioned most often was the difficulty identifying and reaching caregivers who are not already connected to a service, a problem reported by nearly 80% of responding AAAs. A lack of an adequate system for collecting data about service users was also a problem for some AAAs, as
were cultural, linguistic, and attitudinal barriers, and an absence of resources necessary to
do proper assessments of caregiver needs.

Our analysis resulted in the identification of six tasks that are essential to the
caregiver needs assessment and community planning process, along with recommended
options for accomplishing these tasks:

1. Describe the current population of caregivers
   Action: Compile a descriptive and demographic profile of caregivers in your PSA
   using a household caregiver survey, modifications in statewide population
   surveys, and/or modifications in local senior surveys.

2. Determine existing and unmet needs of caregivers
   Action: Solicit input from professionals, consumers, and advocates using
caregiver follow-ups to population surveys, caregiver intake assessments, family
   assessments in long-term care and child welfare services, targeted outreach,
   and/or internet-based reporting.

3. Inventory existing caregiver resources and services
   Action: Identify programs and services already serving caregivers using a
   community resource assessment.

4. Identify service gaps, including existing barriers to equitable access to caregiver
   resources and services
   Action: Assess gaps and analyze barriers using service user intakes, caregiver
   focus groups, service utilization data, and/or interviews with community
   representatives and key informants.

5. Prioritize the identified service needs of caregivers
   Action: Synthesize information gathered; weight and rank needs using meetings of
   key stakeholders, public hearings and/or community meetings.

6. Design a plan for the delivery of caregiver services that reduces identified barriers
to access, supplements existing services, and creates new services where none
exist, in the most effective and efficient manner possible
   Action: Evaluate the potential efficacy of available service options using a review
   of existing program evaluation literature, consumer feedback, formal service
   evaluation, and/or service utilization and expenditure analysis.

In conclusion, needs assessment is an essential part of the community planning
process. Information about caregivers and their needs, examined in the context of
existing services, enables AAAs to identify service gaps and priority areas for change. In
this way, the needs assessment process can assist AAAs to allocate limited resources in
the most effective and efficient manner. Data regarding caregivers’ needs and the
effectiveness of existing services for meeting those needs can be a powerful tool in
providing a basis for assuring that resources are targeted where they are most needed, that
services are provided in an effective and equitable manner, and that caregivers receive the
support they need.
II. INTRODUCTION

Conducting community needs assessments of the 60+ population has been at the core of the Area Agency on Aging (AAA) planning process since 1980. With the passage of the National Family Caregiver Support Program (NFCSP), the definition of the AAA client has changed. Both the definition of the service population, as well as the type of needs that AAA services and programs are intended to target have been significantly altered. Specifically, two of most important changes made to the existing AAA service guidelines are:

1) The *AAA client does not have to be 60+; the caregiver client may be any adult relative or non-relative- who is 18+ and caring for any individual who is 60+.*

2) The AAA now targets the needs of *individuals who are 60+ - who are relatives or guardians by formal arrangement - and caring for children under the age of 18.*

In consideration of these changes, this discussion aims to identify some of the central issues that have arisen with the introduction of this new caregiver client population to the AAAs as it specifically impacts the needs assessment process.

The purpose of this report is to identify the process, methods, and practice by which the AAAs may most effectively and accurately identify the needs of caregivers in their Planning and Service Area (PSA). This report is intended to provide information to the AAAs that can be used to proactively address some of the challenges brought about by the addition of this population to the client roster, to recognize some potential opportunities presented by the introduction of this new population of clients, and to highlight some important considerations for the continued planning of caregiver services.

The specific objectives of this report are to sample, and make recommendations related to local needs assessment methods including, but not limited to, the local profiling
of caregivers, the determination of caregiver needs, and the determination of unmet caregiver needs. The recommendations presented here are designed to build on the strengths of the existing AAA planning process. The ultimate goal is to refine the needs assessment process to most effectively identify and address the needs of the new caregiver client population targeted by the NFCSP.

A. BACKGROUND

Historically, AAA services have been available to all persons in the 60+ population, with established mandates [Older Americans Act (OAA)/Federal Code of Regulations (FCR), Older Californians Act (OCA)/California Code of Regulations (CCR)] to target and prioritize service to: “older individuals with greatest economic and/or social need, with particular attention to low-income minority individuals; older Native Americans; isolated, abused, neglected, and/or exploited older individuals; older individuals with severe disabilities; older individuals residing in rural areas; older individuals who are of limited English-speaking ability; older individuals with Alzheimer’s disease or related disorders with neurological and organic brain dysfunction and the caretakers of these individuals; and unemployed low-income individuals who are 55 years old or older.” (California Code of Regulations: Title 22. Social Security. Division 1.8. Article 3. §7310)

Although existing targeting mandates include “older individuals with Alzheimer’s disease or related disorders with neurological and organic brain dysfunction and the caretakers of these individuals” (California Code of Regulations: Title 22. Social Security. Division 1.8. Article 3. §7310), it is important to recognize that the caretaker role referenced here is limited to caregivers of individuals with very specific diseases and disorders and the care recipient remains the primary target of intervention. In the context
of this definition, the caregiver is presented as an adjunct component of the care provided for the impaired individual, and as such, their needs are not targeted directly.

While AAAs have been, albeit secondarily, serving the aforementioned “caretakers” as well as others in the 60+ population who are coincidentally caregivers, no AAA services and programs have previously been funded to explicitly and independently serve caregivers in California. While it is essential to recognize the dyadic nature of the caregiver-care recipient relationship and all the complexity it encompasses, the clear target of the NFCSP intervention is the caregiver. The intention of the NFCSP is to provide services to caregivers which address their individual needs as impacted - but not directed - by the needs of the care recipient.
III. CAREGIVER NEEDS ASSESSMENTS PROCESS

Community needs assessments of the 60+ population have been central to the AAA’s practice for more than two decades. Guidelines for the effective implementation of needs assessments have previously been provided to the AAAs (Program Memo: PM 00-12. Dated May 31, 2000) and include a standardized tool of core questions which the AAAs may opt to use when conducting their local community survey of the 60+ population.

While, arguably, the basic process and principles of conducting an effective needs assessment remain the same across diverse populations, the definition of caregiver need is unique by virtue of the caregiver’s function; i.e., the care recipients’ needs have a direct impact on the caregivers’ needs and, therefore, it is quite difficult and impractical to separate the two. Recognizing the interdependent nature of the caregiver – care recipient dyad will facilitate the identification of critical factors that should effectively and appropriately inform both the targeting efforts employed, as well as the methods and content of the assessment instruments selected to carry out the needs assessment process.

A. Conceptual Framework for Caregiver Needs Assessment

Needs assessment has been defined as “a systematic and ongoing process of providing usable and useful information about the needs of the target population – to those who can and will utilize it to make judgments about policy and programs. [It] is population-specific, but systematically focused, empirically based, and outcome-oriented. [It] is a form of applied research that extends beyond data collection and analysis to cover the utilization of the findings” (Reviere, Berkowitz, Carter, & Graves Ferguson, 1996).

For the purpose of this analysis, we have adapted and integrated three distinct models of need analysis illustrated by McKillip (1987): 1) the discrepancy model, which
identifies what is desired; measures what exists; then, determines unmet need as the discrepancy between what is desired and what exists; 2) the marketing model, which examines needs as they are defined by service utilization patterns; then, targets services accordingly; and 3) the decision-making model, which identifies needs, identifies or develops options to address these needs, then, makes decisions based on the weighting and ordering of prioritized need.

The resulting merged model provides a framework that begins with a policy mandate or directive; solicits input from professionals and consumers; assesses existing resources and/or gaps in service; synthesizes and prioritizes these multiple sources of information; and, finally, implements a decision-making process which results in a plan of action.

Within this framework, we will examine six general steps in the needs assessment process as they specifically apply to the caregiver population: 1) Describe the current population of caregivers; 2) Determine existing and unmet needs of caregivers; 3) Inventory existing caregiver resources and services; 4) Identify service gaps, including existing barriers to equitable access to caregiver resources and services; 5) Prioritize the identified service needs of caregivers; and 6) Design a plan for the delivery of caregiver services that reduces identified barriers to access, supplements existing services, and creates new services where none exist, in the most effective and efficient manner possible.

In developing this model, consideration was given to both the minimum requirements put forth by California Code of Regulations §7300, and to the guidelines provided by the California Department of Aging Program Memo (PM) 01-10. The California Code of Regulations (CCR) include regulations that have been formally adopted by state agencies, reviewed and approved by the Office of Administrative Law,
and filed with the Secretary of State. The California Department of Aging (CDA) periodically publishes official program memoranda that establish standard procedures and guidelines for the implementation of the programs and services that it administers through the AAAs. Our intent is to incorporate these regulations and guidelines into a comprehensive and practical framework of caregiver needs assessment.

CCR §7300 pertains to the minimum requirements for conducting the general 4-year Area Plan needs assessment, which include:

- An analysis of Department of Finance or US Census demographic data
- A review of data from other social service agencies
- Completion and analysis of a sample survey in the PSA aimed at identifying, at a minimum, age; race; ethnicity; educational background; income level; and perceived needs

CDA Program Memo (PM) 01-10 is specific to the implementation of the NFCSP and the assessment of caregiver needs, and stipulates that the AAAs carry out and report the results of a review of caregiver needs including, in part:

- An assessment of the local need for family caregiver services
- Consideration of available data, including:
  - Area Plan needs assessments conducted in preparation for the four-year plan
  - Input from I&A programs and other service providers regarding unmet needs
  - Community forums
  - Surveys
- An inventory of existing caregiver support services
- A program description resulting from the review of needs
- Documentation that the resulting plan consider all other existing and potential caregiver support services operating locally

B. Steps in the Caregiver Needs Assessment Process

1. Describe the current population of caregivers

   As a first step in conducting a needs assessment, it is important to compile a descriptive and demographic profile of the caregiver population in the community. A fundamental knowledge of the caregiver population is necessary to effectively implement
and target the needs assessment activities. While a random sample community survey is
the method likely to provide the most accurate demographic profile of caregivers, it is
recognized that - given the scarcity of resources – this may not be feasible for individual
AAAs. Information may be extrapolated and estimates made from a variety of sources,
including: US Census data; Department of Finance projections; service provider, county,
or employer surveys and databases; as well as from other local, statewide, or national
studies.

2. Determine existing and unmet needs of caregivers

There are three major sources from which one may identify the unmet needs of
caregivers. First, one may begin by examining the experiences and preferences of current
users of caregiver services. Consideration should be given to the existing demand for
services, i.e., what consumers say they need and want. Other useful information may be
gathered from an examination of those services that are wait-listed, as well as those that
are underutilized. Valuable information may also be derived from consumer satisfaction
surveys and program evaluations. The AoA Performance Outcome Measures Project
(POMP), for example, includes an instrument designed to gather information from
consumers of caregiver support programs.

Second, service providers can serve as key informants regarding caregivers’
unmet needs. Service providers can offer their perspective and expertise regarding
current service users’ expressed preferences and patterns of service use. Surveys, focus
groups, and invitational meetings can be used to gather and assess the observations and
opinions of these key informants.

