

# **CASE MANAGEMENT FOR CAREGIVERS**

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This section addresses the definition, goals, and functions of case management. It examines the issues related to providing this service to family caregivers. Next, models and outcomes of case management practice for caregivers are discussed. It concludes with recommendations to maximize the benefits of caregiver services based on the results of evaluation research.

## **DEFINING CASE MANAGEMENT**

The goal of case management is to ensure that the caregiver and care receiver have assistance identifying their needs and accessing related services on an individual or “case-by-case” basis and, at the same time, make most appropriate use of limited resources. Case management evolved as one approach to overcome systemic problems with health and social services, namely, fragmentation. Service fragmentation poses severe challenges for persons with multiple and complex care needs. For this reason, case management generally is targeted to special populations considered “at risk” because their needs are unlikely to be met without professional intervention and oversight.

There is no consensus on a definition for case management and the terms case management, care management and service coordination have been used interchangeably (Kleyman, 2001). In this report, the term case management is used. Although there is no agreement on a definition for case management, there appears to be consensus on the key functions performed by case managers.

## **KEY FUNCTIONS OF CASE MANAGERS**

The key functions of case managers have been outlined by various researchers and clinicians (as examples, see White and Gundrum, 2001; Lowenstein, 2000) and include case identification, assessment, care plan design and implementation, service monitoring, and quality assurance. How the functions are performed varies by the type of provider organization, the case management model used, the discipline of the provider, and the way services are financed. Because the assessment function is given extensive treatment in another issue brief, it is addressed only briefly here.

### **Case Identification**

It is essential to define carefully both the target population of caregivers and their needs and the corresponding resources and services available in a specific locale to meet those needs. Without careful definition, case managers will not be able to successfully conduct outreach activities, make good use of referral sources, and have a complete and accurate resource/service directory for arranging and coordinating services.

Intake criteria based on the defined target population’s characteristics should be established so that caregivers who do not meet the criteria are screened out. When case management organizations set out to serve family caregivers, they must be clear about their objectives: Is it to serve as many caregivers as possible? Is it to prevent health problems or other negative effects by targeting caregivers who are most at risk? Is it to keep care receivers out of high-cost residential care or minimize their use of formal services by targeting caregivers most

likely to give up their role or those caring for persons who could not live at home with the caregiver's help? These are mission and policy issues that should form the basis of an agency's strategic approach to targeting and serving caregivers.

A central issue in case identification is whether caregivers should receive case management services separate from the care receiver or whether the caregiver-care receiver dyad should be defined as the case. The argument for a separate case manager is that the caregiver's needs and concerns would receive more focused attention. The case manager also would have expert knowledge about caregiver problems and concerns, how to assess them with specialized tools, and expertise in services and interventions designed for caregivers.

There are several arguments why the caregiver and care receiver should be approached as a dyad. First, their relationship is intimately intertwined and the needs of one are closely linked to the needs of the other. In fact, in a number of situations, particularly those involving older couples, the case manager is often challenged to distinguish who is the caregiver and who is the care receiver because both are equally impaired and provide help to each other. Second, caregivers often take responsibility for the care receiver's use of services by contacting service agencies to obtain assistance and arranging for and monitoring services, or they may share these responsibilities with the care receiver's case manager. Third, the services provided to the care receiver often are intended to benefit the caregiver as well; for example, while the care receiver receives socialization at an adult day program, the caregiver receives respite. Lastly, if the caregiver and care receiver have separate case managers, the goal of an integrated care plan could be undermined or, worse, the case managers could be working at cross purposes.

For these reasons, Twigg (1993) asserts that a dyadic approach to case management should be taken. In this situation, the case manager works jointly with the caregiver and care receiver and has a clear mandate to act upon and protect the needs and interests of both. If this approach is not used, the caregiver's case manager should be certain to coordinate assessment, care planning and service monitoring activities with the care receiver's case manager, and they should establish consensus on priorities, goals and interventions for the dyad.

## **Assessment**

Case managers must be attentive to the content and process of assessment. Content refers to information collected on the characteristics, preferences, needs, capabilities, and resources of the caregiver and the care receiver. This includes health and functional status, the social support network, physical environment, and use of health and social services. The information gathered serves as the basis for establishing goals, priorities, and measurable outcomes for the individualized care plan.

