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## Toolkit for Evaluating Family Experiences with Severe Mental Illness

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# Evaluating Family Experiences with Severe Mental Illness

*To be used in conjunction with  
The Family Experiences Interview Schedule (FEIS)*



1993

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For your convenience...

We have included the following items in a separate section labeled “PN-5 Supplementary Documents” following the Addendum:

- The Interview Schedule  
INTSCH.ASC
- The Call Report Form  
CALLREP.ASC
- The Introductory Letter  
INTLTR.ASC
- The Information Sheet  
INFSHT.ASC
- The Informed Consent Form  
INFCON.ASC
- The Pledge of Confidentiality  
PLECON.ASC

This Toolkit is one of a series of such kits commissioned by the Evaluation Center@HSRI. The Center is a grant program of the Substance Abuse and Mental Health Services Administration, Center for Mental Health Services. The mission of the Evaluation Center is to provide technical assistance related to the evaluation of adult mental health system change.

The Center offers six programs, all of which are designed to enhance evaluation capacity.

- The Consultation Program provides consultation tailored to the needs of individual projects.
- The Topical Evaluation Networks Program maintains a forum for ongoing dialogue via electronic conferencing.
- The Toolkit Program develops manuals that provide evaluators with tested methodologies and instruments related to specific topics.
- The Materials Program is an evaluation materials program which supplies evaluators with original papers on selected topics and identifies relevant literature in the field.
- The Conferences and Training Program is designed to enhance the evaluation skills of producers and consumer of evaluations.
- The Multicultural Program focuses on evaluation issues related to culturally, racially and ethnically diverse populations.

The Toolkits are designed to provide evaluators with complete descriptions of methodologies and instruments for use in evaluating specific topics. Based on information from a needs assessment study conducted by the Center and on feedback from evaluators in the fields, we have identified a number of important topics that evaluators are frequently interested in examining. Expert consultants have been engaged to review the background of these topics and to compile Toolkits that provide evaluators with state-of-the-art evaluation techniques to use in their own work.

The Evaluation Center@HSRI is also interested in supporting "user groups" for its Toolkits. These groups will provide a forum for Toolkit users to share their expertise and experiences with the Toolkits. If you would like to participate in a user group, please complete the postcard enclosed and return it to the Evaluation Center@HSRI.

We hope that this *Toolkit for Evaluating Family Experiences with Severe Mental Illness* will be helpful to those evaluators who are interested in assessing the impact of system changes on the life circumstances of persons with severe mental illness.

H. Stephen Leff, Ph.D.  
Director

Virginia Mulkern, Ph.D.  
Associate Director

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## **INTRODUCTION & OVERVIEW**

### **Statement of Purpose**

The Toolkit for Evaluating Family Experiences with Severe Mental Illness is designed to provide technical assistance to mental health services researchers who wish to include family outcomes when designing evaluation studies. The Toolkit is organized around a particular instrument, The Family Experiences Interview Schedule (FEIS). The FEIS is a revision of the Family Burden Interview Schedule (FBIS), which was developed in the tradition of a line of research on the family experience going back to the early days of deinstitutionalization in which the family experience of caregiving was conceptualized as "burden." More recently there has been interest in expanding the conceptualization and measurement of family experiences to include the positive aspects of caregiving. Thus the FEIS also includes measures of the special rewards, benefits and gratifications that may derive from caregiving.

The material contained in this Toolkit is relevant to situations in which the relative is an adult, between 18 and 65 years of age, with a major mental illness such as schizophrenia or bipolar disorder. Depending on the stage of the family life cycle, caregiving may involve parents caring for an adult child, adult children caring for a parent, a well spouse caring for an ill spouse, or a sibling caring for a disabled brother or sister. This Toolkit is not intended for routine clinical use, or for studies of caregiving to minor children with serious emotional disorders or to the elderly with dementias.

The Toolkit includes four major sections:

1. An introduction to research on the family experience which includes the background and significance of the topic as well as methodological issues and trade-offs.
2. A narrative description of the Family Experiences Interview Schedule, including its history and characteristics, modular descriptions and rationales, an outline of measures, and procedures for scale and index construction.
3. The FEIS itself which uses a modular format.
4. A concluding section entitled "Putting A Family Study into the Field."

When the aim is to assess reduction in caregiving as a criterion for evaluating program impact, there may be no obvious need to expand the scope of the family interview beyond the measurement of caregiving. However, when investigators wish to expand the analysis beyond linking services and caregiving burden, it then becomes necessary to measure other aspects of the family's experience. The FEIS includes measures of the consumer's contribution to the household (Sweet et al. 1988), positive feelings about the relative as well as negative attitudes towards him or her or towards his or her behavior (Kreisman et al 1987), stigma (Lefley 1989) and contact with and attitudes toward professionals (Tessler et al 1991). It also includes family structure and sociodemographic variables.

