

VI. WORKING WITH FAMILIES AND OTHER CAREGIVERS

This chapter provides information to help understand the family and the caregiver context, the application of caregiver assessment and care management, and caregiver use of the formal service system.

When designing and implementing family interventions, the objective is to emphasize the family strengths and resources and build on existing resources, rather than focusing on problems and weaknesses. Likewise, caregiver system developments and enhancements must support and not disturb the “fabric of the family relationship.”¹

UNDERSTANDING THE FAMILY

The National Family Caregiver Support Program (NFCSP) calls for the aging network to expand its focus to support caregivers as direct consumers—with needs distinct from, but circumstances intertwined with, the care recipient. The broad definition of *family caregiver* under the NFCSP allows flexibility in supporting the needs of those who care for close family members, other relatives, friends, neighbors, domestic partners, and others. It involves working with individual caregivers and with families.

In working with families, the network should consider the following set of reminders, developed by Lisa Gwyther.²

Basic Concepts

- Family care is an adaptive challenge; the family is not necessarily the problem.
- The family is rarely a single voice, and few families have only one person needing care at a time.
- No one right or ideal way or place to offer family care exists. Many families are forced to choose among equally unacceptable options.
- No perfectly fair and equal division of family care responsibility exists. Families can expect a permanent imbalance in the normal give and take of family relationships but still work toward a more equitable sharing of responsibility.

¹ McGuire, D. AoACarenet Listserv, April 30, 2001.

² Adapted from Gwyther, L. Caregiver Counseling, Education and Support Groups, October 15, 2001.

Elements for Success

- Successful family caregivers are flexible in adjusting expectations of themselves, the dependent elder, and other family members to fit needs and capacity of all.
- Coping with family care requires a sense of humor, a strong faith or value system, creativity, practical problem-solving skills, and support from friends and family.
- Successful family caregivers gather information, take direct action when possible, and often reframe in more positive terms things they cannot change.

Challenges

- Underreporting of burden and underuse of services is common among caregivers.
- A family caregiver's knowledge of, need for, and access to an available service do not necessarily lead to appropriate timely use of services.
- No bad defense mechanisms exist. Some people need to deny the inevitable outcome (i.e., loss of a loved relative) to provide hopeful, consistent care.
- No perfect control exists in a care situation. Families are better off if they work on their reactions to stress or lack of control. Even in ideal situations, contingency plans are necessary.

UNDERSTANDING THE CAREGIVER CONTEXT

Caregiver situations vary, and different situations require different interventions. To support caregivers effectively with the right services at the “servable moment,” the network must understand and appropriately respond to the unique caregiving situation.³ The network must be prepared to address savvy caregivers as well as caregivers who harbor misconceptions about service coordination. Caregiving circumstances can affect the quality of information exchange and ultimate service delivery.

Exhibit VI.1 depicts the following elements, which circumscribe the major dimensions of the caregiving context to consider when working with caregivers.

Contextual Dimension

- Relationship of the caregiver and care recipient (spouse, adult child, in-law, grandparent, grandchild, friend)
- Location of the caregiver relative to the care recipient (co-residence, nearby, long-distance)
- Family values and beliefs (cultural background)
- Health of the caregiver (physical, mental, social)

³ Montgomery, R.J.V. Presentation at the U.S. Administration on Aging Conference, *National Family Caregiver Support Program: From Enactment to Action*, September 6, 2001.

- Nature of previous family relationships (conflicted, distant, estranged, nurturing, supportive)

