

Assessing the Quality of Caregiver Support Services

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Introduction

This project, supported by the U.S. Administration on Aging, was undertaken cooperatively by the Ohio Department of Aging, the Scripps Gerontology Center, Miami University, and three area agencies on aging in Ohio, between 2001 and 2005. The project's primary objective was to design and test an outcome-focused system for quality monitoring of caregiver-support services based largely on input from caregivers themselves.

To develop the quality monitoring system, the project began by conducting focus groups comprised of caregivers, recipients of care and service providers to better understand quality from a range of stakeholders involved in the service delivery system. The ideas and perspectives of the focus groups were supplemented by a literature review as well as interviews with aging service program administrators. Once formalized, the quality monitoring system was tested in three area agencies on aging in Ohio, representing a mix of urban and rural areas as well as a diversity of approaches to administering services under the National Family Caregivers Support Program (NFCSP).

The project emphasizes that the essential components of an outcome-focused quality monitoring system differ markedly from more traditional systems that lend themselves to more easily measured structural information, such as: licensure, hours of in-service training, and number of service units delivered. While structural and process-oriented information is necessary, it is not sufficient. A solid quality system for caregiver-support services must focus on the caregivers themselves.

It follows that an optimal system of assessing and monitoring caregiver-support services should consistently put the ideas, observations and concerns of caregivers at its center and use them in pursuit of the continual improvement and constant fine-tuning that

true quality demands. Those ideas, observations and concerns constitute the essence of this work on quality monitoring of caregiver support services.

Background

As the United States' older population grows, so does the number of persons providing care for aging family members and friends. Today, nearly one in four households help care for an older person (Coleman 2000), and roughly 80% of care for people with chronic disabilities is provided by informal, unpaid caregivers (Mehdizadeh & Murdoch, 2003). In total, there are now more than seven million caregivers looking after more than 4.2 million older persons with a wide range of physical and/or mental disabilities in their own homes and communities. The efforts of these unpaid caregivers are valued at over \$250 billion dollars per year (Feinberg et al., 2004). Many care in anonymity under difficult circumstances. And their numbers will grow along with the older population in the years to come.

In recognition of the important and challenging role faced by caregivers, the Administration on Aging initiated the National Family Caregiver Support Program (Public Law 106-501). The national program provides funds in five key areas to support caregivers. Those five areas are: Information and Referral; Access to Services; Caregiver Training and Support Groups; Respite Care; and Supplemental Services.

While providing support to the growing number of persons in this country caring for older family members and friends is important, it remains crucial that the support offered is as effective and efficient as possible in helping to assist caregivers in the manner that they most need, want and value such assistance.

Ensuring the quality of caregiver-support assistance can be complicated. Traditionally, quality monitoring in the aging services network has focused on more structural indicators, such as: licensing and certification, amount of services performed, hours of training time, and criminal background checks of employees. Though important, these measures leave out what should be the central component of quality – the customer; i.e., consumers and others with a stake in his/her well-being and satisfaction. The extent to which the services provided actually improve the life and service quality of those receiving the services should be the essence of a quality system.

Also overlooked in more traditional quality assurance systems are measures to instill mechanisms for continuous improvement, an increasingly vital aspect of progressive quality systems. The primary objectives of this project are to define what constitutes a high quality system of services from the caregivers' perspective; devise a mechanism that incorporates that perspective into the services; develop a system that monitors the services for continuous improvement; and test that system at three area agencies on aging for optimal operation.

Defining Quality

The first step in examining quality is not only defining it, but also deciding whose definition of quality to use. In the case of caregiver-support services, that definition would best come from the caregivers and care receivers themselves, but an understanding of the term “quality” also benefits from input by others with something at stake in those services – the providers, funders, and regulators.

To better understand quality, we conducted eight focus groups across the state of Ohio. The groups were generally comprised of six to eight members. In all, 52 people participated, 39 caregivers, seven care receivers and six care providers. Caregivers with a range of backgrounds and caregiving experiences were selected for inclusion in the focus groups. Ages ranged from 40 to 94 years. As is the case in the general population, most caregivers were women caring for their husbands, followed by daughters (and daughters-in-law) caring for parents. Participants were from both urban and rural areas of the state. One had been caring almost full-time for a relative for 17 years; another had been providing part-time care for less than a year.

Each group met for 90 minutes and discussed perceptions of quality from their individual perspectives as caregivers, care receivers and service providers. These views provided a collective definition of quality that was used in designing the quality system for this project. (The findings below also appear in more detail in a book chapter “Caregivers as Consumers” in *Consumer Voice and Choice*, Kunkel & Wellin, 2006.)

Quality Lessons

The focus groups discussed quality of caregiver-support programs using the following four questions as a framework: (1) When do services make a positive difference for the caregiver? (2) When do services (or lack of them) have a negative effect on the caregiver? (3) What do caregivers most want services to accomplish? (4) How do caregivers know when their wants/needs have been met?

From these questions, caregivers shared stories covering a wide range of situations. Overall, the focus groups provided a picture of the strength, adaptability,

courage, struggle, and sacrifice that is part of family caregiving. In addition to powerful testimonies that underscore the need for caregiver support services, three major categories of information emerged to help us understand caregivers' conceptions of quality: Quality of Life, Quality of Services, Quality of the Service System.

Quality of Life

Participants helped us understand what was important to them, and what they as caregivers needed to have for a good quality of life. These themes can best be summarized as fill-ins to the statement — “To achieve quality of life I need to -- feel ok about myself and my decisions -- feel ok about the services my care receivers gets -- keep activities at home as normal as possible -- continue usual roles as much as possible-- have true respite (vs. simply time off) -- take care of myself -- and know that help is there if and when I need it.” These views of quality have implications for how services are designed and delivered. For example, in one instance a new care manager ordered home delivered meals for a couple, taking away the one tangible role that the spouse felt she could still perform as a caregiver.

Quality of Services

Caregivers, service providers, and care recipients discussed the ways in which services made life better, or failed to make a positive difference for caregivers and care recipients. Focus group participants were asked specifically about three caregiver support services that were commonly funded under the NFCSP: information and assistance, transportation, and respite, both in-home and adult day services.

Three major quality themes were identified by focus group participants: timing of services received; information about the care recipient and his/her services; and the impact of workers.

Timing— A long-standing criticism of in-home care is that services were delivered when it was convenient for the providers, but not necessarily when it worked for the care receiver and caregiver. A consistent theme discussed by caregivers was getting services when they needed them. This was especially true when caregivers discussed the concept of respite. For example, caregivers needing respite to attend religious services or a health care appointment described needing respite on their schedule, not the provider's.

Information— Caregivers discussed the importance of getting the necessary information about service options. How information was presented to caregivers was also considered to be critically important. For example, many caregivers discussed a hesitancy to ask for formal services help, and thus a negative experience at the information and referral stage would often result in a withdrawal from the service system. Caregivers also discussed the importance, especially for respite services, in getting information about the care recipient's service experience.

Workers— Regardless of whether the service was transportation, personal care, information and assistance, or adult day care, many of the quality comments focused on the workers. Trust, respect, caring, listening, and going above and beyond, were words commonly used to describe workers and their contributions to quality.

Quality of the System

Regarding quality of the service system, common themes most often emerging were: the importance of having a system designed around the outcomes most sought after

by the caregiver; a system flexible enough to respond to the varying individual needs of caregivers; a system flexible enough to respond to the varying needs of care receivers; a system able to adjust and respond to the changing medical conditions and needs of the care recipients; and a system able to adjust to the changing situations and needs of the caregivers. A universal comment across each of the stakeholder groups was that often times the system failed in achieving these principles.

Quality Model

The observations and concerns of the focus groups were blended with research on quality assurance and improvement to form a strategy for the demonstration. The quality model developed included three basic components: creating a culture of quality for the agency, focusing on the caregiver as the customer, and collecting data to evaluate outcomes.

Creating a Culture of Quality

Organizational culture has a major effect on quality. Those agencies that are able to become top quality providers are able to infuse quality in to every aspect of organizational life. Driven by the attitudes of senior management, this culture of quality is achieved by:

- Involving a range of employees within the organizations;
- Using group problem-solving processes rather than individual solutions;
- Obtaining commitment to quality from all members of involved organizations' staff members;

- Understanding that the provision of high-quality services involves striving for continual improvement.

Focusing on the Caregiver as a Customer

Although caregivers are typically consulted in the development of an in-home service plan of an older person, it is rare that a systematic assessment of the caregivers needs and circumstances is undertaken as part of this process. In NFCSP the caregiver is the primary customer and the system should be centered on the caregiver. Quality is achieved by:

- Listening to caregivers and consumers in the development of the service plan;
- Allocating staff time and resources to ensure that mechanisms are established to hear the voices of caregivers and care receivers;
- Creating an improvement process that uses the expertise of caregivers and care receivers to modify services.

Evaluating Outcomes of the Program

To achieve quality it is critical that data are collected on the outcomes of the services being delivered. This occurs by:

- Establishing reliable, relevant outcome measures;
- Creating mechanisms for data collection related to outcome measures and using data to continually fine-tune and adjust services to best accommodate the needs of caregivers and, to a lesser extent, care recipients and providers.

Area Agency Demonstration Sites

Three sites (of 12 area agencies on aging statewide) were selected to test the caregiver-support quality assurance system based on their willingness and ability to participate, difference in geographical and demographic setting, and variation in

caregiver-support service delivery. The sites participating in this demonstration project are: PSA 2, located in Dayton, PSA 6 in Columbus, and PSA 7 in Rio Grande.

The Area Agency on Aging— PSA 2

PSA 2 covers a 9 county area, including one large urban center. It serves a population base of 1.1 million, of which 18% are age 60 and older. Caregiver-support programs are integrated into care management programs throughout the agency, with NFCSP funds being integrated with PASSPORT and care coordination programs. PSA 2 offers what is considered to be a medium level of service availability.

