

## V. PROGRAM EFFECTIVENESS

Measuring the quality, benefits, and accomplishments of the National Family Caregiver Support Program (NFCSP) can assist agencies in a variety of ways, by providing vital information for setting and refining program goals, identifying training and technical assistance needs, allocating resources efficiently, recruiting volunteers, and improving the effectiveness of services. Moreover, structuring quality assurance activities and assessing program effectiveness and outcomes enables agencies to ensure that programs provide value to consumers. Title III-E and Title VI-C of the Older Americans Act (OAA) includes a requirement for State Units on Aging (SUAs) and Indian Tribal Organizations (ITOs) to develop quality assurance mechanisms designed to assure the quality of services provided.<sup>1</sup>

Assessing program effectiveness involves the following concepts:

- Context – sponsoring group’s organizational structure and program partnerships (e.g., independent state aging department or housed within a broader state agency that includes the Medicaid single state agency)
- Process – program resources (inputs) and type or level of program activities conducted (e.g., the availability of each of the five NFCSP service components)
- Outputs – direct measurable results of the program (e.g., number of caregivers that received respite services)
- Outcomes – results of program activities that capture whether objectives and goals have been met (e.g., new knowledge gained)
- Performance Measures – ongoing monitoring and reporting of program accomplishments, which can include process, outputs, and outcomes
- Impact Evaluation – one-time or periodic assessment of program results relative to the absence of the program

Given the early stage of development of the NFCSP, this chapter focuses on performance measurement rather than on impact evaluation. Performance measures indicate what actually occurred in terms of implementation and meeting program goals and objectives. As a result of their ongoing nature, performance measures can serve as early warning mechanisms for management and a vehicle for improving public accountability. Reaching consensus on these measures and establishing mechanisms for their ongoing measurement early in the program’s development will put the network in a better position to respond to caregiver need and eventually determine program impact.

This chapter provides a starting framework for assessing the effectiveness of the multifaceted caregiver support program. It builds on the 2001 Administration on Aging (AoA) NFCSP conference presentations of David Lindeman, Lynn Feinberg, and Ken

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<sup>1</sup> Older American Act, Title III, Part E, Section 373(e)(1).

Wilson.<sup>2</sup> Due to the newness of the NFCSP, the sections emphasize key quality assurance and evaluation issues associated with the early stages of a program lifecycle. Topics covered include conceptualizing and assessing effectiveness, information system development, and current measurement efforts under way at AoA.

## **CONCEPTUALIZING CAREGIVER PROGRAM EFFECTIVENESS**

As outlined in previous chapters, the NFCSP presents the aging network with an ambitious goal to develop a multifaceted and coordinated system of supports and services responsive to the ever-changing needs of caregivers. To do so, the program will transform the way states and communities view community-based long-term care by integrating a central, yet often invisible, population—caregivers—into the service system. Developing and sustaining a delivery system around caregivers requires the aging network to shift the focus from primarily care recipients to both recipients and caregivers. A similar shift will be necessary in conceptualizing program effectiveness.

A responsive caregiver system requires the aging network to know which implementation efforts work, for whom, and under what conditions. Additionally, because the NFCSP connects to the larger long-term care system, understanding how and to what extent caregiver support services mesh with other services, including the health, behavioral health, and social services, becomes critical. Ultimately, policymakers will want to know whether these programs merit the investment. Such knowledge entails developing short-term (e.g., initiation of a program), intermediate (e.g., enhanced caregiving skills, reduced social isolation), and long-term measures (e.g., establishment of an integrated system).

NFCSP effectiveness can be assessed according to the overall goals of the program and for each of the specific service components. The specific measures of effectiveness will depend on the level of analysis (e.g., state or community system, organization, and individual) as well as on the specific goals of each activity implemented. NFCSP presents a particular challenge because its inherent flexibility makes prescribing concrete outputs to measure difficult. The focus must be on outcomes that are often more problematic to observe and measure partly because of the need for follow-up. The nature of the program will require a heavy emphasis on caregiver and family perceptions to measure progress.