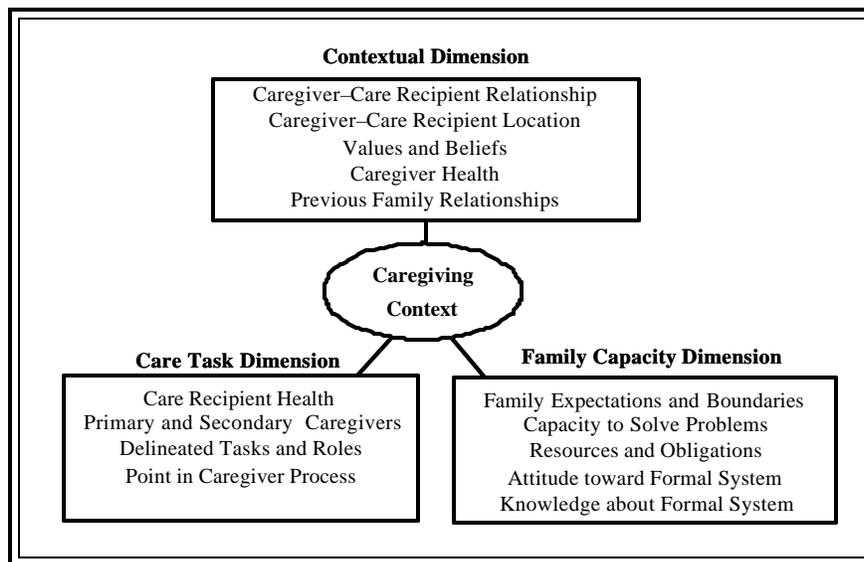
Care Task Dimension

- Health of the care recipient (conditions, cognitive, functional, and behavioral strengths and deficits)
- Existence of both primary and secondary caregivers (decision-making and perception of who is in charge)
- Sharing of caregiving tasks and delineation of roles (structure to accomplish caregiving tasks)
- Point in the caregiving process and the caregiver’s receptivity to support (see discussion of Montgomery’s “marker framework” in *Chapter III*).

Family Capacity Dimension

- Underlying family expectations and boundaries (inclusion and exclusion of family members)
- Family capacity to solve problems (ability to identify and discuss problems, explore alternative solutions, and resolve problems)
- Available resources and caregiver obligations (work, caring for others, income, informal resources)
- Family attitude toward the formal service delivery system (factors include culture, ethnicity, religion, socioeconomic status, geography, past experience, and others)
- Caregiver’s knowledge about the formal service delivery system (how it operates, service coordination)

**Exhibit VI.1
Dimensions of the Caregiving Context**



CAREGIVER ASSESSMENT

Conducting a caregiver assessment formally captures information on the caregiving context and institutionalizes the acts of listening to and directly supporting caregivers. It reinforces the program goal to expand the network focus on caregivers and families. Caregiver assessments “clarify the nature of the caregiving situation both in terms of the caregiver’s characteristics and competing demands, and the care recipient’s characteristics that influence the caregiving experience.”⁴ Using an assessment instrument might support collection of demographic data on caregivers served by the program, help to ensure uniform procedures are followed, and assist agencies in making fair decisions about resource allocation when the demand for services exceeds the supply. Furthermore, assessments aid in evaluating service effectiveness and continuous quality improvement.

Some of the common reasons given for not pursuing caregiver assessments include: 1) burden in the amount of time needed to complete the assessment (service provider and caregiver burden), 2) hampered ability to develop trust and rapport with caregivers and care recipients (probing questions before reaching a level of comfort), and 3) interference with the natural flow of the clinical process (available interventions cannot address caregivers’ concerns, or issues are raised prematurely).⁵ *Exhibit VI.4* at the end of this chapter offers tips that can help minimize these concerns. Regardless of whether an agency decides to adopt a caregiver assessment instrument, an inevitable challenge will arise in working with frustrated or skeptical caregivers who might have completed assessments in the past as part of the care recipient’s care but received no intervention addressing their own expressed concerns, expectations, or preferences.

Agencies considering the use of caregiver assessments will have to: 1) establish the constructs to be included in the assessment, 2) design the instrument, and 3) develop implementation procedures.⁶

Constructs of Existing Assessment Instruments

The major domains of caregiver assessments often include:

- Caregiver well-being and health;
- Health, functional status, preferences, and behaviors of care recipients;
- Level of care, skills, supervision, or tasks required to care for recipient;

⁴ Guberman, N., Keefe, J., Fancy, P., Nahmiash, D., and Barylak, L. (2001). *Assessment Tools Serving the Needs of Caregivers: A Document to Better Understand the Importance of Assessing Caregivers’ Needs*. Project funded by the Health Transition Fund of Health, Canada.

⁵ Bass, D. (2002). *Content and Implementation of a Caregiver Assessment*. Issue brief prepared for the U.S. Administration on Aging. Available at <http://www.aoa.gov/carenetwork/issuebriefs.html>.