The Central Ohio Area Agency on Aging— PSA 6

This planning and service area is headquartered in urban Franklin County, but also serves seven other mostly rural counties as well. Persons age 60 and older comprise 14% of the 1.6 million Ohioans living in this planning and service area. The caregiver-support services in PSA 6 are de-centralized; that is, they are operated by sub-contractors at the county level and not by the planning and service area itself. Because of additional funding received from a senior service levy supported by local taxpayers, PSA 6 is able to provide an array of in-home services, in addition to those delivered under Ohio's in-home Medicaid waiver program.

The Area Agency on Aging— District 7

PSA 7 is the most rural of Ohio's area agencies on aging, serving counties in the southern part of the state. Persons age 60 and older comprise 18% of the 400,000

Ohioans living in this area. The caregiver-support service program in this area is operated out of a separate department within the planning and service area. Due to limited local support, higher than average rates of poverty, and increased traveling distances, PSA 7 is considered a high need region of the state. PSA 7 has allocated NFCSP funds to a caregiver in-home training program, a caregiver newsletter that it sends out to all identified caregivers in the area, and an array of community-based services.

Implementing the Quality Model

Creating a culture of quality— The first step for the demonstration sites in implementing a quality assurance and improvement model was to develop a culture of quality within the organization. Three major activities were identified in this area: agency commitment to quality improvement, involving a wide range of employees in the improvement process, and developing a continuous quality improvement process.

Agency commitment— Our research and program experience and the quality literature (Applebaum, Straker, & Geron, 2000) discuss the importance of commitment, particularly from senior management, in quality efforts. Two sets of activities were undertaken in this area. First, study staff met with the executive directors and other senior managers of each of the partner area agencies on aging to discuss the quality philosophy underlying the project. The important role of senior management in infusing quality throughout the organization was highlighted. Similar meetings were held at the state department of aging as well. Second, because a critical quality principle is that everyone working in the agency -- whether they are management, direct service, or support positions -- need to share the quality vision and values of the organization, agency

training was developed. The commitment to meeting and exceeding caregiver and care recipient expectations needed to become a dominant part of the approach to services. The training stressed the importance of involving all employees, from top to bottom, in creating that culture, encouraging and valuing their input, especially those closest to the agencies' operations and customers, in this case, the caregivers. The training also emphasized the quest for continuous improvement, and not just compliance with rules and regulations; and that improvement should be based on customer/client input.

Involving a range of employees in quality— In many organizations, when quality problems arise the agency inclination is to use senior managers to solve the problems. While managers are certainly competent, the philosophy underlying this effort is that staff involved in all aspects of the delivery system need to be included in quality monitoring and improvement activities. Agencies were encouraged to establish quality improvement committees that included a range of area agency staff, providers, and caregivers. (A description of steps in developing a quality improvement committee can be found in Appendix A.)

Developing a continuous quality improvement process— The traditional approach to quality in aging services programs has relied heavily on an inspection model.

Administrative or case management agencies typically use a combination of structured requirements and audits to ensure quality. Often audits are based on a review of agency records, with direct interviews with customers included minimally, or not at all. Problems found in this annual inspection are typically addressed on a case-by-case basis. A continuous quality system is designed to create an ongoing process that corrects individual quality problems, but also develops systematic responses, such that problems

can be prevented in the future. We identify five elements of continuous quality improvement that are important for developing quality systems in aging service programs. (For a more detailed description of these principles see Applebaum, Straker, & Geron, 2000.):

1. Know who your customers are— Quality management indicates that the organization needs to recognize that it has multiple customers. For example, for the NFCSP the caregiver is the customer, but so too are the care recipient, funders, and regulators. Customers don't always have the same objectives. Organizations must make decisions about how to resolve customer conflict, but first they must know it exists.
2. You must hear the voices of the consumer— After identifying the range of customers it is critical to hear their voices. In many programs systematic efforts to hear from consumers have been limited. All of us have been consumers and recognize the importance of feedback, but in aging services consumer input often is discounted, because we assume the consumer does not have adequate expertise. Quality management indicates that without access to information from consumers, efforts to deliver high quality care will not be successful.
3. Information is essential for decision making— A key principle for continuous improvement is that organizations need good information to make good decisions. Many aging network agencies have limited data on even the most basic descriptive characteristics about the clients they serve. Quality management uses the concept of benchmarking as an improvement technique. Benchmark data allows an organization to compare its performance over time and/or to similar types of organizations.
4. Involving a range of staff in improvement activities— An important element of continuous improvement is that those individuals involved in the delivery and receipt of care must be involved in the quality improvement process.
5. Agreeing on a common and unifying organizational goal— Quality improvement stresses that, rather than having individual objectives or missions, organizations should have one goal—delivering high quality services. Each unit within the agency needs to have a common unifying goal, rather than competing ones.

Focusing on the Caregiver— The development of the in-home service delivery system has been appropriately organized around the care receiver. However, one of the critical lessons of our focus group work, a lesson reinforced by the literature, is that for older

people services are usually received by families. The demographic data show that the majority of older people with disabilities who receive in-home services have an informal caregiver, most often a family member. While a comprehensive assessment of the care recipient has become a key component of the in-home services system, the caregiver has been all but ignored. Area agencies in Ohio and around the nation did not typically have an assessment tool or process to ascertain the needs of the caregiver as they helped to develop the necessary service plan.

Two strategies were developed to respond to this area of concern. First, a caregiver assessment tool was developed as part of the intake process for the NFCSP services. The tool, which included information about the caregiver and care receiver circumstances, caregiver needs, and desired outcomes, served as a focal point for developing services under the NFCSP. Just like the care recipient assessment used in home care programs, the caregiver assessment gave the service coordinator a clearer perspective on the needs of the family.

The assessment tool was especially important in the PSA 6 demonstration site. To implement the NFCSP, the site had used a de-centralized model with a provider in each county operating the program. Each provider was using a different assessment process and had chosen to use service dollars in different ways. The premise for this approach was that local counties would be in the best place to identify community needs. While counties continued to tailor the allocation of funds to their local areas, having a common assessment proved quite useful from both a service planning and monitoring perspective.

Introducing the caregiver assessment into the service delivery system can result in problems that need to be addressed. For example, such a process could identify situations

where the caregiver and care recipient have different service objectives. A focus group caregiver talked about the need for respite, which could be achieved by using an adult day care service that was strongly resisted by the care recipient. It is our view that it is better in the long run to address these issues during the planning process.

A second mechanism used to focus on caregivers is through the survey process. As described in the following section, each of the area agencies collected data from caregivers about their experience in the program. Very little caregiver satisfaction work has been done in previous programs.

Evaluating outcomes of the program— A clear expectation about the anticipated outcomes of the program is another component of the quality equation. Once an organization knows what is important to its primary stakeholders, it then needs to develop outcome measures and data collection processes to make sure those outcomes are achieved. The focus groups, described earlier, provided the foundation for developing outcome indicators and measures for the program.

One approach used was the development of a caregiver survey by Scripps, in conjunction with ODA, and the three area agencies on aging participating in the demonstration project (see Appendix B). The questionnaire was designed to fit the specific goals of the agencies using them. The area agencies pilot tested the instruments. Scripps provided training on interviewing techniques for AAA staff that conducted interviews. The caregiver survey included demographic information on caregivers, such as age, race and gender, as well as detailed information pertaining to the caregiver's relation and time commitment to the care receiver. The major focus of the survey was

caregiver satisfaction with the services they received, the timeliness and utility of the services and the courtesy and respect with which those services were delivered. A final page, titled “Personal Outcomes,” was reserved for caregivers’ open remarks on their expectations, goals and perspectives on how those expectations and goals were, or were not, met.

To supplement the data collected directly from caregivers, other quality indicators were also identified for review. These data included such areas as elapsed time to receipt of services, characteristics of care recipients in relation to program eligibility criteria, and rate and reasons for program termination. These data, when combined with caregiver satisfaction survey information, could be used to assure and improve program quality.

Survey Results

As noted, all three area agencies were involved in pilot testing a caregiver satisfaction survey. Although the core elements of the survey were similar, each area agency tailored the instrument to its needs and circumstances. Below, we provide results from each of the pilot tests. In a subsequent section we will discuss using these data to improve quality and the challenges associated with these activities.

PSA 2 Survey Results

Thirty-three caregivers participated in the pilot test in PSA 2. The age of caregivers surveyed ranged from age 25 to 85 years; and the ages of their care recipients varied between 62 to 95 years. The period of time that caregivers had provided care ran from nine months to 14 years. “Most” of the caregivers were female, African-American and lived with the person for whom they provided assistance.

Regarding information and referral services, respondents overwhelmingly reported satisfaction relating to the assistance they received, particularly in the areas of being clearly understood, being treated with respect, and receiving the information and services they needed. All stated that they would recommend the service to friends. One area of common concern, however, pertained to the waiting time involved in talking to a person when first calling for information and assistance.

In relation to respite services and personal care workers' performance in assisting or relieving caregivers, the majority of caregivers responded that "workers always do a good job," are "dependable," and competent. Respondents universally indicated that respite and personal care workers treated care recipients with respect. Additionally,

- 54% of caregivers responded that personal care respite workers went "above and beyond" in providing services;
- 82% of caregivers responded that they would recommend the personal care respite services to a friend;
- 33% of caregivers responded that respite services helped them maintain their employment;
- 76% of caregivers responded that respite services gave them breaks without worry or concern for the care recipient;
- 87% of caregivers responded that respite services helped them keep life as normal as possible;
- 100% of caregivers responded that respite services helped them feel less stress and worry.