## **ASSESSING PROGRAM EFFECTIVENESS**

Tracking and measuring context, process, outputs, and outcomes can help determine the extent to which the NFCSP makes a difference, strengthening and improving existing services, and serves as a component of quality assurance. A range of stakeholders (e.g., administrators, frontline staff, consumers, community members, partners, etc.) involved in defining the intended goals of the program or particular intervention helps ensure

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<sup>2</sup> Lindeman, D., Feinberg, L., and Wilson, K. Presentation at the Administration on Aging Conference, *National Family Caregiver Support Program: From Enactment to Action*. September 6, 2001. Available at <http://www.aoa.gov/carenetwork>.

relevance. Documenting the goals in the form of a mission statement can facilitate consensus. This type of focused discussion about the purpose of and outcomes expected from specific program activities forces all parties involved to express and examine their beliefs about what works, for whom, and under what conditions. With systematic examination, planned activities can be refined, if necessary, and brought into better alignment to achieve the desired program outcomes. This process also offers the opportunity to examine the feasibility and potential burden of collecting data to analyze desired outcomes. If the staff involved understand the value of collecting the data necessary for assessing outcomes, they might be more diligent in the quality of their data collection.

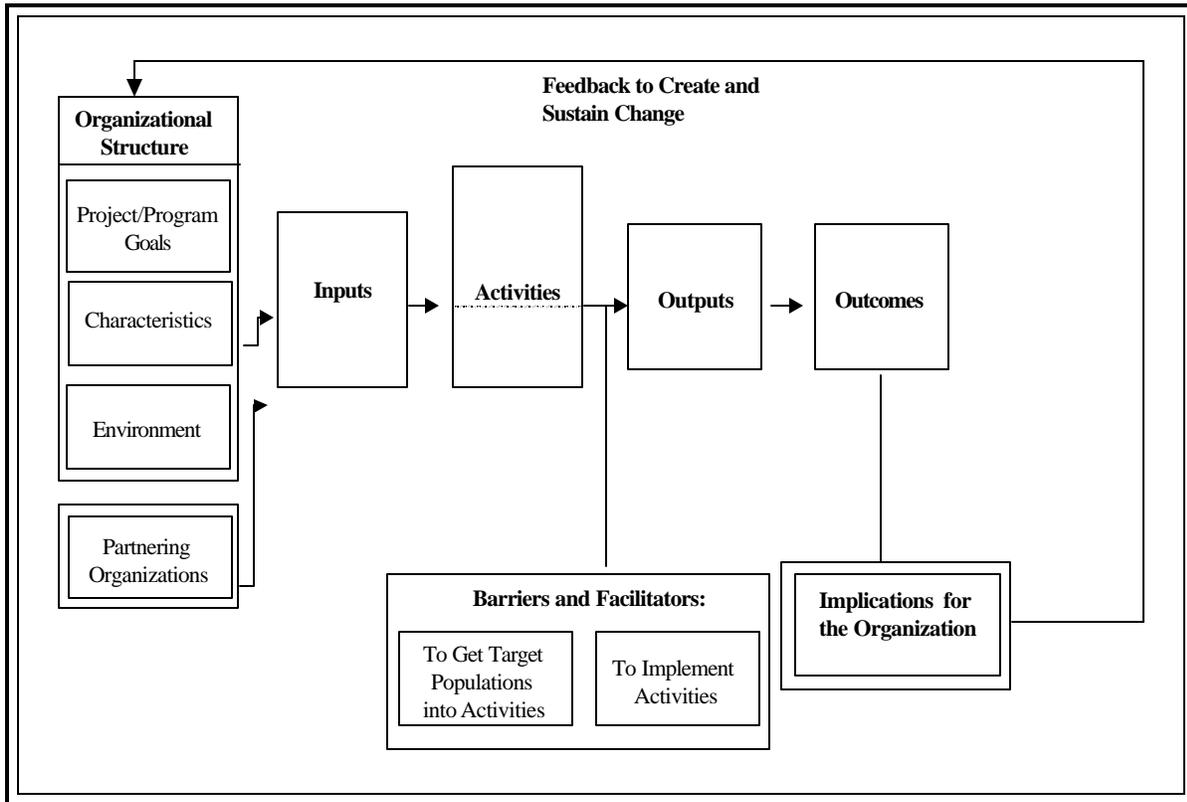
*Exhibit V.1* presents a framework for tracing the logic of a program and the relationships between the different components that influence program effectiveness. In addition to context, process, outputs, and outcomes described previously, two components that straddle context and process and can be helpful for conceptualizing indicators and outcomes include:

- Barriers (structural and other impediments that will affect the ability of activities to achieve intended outcomes, such as regulations, funding requirements, lack of available and appropriate staff and volunteers, inadequate infrastructure, etc.) and
- Facilitators (structural and other factors that will augment or affect favorably the ability of activities to achieve intended outcomes, such as partnerships and community linkages, internship arrangements, etc.).