The basic characteristics of the FEIS are summarized in the FEIS Quick Reference Guide, which follows this statement of purpose. The FEIS is a 180 item structured personal interview. It takes about 60 minutes to administer in person at baseline and 30 minutes to administer as a follow up by telephone. Interviewers do not need special background, but do require some training. An Interview Training Manual is included in Section IV of this Toolkit.

The design of the FEIS follows a modular format. We have used this format, with separate numbering within each module, to make it convenient for researchers to tailor the FEIS for their particular research questions. If the research design includes more frequent administrations, it may be appropriate to prune down the instrument to reduce respondent burden. Thus, it is possible with minimum effort to choose not to include a particular module or modules, or to rearrange the order of the modules. Before making such decisions, however, researchers are encouraged to review the rationales for including specific modules (see Section II, B). The Evaluation Center@HSRI is prepared to assist researchers in customizing the instrument for specialized purposes.

<b>FEIS QUICK REFERENCE GUIDE</b>	
<b>Topic</b>	<b>Guidelines</b>
<b>Consumer Populations</b>	<ol style="list-style-type: none"> <li>1. Major mental illness including schizophrenia and affective disorders</li> <li>2. Residing in the community</li> <li>3. Ages 18-64</li> </ol>
<b>Caregiver Populations</b>	<ol style="list-style-type: none"> <li>1. Primary caregivers</li> <li>2. Multiple respondents per consumer</li> </ol>
<b>Family Roles</b>	<ol style="list-style-type: none"> <li>1. Primary kin, including parents, siblings, adult children, spouses, and significant others</li> <li>2. Secondary kin, including aunts, uncles, grandparents, etc.</li> </ol>
<b>Type of Study</b>	<ol style="list-style-type: none"> <li>1. Exploratory, descriptive, program evaluation, and randomized clinical trial</li> </ol>
<b>Type of Instrument</b>	<ol style="list-style-type: none"> <li>1. Structured personal interview at baseline</li> <li>2. Telephone follow-up interview</li> </ol>
<b>Number of Questions</b>	180 (maximum count of questions in all modules)
<b>Time Frame for Caregiving Measures</b>	The past 30 days
<b>Completion Time</b>	<ol style="list-style-type: none"> <li>1. 60 minutes baseline</li> <li>2. 30 minutes follow-up</li> </ol>
<b>Interviewing Requirements</b>	<ol style="list-style-type: none"> <li>1. Special training in structured interviewing</li> <li>2. Clinical background not required</li> <li>3. Interviewer ratings not required</li> </ol>
<b>Family Caregiving</b>	<ol style="list-style-type: none"> <li>1. Financial Expenditures</li> <li>2a. Objective caregiving: ADL Care</li> <li>2b. Subjective caregiving: ADL Care</li> <li>3a. Objective caregiving: Supervision</li> <li>3b. Subjective caregiving: Supervision</li> <li>4. Impact of Daily Routines</li> </ol>
<b>Negative Aspects of the Family Experience</b>	<ol style="list-style-type: none"> <li>1. Worry</li> <li>2. Displeasure</li> </ol>
<b>Positive Aspects of the Family Experience</b>	<ol style="list-style-type: none"> <li>1. Benefits</li> <li>2. Gratifications</li> </ol>
<b>Cronbach's Alpha</b>	See Table 1 in Section II

## **Background & Significance**

The study of the family experience with severe mental illness goes back several decades to the beginning of deinstitutionalization (Kreisman and Joy 1974; Fisher et al. 1990). As noted, most past research has focused on what has come to be known as "family burden" and has emphasized the negative aspects of caregiving (for reviews, see Maurin and Boyd 1990; Schene 1990; Biegel et al. 1991). Family burden research has also included the increased financial expenditures related to consumer care and treatment (Frank 1990; Clark and Drake 1994). Current research is attempting to balance the ledger by looking at more positive aspects of the family experience such as the client's contributions to the family and reciprocal emotional support (Bulger et al. 1993; Greenberg et al. 1994).

Another significant dimension of the family experience is negotiating with the professional system of care. In the past, some families felt blamed and excluded from treatment decisions (Holden and Lewine 1982). Fortunately this is less true today, as recent research on family attitudes toward professionals indicates, and new partnerships are emerging which acknowledge the strengths of families (Tessler et al. 1991).