⁶ Bass, D. (2002). *Content and Implementation of a Caregiver Assessment*. Issue brief prepared for the U.S. Administration on Aging. Available at <http://www.aoa.gov/carenetwork/issuebriefs.html>.

- Negative caregiving consequences;
- Caregiver strengths; and
- Informal and formal network of support for care recipients and caregivers.

Many researchers and practitioners also include the construct of caregiver burden in caregiver assessments. Most measures of caregiver burden recognize that burden is multidimensional and includes both subjective and objective dimensions. Steven Zarit's caregiver burden scale focuses on the intra- and interpersonal experiences of the caregiver. Most multidimensional scales have two drawbacks: 1) they tend to be lengthy (possibly causing respondent fatigue and aversion to seeking further assistance) and 2) they are unvalidated for use with culturally and ethnically diverse caregiver populations.⁷

Assessing the functioning of families as caregiving systems is another possible component of a caregiver assessment. In this case, the focus is on family processes around caregiving and the perception of family support. Gathering information about the network of family and friends is critical for interventions designed to support and mobilize the informal care network.⁸

Exhibit VI.2 showcases several instruments for assessing caregivers. A helpful resource for the network, scheduled for release in July 2002, is a "promising practices" monograph on caregiver assessment prepared by the Family Caregiver Alliance's National Center on Caregiving. The monograph will discuss caregiver assessment issues from a practice perspective. It will include a brief history of caregiver assessment, cover the importance of assessing the needs and situation of the family or informal caregiver, summarize existing caregiver measures, identify "best practice" criteria for caregiver assessment tools, and discuss how caregiver assessments can be used to inform policy and practice. Information about its release will be posted on the Family Caregiver Alliance Web site at <http://www.caregiver.org/>.

⁷ Gupta, R. (1999). The Revised Caregiver Burden Scale: A Preliminary Evaluation. In *Research on Social Work Practice*. 9(4): 508–520. Sage Publications, Inc.

⁸ Bass, D. (2002). *Content and Implementation of a Caregiver Assessment*. Issue brief prepared for the U.S. Administration on Aging. Available at <http://www.aoa.gov/carenetwork/issuebriefs.html>.

Exhibit VI.2 Caregiver Assessment Instruments

California Caregiver Assessment Tool and Instruction Manual

These assessment materials were developed by the Family Caregiver Alliance (FCA) and are used by the state's Caregiver Resource Centers to examine the needs of families caring for adults who suffer from chronic brain disorders. FCA conducts thorough training for all staff who administer the assessment. Direct requests for the instrument and instruction manual to Lana Sheridan, Family Caregiver Alliance, National Center on Caregiving, 690 Market Street, Suite 600, San Francisco, CA 94104. Your request should include a check for \$25 to cover the cost of printing, handling, and shipping.

Pennsylvania Department on Aging Caregiver Assessment

The caregiver assessment is part of Pennsylvania's Comprehensive Options Assessment Instrument used for home- and community-based programs for older adult care recipients. A practical, user-friendly assessment, it captures information about the informal support network and more detailed information about the primary caregiver. It includes a modified version of Steven Zarit's Caregiver Stress Interview along with scoring instructions. Forms and instructions are provided on AoA's Web site at <http://www.aoa.gov/carenetwork/Tools.html>.

Caregiver Risk Screen and Caregiver Assessment Tool

Nancy Guberman and colleagues developed these tools and presented them at the 2001 GSA conference. The screen is a simple, validated instrument that can be used by the aging network, medical clinics, and others. It is designed to: 1) rapidly and systematically give a concise picture of the caregiver's situation; 2) evaluate the level of risk to the caregiver's mental and physical health as a result of caregiving; and 3) evaluate whether the care is adequate. The assessment tool is a longer, validated, multidimensional instrument designed to evaluate the conditions and needs of caregivers by gathering information from the caregiver's perspective and allowing the assessor to add his or her own comments. The tool is intended to be adapted to the specific situation of the caregiver, and therefore it depends on what sections the caregiver wants to cover. It need not be completed in one session. A user guide appears on the facing pages of the tool to provide further context and examples. For more information, contact Nancy Guberman at guberman.nancy@uquam.ca or Janice Keefe at janice.keefe@msvu.ca.

