

Overcoming Barriers Faced by African-American Families with a Family Member with Mental Illness*

David E. Biegel**, Jeffrey A. Johnsen, and Robert Shafran

A qualitative research design combined with a quantitative analytic technique, concept mapping, was used to examine and address barriers to African-American families' involvement in the treatment of their family members with mental illness. Focus groups were formed with lay and professional informants. The focus groups recommended a variety of strategies for improving caregiver supports and increasing the involvement of caregivers in the treatment process. The implications of these findings for mental health professionals are discussed.

Family members of persons with severe mental disability can play critical roles in enhancing the treatment and care of their ill family members. However, the ability of families to fulfill their caregiving role is negatively affected by a number of barriers, including significant levels of perceived burden experienced by many caregivers and a lack of perceived support from mental health professionals and from caregivers' own informal social networks (Biegel, Milligan, Putnam, & Song, 1994). A major gap in the literature is a lack of full understanding of the role of race and ethnicity in family caregiving for persons with mental illness. There is a large body of research evidence documenting the fact that different groups of individuals meet needs and solve problems in differing ways and that there are often obstacles—systemic and personal—that differentially affect the ability, opportunity, and willingness of specific population groups to participate in organized help-seeking and receiving activities (Giordano, 1973; Naparstek, Biegel, & Spiro, 1982; Neighbors & Jackson, 1996; Padgett, 1995). Nevertheless, the role of race and ethnicity has received relatively little attention in the mental health family caregiving literature (Davis, 1982; Davis & Proctor, 1989). Thus, a fuller understanding of obstacles and barriers faced by minority populations in family caregiving for persons with mental illness is needed.

Understanding the barriers facing African-American family caregivers is of particular concern to mental health professionals for several reasons. First, African-American consumers with severe mental disability would appear to have even greater needs for family support than do Caucasian consumers, given the fact that they have higher rates of use of in-patient mental health services. In addition, African-American consumers have lower utilization and higher drop-out rates for out-patient mental health services than do Caucasian consumers (Snowden & Cheung, 1990). Second, the samples of only a few research studies have included a sufficient number of African-American family caregivers to allow a specific examination of their problems and needs (Biegel, Milligan, Putnam, & Song, 1994; Pickett, Vranik, Cook, & Cohler, 1993; Struening, Stueve, Vine, Kreisman, Link, & Herman, 1995).

Conceptual Framework and Research Questions

This study specifically focused on ways to enhance the involvement of African-American families in the treatment and care of their family member with mental illness. A systems theoretical orientation underlies the design of this study. General systems theory (Bertalanffy, 1969) broadly defines a system as a complex of interacting elements which function together to manage the environment. Individual system elements or components are embedded within a web of interlocking relationships such

that change in any one element ultimately affects the entire system. In order to truly understand the functioning of any one system element, it must be examined from within the context of the system of which it is a part.

The key informants targeted in this study—family caregivers, mental health consumers, agency case managers, and staff of the county mental health board authority—each represent major components of the local mental health system which have the greatest direct impact on the day-to-day conduct of family caregiving to persons with severe mental disability. It is recognized, of course, that this local system is itself embedded in systems of greater scope and breadth which have indirect impacts on family caregivers. For example, state and national legislatures which establish mental health treatment policies and funding priorities, schools which train mental health professionals and prepare them for work in the field, and government and non-profit institutions which sponsor mental health research, to name but a few.

Two research questions were examined in this study: (1) What barriers or obstacles hinder African-American families' involvement in the treatment and support of their family members with mental illness? and (2) How can these barriers or obstacles be overcome? Because of their different perspectives, it was felt that the use of a variety of key informants in this study would help provide a more comprehensive understanding of the needs of family caregivers. In addition, each of the informant groups included in this study needs to be intimately involved in addressing the solutions to identified needs.

Methodology

Study Design

This study used a combination of qualitative and quantitative research methodology. Separate focus groups were formed with the four types of informants mentioned above, caregivers, consumers, agency case managers and staff from the county mental

*This research was supported by a grant (94.1076) from the Office of Program Evaluation and Research, Ohio Department of Mental Health and through a contract from the Cuyahoga County Community Mental Health Board.

**Address correspondence to: David E. Biegel, Ph.D., Henry L. Zucker Professor of Social Work Practice, Mandel School of Applied Social Sciences, Case Western Reserve University, 10900 Euclid Avenue, Cleveland, OH 44106.

Key words: African-American, concept mapping, family caregiver, focus groups, mental illness.

(*Family Relations*, 1997, 46, 163-178.)

health board, which is the local mental health planning and funding agency. Each informant group participated in two focus group sessions, one to two weeks apart. Focus group sessions were facilitated by a professional focus group leader and were three hours in length.

Data from these focus groups were analyzed with the application of a recently developed quantitative analytic technique called concept mapping (Trochim, 1989). Concept mapping is a statistical technique designed for the management and interpretation of a certain type of qualitative data, i.e., the statements generated during a “brainstorming” session. Statements brainstormed within a focus group setting are sorted into conceptually similar piles and rated for their importance by each focus group participant working independently. Multivariate statistical techniques—multidimensional scaling and cluster analysis—are then applied to this information and results are depicted in the form of a “map” of clusters of statements, each ostensibly representing some underlying concept. Concept mapping has been used in the mental health field to study the perceptions of mental health staff and mental health consumers on a variety of issues. Examples include the adaptation of a rehabilitation technology to a core urban, homeless population with psychiatric disabilities (Shern, 1993), staff perceptions of a mobile job support program for persons with severe mental illness (Cook, 1993), quality in intake assessment and case management (Marquart, Pollak, & Bickman, 1992), and mental health outcomes from the perspective of consumers (Trochim, Dumont, & Campbell, 1993).

Sampling

This study was conducted in a large, midwestern, urban community. Each focus group sample was derived differently. Consumers were selected from two sources. Case managers from four mental health agencies serving a predominately African-American clientele were asked to nominate African-American adult consumers with severe mental disability whom they felt would be able to actively participate in a focus group setting. The investigators randomly selected 75% of the consumer focus group from this pool of nominees. The remaining 25% of the sample was randomly selected from among consumers in the mental health board’s data system as a check against the possibility that case managers would nominate only consumers with very high levels of functioning and favorable attitudes toward the mental health system.

Family caregivers were randomly selected from nominations by case managers from these same four agencies. Case managers from the four agencies were randomly selected and asked to participate in the case manager focus group. In addition, volunteers from the mental health board staff were recruited to participate in the mental health board focus group.

A total of 76 individuals agreed to participate in the focus groups: 24 consumers, 22 caregivers, 19 case managers, and 11 mental health board staff. Refusal rates were low. Of those nominated individuals whom we were able to contact, 80% of the caregivers, 76% of the case managers, and 75% of the consumers agreed to participate.

Procedures and Data Analyses

In the first focus group session, participants brainstormed the question, “What barriers or obstacles hinder African-American families in the treatment and care of their family member with

mental illness?,” generating individual statements. This process continued until the group members felt they had exhausted the range of possible statements. Group participants then sorted and rated the statements according to the concept mapping procedures described above.

In the interval between focus group sessions, concept mapping was used to conceptualize the statements generated from the participants in the focus groups. Using the Concept System¹ software developed by Trochim, project staff generated a cluster map for each of the four focus groups, and named all clusters based on their constitutive obstacle statements.

Project staff further grouped the clusters into one of four “regions”—Family, Consumer, System or Community, based on the locus of the brainstormed statements. This conceptualization is consistent with the overarching systems orientation of this research. These four regions describe major elements of the broader caregiving system. While each is connected with and influences all others, each exercises a dominant influence over particular aspects of caregiver functioning, and is thus the appropriate focus in addressing ways to improve caregiver functioning. It was felt that such groupings, which were based on service delivery research literature (Biegel & Farkas, 1989), would help clarify the locus of the barriers and also would later facilitate attention to the levels at which solutions to these obstacles might best be addressed.

Clusters were assigned to regions from a list of clusters without reference to their location on the cluster map, based on a consensus of project staff. Only then was the map consulted to see if clusters which had been grouped together in the same category were, in fact, contiguous with one another and constitutive of a true map “region.” In all cases, true map regions resulted from the assignation of clusters to categories, thus providing empirical support for the conceptualization of data by project staff.

For the second focus group session, participants were given a complete listing of the obstacle statements brainstormed at the first focus group session. The statements were grouped under the cluster names which had been assigned by project staff according to the procedures described above. After discussion and clarification of the cluster names, participants were asked to brainstorm solutions specific to the obstacles identified by each *cluster name*, referring to individual statements within a cluster only to get a better sense of the meaning of the cluster name. Because time did not permit the brainstorming of solutions for all cluster names on the list, only the most important in each region, based on the importance ratings computed from the first session’s data, were targeted for solution statement brainstorming.

Following a short break, participants were given a complete list of the brainstormed solution statements, organized under each obstacle cluster name. Participants were then asked to individually rate the importance of each statement as a solution to the problem identified by the obstacle cluster name, using the same five-point rating scale used to rate the obstacle statements. Time constraints prohibited the sorting of solutions statements by the participants.

In order to discern more meaningful patterns and trends within the solutions data, Concept System software was used to produce a solutions cluster map for each focus group. After being screened for duplication, the solution statements of each focus group were sorted according to Concept System protocol by each of the five members of the project research staff. This sorting

took place prior to any substantive discussion of the solutions data so as not to prejudice the sorting process in any way. The results of this sort were entered into the Concept System software, as were the ratings of the solution statements obtained from the focus group participants. The resulting solutions cluster maps (see Figures 5-8), therefore, are hybrid creations, consisting of the rating scores of the focus group participants and the sortings of the research staff. The solutions cluster maps represent an innovative adaptation of concept mapping, and demonstrate the versatility of this technique. Because sorting and rating are completely independent processes within concept mapping, the fact that different sets of individuals performed each of these two tasks does not compromise the validity of the results. Clusters were named by project staff using the same procedure described above for the obstacle clusters.