Third, to most effectively plan caregiver services, an effort must be made to
determine the unmet needs of caregivers who are not already receiving services and/or
whose voice is underrepresented, who make up the majority of caregivers in most
communities. It has been well documented that caregivers generally underutilize available services, even when they are low-cost or free of charge. Often when caregivers do access services, it is relatively late in the caregiving experience; the caregiver may now have problems of deteriorating physical or mental health, and/or the care recipient may be extremely disabled. The most effective method of identifying the unmet needs of this population of caregivers is the use of community surveys. However, key informants who are knowledgeable about particular populations in the community may be able to provide insight into the needs of caregivers in those population groups.

3. Inventory existing caregiver resources and services

Having identified the unmet needs of caregivers, the next step is to identify the potential resources existing in the community that address each of these unmet needs. Beyond the mere existence of formal services, it is important to consider informal and community supports that transcend the limits of Title III-E. Moreover, the adequacy and appropriateness of the services that are available also should be considered. This determination should take into consideration the following elements: who is eligible to be served, who is being served, what are the benefits, and what are the risks of participation. The process of identifying existing services naturally reveals gaps in service, including services that are either nonexistent or insufficient. By determining the scope and range of existing caregiver services, informed decisions can be made as to whether these services need to be supplemented, adapted, or otherwise enhanced.

4. Identify service gaps, and barriers to caregivers’ access to resources

It is important, albeit difficult, to identify factors that make it difficult for caregivers to access services. This requires soliciting - and listening to - the voice of consumers, to find out what their experience has been. Overall, have they found that services are available, appropriate, accessible and adequate? If not, consideration should
be given to issues of access, including barriers that may be attributable to socioeconomic, geographic, linguistic, or cultural factors. Observations made by service providers and other key informants are also integral to this process. Drawing from their experience, one can explore the possible myriad reasons for underutilized services.

5. **Prioritize the identified service needs of caregivers**

   Once all the information has been gathered and analyzed, a process of weighting and prioritizing the identified needs must follow. This decision-making process will be impacted by a variety of considerations, including: the resources available; the stakeholders involved and their ability to reach consensus; the types of caregivers determined to be most “at-risk;” service providers’ policies and philosophies; the demographic and social make-up of the community; and, local political realities.

6. **Design a plan for the delivery of caregiver services**

   The final service plan represents a determination of how resources will be allocated. Ideally, it is based on an identification of caregiver needs, an examination of service gaps and barriers, and a prioritization of residual service needs. In developing a service plan, attention should be given to existing evidence regarding which services and intervention approaches have been shown to be the most effective in responding to the identified high priority service needs among particular populations, in order to provide the most efficient and effective mix of services for caregivers in the local community.
IV. OVERVIEW OF NEEDS ASSESSMENT METHODS

The next section provides a brief description and critique of some of the most commonly used needs assessment methods. Although a more in-depth discussion of methods is beyond the scope of this report, there exists a wealth of information about needs assessment methods in the literature (Johnson, Meiller, Miller, & Summers, 1987; McKillip, 1987; Reviere, Berkowitz, Carter, & Graves Ferguson, 1996). These references comprise the main sources from which the ensuing discussion of needs assessment methods was drawn; the reader is likewise encouraged to make use of these references, which represent a rich resource from which to gather more detailed information.

A. Surveys

1. General population surveys

Representative population data can be obtained from a probability sample using a standardized, structured survey instrument that may be administered by phone, mail, e-mail, or in-person. Sample design is especially critical to the quality and validity of the data generated. Typically, a cross-section of the population is interviewed and information gathered which addresses community members’ identified problems, special population needs, service use and consumer satisfaction issues.

When properly applied, surveys afford a high degree of generalizability and validity. It is possible and relatively easy to adapt an existing survey instrument for the current purpose. Although mailed surveys tend to get the lowest response rates, they are time-efficient and easy to coordinate. Disadvantages of the survey method are that they tend to be expensive and time-consuming. Also, technical skills are required to employ proper sampling techniques, to construct and validate the survey instrument, and to process data. Finally, it is important to remember that all perceptions of need,
irrespective of how they are gathered, will have a subjective element that will affect the findings.

2. **Target population surveys**

These surveys tend to be narrower in scope, are focused on a specifically targeted population and have the capacity to provide more in-depth information. This method is even more effective when the population targeted is already being served because they can then provide valuable information about the effects of current service use and/or barriers to access. Drawbacks are that target population surveys may be expensive and time-consuming. Also, subgroup characteristics can limit the generalizability of the information gathered.

**B. Secondary Data**

Secondary data refers to the analysis of statistical information that has previously been collected for a purpose distinct from the current application. Secondary data may be found in a variety of sources including census data, previous survey data, and administrative record data. Secondary data are particularly useful for the initial steps of a community needs assessment, when a descriptive and demographic profile of the target population needs to be compiled. Other advantages to using secondary data include the relative ease of using existing information, the facility of accessing these information sources, and the low cost of obtaining this type of data.

The choice of an appropriate secondary data set is critical to its effective use, and requires careful evaluation of available sources to determine the degree to which they provide a conceptual, representational, and functional match with the current study objectives. Use of secondary data is limited, moreover, by how study variables were originally defined and measured, as well as by the process with which the data were collected and tabulated.
C. Focus Groups

Focus groups provide a method for exploring in more depth the needs and experiences of caregivers, especially traditionally marginalized groups who typically are underrepresented in other needs assessment methods. Focus groups are usually comprised of 8-10 participants who represent the target population. One or two moderators lead the discussion, employing qualitative interviewing techniques with the use of unstructured, open-ended questions. These exploratory questions are designed to elicit participants’ feelings and beliefs around the issue of interest. Between 60-90 minutes is typically dedicated to these sessions.

One of the strengths of the focus group method is that it gets information directly from the consumer. Moreover, the group setting provides a rich and dynamic environment from which the interaction of participants produces experiential data that may be difficult to obtain in individual interviews. By the same token, focus groups provide a forum in which a large amount of in-depth information may be collected in a relatively short period of time.

One drawback of focus group methodology is the inherent challenge of managing group dynamics in a way that most effectively gets to the core issues. In order to get the most accurate and representative information possible, focus groups must be skillfully managed, particularly when the group is diverse. While more homogenous groups tend to be easier to manage, they are unlikely to be representative of the target population and the information generated will be limited in its application. One way to address diversity issues is to hold multiple focus groups, each representing a distinct subgroup within the target population.
D. Service Use Data

Analysis of service utilization data provides a mechanism for comparing expected service utilization with the rate of services actually provided. Most service use studies look at rates of intake and provide analyses of the percentage of those who use services as compared to those who are eligible to receive them. Analyses of service use data can produce rich information regarding potential barriers to service use such as awareness, availability, accessibility, and acceptability.

These data must be interpreted with caution, however, as different explanations may apply depending on the context. If service use is not directly related to need, it may not provide an appropriate measure. For example, it is often argued that services may provide a solution without necessarily addressing the source of the problem. Alternatively, one may argue that heavy service use is an indicator of need as evidenced by waiting lists; light use is an indicator of need because it is assumed that service is needed; and non-use is an indicator of comparative need because it is expected that similar subgroups will demonstrate similar use rates. Finally, it is helpful to keep in mind that service utilization data don’t give us any information about non-users; therefore, whenever possible, they are best supplemented with data from other relevant populations, such as members of the target population who are non-users.

E. Community Representatives/Key Informants

This method requires the identification of both formal and informal community leaders, i.e., those persons who have a wide range of contacts with the target population. Examples of key informants might include service providers, religious leaders, educators, business owners, and other involved and interested members of the community who have knowledge of, and/or contact with, the target population.
Interviewing key informants affords the opportunity to gather their impressions, opinions, and expertise regarding the target population’s needs. In addition, key informants may be particularly useful in identifying and bringing forward members of the target population so that they can participate in other, more direct, needs assessment activities. Service providers can be especially useful informants regarding staff perceptions of unmet needs and barriers confronting the target population within the context of the service delivery system. The use of service providers as informants also has the potential to be cost effective if integrated with other existing data collection mechanisms within the service agency.

One limitation of the key informant method is that the opinions expressed may reflect cultural, class, professional, and even bureaucratic bias. It is important to recognize that information provided by community representatives and key informants may not always accurately represent the perspectives of the target population.

F. Public Meetings

1. Public hearings

Public hearings provide a standardized and regulated forum in which information that affects the public interest may be generated, exchanged, and/or delivered. Most often initiated in response to regulatory requirements, the typical format of a public hearing includes the publication of pre-hearing notices; the presentation of a proposal plan or issue; the delivery of relevant oral or written testimony; and documentation of the proceedings as a matter of public record.

The public hearing is a political, investigative, and evaluative tool. It is the needs assessment method most frequently used when public display is critical to acceptance of the outcomes. This method is especially useful when there is dissension around an issue,
and a goal to reach consensus. The intent of the public hearing is to engage people in the process, gather public opinion, and generate support for an issue.

Public hearings can be problematic, however, because they are frequently dominated by vested interest groups. Hearing times are often inconvenient or inaccessible, particularly for low-income and minority groups. Consequently, the information gathered using this method is unlikely to provide an accurate or fair representation of more general and diversified public opinion.

2. Community forums

Also referred to as “town meetings,” this method of needs assessment provides a tool for building community support. Generally, these forums are more informal and more politically neutral than public hearings. The community forum is organized around a particular issue and ideally brings together a representative cross-section of the population. The community forum usually has a leader – either self-appointed or selected - who facilitates the establishment of a clear purpose and a set of “ground rules” under which the forum will pursue its’ objectives. Community forums have the potential to gather a lot of information in a relatively short period of time.

As is evidenced by most of the needs assessment methods previously described, diverse population representation is one of the biggest challenges of the community forum method. The community forum most easily attracts those already represented and involved with the issues being addressed. The challenge is to target and attract those impacted by the issue(s) whose voices have not yet been heard.
V. METHODS

Our analysis of the AAA family caregiver needs assessment process is based primarily on two sources of information: (1) a review of Title III-E Area Plan addenda, which describe the initial proposed plan for the delivery of caregiver services in each of the Planning and Service Areas (PSAs); and (2) responses to a survey emailed to all of California’s 33 AAA planners/program specialists, designed to enhance the information gathered from the area plan addenda.

A. Title III-E Area Plan Addenda

The Title III-E Area Plan addenda from each of the 33 AAAs were reviewed for content, first, and all documentation and details regarding needs assessment methodology were extracted and then summarized. Each type of methodology reported as used by the AAAs was included for the purpose of this analysis. A sum score of all AAAs reporting the utilization of a specific method was then tallied and a percentage of the entire sample was calculated.

Second, a summary of all identified needs was compiled and categorized by the five service categories originally outlined by the NFCSP: i.e., service information; access; caregiver support; respite; and supplemental services. In addition, an “other” category was included to capture those identified needs that either didn’t fit into the aforementioned categories, cut across categories, or were so specific that it was deemed more informative to categorize them separately. The identified needs were summarized, both within each category and as a sum of all categories, and the relative frequencies were tabled.