Regarding goals that caregivers offered for caregiver-support services, 44% replied that the services had met their goals (i.e., dependable, respectful, professional

help, less stress, more free time, and a more normal life); four percent indicated that the services had not met their goals; and 52% did not respond to the question.

PSA 2's survey allowed for open-ended comments, and while most of these were positive, several suggested problems regarding the dependability of workers and/or provider agencies sending out too many different workers to the same home (e.g., "aides do not show up"). Other comments indicated disappointment in worker performance (e.g., "worker does not do much, family requesting different agency," "service a good idea, but missed a lot," "little things that do not get done.")

PSA 2 acted upon the information gained from the quality assurance survey and immediately took steps to improve:

- Work with providers to improve personal care and respite workers showing up on time;
- Encourage agencies to send out the same, familiar workers;
- Improve training and supervision of workers to do a better job of pleasing clients.

PSA 6 Survey Results

PSA 6 analyzed 75 caregiver-support service assessments, 53% of which were from urban Franklin County. The ages of caregivers in the survey ranged from 34 to 88 years (average 61). The ages of their care recipients spanned from 61 to 97 (average 79). Duration of the caregiving arrangements was from about two months to 15 years. More than three-fourths of caregivers lived with the person for whom they cared. Thirty-six percent of the caregivers were spouses and 30% were daughters of the care recipients. Nearly 80% of the caregivers were Caucasian; almost 20% were African-Americans.

Roughly 40% were retired; 30% employed full-time; and eight percent employed part-time.

PSA 6 geared its caregiver-support survey toward outcomes, focusing on four basic questions to caregivers:

- When you contacted us, what did you want to happen?
- Were you able to achieve those goals?
- Describe the ways in which the goals have (and have not) been accomplished.
- How could we make the program better for you?

Four themes emerged in response to Question 1: financial matters; housekeeping and personal care; information; and respite. Of the 68 responses to this question (seven non responses), 34% pertained to respite (time to one's self; time for personal errands, such as doctor's visits, church, therapy sessions; just to get away for awhile); 21% to housekeeping and personal care (cleaning; laundry; vacuuming; changing bed clothes); 20% to financial issues (usually prescription drugs; medical bills; medical equipment bills; taxes; utilities); and 13% to information (availability of services; advice on caring for care recipients with dementia). In nine cases, caregivers' responses applied to more than one category.

Concerning goals and the ways in which they were achieved or not, most respondents indicated that their overall goals were being met by the caregiver-support services. Some referenced specifics, such as:

- "Mother attended adult day program; this gave me time to do things for myself."
- "Have been able to spend time with grandson and great-grandson."

- “(Have) time to run errands. Relieves stress of 24-hour care.”
- “Goals have been met; I have an excellent support system now.”
- “The aides that came out have been really good – became a part of my mother’s life.”

The ways in which goals for caregiver support services were not met were much more connected to the duration and frequency than to their availability. The word “more” was mentioned in many of the responses, as in, “I could use more free time; more help.” The initiation of the caregiver-support services seemed to awaken caregivers to just how thinly stretched out their lives are in caring for another, and how much they benefit from a little help. As one caregiver noted, “The more I get away, the more I see how necessary it is.”

“More” was also the dominant theme for caregivers responding to how the caregiver-support services could be made better. Though many were complimentary and suggested the services needed no improvement (“Everything is fine,” “Can’t think of anything to make it better,” and “This program was a lifesaver ... I cannot really suggest any changes”), most respondents’ ideas on improving services in all categories – financial, housekeeping, respite and information – touched upon the need for more: more money; more services; more weekend and evening services.

As with the caregivers in PSA 2, the PSA 6 caregivers surveyed gave personal service workers extremely high marks for treating clients with respect, with 100% of those surveyed giving workers at least a nine on a one-to-ten scale, with the overall average at 9.9. When asked how they would evaluate the caregiver-support program

overall, the average score (again, on a one-to-ten basis) was 9.6. Accordingly, 97% indicated they would recommend it highly.

Concerning other areas of satisfaction with service workers in PSA 6:

- 100% of caregivers stated the workers always or usually knew how to perform their jobs;
- 81% of caregivers stated that they could “always” depend on their worker;
- 88% of caregivers stated that they would recommend personal care services to a friend;
- 89% of caregivers stated that their personal care worker always or usually went “above and beyond” what is expected in providing services.

PSA 7 Survey Results

PSA 7 distributed caregiver surveys to 70 caregivers, primarily centering the survey on outcomes, specifically ways in which the caregiver support services had or had not met their expectations. But first, the survey helped identify what those expectations were. Basically, the expectations of those in PSA 7 fit in three categories:

- Help with information (e.g., on understanding particular diseases, disorders and the aging process).
- Help with emotional support.
- Help with services (respite, housecleaning, bathing, lifting).

PSA 7’s survey indicated that roughly 70% of respondents felt their expectations and needs were being met and that they were satisfied with the services they received from the program. Individual comments included:

- “Kindness, understanding and encouragement are in abundance ... I love the newsletters.”
- “Surprised with help; has definitely met expectations.”
- “It has definitely helped; taken a lot of stress off of me.”

- “They try to get everything for me. Whatever I ask for I get.”

Only two negative responses were noted regarding not meeting expectations, and those were from people who had not qualified for the program. Both suggested offering some type of support services for caregivers whose incomes may be over the limit but still not enough to afford purchasing services on their own.

Other categories revealed satisfaction levels approximating positive levels found in PSAs 2 and 6, and included:

- 92% of callers received the information they were looking for upon first contacting caregiver-support information and assistance;
- 96% felt that the information was explained in an understandable fashion;
- 84% said the information they received was helpful in assisting with the problems concerning them;
- 80% said they were “very satisfied” with the way their calls were handled; and 10% said they were “satisfied”;
- 94% said they would recommend the caregiver-support program to a friend.

When asked for specifics on how to improve information and assistance for caregivers, respondents suggested:

- An increase in the hours of service availability;
- Elimination of voice mail and substitution of a human being;
- More timely return of phone calls;
- Better advertising of services;
- Reduced waiting time for receiving services;
- More moral support for caregivers;
- More LPNs that can assist with suctioning, feeding tubes, etc.

Using Data to Improve Services

Having taken steps to create a culture of quality in the area agencies, and having focused on caregiver concerns and having devised methods to quantify and gather those concerns, the next step for the area agencies was to analyze the data collected and use their findings to improve services. Each of the area agencies discovered areas where their services could be adjusted for better satisfaction of their customers – the caregivers.

PSA 2 found that their caregivers voiced problems in regard to workers showing up on time and providers too often sending different workers to the same house. Given acceptable service, most care recipients, and caregivers, prefer not to have a number of different people coming into their homes performing what can often be personal care of a very sensitive nature. Also, a number of caregivers were not satisfied with the thoroughness of the work performed by their housecleaners.

PSA 6 noted few complaints about services provided other than that there were not more hours of the services offered, and more hours of the services available at traditional off times, such as weekends and evenings.

PSA 7, like PSA 6, also noted a need for more of the services offered, and a need for services in the evenings and weekends. PSA 7 also elicited recommendations for a number of other improvements, such as the elimination of voice mail, more moral support for caregivers (read: more caregiver support groups and counseling); more LPNs; reduced waiting time for services; reduced waiting time for returned phone calls; and better advertising of services.

These pilot tests represent just the first step in using client input in achieving the continuous improvement that is the hallmark of quality, but they offer useful examples of

how each site can not only learn from its own respective findings, but learn from its neighboring PSAs as well. All three used slightly different survey tools, and all three came up with slightly different, but useful, results.

Regarding continuing improvement, it should be noted that while the surveys found very high percentages of satisfaction in almost all areas, it would be a mistake to assume that the high percentages mean that there is not opportunity to improve. In PSA 2, for example, 82% of caregivers reported that they would recommend support services they received to a friend, and 87% said that the services helped them maintain a normal life. Although a high satisfaction rate was recorded, it is also important to understand why 18% of caregivers would not recommend the services and why 13% did not feel the services helped them maintain a normal life.

In PSA 6, where 81% of caregivers said they could always depend on their worker, why did nearly one of five feel they could not count on their worker? And why, in PSA 7, did only 84% of information and assistance callers state that the information they received was helpful?

One of the questions facing agencies involved in quality management activities is how are data used to improve services? Organizations have recognized the importance of collecting data from consumers, but questions arise about how such data should be processed, analyzed and ultimately used. Once data are tabulated, how can they be used to improve services. Some programs use senior staff to apply data, while others use quality improvement committees. For example, PSA 6 established an improvement committee for its caregiving program and one of the functions of this group was to examine the results of data generated in the project. An important maxim is: if you

collect data, use it. If data are not used to improve the quality of services, then the organization has wasted time and resources that could have been used to provide services. It is essential to allocate resources for quality assurance and improvement, but only if those resources are going to be used to improve services in the program.

Future Directions for Quality in NFCSP

In implementing this project we learned a number of lessons that we believe are critical for the NFCSP and other in-home service programs as they strive to ensure and improve quality for caregivers and care recipients. In this section we identify and discuss five issue areas that we think represent critical challenges to quality.

- Determining outcomes is difficult, but critical to achieving quality.

The growing emphasis on outcomes is a positive step in efforts to improve quality. The complicated questions are: What are the right outcomes? Who chooses them? Can we measure them? Two major problems have arisen in this area. First, identifying the right outcomes has been an ongoing challenge. Because programs have multiple stakeholders, it is difficult to develop a series of outcome measures that meets the needs across the range of constituents. Historically, measures have focused on outcomes that were important to administrators and regulators, but often minimized consumer input. Efforts to more heavily involve consumers, or, in this case, caregivers, are deemed critical to quality. In this project the outcomes developed came directly from the focus groups conducted with caregivers, care recipients and providers. There has been some criticism of the heavy focus on consumers. Some worry that focusing on consumer

input, without other types of indicators, does not provide an accurate picture of quality. Others have expressed concern about the consumer's ability to critically review the in-home services received. Our research on this project and other efforts (Applebaum, Uman, & Straker, 2006) suggests that the majority of older people with disability, even those in nursing homes, are able to report about their level of satisfaction with services. We recommend that the range of stakeholders served in home care programs is recognized, and outcomes are developed accordingly. However, the consumer—the caregiver and care recipient—must be at the center of the outcomes approach.