Findings

Sample Characteristics

Twenty-two African-American mental health consumers participated in one or both focus group sessions. Almost three-quarters (73%) were female with a mean age of 42 years. All of the consumers were certified by the State of Ohio as having severe mental disability. The most common diagnosis among these

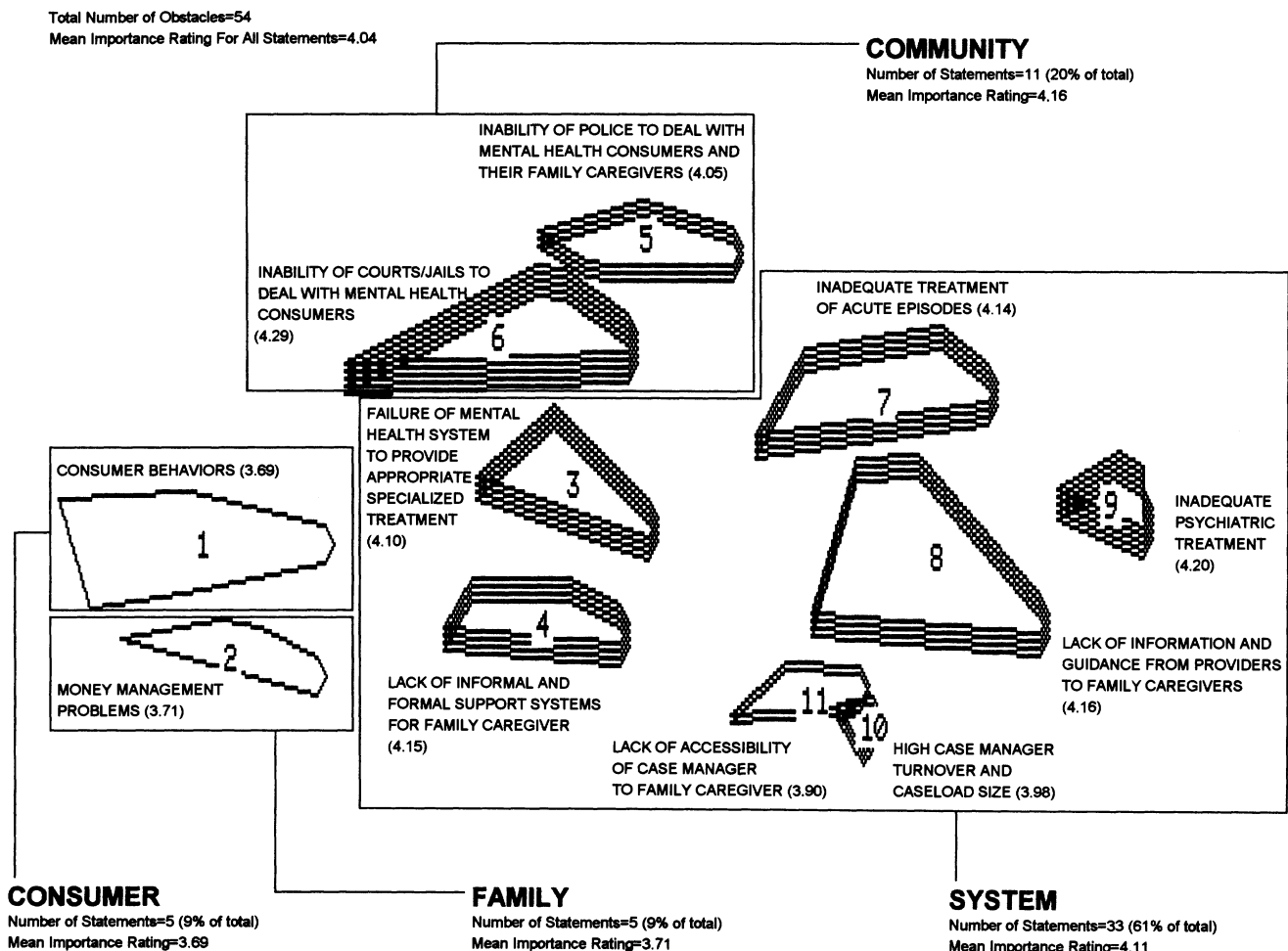
individuals was Schizophrenia (59%), followed by Affective Disorder (27%), Anxiety Disorder (9%) and Adjustment Reaction (5%). Over half (55%) had one or more hospitalizations in a public mental hospital within the last five years. Of those hospitalized, the mean number of hospitalizations was 7.6.

There were twenty African-American family caregivers who participated in one or both focus group sessions, of whom the substantial majority were female (85%). Almost two-thirds (65%) of caregivers were parents of their family members with mental illness, one-quarter of the family caregivers were siblings, while 10% were other relatives. Data on caregiver age is not available.

Seventeen mental health case managers and one case management supervisor attended at least one focus group session. Most were African-American (61%) and female (56%), with a mean age of 33.5 years. The bachelors degree was the highest education degree of almost two-thirds (65%) of the case managers, while almost one-fifth (18%) held a Master's degree. Participants had been case managers for an average of almost three years.

Finally, eleven staff members of the local mental health board participated in one or both focus group sessions. Almost three-quarters were female (73%) and almost half (45%) were African-American, with a mean age of 45 years. Participants held a variety of professional positions at the mental health board, and

Figure 1. Obstacles Cluster Map. Family Caregiver Focus Group



had been in their present position for an average of approximately one and one-half years.

Obstacles Identified by Focus Groups

Family Caregiver Focus Group. As can be seen in Figure 1², the family caregivers' Obstacles Cluster Map is dominated by the System region, accounting for 61% of the total number of statements, and containing seven of the eleven clusters. The Community region follows in terms of size, comprised of 20% of the total statements in two clusters. The Consumer and Family regions each consist of a single cluster of five statements.

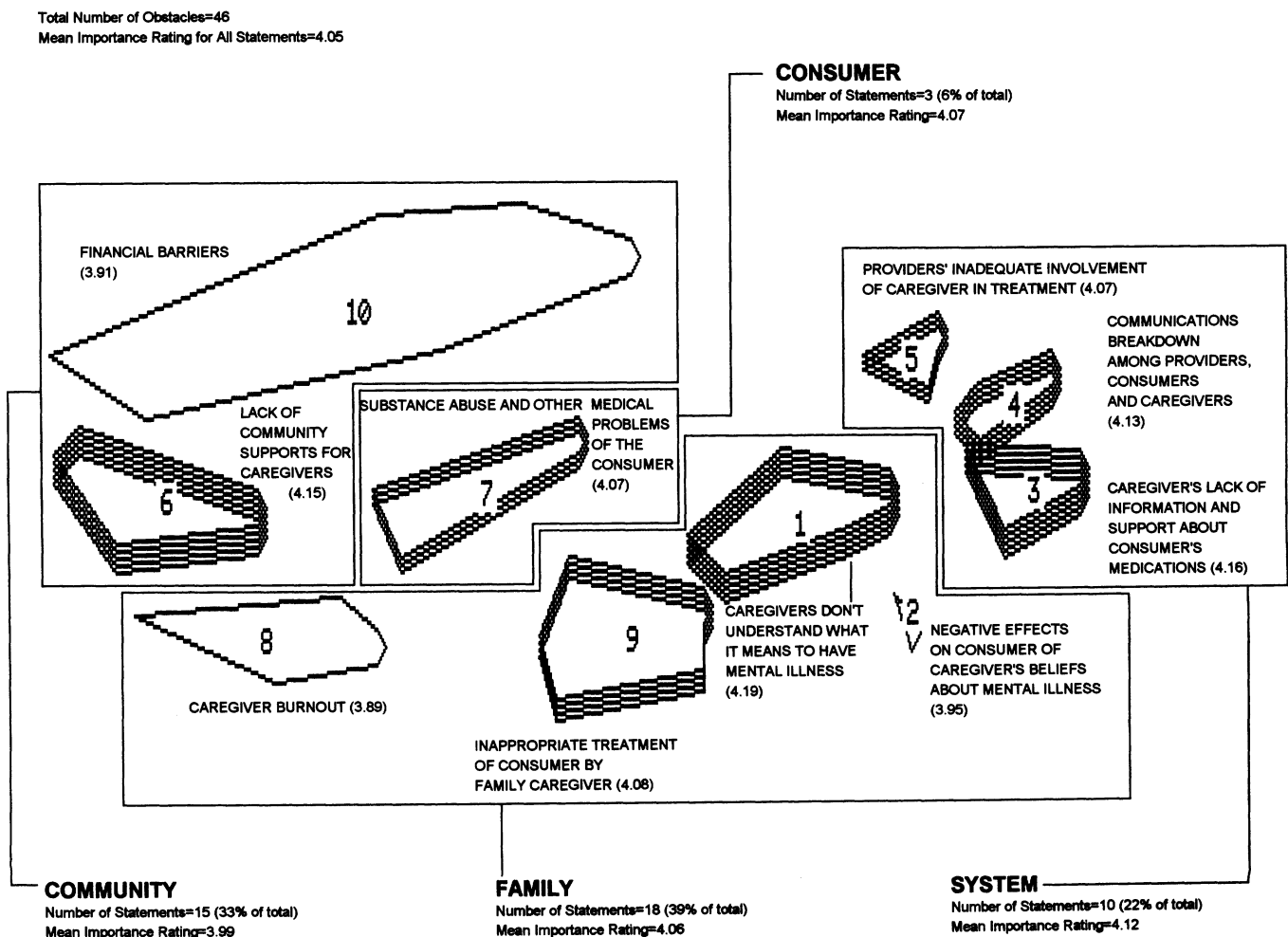
The cluster names of the System region suggest two major types of barriers. Clusters #3, #7 and #9 describe barriers resulting from the inadequate treatment received by consumers from the mental health system, whether that treatment is routine (Cluster #9) or specialized (Clusters #3 and #7). Clusters #4, #8, #10, and #11 describe the caregivers' sense of isolation, of being left to their own resources and of not receiving sufficient help from providers. This lack of help stems from providers being generally inaccessible to caregivers (Cluster #11). There is recognition by the caregivers, however, that this inaccessibility may in part be due to case managers' large caseloads and high burnout rates (Cluster #10). Furthermore, providers who are accessible are very often perceived as less than helpful (Cluster #8). The lack of in-

formal, as well as formal supports (Cluster #4) completes the picture of the isolation felt by caregivers, who often feel they must go it alone.

The focus of the two clusters in the Community region is the inability of the legal system to deal appropriately with mental health consumers and their family caregivers. These two clusters chronicle essentially the same set of problems, but apply them to different segments of the legal system. Cluster #6 addresses the judicial system's inability to deal with consumers, either as the result of ignorance or indifference. Cluster #5 reflects much the same level of unpreparedness of the police for dealing with consumers. In addition, problems stemming specifically from police/caregiver interactions are noted. These consist of an unwillingness or inability on the part of police to give due credence to the caregivers' portrayal of domestic situations involving the consumer which require police intervention.

Comprised of only one cluster, the Family region highlights the difficulties caregivers face in managing the finances of their family members with mental illness. The cluster focuses on three areas: legal red tape pertaining to caregivers' functioning as payees, conflict between caregivers and consumers over the handling of the consumer's money, and conflict between the caregiver and their other family members about financial priorities.

Figure 2. Obstacles Cluster Map. Consumer Focus Group



The Consumer region, similarly comprised of one cluster, focuses on consumer behaviors which generate obstacles for caregivers. There are two types of behaviors included in the cluster. Passive behaviors include those through which the consumer is taken advantage of by another, be it an unscrupulous merchant or alleged friend. The active consumer behaviors that may create obstacles include such things as the consumers' manipulation of the mental health system and refusal to participate in treatment.

Overall, only two of the fifty-four (4%) statements of the family caregiver focus group, "Mental hospitals discriminate against African-American consumers," and "Cultural differences between consumers and Asian psychiatrists, especially with language, creates barriers," are explicitly related to issues of race.³

Consumer Focus Group. As can be seen from Figure 2, no single region dominates the consumers' Obstacles Cluster Map. Only the Consumer region is disproportionately small, consisting of a single cluster of only three statements. Overall, the consumers viewed obstacles as arising primarily from caregiver inadequacies and from poor communications among caregivers, providers, and consumers. To a lesser degree, consumers understood barriers to be caused by poverty, a lack of caregiver formal and informal supports, and negative consumer behaviors.