AMA Caregiver Self-Assessment Questionnaire

The caregivers self-assessment tool, with instructions for use, was developed and tested for distribution to physician offices by Dr. Joanne Schwartzberg. It contains 16 Yes/No items and two global scale items designed to measure indices of emotional and physical distress. English and Spanish versions of the instrument are available on the AMA's Web site at: <http://www.ama-assn.org/ama/pub/category/4642.html>.

University of Wisconsin Family Assessment Caregiver Scale

This 21-item scale looks at the functioning of the family as a caregiving unit. It consists of five dimensions of family functioning relevant to caregiving: validation, family of origin, problem-solving, roles, and boundaries. The tool was developed to assess family processes around caregiving and should be viewed only as one component of a total caregiver assessment. This information appeared in Greenberg, J.R., Monson, T., and Gesino, J. (1993). Development of the University of Wisconsin Family Assessment Caregiver Scale: A New Measure to Assess Families Caring for Frail Elderly Members. *Journal of Gerontological Social Work*. 19(3/4): 49-68.

Assessment Design

The major factors to consider when designing and using a caregiver assessment are as follows:

- Is the tool for one primary caregiver with one primary adult care recipient?
- Is the tool for more than one primary caregiver?
- Is the tool adaptable for unique caregiver situations?
- Is the tool multidimensional?
- Does the tool take into account the caregiver's perspective?
- Is the tool appropriate for ethnically and culturally diverse caregivers?
- How long is the tool, and how much time does it take to administer it?
- How can the tool be integrated with existing tools?^{9,10}

Building on available measures and existing tools and modifying them to align with specific program goals is more practical than starting from scratch. In designing an assessment, the network should consider involving clinical and direct service staff. Caregiver assessments may be derived from multiple sources, such as direct questioning of caregivers and care recipients, observation, performance testing, and self-administered questionnaires. Caregiver strain, for example, can be measured during an interview or in a self-administered form. Information on informal support can be collected through picture drawings. Assessment experts recommend including an assessment feature that can capture the source of information (e.g., direct observation versus caregiver responses) and the collection method (e.g., self-administered versus clinical interview) in the instance when multiple collection procedures are adopted.¹¹

Assessment Implementation

David Bass notes in his issue brief that although many sources can be used to construct an assessment, less is known about successful implementation. The network should consider approaches that minimize burden and create realistic expectations about the level of support that could be provided. He offered the following tips for the network in designing and implementing a useful assessment.

Flexibility in Timing and Methods

- Allow some flexibility in the timing of when the information is collected.

⁹ Guberman, N., Keefe, J., Fancey, P., Nahmiash, D., and Barylak, L. (2001). *Assessment Tools Serving the Needs of Caregivers: A Document to Better Understand the Importance of Assessing Caregivers' Needs*. Project funded by the Health Transition Fund of Health, Canada.

¹⁰ Bass, D. Presentation at the U.S. Administration on Aging Conference, *National Family Caregiver Support Program: From Enactment to Action*, September 6, 2001.

¹¹ Bass, D. (2002). *Content and Implementation of a Caregiver Assessment*. Issue brief prepared for the U.S. Administration on Aging. Available at <http://www.aoa.gov/carenetwork/issuebriefs.html>.

- Allow flexibility in the method used to collect the information (e.g., structured questions, observation, extracted from clinical interview, provided by an informant).
- Decide if certain parts of the assessment can be self-administered by caregivers.

Striving for Short and Simple

- Eliminate redundant information, avoiding overlap with care recipient assessment. However, some subjective information that is redundant between the caregiver and the care recipient is helpful to reflect important differences.
- Simplify answer categories, and use only items essential for a valid and reliable measure of each characteristic.
- Control the length of the assessment by using a filter question and dividing the assessment into sections—some parts for all caregivers and other parts for caregivers with certain characteristics (e.g., spouse caregivers, working caregivers).