The context and process heavily influence a program's ability to produce the desired outputs and outcomes. A feedback loop from program outcomes to the program then formalizes an important mechanism by which programs can understand what does and does not work and then use this information to adapt and refine the program, program activities, or both to improve effectiveness.

Measuring and demonstrating program effectiveness typically occurs at the levels of the individual and the program. Yet, also examining how these outcomes can contribute to broader organizational- and system-level goals provides an opportunity to consider broader implications of the NFCSP, such as expanding system capacity for caregiver programs, leveraging funding and maximizing resources through partnerships and linkages with other entities within the system, and creating other possible system-level changes.

**Exhibit V.1  
Program Effectiveness Framework and Feedback Loop**



Source: The Lewin Group Program Effectiveness Framework

**Individual Level**

The focus on the caregiver, care recipient, or both involves the development of new program goals and expectations. Because of the variability and mutability of caregiver needs for services and supports, traditional methods of measuring and assessing the effectiveness of services might be inadequate. The aging network can use the existing knowledge base regarding service and support needs of caregivers to plan and develop a responsive system of supports for this population. However, assessing the effectiveness of this type of system, and the programs within it, presents a challenge similar to other social service programs.

Ensuring a truly effective and responsive system necessitates a re-conceptualization of program outputs and outcomes to include assessing the value programs provided to caregivers.<sup>3</sup> For example, examining the concept of program responsiveness to the caregiver would likely combine context, process, and output and outcome measures at the individual level, such as the following:

<sup>3</sup> Feinberg, L.F. and Pilisuk, T.L. (October 1999). *Survey of Fifteen States' Caregiver Support Programs: Final Report*. San Francisco, CA: Family Caregiver Alliance.

- What are the characteristics of the caregiver and his or her current situation? (context)
- Were the individual's needs assessed and preferences elicited? (process)
- What were the number and types of service units received by an individual? (output)
- Did a match exist between what the caregiver asked for, qualified for, and received? (outcome)
- Was the caregiver satisfied with the service availability and the services received? (outcome)
- Did the caregiver's initial depression scale score improve after the FCSP intervention? (outcome if the program's goal or mission includes reducing caregiver stress)

The initial program emphasis on caregiver information and assistance as critical components of systems change suggests the network might want to focus first on issues related to caregiver access.

### **Organizational Level**

The overarching system goals, as well as the goals organizations specify for planned and implemented activities, will influence conceptualizing the effectiveness goals at the organizational level. Potential measures from the same example goal of program responsiveness from the individual level discussed above can be framed for the organizational level:

- What are the general characteristics of the caregivers accessing the program, and how do subgroups differ? (context)
- What percentage of caregivers has a documented assessment? (process)
- Have caregivers been involved in program planning? (process)
- What percentage of caregivers receives each of the five service components? (output)
- What percentage of applicant caregivers received the help he or she requested? (outcome)
- What percentage of caregivers was satisfied with the service availability and the services received? (outcome)
- What percentage of caregivers' has reduced depression following the FCSP intervention? (outcome if the program's goal or mission includes reducing caregiver stress)

Other goals specific to organizations could include the following:

- Broad dissemination of information about available services
- Ensuring sufficient capacity to meet demand for caregiver services
- Establishing responsive and collaborative service networks with families

- Leveraging resources (e.g., funds from other sources and volunteers) and developing partnerships with other agencies and businesses
- Involving caregivers in program development and implementation
- Improved timeliness of interventions
- A specific percentage of caregivers indicating that he or she was very satisfied with services provided.

A critical component of program-wide and system-wide effectiveness is leadership that promotes the consumer's perspective of effectiveness throughout the activities of an organization and system.<sup>4</sup> **Exhibit V.2** describes one of Pennsylvania's SUA activities to monitor and improve services provided by Area Agencies on Aging (AAAs) as an integral part of their existing quality assurance activities. Organizations that actively solicit input and suggestions about quality improvement from consumers ultimately prove to be more responsive to consumer needs. **Exhibit V.3** provides an example of an evaluation of a specific intervention that solicits feedback from participants and measure outcomes that should change as a result of the training, measures which could inform whether the training appears to be worth the investment and should be expanded.