Once outcomes have been identified, a daunting task is to actually develop measures. Because measurement is difficult, quality efforts have had a tendency to focus on the outcome areas easiest to measure. This has resulted in an emphasis on structural and process measures, such as hours of training and number of units delivered, rather than on consumer outcomes. Consumer outcomes of importance in home care services, such as being treated with dignity and respect, being able to live a life as normally as possible, or reducing caregiver stress are difficult to operationalize. Identifying the right outcomes and figuring out how to measure them is a critical step in achieving quality.

- Agencies need assistance with collection, processing and analyzing of quality data.

An important premise of this and other quality work is that a good quality assurance and improvement system requires the collection, processing, and analysis of information. Two data related challenges arise in this area. First, data collection can be expensive. Telephone interviews by trained research interviewers can cost \$40-\$45, and in-person interviews can easily cost twice that amount. Aging network agencies rarely

have the resources to collect data on an adequate sample over time. One option that we have explored in this and other projects is to have data collected by agency staff as part of their routine assessment and/or communication process. Our research has shown that, if properly trained, agency staff can collect reliable data from consumers, which is comparable to data collected by trained research interviewers (Murdoch, Kunkel, Applebaum, Straker, 2004).

A second issue is that these data need to be collected and processed routinely, and most aging network agencies are not well equipped to do this kind of work. Agencies that have successfully addressed this issue have used two techniques. One is to develop the capacity to process and analyze data in-house. This strategy requires some up front training expenses and an ongoing commitment of resources. It has the advantage of allowing the organization to process its own data and also creates more capacity in the organization for additional quality and evaluation activities. A second approach is to develop a formal relationship with a local University or research organization. The advantage of such a strategy is that limited internal expertise is required. The disadvantages are that the organization does not develop or expand its level of expertise, and typically higher costs.

- Challenges associated with management information systems threaten quality.

One of the more dramatic challenges faced by the project involved management information systems. Problems were identified at the state, regional and local levels. At the state level, for example, a major problem involved integration of data systems. The state operates one system for its in-home Medicaid waiver program (PIMS) and one

system for its caregiver program, called SAMS. One system is client-based, the other provider and client-based. Even though family records could be in both databases, there are no linkages across these two systems. These systems are used at the regional level through the area agencies on aging, and these same integration problems were described at this level as well. Even though the area agencies have well developed management information systems, they were unable to integrate the two major home care systems and were thus unable to link caregivers with Medicaid and care receiver information. Even though service delivery information can be easily linked between the caregiver and care receiver in the case of NFCSP caregivers, outcomes were still difficult to track.

A second information system problem involved the local provider organizations implementing NFCSP in PSA 6. Aside from the urban county provider, none of the other providers in the region had automated information systems to record even basic information, such as demographics or cost of services. This was also a challenge for the rural area agency, PSA 7, which was part of the state management information system for the Medicaid waiver program, but did not have the capability to process outcomes based quality data outside of that system. Being able to collect longitudinal data on program participants is a core element of any quality improvement system, and, as noted above, many agencies across the network simply do not have the capability to process and analyze these types of data.

Even states or agencies that have relatively good information systems are not well suited to enter and analyze quality information. There are some area agencies that have developed expertise in this area by using scanners and statistical software packages to analyze data and to generate reports. However, the vast majority of aging network

agencies in the U.S. do not have the capacity to process these data. An ongoing quality improvement system cannot work without the ability to access, analyze, and use data.

- Quality management requires the state to balance monitoring and technical assistance.

Long-term care is very much a state issue. States are typically responsible for reimbursement and regulatory oversight. In the NFCSP, the Ohio Department of Aging is responsible for monitoring how area agencies implement the programs and how funds are spent. Although the department is required by the Administration on Aging to ensure that the program is being implemented according to the federal guidelines, the department also has the ability and opportunity to provide technical assistance to the aging network. And herein lies the dilemma for states. On one hand, the state has regulatory responsibility, and, if it does not fulfill this responsibility, the Administration on Aging will be critical of its actions. On the other hand, if the states are serving as monitoring or regulatory bodies the area agencies will be less likely to use them for technical assistance, since oftentimes a request for technical assistance requires an organization to identify a problem area. State units are able to gain a great deal of insight into program implementation because they are in the unique position of watching a range of agencies implementing the program. They get to see what works and what does not, placing them in an excellent position to provide technical assistance.

How does a state strike a balance in this area? One possibility is to separate the monitoring and technical assistance roles. The state can develop standardized review criteria and identify a unit with monitoring responsibility to examine these data and provide any necessary follow-up reviews. A second unit could then focus on technical

assistance activities. In this way states could be involved in both quality assurance and improvement activities.

- Balance flexibility and standardization in program design and quality management.

The NFCSP was designed to provide states, regions and localities with a maximum amount of autonomy in developing services for caregivers. From a quality perspective, the strength of such an approach is that it allows programs to tailor services to best meet the needs of individual consumers and should enhance caregiver outcomes. It also means that quality assurance and improvement activities are a bit more difficult to standardize across the state. For example, because PSA 6 has a local property tax levy that generates funds for in-home services in Franklin County, it uses NFCSP funds for short-term services, three months or less. On the other hand, PSA 7, located in a rural community with limited services, makes caregiver support services available over a longer period of time. While operating under the same guidelines, these two area agencies are using funds in very different ways.

Both of these organizations are committed to quality assurance and improvement for their caregiver support programs. However, the differences in implementation mean that the specific approaches to quality may vary. For example, many states have mandated 6 or 12 month consumer surveys as part of their in-home services quality approach. While we believe that hearing from consumers is an essential element of quality, questions about how and how often are better left to the program to determine. Such a requirement would not work for PSA 6, where caregivers need to be interviewed after 2 or 3 months. We do believe that it is reasonable for a regulatory agency to ask a

program to demonstrate how it gets feedback from participants, and to make an assessment of whether that approach is successful. The lesson is that states need to develop quality principles without prescribing specific strategies in order to balance program flexibility with efforts to standardize state monitoring responsibilities.

Conclusion

This report describes Ohio's experience in developing a quality model for caregiver support services provided under the NFCSP. As state's continue to expand home and community-based services, there will be continued pressure to develop mechanisms to assure and improve the quality of services for both care recipients and caregivers. It is our hope that the experiences of the pilot area agencies in this effort will help other programs as they move forward in their efforts to improve the quality of services provided in the aging network.

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Appendix A

QUALITY IMPROVEMENT COMMITTEE

Role and Purpose

An effective quality improvement committee fulfills for the program significant functions that are not easily handled in any other way. With responsibility and authority for centralized oversight of quality management, the committee will have the advantage of the broadest and the most singularly focused view of quality within the organization. Because programs are so complex, multi-faceted, and often understaffed, it is reasonable for each unit or component to focus on its own work, without time or opportunity to see how its work intersects with, and affects, the work of other units. While quality is a concern of every unit and every staff person, time taken away from the provision or administration of services in order to systematically reflect on improvement is often a luxury. The quality committee provides a way for all quality management activities to be designed, conducted, and used as part of an integrated system of feedback and improvement.

The quality improvement committee will have ongoing responsibility for providing feedback and suggesting improvements to the program. With support from staff, the group will have responsibility for reviewing, and in some cases generating, information about program performance. The committee will be involved in helping the organization use data to improve services, the system, and the quality of life of consumers. The committee can help the program stay focused on the consumer-centered principles of quality.

Size and Composition

The quality committee is a working group and so should have enough members to share the work, but should not be so large that it is cumbersome. We recommend an optimum size of ten members. Core members would include:

- area agency program staff,
- caregivers,
- providers,
- information system or research staff.

Composition is expected to vary across areas, with programs adding members based on their unique structures.

Work of the Committee

An effective quality improvement committee requires a significant investment of time and other resources, such as technical support for data processing and analysis. Scope of responsibility and authority, specific tasks to be completed, and timeframe need to be established at the outset. Staff support will be needed to help with meeting arrangements, background work, and possibly data collection and processing.

An important early task for the committee will be to review information currently collected. Based on this and other work, the quality improvement committee can identify which improvement efforts are the highest priority for the program. In some cases committee members might work on planned improvements; in other cases, the committee would provide feedback on planned activities. In all cases, an important function of the committee would be to ensure that mechanisms exist for continuous feedback.

Training

An initial orientation for committee members is essential to discuss and agree upon expectations, roles and responsibilities. Program commitment to improvement needs to be emphasized. Ongoing needs for training and resources will be identified as the committee begins its work.

STEPS FOR THE DEVELOPMENT OF QUALITY IMPROVEMENT COMMITTEE

Step 1. Agree on role and responsibility of committee.

- A. The detailed implementation steps that follow contain our proposal for how the committee would operate. But it is essential that we have a shared vision with program staff concerning the role and responsibilities of the quality improvement committee.
- B. Write up description of scope of effort. This activity would be completed through a joint working session of program staff and the Scripps team.

Step 2. Identify quality committee composition and invite members.

Choose members to ensure that the committee represents the points of view of the major stakeholders of the program. Potential members:

- program staff
- caregivers
- providers
- information system or research staff
- consumer advocacy group
- others to be identified by program

Step 3. Identify staff and other resources for committee use.