Data from the Family region indicate concern over the negative impact which caregivers may have upon consumers. Cluster #1 describes the inability of the caregiver to effectively relate to the consumer due to caregiver illiteracy, lack of knowledge about mental illness and medications, or simply a lack of time and energy resulting from other commitments and obligations. The consumer's frustration with his/her illness, which often leads to withdrawal from the caregiver, was also noted in this cluster.

Cluster #9 describes caregiver behaviors which adversely affect the consumer. These behaviors are seen as having a variety of causes, including caregivers' fear of the consumer, caregivers' desire to take advantage of the consumer or the caregiver's own mental illness. Caregiver beliefs and attitudes that adversely affect consumers make up Cluster #2. These include discounting the formal diagnosis of the consumer in favor of the caregiver's own personal theory of the consumer's illness, and viewing multiple consumer family members stereotypically as all having the same problems and, therefore, the same needs. Cluster #8 discusses the need for caregiver respite due to burnout. The lack of availability of caregiver respite may result in inappropriate treatment of the consumer, such as hospitalizing the consumer simply so the caregiver can have a break.

The Community region highlights barriers that derive from structural inadequacies of the caregivers' formal and informal networks. Some of these inadequacies are a general lack of supports, such as a lack of child care and lack of supports from other family members (Cluster #6), while others more specifically result from financial barriers, such as the lack of insurance coverage for caregivers and consumers, poor access to transportation, and difficulties in obtaining government benefits (Cluster #10).

The System region may be understood to revolve around the theme of poor communications among consumers, caregivers, and providers. These poor communications manifest generally and more specifically in the form of caregivers being given inadequate information by providers regarding consumer medications (Cluster #3) and other aspects of treatment (Clusters #4 and #5).

Cluster #4 describes a general breakdown of communications among providers, caregivers and consumers. Specific causes of such breakdown include consumer illiteracy, caregivers' lack of knowledge regarding mental illness, and cultural barriers between providers and caregivers. Consumers also feel that providers are not giving caregivers the kind of information they need to be effective in aiding the consumer (Cluster #5).

The Consumer region consists of a single cluster which addresses the obstacles created for caregivers by the confounding behaviors and medical conditions of the consumer. In particular, substance abuse was seen as a major problem.

As was the case with the family caregiver focus group, few obstacles cited by consumers pertained explicitly to issues of race. Three (7%) of the consumer focus group statements cited issues of provider racial prejudice, lack of culturally specific activities for consumers, and providers' failure to understand the caregiver's culture.

Case Manager Focus Group. A 14-cluster solution appeared optimal to the research staff. To arrive at that, a 16-cluster solution was generated, Cluster #13 was dropped due to a lack of thematic connection between its constitutive statements, and clusters #1 and #6 were combined into a single cluster (see Figure 3). As can be seen from Figure 3, the Family and System regions dominate the map, accounting for 90% of all of the brainstormed obstacle statements. By contrast, the other regions are quite small. The Consumer region consists of two clusters, each containing only two statements, while the Community region is comprised of a single cluster of four statements.

The cluster names of the Family region suggest two major types of barriers: caregivers' capacity to provide care and caregiver attitudes. Barriers arising from a limited caregiver or family capacity to provide care were described as stemming either from a lack of caregivers' knowledge about mental illness in general or lack of knowledge of specific treatment plans (Clusters #1 and #6), or family structural factors (Clusters #2 and #3). Barriers related to attitudes were the result of either the prejudices and norms imposed from without by the dominant culture (Clusters #4 and #5) or the beliefs and attitudes embraced from within African-American culture (Cluster #7).

The System region can be seen to embody two major themes. Clusters #11, #12, #15, and #16 describe barriers arising from deficiencies in the mental health system. These deficiencies may be attributed to the exclusion of the family from the treatment process (Clusters #11 and #16), stereotyping of African-Americans by the mental health system (Cluster #15) or by more general causes (Cluster #12). The second theme is found in Cluster #10, which points to the lack of adequate community support systems for caregivers.

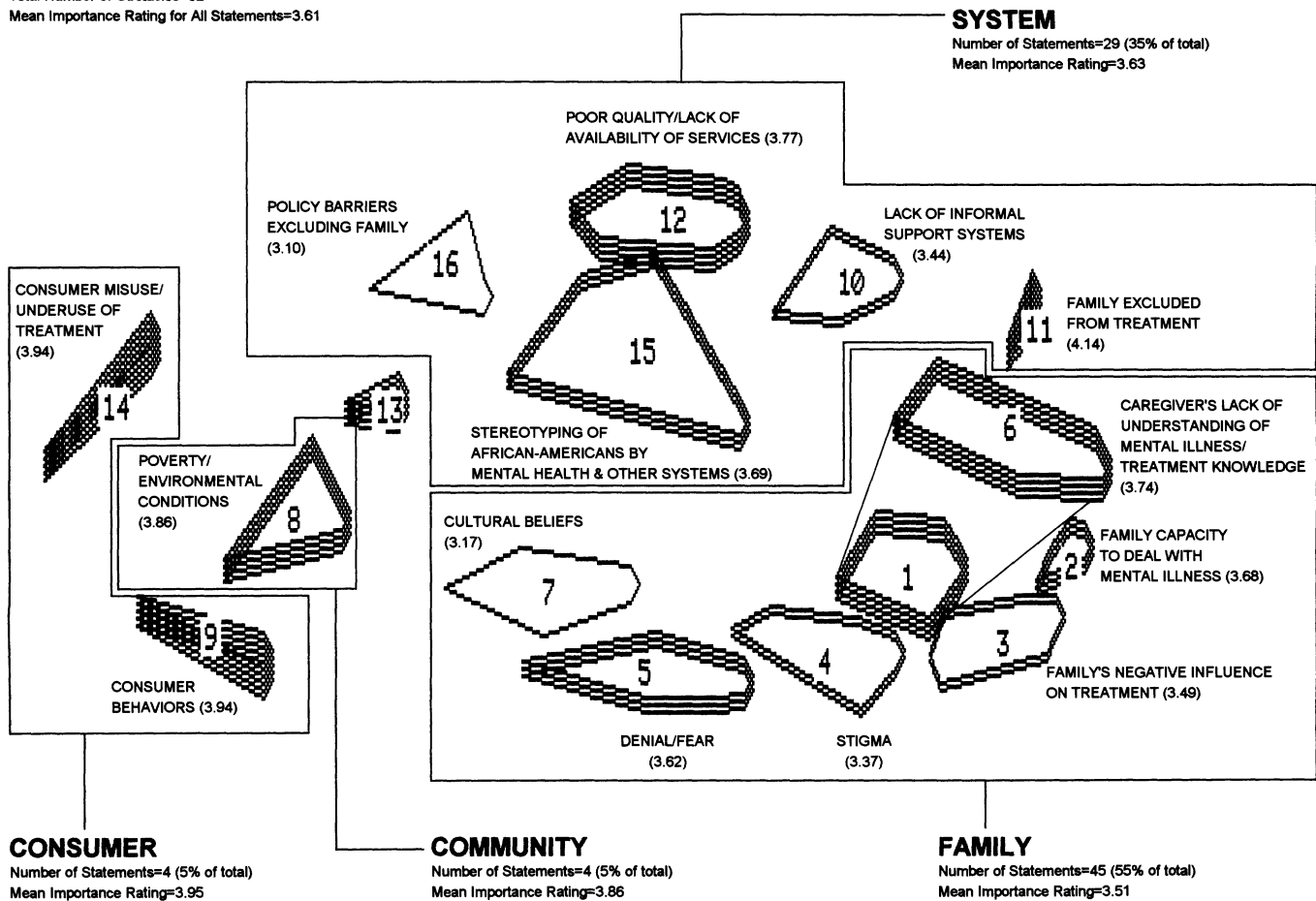
The Consumer region highlights consumer behaviors as a source of barriers to caregivers. Both clusters in this region point to the role played by negative consumer behaviors, such as substance abuse and the refusal to get treatment, in creating obstacles for family caregivers.

The Community region, consisting of only Cluster #8, emphasizes the poverty in which many African-American consumers and caregivers live as a source of barriers to caregiver involvement with their mentally ill family member.

Overall, case managers cited issues of race to a greater degree than did the family caregiver or consumer focus groups,

Figure 3. Obstacles Cluster Map. Case Manager Focus Group

Total Number of Obstacles=82
 Mean Importance Rating for All Statements=3.61



with 8 of 82 (10%) statements pertaining to race. Case managers made reference to a lack of culturally sensitive mental health services, provider knowledge and attitudes, and racial discrimination.

Mental Health Board Focus Group. The 16 clusters on this map were assigned to only three regions: Family, Community, and System, with no clusters deemed to properly belong in the Consumer category. The Family and System regions dominate the map.

The major types of obstacles cited in the Family Region are those stemming from attitudes and beliefs. These attitudes and beliefs are those of the caregiver (Clusters #3, #9, and #12), the consumer (Clusters #3 and #9) and, in some instances, the mental health system and the larger society (Cluster #5). Cited beliefs and attitudes range from somewhat generalized caregiver fears of the mental health system and the experience of social stigma to specific cultural beliefs about the nature of mental illness and caregivers' fear that the consumer will become dependent upon them. Another type of obstacle is seen as deriving from the limited capacity of the caregiver to provide care, either due to personal traits of the caregiver or family structural impediments. Other themes are obstacles which result from a breakdown of relationships with the caregiver, whether they be relationships between the caregiver and the consumer or those between the caregiver and the provider.

All of the clusters in the System region, with the possible exception of Cluster #14, point to inadequate services and supports being available through the mental health system. These inadequacies may in turn be caused by problems of the mental health system, caregivers' inability to access resources, or the absence of needed services or supports. Cluster #16 focuses on education and training needs or issues, such as providers' lack of understanding of the culture of African-American families.

Cluster #13 cites the lack of adequate funding and the absence of culturally relevant services and supports as important caregiver barriers. Obstacles that arise due to differences of opinion between the caregiver and provider make up Cluster #14. Such differences of opinion may be in regard to what is considered appropriate treatment of the consumer, or may be focused on what is considered an appropriate level of provider support for the caregiver. Caregiver ignorance of mental health issues is cited as a contributing cause.

Two distinct themes, both revolving around cultural sensitivity, emerge from the statements of Cluster #1. On the one hand, there is a need for increased cultural sensitivity on the part of providers to African-American family culture and values. On the other hand, there is the stereotyping of African-American families as all having the same culture and values, without adequate attention being paid to individual family uniqueness.

Cluster #15 focuses on the general “user-unfriendliness” of the mental health system. It includes the difficulties of accessing services, the confusion, frustration, and lack of continuity that result from having to deal with multiple systems for services and the lack of continuity which results from high provider staff turnover. Another type of obstacle specifically mentioned is the lack of practical skills training for caregivers. Finally, obstacles which arise as a result of a lack of funding for needed services and supports and the mental health system’s structural incapacity to deal with consumers with multiple disabilities are described in Cluster #7.

The Community region consists of Clusters #6 and #8. Cluster #6 describes obstacles that result from the family’s mistrust of institutions. Obstacles resulting from the limited resources available to caregivers make up Cluster #8. The statements in this cluster distinguish between the absence of needed resources and the lack of access to existing resources. Reasons for lack of access might be a lack of adequate transportation, ignorance of the existence of the resource, or being so overwhelmed by a feeling of racial oppression that one simply has not the energy nor the motivation to attempt to access existing resources.