Utility of the Information

- Analyze assessment information, and provide the results to those completing the information.
- Directly link the assessment, care plan, and reassessment so assessment information is used to guide service delivery.
- Consider use of information technology that can help streamline the process.¹²

The longer the assessment, the more difficult and time consuming it will be to use. Practical assessments should be developed that are limited to the essential items for designing a care plan, delivering interventions, and evaluating outcomes. Items most likely to inform outcomes are those that change over time from the baseline assessment to reassessments (e.g., caregiver strain, caregiving mastery, family members' involvement in caregiving, social isolation). Improvements in outcomes are more likely when: 1) the initial assessment indicates some type of problem, 2) appropriate timing and dosing of the intervention occurs after the initial assessment, and 3) the expected outcomes and goals of the intervention are closely aligned.

In addition, the network is encouraged to consider adopting a statewide assessment that is implemented in a standardized fashion for all caregivers. This kind of assessment allows similar information to be collected and analyzed across programs so evaluators can draw meaningful conclusions about overall program effectiveness. (See *Chapter V* for further information about evaluating program effectiveness.) The development of a statewide assessment does not preclude acknowledging local innovation because it could require certain common elements and then permit Area Agencies on Aging (AAA) to add their own items that match local program goals.

¹² Bass, D. Presentation at the U.S. Administration on Aging Conference, *National Family Caregiver Support Program: From Enactment to Action*, September 6, 2001.

Lastly, a direct link between the assessment, care plan, and reassessment is important to guide service delivery. Done effectively, care planning helps clarify roles, sources of care, financial limitations, need for care, service priorities, and expectations.¹³ Care planning should be a collaborative process among caregivers, care recipients, and service coordinators.

CARE MANAGEMENT-SUPPORT COORDINATION FOR CAREGIVERS

Roles and Skill Sets

Supporting caregivers and families requires a shift in how the care management system currently operates. Although our current system often acknowledges the caregiver as an important customer, it has not treated them as clients in need of formal services. Even the term “care manager” might need replacing with more appropriate terminology of support coordination.¹⁴ For example, some of the existing caregiver programs use the terms “caregiver consultant” or “support specialist,” emphasizing the caregivers’ decision-making role. This section uses the term “support coordinator” to reflect the NFCSP’s ideals of caregiver empowerment.

Support coordinators can play an important role in supporting caregivers under the NFCSP in the following ways:¹⁵

- Teacher – providing timely, appropriate, dosed, and relevant information specific to the caregiving situation
- Networker – linking families to needed formal and informal resources for both the caregiver and the care recipient
- Counselor, Validator, and Advocate – supporting caregivers through acknowledgment, absolution, encouragement, and decisional support
- Family Guide – navigating families through the maze of eligibility requirements, service definitions, and funding

Linda Noelker notes that the extent to which the caregiver is capable of and willing to access, coordinate, and monitor services largely affects the role of the support coordinator.¹⁶ When caregivers are capable of assuming all of these functions, the support coordinator acts as a *family/caregiver consultant*. When the caregiver’s ability is limited by disability or family conflict, the support coordinator takes on a more active

¹³ Bass, D. (2002). *Content and Implementation of a Caregiver Assessment*. Issue brief prepared for the U.S. Administration on Aging. Available at <http://www.aoa.gov/carenetwork/issuebriefs.html>.

¹⁴ The disability community has adopted more contemporary terminology, and collaboration between the networks would be beneficial in enhancing support coordination strategies.

¹⁵ Gwyther, L. Presentation at the U.S. Administration on Aging Conference, *National Family Caregiver Support Program: From Enactment to Action*, September 6, 2001.

¹⁶ Noelker, L. (2002). *Case Management for Caregivers*. Issue brief prepared for the U.S. Administration on Aging. Available at <http://www.aoa.gov/carenetwork/issuebriefs.html>.

coordinator role. Lastly, when the caregiver cannot take responsibility for any of these tasks, the support coordinator assumes the role of a *manager*.