After agreeing on committee scope and membership, it is important for program staff to examine the necessary resources required to support the committee. This will include identifying staff responsibilities and additional supports that may be required. Scripps researchers will work with program staff to develop resource estimates.

Steps 4-10 will be completed by the committee

Step 4. Develop a common vision of quality in the state program.

- A. Develop a common understanding of how program works.
Receive overview of program operations and structure.
Review program policies and training materials.
Receive input from committee members involved in program operations.
Receive information about state and federal laws and regulations that effect quality.
- B. Develop a common understanding about quality in the state program.
Provide background materials about quality in home care and NFCSP.
- C. Discuss some of the challenges faced in examining quality in NFCSP (different stakeholder views and emphasis).

Step 5. Complete Self-Assessment of Consumer-Directedness of Program.

- A. Decide on approach for how committee will assess program activities: appoint sub-committee to complete assessment, or assessment completed by state program staff, or complete by full committee.
- B. Agree on completion strategy and identify specific steps for self-assessment to be completed.

Step 6. Review of Assessment Process.

- A. Committee reviews finding from assessment. Examine assessment in the context of committee's vision of quality.
- B. Review detailed questions in areas where improvement activities may be warranted.

Step 7. Develop an initial list of areas for improvements based on assessment.

- A. List areas of improvement:
Include details of areas of concerns and examples of problems.

Identify areas that may require additional information.
Assess committee agreement on nature and extent of problem.

Step 8. Identify Other Sources of Data for Assessing Program Quality.

- A. Systematically examine sources of quality data received by program.
- B. Examine data from quality areas where available.
- C. Conduct additional analysis where necessary. (Consumer satisfaction measures)
- D. Identify potential list of quality problems based on review of existing data.
Combine with list of problem areas identified in the self-assessment.

Step 9. Refine and Prioritize Areas of Improvement.

- A. Committee prioritizes areas for improvement. Examine the importance of the improvement area, likelihood of success in being able to improve, and cost of improvement activity.
- B. Based on these criteria, committee selects specific improvement projects and develops a timeline for efforts.
- C. Committee will develop plan for how improvement efforts will be implemented. Could be done with a sub-committee from overall group, could include other individuals, or a combination.

Step 10. Develop ongoing quality improvement plan.

- A. Assess the quality activities currently underway.
- B. Make judgments about the importance of activities, including data collection efforts and improvement actions.
What are the barriers to improving the quality of the program?
Are there changes that need to be made to the approach?

VII.2. Does the program periodically (e.g., every quarter, semi-annually) solicit input from caregivers (in writing, by telephone or visit) regarding the quality of the services they receive?

VI-1.3. Are caregivers asked specific questions about program quality, such as:
a. are you satisfied with the services you receive?
b. are you receiving the services you want and need?
c. are services provided in a manner that responds to your preferences regarding how things should be done?

- d. have you had any problems and/or made any complaints about your services and/or provider?
- e. were problems (including any emergencies that have occurred) handled satisfactorily?
- f. do you have suggestions for improving the quality of the services you receive?
- g. do you have ideas for improving the quality of home and community based services?

Appendix B

**National Family Caregiver Support Program
Outcomes-Based Follow-up Tool**

2004

Interviewer Training Manual



Part 1 - Special instructions for pre-test interviews

We need your help to make this questionnaire as clear and user-friendly as possible. We've tried to write questions that are clear, provide space for recording the important information the caregiver tells us, and ask questions about all of the topics that might be important for the caregiver. But we're sure that the questionnaire can be improved. Your notes about these issues will be essential to help us make these improvements. After you have completed these pre-test interviews, we will have conference call with you about how the interview form works. Ultimately, we hope that the information learned in these interviews, using an interview protocol revised according to your experiences, will be useful to improve an individual caregiver's services, and to improve the program overall.

General Guidelines:

We are asking you to complete eight interviews. Since we would like to find out as soon as possible how the questionnaire works, we'll follow up with you in a week or two to see how things are going.

As you complete these interviews, please follow the "official" instructions; feel free to write your comments and questions all over the questionnaires.

When you have completed each interview, please fax the form to Shawn Davis, Scripps Gerontology Center, 513-529-1476. In the interest of protecting your caregivers' privacy, please black out their names. But, since we may want to refer to individual questionnaires when we have our conference call, please leave a consumer ID number on each survey.

Pre-testing Guidelines:

Make notes directly on the questionnaire anytime the caregiver had difficulty understanding a word or phrase. Try to write down the word or phrase you used to help the caregiver understand what we meant.

Be sure to take notes about the questions regarding specific services. Were caregivers reluctant to offer suggestions or negative comments? Do you have any suggestions about how to have agency staff do these interviews AND elicit necessary information about services?

Notice whether the "Never," "Hardly Ever," "Sometimes," "Usually," and "Always" responses work. Would it be easier for interviewers or for caregivers to have more response options or more structured questions? While we want these questions to have a conversational tone, we do not want the recording of answers and issues to become burdensome for interviewers.

Note how long the interview took. This will help us know what future interviewers should tell consumers about the process.

Make any suggestions you can think of regarding format of the questionnaire. Does the order of questions make sense? Do we need transition statements or explanatory paragraphs to introduce the sections of the questionnaire?

Did we cover all of the important topics? If not, what else should we include?

Thanks so much for your valuable contributions to this project!

Part 2 - Conducting Outcome-Based Interviews - Instructions

The Outcomes-based follow-up tool is one way to get caregiver feedback on how well the program responds to the preferences and needs of caregivers. The information is intended to guide AAAs' in assisting the caregiver and to provide input into the Program's quality improvement process.

The following instructions will ensure that all interviewers are using the questionnaire to conduct interviews in the same way. This will allow confidence in the results when the information is aggregated and analyzed.

1. Who should you interview?
 - a. The first choice is to interview the primary caregiver if possible.
2. If possible, interview without the care-recipient present, but since most care-recipients are family members, their presence shouldn't present a serious issue.
3. Before starting, remind them that their participation and their honesty will not affect the level or quality of care they receive.
4. General points:
 - a. Follow instructions carefully
 - b. Read the questions just as they are written, and in the order in which they appear.
 - c. Circle the answer given. Use the follow-up question to get more information about a problem so you can assist the person in addressing it.
 - d. If the answer doesn't represent a problem, but the person offers more detail that a simple "Never," "Hardly Ever," "Sometimes," "Usually," and "Always," record the detail in the space provided.
 - e. Always ask all of the questions.
5. Don't attempt to influence responses in any way. The truth is all that really counts - what the person really thinks or feels about the subject.
6. When "Never," "Hardly Ever," "Sometimes," "Usually," and "Always," answers are accompanied by qualifications such as "Never, but..." or "Usually, but not..." record the comments. These responses may reveal something important about the question that was not anticipated.
7. Record any comments or remarks just as they are given. The exact words people use to describe their feelings are important, so include the caregiver's language, rather than summarize the comments in your own words.
8. If a caregiver does not give an adequate response to a question, or if she/he seems to misunderstand the question then you should repeat the question with the prefacing

remarks, “Let me read that question again.” If your consumer still does not give an adequate response, reword the part that is giving them trouble. It is very important that you be careful not to put an answer in his/her mouth, or to suggest a “correct” answer.

9. Get all the information you are asked to get. That means, ask every question and record every answer - in the correct place. A questionnaire with serious omissions or errors isn't very useful. Therefore, check over the questionnaire at the end of each interview. Say, “Now, let's see if we've got everything,” to allow you to look over each statement to see that it is answered and the answer recorded correctly.

PSA 2
Information and Assistance Survey

Hello (caregiver's name). My name is _____ I'm from the Area Agency on Aging. I am following up with people who have called our agency in the past few months, to ask for their feedback about the Information and Assistance Services. This will just take a few minutes, and will help improve our service to callers. Your responses are completely confidential and will not affect the services that you are receiving in any way.

1. Please tell me for whom you called.

- _____ For self
- _____ For relative/friend
- _____ For care recipient
- _____ Other (describe): _____

2. Have you ever used this service before?

- _____ Yes
- _____ No

3. How quickly was your call answered?

- _____ After 1 ring or 2 rings
- _____ 4 or 5 rings
- _____ 5-15 rings or
- _____ More than 15 rings

4. Was the phone answered by voice mail or by a person?

- _____ Person (Skip to 7)
- _____ Voice mail

4b. How well did you understand the voice mail instructions?

- _____ Very well
- _____ Somewhat well
- _____ Only a little
- _____ Not at all

4c. Did someone call you back?

- _____ Yes
- _____ No (skip to 4d.)

4d. When did someone call you back?

- Within an hour
- In the same day
- In the same week
- More than a week

5. Overall, did the person(s) listen carefully to what you wanted?

- Yes, definitely
- Yes, I think so
- No, I don't think so
- No, definitely not

6. Did she/he explain things in a way that you could understand?

- Yes, definitely
- Yes, I think so
- No, I don't think so
- No, definitely not

7. Overall, did you receive the information from the Area Agency on Aging that you were looking for?

- Yes, definitely
- Yes, I think so
- No, I don't think so
- No, definitely not

8. Do you expect that the information you received from the Area Agency on Aging will be helpful in resolving the issue you called about?

- Yes, definitely
- Yes, I think so
- No, I don't think so
- No, definitely not

9. Would you recommend this service to a friend or colleague who needs the kind of information and assistance you did?

- Yes, definitely
- Yes, I think so
- No, I don't think so
- No, definitely not

10. Overall, how satisfied were you with the way your call was handled?

- Very satisfied
- Satisfied
- Somewhat satisfied
- Not at all satisfied

11. Do you have any recommendations on how to make the Information and Assistance better? (Do not read list. Check all that apply.)