Consumers, professionals, and caregiving family members are or should be part of a "health care triad" (Haug 1994). All three parties form a triangle which is often critical to the success of long term care. To ignore any of the parties may adversely affect the consumer's quality of life, and cause distress for the family caregiver, and frustration for the professional. When families are perceived as potential sources of help rather than as disinterested or meddling outsiders, then family members may function as real helpers in a mental health care triad which supports the rights and obligations of all three parties. This Toolkit is designed to help researchers obtain measures of the family experiences which can be integrated with consumer and service data to provide a comprehensive view of this triad.

There is accumulating evidence of the beneficial effects of services that are intended specifically for families (Pfeiffer and Mostek 1991). Among the possible approaches that have been highlighted are respite care (Geiser et al. 1988), family education (Strachan 1992), including family members in treatment planning (Hatfield 1979), and developing mobile teams that are responsive to families when the client is in crisis (Francell et al. 1988).

In summary, the purpose of family research is to produce information leading to improved family outcomes. As an evaluation tool, the measurement of family experiences reveals the impact of programs and treatments on the family. Family research may also be used to learn about the relationship between the relative with mental illness and his or her family members, and how that relationship may be best supported (Kuipers and Bebbington 1985; Francell et al. 1988).

### ***The Concept of Caregiving***

Caregiving needs to be distinguished from dependency relationships that are age appropriate and culturally expected. We begin and may end our lives with a period of dependency during which it is crucial that others provide care and support. The institution that typically provides this care is the family. Kinship ties are among the most enduring of all supports available, although expectations may vary from culture to culture, and from one historical era to another. In modern industrialized societies, adults are expected to be independent of their family of origin and to care for themselves from the moment they end their education unless they are disabled by illness.

Caregiving is a relatively modern concept that has come to describe the relationship that exists between adults who are related through kinship. One, the caregiver, assumes an unpaid and unanticipated responsibility for another. The second, the care recipient, is typically disabled and unable to fulfill the reciprocal obligations associated with normative adult relationships. Care becomes caregiving when it is out of synchrony with the appropriate stage in the life cycle. Caregivers are bound by kinship obligations that go beyond those normatively associated with a family role at a particular stage. The onset of a severe mental illness affects all family members although caregivers are disproportionately female (Cook 1988; Findley 1989).

To some extent the need for caregiving has resulted from changing policies toward persons with mental illness. Social policies toward persons with mental illness in the last three decades mandate an increasing emphasis on community care. This deinstitutionalization movement brought age old responsibilities back to family members, who saw themselves after one hundred years of institutionalization confronted with new obligations towards their ill or

handicapped members (Fisher et al. 1990). The role of the family in providing care may once again change as the organization, delivery and financing of mental health services are transformed.

It is important to remember that the modern family is rarely prepared for giving long term care to an ill family member (Parsons and Fox 1952). Their lack of preparedness notwithstanding, some family members accept the caregiving role to a relative with mental illness with a great sense of familial obligation, perhaps believing that the family is providing the only real care available. They advocate for their relative, provide shelter, assist in activities of daily living, supervise troublesome behaviors, and encourage their relatives as needed. Other families also faced with long term mental illness prefer that their relative obtain as much independence as is feasible, and look to the professional system of care to make this possible. This does not mean that such family members wish to be uninvolved, but rather to be involved as one would with any other family member. Such families will come to the rescue as the safety net of last resort, stepping in only when independent housing and vocational solutions fail (Tessler et al 1987). But the commitment of these families is more limited and is meant to be short term. In those instances in which levels of the burdens associated with caregiving have become unbearable, and the limits of generosity reached, some family members choose to disengage from the relative with mental illness. In other cases, the consumer may choose to disengage from his or her family (Stoneall 1983). Kinship obligations are strong but not indestructible (Tessler et al. 1992).

### ***The Nature of Caregiving***

As noted, the vast majority of research on the impact of mental illness on families over the past 30 years has emphasized the negative aspects of family caregiving experiences. The following discussion summarizes and draws from this "family burden" literature. The special rewards of caregiving are discussed in a separate section.

Caring for a relative with mental illness can be burdensome in many different ways. Consider first that family members are often concerned and worried about the health and well-being of their relative with mental illness. Many family members provide financial

assistance, shelter, and assistance in performing everyday tasks. Persons with serious mental illnesses often engage in behaviors that are frightening, troublesome, disruptive, or at least annoying, and many relatives are obliged to control, manage, or at least tolerate these behaviors. In addition, there is the emotional distress experienced by family members whose lives are in various ways disrupted, and whose health may be jeopardized (Gallagher and Mechanic 1993; Greenberg et al. 1993). Existing instruments typically use more than one of these dimensions to measure the burden of severe mental illness on the family (Schene et al. 1994).