In interacting with caregivers, support coordinators must be particularly skilled at empathetic listening, engaging family caregivers in the service coordination process, and integrating caregivers into the care system. Family participation in the decision-making process constitutes a critical piece to realizing the goals of a caregiver-focused program. Experience shows that responding to caregivers' preferences and setting clear expectations are the key determinants of caregiver satisfaction. The support coordinator must, therefore, be a skilled objective and subjective listener and be able to suggest appropriate resources to enhance what the family is considering based on the family's unique preferences. Furthermore, support coordinators assume responsibility for consulting with service providers to improve service quality based on feedback from caregivers and care recipients.¹⁷

Support coordinators should be able to assess family dynamics and assist caregivers with: 1) maintaining family communication and the exchange of information, 2) balancing the needs of the care recipient with the needs of other family members, 3) managing feelings toward family members who fail to help, 4) maintaining the family as an effective decision-making group over the long term, and 5) asking for help from other family members when necessary.¹⁸

A great tension exists between two goals of our long-term care system: to reduce caregiver burden and stress and to maximize the length of stay of seniors in the community. The goal of maximizing length of stay in the community is often achieved at the expense of the caregivers' quality of life. A significant proportion of families experience family conflict associated with caregiving, particularly around the issue of timing of formal service use or institutional placement. Therefore, providing caregiver support services early in the caregiver's career and being able to identify and respond at the servable moment is critical. If caregivers come in contact with the system only after they have exhausted all their physical and emotional reserves and institutional placement is the only option they are willing to consider, this conflict between the two values in our system emerges. The NFCSP provides an opportunity for the network to play an important role in helping minimize the conflict through the provision of timely and accurate information and caregiver support. In doing so, support coordinators must be able to help families make decisions that consider both the care recipients' and caregivers' needs and preferences.

Working with caregivers of persons with dementia requires additional skills. Support coordinators often can establish effective communication with these caregivers through

¹⁷ Noelker, L. (2002). *Case Management for Caregivers*. Issue brief prepared for the U.S. Administration on Aging. Available at <http://www.aoa.gov/carenetwork/issuebriefs.html>.

¹⁸ Toseland, R.W. and Smith, T. (2001). *Supporting Caregivers Through Education and Training*. Issue brief prepared for the U.S. Administration on Aging. Available at <http://www.aoa.gov/carenetwork/issuebriefs.html>.

continued reiteration and processing over time.¹⁹ Support coordinators should be prepared to assess both the primary caregiver and other family members for their ability to accept recent diagnoses and other changes to come. Assisting the caregiver and care recipient with care decisions becomes a particularly delicate issue when the care recipient with cognitive impairments might be unable to make decisions and voice his or her preferences. The research suggests that it might be useful for families and support coordinators to incorporate a structured values assessment around the issues of daily care preferences at home to improve understanding and enhance communication between the caregiver and the care recipient.²⁰

Zarit, Whitlatch, and Femia are designing and evaluating an intervention to help families in the early stages of dementia or other cognitive impairments.²¹ The goals of this intervention study, funded by the NFCSP, are to: 1) develop positive communication patterns between the caregiver and the care recipient; 2) increase knowledge and understanding of available services, preferences for care, and care values; and 3) increase the care recipient's active participation in his or her care plan. Anticipated outcomes of this intervention are that caregivers and care recipients experience improved well-being and self-esteem and an increased sense of self-efficacy in managing the consequences of cognitive impairments.

Care Management - Support Coordination Infrastructure

If formal support coordination of caregivers is pursued, care management systems for caregivers must depart from the traditional caseload model and move toward a model that supports families coming in and out of the system of care over many years, based on their strengths, needs, and resources, which change over time. Considerations of the aging network in implementing support coordination for caregivers include:

Structure

Agencies must decide which is more beneficial: merging support coordination systems (support coordinators assisting both caregivers and care recipients) or keeping those roles separate (caregiver support coordinator and care recipient support coordinator) and the level of integration between information and assistance (I&A) and care coordination. Some members of the network argue that a separate structure might allow the caregiver to receive more focused and specialized attention. Others assert that the relationship between the caregiver and care recipient is intimately intertwined and that separating the two could undermine the goal of an integrated care plan with support coordinators at

¹⁹ Cummings, S.M. (1996). Spousal Caregivers of Early State Alzheimer's Patients: A Psychoeducational Support Group Model. *Journal of Gerontology*. 55B(3): 163–172.

²⁰ Whitlatch, C.J. (2001). *Consumer Direction for Family Caregivers and Care Recipients: Challenges and Opportunities*. Issue brief prepared for the U.S. Administration on Aging. Available at <http://www.aoa.gov/carenetwork/issuebriefs.html>.