- None
- Increase the hours the service is available
- Reduce the waiting time to speak to someone
- Eliminate voice mail system/have persons answer the phone
- Get more knowledgeable persons to answer the phone
- Try to answer all questions on first call
- Be more timely in returning phone calls
- Better advertising of services
- Reduce the wait time on services
- Other (describe): _____

12. Did you experience any of the following communication problems? (Check all that apply)

- Language problem (e.g.. did not speak Spanish)
- Hearing problem
- Operator need to speak louder and slower
- Operator needed to listen more
- Other (specify): _____
- None

13. After your call to the AAA did you make any other calls to agencies to get the information or help you needed?

- Yes
- No

13b. About how many calls did you have to make before you got the information or help you needed? _____

13c. Did you get the information or help you needed?

- Yes
- No

Next, I am going to ask you a few questions regarding Assistance

14. Were you offered an assessment?

- Yes
 No

15. How quickly were you contacted by one of our Assessors in order to set up an assessment?

- Within a week
 Within 2 weeks
 Within a month
 Over a month
 Other (How long?)_____

16. Was the assessment date and time set up at a time that was convenient for you?

- Yes, definitely
 Yes, I think so
 No, I don't think so
 No, definitely not

17. How long was it from the time you called in to the time you were seen?

- Within a week
 Within 2 weeks
 Within a month
 Over a month

17b. Did this time frame meet your needs?

- Yes
 No

17c. Was it satisfactory to you?

- Yes
 No

18. Overall, did the Assessor listen carefully to what you wanted?

- Yes, definitely
 Yes, I think so
 No, I don't think so
 No, definitely not

19. Overall, did the Assessor understand what you wanted?

- Yes, definitely
 Yes, I think so
 No, I don't think so
 No, definitely not

20. Did she explain things in a way that you could understand?

- Yes, definitely
- Yes, I think so
- No, I don't think so
- No, definitely not

21. Do you feel you were linked with appropriate options/resources based on the needs you identified at that time?

- Yes, definitely
- Yes, I think so
- No, I don't think so
- No, definitely not

22. Overall, were you satisfied with the outcome of your assessment?

- Yes, definitely
- Yes, I think so
- No, I don't think so
- No, definitely not

**PSA 6
Follow-up Survey
NFCSP**

Introduction

We would like to ask some question about the services received by you and your loved one. We are asking these questions of everyone participating in our program to make sure we are doing a good job. We really appreciate your help. First, we would like to ask you a few questions about you and the person you are a caregiver for.

(To be completed by staff)

1. Caregiver's Name _____
2. Caregiver ID # _____
3. Phone Number _____
4. County: _____
5. Service Start Date: _____
6. Service Stop Date: _____

Demographic Information (Complete with respondent)

7. Care Recipient's Name _____
8. Who is the care-recipient's Service Provider _____?
9. What is your relationship to _____?
(Care recipient's name)
10. Do you live in the same house with _____?
(Care recipient's name)

_____ Yes

_____ No
11. (If no) How far away do you live?
_____ Less than 20 minutes away
_____ Between 20 and 60 minutes away
_____ Between 1 and 2 hours away
_____ More than two hours away

12. How long have you been caring for _____ Years _____ Months
(Care recipient's name)

13. What is _____ date of birth? ___/___/___
(Care recipient's name)

14. Record the gender of _____
(Care recipient)

_____ Male _____ Female

Now a few questions about yourself

15. What is your date of birth? ___/___/___

16. Record gender of caregiver

_____ Male
_____ Female

17. How would you classify your race?

_____ White/Non Hispanic _____ Black or African American
_____ Asian _____ American Indian
_____ Hispanic _____ Other

18. What is your current marital status?

_____ Now married _____ Widowed
_____ Divorced _____ Separated
_____ Never married

19. Who lives in your household? (Check all that apply)

_____ No one else: I live alone
_____ Spouse (Husband or Wife)
_____ Mother
_____ Father
_____ Mother-in-Law
_____ Father-in-Law
_____ Siblings (brother or sister)
_____ Child(ren) under 18. How many? _____
_____ Child(ren) over 18. How many? _____
_____ Another person for whom I am caring.
What is their relationship to you? _____
_____ Other persons.
What is their relationship to you? _____

20. Employment Status

_____ Employed full-time
_____ Employed part-time

_____ Unemployed
_____ Retired

Personal Outcomes

When you contacted us, what did you want to happen?

Were you able to achieve these goals? ____ Yes ____ No

Describe the ways in which the goals have/have not been accomplished.

How could we make this program better for you?

Assessment of Caregiver Services

For each statement, please tell me how much you agree or disagree. Please give me a number from 1 to 10, with 1 meaning definitely not and 10 meaning definitely yes.

Did the professionals who assisted you treat you with respect?

Definitely	Definitely
NOT	YES
1	2
3	4
5	6
7	8
9	10
	N/A

Did the caregiver services help you to reduce stress?

Definitely	Definitely
NOT	YES
1	2
3	4
5	6
7	8
9	10
	N/A

Do you have an increased awareness of the importance of taking better care of yourself (personal well-being)? as a result of the caregiver services provided?

Definitely	Definitely
NOT	YES
1	2
3	4
5	6
7	8
9	10
	N/A

Did you have assistance with planning for services after the caregiver program ended?

Definitely										Definitely
NOT										YES
1	2	3	4	5	6	7	8	9	10	N/A

Would you recommend this program to others who may need this service?

Definitely										Definitely
NOT										YES
1	2	3	4	5	6	7	8	9	10	N/A

Note to interviewer—notice category shift from no/yes to poor to excellent.

How would you rate the caregiver program overall?

Poor									Excellent
1	2	3	4	5	6	7	8	9	
10									

How would you rate your ____'s (relationship of the care recipient) satisfaction with services?

Poor									Excellent
1	2	3	4	5	6	7	8	9	
10									

QUESTIONS TO BE ASKED BY PARTNER AGENCIES

In the past 3 months, has your family member received personal care/respice services? (Can use same questions for homemaker). I am going to read some statements about your in-home care worker. I want to hear your honest opinion- there are no right or wrong answers. Please use the response categories that are given. Do you have any questions before we start?

	Never	Hardly Ever	Sometimes	Usually	Always
1. The worker knows how to do her job.					
2. The worker treats my (_____) with respect. Fill in relationship					
3. The worker does a good job.					
4. I can depend on the worker.					
5. The worker goes above and beyond in providing service.					
6. Would you recommend this personal care service to a friend.					

In the past 3 months, has your family member used institutional respice? I am going to read some statements about institutional respice care. I want to hear your honest opinion-there is no right or wrong answers. Please use the response categories that are given.

	Never	Hardly Ever	Sometimes	Usually	Always
1. I felt comfortable leaving my loved one for an extended period of time.					
2. Staff listens to me.					
3. The workers do a good job.					
4. The facility goes above and beyond in providing service.					
5. Would you recommend the facility service to a friend.					

In the past 3 months, has your family member used adult day care services? I am going to read some statements about the adult day services. I want to hear your honest opinion-there is no right or wrong answers. Please use the response categories that are given.

	Never	Hardly Ever	Sometimes	Usually	Always
1. Staff treat my _()_ with respect. (Fill in relationship)					
2. Staff listens to me.					
3. I feel well informed about how my (relationship)_____ is doing at the center.					
4. The adult day care service does what I need it to do.					
5. Staff go above and beyond in providing service.					
6. I would recommend this adult day care service to a friend.					

In the past year have you may have received additional assistance through the caregiver support program? I am going to read some statements about supplemental services. I want to hear your honest opinion-there are no right or wrong answers.

1. What was the additional assistance that you received? _____

INTERVIEWER: if caregiver's additional assistance did not involve face-to-face contact with personnel, skip to Question 2.

	Yes	No	I Don't Know	Not Applicable
1b. Did the individual(s) providing support treat you with respect?				
2. Did the additional assistance help reduce stress?				
3. Did the additional assistance help you to provide better care?				
4. Would you recommend this service to a friend?				

Personal Outcomes

When you contacted us, what did you want to happen?

Were you able to achieve these goals? ____ Yes ____ No

Describe the ways in which the goals have/have not been accomplished.

How could we make this program better for you?

10/29/04

Area Agency on Aging 7 Caregiver Support Program Survey

Hello (caregiver's name). My name is _____ and I am from the Area Agency on Aging. I am following up with people who have called our agency in the past few months, to ask about your services. This will just take a few minutes, and will help improve our service to callers. Your responses are completely confidential and will not affect the services that you are receiving in any way.

1. Please tell me the reason why you called the caregiver support program.

- _____ For self
- _____ For relative/friend
- _____ For care recipient
- _____ Other (describe): _____

2. Did the person you spoke with explain things in a way that you could understand?

- _____ Yes, definitely
- _____ Yes, I think so
- _____ No, I don't think so
- _____ No, definitely not

3. Overall, did you receive the information about the caregiver support program from the Area Agency on Aging that you were looking for?

- _____ Yes, definitely
- _____ Yes, I think so
- _____ No, I don't think so
- _____ No, definitely not

4. Was the information you received from the Area Agency on Aging helpful in resolving the issue you called about?

- _____ Yes, definitely
- _____ Yes, I think so

- _____ No, I don't think so
- _____ No, definitely not

5. Would you recommend the caregiver support program to a friend?

- _____ Yes, definitely
- _____ Yes, I think so
- _____ No, I don't think so
- _____ No, definitely not

6. Overall, how satisfied were you with the way your call was handled?

- _____ Very satisfied
- _____ Satisfied
- _____ Somewhat satisfied
- _____ Not at all satisfied

7. Do you have any recommendations on how to make the Information and Assistance better? (Do not read list. Check all that apply.)