The process for assessment can involve a single case manager such as nurse or social worker or a multidisciplinary team. As noted in the case management outcomes section of this paper, the discipline of the case manager has been shown to influence outcomes for certain populations. Specifically, better outcomes for caregivers and care receivers with dementia were obtained when nurse case managers were used compared to social workers (Arnsberger, Fox and Zhang, 1999). Both the content and process of assessment will be determined by the model of case management used.

## Care Plan Design and Implementation

Ideally, designing the care plan is a collaborative process between the caregiver, care receiver, and the case manager. The care planning process begins with goal setting. Helping caregivers to gain insight into their needs and accept services can be challenging, particularly if the caregiver has not reached the point when he or she is receptive to service use (Montgomery and Kosloski, 1999; Kosloski, Montgomery and Karner, 1999). Generally, husbands and adult child caregivers are more open to service use, while older wives caring for disabled husbands tend to be most resistive to service interventions. Unfortunately, they are often the most in need of help because advanced age and related health conditions increase their vulnerability to the negative effects of caregiving.

Research shows that family caregivers are more receptive to service use when they believe it benefits the care receiver (Noelker & Bass, 1995; Schmall, 1995). Case managers can capitalize on this to break down caregivers' resistance to service use and also achieve efficiencies in service use by arranging for services that are dually beneficial. For example, the care receiver can benefit from a home care worker's help with personal care tasks, like bathing, and the caregiver can be educated by the worker or her nurse supervisor about safe and effective bathing techniques.

There are several issues related to care plan design and implementation for caregivers. For example, one is the depth of the case manager's knowledge of services, service availability, eligibility criteria, cost, and quality and relationships with provider organizations. This professional expertise is essential in order to educate caregivers about what is available to meet their needs and supply help accessing them. At a recent conference on family caregiving, the following preferences of caregivers regarding services were voiced: fewer services of high quality rather than a wide range of mediocre ones, no waiting lists, services available 24/7, and the ability to access services from a variety of venues such as fax or Internet (Internet Radio, Older Americans Report, September 14, 2001).

Findings from national surveys of family caregivers indicate that education and training are the most widely requested services by caregivers (Noelker and Bass, 1995; AARP, 1989). Typically, these interventions are designed to help caregivers better meet the care receiver needs, making them more appealing to caregivers. Schmall (1995) has identified eight key educational areas for caregivers: the patient's health condition, personal coping skills, family disruption, anger and other relationship issues, communication, community services, emotions including guilt, and long-term care planning.

An innovative approach to caregiver education is through Internet Radio (Older Americans Report, December 14, 2001). In Cincinnati, Ohio, radio station WMKV provides 24-hour senior programming via streaming audio over the Internet. The most popular show is "The Family Caregiver Hour" aimed at homebound caregivers who cannot attend support groups. Listeners call in for information and to share their strategies for successful caregiving. Because the shows are archived, previous shows that were missed can be accessed through the station's Web site ([www.wmkvfm.org](http://www.wmkvfm.org)).

Other services designed specifically to meet the caregivers' needs include individual, family, and group counseling and support; respite through adult day programs, home care, or short-stay in residential settings; telephone reassurance; emergency response systems; home adaptation; and hospice. (See Zarit and Teri, 1991 for detailed discussion of caregiver services.)

Another issue in care plan design and implementation is the extent to which other family members can and should be enlisted to provide (more) assistance for the care receiver in order to alleviate the burden on the primary caregiver. In prior decades, a central tenet in social work case management was that family members are the primary source of help for older relatives in need, and formal services are used only to fill in the gaps. In fact, Margaret Blenkner (1965) asserted that it was the social worker's role to help adult children accept their responsibilities for parent care and develop "filial maturity." A more pragmatic reason why some case managers rely as much as possible on family members and other unpaid helpers to provide the bulk of care is the limited availability and cost of home- and community-based services.

This approach, however, is being challenged by changes in family size and structure and redefinition of women's roles, all of which have altered family members' ability to shoulder caregiving responsibilities. There are simply fewer family members available to take on caregiving than in years past and this trend is expected to continue. Furthermore, a large body of research findings shows that long-term caregiving can have a wide range of negative effects on caregivers. Care managers have to consider carefully the capacity of the family as a whole to provide care and caregiving's long term effects on their health and well-being. In fact, a critical part of the case manager's role is to help caregivers determine when they need to relinquish some or all their responsibilities to others and encourage them to follow through on the decision (Twigg, 1993).

