EVALUATING CAREGIVER PROGRAMS
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Overview of CASAS FCSP Project
For the past two years, we have been examining the needs of caregivers and
strategies for meeting those needs, in an effort to assist the California Department of
Aging to implement and evaluate the National Family Caregiver Support Program (Title
III-E of the reauthorized Older Americans Act). We have conducted a Statewide Survey
of California Caregivers, a telephone interview with a random sample of 1,643 California
residents who provide care to someone age 50 or over. We also assessed the availability
of caregiver support resources throughout California, examined AAA efforts to assess the
needs of local caregivers and develop programs to meet those needs, and developed a set
of recommendations regarding how AAAs can more effectively plan for and serve their
local family caregivers. Reports of our findings are available on the Center’s web page.

Today, I want to share with you some of our findings and recommendations
regarding how to evaluate the effectiveness of caregiver support programs.

Reasons to Evaluate Caregiver Programs

Why evaluate?

1. To make sure that caregivers are receiving the services they need. On the one
   hand, California has a vast array of potential caregiver support resources.
   Indeed, 70% of California caregivers report receiving one or more support
services from a community agency or other formal service provider. However, some groups appear to be underserved. Latinos, Asian Americans and Pacific Islanders are about one-half as likely to use services as are White non-Hispanic and African American caregivers.

2. **To make sure that services are going to those who need them most.** Some California caregivers experience especially high levels of financial, physical, and emotional strain. These include those who care for someone with mental illness, dementia, behavioral problems, or stroke or paralysis, especially if the caregiver is female, Hispanic, low income, or in poor health. We need to know whether these caregivers who are especially vulnerable are receiving the services they need, and whether those services are actually meeting their needs.

3. **For effective community planning.** AAAs are forced to make decisions regarding how best to utilize limited resources. This means knowing which programs are likely to be most effective at meeting the needs of caregivers in the local community.

4. **To justify further funding.** When it authorized Title III-E of the Older Americans Act, Congress required AoA to show that the new program was having a positive impact on caregivers. A number of state legislatures have required the same of their State Units on Aging. Unless we can provide information showing that caregiver programs are effective, and that the money is being well-spent, it will be difficult to make the case that Congress should enhance funding, or even maintain current funding levels.

**Overarching goals of a caregiver support system**

The first step in developing an evaluation is figuring out what you are trying to evaluate. That is, we can’t decide if a caregiver support program is effective unless we know what goals it is trying to reach. From our point of view, the fundamental goals of caregiver services include:
1. Improvements in caregiver well-being, including prevention or amelioration of potential deleterious impacts of assisting an elderly/disabled family member.

2. Improvements in care recipient well-being, often through enhancing the ability of individuals and their families to provide and/or manage care.

3. Increased support for caregivers by formal and informal community support structures, including service providers, physicians, churches and employers.

4. Increased public awareness of and support for family care, including planning for personal and familial care needs, and public knowledge regarding services and informal support for caregivers.

5. Increased political support for caregiver support policies and programs.

### Goals of an effective caregiver support system

- Improvements in caregiver well-being
- Improvements in care recipient well-being
- Increased support for caregivers by formal and informal community support structures
- Increased public awareness
- Increased political support for caregiver-friendly policies and programs

### Evaluation Domains

In evaluating the effectiveness of caregiver support efforts, we focus on three possible areas of impact:

1. Individual caregivers and their families

2. The local service delivery system

3. The overall community
Individual and family impact of using services

What to evaluate

The simplest way to collect information about the impact on consumers is to ask them. Typically, this is done using a general satisfaction questionnaire that usually asks something like, “Did you like the services you used?” The problem is that consumers generally say they like whatever services they use, and you learn very little about whether or how those services may have made a difference in the caregiver’s ability to provide care and/or the stress they experience. On the other hand, if you look at the impact of most services on major caregiver problems such as depression, burden, or institutionalization, you may find very little overall impact for most service users.

Much more useful information can be gained if you consider the intended goals of each specific type of caregiver support program, and evaluate whether those specific goals are being met. For example, here are some primary impacts that might realistically be expected to be achieved by each of the major types of caregiver services under the NFCSP:

Realistic Primary Impacts:

1. **Information and Outreach**
   a. Increased knowledge of services available in the local community

2. **Access**
   a. Perceived ability to access needed services
   b. Actual increase in service use

3. **Training**
   a. Knowledge about the care recipient’s illness, its course, and treatment
   b. More confidence as a care provider
   c. Increased ability to meet the care recipient’s needs
   d. Improved care recipient well-being and independence
4. **Counseling and support groups**
   a. Reduced emotional distress (e.g., guilt, anger)
   b. Greater social support
   c. Enhanced self-esteem
   d. More effective coping strategies
   e. Knowledge about the care recipient’s illness, its course, and treatment
   f. Increased knowledge of services available in the local community

5. **Respite care**
   a. Time for personal activities
   b. Time with family, friends
   c. Ability to meet own health needs
   d. Doctor visits
   e. Decreased role strain

**Possible Secondary Impacts:**

We would hope that these primary impacts of caregiver programs might also have secondary impacts on the overall well-being of both the caregiver and care recipient, such as:

**Caregiver:**
- Health and Well-Being (e.g., Physical Strain)
- Financial hardship
- Emotional distress (e.g., anxiety, guilt, anger, depression)
- Role strain
- Work disruption
- Family conflict (incl. domestic violence)
- Resilience (ability to cope with challenging care situations)

**Care Recipient:**
- Health and Well-Being
- Adequacy of care (incl. neglect and abuse)
- Multiplicity of care providers (i.e., less reliance on a single care provider)
- NH placement

**How to evaluate caregiver impacts**

1. **Pre-post evaluation**

   The best way to evaluate the impact of caregiver services is to collect information from consumers before they use specific services and again 3-6 months later, and see whether there has been an improvement in specific outcomes of interest. As Lynn has
noted, the California Caregiver Resource Centers have been doing this for a number of years. It is likely that much of this information already is being collected by AAAs and/or contractors as part of existing client intake processes. Ideally, this intake information might be standardized, in order to facilitate an examination of service users and program impacts locally or statewide.