### **Exhibit V.2**

#### **Incorporating the NFCSP into Ongoing Quality Assurance**

**Title:** Clinical Consultants

**Affiliation:** Pennsylvania Department of Aging (SUA)

**Status:** Operational

**Approach:** Six clinical consultants work in the state of Pennsylvania to monitor AAA quality. Each clinical consultant is assigned AAAs, and he or she visits each AAA four times a year. Over three years, at least one visit must focus on the caregiver program. The consultants review a 50 percent case sample and evaluate the assessment, the care plan, the statement of accountability, and the generic care management notes. They also look at nursing facility eligibility. If the facility is eligible, the consultant makes sure a registered nurse (RN) reviewed and signed the plan and checks why the caregiver is in the FCSP rather than in the Medicaid Home- and Community-Based Waiver (HCBW) program. When problems are identified in the care plan, the consultant looks for and reviews the plan of action.

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<sup>4</sup> Polister, B.H., Blake, E.M., Prouty, R.W., and Lakin, K.C. (1998). *Reinventing Quality: The 1998 Sourcebook of Innovative Programs for the Quality Assurance and Quality Improvement of Community Services*. Minneapolis, MN: University of Minnesota, Research and Training Center on Community Living, Institute on Community Integration (UAP).

### Exhibit V.3 Measuring Outcome from a Specific Intervention

**Title:** Caregiver Training Evaluation

**Affiliation:** Olympic AAA, Washington

**Status:** Operational

**Target Population:** Caregivers who complete the “Powerful Tools for Caregiving” training. (For a discussion of this program, see *Exhibit VII.17* in *Chapter VII*.)

**Approach:** Participant caregivers in the “Powerful Tools for Caregiving” training complete a survey before and after the training to quantify a number of aspects of caregiver health. The survey includes questions such as “How much have you slept? Exercised? Had social contact? Avoided Conflict?” Comparing the results of the post-training survey with those of the pre-training survey to evaluate caregiver stability, evaluators can see if caregiver health declines, remains stable, or improves.

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#### System Level

At the system level (federal, state, and community), definitions and indicators of program effectiveness can be linked directly to the requirements specified in the NFCSP legislation, the program guidance issued by AoA, and goals established by the aging network more broadly. Examples of these goals include the following:

- Implementation of the NFCSP at the state and local levels, including all five program elements, serving the priority populations
- State implementation of a quality assurance system
- Establishment of an accessible, responsive, and multifaceted caregiver support system at the AAA and ITO level, funded by multiple sources, including Title III-E
- Formation of broad-based coalitions to leverage and enhance caregiver support, which involves and solicits feedback from caregivers
- Evidence of a shift in focus from individual care recipients to both the caregiver and care recipient
- Increased public awareness of caregiver issues and needs

These program goals are broad yet flexible enough to allow for regional and local responsiveness to specific community needs. Their general nature opens the opportunity for SUAs, AAAs, and ITOs to determine specific performance indicators that make sense given their specific political and economic contexts, the current capacity and starting point of their systems, and what is appropriate and culturally relevant for their caregiving populations.

Some of these goals easily translate into output and outcome measures. For example, counts of individuals receiving each of the five service components by priority population designation for each AAA in a state would measure the degree of success relative to the first goal. Other goals will present a greater challenge to develop outcome measures.

Demonstrating that an accessible, responsive, and multifaceted caregiver support system at the AAA level, funded by multiple sources, including Title III-E, has been established will require measures that follow up with caregivers regarding these aspects of the system or measure broader activities. One measure of the program's being multifaceted might be the extent to which states and local communities mobilize working task forces with diverse membership. Measures of access might include the following questions: Do families know what services are available? Do families know how to access services? What is the evidence of accessibility?

The aging network can build on activities and outcome measures at the individual level to develop outcome measures at both the organizational and system levels. For example, caregiver assessments conducted by AAAs allow a care manager to document the caregiver's characteristics, expressed needs, and measures of burden and stress. These factors can be used to develop a responsive approach to meet the individual's needs. At the organizational level, generating regular reports summarizing the characteristics of the caregivers served and their needs can assist AAAs in refining the target audience and the interventions that must be developed further. At the system level, if a statewide, electronic uniform assessment has been developed, data from across AAAs could be combined to examine the degree to which priority populations are served. In the absence of statewide electronic systems, AAAs could report the data to the SUA.