Overall, mental health board staff explicitly cited issues of race as an obstacle to a greater degree than any of the other three focus groups. Ten of 80 (13%) statements generated by this group, pertained to race. Racial barriers cited were similar to issues cited by the case manager focus group. These barriers included the lack of culturally specific mental health services, provider knowledge and attitudes, and racial discrimination. However, mental health board staff also cited cultural values and belief systems of caregivers as being the locus of barriers.

Convergent and Divergent Obstacle Themes Across Focus Groups

The above findings demonstrate the value of utilizing a wide variety of different constituencies in the mental health system to examine service needs and barriers. Doing so enables us to identify foci and themes cited across groups as well as those cited by only one or two groups. We turn now to an examination of some of the dominant obstacle themes that found expression across focus groups, as well as some themes that were group specific.

Overall, the great majority of the statements generated by the case manager and mental health board groups (90%) fell in the Family and System regions. The statements of the consumer group were spread more evenly across the Family, Community, and System regions, while over half (61%) of all obstacle statements of the caregiver group fell within the System region. All four groups had the lowest percentage of obstacle statements in the Consumer region.

All four focus groups voiced significant concern over the *exclusion of the family from the treatment process*. Exclusion of the family was seen to stem from several sources, including: caregiver ignorance of existing resources and programs due to the lack of any formal mechanism for communicating this information to caregivers on a regular and timely basis; a devaluation of the importance of family involvement on the part of the mental health system; and structural barriers such as a lack of transportation and child care which would enable caregivers to be more involved. Of the four groups, the case managers and caregivers placed the greatest emphasis, and the mental health board group

the least amount of emphasis, on the lack of involvement of the family in the treatment process.

Another broad area of concern identified by all four focus groups was *inadequate caregiver supports*. Understandably, the caregiver group placed the greatest emphasis on this obstacle. As previously noted, the caregivers’ sense of isolation was pervasive throughout the obstacles identified by that focus group. Other dimensions of inadequate caregiver supports include the lack of telephone supports, including information and emergency hot-lines; the absence of self-help groups for caregivers; the absence of support in the areas of consumer finance and medication management; and structural inadequacies such as inadequate transportation, child care, and respite services.

The above two concerns were the only major obstacle themes identified by all four focus groups. However, several other themes were identified by three of the four groups. The *availability and quality of mental health services* was a theme which received significant attention from the case manager, caregiver, and mental health board focus groups. For the most part, the services referred to were consumer services from mental health provider agencies, although some reference was also made to services targeting caregivers. Areas of cited deficiencies included: a general shortage of services in all types of mental health programs; lack of continuity of services, due to high case-loads, leading to case manager burnout and high turnover rates; and bureaucratic red tape and the general user-unfriendliness of the mental health system. Poor quality or lack of services arguably represents the greatest concern of both the case managers and mental health board groups, as reflected in their obstacle statements. The caregivers placed somewhat less emphasis on these obstacles than did the other two groups, though their concern was still significant. Interestingly, while the consumer group indicated its displeasure with the perceived quality of the services that consumers receive, these were more or less isolated statements that did not emerge as a theme of any consequence.

The limited caregiver or family capacity to provide care was a common theme of the case manager, consumer, and mental health board focus groups. Limitations were seen to arise from either personal traits of the caregiver, such as an unwillingness to acknowledge the mental illness of the family member or the caregiver’s own mental illness, or from structural impediments, such as poverty and lack of education. Of the three groups, the consumers probably gave this theme the most emphasis, particularly if one understands it to include the general theme of caregiver inadequacies, which was prominent in the consumer obstacles data. Not surprisingly, the caregivers did not share this perspective. Their emphasis was on not having access to services and information, and on feeling isolated, unsupported, and overwhelmed. However, it is possible to also view these caregiver concerns as a form of expressing limited capacity to provide care.

A theme that was expressed by the caregiver, consumer, and case manager focus groups was that of *negative consumer behaviors*. All three of these groups attached roughly equal importance to this class of obstacles, which was seen to include the use of illicit drugs, non-compliance with medications and treatment regimen, and the consumer’s manipulation of the mental health system.

Several additional themes were expressed by only two of the four focus groups. The case manager and mental health board groups expressed a common concern over *attitudes and beliefs*

which affect treatment. While predominately referring to caregiver attitudes and beliefs, they also included those of consumers, providers, and the society at large. Included among these beliefs are those stemming from racial and cultural perceptions, such as fear of the mental health system and beliefs about the etiology of mental illness, as well as the more generalized stigma attached to mental illness. The case managers tended to focus more on caregiver-held beliefs and attitudes, whereas the mental health board group's focus was broader and more generalized.

The case manager and consumer groups expressed a common concern over the *potential negative impact of caregivers upon consumers*, which was seen as stemming from a variety of sources. These sources included caregiver attitudes and beliefs about mental illness, outright mistreatment of the consumer by the caregiver, and neglect and oversight due to burnout and the weight of other caregiver responsibilities.

Concern over issues surrounding *consumer medications* emerged from both the caregiver and consumer obstacles data. Concern was expressed over proper diagnosis and correct prescriptions being issued, proper dosages and monitoring issues, compliance issues, side effects and interaction effects of prescribed medications with particular foods and with illicit drugs and alcohol.

As interesting as the common themes voiced by more than one focus group were, so were some of the themes expressed by

only a single group. Two important themes emerging from the caregivers obstacles data were not echoed by any of the other groups. These were *managing the finances of the consumer*, and *the inability of the legal system to deal appropriately with mental health consumers and their family caregivers*. Both of these themes commanded considerable attention from the caregiver group. Regarding financial management, caregivers pointed to the difficulties of functioning as payee for the consumer, particularly to the confusion and red tape entailed. In addition, they pointed to the strain of managing the consumer with regard to money matters. Regarding problems with the legal/judicial system, the caregivers pointed to a general and seemingly systemic lack of sensitivity and awareness within the legal/judicial system as to the special needs of consumers and their family caregivers.

The consumers expressed a concern with *age*, of both the consumer and the caregiver, which was not echoed by any other group. Concern focused on the caregiver's ability to distinguish natural aging processes from mental illness symptoms in elderly consumers, as well as the elderly caregiver's ability to provide competent care. It should be noted, however, that this was a relatively minor theme of the consumer obstacles data.

Solutions Identified by Focus Group

Family Caregiver Focus Group. The solutions cluster names in Figure 5 suggest three broad types of solutions: (1) increased

Figure 4. Obstacles Cluster Map. Mental Health Board Focus Group

Total Number of Obstacles=80
Mean Importance Rating for All Statements=3.23

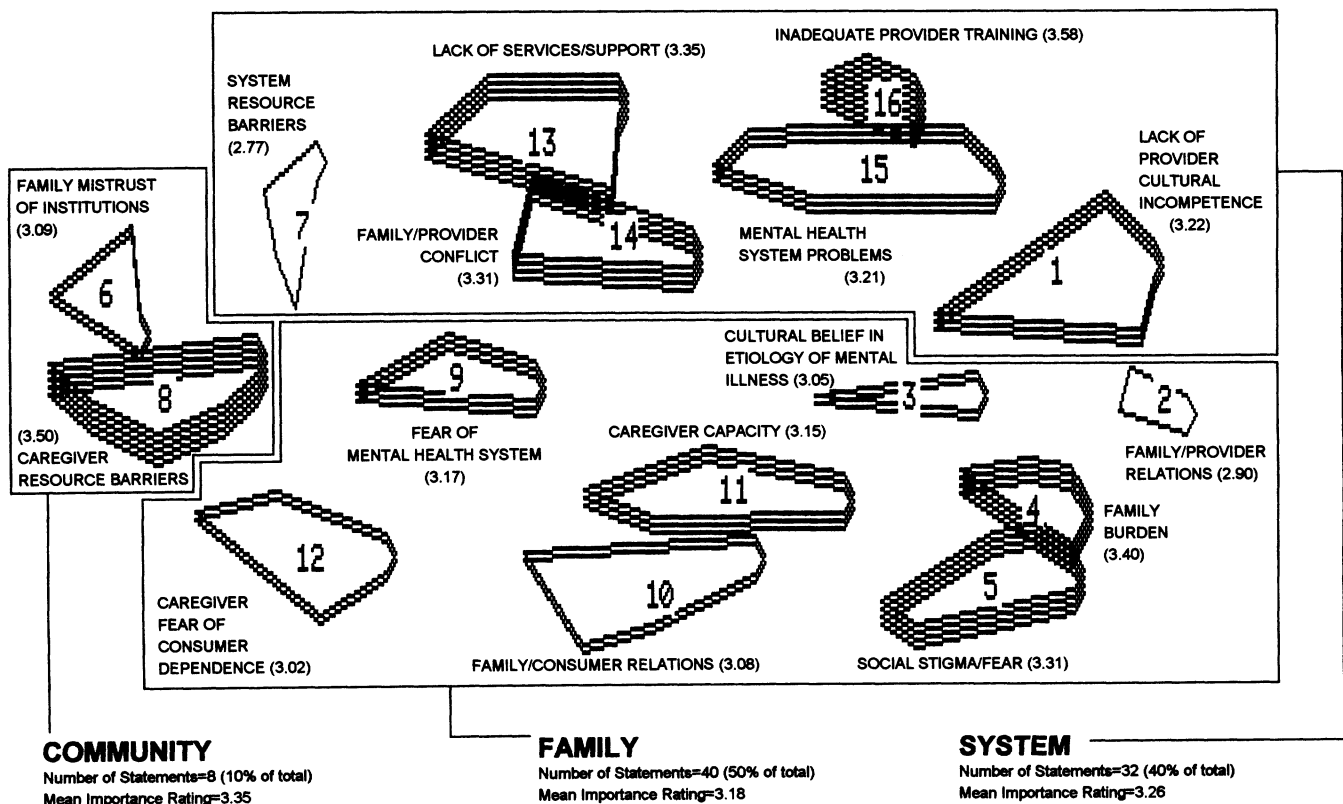
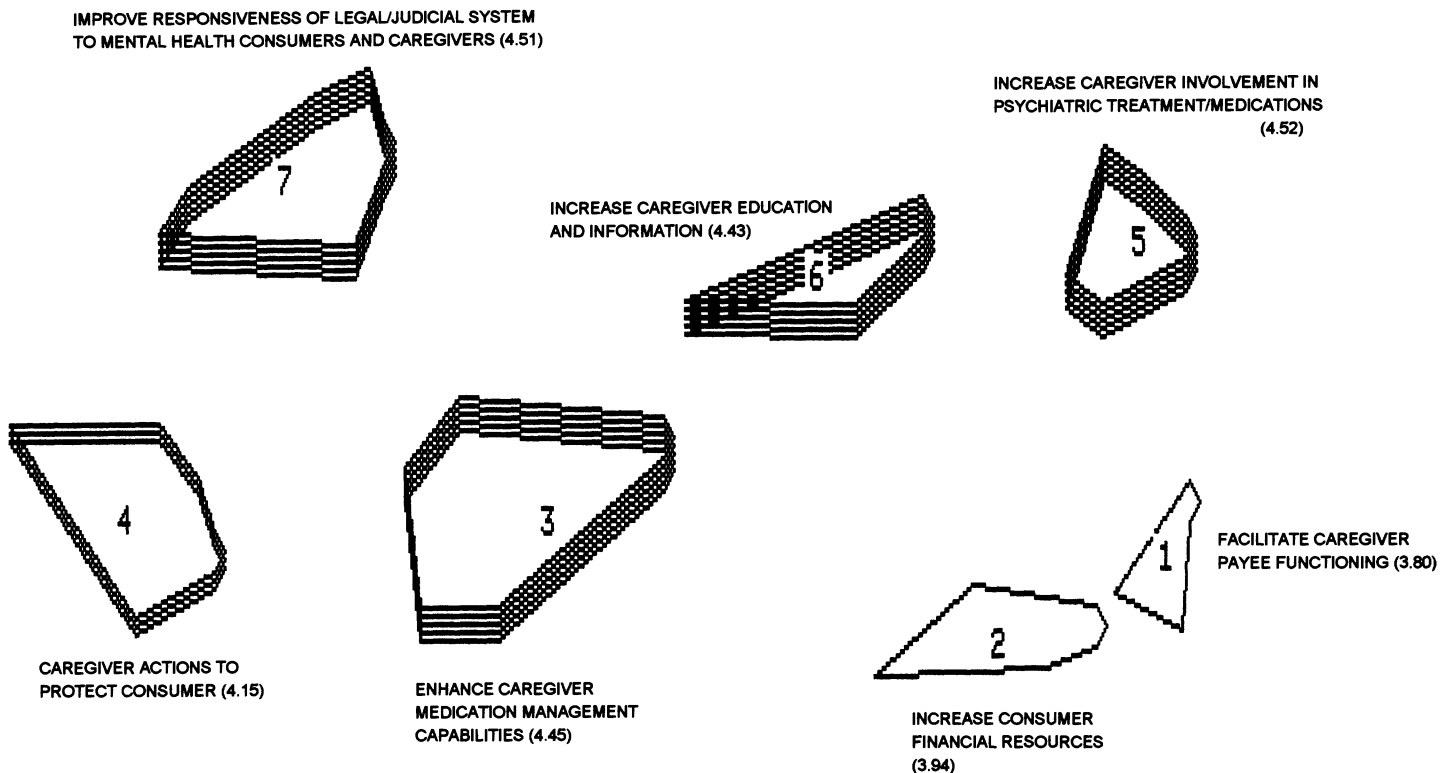


