Role of the Family in Case Management of the Mentally Ill

by James Intagliata, Barry Wilier, and Gladys Egri

Abstract

This article provides a systematic discussion and assessment of the actual and potential contributions that families of the chronic mentally ill can make to the case management of their patient-relatives. It examines family members' involvement with six major case management functions including assessment, linkage, monitoring, assistance with daily problems, crisis intervention, and advocacy. For each function, the authors consider the potential of family members to make a contribution, specific activities that are more appropriately assumed by professional staff, and any limitations or caveats about family members' involvement with the given case management activity. The article points out that family members are clearly quite capable of making significant contributions in almost all aspects of managing their patient-relatives and that their potential contributions are too frequently ignored or underused by professionals. The authors recommend that professionals give greater acknowledgment to the case management efforts of family members, work to integrate the contributions of these natural helpers with formal case management systems, and provide family members with the encouragement and support they need to enhance their caring contributions.

Over the past 20 years, the views of many mental health professionals toward families of the mentally ill have been a significant obstacle to the development of a potentially powerful helping alliance between the two groups (Appleton 1974; Lamb and Oliphant 1978; Beels and McFarlane 1982). As noted by Beels and McFarlane (1982), scientific debate about causal factors in schizophrenia, in which the family itself has been proposed as a contributing factor, has raised the tension level between professionals and families and has added to the burden of family guilt. Further, based on their views of the family role in mental illness, many clinicians have excluded family members from the treatment process altogether or invited them to participate only on the condition that they themselves be treated as part of their relative's problem (Moroney 1980).

Fortunately, this situation has begun to improve significantly in recent years. One major reason has been the growing acceptance of a diathesis-stress model for explaining the cause and course of schizophrenia (Zubin and Spring 1977; Liberman 1982; Liberman, Falloon, and Wallace 1982). In such a multidimensional model, the development and manifestation of severe mental disorders are seen to be influenced by a host of interacting factors including personal variables, such as biological vulnerability and social competence level, and environmental variables, such as the level of stress and the availability of social and emotional support. One important implication of this model is that family members of mentally ill persons can play a positive role in the treatment process. Specifically, they can provide the protection and support needed to counteract the potentially debilitating effects of their relative's biological vulnerability and stressful environment.

A second major reason for the changing views of mental health professionals and their improving relationships with families of the

Reprint requests should be sent to Dr. J. Intagliata, Management Consultant, 1160 South Clinton, Oak Park, IL 60304.
mentally ill is the significant progress made in developing practical and effective models of family treatment. A number of excellent programs have been developed by mental health researchers and clinicians in just the past few years (Anderson, Hogarty, and Reiss 1981; Falloon et al. 1981; Liberman et al. 1981; Leff et al. 1982). The research evidence gathered on such programs thus far has demonstrated that when schizophrenic patients and their families participate, rates of relapse can be reduced significantly. These programs have been well received by families because their approach avoids blaming, provides much needed information, teaches coping skills, and communicates the message that families have the power to influence the course of their relative's illness for the better. The demonstrated success of these programs has also made it quite clear to mental health professionals that the families of their patients are a crucial resource that they can enlist in the treatment process.

A third major reason for the increasingly more positive regard of mental health professionals for families of the mentally ill is the growing acknowledgment of the crucial role that family members play in providing primary care and aftercare as a result of deinstitutionalization efforts. Without the willingness of family members to assume the significant responsibility of caring for their relatives, deinstitutionalization of the mentally ill could never have taken place in the magnitude that it has. Nationwide data collected by the Division of Biometry and Epidemiology of the National Institute of Mental Health (Goldman 1982) indicate that there are an estimated 800,000 to 1.5 million chronically mentally ill persons in this country. According to various reports (Lamb and Goertzel 1972, 1977; Minkoff 1978; Tessler et al. 1982; Baker and Intagliata 1984), one-quarter to one-third of these chronically mentally ill persons live with family members, most often with their parents. Further, the data indicate that if one considers not just the chronically mentally ill, but all individuals discharged from inpatient psychiatric facilities, perhaps as many as 65 percent return to live with relatives.