Reassessments provide an opportunity to measure change over time and inquire whether the caregiver and his or her family feel that the AAA has responded to their needs and can be relied on going forward. If the proportion of caregivers indicating that the AAA has been responsive proves lower than expected, the organization has to determine the cause and adjust its manner of doing business. This feedback aspect of outcome measurement can enhance clinical practice of individual staff, processes of the organization, and development of resources at the system level.

## **NFCSP MEASUREMENT DEVELOPMENT ISSUES**

As noted above, programs commonly measure and assess program activity outputs without ever assessing program outcomes. This situation occurs for a variety of reasons, including insufficient measures, data, and knowledge about how to operationalize outcome measures and the perception that measuring outcomes requires too much time relative to the value of the information obtained through this activity. Notwithstanding, in the interest of sustaining and expanding the NFCSP, the aging network must develop evidence of program effectiveness and value to caregivers.

The framework presented above offers a way to begin thinking about measuring program effectiveness and value to caregivers. However, the multifaceted nature of the NFCSP means that the connection between cause and effect will sometimes be unclear or difficult to measure. Mapping interventions directly to outputs and outcomes can prove complex because many factors (i.e., barriers and facilitators) intervene and influence the implementation of activities associated with interventions. In addition, many factors beyond the influence of the intervention can affect program outcomes on individuals. Therefore, to the extent feasible, those developing outcome measures have to anticipate

and attempt to measure these factors and ensure that expected outcomes are attainable through the intervention.

As discussed in *Chapter IV*, based on her review of 15 state-funded caregiver programs, Feinberg outlined eight systems development principles that underpin the goals of the NFCSP and can provide a framework for thinking about potential outcomes: 1) family role, 2) access, 3) coordination, 4) comprehensive services offering choice, 5) diversity, 6) participation, 7) respect, and 8) accountability.<sup>5</sup>

Also discussed in *Chapter IV*, an important tenet of the NFCSP is to leverage funding and resources with other systems and services in the community. This opportunity to blend funding and integrate services presents another complexity to measuring and accounting for the effectiveness of caregiver services. Further, the NFCSP might encompass other AoA services. For example, the information and assistance (I&A) program might be the primary provider of information for caregivers, and provision of home-delivered meals might be a part of in-home respite services. Developing a data system that appropriately counts units of caregiver support provided by other aging programs presents a major challenge. SUAs, AAAs, and ITOs involved in partnerships and service linkages will have to think carefully about the definition and measurement of effectiveness in the context of these complex, yet necessary, arrangements. Methods of gathering and measuring caregiver's perceptions will likely emerge as the core of these efforts.

As noted earlier, the very nature of supporting caregiving as a program requires coordination and cooperation across the aging network and other networks that serve caregivers. This coordination and cooperation could be accomplished by mobilizing working task forces within and across states. An expanded base of supporters might help strengthen the system of caregiver support, enabling program expansion across the state. For reasons of sustainability, each task force member needs to benefit from his or her involvement, either personally or for the organization represented. The aging network is positioned to learn from and collaborate with others oriented to family support, such as the developmental disabilities agencies and agencies administering Temporary Assistance to Needy Families (TANF). *Exhibit V.4* provides an example of how approaches targeting other populations that focus on families could be adapted to measuring outcomes for NFCSP caregivers.

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<sup>5</sup> Feinberg, L. F. (2001). *Systems Development for Family Caregiver Support Services*. Issue brief prepared for the U.S. Administration on Aging. Available at <http://www.aoa.gov/carenetwork/IssueBriefs.html>.

**Exhibit V.4**  
**Adapting Outcome Measures from Other**  
**Family-Centered Interventions**

Early Childhood Intervention Outcomes	Possible Adaptation for NFCSP
Do the family see early intervention as appropriate in making a difference in their child's life?	Do the caregiver, family, or both see the NFCSP services as appropriate for making a difference in their (caregiver recipient's) life?
Do the family see early intervention as appropriate in making a difference in their family's life?	Do the caregiver, family, or both see NFCSP services as appropriate in making a difference in their family's life? Measurements could include stress and routines and activities constructed by families to achieve basic functioning.
Do the family view professionals and the special service system positively?	Do the caregiver, family, or both view professionals and the special service system positively?
Did early intervention enable the family to help their child grow, learn, and develop?	Did NFCSP enable the caregiver, family, or both to continue providing assistance to the care recipient or reach resolution as to the appropriate course of action?
Did early intervention enhance the family's perceived ability to work with professionals and advocate services?	Did the NFCSP enhance the perceived ability to work with professionals and advocate services for the caregiver, family, or both?
Did early intervention assist the family in building a strong support system?	Did the NFCSP assist the caregiver, family, or both in building a strong support system?
Did early intervention help enhance an optimistic view of the future?	Did the NFCSP help enhance an optimistic view of the future?
Did early intervention enhance the family's perceived quality of life?	Did the NFCSP enhance the perceived quality of life for the caregiver, family, or both?