Figure 5. Solutions Cluster Map. Family Caregiver Focus Group

Total Number of Solution Statements=58

Mean Importance Rating for All Statements=4.27



support and involvement of the caregiver and consumer by the mental health system; (2) caregiver self-help initiatives; and (3) improved responsiveness of the legal/judicial system to caregiver and consumer needs.

By far the greatest emphasis of the family caregivers was on increasing the support to, and the involvement of, family caregivers in the treatment process. Clusters #1, #2, #3, #5, and #6, which offer a variety of suggested strategies, all focus on these types of solutions (see Figure 5). Cluster #5, *Increase Caregiver Involvement in Psychiatric Treatment/Medications*, suggests two types of solutions: those involving innovative programming, and those calling for improved performance by existing programs and services. The top-rated of all 58 caregiver solution statements (importance rating = 4.95) suggests one such innovation: "Doctors should have a conference with the consumer and caregiver on the consumer's diagnosis, treatment plan, and prognosis." Examples of improving performance of existing services include doctors spending more time with consumers and doing a better job of monitoring medications.

Enhance Caregiver Medication Management Capabilities (Cluster #3), also suggests two types of solutions: those stemming from provider-initiated assistance to the caregiver, such as the implementation of agency family group meetings; and those arising from caregiver-initiated actions, such as referencing medical textbooks to verify suspected side-effects of consumer medications. The statements of Cluster #6, *Increase Caregiver Education and Information*, suggest that this should be accomplished in two ways. The first would be through programs and initiatives

which directly target caregivers as information recipients. A second means would be through media campaigns aimed at the general public, but which would also reach many caregivers in the process.

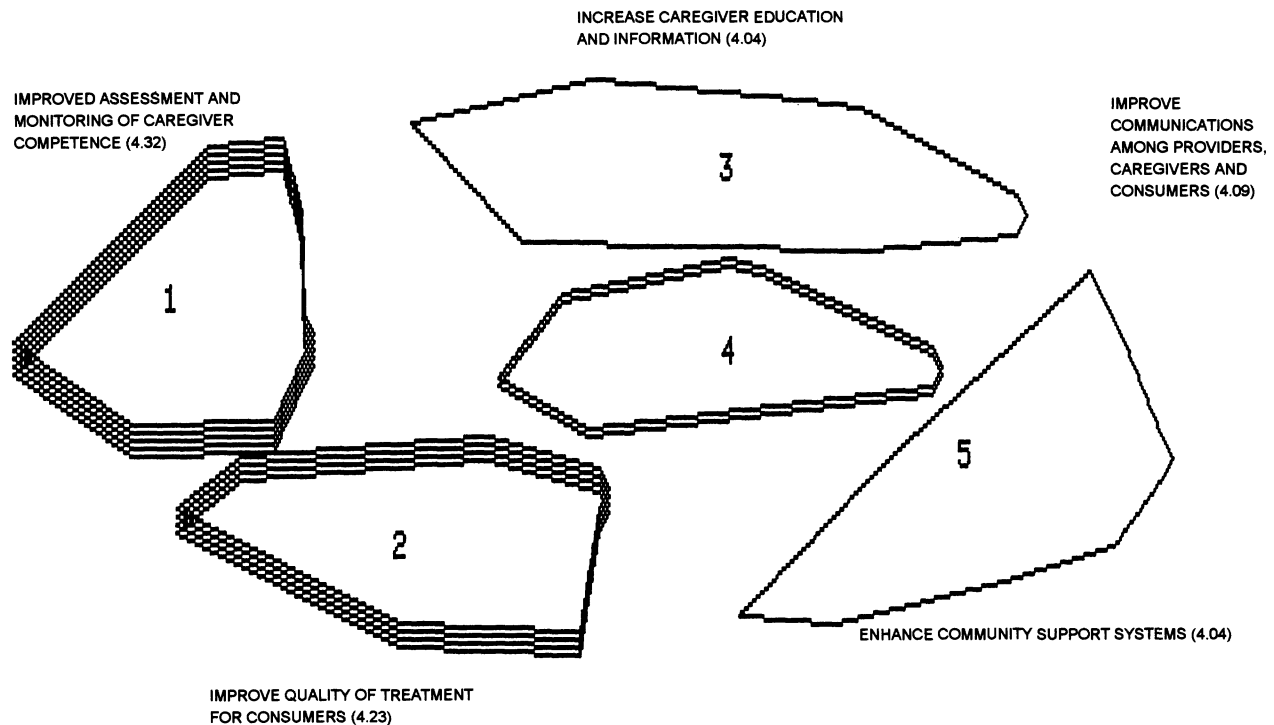
Increase Consumer Financial Resources (Cluster #2) proposes two different approaches. One way is to increase funding to the programs which serve consumer needs. A second way to increase consumer financial resources is to eliminate or reduce the red tape surrounding the consumer's finances. Cluster #1, *Facilitate Caregiver Payee Functioning* is closely related to Cluster #2, dealing with finances, but focuses exclusively on issues arising from caregivers' functioning as payees to consumers. Two types of solutions are offered: systemic change, perhaps involving the creation of a special agency to function exclusively in the payee capacity; and improved caregiver management of the consumer regarding money matters.

The second broad type of solution, those focusing on caregiver self-help initiatives, can be seen in Cluster #4, *Caregiver Actions to Protect Consumers*, which describes a variety of individual caregiver actions which all have the general quality of "looking out" for the consumer. These include defending the consumer against unscrupulous merchants and insulating the consumer from individuals who pose the risk of being a bad influence.

Finally, solutions pertaining to improved responsiveness of the legal/judicial systems to caregiver and consumer needs can be seen in Cluster #7. Solutions include recommendations for spe-

Figure 6. Solutions Cluster Map. Consumer Focus Group

Total Number of Solution Statements=80
Mean Importance Rating for All Statements=4.13



cial training of legal/judicial personnel, increased lobbying on behalf of consumers, and legal reforms which would facilitate identification of mental health consumers by the legal system to ensure proper treatment.

Noticeable by their total absence from the caregiver solutions data are any statements explicitly citing race or culture as factors in the removal of barriers.

Consumer Focus Group. Figure 6 reveals several interesting patterns within the solutions data. The five cluster names suggest four major types of solutions: (1) improved caregiver performance, to be achieved through caregiver training, education and accountability; (2) improved mental health system services for the consumer; (3) improved all-around communications among providers, consumers and caregivers; and (4) greater community supports for caregivers and consumers.

The theme of improved caregiver performance through caregiver education, training, and accountability can be seen in Clusters #1 and #3. Cluster #1, *Improved Assessment and Monitoring of Caregiver Competence*, is the highest-rated of the five clusters of Figure 6, with an importance rating of 4.32 (i.e., very-extremely important). Solutions include establishing minimum legal competency standards for caregivers and dramatically increasing caregiver accountability, with a call for sanctions for abuses. Cluster #3, *Increase Caregiver Education and Information*, suggests two means by which this may be achieved. The first is through programs specifically aimed at caregivers, the other through educational programs aimed at the general public.

Improved mental health services for the consumer is the theme of Cluster #2. The implicit premise underlying this cluster