Many family members also remain quite involved with their mentally ill relative even when they do not live together. They continue to show concern for their family member who may live in a group home or apartment by assisting the relative in dealings with the community (e.g., service providers), by providing direct material assistance (e.g., food, money, clothing), or by providing temporary housing if their relative's alternative living arrangement becomes untenable.

The fact that so many families are actively assisting their patient-relative on a day-to-day basis has led some authors (Minkoff 1978; Hatfield 1981a) to suggest that it is the family, and not the traditional formal treatment system, that has assumed primary responsibility for case management of the mentally ill in this country. In view of the importance of case management for successfully maintaining the chronic mentally ill in the community (Test 1979; Bachrach 1980; Intagliata 1982; Tessler et al. 1982; Miller 1986), the role that families can and do play in providing such a supportive service merits closer examination.

The present article is intended to assist professionals in their consideration of this issue by presenting a systematic discussion of family members' actual and potential contributions to each of six specific aspects of the case management described by Intagliata (1982). These aspects include (1) being aware of the comprehensive needs of patients, (2) assisting patients in getting linked to and remaining engaged with the services they need, (3) monitoring the quality of the services being provided, (4) assisting patients with the management of simple life activities and practical daily problems, (5) assisting the patient in times of crisis, and (6) engaging in advocacy efforts at an individual or systems level to enhance the quality of clients' services and lives. In addition, while the "natural helping" capabilities (Bachrach 1983) of the family are highlighted, attention is also given to the limitations and caveats related to family members' involvement in case management activities.

Families and Case Management

Table 1 summarizes much of the discussion that follows. It operationalizes each of the six major case management functions and delineates how various case management activities might be shared between family members and professional staff.

Assessment. The first and perhaps most basic role that must be played by case managers in any system is to be aware of the comprehensive needs of their patients. When professionals or paraprofessionals assume the case-management role, they generally either take primary responsibility for or are actively involved in some systematic process to assess their patients' needs. This process usually provides the basis for the subsequent treatment plan. For the treatment plan to be most useful, information gathered in the needs assessment...
should be as complete and current as possible.

Family members clearly have a major contribution to make in identifying the needs of their mentally ill relative. A number of authors (Appleton 1974; Ryglewicz 1981; Yess 1981; Smets 1982) have acknowledged the family as an extremely important source of information about their relative’s history of illness, treatment, and current functioning. Further, there is empirical evidence (Ellsworth et al. 1968) that family members’ ratings of their ill relative’s behavior are generally as valid as those of professional staff in predicting length of hospital stay, patients’ self-report of symptoms, and future community tenure.

The fact that many family members are quite knowledgeable about their mentally ill relative seems natural when one considers that they alone have the firsthand knowledge that comes from living together daily in a nonhospital setting. Further, unlike the views of mental health professionals, which are typically based on cross-sectional assessments of their patients, family members have a longitudinal perspective of their relative’s needs and functioning. It is their close, ongoing, long-term contact with their relative that frequently enables them to be the first to recognize the early signs of decompensation and relapse and to help to intervene to avoid it (Leavitt 1975; Herz and Melville 1980; Hansell 1981; Miller 1986). Finally, because of their extensive daily contact with their relative, family members are in a better position to be sensitive to many simple personal needs that may not come to the attention of the mental health professionals who interact with patients less frequently and generally only in treatment settings (Sullivan 1981).

Despite the fact that family members have considerable knowledge of their relative’s needs, mental health professionals have not routinely invited them to discharge planning meetings where their relative’s needs are to be discussed. In cases where the family is contacted, treatment staff often do little more than call the family in to inform them of what has already been decided without their input (Appleton 1974; Leavitt 1975; Ryglewicz 1981). By not inviting the input of the family as part of the assessment and treatment planning process, mental health professionals cut themselves off from a valuable information resource. In addition, they run the risk of alienating the family members whose understanding of and involvement in the rehabilitation process can be powerful determinants of their relative’s successful adjustment in the community (Goldberg, Schooler, and Hogarty 1977; Krauss 1980; Falloon et al. 1982; Leff et al. 1982).