Severe mental disorders such as schizophrenia, bipolar and major depression may represent obstacles to independent living and life satisfaction for those who suffer from them. Employment opportunities may be reduced, self-care may be impeded, and the capacity for social relationships may be severely diminished. When a family takes on the dual role of housing provider and primary caregiver, the potential burden of care may be very large indeed. Even when the consumer lives separately, families often provide care informally, and they are likely to get involved during crises. The burden of support and concern born by families of persons with severe mental illness has been documented in numerous studies over the past 30 years (Grad and Sainsbury 1963; 1968; Hoenig and Hamilton 1966; Herz et al. 1976; Hatfield 1978; Test and Stein 1980; Thompson and Doll 1982, Carpentier et al. 1992).

An important distinction is that between the objective and subjective burdens associated with caregiving. The consequences of being related to someone suffering from severe mental illness can be roughly divided into the obligation to offer long-term extensive care and the emotional distress and worries related to the consumer. The former requires close contact between the relative with mental illness and other family members, while the latter may also exist when kinship ties have unraveled or the amount of contact is very small. The former is related to what family members actually do for their relative while the latter is concerned with how they feel. Researchers have also described this distinction as caring for and caring about (Graham 1983).

Just as the personality of the relative suffering from mental illness may change, so may the relationship with that person. Some family members experience a sense of loss with accompanying grief, comparable to the process of bereavement (Miller et al. 1990). The great

difference, however, is that with mental illness the 'lost' person stays alive and the relationship may need to be reconstructed.

How family members respond to the mental illness of a relative can be described in terms of stages, although the process of adaptation varies from family to family (Tessler et al. 1987). First, there is an initial awareness of a problem. In the beginning phase of the illness family members are uncertain about the diagnosis, and may deny that mental illness is involved. Next the family accepts the labeling of the problem as one which requires intervention from outside the family. When this occurs in most cases it is family members who get the relative to professional help. In this stage family members typically have great faith in mental health professionals, and are hopeful that a cure can be found. As crises reoccur, there develops a grim recognition that cures are neither quick nor certain. The recognition of chronicity is often followed by a loss of faith in mental health professionals, or at least a lessening of confidence in them. With the loss of confidence in professionals comes a belief in the family's own expertise, which is based on experience dealing with recurrent crises. Some families may insist during this period that the consumer lead as normal a life as possible by establishing an independent residence. However, even under the best of circumstances, families tend to worry about the future and what will happen to their relative with mental illness when they are no longer there to help (Lefley 1987). In extreme cases, family members may live with uncertainty because they have lost all contact, and do not know where their relative can be found (Tessler et al. 1992).

Family members who remain involved often give a great deal of assistance in activities of daily living: providing personal care, preparing meals, doing household chores and laundry, shopping, and helping with transportation. Some also have to learn to cope with delusions, hallucinations, attention seeking, stealing, inappropriate sexual behavior, unreasonable demands, verbal abuse, disturbances during the night, behaviors that are threatening or violent, talk or threats of suicide, and alcohol or drug abuse (Creer et al 1982; Tessler and Gamache 1994). Coping with these symptoms and behaviors may often require lengthy, complex, and distressing negotiations (Lefley 1987).

Either caring for or caring about a relative with mental illness may have an impact on family and marital relationships, as well as on social relations outside the household. When



reciprocal relationships are disrupted by illness, other family members may be forced to take on a greater proportion of formerly shared tasks. As a consequence the interpersonal relationships within the household can become strained (Stoneall 1983). When marriage has taken place before the onset of the mental illness, disruption of the marital relationship is often followed by separation and divorce. When the consumer is also a parent, it may be necessary for other family members to help in caring for his or her minor children (Gamache et al. forthcoming).

If the onset of mental illness comes after the attainment of gainful employment, there may be financial consequences when the consumer is not able to work at all or when because of the illness he or she works fewer hours. Caregiving may also force relatives to work less or to give up their jobs. Ironically both events may occur along with a rise in expenses related to mental health treatment and medication (Clark and Drake 1994). Other economic repercussions may flow from the consumer's inability to manage money, or as a result of destructive behavior.

Personal relationships outside the household may also be affected adversely by having less time for social activities, and by stigma -- leading to attempts to conceal the mental illness (Lefley 1989). Both time constraints and stigma tend to limit the amount of social contact outside the family and can result in a profound sense of isolation. Family self help groups can provide a set of new relationships and offer a way for family members to join in sharing their experiences with others in similar situations (Fisher et al 1990). While relationships with professionals can offer reassurance, some family members report feeling unsupported, uninformed, blamed, and judged (Holden and Lewine 1982).