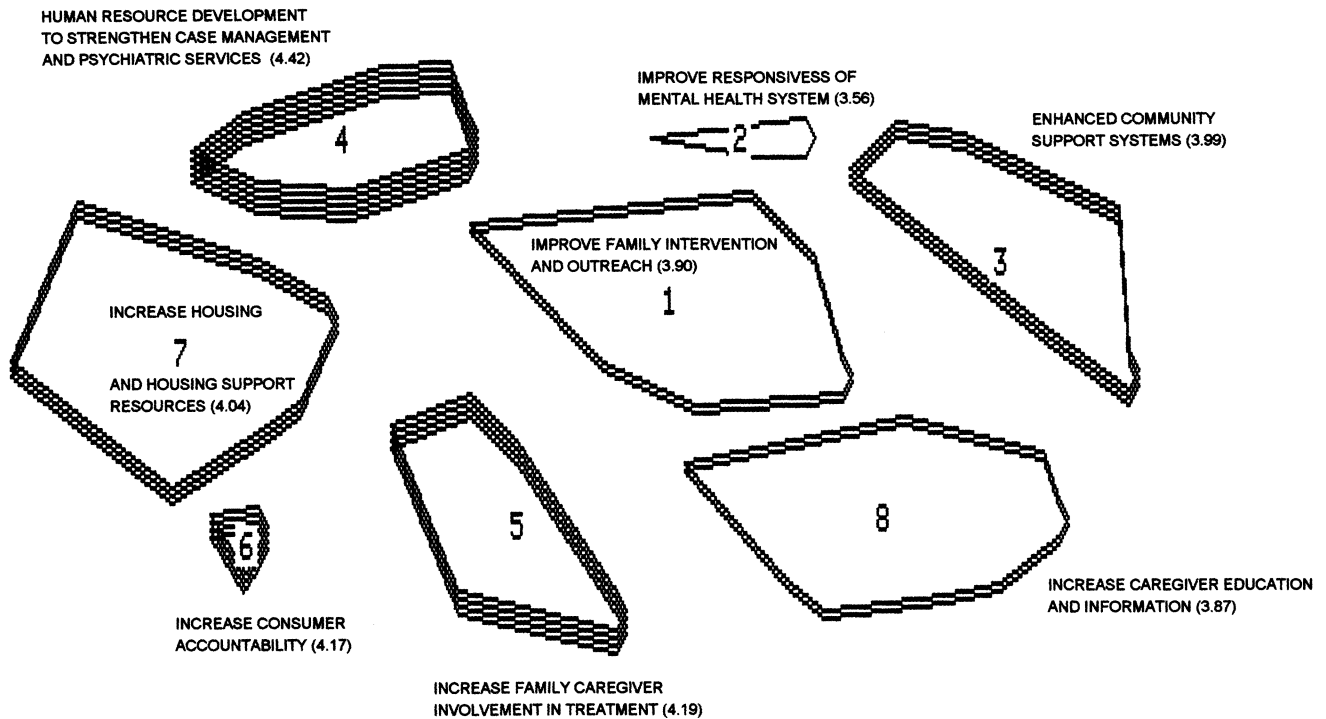
is that improving the quality of the services consumers receive from the mental health system will proportionately decrease the burden of the caregiver. Both the provision of additional services, as well as the improvement of existing services, are called for by consumers. Specific focus is placed upon better diagnosis and medication monitoring, reduction of case manager caseloads, making available more high quality housing, improving communications, and generally making the mental health system more user-friendly.

While such improvement in communications among all parties is cited in Cluster #4, overwhelmingly the need expressed is for improved communications between caregivers and providers, particularly with regard to consumer medications. Finally, Cluster #5, *Enhance Community Support Systems*, describes solutions which call for increasing caregiver supports in a variety of ways, such as providing caregiver home aides, telephone supports and support groups, respite (including subsidized recreational activities), financial support enabling the caregiver not to work outside the home, and child care for the children of both the caregiver and the consumer.

As was the case with the family caregiver data, none of the solution statements from the consumer focus group explicitly cite race or culture as a factor.

Case Manager Focus Group. The cluster names of Figure 7 suggest three very broad types of solutions: (1) those stemming from increased supports for caregivers; (2) those stemming from an improved mental health system and, (3) those deriving from increased consumer accountability.

Total Number of Solution Statements=98
 Mean Importance Rating for All Statements=4.02



The theme of increased supports for caregivers can be seen in Clusters #1, #3, #7, and #8, which identify a variety of supports. Cluster #7, *Increase Housing and Housing Support Resources*, addresses two related but distinct housing resources needs, (1) the need to improve the living conditions of the caregiver in order to make it easier (or merely possible) for the caregiver to provide adequate care, and (2) the need for more and better residential facilities for consumers. As regards housing support resources, better and cheaper access to transportation also emerges as a significant theme. Cluster #3, *Enhanced Community Support Systems*, encompasses a wide variety of suggested solutions, a reflection of the broad range of potential community supports. However, these may be divided into several broad categories: neighborhood-based centers for caregivers and consumers; more caregiver telephone support services (e.g., hot-lines); support groups for caregivers; improved and expanded community-based crisis intervention capabilities; and more treatment centers for consumers, particularly for African-American females, dual-diagnosis consumers and consumers being released from jail.

Cluster #1, *Improve Family Intervention and Outreach*, also contains a range of diverse solutions. One theme which emerges is the call for better family counseling services, including better early assessment of the family as a whole, improved early intervention, and the creation of family support groups to discuss different mental illnesses and medications.

Cluster #8, *Increase Caregiver Education and Information*, is a very coherent cluster which voices one of the major leitmotifs to emerge out of the case manager solutions data. The vast

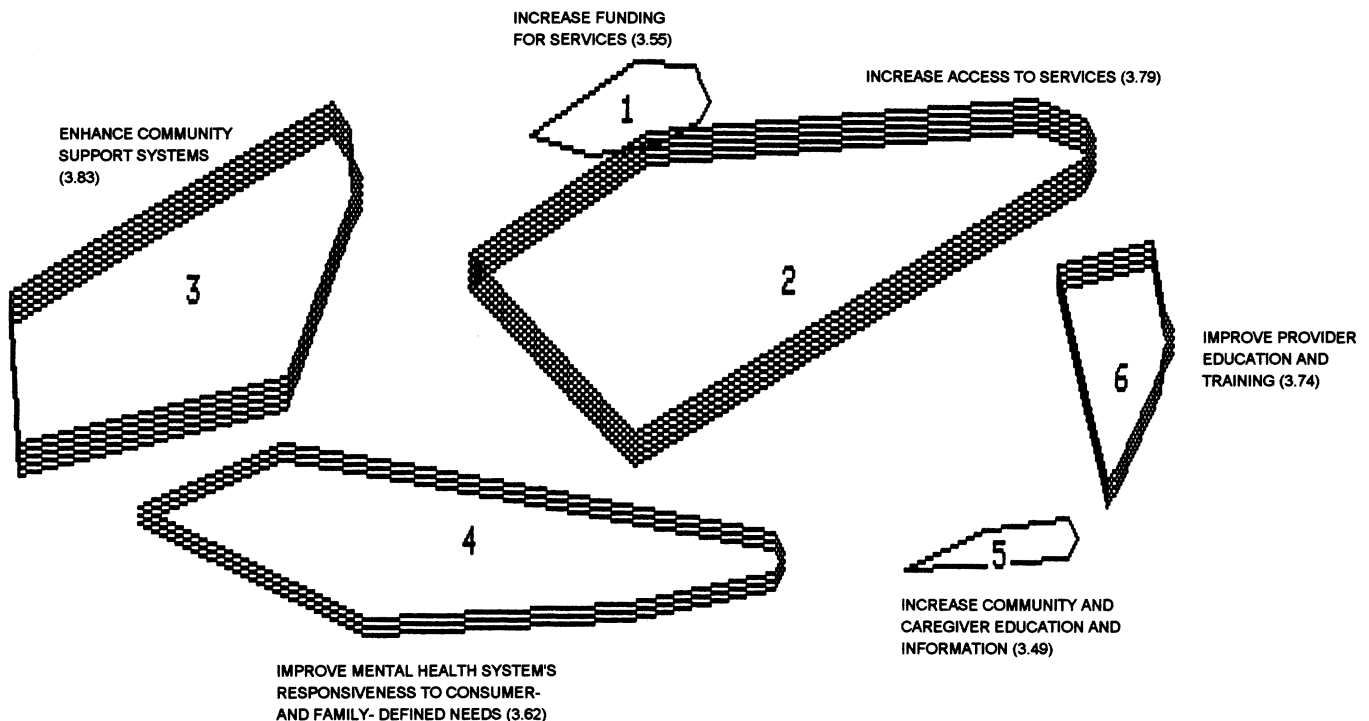
majority of statements in this cluster make an explicit reference to caregiver education, whether it be through classes, videos, call-in information lines, media ads, in-home programs or newsletters.

Solutions focusing on needed improvements in the mental health system can be seen in Clusters #2, #4, #5, and, to some extent, #1. Cluster #4, *Human Resource Development to Strengthen Case Management and Psychiatric Services*, which was the highest rated of all the solutions clusters, focuses on the need of the mental health system to develop its personnel resources in two key areas: case management and psychiatric services. With regard to case managers, a number of incentives are suggested to assure better quality and continuity of services from existing case managers and also a number of strategies are suggested to attract a better quality of applicant to the field as a whole. These incentives include higher case manager salaries (which were directly linked by group participants to a reduction in turnover rates), payment of case manager licensure fees, and financial supports for continuing education. Noteworthy is the fact that the top-rated solution overall was "Hire more case managers" (importance rating = 4.78).

Regarding psychiatric services, a concern with cultural bias and language barriers was manifest. In particular, ways to overcome communications problems arising from an increasingly Indian and Asian pool of psychiatrists who have great difficulty understanding their African-American consumers, as well as making themselves understood to them, were called for. The call for incentives to African-Americans to enter the psychiatric profession should be understood as addressing these language barriers,

Figure 8. Solutions Cluster Map. Mental Health Board Focus Group

Total Number of Solution Statements=78
 Mean Importance Rating for All Statements=3.68



as well as addressing cultural biases in diagnosis and treatment. As with the need for more case managers, there was strong agreement about the need to hire more psychiatrists.

Cluster #5, *Increase Family Caregiver Involvement In Treatment*, points to the need for routinely involving family members (including those other than the primary caregiver) in all phases of the treatment process, beginning with assessment and treatment planning. A modification of the confidentiality laws was suggested as a way of enhancing family involvement. Cluster #2 addresses the need to make the agencies and services of the overall mental health system more sensitive and responsive to the needs of both family caregivers and mental health consumers.

The third broad type of solution, consumer accountability, is the theme of Cluster #6, *Increase Consumer Accountability*. This is a highly coherent cluster which captures one of the strongest and most consistent themes to be found among the solution statements of the case manager focus group. Consumer accountability is to be enhanced primarily through the mandating of certain kinds of treatment, including mandatory treatment for consumers receiving entitlements, and the imposition of sanctions for non-compliance.

Race and cultural issues emerged as a theme of the case managers' solution statements. A total of 7 solution statements (7% of the total) make explicit reference to race and/or culture as a factor. These include calls for the training and hiring of more African-American psychiatrists, more treatment centers specifically targeting African-American females, measures to reduce language barriers and cultural bias in dealings with foreign-born

psychiatrists and physicians, and greater education of the general public concerning African-American culture.

Mental Health Board Focus Group. The cluster names of Figure 8 suggest three broad categories of solutions: (1) those involving improving access to services, either through increased funding for new or existing services, greater responsiveness to the needs of the consumers, or through other measures; (2) solutions involving increased and improved education, whether it be of the provider, the caregiver, or the community at large; and (3) solutions involving the enhancement of caregiver supports.

The theme of increasing access to services can be seen in Clusters #1, #2, and #4. *Increase Access to Services* (Cluster #2) depicts two broad categories of solutions. The first derive from increased supports to providers (e.g., hiring more staff and increasing salaries) and improved staff performance (e.g., better phone availability and more varied working hours to assure availability during the evenings and on weekends.) The second type of solution involves increasing caregiver supports, through such means as telephone hot-lines, respite care and reduction of appointment barriers. Cluster #4, *Improve Mental Health System's Responsiveness to Consumer- and Family-Defined Needs*, emphasizes the desirability of allowing families a greater voice in treatment planning and execution. Cluster #1, *Increase Funding for Services*, recommends better fiscal management of existing programs, as well as funding for a broader range of services, including some which are not traditionally looked upon as "services" per se, such as consumer hobbies, family recreation, and homemaker services for caregivers.