²¹ Zarit, S.H., Whitlatch, C.J., and Femia, E. (2001). Early Diagnosis of Dementia: Dyadic Counseling for Family Caregivers and Patients. Research grant in progress funded by the U.S. Administration on Aging's National Family Caregiver Support Program.

cross purposes. A combined approach might be more practical in pursuing coordinated assessment, care planning, and service monitoring activities through understood priorities, goals, and desired interventions for the family.²² **Exhibit VI.3** presents several examples of a combined approach.

Standards

Organizational culture, governance, and caregiver input likely will drive standards for caregiver support coordination. For example, the New Jersey Easy Access, Single Entry system (see **Chapter VII, Exhibit VII.10**) includes both county service coordination protocols and state performance standards (organizational, process, outcome, reliability, and validity testing). Key components of support coordination standards include the definition, eligibility/closure criteria, support coordination volume, and caregiver rights and responsibilities.

Recipient of Support Coordination

Agencies must examine their program objectives (e.g., serve as many caregivers as possible, prevent health problems/negative effects by targeting caregivers most at risk, delay/prevent institutionalization of care recipients) and decide which caregivers formal support coordination will support. Gwyther recommended that the aging network target support coordination for the most vulnerable caregivers (“high-risk family care”). Possible target populations include frail, older spouse caregiver; existence of caregiver stress, ignorance, or apathy; presumed unintentional neglect or other abuse; history of conflict or estranged relationships; family financial situation; and combative, disruptive care recipient.²³

Caregiver Outcomes

Agencies must consider what outcomes they hope to achieve through support coordination. Possible outcomes include caregiver health; appropriate, timely use of help; reduction of passive neglect, abuse, stress; increased effectiveness of care and coping; increased satisfaction with preferred level of involvement; decreased negative consequences on family; and minimized family conflict.²⁴ Support coordinators play a role in monitoring outcomes of support coordination itself as well as the quality of outcomes of other services used by the caregiver and care recipient.²⁵

²² See Noelker’s issue brief, Case Management for Caregivers, at <http://www.aoa.gov/carenetwork/issuebriefs.html> for a more detailed discussion of this matter.

²³ Gwyther, L. Presentation at the U.S. Administration on Aging Conference, *National Family Caregiver Support Program: From Enactment to Action*, September 6, 2001.

²⁴ Gwyther, L. Presentation at the U.S. Administration on Aging Conference, *National Family Caregiver Support Program: From Enactment to Action*, September 6, 2001.

²⁵ Noelker, L. (2002). *Case Management for Caregivers*. Issue brief prepared for the U.S. Administration on Aging. Available at <http://www.aoa.gov/carenetwork/issuebriefs.html>.

Technology Applications

Agencies might want to assess technology options that could facilitate efficiencies in support coordination. Some applications might include technology that assists in capturing data, improves communication between support coordinators and caregivers as well as with service providers, and enables real-time access to service information and available resources. The use of laptop computers at home visits could be beneficial for capturing information from the assessment.

Exhibit VI.3 Combined Support Coordination at the Local Level

Combining the Components of Information with Assistance

Pierce County Aging and Long Term Care (AAA in Washington) established a new fulltime Family Caregiver Support Specialist position within the existing agency Case Management In-House Team. This position provides information and outreach to caregivers and the community and assists caregivers in accessing available services.

Combining Caregiver and Care Recipient Coordination

Eastern Agency on Aging (AAA in Maine) plans to establish “care teams” comprising a Community Service Consultant and a Family Caregiver Specialist to provide a holistic approach to serve both the caregiver and the care recipient.

In Pennsylvania’s experience, the Family Caregiver Support Program demonstration included a separate system of both assessment and care management for caregivers. When the program went statewide, the integration of these systems was thought to be much more practical. Officials in Pennsylvania noted that this approach vastly improved caregivers’ portability throughout the system as their needs changed.