What seems advisable is that mental health professionals more consistently invite the active input of family members in the assessment and treatment planning process. As noted in table 1, however, certain tasks related to assessment must continue to be the responsibility of the professional case manager. These include assessing the family itself regarding such issues as communication and affective styles as well as taking responsibility for integrating the wide variety of information on a patient’s needs into a comprehensive systematic plan of treatment. As noted throughout the case management literature, case management is a process that involves a variety of functions that need not all be performed exclusively by a single formal case manager. Thus, although it would be inappropriate for family members to take sole or even primary responsibility for assessing their relative’s treatment needs, they can nevertheless provide considerable valuable assistance to the professional who has assumed ultimate case-management responsibility.

Linking. A second major function of the case manager is to link clients to services that will meet their needs. Many mentally ill persons lack the capacity to orchestrate the complex combinations of services that may be required. Thus, a case manager who is knowledgeable about the variety of available resources and who takes personal responsibility for ensuring that patients get the services and other supports (e.g., foodstamps, SSI payments) that they need can play a central role in making the system work as intended.

Assuring that clients get linked to needed services is not an easy task, especially when the clients are chronically mentally ill. In addition to the barriers that are inherent in the structure of the service system itself (e.g., eligibility criteria), many mentally ill persons are unable to become or stay engaged with the support services to which they are referred (Evans and Stellman 1977; Anthony, Cohen, and Vitalo 1978; Turner and Shiffren 1979; Krauss 1980). One way to increase the likelihood that the mentally ill will get and stay linked to the various services and supports that they need is to provide them with assertive case management (Beard, Malamud, and Rossman 1978; Stein and Test 1980). Another alternative is to follow the approach developed by Liberman and Falloon (Liberman et al. 1981) and focus on teaching patients themselves the social skills necessary to conduct the problem solving and self-advocacy needed to locate adequate
<table>
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<tr>
<th>Functions</th>
<th>Family members</th>
<th>Professionals</th>
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<tr>
<td><strong>Assessment</strong></td>
<td>1. Provide accurate historical information &amp; longitudinal perspective on patient's functioning &amp; symptoms</td>
<td>1. Seek out information on patient's functioning &amp; needs from all relevant sources, including family</td>
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<td></td>
<td>2. Provide accurate information on clients' current level of functioning at home &amp; in community</td>
<td>2. Invite &amp; encourage family members to be part of the treatment planning &amp; process</td>
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<td></td>
<td>3. Help to identify patient's needs not apparent to treatment team</td>
<td>3. Assess the family unit itself to determine its needs and resources</td>
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<td>4. Integrate all relevant information in a comprehensive treatment plan for the patient</td>
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<td><strong>Linking</strong></td>
<td>1. Be aware of what the patient's treatment plan entails (medications and/or treatment program activities)</td>
<td>1. Be aware of the wide variety of potential programs &amp; resources to which patients &amp; families could be linked</td>
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<td>2. Provide encouragement &amp; support that patient may need to comply with treatment plan (e.g., reminders about medication)</td>
<td>2. Assist patient to overcome barriers that might exist in becoming engaged with prescribed services or taking advantage of available supports (e.g., follow up on referrals, assist client with SSI paperwork)</td>
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<td></td>
<td>3. Support patient in taking as much responsibility as possible for carrying out treatment plan</td>
<td>3. Support patient in taking as much responsibility as possible for carrying out treatment plan</td>
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<tr>
<td><strong>Monitoring</strong></td>
<td>1. Try to get a sense for how patient is responding to treatments being received</td>
<td>1. Maintain regular contact with patient &amp; family to monitor progress</td>
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<td>2. Notice changes in patient's community behavior &amp; share them with staff</td>
<td>2. Maintain regular contact with agencies from which patient is receiving services, including making occasional visits</td>
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<td>3. Keep historical perspective on what does or does not seem to help patient</td>
<td>3. Regularly assess whether patient's participation in programs or use of medications produces intended changes</td>
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<td><strong>Assistance in daily living</strong></td>
<td>1. Encourage patient to be as independent as he/she can manage</td>
<td>1. Encourage patient to be as independent as he/she can manage</td>
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<td></td>
<td>2. Within appropriate limits, provide patient with direct assistance &amp; help in managing practical problems when necessary</td>
<td>2. Help family members set realistic limits on their level of involvement with helping patient meet needs</td>
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Table 1. Case-management functions and activities—Continued