### **Service Monitoring and Quality Assurance**

Persons with chronic disabilities and their caregivers have changing needs that often require a variety of services from diverse sources and in different care settings. A key function of case managers is service monitoring to ensure that needs are identified, the care plan is amended if necessary, and there is continuity in care. White and Gundrum (2001) note that as part of this monitoring function, case managers have responsibility for providing professional consultation to service providers to improve service quality based on feedback from caregivers and care receivers. Additionally, careful service monitoring can control costs by forestalling problems and ensuring timely discharge from service programs. Case managers also have responsibility for monitoring the cost and outcomes of case management as well as the quality and outcomes of other services used by the caregiver and care receiver, a topic that will be returned to later.

The extent to which the caregiver is capable of and willing to access, coordinate, and monitor services should be determined as part of the assessment process. McCallon, Toseland and Diehl (1994) have specified how the caregiver's capability affects the role of the case manager. When caregivers can assume case management activities, the case manager functions as a *consultant* to the dyad (McCallon, Toseland, and Diehl, 1994). In other situations where the caregiver has disabilities or there is family conflict about caregiving, the case manager takes on the service *coordinator* role to ensure that needed services are in place and delivered properly.

When the caregiver cannot take any responsibility for these tasks, the case manager assumes the *care manager* role and has complete oversight and responsibility for services.

## MODELS AND OUTCOMES OF CASE MANAGEMENT

### Case Management Models

The various models of case management vary by the extent to which the case manager has responsibility for the key functions discussed previously and controls service dollars (Twigg, 1993). In one model, the case manager primarily serves to assess the caregiver's needs, help formulate a care plan, and refer the caregiver to different providers whom the caregiver contacts to obtain services. In this model, the case manager has no control over services or dollars, but would have an **advocacy role** to make certain that local organizations are making needed services available. Obviously, this model would target caregivers at higher functional levels who are capable of arranging, coordinating and monitoring their services.

In another model, the case manager functions in a **broker role** to assess caregiver needs and then design and implement a service plan using services available directly through the case management agency or through contracts with provider agencies. In this model, the case manager has more flexibility in designing the care plan but is still limited by the services the agency makes available directly or through its contracts. This model lends itself to serving caregivers who have limited or no ability to assume case management functions.

The model allowing case managers optimal flexibility in service plan design gives them a **cash management role** by allowing them to control dollars available to purchase services or goods and does not restrict them to service sources through contracts or other regulations. An example of this model is the Program of All-Inclusive Care for the Elderly (PACE) in which capitated dollars cover the costs of all health, social and other services required by care receivers. These dollars also are used for services for family caregivers should they be needed to ensure the well-being of the care receiver.

In all of these models, the case manager can have a **clinical role** providing counseling, emotional support and other therapeutic interventions as part of the case management process. Research shows that case managers serving older persons and family caregivers regard their clinical work with clients and caregivers as their primary function (Arnsberger, Fox, and Zhang, 1999; Lowenstein, 2000). In the broker and cash management models, case managers can provide clinical services directly by including them in the care plan. Recent research has produced a brief screening tool for case managers to determine the need for these clinical or more intensive social work services (Diwan, Ivy, Merino, and Brower, 2001). Their findings showed that in 61 percent of the cases they investigated involving elderly persons receiving case management, clinical services were indicated because of caregiver burnout or problems in the relationship between the caregiver and care receiver.

There have been assertions that caregiver services, including case management, have been biased by the stance that caregiving is a stressful process fraught with negative outcomes for caregivers. The stress-burden model focuses on assessing for caregiver problems and deficits and providing services for purposes of relief and respite. In response, others have argued for

adopting a case management approach that emphasizes empowering service consumers and building upon their capabilities (Schmall, 1995; Coleman, 2001). Berg-Weger and Tebb (1998), strong advocates of a shared case management approach with caregivers, have developed a Caregiver Well-being Scale as a case management practice tool. The scale is designed to direct caregivers' and case managers' attention to the following: assessing caregivers' strengths, prioritizing case management activities, educating caregivers about how to carry out these activities, and capitalizing on community resources. They assert that the application of this approach will optimize the potential for a positive caregiving experience and enhance the well-being of caregivers as well as care receivers.