**Source:** Bailey et al. (1998). Family Outcomes in Early Intervention: A Framework for Program Evaluation and Efficacy Research. *Exceptional Children*. 64(3): 313–316.

In the future, the network should benefit from the results of an AoA Innovation Grant awarded the Ohio SUA, detailed in *Exhibit V.5*, to develop a model outcome-based quality assessment system for caregiver programs that will incorporate the recommendations of caregivers, older adults, the aging network, and service providers. Project Director Richard LeBlanc, summarized the importance of the project as follows: “We believe that the key innovation here is that the mechanisms of accountability implemented as a result of this grant will be perceived and will, in fact, be directly supportive of the efforts of family caregivers rather than being perceived as an ‘inspection’ to monitor if the services are delivered according to structural specifications. Consumers will not feel at the mercy of the service system.”<sup>6</sup>

<sup>6</sup> LeBlanc, R. Email to Lisa Alexih. February 14, 2002.

## Exhibit V.5 NFCSP Innovative Grant for Outcome Development

**Title:** An Outcome Based System for Enhancing the Quality of Caregiver Support Services

**Affiliation:** Ohio Department of Aging (SUA)

**Status:** Operational

**Target Population:** Caregivers that receive service from the FCSP

**Approach:** In Ohio, as in most other states, agencies take responsibility for the quality of support services. This project is predicated on the premise that traditional notions of quality assurance rely heavily on structural and process requirements that, all too often, are unrelated to what consumers define as “quality” service. The project is designing and testing an outcome-focused quality monitoring system for the range of OAA services that benefit caregivers as well as older people. Developed with input from caregivers, older consumers, the aging network, and service providers, the system will place primary emphasis on the needs of the caregiver, recognizing and supporting management of services by the family, including voucher-based reimbursement approaches. With the assistance of the Scripps Gerontology Center, the project includes a literature review, the organization of an advisory group and regular meetings, focus groups, and development and evaluation of measures. The resulting outcome-based measures are being used to create a guide for SUAs, AAAs, and providers interested in improving the quality of caregiver support services delivered through the aging network.

**Cost/Funding:** This program is funded through an AoA grant.

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### AOA’S PERFORMANCE OUTCOME MEASURES PROJECT

In this early phase of NFCSP implementation, AoA is working actively with the aging network to develop data reporting requirements and assessment requirements that maximize the utility of information gathered while minimizing reporting burden. Currently, states report a number of outputs as a stand-alone report—expenditure data, units of service, and number of people served for the five categories of service (i.e., information; assistance; individual counseling, support groups, and training; respite care; and supplemental services). AoA is still determining the most effective way to incorporate Title III-E reporting into the Title III reporting system.

In conjunction with output reporting, AoA has sponsored a project, Performance Outcomes Measures Project (POMP), to develop and test a core set of performance measures for state and community programs on aging operating under the OAA. (For further information on POMP, please visit <http://www.gpra.net/>.) This initiative aims to assist SUAs and AAAs address their respective planning and reporting requirements, while helping AoA meet the accountability provisions of the Government Performance and Results Act (GPRA).

Given the advent of GPRA and related state and local initiatives that link continued funding to demonstrated benefits and outcomes, collecting timely, accurate, and comparable data becomes particularly significant. GPRA requires federal agencies to

develop performance plans and set specific, measurable outcomes for their programs to achieve. Through annual performance reports, agencies provide detailed information on their progress in meeting performance objectives. Notably, Congress now uses GPRA information to support decisions on appropriation levels and reauthorization of programs. Many state and local governments demand similar systems of accountability to document results and justify funding.