Next, the addenda program descriptions were reviewed and analyzed for program planning content. All of the addenda program descriptions were illustrated by a
statement of goals and/or objectives and, for the purpose of this review, were summarized by the following (3) categories: 1) Goal statements: i.e., broadly defined goals for program and service delivery, but lacking specific plans for implementation; e.g., “To support the tradition of family caregiving through both formal and informal sources of care that provides respite to caregivers;” 2) Process objectives: i.e., developmental plans for administering or coordinating programs and/or services, but lacking detail regarding the programs that were to result; and, e.g., “To develop a system to receive and respond to input from family and relative caregivers” or “To issue a Request for Proposals, award contracts, provide technical assistance, and monitor effectiveness of new programs;” 3) Programmatic objectives: i.e., a series of action steps necessary to the implementation of a specific program and/or service; e.g., “To purchase equipment, staff time, and postage for the production and distribution of electronic and written outreach materials, and to distribute said materials via internet and newsletter with the purpose of reaching 4,000 community seniors and making them aware of Title IIIIE respite and community-based services”.

Finally, all AAA addenda were analyzed to determine the degree of match between the identified needs and the resulting program plan. For each AAA addendum, the number of identified needs was determined and the percentage of needs explicitly addressed in the resulting program description calculated. The findings were grouped into percentage categories and summarized in a table format.

B. Follow-up E-Mail Survey

The second source of information was a survey e-mailed to all of California’s AAA planners/program specialists regarding implementation of the NFCSP. A series of follow-up questions were designed to enhance the information gathered from the Area Plan addenda and gain a more qualitative perspective of the AAAs experience in
identifying the needs of caregivers. Responses were received from 24 (73%) of California’s 33 AAAs, following telephone and e-mail requests for information.

Five of the survey questions were specific to the needs assessment process. These questions were designed to elicit information regarding: the most effective methods used in the needs assessment process; methods not employed, and why; stakeholder involvement in the process; success in identifying caregivers’ needs across diverse populations; barriers encountered in obtaining accurate information about caregivers; and types of assistance that might enhance the needs assessment process in the future.

The results of this survey are summarized and presented in a series of tables which detail needs assessment methods identified by the AAAs as most effective, stakeholders involved in the needs assessment process, success rates in identifying caregiver needs across diverse populations, and some of the barriers encountered to obtaining accurate information about caregivers. A narrative description of these findings is provided along with a summary of the AAA directors’/program specialists’ responses to open-ended questions pertaining to: why certain needs assessment methods were not used; how stakeholders were involved in the needs assessment process; and the identification of types of assistance that might be helpful for future caregiver needs assessments.

C. Limitations Of The Data

It is likely that more comprehensive needs assessment activities were carried out than were explicitly detailed in the Area Plan Addenda and other materials reviewed here. It is further recognized that the implementation of this process was characterized by some rather challenging time constraints and therefore may not accurately represent the true capacity of the AAAs to conduct comprehensive and effective needs assessments of caregivers, given sufficient time and resources. A more in-depth discussion of some of
the potential barriers to needs assessment implementation will be covered later in this report.
VI. FINDINGS: TITLE III-E AREA PLAN ADDENDA

The findings from our review and analysis of the content of the Title III-E Area Plan Addenda follow. First, we present findings from an analysis of needs assessment methodology used by the AAAs, organized by assessment type. Second, we summarize the needs that were identified through these assessments. Third, we examine the types of activities that define the program plans resulting from these assessments. Lastly, we evaluate the extent to which program plans actually reflect identified needs.

A. Needs Assessment Methodology

1. Population Surveys

Table 1. Needs Assessment Methodologies By Data Source*

<table>
<thead>
<tr>
<th>1. Descriptions of the Caregiver Population</th>
<th>Total # of AAAs (N = 33)</th>
<th>% of total</th>
</tr>
</thead>
<tbody>
<tr>
<td>a. Regional, state, or national survey data</td>
<td>16</td>
<td>48%</td>
</tr>
<tr>
<td>b. PSA survey data, general population</td>
<td>20</td>
<td>61%</td>
</tr>
<tr>
<td>c. PSA survey data, caregiver specific</td>
<td>3</td>
<td>9%</td>
</tr>
<tr>
<td>d. PSA survey data, grandparent/kinship specific</td>
<td>4</td>
<td>12%</td>
</tr>
</tbody>
</table>

*For the complete table, please see Appendix B: Table I

a) Regional, state or national survey data

Definition: This category includes information gathered from US Census data, Department of Finance data, and other regional, state, and national research and survey data.

As part of the Area Plan needs assessment process, CCR §7300 requires an analysis of Department of Finance or US Census demographic data. Although only 9% of the AAAs reported a review of Department of Finance or US Census data, 12% reviewed research conducted at the state or national level, and an additional 27% used data collected from a regional survey of the 55+ population which included questions specific to caregiving issues. In total, 48% of AAAs described the caregiver population in their PSA using a combination of regional, state, or national survey data.
Four out of 33 AAAs (12%) used grandparent-specific PSA survey data to describe the size of the population of those caring for kin/grandchildren. Descriptions of this specific caregiver “sub-population” mostly consisted of the percentage of those surveyed caring for children.

AAA Examples

One AAA used information drawn from several different sources to determine the prevalence of caregiving in their PSA. First, they used data drawn from a national caregiving survey to make the following two assumptions: 1) approximately 20% of the households in the PSA contained at least one caregiver, and 2) close to 75% of these caregivers were providing care to a relative or friend who was at least 50 years of age. Next, the AAA gave consideration to local population data, estimating that 35,000 persons in the county were over the age of 85, and to Alzheimer’s Association data, estimating that more than 40,000 older adults in the county had Alzheimer’s disease. From these data, i.e., an estimate of the number of “oldest-old” and/or cognitively impaired in the PSA, a projection was made as to how many members of the population were in need of - and likely receiving - the assistance of a caregiver with one or more activities of daily living.

Another AAA reviewed statewide data produced by Family Caregiver Alliance to compile both an estimate of the number of informal and family caregivers in their PSA, and an approximation of the number of hours of unpaid care provided by these caregivers. The same AAA also reviewed 2000 Census American Service Profile data to estimate the number of grandparent caregivers in their PSA.

b) PSA survey data, general population

Definition: This category includes information gathered from community surveys conducted within the PSA which specifically targeted the 60+ population.
In accordance with the minimum requirements put forth by CCR §7300, the majority of AAAs, 61%, reported reviewing the findings from a sample community survey which was conducted for the purpose of the general 4-year Area Plan. CDA Program Memo (PM) 01-10 also calls for the consideration of other survey data. Thirty three percent of AAAs also reviewed other local survey data, e.g., city, county, employee, consumer satisfaction, and access to health insurance surveys, to gather information about the 60+ population.

AAA Examples

As part of a more general needs assessment, one AAA began collecting information on caregivers in 1995. This community survey was used to estimate both the number of 55+ year old adults providing care for another individual, and the age groups of the care recipients. This survey also gathered information about some of the difficulties caregivers reported experiencing; One-third of the caregivers reported the following problems: exhaustion/fatigue; lack of support from other family members/social service organizations; and little/ no experience in providing specialized care, such as to a person with Alzheimer’s disease.

The same AAA collected additional information on caregivers from a needs assessment conducted in 2000 and found the following: caregivers tend to be confined to their settings with care recipients and are significantly less able to travel; compared to non-caregivers, caregivers were less likely to have a social network that was nearby and provided relief; financial support was reported to be a major barrier in providing care; caregivers were less apt to report their health as good or excellent; and more likely to report experiencing higher levels of stress.

In another example, two different groups of AAAs, representing 30% of all AAAs, pooled resources to conduct regional surveys of the 55+ population. A random
telephone survey included a section dedicated to the issues of older adults as caregivers. The information gathered included: an estimated percentage of the 55+ population who had daily caregiving responsibilities; the average number of hours per week spent providing care; age groups of both the caregivers and care recipients; and the caregiver’s relationship to the care recipient, including identification of those assisting a non-relative, i.e., a neighbor or a friend. These caregivers were also asked to rate on a 4-point Likert scale, how physically and emotionally stressful their caregiving experiences had been, as well as to indicate what their current needs were, and what types of assistance would be most beneficial.

c) PSA survey data, caregiver specific
Definition: This category includes information gathered from community surveys conducted within the PSA which specifically targeted the caregiver population.

CDA’s Program Memo (PM) 01-10 states that a review of caregiver needs should include an assessment of the local need for family caregiver services. Although caregiver specific surveys have the potential to provide the most accurate and useful information about caregivers in the PSA, only 9% of the AAAs reported collecting and analyzing data from a sample survey that was caregiver-specific.

AAA Examples

One AAA conducted a caregiver specific survey by mail. Of the 50,500 surveys mailed, 6,684 (13%) were completed and returned. After identifying respondents who were caregivers and determining whether or not they were primary caregivers, the following information was gathered: the relationship of the caregiver to the care recipient; the number of hours per week spent providing care; and the caregiver – care recipient living arrangement. The survey also included questions which asked whether community programs and services were sufficient in providing caregivers with the
assistance they needed, and also asked them to rank, in order of priority, three specific services that would be most helpful to them.

2. Information about Service Users

Table 2. Needs Assessment Methodology By Data Source*

<table>
<thead>
<tr>
<th>2. Information about Service Users</th>
<th>Total # of AAAs (N = 33)</th>
<th>% of total</th>
</tr>
</thead>
<tbody>
<tr>
<td>a. Service providers</td>
<td>5</td>
<td>15%</td>
</tr>
<tr>
<td>b. Service users</td>
<td>11</td>
<td>33%</td>
</tr>
</tbody>
</table>

*For the complete table, please see Appendix B: Table I

a) Service providers
Definition: This category includes information about caregivers gathered from service providers using a variety of methods including surveys, focus groups, and public meetings.

CCR §7300 requires a review of data from other social service agencies and CDA Program Memo (PM) 01-10 asks AAAs to consider input from other service providers regarding unmet needs. 15% of AAAs reported gathering information about service users from service providers. This information was generated from a variety of sources, including surveys, focus groups, planning forums, public hearings, informational sessions, advisory, and other ad hoc committee meetings. Two AAAs (6%) reported that they collected information from service providers in the community to determine needs specific to grandparent/kinship caregivers. The methodologies used to collect this information included service provider surveys and one focus group. While it is likely that service providers were represented in other information gathered by the AAAs, we were unable to determine this from the addenda information reviewed.

AAA Examples

One AAA sponsored a provider planning forum in which 26 provider attendees were each given “$1000” to allocate, as needed, to each program element provided by the 5 NFCSP categories of service. Another AAA sent out questionnaires to 62 service providers in the PSA. 11 (18%) of the providers responded to the following 3 questions:
1) As a Service Provider, what are the major problems and gaps your program encounters as they relate to family caregivers? 2) Do you know what caregiver services exist now? If your answer is yes, would you list those services that you know? 3) Can you advise the [PSA or county name] AAA how we can best use this new NFCSP funding to maximize or generate new resources?

b) Service users
Definition: This category includes information about caregivers generated from existing service user records, databases, and surveys.