Increased education is the theme of Clusters #5 and #6. Cluster #6, *Improve Provider Education and Training*, suggests that improvement needs to occur in two domains: (1) the formal education received by the provider prior to employment, and (2) on-the-job and in-service training. Upgrading of curricula at those institutions charged with training providers, and the establishment of apprenticeship programs and mandatory in-service training standards are also recommended. Cluster #5, *Increase Community and Caregiver Education and Information*, as its name suggests, outlines the need for two types of educational efforts: those targeting family caregivers specifically, and those aimed at the public at large. Significantly, the education campaign outlined for the general public includes the lofty goal of bringing about a fundamental change in society's perception of mental illness.

Finally Cluster #3, *Enhance Community Support Systems*, focuses on strengthening caregivers' systems of social support through two types of approaches. The first is increasing the quantity and quality of existing support systems. The second kind of solution revolves around legal/political activity, such as changing the confidentiality laws to facilitate caregiver participation in treatment, and comprehensive and coordinated lobbying efforts on behalf of mental health issues.

Overall, then, the emphasis of the mental health board group's solutions points overwhelmingly toward improving the quality, availability and access to system services. Of secondary concern is enhancing the community supports available to caregivers.

The themes of race and cultural sensitivity are well-represented among the mental health board group's solutions data. Eight statements appearing in six different solutions clusters make explicit reference to race or cultural issues (10% of the total). Issues of race and cultural sensitivity are viewed as more or less pervasive by the mental health board group, to be attended to in every undertaking.

Convergent and Divergent Solution Themes Across Focus Groups

Once more we turn to an examination of some of the themes to emerge from the solutions data. Themes that were expressed across focus groups, as well as those themes that were group-specific are discussed.

Only one solutions theme received the endorsement of all four focus groups: *improved caregiver supports*. This theme was a major concern of the case managers and the mental health board staff, and was implicit in many of the solutions statements made by the caregivers. This theme was also expressed by the consumer focus group, although it was not seen to be as important as increasing caregiver accountability and improving the quality of services to consumers. Improved caregiver supports were seen to encompass improved housing, support groups and telephone hotlines, respite support and recreational activities, in-home aides, workshops and greater access to information, and caregiver counseling.

Two important themes were voiced by three of the four groups. The need to *increase the involvement of the caregiver and family in the treatment process* emerged from the solutions data of the caregiver, case manager, and mental health board groups. Means for accomplishing this goal were seen to include active recruitment of family involvement by case managers and

others, rendering the mental health system more user-friendly, including reduction of appointment barriers, and adopting a more family-centered, rather than consumer-centered, approach to counseling and needs assessment. It should be noted that the consumers voiced a somewhat different but related theme. They called for a more general improvement in communications, particularly among providers and consumers, and generated only a relatively few statements specifically calling for the increased involvement of the caregiver in the treatment process.

Another theme receiving the endorsement of three of the four focus groups was the call to *improve the mental health system*, particularly the services provided to consumers. This theme emerged as a major concern of the case managers, while receiving only slightly less emphasis from the consumers. While the mental health board focus group certainly called for an improvement of the mental health system, the tone of their solution statements was far less strident than was that of the case managers or consumers. The latter two groups were quite direct in their criticisms of the system. They indicated the need for major overhauls in the areas of personnel and programming, calling for streamlined procedures, tighter quality control measures, and more stringent criteria regarding the formal and ongoing training of personnel. The mental health board group, on the other hand, spoke more in terms of making the system more responsive, more culturally sensitive and more user-friendly. It is noteworthy that the caregiver focus group failed to identify this theme to any significant degree. Their focus was almost exclusively on things that could be done to enhance their own performance and effectiveness as caregivers.

Both the caregivers and consumers shared a major focus on solutions centered around *better management of medications*. Specific concerns were expressed about diagnoses, incorrect dosages, side effects of medications, interaction effects with foodstuffs and illicit drugs and alcohol, and the availability of medications when needed. It is telling that both the case manager and mental health board focus groups were silent on this theme that was of great concern to the others.

Several important themes were cited only by individual focus groups. Perhaps chief among these was the caregivers' call to *improve the responsiveness of the legal/judicial system to the needs of consumers and caregivers*. Caregivers cited the general need for greater sensitivity to the special needs of mental health consumers on the part of the legal/judicial system and made specific recommendations regarding police training for special handling of mental health consumers.

The case managers were very vocal in calling for an *increase in consumer accountability*, expressing a willingness to mandate certain domains of treatment and impose sanctions for non-compliance. Consumers, by the same token, were equally vocal in calling for an *increase in caregiver accountability*. They called for the establishment of minimum standards of caregiver competence and legal sanctions in cases of abuse.

Whereas many of the solutions proposed by other focus groups implicitly entailed an increase in funding, funding specifically emerged as a major theme of the mental health board focus group. Fully 15% of this group's brainstormed solution statements explicitly call for either increased funding, more efficient utilization of current resources, a redefining of funding priorities, or some other facet of improved resource management. In addition to the 15% of statements making explicit reference to fund-

ing issues, a great many others implicitly entail increased expenditures. As the funding authority for the local mental health system, this emphasis of the mental health board group is understandable.

Discussion and Implications for Service Delivery, Policy and Research

In general, there was good consistency between the obstacles and solutions generated within each group. However, there were some inconsistencies with which obstacles and solutions themes were identified by the various focus groups, yielding several interesting observations. For example, all groups identified the exclusion of family members from the treatment process as a significant barrier. However, increasing family involvement did not emerge as a solution theme among the consumers. Rather, their concern was directed more toward the inadequacies of family caregivers that prevent them from becoming meaningfully involved. Unless these problems can be overcome, consumers appear reluctant to suggest ways in which family participation can be increased. Thus, the data suggest that, at least from the perspective of consumers, system changes designed to improve caregiver competence and capacity should precede attempts by the mental health system to "legislate" family involvement.

Another example involved the availability and adequacy of mental health services. Consumers did not draw a connection between the services they receive and the involvement of family caregivers. On the other hand, they were very vocal about how service quality and availability should be increased as solutions. Family members, however, exhibited just the opposite pattern. They identified the existing services as a barrier, but did not suggest improving services as an approach. These findings are indicative of differing loci as to where change needs to take place. Consumers tended to focus on the need for external change, including changes in the mental health system and caregivers. The caregiver group, however, tended to internalize the need for change and talked much more about ways in which they could change and things they could do to improve their own involvement.

The absence of particular themes from the statements of some groups was also of interest. As noted above, case managers and mental health board staff failed to identify medication issues as a theme. The mental health board staff also omitted consumer behaviors as an obstacle. These groups, to the exclusion of the others, were the ones that mentioned attitudes and beliefs. These findings are likely the result of the differing roles played by each of the constituent groups and the perspectives they bring.

Differences among the groups also extend to the explicit mention of race and culture in both barriers and solutions. Only a relatively small percentage of both obstacle and solution statements by the focus groups explicitly cite race and/or culture as a factor. If we once more invoke our caveat about drawing conclusions from these data (see Endnote 3), it nevertheless strikes us as significant that not a single solutions statement from either the caregiver or consumer focus groups made any explicit mention of race or culture as a factor to be considered in the amelioration of caregiver obstacles. It should be noted that the case manager and mental health board staff groups were both culturally mixed. The other two groups were composed entirely of African-Americans. It is possible that group composition may affect the degree to which race and culture are explicitly attended. Additional re-

search is needed, controlling for the racial mix of the respondent groups, in order to investigate this question.

All of these observations underscore the importance of gathering multiple perspectives when assessing needs and developing plans to address these needs. The results also clearly illustrate the interactive nature of the mental health system. While there is considerable agreement across groups as to where barriers exist, there is less agreement on how these barriers should be addressed. There is also variability in where the various groups place their priorities. System design or redesign must incorporate these interactions and interrelationships in order to be successful. Thus, while many of the results from individual groups have been noted in previous research, this study adds an additional dimension to our understanding by allowing the comparison of the conceptualization of the same issue by multiple groups, each of which is an integral part of the total mental health system.

Overall, study findings demonstrate that family caregivers of African-American mental health consumers face a number of barriers which inhibit their involvement in the treatment and care of their family member with mental illness. The loci of these barriers are on multiple levels—consumer, family, community, and the mental health system. Though progress has been made by mental health professionals over the past decade in addressing the needs of caregivers, clearly further work is needed, especially with minority families.

The needs of African-American families are not being adequately addressed or recognized by mental health systems. Mental health systems that are defined as consumer-driven need to be re-conceptualized as consumer *and* family driven. This change in philosophy needs to be accompanied by the development of specific mechanisms for greater inclusion of families in the treatment process. This will enhance the support which families receive from mental health professionals and in turn will strengthen a family's abilities to provide support to their mental health consumers. The issue of enhancing relationships between African-American families and mental health professionals cannot be addressed simply by offering a smorgasbord of services and resources for families. Rather, African-American families need to be viewed by professionals as true partners in the care of their family members with mental illness. In addition, the differing needs of families, based on family history, family support systems, and family life stage, need to be taken into consideration.

Partnerships by mental health professionals and family caregivers means early involvement of families in the treatment process and the establishment and maintenance of ongoing channels of communications. This increased involvement may also help address the negative perceptions that consumers have of family caregivers as expressed in our study findings. By involving families to a greater degree in the treatment process, by increasing their knowledge and social support and assisting their efforts at self-help and advocacy, family caregivers should be able to function more effectively, thereby reducing tensions and sources of conflict with their care recipients.

Family caregivers in this study expressed a genuine willingness to use self-help mechanisms to address their needs. Therefore, the role of mental health professionals in working with families does not have to be primarily a direct service one. It should include also serving as *enablers, educators, facilitators, consultants, and advocates*. Given the changing nature of mental health

care due to the fiscal constraints of managed care, such a strategy can be both timely and cost-effective.

While all of the issues addressed in this study are not unique to African-American family caregivers, our results clearly indicate that African-American family caregivers face some particular challenges that need to be addressed by mental health professionals. It is important to recognize that race and social class may interact to exacerbate needs felt by minority family caregivers. The need for greater sensitivity by mental health professionals and institutions to issues of ethnicity and culture was a prominent theme in this study. Furthermore, this need was seen by some focus groups as being more or less pervasive, involving all aspects of the mental health service delivery system, from the recruitment and training of staff and professional workers, to the restructuring of existing facilities and services to render them more "user-friendly" to minority clients.

Notwithstanding the above, a number of the obstacles and solution statements brainstormed by the caregivers, consumers, case managers, and mental health board staff in this study can be applied generically across family caregivers, regardless of race. In particular, a number of the barriers cited in this study are consistent with findings concerning caregiver needs from research literature over the past two decades (Davis, Dinitz, & Pasaminick, 1974; Doll, 1976; Grad & Sainsbury, 1963; Hatfield, 1978). Our findings, in part, are thus demonstrative of commonalities in the caregiving experience across race and social class. However, as with any qualitative study, the external validity of this study is limited. The number of study participants in each of the focus groups was small and each group was not necessarily representative of its broader constituency. Therefore, care needs to be taken in the interpretation and utilization of study findings.