POMP could offer a potential source of effectiveness measures for the aging network. One of POMP's eight client-service domains includes caregiver well-being, support, and satisfaction questions. (For the most recent and past versions of the caregiver survey tool as well as methodological information, visit <http://www.gpra.net/CGmain.htm>). The 2001 version included 64 primarily categorical questions that asked caregivers to:

- Rate the quality of services provided to the care recipient and themselves, a subset of which are specific to NFCSP services;
- State their level of satisfaction with services and benefits of the services;
- Identify areas of unmet need in both services and information;
- Delineate the amount of care they provide and other support available;
- Enumerate burden and benefits of caregiving; and
- Provide information about their personal characteristics and situation.

The responses to this set of questions, or a subset of them, could be used to develop:

- Individual-level measures of outputs (e.g., how many individuals receive what types of caregiver services or combination of services) and outcomes (e.g., the percentage of caregivers rating services as very good or excellent) that could then be aggregated for the organization,
- Information for targeting (e.g., what are the characteristics of caregivers accessing particular types of services), and
- Areas for improvement (e.g., the most prevalent area of unmet need identified).

If other POMP domains focused on the care recipient (e.g., physical functioning, social functioning, and emotional well-being) were administered to individuals receiving care from caregiver survey respondents, the combination could more robustly assess the interaction of services related to the care recipient and caregiver.

Another POMP component involves developing measures that address program-level outcomes, such as capacity building, to measure the results of work conducted by SUAs and AAAs to enhance the size and scope of services for the aging. These activities include fundraising, coordination, advocacy, legislation development, and policy initiatives that affect service systems, often outside the scope of SUA and AAA programs. They also cover expanding the availability of nursing home alternatives, such as Medicaid HCBW among other alternatives to institutionalization. To improve access to and streamline the availability of existing services, these capacity-building activities also include such service system enhancements as centralized intake and assessment

across multiple agencies and programs. These process measures provide tested methods to round out and possibly model NFCSP-specific measures for a program effectiveness assessment.

## **INFORMATION SYSTEM INVESTMENT AND DEVELOPMENT**

The aging network recognizes the need to incorporate mechanisms for assuring program quality and effectiveness in caregiver support programs. Information systems that promote systematic collection and data analysis are a necessary component to any caregiver program. To be most effective and efficient, data collection systems must be developed before, rather than after, programs begin to provide services and supports. The majority of state programs apply some form of assessment tool to determine the care plan for the care recipient; however, before the NFCSP, most states assessed inconsistently and unsystematically the needs and situation of the family caregiver. A systematic assessment of the care recipient and not the caregiver, places the care recipient at an advantage over the caregiver in documenting, and possibly responsiveness to, identified need.

Developing a uniform, statewide information system would be an important investment to improve the quality of care and advance policies and programs to support and strengthen caregiver systems. As Feinberg notes, caregiver information systems, at a minimum, should include: 1) data from uniform, psychosocial assessment of the caregiver needs; 2) data from reassessments of caregiver need at regular intervals to track change over time; 3) community resources for the caregiver and care recipient; 4) information on the numbers of caregivers served, types of services provided, costs and amount of services delivered; and 5) data on outcomes achieved.<sup>7</sup> The initial investment for developing information systems might appear costly; however, over time, this type of system can actually reduce costs and provide a firm foundation for efficient care planning and service delivery. In addition, this type of system enables ongoing assessments of program outcomes and quality and strategic planning for new services and initiatives.

Many states are developing information systems to incorporate program data from NFCSP efforts. The challenge is to create a system that enables tracking of both care recipients and caregivers and to build in a mechanism that links the populations. Moreover, considering the technological capacity (i.e., computer hardware, software, and staff training) of AAAs is important. Ideally, new data system development would be compatible with data systems already in place so information could be integrated, if needed. Some states, such as Minnesota, are considering a more comprehensive overhaul of their data reporting systems. Minnesota is examining the feasibility of integrating Title III-E data with other OAA data as well as with a comprehensive state long-term care (LTC) database. Other states are seeking more targeted solutions to building databases to collect and assess caregiver program information. For example, North Carolina plans to

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<sup>7</sup> Feinberg, L.F. (2001). *Systems Development for Family Caregiver Support Services*. Issue brief prepared for the U.S. Administration on Aging. Available at <http://www.aoa.gov/carenetwork/IssueBriefs.html>.

build a database using spreadsheet software that will allow collection and assessment of caregiver data over time (see *Appendix B*). In developing this information system, a core consideration was creation of a user-friendly system that was compatible with their existing hardware and software.