### ***The Special Rewards of Caregiving***

Although the literature has given less attention to positive aspects of the family experience, caring for or caring about a relative with mental illness also brings special rewards to family members. Caregivers potentially derive a variety of benefits and gratifications. Caregivers may enjoy the company of the family member, feel he or she is an important part of their life, feel pride and experience happiness as a result of their continuing relationship. To the extent that consumers can contribute to the functioning of the household, provide companionship, or M other supportive familial obligations, the costs to the family may be more than offset. The client

may also benefit. Kreisman and Joy (1974) noted that "when the patient contributed to the household rather than taxed its limited resources, there was significantly greater likelihood that the patient would remain out of the hospital (p. 48)."

A more recent study found that parents experienced more gratifications than burdens when caring for adult sons and daughters with schizophrenia (Bulger et al. 1993). Other recent research in rural Wisconsin has similarly reported that the instrumental and expressive contributions of adult persons with serious mental illness to their families are substantial. Between 50 and 80 percent of the clients in Us survey contributed to their families (Greenberg et al. 1994).

### **Methodological Issues and Trade-offs**

The study of family experience hinges on how family is defined, who in the family is interviewed, how caregiving is defined and measured, and the theory that underlies the analysis of the collected data. How researchers resolve such issues and a variety of other issues to be discussed below will have much to do with the results and interpretations, as well as the generalizable applications of the research.

### ***Sampling and Design***

Most studies of the family experience with severe mental illness are actually studies of the family burden of primary caregivers. In a typical study, users of mental health services are asked to identify the family member with whom they are most involved on a daily basis, or who provides them with the most support or care. Some studies further limit the sample to caregivers who are living with their relative with mental illness. This also implies that in most cases "family" burden is a misnomer, in as much as all family members are rarely, if ever, interviewed. The term "caregiver" burden better describes most studies. Research experience indicates that substantially higher levels of burden will be detected if the sample is limited to those primary caregivers who are currently living with the care recipient (Tessler and Gamache 1994). However, co-residence does not necessarily determine involvement, since even family members

who live apart may sustain high levels of personal involvement, and people living under the same roof may interact negatively or not at all.

The generalizability of the results depends on the representativeness of both the user of mental health services and caregiver samples. For example, the results from a survey administered to members of a family organization, or where the consumer sample is limited by a single diagnosis, may not generalize beyond these groups. For this reason it is important that the characteristics of the sample be carefully described, and the rates of refusal of both consumers and family members noted, so that other researchers and policy makers can judge the relevance of the research findings to other populations of interest.

It is not crucial that consumers be interviewed as part of a family study. In fact, the majority of published studies do not attempt to link family data with relevant consumer data. But if such is possible, the linking of consumer and family data increases the range of substantive issues that can be addressed. When consumer interviews are used they should be closely coordinated with family interviews so that the family members and the consumers can be studied at the same moment(s) in time.

Sampling issues clearly interact with the goals of the research. If, for example, the aim is to estimate the prevalence of burden in families of the severely mentally ill, or if the aim is to understand why some kin remain involved while others do not, then a sample that consists solely of primary caregivers would be clearly inappropriate. Without interviewing multiple kin, examination of the distribution of burden in the family is possible in only the most limited of ways. It may also be of interest to interview family members who are not presently involved with the consumer such as siblings who may be asked to take up the slack when parental caregivers age and die (Horwitz et al. 1992). Such persons would, of course, be missed in a sample consisting solely of primary caregivers. If, however, the aim is to estimate the effect of an experimental treatment on those kin who at baseline were providing the most care and support to their relative, then selecting for primary caregivers is clearly more appropriate.

In designing studies of the impact of mental illness on families, it is important to build into the research design one or more meaningful bases for comparison. Various alternatives exist. One is to integrate a family study with a controlled clinical trial involving a psychosocial

and/or pharmacological intervention in which users of mental health services are randomly allocated between experimental and control groups. A second is to interview the same family members over time, thus treating each individual respondent as his or her own control. Ideally, both alternatives would be employed, and the sample sizes involved would be large enough to detect significant differences. The more comparisons to be examined, the larger the sample size that is required.

Some useful contrasts are possible even without experimental or longitudinal bases for comparison. These arise from natural variations in consumer status and care. For example, the fact that consumers are exposed to the same system of care does not mean that they utilize the system in the same ways. Variations in patterns of use of services may be associated with varying levels of family burden and gratification.

When the sample contains multiple subgroups it is important to examine whether programmatic factors have similar effects across all subgroups. For example, when there are a variety of diagnostic groups represented, or different types of family members (e.g. parents, spouses, siblings), or different living arrangements, it is crucial that enough members of each group be included in order to detect statistically significant differences.