CDA Program Memo (PM) 01-10 requests consideration of available data, including input from Information & Assistance (I&A) programs regarding unmet needs. CCR §7300 also requires a review of data from other social service agencies. Thirty three percent of the AAAs reported using information gathered from service users. Twenty-four percent reported using data from existing I&A records, most typically by tracking over a distinct period of time the numbers and percentages of incoming calls pertaining to caregiving issues. An additional 9% of AAAs gathered data from surveys, informational sessions, and other public meetings attended by service users. Although it is likely that service users were represented in other information gathered by the AAAs - e.g., 33% reviewed county, regional, customer satisfaction, and access to health insurance surveys - we were unable to make this determination based on the information reviewed. One AAA (3%) reported gathering information from recipients of kinship services through a survey of kinship service recipients.

AAA Example

One AAA conducted a “random sample survey” of service users drawn from three separate and distinct service provider databases in their PSA: 1) Caregiver Resource Center records of services to caregivers of persons with adult-onset brain impairment; 2) Title IV of the Social Security Act Public Assistance for Children in on-needy Caretaker
Situations (Cat 33); and 3) In-Home Supportive Services records of in-home assistance to low-income eligible care recipients. A sub-sample was drawn from the total sample comprised only of those respondents who either were (a) 60 years of age or older or (b) caring for someone 60 years of age or older.

Information collected by the survey included: demographic information such as the gender, age, race/ethnicity and income of the caregiver; the caregiver’s relationship to the care recipient; the living arrangement; and the number of hours per week spent engaged in caregiving activities. Questions also targeted the caregiver’s service needs and practices. For example, one question asked if the respondent had ever contacted a State or County Agency for assistance related to their caregiving activities; another asked whether the caregiver was currently paying for any specific service(s); a final set of questions asked whether a specific service would or would not be helpful, and whether the caregiver was already receiving a specific service.

3. Focus Groups

<table>
<thead>
<tr>
<th>Table 3. Needs Assessment Methodology By Data Source*</th>
</tr>
</thead>
<tbody>
<tr>
<td>Total # of AAAs (N = 33)</td>
</tr>
<tr>
<td>3. <strong>Focus Groups</strong></td>
</tr>
<tr>
<td>a. General senior population</td>
</tr>
<tr>
<td>b. Caregiver specific</td>
</tr>
</tbody>
</table>

*For the complete table, please see Appendix B: Table I

a) **General senior population**  
Definition: This category includes information gathered from focus groups convened to address issues specific to the 60+ population.

Twenty-one percent of AAAs report conducting focus groups addressing concerns of the 60+ population. These groups comprised a variety of participants including consumers, service providers, in-home support providers, professionals, community representatives, and other key informants. The topics addressed by these focus groups
were many and included, for example: information; nutrition; assistive devices; transportation; community care; and employment. One AAA (3%) utilized a focus group of service providers and other professionals in the community to identify needs of grandparent/kinship caregivers in addition to the needs of caregivers in general.

**AAA Example**

One AAA reported that they extracted results specific to caregiver issues from focus groups of the general senior population convened for the purpose of the 4-year Area Plan. This AAA reported holding a total of 5 focus groups for the general senior population that included the following questions:

1) Do you know any family members or friends who are unpaid caregivers?

2) What kind of support do these caregivers need?

They reported the two most important needs cited by group members at all meetings were 1) respite care and 2) coordinated information and referral systems.

The same AAA conducted 8 phone interviews in Spanish using the same focus group questions. Only 3 of the 8 participants knew of someone who was an unpaid caregiver. The respondents cited emotional support; information from social services regarding ways to meet the financial burden; payment/wages; recognition –such as publicity in the local newspaper; and respite as the most critical caregiver needs but these needs were listed in no particular order of priority.

b) **Caregiver specific**

Definition: This category includes information gathered from focus groups convened to address issues specific to the caregiver population.

Two AAAs (6%) reported gathering information through caregiver specific focus groups. Although both groups addressed caregiver specific issues, the source of
information was different; one group was attended by service providers and professionals, while the other group represented caregivers.

**AAA Example**

One AAA convened two focus groups of professionals and service providers representing the Alzheimer’s Association, the local adult day health and Alzheimer’s Day Care Resource Center, Family Caregiver Alliance, hospice agencies, senior centers, residential care facilities, local private foundations, and County mental health and social services divisions. Participants were asked what services currently exist for family caregivers, what gaps exist, what critical issues caregivers face, how to best reach adult family caregivers, how to support grandparent caregivers, and how to best leverage and utilize FCSP funds.

4. **Public Meetings**

**Table 4. Needs Assessment Methodology By Data Source***

<table>
<thead>
<tr>
<th>4. Public Meetings</th>
<th>Total # of AAAs (N = 33)</th>
<th>% of total</th>
</tr>
</thead>
<tbody>
<tr>
<td>a. General senior population</td>
<td>11</td>
<td>33%</td>
</tr>
<tr>
<td>b. Caregiver specific</td>
<td>10</td>
<td>30%</td>
</tr>
</tbody>
</table>

*For the complete table, please see Appendix B: Table I

a) **General senior population**

*Definition: This category includes information gathered from public hearings and community forums convened to address the interests of the 60+ population.*

Only one-third of AAAs (33%) reported gathering information from and about the 60+ population at public hearings. However, public hearings are one of the required components of the 4-year AAA planning process and, therefore, it is likely that all AAAs conducted at least one general senior population public hearing but simply did not reference it in the Title IIIE addendum.
AAA Example

One AAA held a series of 39 public hearings over a total time period of five months. These forums were attended by both seniors and younger individuals with disabilities. Approximately two thousand persons attended these community forums and identified the following top four service needs: transportation, nutrition, health care, and housing. Based on the identification and assessment of these priority issues by the participants, the AAA developed a series of recommendations to address these concerns.

b) Caregiver specific

Definition: This category includes information gathered from public hearings and community forums convened to address the interests of the caregiver population.

Thirty percent of AAAs identified needs through caregiver specific public hearings and community forums. Most of these hearings were structured as informational sessions, designed to inform the community about the National Family Caregiver Support Program. Some AAAs also used this forum to gather more information about caregiver needs from community members and other attendees, i.e., service providers and other professionals. This information was gathered in a variety of ways: some AAAs gathered information through informal discussion, some posed a series of specific questions, while others distributed a survey questionnaire used in previous applications. Although needs for grandparent caregivers arose through some of the public hearings and community forums held for caregivers, these forums or public hearings were targeted for caregivers in general. Public hearings or community forums held specifically for grandparent or kinship caregivers were not identified by any AAA as needs assessment activities in our review of addenda.
AAA Examples

One AAA held 4 caregiver specific public hearings within a one-month time period. All hearings were held at different locations and at different times. 30 day public notice of each of these hearings was published in the county newspaper. In addition, these hearings were publicized with a news release that invited caregivers of the 60+ population and the 60+ population caring for children under 18 years of age to participate, through the distribution of flyers to community centers, and by posting the information on the community web site. This AAA also collected contact information from the meetings’ attendees and started a caregiver database to be used for current and future mailings.

Another AAA held a series of public forums in 10 different cities located within the PSA and invited both caregivers and service providers to attend. 59% of attendees were caregivers; 36% were service providers; 5% represented other interested parties. Participants were asked to indicate what caregiver services they either received or provided, and to identify any unmet needs of which they were aware. As a method of prioritizing the identified unmet needs, participants were each given $100 “dollars” and asked to “spend” it on the 5 different categories of NFCSP services, as needed.

Recognizing that many caregivers are unable to leave the care recipient to attend public meetings, one AAA held a public forum call-in program over a period of several days. Caregivers had the opportunity to talk to AAA staff about their needs and were also able to participate in the group process of the community meeting because the AAA arranged to have the public forum wired for call-in accessibility. In addition, the call-in program was TDD accessible and translation services were provided.
5. Community representatives/ Key informants

Table 5. Needs Assessment Methodology By Data Source*

<table>
<thead>
<tr>
<th>5. Community representatives/ Key informants</th>
<th>Total # of AAAs (N = 33)</th>
<th>% of total</th>
</tr>
</thead>
<tbody>
<tr>
<td>a. General senior population</td>
<td>7</td>
<td>21%</td>
</tr>
<tr>
<td>b. Caregiver specific</td>
<td>4</td>
<td>12%</td>
</tr>
</tbody>
</table>

*For the complete table, please see Appendix B: Table I

a) General senior population

Definition: This category includes key informant surveys and meetings specific to the 60+ population.

Some AAAs were able to extract information about caregivers from these more general key informant sources. For example, in one PSA, inferences were drawn from a general key informant survey suggesting the need for integration of senior services, generally, including “one-stop shopping” for seniors and/or caregiver services, as well as the integration of caregiver training and support through programs such as CBSP, MSSP, Senior Day Care, Housing Assistance, Energy Assistance, and for the grandparent caregiver, the WIC program. One AAA extracted needs specific to grandparent/kinship caregivers from a focus group of key informants in the community.

AAA Examples

One AAA regularly uses a key informant survey as part of its 4-year planning process. Participants from past surveys are included to ensure continuity of the assessment process, while new key informants are invited to participate in an effort to broaden the representation of growing racial and ethnic communities within the PSA. The AAA administers the key informant survey by phone and in its most recent application was successful in achieving a 91% response rate. The questionnaire is composed of the following six (6) questions: 1) In your community (specify), or in the County as a whole, what are the most serious problems facing the elderly population? You may name
several. 2) Of the services and programs currently provided to the elderly in your local community (specify), or in the County as a whole, what changes or improvements are needed? 3) The Area Agency on Aging (AAA) seeks to develop a coordinated community based system of services for the elderly. What areas/issues of coordination or cooperation among the different agencies serving the elderly would you like the AAA to address? (3-5 coordination issues) 4) What do you consider the greatest unmet need for the elderly in the County? 5) What advocacy efforts should be undertaken at the local, state, or federal level on behalf of the elderly? What issues should be addressed and/or what legislation would you like to see adopted? 6) From your perspective in your local community or in the County as a whole, what do you feel is being done well for the elderly population?

Another AAA included the following caregiver specific question within the context of a general key informant survey: “How well are unpaid caregivers of older adults, such as family members and friends, supported in the community/county? If not supported well, do you have suggestions for improvement?”

b) Caregiver specific
Definition: This category includes key informant surveys and meetings specific to the caregiver population.

Twelve percent of AAAs reported gathering information from a variety of meetings in which caregiver specific issues were addressed, including: board of directors meetings, advisory councils, advocacy groups, and other ad hoc committees. No key informant surveys specific to caregiving were reported.

B. Caregiver Needs Identified

The majority of AAAs (91%) included a list of identified caregiver needs in their Title IIE Area Plan Addenda. In total, 277 needs were independently cited. While some
AAAs cited as few as 2 needs, others identified more than 40 needs. Most AAAs did not present the list of needs in order of priority. Moreover, the 3 AAAs (10%) that did prioritize the list of itemized needs did not specify how the order of priority was determined.

Most AAAs cited needs that were defined quite broadly, e.g., “respite,” “information and assistance,” and “transportation.” Others listed needs that were more specific and targeted in their definition, e.g., “respite and assistance for IHSS program staff, which includes family caregivers,” “assistive technology such as referrals to a showroom or online where a caregiver could view a demonstration on assistive devices or technology,” or “more physical assistance with lifting and transferring the care receiver to reduce physical strain as the caregiver”.