CAREGIVERS’ USE OF FORMAL SERVICES

We must learn how to better integrate our formal services into family caregiving so that we can maximize the effect of both. This shift in approach focuses on helping families decide how best to integrate supportive services to complement and supplement their informal caregiving, rather than determining when and how to intervene when families can no longer care for their own. With this perspective, the family caregiver is the “key provider” [partner], not just a service recipient or client.²⁶

Services should be designed and implemented in a way that meets the needs and preferences of different types of caregivers. The services must be marketed to the appropriate groups at the point that the groups are receptive to using the services. If caregivers are too frail themselves to attend programs outside the home, for example, the system must offer alternative options and communicate them effectively to caregivers.

How caregivers perceive access, red tape, expectations, and benefits greatly influences their willingness to seek formal assistance. Past experience, particularly for long-term

²⁶ Taken from the North Carolina Division on Aging slide presentation, *North Carolina Moves Forward for Caregiver Information and Support*. Slide 10.

caregivers, likely will influence caregivers' receptivity to new interventions.²⁷ A common attitudinal barrier in many rural communities is the reluctance to seek community-based services because they are seen as welfare or handouts as well as a perceived stigma associated with the use of mental health or counseling services. Some common program-related barriers for the network to alter include poorly publicized programs, programs perceived as involving too much red tape, and programs with restrictions such as those that are means tested.

Culture also influences how families interact with the formal system. In many African American families, for example, when some members want to receive paid help but elders refuse it, the family members generally respect their wishes, unless the care burden becomes so great that a nursing home is the next choice.²⁸ As another example, some Indians and Pakistanis seem reluctant to talk about personal issues outside the family because they consider it shameful to do so.²⁹ Certainly caregivers' racial and ethnic backgrounds can affect the caregiving situation and are factors to consider in assessing and addressing their needs. However, these cultural factors must be considered along with the caregiving context (e.g., adjustment levels, family functioning, availability of extended family support) to fully address the unique needs for a particular family.³⁰ (See *Chapter VIII* for further information about planning and implementing programs that support ethnically and culturally diverse caregivers).

Gwyther notes family caregivers want the formal system to provide relevant information, acknowledgement, reminders or tips, absolution, and decisional support.³¹ The aging network has a role in assisting caregivers in identifying personal and community resources, formal and informal supports. *Exhibit VI.4* presents tips for encouraging families to accept assistance.

²⁷ Bass, D. (2002). *Content and Implementation of a Caregiver Assessment*. Issue brief prepared for the U.S. Administration on Aging. Available at <http://www.aoa.gov/carenetwork/issuebriefs.html>.

²⁸ Taken from Metropolitan AAA/Minnesota Minority Service issue brief, August 9, 2001.

²⁹ Gupta, R., (1999). The Revised Caregiver Burden Scale: A Preliminary Evaluation. In *Research on Social Work Practice*. 9(4): 508–520. Sage Publications, Inc.

³⁰ Toseland, R.W. and Smith, T. (2001). *Supporting Caregivers Through Education and Training*. Issue brief prepared for the U.S. Administration on Aging. Available at <http://www.aoa.gov/carenetwork/issuebriefs.html>.

³¹ Gwyther, L. Presentation at the U.S. Administration on Aging Conference, *National Family Caregiver Support Program: From Enactment to Action*, September 6, 2001.

Exhibit VI.4

Tips for Encouraging Families to Accept Assistance

Offer Emotional Support

- Acknowledge what is working in the family caregiver's plan.
- Normalize initial reluctance (fears, stigma) to seek help. Allow time for the family to express fears and talk about barriers.

Realistically Educate

- Suggest to the caregiver how proposed services might benefit the elder (personal relevance and timing).
- Do not oversell the services or outcomes.
- Correct misconceptions about service use and eligibility.

Seek Outside Reinforcement

- Suggest that the family talk to a current family caregiver user of the service.
- Have physician, clergy, or trusted family friend reinforce service use.

Tailor Services to Family Circumstances

- Recognize the family's comfort level and seek informal, volunteer, low-cost, subsidized, or alternative payment services before more formal assistance.
- Offer only one change in service use at a time.
- Match providers with the consumers carefully, and offer an alternate if the match fails to work.
- Use culturally sensitive and jargon-free service descriptions.

Source: Adapted from Gwyther, L. Caregiver Counseling, Education and Support Groups, October 15, 2001.