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<th>Functions</th>
<th>Family members</th>
<th>Professionals</th>
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<td><strong>Crisis</strong></td>
<td>3. Make patient’s unmet needs for such assistance known to treatment staff</td>
<td>3. Identify or develop resources that will provide the patient with assistance</td>
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<td><strong>intervention</strong></td>
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<td>or do so directly if necessary</td>
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<td></td>
<td>1. Learn the early warning signs of crisis or relapse</td>
<td>1. Assist family members in identifying early signs of crisis or relapse in patient</td>
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<td>2. Inform case manager or other appropriate treatment staff of impending</td>
<td>2. Identify or develop resources that</td>
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<td>crisis/relapse in a timely fashion</td>
<td>patient or family can turn to for</td>
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<td>3. Be available to patient to provide basic life supports (e.g., money,</td>
<td>immediate help in crisis</td>
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<td>housing) in times of crisis</td>
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<td><strong>Advocacy</strong></td>
<td>1. Make case manager aware of any need for formal advocacy efforts on</td>
<td>1. Use formal channels to advocate for</td>
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<td>behalf of the patient</td>
<td>individual patients who are being denied</td>
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<td>2. Become actively involved in consumer advocacy groups that strive to</td>
<td>needed services</td>
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<td>improve care for the mentally ill</td>
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<td></td>
<td></td>
<td>2. Identify gaps &amp; needs not met by the current service system; make this</td>
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<td>information known to those responsible for planning and administering the</td>
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Clearly, it is important to strike a balance between these two approaches such that the patient is permitted to function as independently as possible but still receives the case-management support necessary to be linked to needed services.

Note that for those patients who do need assistance in getting linked to services, the nature of this assistance can vary greatly in formality and intensity. Examples of the kinds of assistance that might be provided include: reminding patients about an appointment or the medication they need to take, providing them with transportation to a needed service if they cannot get there on their own, accompanying them to a service appointment not only to make sure that they get there but also to ensure that the provider understands and is responsive to their needs, and discussing with them their fears of or misgivings about treatment efforts so that they might maintain their motivation for treatment.

As suggested in table 1, some aspects of the linkage functions are probably best handled by a professional case manager. These include being aware of the wide range of service and support alternatives available and assisting patients in getting through the often considerable bureaucratic red tape that is required for them to get started with entitlement programs as well as some supportive services. However, there are many types of assistance and encouragement that can help facilitate patients’ linkage to services and that do not require any complex or technical knowledge about the service system. These may make the difference between a patient continuing with or dropping out of a needed treatment. Such assistance can be provided effectively only by someone who is actively concerned about the patient, has the time and motivation needed to manifest this concern through action, and can develop a trusting, supportive relationship with the patient.

Family members clearly have an important contribution to make in this regard. Their understanding of and attitude toward treatment can be a very strong influence on whether or not their patient-relative uses it as prescribed (Schwartz and Schwartz 1964; Stevens 1972; Goldberg, Schooler, and Hogarty 1977). For mental health professionals to ignore this reality and fail to encourage and assist family members in taking an active and positive role in linking
their relative to services would be an unfortunate underutilization of their capabilities.

Monitoring. The third essential case management function is to monitor the services being provided to patients. This requires the case manager to assess in some ongoing fashion whether the services to which a patient has been linked seem to be appropriate and effective. To do this, the case manager must take into account the patients’ own satisfaction with their service involvement as well as be intimately familiar with the goals and objectives that members of the treatment team have set for patients. Monitoring may also entail the case manager visiting occasionally with the patient at the program where he or she is being served. This kind of firsthand contact may provide valuable information about the degree of fit between the client and the service that would otherwise be overlooked. Monitoring provides the system with valuable feedback about the extent to which the prescribed interventions are actually meeting the patients’ needs and thus informs staff members about important needed modifications in treatment plans.

As is indicated in table 1, the monitoring activities of family members and professional staff are generally similar. They differ only in that each brings a somewhat different perspective to the monitoring responsibility. While treatment staff may be highly skilled in their abilities to observe and understand patients’ response to treatment, their role in monitoring is severely limited by the fact that the majority of their time in contact with the patient is restricted to the clinical program setting. Although it is important to follow how patients respond in treatment settings, it is perhaps even more essential to know whether patients are successfully using these skills in their natural environments.