In the majority of Title III-E Addenda reviewed, the source of the list of identified caregiver needs was not made clear. Moreover, although some AAAs reported that the list of caregivers’ needs was drawn directly from the results of the needs assessment, several AAAs appear to use only the results from one of several applied needs assessment methods to represent the needs of all caregivers in the PSA.

As shown in Table II (Appendix B), of the 277 caregiver needs that were identified, approximately 19% were for caregiver support, 17% were for services considered “supplemental” under Title IIIE, 15% were for access, 15% were for respite, and 8% were for service information. Interestingly, the remaining 26% of identified needs did not fall cleanly into any of the NFCSP categories, either because they fell outside the parameters of the five NFCSP types or because they cut across the various categories. Among the caregiver needs included in this “other” category were the following: the need for resources in multiple languages and culturally appropriate services; the need for more flexible, affordable, and available services; the need for
greater numbers of trained care providers; more resources, both funding and services; specialized information about diseases; and financial assistance or money management.

C. Program Descriptions

As part of Title III-E Area Plan Addenda requirements, AAAs are requested to submit a program description which provides an overarching statement that reflects the AAA’s vision for a comprehensive system of support services for family caregivers, identifies sources of funding, develops a plan for delivery of family caregiver services based on needs, and culminates in a specific plan for support of caregivers. We examined AAA program descriptions regarding the specificity of the plans for meeting the needs of caregivers. In this regard, attention was given to three levels of planning statements: 1) Goal statements: i.e., broadly defined goals for program and service delivery, but lacking specific plans for implementation; 2) Process objectives: i.e., developmental plans for administering or coordinating programs and/or services, but lacking detail regarding the programs that were to result; and, 3) Programmatic objectives: i.e., a series of action steps necessary to the implementation of a specific program and/or service (see Appendix B: Table III).

Nearly all of the AAA plans (93%) included general goal statements; 48% included process objectives; and, 69% included at least some programmatic objectives. It should be noted here that the absence of more specific programmatic objectives may very well reflect the time constraints experienced in the start-up phase of this program.

D. Translation of Identified Needs Into Program Descriptions

The next step in the Addenda review process was to examine the extent to which program descriptions reflected the needs that had been identified. A summary of the identified needs was tallied for each PSA and the program descriptions were reviewed to determine the percentage of identified needs explicitly addressed in the resulting program
plan (see Appendix B: Table IV). Six AAAs (18%) provided a program description that addressed 100% of the caregiver needs they had identified through their needs assessment activities; however, 9 program descriptions (27% of the AAAs) included fewer than one-quarter of identified needs, and a total of 14 (42%) included fewer than one-half of the identified needs.
VII. FINDINGS: FOLLOW-UP E-MAIL SURVEY

In total, 24 of 33 AAAs (73%) responded to the follow-up email survey. Responses to the five (5) needs assessment questions on the follow-up email survey are summarized here. These questions were designed to elicit the following information: the most effective methods used in the needs assessment process; methods not employed, and why; stakeholder involvement in the process; success in identifying caregivers’ needs across diverse populations; barriers encountered in obtaining accurate information about caregivers; and types of assistance that might enhance the needs assessment process in the future.

A. Most Effective Needs Assessment Methods By Source

Twenty-four (100%) of survey respondents answered the question, “Of the methods you have used, which have been most effective in helping your PSA identify caregivers’ needs?” In total, respondents cited 64 need assessment methods particularly effective in assessing caregiver needs (see Appendix C: Table I). While some AAAs reported numerous applications of one method, others reported one application of several different methods.

We have tabled and reported our results using the same five (5) categories of data source used for the Title IIIIE addenda review: 1) Descriptions of the Caregiver Population; 2) Information about Service Users; 3) Focus Groups; 4) Public Meetings; and 5) Community representatives/ Key informants. Sub-categories were omitted here because the information given was not specific enough to accurately identify these sub-categories.

Almost two thirds (63%) of AAAs responding indicated that the most effective method used in their caregiver needs assessment was a description of the caregiver
population - i.e., using either secondary data, such as that provided by the US Census, Department of Finance, or other regional, state, or national data sources; or using primary data, such as that generated by a sample community survey. Most AAAs used secondary data sources to create a caregiver profile, indicating that the time and expense involved in conducting a caregiver specific sample survey was prohibitive.

One half (50%) of AAA respondents indicated that community representatives and key informants provided the most effective method and source of information used for the caregiver needs assessment. Several respondents indicated that due to limited resources, they were unable to conduct a key informant survey. However, the input of community representatives and key informants was often solicited by other means, e.g., through their participation in focus groups, public meetings, and other community forums.

Public meetings were cited by 46% of the respondents as providing the most effective method and data source from which to conduct a caregiver needs assessment. However, one AAA indicated that community forums were not a successful method for reaching people because of limited attendance, and another AAA cited time constraints as a deterrent to convening public hearings. Forty six percent of the respondents also cited information about service users as an effective needs assessment data source. One AAA reported, however, that service user data was not available.

Only 21% of the responding AAAs cited focus groups as the most effective caregiver needs assessment method used. One AAA that did not use focus groups to assess caregiver needs commented that it might prove to be an effective method, although several other AAAs cited a lack of resources, staff, and time as obstacles to organizing and conducting caregiver focus groups at this time.
B. Stakeholders involved in the needs assessment process

Twenty-two AAAs, representing 92% of survey respondents, indicated that stakeholders were involved in the needs assessment process (see Appendix C: Table II). The most frequently cited stakeholders were consumers/ consumer advocacy groups and private non-profit service providers; 71% of AAA respondents cited both of these groups as involved stakeholders. Other prevalent stakeholders reported were other public service providers and local government officials, representing 67% and 58% of responses, respectively. Faith-based organizations and private for-profit service providers were each cited by 50% of respondents, health/ medical providers by 46%, while other stakeholders were mentioned by 13% of the AAAs surveyed.

When asked how these identified stakeholders were involved in the needs assessment process, survey respondents reported that they were involved in a variety of ways, including: collaborative meetings; exchange of information and service user data; county and public hearings; referrals, follow-up phone calls and interviews; participation in forums, surveys, focus groups, committees, and conferences.

C. Identifying caregiver needs by target population

Another part of the Email survey asked how successful the AAAs were at identifying the needs of target groups within the more broadly defined caregiver population. These target groups were categorized as follows: by age; by race/ethnicity; by duration of caregiving; and by “other” caregiver populations defined, for example, by socioeconomic status, geographic location, and care recipient impairment (see Appendix C: Table III).

1. Caregivers by age

Between 60% and 70% of survey respondents indicated that they were successful or very successful in identifying caregivers of all age categories (i.e., under the age of 60;
between 60 – 64 years of age; between 65 – 84 years of age; and 85 years of age and older), with marginal increases evidenced as the caregiver’s age group increased, up to the 65-84 age group.

2. **Caregivers by race/ethnicity**

   Seventy-five percent of respondents indicated they were successful or very successful in identifying the needs of White/ Caucasian caregivers, as compared with only 40% of Hispanic/ Latinos, 37% of Black/ African Americans, 30% of Asians, 20% of Pacific Islanders, and 15% of Native Americans.

3. **Duration of caregiving**

   Most respondents indicated a moderate degree of success in identifying the needs of caregivers, regardless of the duration of care provision. The greatest success was reported with regard to those caregivers providing care between 1–5 years, with 43% of AAAs reporting being successful or very successful in identifying the needs of this group.

4. **Other caregiver populations**

   Other caregiver populations whose needs were most successfully identified included caregivers of cognitively impaired (reported as successful or very successful by 56% of respondents), grandparent caregivers (44%), and low-income caregivers (44%). AAAs reported being least successful in identifying the needs of gay/ lesbian caregivers (reported as little or no success by 59% of respondents), non-English speaking caregivers (44%), rural caregivers (38%), and disabled caregivers (37%).

D. **Barriers to obtaining accurate information about caregivers**

   AAA respondents were asked to identify any barriers they may have encountered to obtaining accurate information about caregivers in their PSA. They were also asked to identify types of assistance that might help with the caregiver needs assessment process.
Several themes emerged from the responses given to these open-ended questions (see Appendix C: Table IV).

1. **Identifying and reaching caregivers**

   As reported by 79% of respondents, the most prevalent barrier to obtaining accurate information about caregivers is not being able to identify and reach caregivers in the community. Those who are engaged in caregiving roles but who don’t identify as caregivers, and/or are not already connected to a service, were cited as particularly difficult to identify. One AAA reported that some caregivers don’t admit to having difficulties with caregiving and are, therefore, unlikely or unwilling to seek assistance.

2. **Lack of available caregiver data**

   Twenty-nine percent of respondents indicated that inadequate data about current service users is a barrier to obtaining accurate information about caregivers in the community. Some AAA respondents noted that caregiver programs haven’t been in operation long enough to collect thorough and reportable data about caregiver needs. One AAA indicated a lack of coordination between service providers and researchers as a detriment to compiling comprehensive caregiver data, while others cited low survey response rates as a barrier to obtaining accurate caregiver data. Other AAAs noted that the caregiver information gathered was not likely to be fully representative; one respondent explicitly stated that certain groups of caregivers were either not reached or not identified.

3. **Caregiver isolation**

   Twenty-nine percent of AAA respondents reported that caregivers were frequently unable to access and participate in needs assessment activities. They noted that caregivers were too busy, too restricted, or too overwhelmed to break away from their caregiving responsibilities in order to complete surveys, or to attend meetings,
forums, hearings, or focus groups. Furthermore, it was suggested that some caregivers may be isolated by a lack of knowledge about services, transportation and the need for respite.

4. Lack of resources

One fourth (25%) of respondents indicated that a lack of resources - i.e., money, staff, and time - impeded the process of obtaining caregiver information. Some reported that the resources allotted were not sufficient to obtain the degree of detail necessary to properly describe and assess caregivers in their PSA. Others indicated that additional resources were specifically needed to effectively reach underrepresented caregivers with little or no access to services and programs in the community.

5. Negative service attitudes or experiences

Several AAAs (21%) reported that negative attitudes or experiences created a barrier to obtaining information about caregivers. Respondents noted that some caregivers were reluctant to give out personal information and felt that the questions asked, both for reporting and assessment purposes, were too personal and intrusive.

6. Cultural and/or linguistic barriers

Twenty-one percent of AAA respondents indicated the existence of cultural and/or linguistic barriers to obtaining accurate caregiver information. One AAA noted that the participation rates of non-English speaking caregivers and caregivers from different cultural groups in needs assessments are consistently low. Some respondents cited both cultural and generational differences in attitudes towards providing information and using services. Others noted that cultural differences in attitudes and beliefs about family responsibility further impact the rate of caregiver participation in needs assessment efforts.
E. Assistance Desired

Respondents also were asked to identify types of assistance that might help with the needs assessment process in the future. The most frequently cited assistance needs included: more resources; better data; outreach; and, standardized needs assessment tools (see Appendix C: Table V). Not surprisingly, these assistance needs are consistent with the barriers identified in the previous section.

Forty-two percent of respondents cited the need for more resources. Several respondents indicated that in order to conduct a more thorough and accurate analysis of caregiver needs, they need more financial support. Some suggested that funding specifically earmarked for a caregiver needs assessment is needed. Several AAAs also noted the need for more staff and/or more time to conduct a proper assessment. Additionally, one respondent noted a specific need for assessment materials in different languages.