### ***Measurement***

Most of the measurement work related to the family experience with mental illness has focused on burden. The measurement of the burdensome aspects of caregiving hinges largely on how burden is defined. Burden is a very general concept, referring to a broad range of difficulties experienced by family members in caring for and dealing with their relatives with mental illness. Even though the effects of "burden" tend to be experienced as cumulative, burden does not lend itself to a single measure but rather invites a multidimensional approach. In some cases analysis of individual items may provide the most insight into the family experience.

It is likely that various measures of the burden associated with caring for or caring about a relative with mental illness will be correlated. . The presence of significant correlations among measures of burden does not mean that there is a single, underlying trait called burden which accounts for the correlations. Instead, the correlations arise because of consumer and family

member characteristics which lead to patterns of behavior and accommodation that are in turn associated with different areas of caregiving. If a family member is at all involved with their relative, he/she is likely to be affected in many ways. On the other hand, family members who dissociate themselves from their relative tend to avoid all areas of exposure.

Although the distinction between objective and subjective burden is widely viewed as important, there exists considerable uncertainty about how the subjective component should be measured. At its core the issue is whether subjective burden should be understood as a response to the need, or alternatively whether it is best understood to refer to the emotional response to the giving of assistance. The subjective side of burden has also proved to be difficult to measure empirically because it is unclear how best to differentiate burden and resignation. Resignation may indicate that one has given up and simply endures without complaint or that one has gotten used to carrying the burden. In a validation of the Social Behavior Assessment Scale raters had difficulty distinguishing between distress and resignation (Platt et al. 1980).

It should be noted that researchers also do not agree on whether or not burden can be reduced to a single (total) scale. The FEIS takes a multidimensional approach which attempts to distinguish different aspects of burden from one another and from other related constructs.

The following dimensions of burden associated with caring for or caring about a relative are measured:

- Assistance in daily living (Objective and Subjective ADL Care)
- Supervision of bothersome or troublesome behaviors (Objective and Subjective Supervision)
- Impact on daily routines (Objective impact)
- Financial expenditures (Objective Money)
- Affective responses (Subjective Worry and Distress)
- Global (single item) measures are also available for financial expenditures and affective response.

As previously noted, most studies of the family experiences are really studies of a particular caregiver's burden, raising the issue of whether the respondent should be asked to provide proxy reports for other family members who may not be interviewed. While proxy data are sometimes of questionable reliability, reports about others' involvement may nonetheless

provide a useful adjunct and help to give a picture of the total support network. Caregiving may be focused on a single individual in the family, but other kin may help as well. It is possible to distinguish patterns of help giving in which the respondent alone responds to consumer need from shared patterns of assistance, and to identify cases in which other person(s) helped but the respondent was not personally involved. The FES provides a checklist for the respondent to report caregiving by others, including professionals, on an item by item basis.

Researchers often find that consumer and family perceptions of need are only weakly associated. This is not surprising since the bases for such perceptions are different. In some cases the family member is simply not aware of the consumer's current needs and problems. In other cases, the family member may infer need based on assistance rendered by themselves or others.

There are also a variety of miscellaneous concerns that are relevant to the reliable and valid measurement of family experiences. Among these are the choice of method of data collection (questionnaire, telephone, or in-person interviewing), the most appropriate time frame to use in asking questions, the selection of response categories to use in measuring severity, and how to treat family respondents who have had no recent contact with the consumer.

In-person interviewing is clearly the method of choice whenever possible. Personal interviews can be longer, the respondent has more opportunity to ask for clarification, and the probability of agreeing to the interview in the first place also tends to be higher. However, in-person interviewing is extremely costly. Fortunately, once a family respondent has completed an in-person interview, it is possible with only minimal attrition to conduct follow up interviews over the telephone. The advantage of questionnaires is that large numbers may be administered at lesser cost. However, because of the lack of control over the conditions in which they are administered, and because of the problem of nonresponse, questionnaires should only be selected when other methods of data collection are unavailable. The FEIS is not designed or recommended for use as a questionnaire.

The FEIS uses a recall period of the past 30 days for asking about the caregiving aspects of burden. The advantages of a limited time frame are that it aids in accurate recall, increases reliability of measurement, and allows for a more sensitive measure of change. The main disadvantage is that the past 30 days may not be representative, and some of the most

burdensome experiences may have occurred months or years ago. Thus, for a descriptive study, a longer time frame may be worthwhile, but for the measurement of change one needs a short time frame focusing on relatively common aspects of caregiving.