The methodology utilized in this study also has implications for the planning and delivery of mental health services by mental health professionals. The focus group methodology coupled with concept mapping offers mental health professionals an efficient and cost-effective approach to identifying and developing strategies to address unmet mental health needs, and one requiring only modest levels of training in order to be successfully implemented. Furthermore, as previously mentioned, study findings demonstrate the value of utilizing a diverse set of constituencies in the mental health system to examine service needs and barriers. This approach leads to the identification of themes cited across multiple groups as well as those cited by only one or two groups. The end result is the potential for the development of a set of interventions and strategies which can more comprehensively address unmet needs.

Another potential benefit deriving from the methodology employed in this study is the very large number of obstacle statements which were generated by the focus groups. These statements can be used in future research to generate and test a scale designed to measure obstacles to involvement of families in the treatment and support of their family members with mental illness. The scale could include both generic obstacles as well as obstacles that are particular to specific racial or ethnic groups. Once developed, the scale could be used across constituent groups—family caregivers, consumers, case managers and mental health board staff—in a broader study to examine the impact of these obstacles on family caregivers and the degree to which the identification of particular obstacles or groups of obstacles

varies by constituency group, constituent group characteristics such as race or ethnicity, or by geographic area.

Although a number of the solutions suggested in this study are not new (e.g., improved caregiver supports and increasing the involvement of family caregivers in the treatment process), they do support previous recommendations by family researchers and advocates (Biegel, Milligan, Putnam, & Song, 1994; Lefley & Johnson, 1990). While there is no consensus in the mental health field regarding the adequacy with which mental health professionals are currently meeting the needs of families (Biegel, Song, & Milligan, 1995; Hatfield, 1986; Marsh, 1992), it is clear that mental health professionals have the technology, knowledge and skills, to do so.

Endnotes

¹Concept System software was used for all concept mapping data analyses in this study. The statements and the individual sortings and ratings obtained from the focus groups are the raw data from which the Concept System software constructs a series of "maps" for each of the four focus groups. From the sort information for each group, an $N \times N$ ($N =$ number of statements) binary, symmetric similarity matrix is constructed for each participant. For any two items sorted in the same pile, a '1' is placed in that row and column, while a '0' is placed when they are not. Subsequently, a group similarity matrix is obtained by combining the individual matrices. This matrix also has as many rows and columns as there are statements. The number placed on any pair of statements indicates how many focus group members grouped that pair of statements in the same pile. A multi-dimensional scaling procedure then utilizes this matrix to produce a "point map," with each point representing one statement and the distance between points indicating the sorting similarities and differences. Finally, hierarchical cluster analysis, using Ward's algorithm as the distance measure, groups the individual statements into clusters which presumably reflect similar concepts (Trochim, 1989). The software permits specification of the number of clusters desired in the "solution." Indeed, a major task of interpreting data using Concept System software lies in deciding on the cluster solution that provides the best "fit" with the data.

²"Fences" drawn around each cluster in Figures 1-8 represent the average importance rating of that cluster, with more "fences" indicating a higher average importance rating. The average importance rating of each cluster appears in parentheses after the cluster name. The geographical size of a map cluster is not related to the number of statements it contains, but rather the perceived coherence of its constituent statements with one another, as reflected in the sortings of the focus group participants. The number appearing inside each cluster is its identifying number, and has no statistical significance or meaning.

³A legitimate methodological question surrounds treatment of brainstormed statements which make explicit reference to race and/or culture as a factor. Since the focus questions asked were, "What barriers or obstacles hinder African-American families' involvement in the treatment and support of their family member with mental illness?" and "How can barriers or obstacles which hinder African-American families' involvement in the treatment and support of their family member with mental illness be overcome?," it can rightfully be argued that *all* of the statements brainstormed in response to these focus questions have a racial component to them. It is certainly the case that a great many statements, although making no explicit reference to race or culture, nevertheless assume the context of the focus questions. In contrast, statements making explicit reference to race and/or cultural issues do apply exclusively to African-American family caregivers and, what is more, were stated by group participants in order to explicitly and specifically reference African-Americans in contradistinction to other groups. Therefore, such statements are treated as a special category indicative of observations and concerns in which race and/or culture is viewed as being critically relevant. These items will be tracked throughout the discussion of the data, with the understanding, however, that they do not represent the entire breadth and scope of the impact of race and culture in these matters.

References

- Bertalanffy, L. V. (1969). *General system theory, foundations, development, applications*. New York: G. Braziller.
- Biegel, D. E., & Farkas, K. (1989). *Mental health and the elderly: Service delivery issues*. Cleveland: Monograph Series, Western Reserve Geriatric Education Center, Case Western Reserve University.
- Biegel, D. E., Milligan, S., Putnam, P., & Song, L. (1994). Predictors of burden among lower socioeconomic status caregivers of persons with chronic mental illness. *Community Mental Health Journal*, 30(5), 473-494.
- Biegel, D. E., Song, L., & Milligan, S. (1995). A comparative analysis of family caregivers perceived relationships with mental health professionals. *Psychiatric Services*, 46(5), 477-482.
- Cook, J. A. (1993). *Mapping staff perceptions of a mobile job support program for persons with severe mental illness*. Presented at the National Conference on Mental Health Statistics, Center for Mental Health Services, June 6-9, Washington, DC.

- Davis, K. (1982). An alternative theoretical perspective on race and voluntary participation. *Journal of Voluntary Action Research*, 11(2-3).
- Davis, A., Dinitz, S., & Pasaminick, B. (1974). *Schizophrenics in the new custodial community*. Columbus: Ohio State University Press.
- Davis, L., & Proctor, E. K. (1989). *Race, gender and class: Guidelines for practice with individuals, families and groups*. Englewood Cliffs, NJ: Prentice Hall.
- Doll, W. (1976). Family coping with the mentally ill: An unanticipated problem of deinstitutionalization. *Hospital and Community Psychiatry*, 27(3), 183-185.
- Giordano, J. (1973). *Ethnicity and mental health*. New York: AJC.
- Grad, J. P. D., & Sainsbury, P. M. D. (1963). Mental illness and the family. *Lancet*, 1, 544-547.
- Hatfield, A. B. (1978). Psychological costs of schizophrenia to the family. *Social Work*, 23(5), 355-359.
- Hatfield, A. (1986). Semantic barriers to family and professional collaboration. *Schizophrenia Bulletin*, 12, 325-333.
- Lefley, H. P., & Johnson, D. L. (Eds.). (1990). *Families as allies in treatment of the mentally ill*. Washington, DC: American Psychiatric Press, Inc.
- Marquart, J. M., Pollak, L. B., & Bickman, L. (1992). Quality in intake assessment and case management: Perspectives of administrators, clinicians and consumers. In K. Kutash, C. Liberton, & R. Friedman (Eds.), *A system of care for children's mental health*. The Fifth Annual Research Conference Proceedings. Tampa, FL: Florida Mental Health Institute, University of South Florida.
- Marsh, D. T. (1992). *Families and mental illness: New directions in professional practice*. New York, Praeger Publishers.
- Naparstek, A., Biegel, D., & Spiro, H. (1982). *Neighborhood networks for humane mental health care*. New York: Plenum Press.
- Neighbors, H. W., & Jackson, J. S. (Eds.). (1996). *Mental health in Black America*. Newbury Park, CA: Sage Publications.
- Padgett, D. K. (Ed.). (1995). *Handbook on ethnicity, aging, and mental health*. Westport, CT: Greenwood Press.
- Pickett, S. A., Vraniak, D. A., Cook, J. A., & Cohler, B. J. (1993). Strength in adversity: Blacks bear burden better than whites. *Professional Psychology: Research and Practice*, 24(4), 460-467.
- Sherm, D. L. (1993). *Mapping the adaptation of rehabilitation technology to a core, urban, homeless population with psychiatric disabilities*. Presented at the National Conference on Mental Health Statistics, Center for Mental Health Services, June 6-9, Washington, DC.
- Snowden, L. R., & Cheung, F. K. (1990). Use of inpatient mental health services by members of ethnic minority groups. *American Psychologist*, 45(3), 347-355.
- Struening, E. L., Stueve, A., Vine, P., Kreisman, D. E., Link, B. G., & Herman, D. B. (1995). Factors associated with grief and depressive symptoms in caregivers of people with serious mental illness. *Research in Community and Mental Health*, 8, 91-124.
- Trochim, W. M. K. (1989). An introduction to concept mapping for planning and evaluation. *Evaluation and Program Planning*, 12, 1-16.
- Trochim, W., Dumont, J., & Campbell, J. (1993). *Mapping mental health outcomes from the perspective of consumers/survivors*. A Report for the State Mental Health Agency Profiling System. Presented at the National Conference on Mental Health Statistics, Center for Mental Health Services, June 6-9, Washington, DC.

David E. Biegel, Ph.D., is Henry L. Zucker Professor of Social Work Practice and Co-Director, Cuyahoga County Community Mental Health Research Institute, Mandel School of Applied Social Sciences, Case Western Reserve University

Jeffrey A. Johnsen, Ph.D., is Director of Research and Education and Co-Director, Cuyahoga County Community Mental Health Research Institute, Cuyahoga County Community Mental Health Board

Robert Shafran, M.S.S.A., is a Doctoral Candidate and Research Assistant, Mandel School of Applied Social Sciences, Case Western Reserve University

Received 10-10-96
 Revised & Resubmitted 2-3-97
 Accepted 2-5-97

Students,
 professionals,
 & professors
 rely on these
 research tools!

National Council on Family Relations



3989 Central Ave. N.E., Suite 550
 Minneapolis, Minnesota 55421
 Toll free: 888-781-9331
 (612)781-9331 • FAX (612)781-9348
 Email: ncfrc3989@ncfr.com
 Web: www.ncfr.com

Journal of Marriage and the Family

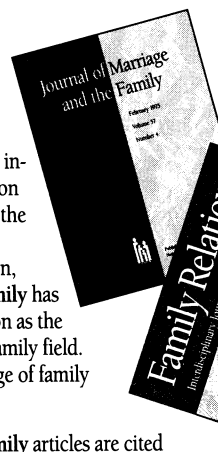
Prestigious quarterly journal features original theory, research interpretation, and critical discussion of topics related to marriage and the family. During more than a half century of continuous publication, *Journal of Marriage and the Family* has earned an international reputation as the premier research journal in the family field. Contributors include a wide range of family specialists.

Journal of Marriage and the Family articles are cited extensively in books, classroom texts, and in the media.

ISSN: 0022-2445 284 pages of original family and marriage research four times per year

Institution: U.S. \$95.00, Non-U.S. \$110.00
 Individual: U.S. \$50.00, Non-U.S. \$65.00
 Student: U.S. \$25.00, Non-U.S. \$40.00

Prices include shipping and handling. Canadian orders must add 7% GST tax 123-830-465.



Family Relations: Interdisciplinary Journal of Applied Family Studies

Scholarly journal for family practitioners and educators. Emphasis is on relationships across the life cycle. Relevant for family therapists, educators, and public policy makers. Articles include original research and practical applications. Published quarterly.

Family Relations articles are referenced in numerous articles, books, and research documents.

ISSN: 0197-6664 120 pages of research with practical applications four times a year.

Institution: U.S. \$85.00, Non-U.S. \$97.00
 Individual: U.S. \$45.00, Non-U.S. \$57.00
 Student: U.S. \$20.00, Non-U.S. \$32.00

Prices include shipping and handling. Canadian orders must add 7% GST tax 123-830-465.

FR497