More current and readily available information about caregivers was cited as a need by 38% of respondents. Some AAAs noted the need for available Census data, both county-specific and caregiver-specific. Other respondents indicated that statewide caregiver surveys would be useful, especially if they included local area profiles. Respondents also indicated that information sharing between the AAAs and State-level coordination of existing caregiver resources would be particularly helpful.

Assistance with marketing, publicity, and outreach to underrepresented caregivers was mentioned by 25% of AAA respondents. One AAA specifically cited the need for assistance in launching a marketing and publicity campaign about the reality of caregiving. Another indicated the need for assistance in publicizing needs assessment activities. Still other respondents stated that assistance was needed for conducting outreach activities directed towards minority and underrepresented caregivers.
Seventeen percent of respondents suggested the need for standardized caregiver needs assessment tools, both for community and individual level assessments. Some noted the need for a more comprehensive assessment tool, designed for use with all caregivers in the community, irrespective of whether they were already accessing services. Finally, 13% of the AAA respondents cited the need for technical assistance with data analysis.
VIII. SUMMARY

A. Methods Utilized to Assess Caregiver Needs

Our review of AAA Title IIIE Area Plan addenda and responses to our follow-up survey suggest that most AAAs utilize a variety of methods in identifying the needs of caregivers in their communities. The method used most often, and considered most effective, was a basic description of the local caregiver population. However, only 3 of the 33 AAAs reportedly used a caregiver-specific survey to obtain this information. In most cases, AAAs attempted to extract information about caregivers from general community surveys of senior citizens, which typically only ask if “taking care of another person, either an adult or a child under 18 years of age, is no problem, a minor problem, or a serious problem”, or from national caregiver surveys, which may not adequately reflect the unique ethnic, geographic, and family diversity found in California and many of its PSAs.

Public hearings, community forums, and meetings with key informants were other common mechanisms for obtaining information about caregiver needs, and these were considered effective by about one-half of responding AAAs. Also considered effective by about one-half of AAAs, but less frequently used, was information from and/or about service users themselves. Focus groups were considered particularly effective sources of information by fewer than one-fourth of respondents; only 2 of 33 AAAs reported conducting caregiver focus groups, and only 7 asked about caregiver issues at general focus groups with elderly community members.

Most AAAs report involving caregivers and their representatives, and public and/or private non-profit service providers in their needs assessment and community
planning processes. About one-half of AAAs involve local government officials, faith-based organizations, private for-profit service providers, and health care providers.

B. Effectiveness of Needs Assessment Efforts

Caregiver age did not appear to be a major factor in AAAs’ effectiveness at identifying caregiver needs; indeed, most AAAs indicated that they were successful or very successful in identifying the needs of caregivers of all ages. With regard to race and ethnicity, AAAs reported the greatest success at identifying the needs of White non-Hispanics, with somewhat less success with Hispanics, African Americans and Asian Americans, and the least success with Native Americans and Pacific Islanders. AAAs also reported being relatively successful at identifying the needs of low-income caregivers and those caring for persons who were cognitively impaired, but considerably less successful at identifying the needs of caregivers who were gay, lesbian, bisexual, or transgendered, non-English speaking, or rural. Some AAAs reported success at identifying the needs of grandparents caring for grandchildren, while others reported difficulties in assessing this population.

C. Barriers and Assistance Requested

The greatest barrier to obtaining accurate information about caregivers is the difficulty identifying and reaching caregivers who are not already connected to a service, a problem reported by nearly 80% of responding AAAs. A lack of an adequate system for collecting data about service users is also a problem for some AAAs, as are cultural, linguistic, and attitudinal barriers, and an absence of resources necessary to do proper assessments of caregiver needs.

Not surprisingly, AAAs were most apt to identify additional tangible and intangible resources as the type of assistance they would find most helpful with their needs assessment process. Statewide data and coordination efforts also were seen as a
potentially useful type of assistance by many AAAs, including better statewide data regarding caregivers, and greater statewide efforts to coordinate assessment efforts and facilitate information sharing among AAAs. Technical assistance with survey efforts, outreach to underrepresented caregivers, and/or data analysis also was requested by some respondents.

D. Needs Identified

A total of 277 needs were identified by the AAAs, divided relatively evenly across the five NFCSP service areas. However, one-fourth of the identified needs did not fall cleanly into any of the NFCSP categories, either because they fell outside the parameters of the five NFCSP service types or because they cut across the various categories.

E. Planning Process

AAAs varied considerably in their apparent ability to utilize information about caregiver needs to develop service plans. Six AAAs (18%) provided a program description that addressed 100% of the caregiver needs they had identified through their needs assessment activities; however, 14 (42%) of the program descriptions included fewer than one-half of the identified needs.
IX. DISCUSSION AND RECOMMENDATIONS

We consider the six tasks identified in Figure 1 to be essential to the caregiver needs assessment and community planning process. These tasks are consistent with both the minimum requirements put forth by California Code of Regulations §7300, and the guidelines provided by the California Department of Aging Program Memo (PM) 01-10.

Figure 1. Steps in the Caregiver Needs Assessment Process

1. Describe the current population of caregivers
   Action: Compile a descriptive and demographic profile of caregivers in your PSA.

2. Determine existing and unmet needs of caregivers
   Action: Solicit input from professionals, consumers, and advocates.

3. Inventory existing caregiver resources and services
   Action: Identify programs and services already serving caregivers.

4. Identify service gaps, including existing barriers to equitable access to caregiver resources and services
   Action: Assess gaps and analyze barriers.

5. Prioritize the identified service needs of caregivers
   Action: Synthesize information gathered; weight and rank needs.

6. Design a plan for the delivery of caregiver services that reduces identified barriers to access, supplements existing services, and creates new services where none exist, in the most effective and efficient manner possible
   Action: Implement a decision-making process that results in a plan of action.

A. Describe The Current Population Of Caregivers

A first step in the caregiver needs assessment process is development of a profile of the basic demographic and social characteristics of the caregivers in a PSA. This profile can then serve as a framework for all other needs assessment and planning efforts. At a minimum, the caregiver profile should include basic characteristics of the caregiver (e.g., age, gender, race/ethnicity, employment status, income, county of residence), the
care recipient (e.g., age, income, county of residence, living arrangement, type and extent of impairment, relationship to caregiver), and the caregiving situation (e.g., types of care provided, whether caregiver is the primary care provider). Information such as this should be gathered for adults caring for elderly family members as well as for older adults caring for children.

We recommend three options for developing a local caregiver profile:

1) **Household caregiver survey.** The most direct way to collect information about caregivers is through a household survey, preferably administered every few years. Because of the expense and expertise required to design and implement a representative household survey, it is most advisable to conduct the survey on a regional or statewide basis. If statewide, the survey would require a sufficient sample size to be representative of California’s regional and racial/ethnic diversity. A household caregiver survey also can include more detailed questions regarding caregivers’ service utilization and unmet needs, as discussed in #2 below.

2) **Piggyback on general statewide population surveys.** A more efficient approach to developing a caregiver profile is to include caregiver-screening items in an existing statewide survey. A prime candidate would be the California Health Interview Survey (CHIS), which is administered every few years to approximately 70,000 Californians. A secondary benefit of using a multidimensional survey such as the CHIS is that those respondents who are disabled could be asked directly about the care they receive, as well as basic information about the family member or friend who is most responsible for their care and resides in California.
3) **Piggyback on local senior surveys.** A similar approach would involve modifying local or regional senior population surveys already being conducted by the AAAs to include better information about respondents who are caregivers. Currently, senior surveys typically only ask a single question about family care responsibilities. However, they also could include additional questions about the nature of family care responsibilities. As with the CHIS, those survey respondents who are disabled could be asked directly about the care they receive, as well as basic information about their primary informal caregiver residing in California. The survey population, however, would need to be expanded to include adults 18-59 in order to obtain information from non-elderly caregivers.

**B. Determine Existing And Unmet Needs Of Caregivers**

Identification of caregivers’ unmet needs requires information regarding the demands of the caregiving situation, their impact on caregivers’ physical and psychosocial well-being, availability and adequacy of informal support systems, utilization and effectiveness of formal support systems, barriers to utilization, and residual problems or concerns. Particular attention should be given to the presence of potential risk factors, such as the following:

- Acute or chronic health problems
- Mental health problems, whether associated with providing care or preexisting
- Problematic health behaviors, including excessive use of alcohol or controlled substances
- Social isolation
- Conflictual relationships with the care recipient or other family members
- Conflict with other major roles (e.g., work, parenting, marital)
• Care recipients who have problematic behaviors, especially those associated with
dementing conditions (e.g., sleep disturbance, unsafe behaviors requiring constant
supervision, uncooperativeness)

Information regarding potential risk factors and other details regarding the
caregiving situation can be useful not only for community planning, but also for care
planning at the individual level. Information such as this, for example, can help service
providers assess a caregiver’s ability to continue to provide care that meets the needs of
the care recipient without undue short-term and long-term deleterious consequences for
the caregiver. One example of a particularly useful caregiver-screening tool is the 12-
item Caregiver Risk Screen developed by Nancy Guberman and her colleagues at the
University of Quebec at Montreal.

We recommend five options for identifying risk factors and unmet needs:

1) Caregiver follow-up to population surveys. Caregivers identified through
statewide, regional, or local population surveys could be contacted with a follow-
up survey to collect more detailed information about the demands of the
caregiving situation, the presence of risk factors, the needs of caregivers and care
recipients, service gaps, etc. This would require that population surveys (e.g.,
CHIS, local senior surveys) collect information regarding the identity and contact
information of caregivers identified as part of the survey process.

2) Caregiver intake assessments. Information about caregiver risk factors and
service needs can be collected when caregivers contact AAAs and service
providers for information and/or assistance. Three distinct levels of intake
assessment might be employed, depending upon the service sought and the
expressed needs of the caregiver:
a) Minimum intake data (e.g., basic characteristics of the caregiver, the care recipient, and the caregiving situation) might be collected when the request is for clearly-defined information or services (e.g., “Depends”), no apparent risk factors are present, and a more complete assessment is neither requested nor warranted.

b) Basic assessment of vulnerability and service needs (e.g., caregiver and care recipient well-being, service utilization, unmet needs, residual problems or concerns) might be conducted when the service request is not clearly specified, when risk factors appear to be present, or a more complete assessment is either requested nor warranted.

c) Comprehensive assessment (e.g., an in-person assessment by a professional nurse or social worker) might be conducted when caregiving situations are particularly complex, the physical or mental well being of caregivers or care recipients appears to be at risk, or a comprehensive assessment is either requested or warranted.

3) Caregiver assessment in long-term care and child welfare. Basic information regarding the needs and well being of caregivers could be collected as a standard component of intake data collected when individuals enter the long-term care system. Similarly, the presence and service needs of elderly primary care providers could be collected as a standard component of child/family assessments throughout the child welfare system. This would require development of standard intake forms reflecting the needs of care recipients as well as caregivers. In the
United Kingdom, for example, the 1995 Carers (Recognition and Services) Act entitles all caregivers to have their own service needs assessed when their care recipient is assessed for community care. One advantage of identifying caregivers through the care recipient is that information could be collected regarding the needs of caregivers who might never attempt to access services for themselves. An integrated assessment system that linked caregiver data to care recipient data would have the added benefit of enabling tracking of service utilization and outcome data, which could be quite useful for long-term planning.