## **Outcomes of Case Management**

A number of research demonstration and evaluation projects have been conducted on case management services for older clients and their family caregivers. These projects have generally produced mixed results about their benefits. The National Long Term Care Evaluation of case management and comprehensive community-based care for the elderly (the Channeling study) investigated the impact of this program on changes in patterns of assistance from informal caregivers (Christianson, 1988). The purpose was to determine whether primary caregivers and other informal helpers changed the types and amounts of assistance they provided when a wider array of services were available and used. Findings showed that there were either no or minimal decreases in the amount of assistance from primary caregivers under the case management models tested.

The Medicare Alzheimer's Disease Demonstration targeted older persons with the disease and their caregivers for case management and other services (Arnsberger, Fox and Zhang, 1999). The demonstration was legislatively mandated to determine the effects of supplying adequate and appropriate services to clients and to caregivers under different case management models. Results showed that client and caregiver outcomes such as changes in behavioral problems or caregiver burden differed by the way models were enacted, that is, the way case managers approached their work. The factors examined in the enactment of the two treatment models were: the case manager's professional background, how they established objectives and priorities, the extent to which they controlled service dollars, and how they organized their tasks and daily activities.

All sites showed some improvement in clients' behavioral problems at 12 months, although the degree to which this was accomplished varied widely. When this goal was made a focus at a site and the site made interventions such as caregiver training in behavior management a priority, larger benefits were realized. Similarly, at most sites some improvement in caregiver burden at 12 months was achieved, but this was not so for caregiver depression. However, this goal was most difficult to attain when clients were deteriorating more rapidly with more severe disease symptoms. Generally, findings showed when case management functions were allocated to nurses compared to social workers, there were more positive outcomes for caregivers and clients with this disease.

A third demonstration and evaluation study of case management services for frail elderly and their caregivers in Haifa, Israel was conducted comparing two case management models (Lowenstein, 2000). One model was the typical case management service provided through the

Social Service Bureau in which case managers were assigned up to 350 cases and had mainly phone contact with provider agencies and few home visits. The new model focused on clinical work emphasizing client and caregiver support through counseling and therapy, advocacy, service coordination, and monitoring. In the clinical model, care plans had to include measurable and time-specific goals and expected outcomes. Findings showed increased quality of life for the elderly clients and their caregivers, more coordination between health and social services, a wider variety of service use, and higher satisfaction with services. This study lends further support to the recommendation that careful attention needs to be paid to case load size. For cases in which more intensive case management is required, including clinical interventions with the caregiver and care receiver, a caseload of 35 to 40 is ideal. When caregivers can take responsibility for or share some case management functions, the upper limit for a caseload is 100.

## **RECOMMENDATIONS TO IMPROVE THE BENEFITS OF CAREGIVER SERVICES**

Over 20 years of evaluation research on services and interventions with caregivers have resulted in a number of guidelines regarding best practice (Feinberg, 1999; Schulz, 2000). Findings show that *individualized* interventions are more effective. Individualized refers to the extent to which interventions are based on thorough assessment of the caregiver, care receiver, their physical environment, and support system. The care plan design and implementation should be responsive to consumers' choices. It should also involve multiple, simultaneous interventions for the dyad that are culturally sensitive.

Research indicates "more is better." That is, multi-component interventions offering a variety of services and supports generate greater benefits for caregivers. This suggests that advocacy to broaden the scope of caregiver services should be considered along with innovative delivery techniques such as the Internet and chat rooms for caregiver education and support. Generally, the objective is to ensure that the services available are as *comprehensive* as possible, thereby accommodating a diversity of caregiver preferences and needs.

Lastly, research indicates that the third key feature of effective caregiver interventions is their *intensity*. Single interventions that are provided more often and for a longer time have a greater impact. However, the intensity needs to be adjusted in relation to changes in the caregiver's and care receiver's status, their environment, and support system. To accomplish this effectively, service goals must be set that are measurable, evaluated regularly, adjusted as needed, and pursued until the goals have been met.

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