A variety of approaches have been used to indicate severity of burden. One alternative is to ask for direct measures of hours per week spent in varying types of caregiving. However, many respondents may have difficulty responding in such specific terms. A second alternative is to include precoded categories to quantify the severity of the burden by using number of days (e.g. every day, 3 to 6 times a week, 1 or 2 times a week, or less than once a week). Another strategy is to offer more general response categories such as never, sometimes, often, and constantly. The latter approach is the most subjective, but may be the easiest for the respondent. The FES uses the second approach for measuring severity of burden.

When users of mental health services identify family members to be interviewed, and when there is a lag between identification and initial interview, it is advisable to screen for recency of contact with the consumer. Some respondents may not have seen or talked to or even had information about their relative within the 30 day time frame that the FES uses. In these cases, the repetition of caregiving questions is redundant and may also anger the respondent, and for this reason should be skipped over. Other measures, such as worrying about the family member with severe mental illness, are still appropriate to administer even in the absence of recent contact.

### ***Analytic Model***

As in other areas of research, it is important to begin with a well defined model. There are various theories in the literature, which overlap to a considerable degree. One issue is whether the more important outcome measure is objective or subjective burden. Some researchers doubt the utility of subjective burden as an outcome measure (Schene 1990) while other researchers consider objective burden to be a predictor variable and subjective burden to be the outcome of interest (Reinhard et al. 1994).

In a recent application of the FBIS in three cities in Ohio, we examined the effect of continuity of care, defined as receiving continuous case management for two years, on objective

and, subjective family burden when controlling for residence and kinship role (Tessler and Gamache 1994). It was hypothesized that continuity of care would directly reduce the family burden of caregiving. ADL-Care (objective), Supervision (objective), and Worry (subjective) measures (these also appear in the FEIS) were used as dependent variables in a series of regressions. Continuity of care was measured using data from consumer interviews spanning two years. Residence was measured as a dichotomous variable, where 1 = resides with respondent and 0 = otherwise. kin relationships were also included as dichotomous variables. Contrary to prediction, the results showed that continuity of care did not lead directly to less family burden. However, there was a significant interaction between continuity and co-residence indicating that continuity of care did reduce both ADL-Care and Supervision under the condition of a shared residence but had no effect when clients did not reside with the family member. In contrast, the worry of family members had little to do with whether the client was receiving continuous services regardless of the consumer's residential arrangement. One consistent finding was that caregiving burden was related to family role, with parents reporting significantly higher levels of objective and subjective burden than other family members.

### **Concluding Note**

The FBIS, upon which the FEIS, is based was designed and tested for use with a variety of family members who have a relative with severe mental illness. There are a number of other instruments from which researchers who have specialized research aims can choose (Schene et al. 1994). Instruments have been designed specifically for relatives of users of mental health services with depression (Jacob et al. 1987; Fadden et al. 1987), and schizophrenia (Herz et al. 1991; Madianos and Madianou 1992). For specialized studies when the focus is on economic contributions by the family to the consumer, the Family Economic Burden Interview may be most appropriate (Clark and Drake 1994). For studying grief reactions, the Texas Inventory of Grief-Mental Illness Version should be consulted (Miller et al. 1990). Instruments also vary in length of administration and method of data collection. Some instruments are much shorter than the FEIS but require interview ratings (e.g., Pai and Kapur 1981), while others can be administered as a questionnaire (e.g., Reinhard et d. 1994).



## **THE FAMILY EXPERIENCES INTERVIEW SCHEDULE NARRATIVE**

### **The History and Characteristics of the FEIS**

The FEIS had its origins in a baseline questionnaire developed for an impact evaluation of the Massachusetts Family Support Program in 1987. Services designed specifically for family members were expected to reduce negative aspects of the family experience. The questionnaire included the ADL Care and Control dimensions of objective burden associated with caregiving and the attitude toward professionals scale in slightly different forms. A Follow-Up Survey of Family Members was designed and administered by telephone to 156 family members. Rigorous psychometric analyses were applied to these items (Fisher 1988). The results of the impact evaluation indicated that reductions in caregiving were associated with education programs and respite (Fisher 1989).

An expanded and revised protocol (known as the Family Burden Interview Schedule or FBIS) was pre-tested in a structured interview format using a sample of National Alliance for the Mentally Ill members in Philadelphia. The version arising from the pre-test experience was then used in an evaluation of the Robert Wood Johnson Program (RWJ) on Chronic Mental Illness. The FEIS is based on psychometric analyses conducted using longitudinal data from the Ohio study. In view of the central role of the Ohio sample in the development of the FEIS, we present a brief summary of the RWJ Ohio study.