4) Outreach. Caregivers can be contacted directly regarding their needs for service and support. Information about caregiving and checklists regarding caregiver risk factors could be prominently displayed in physician offices, hospitals, pharmacies, beauty parlors, post offices, grocery stores, workplaces, and other locations. These tools would enable caregivers to self-assess their situation and provide a number to contact for information and to convey their needs and concerns. This information could most effectively be provided to caregivers at critical junctures in the caregiving process, e.g., at the time of initial diagnosis of the care recipient, or when there are substantial changes in the health or well-being of the caregiver or care recipient. Self-assessment mechanisms help to educate caregivers regarding their caregiving role, and also may facilitate discussions between caregivers and the health care providers in whose offices the information is placed. Indeed, one British study found that 76% of caregivers found a standard caregiver assessment personally beneficial.

5) Internet-based reporting. Websites that provide information for caregivers are a potentially effective source of information about caregiver service needs. Caregiver websites could include a standard set of screening questions regarding
the caregiving situation, experiences with services, unmet needs, etc. With the consent of the consumer, information about website users could be compiled in a secure data base and sorted by PSA, providing a relatively easy mechanism for collecting information from a large number of caregivers.

C. Inventory Existing Caregiver Resources And Services

Caregiver needs must be considered in the context of existing community resources, so that service gaps can be identified. Beyond the mere existence of services, the adequacy and appropriateness of those services also should be considered. Our report for Task IIIA describes in detail the process of identifying community resources to support caregivers.

D. Identify Service Gaps, Including Existing Barriers To Equitable Access To Caregiver Resources And Services

A key part of the needs assessment process is an evaluation of existing community resources in light of identified caregiver needs, in order to identify service gaps as well as factors that may contribute to underutilization of needed services. Consideration should be given to the availability, appropriateness, accessibility, and adequacy of existing services. Issues of access should be examined, including barriers that may be attributable to socioeconomic, geographic, linguistic, or cultural factors.

There are four major sources of information about service gaps and barriers:

1) **Service user intakes.** As part of the standard intake process (described above), caregivers can be asked to complete a brief questionnaire regarding their experiences trying to locate and access services. Questions of interest might include whether they were able to locate the assistance they needed, how long it took and what difficulties (if any) were experienced, other support needs for
which no assistance was found, and recommendations for additional services or other improvements in the service delivery system.

2) **Caregiver focus groups.** Caregivers could be brought together in small groups to discuss their experiences in obtaining assistance and support. Issues to be addressed might include: what led caregivers to seek outside assistance at this particular time; how they knew where to turn; problems obtaining services; services used and where provided; adequacy of service options, including ease of access, range of services available, affordability, linguistic and cultural appropriateness, availability at times when needed; whether the amount and type of service was sufficient, including responsiveness to the individual needs of caregivers, care recipients, and other family members; mechanisms for expressing complaints or concerns; and recommendations for improvement. Focus groups also can provide caregivers an opportunity to share experiences regarding strategies and natural supports that help to alleviate challenging aspects of caregiving, as well as strategies for enhancing positive aspects of providing care.

3) **Service providers.** Evidence regarding service use patterns, including underutilized services and wait lists, could be collected as a component of the standard service reporting system used by providers of OAA programs. In addition, other organizations that provide services to caregivers could be interviewed regarding service use patterns, underutilized services, barriers to access, etc.

4) **Community representatives and other key informants.** Individuals representing the interests of various community groups and constituencies could be polled regarding problems experienced by caregivers in particular communities of interest, barriers to service use, the availability of natural support structures, etc.
E. Prioritize The Identified Service Needs Of Caregivers

The needs assessment process is apt to produce a lengthy list of caregiver needs and related service gaps and barriers, only a small number of which can be addressed at any one time. Caregivers’ identified service needs therefore must be examined in terms of their priority, so that attention can be given to those which are considered to be most pressing or important.

Priorities can be determined in a number of ways:

1) **Meetings of key stakeholders.** In every community, there are certain individuals and organizations which are most knowledgeable, and concerned, about the well being of caregivers. These may include advocates, service providers, community leaders, disease-specific organizations, government agencies, caregivers, and sometimes care recipients. Nominal group processes, such as Delphi, can be particularly effective mechanisms for achieving consensus regarding a small number of priority issues when working with such a potentially disparate set of constituents.

2) **Public hearings and community meetings.** Public hearings and other types of meetings can be a particularly effective mechanism for obtaining input from large numbers of community members. Although it may be difficult for consensus to emerge from such gatherings, the ideas presented can provide planners and decision-makers with information about the community’s priorities and desires. Moreover, community meetings help to inform large numbers of individuals regarding the issues emerging from the needs assessment process, thereby helping to foster caregiver support activities within existing natural communities of interest and legitimize the expenditure of community resources to assist caregivers.
F. Design A Plan For The Delivery Of Caregiver Services

A plan for the delivery of caregiver services should reduce identified barriers to access, supplement existing services, and create new services where none exist, in the most effective and efficient manner possible. Service plans should reflect those services or related activities that are likely to be effective in responding to priority caregiver needs. This requires identification of available options for meeting prioritized needs and consideration of their potential effectiveness and cost.

Information regarding the effectiveness and cost of potential service options can be obtained in a number of ways:

1) Literature review. A number of reports provide excellent sources of information regarding caregiver program models and their effectiveness. Potentially useful information sources include, among others: CASAS’ report on Caregiver Support Interventions, Family Caregiver Alliance’s National Caregiving Center Electronic Policy Digest, NASUA’s NFCSP Service Package Briefs, National Health Council’s Family Caregiving Agenda for Action.

2) Consumer feedback. Most relevant to local planning efforts is data regarding the effectiveness of existing community caregiver programs. The best source of this information is those who use the services. Consumers could be contacted following service use and queried regarding the adequacy of the services they have used, whether their needs were met, recommendations for improvements to enhance services or remove barriers, etc. Questions regarding specific aspects of services (the Home Care Satisfaction Measures are one example) have been shown to be considerably more useful than global satisfaction questions, which typically say more about the respondent’s life satisfaction than about the adequacy of the services that have been used. This requires development of a
central record system for tracking individual use of caregiver services, so that evaluative information can be collected by the AAA or other third party, rather than by service providers themselves. The Caregiver Support and Satisfaction Survey developed as part of AoA’s Performance Outcome Measures Project is an example of an instrument that collects some information about consumer satisfaction, and which can be utilized for national comparability. However, although the POMP process is very useful, the questionnaire itself collects very limited information about the perceived adequacy of specific services. A more useful set of questions might also assess whether interventions are perceived to have resulted in improvements in specific areas supposedly targeted by particular interventions (e.g., do respondents believe they have more information about resources, do they feel less stressed, do they feel more supported).

3) **Formal service evaluation.** More rigorous service evaluation requires that data be collected at intake regarding users’ actual baseline levels on key outcomes (e.g., actual information about resources, stress level, available support), which could then be compared with their levels after using specific services. Ideally, it is best to have a comparison group which does not receive intervention, for example by assigning some applicants to a waiting list or only giving them basic I&A. AAAs may wish to collaborate with universities or researchers in order to implement a more comprehensive evaluation of caregiver services.

4) **Service utilization and expenditures.** Actual service-specific expenditure data provided by service providers can be reviewed in light of available evidence regarding consumer outcomes, in order to develop a sense of the cost and relative cost-effectiveness of various program options.
X. CONCLUSION

Needs assessment is an essential part of the community planning process. Information about caregivers and their needs, examined in the context of existing services, enables AAAs to identify service gaps and priority areas for change. In this way, the needs assessment process can assist AAAs to allocate limited resources in the most effective and efficient manner. Data regarding caregivers’ needs and the effectiveness of existing services for meeting those needs can be a powerful tool in providing a basis for assuring that resources are targeted where they are most needed, that services are provided in an effective and equitable manner, and that caregivers receive the support they need.
XI. APPENDICES
Appendix A. Bibliography


Older Americans Act of 1965. 42 U.S.C. 3021 et seq.


Appendix B: Findings from Area Plan Addenda

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<td>1. Descriptions of the Caregiver Population</td>
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<td>c. PSA survey data, caregiver specific</td>
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<td>d. PSA survey data, grandparent/kinship specific</td>
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### Table II
Caregiver Needs Identified

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<td><strong>Total</strong></td>
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<td>Information and assistance</td>
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<td>Caregiver support group</td>
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</tr>
<tr>
<td>4. Respite</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>General respite services</td>
<td>31</td>
<td>74%</td>
<td></td>
</tr>
<tr>
<td>In-home respite</td>
<td>6</td>
<td>14%</td>
<td></td>
</tr>
<tr>
<td>Day care</td>
<td>4</td>
<td>10%</td>
<td></td>
</tr>
<tr>
<td>Institutional</td>
<td>1</td>
<td>2%</td>
<td></td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td><strong>42</strong></td>
<td></td>
<td><strong>15%</strong></td>
</tr>
<tr>
<td>5. Supplemental Services</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Transportation</td>
<td>11</td>
<td>23%</td>
<td></td>
</tr>
<tr>
<td>Legal assistance</td>
<td>7</td>
<td>20%</td>
<td></td>
</tr>
<tr>
<td>Chore</td>
<td>6</td>
<td>17%</td>
<td></td>
</tr>
<tr>
<td>Assistive devices</td>
<td>6</td>
<td>17%</td>
<td></td>
</tr>
<tr>
<td>Homemaker</td>
<td>5</td>
<td>14%</td>
<td></td>
</tr>
<tr>
<td>Minor home modification</td>
<td>4</td>
<td>11%</td>
<td></td>
</tr>
<tr>
<td>Home delivered meals</td>
<td>3</td>
<td>9%</td>
<td></td>
</tr>
<tr>
<td>Placement</td>
<td>2</td>
<td>6%</td>
<td></td>
</tr>
<tr>
<td>Home security and safety</td>
<td>1</td>
<td>3%</td>
<td></td>
</tr>
<tr>
<td>Visiting</td>
<td>1</td>
<td>3%</td>
<td></td>
</tr>
<tr>
<td>Assisted Transportation</td>
<td>1</td>
<td>2%</td>
<td></td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td><strong>47</strong></td>
<td></td>
<td><strong>17%</strong></td>
</tr>
<tr>
<td>6. Other</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Service access</td>
<td>10</td>
<td>14%</td>
<td></td>
</tr>
<tr>
<td>Recruitment/training of paid workers</td>
<td>7</td>
<td>10%</td>
<td></td>
</tr>
<tr>
<td>More resources; funding/ programs/services</td>
<td>6</td>
<td>8%</td>
<td></td>
</tr>
<tr>
<td>Specialized information: disease specific</td>
<td>6</td>
<td>8%</td>
<td></td>
</tr>
<tr>
<td>Grandparent specific needs</td>
<td>6</td>
<td>8%</td>
<td></td>
</tr>
<tr>
<td>Financial planning: money management</td>
<td>6</td>
<td>8%</td>
<td></td>
</tr>
<tr>
<td>Individual financial assistance</td>
<td>5</td>
<td>7%</td>
<td></td>
</tr>
<tr>
<td>Physical assistance with caregiving</td>
<td>5</td>
<td>7%</td>
<td></td>
</tr>
<tr>
<td>Health services for caregivers</td>
<td>4</td>
<td>6%</td>
<td></td>
</tr>
<tr>
<td>Public awareness/ caregiver recognition</td>
<td>4</td>
<td>6%</td>
<td></td>
</tr>
<tr>
<td>Other needs</td>
<td>13</td>
<td>18%</td>
<td></td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td><strong>72</strong></td>
<td></td>
<td><strong>26%</strong></td>
</tr>
</tbody>
</table>
### Table III
#### Program Descriptions by Type:
Goal Statements, Process Objectives, and Programmatic Objectives