Family members have a key role to play in supplementing the monitoring efforts of professional program staff. They are good observers of the behavioral adjustment of their patient-relative and have the crucial firsthand knowledge that comes from living with them in the community. As such, they are natural monitors of their relative. If their input is invited, family members can provide clinical staff, including their relative’s case manager, with important information about such issues as medication side effects and the degree to which their relative’s behavior at home and in other community settings shows evidence of progress related to treatment goals. Further, to the extent that they are invited by professionals to understand their relative’s treatment goals, family members can not only monitor their relative’s progress but help to facilitate it by encouraging and supporting the same behaviors that are the focus of treatment. Finally, because they are not themselves a part of the formal service system, family members do not have the conflict of interest problems that can compromise the monitoring effects of case managers who work for the same system that provides the clients with treatment.

Assistance in Daily Living. In some mental health systems, case managers for the chronically mentally ill are expected to assist their patients with the management of simple life activities and practical daily problems that they are unable to deal with independently. In this way, they provide the crucial missing personal support that many patients require to succeed. In New York State, for example, case managers of the chronically mentally ill often provide patients with the assistance or encouragement they need for maintaining their personal hygiene or individual households. Other supporting activities might include helping patients prepare a grocery list, accompanying them on a shopping trip, or transporting them to a needed service if no other arrangements can be made (Intagliata 1982).

As with other case-management functions already discussed, providing patients with assistance in dealing with practical daily problems is a task that need not be managed exclusively by the professional case manager but that can be shared with other helpers. Weinman and Kleiner (1978), for example, employed lay persons to act as enablers for chronic mental patients living in the community. These persons spent several hours each day with their individual clients teaching them basic community living skills, escorting and introducing them to services and resources in the community, and acting as a liaison to gain the understanding and support of neighbors and local merchants for their patients. This program was highly successful in facilitating patients’ adjustment to the community.

Perhaps much more so than with any of the other previously discussed case management functions, family members are already extremely familiar with assisting their patient-relative to manage practical, everyday problems. In fact, in many mental health service systems in which case managers either do not exist or are not sanctioned to provide patients with this kind of assistance, there is no one but the family to assume such responsibility. This may be true regardless of whether patients actually live with their families. As noted by numerous authors (Stevens
patients is quite tenuous. Significant crises may be precipitated by unexpected changes in the environment, even events that seem trivial to persons with a "normal" level of coping ability. If such crises are not managed in a timely fashion, they can easily lead to significant deterioration in the patients' levels of functioning and perhaps to their rehospitalization. It is the role of the case manager to be available to both the patients and their family in times of crisis and to be capable of either providing or linking them to needed crisis intervention supports.

Perhaps the most important aspect in crisis intervention is timing. For crisis intervention to be successful, the developing crisis must be identified and appropriate action taken quickly to prevent the situation from deteriorating further. Family members, especially those who live with their patient-relative, have the advantage of being able to spot many developing crises in a timely manner because of their ongoing contact. If they have learned what kinds of signs to look for, they may be the first to recognize the early stages of decompensation and can call this to the attention of their relative's case manager or other treatment staff (Leavitt 1975; Herz and Melville 1980). With other types of crises, they may be able to serve as a key resource to alleviate their relative's stress. They may, for example, intervene to get them through particular crisis periods by providing needed food, money, or housing. These are resources that the mental health system may simply not have to offer, or which it may be unable to provide in a timely manner.

Advocacy. A final case-management function to consider is that of advocacy. Two types of advocacy are important: that which takes place at the individual patient level and that at the systems level (Intagliata 1982). Perhaps the most frequently occurring situation requiring individual level advocacy involves situations where a patient is having difficulty getting linked to a service initially as well as those where a patient is being dropped from a program.

When such situations can be managed simply through informal interpersonal negotiations involving the case manager and the given service provider, this activity is probably subsumed under the linking function described earlier. When such informal negotiation is ineffective, however, successful linkage requires the case manager to become involved in formal advocacy activities. For example, the case manager may need to enlist the support of supervisory or administrative level staff within his or her own agency or to make use of even more formal channels such as seeking the assistance of legal aid services or of agencies that traditionally provide advocacy services for patients in need (e.g., Mental Health Associations).