- _____ None
- _____ Increase the hours the service is available
- _____ Reduce the waiting time to speak to someone
- _____ Eliminate voice mail system/have persons answer the phone
- _____ Get more knowledgeable persons to answer the phone
- _____ Try to answer all questions on first call
- _____ Be more timely in returning phone calls
- _____ Better advertising of services
- _____ Reduce the wait time on services
- _____ Other (describe): _____

Next, I am going to ask you a few questions regarding Assistance

8. Do you feel you were linked with appropriate options/resources based on the needs you

- identified at that time?
- _____ Yes, definitely
 - _____ Yes, I think so
 - _____ No, I don't think so
 - _____ No, definitely not

9. Overall, were you satisfied with the outcome of your assessment?

- Yes, definitely
- Yes, I think so
- No, I don't think so
- No, definitely not

10. During the assessment, was the problem solving helpful in addressing your caregiving situation?

- Yes, definitely
- Yes, I think so
- No, I don't think so
- No, definitely not

11. Do the services that you and/or (care recipient's name) receive help you to be a better caregiver? Would you say...?

- Yes, definitely they help a lot
- Yes, they help a little
- No, they don't help
- No, they make things worse

12. Have these services enabled you to provide care for (care recipient's name) for a longer time than would have been possible without these services? Would you say...?

- Yes, definitely
- Yes, I think so
- No, I don't think so
- No, definitely not

In the past year have you received a supplemental service? If yes, in thinking about the supplemental service, would you say:

	Yes, Definitely	Yes, I Think so	No, I Don't think so	No, definitely not	Not Applicable
1. The item purchased helped me provide better care.					
2. The item purchased helped me to feel less stress.					
3. The item purchased helped me to feel less overwhelmed.					
4. I would recommend this service a friend.					

In the past year have you received an in-home educational visit? If yes, in thinking about the visit, would you say:

	Yes, Definitely	Yes, I Think so	No, I Don't think so	No, Definitely not	Not Applicable
1. The educational visit helped me to provide care in a better way.					
2. The educational visit helped me to feel less stress.					
3. The educational visit helped me feel less overwhelmed.					
4. I would recommend an educational visit.					

Overall Assessment of Caregiver Services

	Never	Hardly Ever	Sometimes	Usually	Always
1. Caregiver services help me to have more time for myself.					
2. Caregiver services help me to have a positive relationship with other family members.					
3. Caregiver services help me to have a positive relationship with friends.					
4. Caregiver services have helped me continue paid employment.					
5. Caregiver services help me to continue doing the activities that are important to me.					
6. Caregiver services give me a break without worry.					
7. Caregiver services help me to keep my life as normal as possible.					
8. Caregiver services helped me feel less stress.					

Personal Outcomes

When you began caregiver services, what did you want to happen as a result of being in this program?

Has the program accomplished these goals?

Describe the ways in which the goals have not been accomplished.

APPENDIX C

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CAREGIVERS AS CONSUMERS: PERSPECTIVES ON QUALITY

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Background

Families have historically been the primary provider of long-term care for older Americans. Almost 25 years ago, the General Accounting Office (GAO) estimated that more than 80% of all long-term care was provided by families (GAO, 1977). Since that time, there has been a continued increase in the size of the disabled older population, particularly in the proportion of the oldest old, those who are most likely to need long-term assistance. At the same time, social change such as an increasing number of dual-worker households has changed the family's capacity to provide assistance. The increasingly prevalent role of caregiver requires enormous emotional, physical, and financial efforts, even though it is often willingly undertaken and a source of great personal satisfaction (Kunkel, Applebaum, & Nelson, 2004; Levine, Reinhard, Feinberg, Albert, & Hart, 2004). A recent national survey of older Americans found that more than 7 million caregivers assist more than 4 million disabled older people residing in the community (Administration on Aging [AOA], 2000). Recognizing that families remain the backbone of our long-term care system, the 2000 Older Americans Act established the National Family Caregiver Support Program (NFCSP). Other recent initiatives, including programs that allow family members to be paid for some of the care they are providing and state-funded respite services also speak to the increasing importance of supporting family caregivers.

Caregiver support programs seek to reduce caregiver burden and stress through supportive services and to improve the quality of care the family provides (Greene & Feinberg, 1999). Despite these important goals and the growth in caregiver support services, there has been little work examining the quality of services designed to assist

family caregivers (Kane & Penrod, 1995; Institute of Medicine [IOM], 2000). Even more problematic, efforts to ask caregivers directly about how they view the quality of services have been quite limited. Current in-home care programs have been roundly criticized for largely ignoring the perspectives of consumers, and caregivers appear to have received even less attention than care recipients when it comes to quality assessment (Applebaum, Straker, & Geron, 2000). As the first phase of a study designed to devise a comprehensive quality management system for family caregiver support services, we sought to learn about quality from those who give and receive caregiver support services.

Understanding and Defining Quality

Efforts to ensure the quality of services in the aging network have relied heavily on the traditional quality assurance approach. Under this strategy, a series of quality standards are usually developed by state and/or federal funding agencies; these standards are typically based on monitoring and compliance, emphasizing structural and procedural dimensions of a program such as criminal background checks, number of hours of training, and proper record keeping. Providers receive an inspection or monitoring visit and they are informed about their compliance rate. Questions about how their rate of compliance affects consumers, how they compare to other providers, and how they can improve are rarely included in the review process. In most instances the monitoring of standards focuses on a review of agency records. Direct contact with consumers themselves is generally quite limited. Because of the exclusion of consumers and the lack of an overall improvement strategy, critics have suggested that our efforts to ensure and improve quality need to be modified (IOM, 2001; Kane, Kane, & Ladd, 1998). In the case of caregiver support programs, additional complexity occurs with attempts to define

the consumer, because both caregivers and care receivers are affected by many of the services, such as respite (through adult day services or home care).

The research reported in this chapter was part of a larger Administration on Aging (AoA)-funded project based on the NFCSP in Ohio. Conducted in collaboration with the Ohio Department on Aging and three area agencies on aging, the project focused on the development of NFCSP service quality standards that are caregiver centered and outcomes based. The early stages of NFCSP implementation provided an ideal situation to design a quality system that avoided some of the problems of the monitoring-focused, regulation-based measures commonly used in long-standing programs.

As the first step in the Ohio NFCSP project, we asked consumers about their definitions of quality. A major challenge at this step was to be sensitive to and clear about who the consumer is. As noted earlier, many caregiver support services directly affect the care receiver. For this reason, we included the voices of multiple stakeholders in the project, but kept the focus on caregivers as primary consumers.

Methods

The research question for the first phase was: what are the critical elements of quality as defined by the caregivers and care receivers? Because this question is relatively unexplored and requires depth and intensity of dialogue, a qualitative design was most appropriate. We used focus groups to allow both shared and divergent experiences and perspectives to emerge in the group interview process.

Sample

Eight focus groups of stakeholders (caregivers, care receivers, and caregiver support service providers) were conducted in the state of Ohio, with a total of 52

participants. There was geographic diversity across groups, from rural to urban, covering the four corners and center of the state. Groups were conducted over a 10-week period.

We began with a commitment to conduct focus groups primarily with caregivers but knew it was important to also include care recipients and formal service providers. Sampling for each group was flexible and emergent by design, with the ongoing analysis of the earlier groups informing group composition, questions, and strategies in the later groups. The first four groups were homogeneous by stakeholder type; three of the final four groups were mixed. We began and concluded with all-caregiver groups. Of the 52 participants, 39 were caregivers, seven were providers, and six were care receivers.

Caregiver support services used by participants included information and referral/assistance, transportation, and respite care (in-home and adult day services). For the most part, the groups were heterogeneous by gender, race, age, and care experience; and among caregivers and care receivers, we sought a diversity of caregiver relationships, for example, filial, spousal, and sibling. Caregiver ages ranged from 40 to 94. Caregiving ranged from instrumental, part-time support in separate living arrangements, to co-residential, intimate, 24-hour personal care. Duration of care ranged from less than one year to more than 17 years. Among caregivers, most were women caring for their husbands, followed by daughters and daughters-in-law, and other relatives. Participants were recruited through Area Agencies on Aging and senior centers. Caregiver and care receiver participants received a stipend (\$25.00) for their time and contribution.

Data Collection and Analysis

Semi-structured interview schedules were constructed to broadly explore four central topics: when support services have made a positive difference in the life of a

caregiver, when services (or lack thereof) have had a negative impact on the caregiver, what caregivers hope services will accomplish for them, and how they know (and we can know) when these goals are accomplished. With the exception of the provider group, each group began by asking participants to briefly describe their care experiences and relationships as well as their use of support services. In the rare case when the group dynamic by itself did not cover the four major topics, the interview schedule was used as a default tool. In the provider group, members were asked to identify caregiver needs, service outcomes, and quality indicators.

Each of the focus groups was facilitated by the same researcher. Interviews were audio recorded and transcribed verbatim. Interview texts were the primary data analyzed; observed nonverbal behaviors and dynamics also informed the analysis. We used an open coding method, refining and revising codes within and across interviews, including a constant comparative method. Through this process, we built a conceptual framework for our analysis.

Results

The caregivers, service providers, and care receivers who participated in our focus groups shared with us a range of experiences, emotions, and insights. We asked participants in all groups to tell us about the four central topics mentioned previously. From these questions, caregivers shared stories covering a wide variety of situations, replete with many issues, concerns, examples, and themes. Overall, the focus groups provided us a picture of the strength, adaptability, courage, struggle, and sacrifice that is part of family caregiving. The need for caregiver support was strongly affirmed by the focus groups. The following quotes from three caregivers help to illustrate the challenge

of their roles; these quotes further underscore the importance of developing a system of services that is built on caregiver needs and evaluated based on caregiver outcomes.

“It just seems like everything I have is falling away. And she’s not financially able to pay out a lot. So, I’ve kind of sacrificed myself, and ... you know, to help her.”