<table>
<thead>
<tr>
<th>Program descriptions by type: goal statements, process objectives, and programmatic objectives</th>
<th>Total # of AAAs (N = 33)</th>
<th>% of total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Goal statements and programmatic objectives</td>
<td>15</td>
<td>45%</td>
</tr>
<tr>
<td>Goal statements, process and programmatic objectives</td>
<td>8</td>
<td>24%</td>
</tr>
<tr>
<td>Goal statements and process objectives</td>
<td>7</td>
<td>21%</td>
</tr>
<tr>
<td>Goal statements only</td>
<td>1</td>
<td>3%</td>
</tr>
<tr>
<td>Process objectives only</td>
<td>1</td>
<td>3%</td>
</tr>
<tr>
<td>NA: to be submitted upon completion of the needs assessment</td>
<td>1</td>
<td>3%</td>
</tr>
<tr>
<td>Programmatic objectives only</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>Process and programmatic objectives</td>
<td>0</td>
<td>0</td>
</tr>
</tbody>
</table>

### Table IV
#### Translation of identified needs into program description

<table>
<thead>
<tr>
<th>Degree of match between identified needs and program description statement</th>
<th>Total # of AAAs (N = 33)</th>
<th>% of total</th>
</tr>
</thead>
<tbody>
<tr>
<td>100%</td>
<td>6</td>
<td>18%</td>
</tr>
<tr>
<td>85-99%</td>
<td>1</td>
<td>3%</td>
</tr>
<tr>
<td>70-84%</td>
<td>4</td>
<td>12%</td>
</tr>
<tr>
<td>55-69%</td>
<td>7</td>
<td>21%</td>
</tr>
<tr>
<td>40-54%</td>
<td>2</td>
<td>6%</td>
</tr>
<tr>
<td>25-39%</td>
<td>4</td>
<td>12%</td>
</tr>
<tr>
<td>10-24%</td>
<td>3</td>
<td>9%</td>
</tr>
<tr>
<td>Less than 10%</td>
<td>6</td>
<td>18%</td>
</tr>
</tbody>
</table>
Appendix C: Findings from AAA Survey

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Table III. Identifying Caregiver Needs by Target Population
Table IV. Barriers to Obtaining Accurate Information about Caregivers
Table V. Assistance with the Needs Assessment Process
Table I
Most Effective Needs Assessment Methods By Data Source

<table>
<thead>
<tr>
<th>MOST EFFECTIVE NEEDS ASSESSMENT METHODS BY DATA SOURCE</th>
<th>Total # of AAAs (N = 24)</th>
<th>% of total</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Descriptions of the Caregiver Population</td>
<td>15</td>
<td>63%</td>
</tr>
<tr>
<td>2. Community representatives/ Key informants</td>
<td>12</td>
<td>50%</td>
</tr>
<tr>
<td>3. Public Meetings</td>
<td>11</td>
<td>46%</td>
</tr>
<tr>
<td>4. Information about Service Users</td>
<td>11</td>
<td>46%</td>
</tr>
<tr>
<td>5. Focus Groups</td>
<td>5</td>
<td>21%</td>
</tr>
</tbody>
</table>

Table II
Stakeholders Involved in the Needs Assessment Process

<table>
<thead>
<tr>
<th>STAKEHOLDERS INVOLVED IN THE NEEDS ASSESSMENT PROCESS</th>
<th>Total # of AAAs (N = 24)</th>
<th>% of total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Q. Were stakeholders involved in the needs assessment process?</td>
<td>Yes = 22</td>
<td>92%</td>
</tr>
<tr>
<td>Consumers/ consumer advocacy groups</td>
<td>17</td>
<td>71%</td>
</tr>
<tr>
<td>Private non-profit service providers</td>
<td>17</td>
<td>71%</td>
</tr>
<tr>
<td>Other public service providers</td>
<td>16</td>
<td>67%</td>
</tr>
<tr>
<td>Local government officials</td>
<td>14</td>
<td>58%</td>
</tr>
<tr>
<td>Faith-based organizations</td>
<td>12</td>
<td>50%</td>
</tr>
<tr>
<td>Private for-profit service providers</td>
<td>12</td>
<td>50%</td>
</tr>
<tr>
<td>Health/ medical providers</td>
<td>11</td>
<td>46%</td>
</tr>
<tr>
<td>Other stakeholders</td>
<td>3</td>
<td>13%</td>
</tr>
</tbody>
</table>
Table III
Identifying Caregiver Needs by Target Population
(n=24)

<table>
<thead>
<tr>
<th></th>
<th>Not at all successful</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>Very Successful</th>
</tr>
</thead>
<tbody>
<tr>
<td>Caregivers by Age³</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>&lt; 60 years</td>
<td>2</td>
<td>1</td>
<td>5</td>
<td>6</td>
<td>6</td>
</tr>
<tr>
<td>60 – 64 years</td>
<td>0</td>
<td>2</td>
<td>5</td>
<td>5</td>
<td>8</td>
</tr>
<tr>
<td>65-84 years</td>
<td>0</td>
<td>1</td>
<td>5</td>
<td>8</td>
<td>6</td>
</tr>
<tr>
<td>&gt;85 years</td>
<td>1</td>
<td>0</td>
<td>6</td>
<td>8</td>
<td>4</td>
</tr>
<tr>
<td>Caregivers by Race/Ethnicity⁴</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>White or Caucasian</td>
<td>1</td>
<td>0</td>
<td>4</td>
<td>6</td>
<td>9</td>
</tr>
<tr>
<td>Black or African American</td>
<td>2</td>
<td>4</td>
<td>6</td>
<td>4</td>
<td>3</td>
</tr>
<tr>
<td>Hispanic or Latino</td>
<td>1</td>
<td>7</td>
<td>4</td>
<td>5</td>
<td>3</td>
</tr>
<tr>
<td>Asian</td>
<td>2</td>
<td>5</td>
<td>6</td>
<td>3</td>
<td>3</td>
</tr>
<tr>
<td>Native American</td>
<td>5</td>
<td>4</td>
<td>6</td>
<td>2</td>
<td>1</td>
</tr>
<tr>
<td>Pacific Islander</td>
<td>4</td>
<td>3</td>
<td>6</td>
<td>3</td>
<td>1</td>
</tr>
<tr>
<td>Other: (NONE SPECIFIED)</td>
<td>1</td>
<td>1</td>
<td>3</td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td>Duration of Caregiving²</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Less than 6 months</td>
<td>3</td>
<td>1</td>
<td>8</td>
<td>2</td>
<td>0</td>
</tr>
<tr>
<td>6 –12 months</td>
<td>3</td>
<td>1</td>
<td>7</td>
<td>3</td>
<td>0</td>
</tr>
<tr>
<td>1-5 years</td>
<td>3</td>
<td>0</td>
<td>5</td>
<td>6</td>
<td>0</td>
</tr>
<tr>
<td>Greater than 5 years</td>
<td>3</td>
<td>0</td>
<td>8</td>
<td>2</td>
<td>1</td>
</tr>
<tr>
<td>Other Caregiver Populations⁶</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Low income caregivers</td>
<td>0</td>
<td>2</td>
<td>8</td>
<td>5</td>
<td>3</td>
</tr>
<tr>
<td>Employed caregivers</td>
<td>3</td>
<td>3</td>
<td>8</td>
<td>4</td>
<td>0</td>
</tr>
<tr>
<td>Disabled caregivers</td>
<td>3</td>
<td>4</td>
<td>8</td>
<td>2</td>
<td>2</td>
</tr>
<tr>
<td>Rural caregivers</td>
<td>1</td>
<td>5</td>
<td>4</td>
<td>2</td>
<td>4</td>
</tr>
<tr>
<td>Non-English speaking caregivers</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Caregivers of cognitively impaired</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Caregivers of severely disabled</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Grandparent caregivers</td>
<td>1</td>
<td>6</td>
<td>3</td>
<td>4</td>
<td>4</td>
</tr>
<tr>
<td>Gay/lesbian caregivers</td>
<td>8</td>
<td>2</td>
<td>4</td>
<td>2</td>
<td>1</td>
</tr>
<tr>
<td>Other: (NONE SPECIFIED)</td>
<td>0</td>
<td>1</td>
<td>1</td>
<td>0</td>
<td>0</td>
</tr>
</tbody>
</table>

³ Note: Of the 24 total survey respondents, between 4-5 did not answer one or more of the items in this section.
⁴ Note: Of the 24 persons responding to the survey, between 4-7 did not respond to one or more of the items in this section.
⁵ Note: Of the 24 total survey respondents, 10 (58%) did not answer any of the items in this section.
⁶ Note: Of the 24 total survey respondents, between 5- 8 did not answer one or more of the items in this section.
### Table IV
**Barriers to Obtaining Accurate Information about Caregivers**

<table>
<thead>
<tr>
<th>BARRIERS TO OBTAINING ACCURATE INFORMATION ABOUT CAREGIVERS</th>
<th>Total # of AAAs (N = 24)</th>
<th>% of total</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Identifying and reaching caregivers</td>
<td>19</td>
<td>79%</td>
</tr>
<tr>
<td>2. Lack of available / existing caregiver data</td>
<td>7</td>
<td>29%</td>
</tr>
<tr>
<td>3. Caregiver isolation</td>
<td>7</td>
<td>29%</td>
</tr>
<tr>
<td>4. Lack of resources</td>
<td>6</td>
<td>25%</td>
</tr>
<tr>
<td>5. Negative service attitudes/ experiences of caregivers</td>
<td>5</td>
<td>21%</td>
</tr>
<tr>
<td>6. Cultural and/ or linguistic barriers</td>
<td>5</td>
<td>21%</td>
</tr>
</tbody>
</table>

### Table V
**Assistance with the Needs Assessment Process**

<table>
<thead>
<tr>
<th>ASSISTANCE WITH THE NEEDS ASSESSMENT PROCESS</th>
<th>Total # of AAAs (N = 24)</th>
<th>% of total</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Resources: money, staff, and time</td>
<td>10</td>
<td>42%</td>
</tr>
<tr>
<td>2. Available and current caregiver information</td>
<td>9</td>
<td>38%</td>
</tr>
<tr>
<td>3. Marketing, publicity, and outreach to underrepresented caregivers</td>
<td>6</td>
<td>25%</td>
</tr>
<tr>
<td>4. Standardized needs assessment tools</td>
<td>4</td>
<td>17%</td>
</tr>
<tr>
<td>5. Technical assistance</td>
<td>3</td>
<td>13%</td>
</tr>
</tbody>
</table>