Systems-level advocacy is a somewhat different case-management function. In general, it involves someone taking responsibility for calling attention to some deficiency in the service system that adversely affects a large number or class of patients. Systems-level advocacy often requires political action and is especially appropriate for citizen groups to get involved in. In the mental retardation field, parents established the Association for Retarded Citizens for advocacy purposes in the 1950s. Since then, they have been particularly effective in calling national attention to the plight and needs of the mentally retarded. Similar advocacy groups

Crisis Intervention. A fifth important case-management function is crisis intervention. The adjustment to community living made by many formerly institutionalized psychiatric
for the mentally ill have at last also begun to emerge—for example, the National Schizophrenia Fellowship in England and the National Alliance for the Mentally Ill in the United States (Hatfield 1981b). In addition to their goals of providing families with needed information and emotional support, they are advocating increased public awareness about mental illness, improved services for the mentally ill, and a greater commitment to research into the causes and treatments of mental illness.

Because of their considerable personal commitment and concern about mental illness, parents and other family members of the mentally ill can make extremely effective advocates for systems-level change. In this regard, their voices may be as, if not more, powerful than those of the mental health professionals. The mental health establishment thus has gained a potentially strong and influential ally in the family. What professionals must understand, however, is that the objectives of such advocacy groups may not always be entirely consistent with their own. Family members are beginning to demand change not only for the system as a whole but from mental health professionals as well. For example, relatives of the mentally ill are demanding not just what mental health professionals themselves would like (e.g., larger service and research budgets) but also more responsiveness and more respect for the family from mental health professionals.

Discussion

In this article we have discussed the contribution that family members can and do make to the case management of chronically mentally ill persons. While we are not suggesting that family members assume primary case-management responsibility for their relatives, it is clear that they are powerful natural helpers who can and do provide crucial supplemental assistance to case managers and other mental health professionals. If mental health professionals are to forge a stronger helping alliance with family members, one way of doing it is to acknowledge the contribution that families are already making to the case management of the mentally ill and to consider including families in the treatment process to an even greater degree if they so wish.

While family members can and should be encouraged to contribute actively to the case management of their patient-relatives, there are some limitations and issues that must be considered about their functioning in such a capacity. Some aspects of the case-management role cannot be relegated to family members because their effective performance requires special professional training or credentials. Further, while there are many ways in which family members can make important contributions to their relative’s case management, it is important to be sensitive to the significant level of burden that family members’ overall caretaking responsibilities may entail. Recently, a great deal of concern has been expressed in the professional literature for the problem of “burnout” among professionals who work with chronic patients (Lamb 1979). If professionals who work with such individuals 8 hours a day are at risk for burnout, what about family members who are involved with their relatives 24 hours a day? Finally, there are some family members who, because of their particular personal situation, are not capable of or willing to be significantly involved in assisting their patient-relative.

In response to these limitations, mental health professionals must (1) take responsibility for assuming those aspects of the case-management function that only trained professionals can carry out effectively, (2) conduct systematic research to identify those complementary aspects of case-management responsibilities that may be beneficial for willing family members to assume, (3) provide families with the encouragement and/or training they need to make a case-management contribution, and (4) acknowledge that some families do not want and should not be encouraged to be significantly involved in their relative’s treatment.

Regarding the notion of training family members to assume case management responsibilities, note that this idea has, in fact, been implemented successfully in at least one regional developmental disabilities service system in California (Franck 1982). In this program, interested family members attend a formal training course and may eventually work as their relative’s certified case manager under professional supervision. While we are not advocating that families of the mentally ill become so integrally involved with their relative’s treatment, the success of this pilot program demonstrates the desire and capability of many family members to carry out important case-management functions.

The case-management process involves a complex set of tasks and responsibilities that must be dealt with for all the available personal and system resources to be brought to bear for the ultimate benefit of the client. While professionals have a major role to play in the case-management process, so do family
members. There is more than enough work to share. It is time for professionals to acknowledge the important contribution already being made by family members and to do whatever they can to enhance and support this contribution.

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The Authors

James Intagliata, Ph.D., is currently a Management Consultant in Chicago, IL. He was formerly a Research Associate Professor, University of Missouri at the University of Missouri at Kansas City. Barry Miller, Ph.D., is Associate Professor, and Gladys Egri, M.D., is Clinical Associate Professor, Department of Psychiatry, State University of New York at Buffalo.