“My mother’s ninety-five. She came to live with us temporarily fourteen years ago.”

“We put the monitoring system in her room. Well, she screams so loud that we had to take it out. My husband couldn’t get any sleep to go to work. My granddaughter couldn’t get any sleep to go to school. I haven’t slept in my bed for two and a half years.... I have to set the alarm every two hours. I have to go and turn her.”

In addition to powerful testimonies that underscore the need for caregiver support services, three major categories of information emerged to help us understand caregivers’ conceptions of quality.

1. Quality of life: What do caregivers need to maintain their quality of life?
2. Quality of services: What do services need to do to support caregivers?
3. Quality of the service system: What system organization issues affect the quality of caregiver support?

Quality of Life

Participants helped us understand what was important to them, what they needed to have a good quality of life as a caregiver. These themes can best be summarized as fill-ins for the statement, **To achieve quality of life, I need to:**

Feel OK about myself and my decisions

Participants talked about the need to achieve a sense of peace in their lives and accept the compromises and difficult decisions they have had to make.

Feel OK about the services my care receiver gets

Caregivers discussed the impact of services on their care receiver as a dimension of quality of life. If a worker was coming in to the home, or the care receiver was going to adult day services, it was important to the caregivers to know that the care receiver was OK with these arrangements.

Keep activities at home as normal as possible

Being able to preserve some sense of a normal or usual everyday life at home was important, including sitting down to dinner, working with kids or grandchildren on homework, and having a conversation.

Continue usual roles as much as possible

Caregivers wanted to maintain their social roles as best they could. They identified the importance of maintaining friendships and other family roles, continuing paid or volunteer work, and continuing activities that they deemed important.

Have true respite (vs. simply time off)

This distinction between time off and a true sense of respite or relief reflects caregivers' need to feel some freedom from the stress and responsibility of caregiving. They made it clear that this sense of relief is not always the same (nor can it be evaluated in the same way) as just getting out of the house or having time away from their care receivers. Further details about true respite are discussed in the section on respite services.

Take care of myself

Caregivers discussed the importance of maintaining their physical and mental health. Having time to be alone was mentioned as important.

Know help is there if and when I need it

Caregivers often were hesitant to use help, but knowing that assistance was available was identified as important.

These revelations about caregivers' definitions of quality of life have explicit implications for specific services and implicit implications for the goals that can underlie the design and delivery of services. For example, knowing that it is important for caregivers to "feel OK about myself and my decisions" can be translated into training tips about communication and interaction for home care workers and information and assistance professionals.

Quality of Services

Caregivers, service providers, and care recipients discussed the ways in which services made life better, or failed to make a positive difference in quality of life. Focus group members were asked specifically about three caregiver support services that are commonly offered under the NFCSP: information and assistance, transportation, and respite, both in-home and adult day care. Table 1 provides a listing of the participants' description of quality for these services. We grouped these responses into the following categories: access to services, timing of assistance, information about the care recipient and his or her services, and worker impact.

Access to Services

Before assessing the quality of a caregiver service, an initial step involves making sure the caregiver and care receiver have access to the assistance needed. This may mean knowing the right person to call for information and assistance, that the transportation service is affordable, or whether there is an adult day care center in the area. Access and affordability are service quality issues. Although most quality assurance efforts don't begin until after someone is enrolled in a particular program, the first step in quality is getting the service to those who need it.

Timing of Assistance

A long-standing criticism of in-home services is that services were delivered when it was convenient for the provider, but not necessarily when it worked for the care recipient and caregiver. A consistent theme discussed by caregivers was the importance of getting the service when they needed it. This was especially true as caregivers discussed the concept of respite. Caregivers who need respite to attend a religious or

TABLE 1
Caregiver Views on Quality of Services

Information and assistance support me when...	Transportation supports me when...	“True respite” supports me when...
<p>I have called the one right person (or agency).</p> <p>I feel understood.</p> <p>I am treated with respect and compassion.</p> <p>I get information right away.</p> <p>I get all the information I ask for.</p> <p>I get above and beyond what I ask for.</p> <p>I am not overwhelmed by information.</p> <p>I know what to do next.</p>	<p>I can count on it (it comes and goes on time).</p> <p>It goes where we need to go.</p> <p>It is affordable.</p> <p>It is good for my care receiver.</p> <p>I know my care receiver is safe and comfortable.</p> <p>My care receiver accepts the transportation.</p> <p>The ride is not overlong.</p> <p>The driver demonstrates a caring attitude.</p> <p>The driver goes above and beyond.</p>	<p>Others communicate to me my right to respite, that I deserve a break, that it is normal to need a break.</p> <p>My care receiver accepts or welcomes the respite arrangement.</p> <p>I can count on my break (that it will happen, that it will be uninterrupted).</p> <p>My break is available when I need it most.</p> <p>What I want to happen, happens.</p> <p>My privacy is protected.</p> <p>I know and trust the workers.</p> <p>I believe the workers genuinely care about me and my care receiver.</p> <p>The worker goes above and beyond.</p> <p>The workers know what they are doing.</p> <p>The workers show patience.</p> <p>The workers listen to, respect, and use my input.</p>

social function, or for a health care appointment described needing respite on their schedule, not the providers' schedule. Service availability for evenings and weekends has been a longstanding challenge for service providers.

Information About Care Recipient and His or Her Services

Caregivers discussed the importance of getting the necessary information about service options and also about how the care recipient responded to the services. Being informed was particularly important to caregivers receiving respite services. For example, caregivers described how important it was to them to know about what was happening in the adult day care setting. How was the care recipient doing at the site? Did she seem comfortable and involved? Were there any concerns from the provider perspective? Caregivers indicated that a service was true respite only if it worked for both the caregiver and care recipient.

Worker Impact

Given the intense relationship between the direct care worker and the caregiver and care receiver, it is not surprising that many of the quality comments focused on the workers. Whether the service was transportation, information and assistance, personal care, or adult day care, respondents were consistent about their definitions of a quality worker. Trust, respect, caring, listening, and going above and beyond were words commonly used to describe workers and their contributions to the quality of life of caregivers and care recipients. It was clear that the worker is an essential ingredient in the quality formula.

Quality of the Service System

Although we did not explicitly ask focus group participants to share views about the way the overall system of services (including services for care recipients and those for care receivers), their comments and concerns revealed some complexities in the system that must be considered as we design measures and processes for quality. Following are some of complexities of the system revealed through the focus group discussions.

Caregivers have a critical role in identifying success in program outcomes.

Quality of a caregiver support service begins and ends with the caregiver. The centrality of caregiver voice in defining quality is illustrated in the following statements:

“An outcome is something I am seeking.”

“An outcome has been achieved when I say it has.”

“Quality is what I say it is.”

For a system that has paid limited attention to consumers in general, this focus on caregivers as consumers of services and as experts on the quality of those services represents a significant shift.

Each caregiver and family is different.

Many common themes and issues were discussed across groups and across circumstances, but we also learned about many unique situations. Quality should take into account the variable dynamics, goals, and situations of families and caregivers. Quality can best be understood as the closest fit between what is needed and sought and what is communicated and provided.

The caregiver is part of a family system.

No matter how, why, or to whom we think we are *delivering* services, nearly all services are *received* by families. For example, home-delivered meals are designed,

delivered, and assessed as a service to care receivers. However, many caregivers mentioned this service as a source of respite for them. Understanding the impact of any service on the entire family is essential. It is equally important to consider the complementary, competing, or conflicting goals for all family members who are affected by services. Adding to the complexity of services and recipients, it is important to keep in mind that one family may have multiple caregivers and/or multiple care receivers. High-quality services must necessarily be the outcome of well-negotiated family decisions.

Services may add stress and costs.

Services induce costs for families, including financial costs, loss of privacy, and loss of control. Services can also introduce or exacerbate stress, especially when the system is confusing, stigmatizing, and intrusive. For services to be regarded as high quality, the value of the service must outweigh its stressors or costs. One focus group member illustrated this point when she said, “Out of the [two-week respite] I may have had three to four days where I could probably put it out of my mind and really try to rest. The rest of the time you’re concerned about, you know, what’s happening with her.”

Services are experienced in stages.

Caregivers and families become involved with the service system in stages, including awareness of the service, making an initial contact, initiating service, transitioning into a new kind or new level of service, and terminating the service. Needs and expectations change according to these stages. Each stage has its own quality issues.

Family circumstances (functional health, resources, family composition, and perspectives) change.

The needs, goals, and expectations of the caregiver and the family change as circumstances change. Because of this dynamic situation, quality systems have to be built to be flexible, so that quality assessment and improvement efforts can accommodate a moving target.

Summary: Caregivers as Consumers and as Experts on Quality

These focus groups provided invaluable insights into understanding quality and its relationship to maintaining care at home. The caregiver stories, their insights, and their challenges, helped us understand the many dimensions and definitions of quality of services and quality of life. Perhaps most importantly, their words helped us sharpen our focus; they helped us to understand what it really means to focus on caregivers, with all that implies in terms of multiple, mutual, and sometimes conflicting needs and agendas played out in the emotional arena of a family trying to do what is best. Family caregivers have generally been recognized as an important part of the aging network, but they have often been the invisible foundation of the system rather than as active consumers and participants. These focus groups reinforced the fact that caregivers are in the center of the picture, right next to the care recipient.

To integrate this perspective into a quality management model requires answers to very specific questions about the measurement of quality: How is quality defined? What questions are asked to assess quality? Of whom and by whom are these questions asked? How are these data used to improve services? An integrated approach to quality requires a balance among family, individual, and regulatory agendas. An integrated quality model also requires a dialog among all of the stakeholders in the quality process (families, consumers, providers, and public agency administrators) to identify, formalize, and

reinforce new common ground and shared agendas in the definition and measurement of the quality of caregiver support services.

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