In addition to client-specific demographic information, intake information might include the following:

- Prior utilization of FCSP services
- Prior utilization of other formal services
- Support received from other sources (e.g., religious, social, and cultural organizations)
- Adequacy of existing services and support
- Unmet needs
- Knowledge of other services available in the local community
- Confidence as a care provider
- Time available for personal and social activities
- Ability to meet own health needs

Information might also be collected regarding indicators of caregiver distress that could be relieved through service use, 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)
- Other indicators of physical, financial, social or emotional distress
The amount of intake information collected would reflect the particular service used and the intensity of caregiver needs, with the most comprehensive intake reserved for those caregivers using intensive services such as case management and having the most intense and complex caregiving situations.

2. Retrospective assessment of service impacts

Individual-level outcomes of service use also can be assessed by asking caregivers who use services supported by Title III-E funds to complete a consumer impact questionnaire 6-8 weeks after service use. Consumers would be asked to evaluate whether the use of specific services resulted in any changes with regard to areas such as the following:

- Knowledge of available services
- Attitudes about using services
- Support from informal sources
- Physical strain
- Financial hardship
- Emotional stress
- Depression
- Sleep
- Conflict between work and family
- Family conflict and communication
- Care recipient functioning
- Perceived ability to provide quality care

**POMP.** The Administration on Aging’s Performance Outcomes Measures Project (POMP) has developed a questionnaire and set of protocols for collecting information from consumers. Currently, the project has developed measures for eight client-service domains, among other areas of performance:

- Physical Functioning
• Nutritional Risk
• Caregiver Well-Being
• Emotional Well-Being
• Home Care Satisfaction
• Transportation
• Information & Assistance
• Social Functioning

However, the POMP has only limited questions regarding the perceived impact of caregiver support services.

3. Consumer Satisfaction

Consumer satisfaction is a complex, multifaceted concept, which can be difficult to assess in an unbiased manner. Specific, directed measures of components of client satisfaction have been shown to provide a more meaningful assessment of satisfaction than a global rating which collapses multiple dimensions of satisfaction into a single judgment. For example, using information drawn from the client tracking system, caregivers could be asked about their experiences with each of the services they utilized during the target timeframe. Specific questions might address the adequacy of the services offered, their timeliness and availability, the competence of service providers, cultural or linguistic barriers, any problems obtaining needed assistance, recommendations for improvements to enhance services or remove barriers, etc.

**Service Delivery System**

Particularly when new programs are first starting up, as has been the case for the past two years with the NFCSP, it may be too early to see major impacts on large numbers of caregivers. However, we are more apt to see changes in the services that are
available and the ways those services are provided. Particular areas where changes might be observed include:

1. Number and types of caregiver support services available
2. Number of service providers with AAA contracts
3. Number of caregivers served (requires non-duplicated counts of service users)
4. Collaboration and cross-referrals among service providers
5. Funding for caregiver programs from non-IIIE sources

The number and types of caregiver support services available in a particular PSA could be inventoried periodically as part of each AAA’s area planning process, and compared with the previous area plan. Interviews with agency representatives and other key informants regarding their caregiver support services, perhaps as part of the AAA’s planning and allocations process, can provide information regarding non-IIIE funding for caregiver programs. AAAs also may wish to encourage inter-agency collaboration in order to better meet the needs of caregivers in each community. Evaluating the number of caregivers served requires that agencies provide the AAA with non-duplicated counts of service users.

**Community impacts**

Ultimately, we hope that Title III-E funding will have positive impacts on the well-being of caregivers throughout the overall community, including:

1. Whether caregivers in general are benefiting
2. Whether the most vulnerable caregivers are being served
The only way to know for sure whether caregivers in general are benefiting, and whether the most vulnerable caregivers are receiving the services they need, is to conduct a community needs assessment, whereby a random sample of households are contacted to identify the number of caregivers in the community and what their needs are. The number and characteristics of caregivers in the community could then be compared with the characteristics of service users, to see what percentage of caregivers actually are being served. Only in this way can you know whether particular caregiver populations are being underserved. Of course, town hall meetings and interviews with key informants can also provide some of this information, at least from those groups that are most visible and vocal.

Conclusion

Clearly, evaluation can be a complicated and time-consuming process. Yet, it is essential to document the impact of the caregiver support services we provide, for community planning purposes as well as to justify the continued expenditure of federal, state, and local dollars to help caregivers.

You are not alone in this effort. Many AAAs are located near universities or research organizations which can assist you in developing and implementing an evaluation that is appropriate for your needs. We at the Center for the Advanced Study of Aging Services have developed a household caregiver survey and related materials, which we are more than happy to share with you if you contact us. NASUA (the National Association of State Units on Aging) currently is developing a report on caregiver evaluation methods, through a grant from AoA. And, as mentioned earlier,
AoA’s Performance Outcomes Measures Project (POMP) has developed a questionnaire and set of protocols for collecting information from consumers who are caregivers. Perhaps we can ask AoA to go even further, and publish a variety of model intake, service utilization, and evaluation tools that AAAs throughout the country could tailor to their local needs. In the mean time, we can use opportunities such as this Conference to share our successes with one another. Thank you for inviting us to be here.