### ***The Robert Wood Johnson Evaluation***

From the beginning of the RWJ Program, it was clear that, among its objectives, the RWJ Foundation intended families to be beneficiaries of an improved service delivery system. Changes in the organization, financing, and delivery of client services were reasoned to affect family members indirectly by increasing the clients' residential independence and continuity of care. The strategy for research was to link family with client data in order to examine whether and in what ways the changes had an impact on families. The original design called for linking with case manager data, but our experience indicates that the significant numbers of case managers who did not return the self-administered questionnaire obviated this part of the design.

Although the RWJ Foundation Program was a nine city program, the family study was limited to three cities in Ohio. The family component spanned two years in the life of the RWJ initiative and also drew on data elements from the client study.

The criteria for inclusion in the client study were: length of index stay in a 24 hour mental health setting of less than 120 days; age between 18 and 64; a primary diagnosis of mental illness other than substance abuse; had to meet Ohio standards of disability including diagnosis, hospitalization, and functional status; could not be a forensic client; and had to be English speaking, and legally competent. A total of 204 clients from Cincinnati, Columbus, and Toledo, Ohio were interviewed shortly after their discharge from Ohio state hospitals or 24-hour crisis care facilities.

Clients were on average in their early thirties, had been ill for an average of 14 years, and first received help for mental health problems on average at the age of 22. More than half of the clients were male and fifty-two percent of the total sample reported they had never been married. The client sample was split about evenly between Blacks and Whites. Almost two-thirds received a diagnosis of schizophrenia with slightly more than a fourth receiving a diagnosis of either bipolar disorder or major depression. Clients averaged a 30 day length of stay in a 24-hour setting prior to participation in the client study.

At the end of their first interview, clients were asked to name up to 4 members of their immediate family, or persons "like family" who were involved in their daily lives. Criteria for the family sample included not being a minor (under 18), not being a consumer of mental health services, and not being a treatment professional. A total of 409 family interviews were conducted between October 1989 and March 1990 (Time 1). A second wave (Time 2) of interviews took place between October of 1990 and March of 1991. Three-hundred and fifty-four family members (associated with 192 clients) were reinterviewed. A third wave was conducted between October of 1991 and March of 1992 when a total of 305 relatives (linked to 175 clients) were interviewed for the third and final time (Time 3).

The 409 family members averaged 49 years of age. Fifty-one percent of the sample of family members were Black. Two-thirds of the family respondents were female. Almost one third reported their 1988 household income as less than \$10,000 a year and average education

was less than a high school diploma. Reflecting the racial and economic diversity of the sample, only about 8 percent reported that they had ever been members of the Alliance for the Mentally Ill or any other self-help, group of relatives of the mentally ill. The relationships to the client were parent (36 percent), adult child (7 percent), spouse (3 percent), sibling (27 percent) and the remaining 27 percent was composed of other secondary kin relationships and persons who were "like family." The role of mother was the most frequently reported relationship (27 percent). Households averaged slightly more than 3 persons. Slightly more than one-half of the respondents were currently married and almost one-half were employed at the first interview.

Multiple respondents were interviewed for a majority of clients at all three points in time. Clients averaged 2.0 respondents at Time 1, 1.7 respondents at Time 2 and 1.5 respondents at Time 3. Compared with family members who dropped out, the 305 family respondents who completed all three interviews were more likely to be female and to be helping the client -with activities of daily living. The proportion of clients having more than one family member interviewed declined over the three waves from 61 percent to 51 percent, reflecting a tendency for less involved relatives to drop out of the study. The participation of family respondents also was related to client symptomatology. The higher the level of symptomatology, indicated by a short version of the Symptom Checklist-90 to which the clients responded, the more likely the family respondent was to complete the study.

### ***Other Applications***

Although the FEIS is derived from the instrument used in the national evaluation of the RWJ Foundation Program on Chronic Mental Illness, the Family Survey used in Massachusetts was disseminated and used in at least two other mental health services studies. The Department of Mental Health in New York State used the Family Survey to collect information about a state-wide organization of families. In addition, researchers in Denver also used this early version to study the impact of service and system change in Colorado (Coen, personal communication).

More recently, the FBIS has been used in an evaluation of the family impact of facility consolidation in Massachusetts (Benson 1994). The protocol has also been used in Connecticut

to study the effects on the family of assertive community treatment and of Clozapine (Essock, personal communications), in an evaluation of service system change in Ohio (Jones and Jones, in press; Jones, Roth, and Jones, in press), in a study of the families of the homeless in Baltimore (Lehman, personal communications), and in a study of rural care provision in Virginia (Kane, personal communications). The FBIS has also been included in two R01 grant applications, one designed to evaluate the impact of a psychosocial educational intervention for families in Washington State (Dyck, personal communications), and another designed to compare the effectiveness of Clozapine and Risperidone in Massachusetts (Green, personal communications).

### ***The FEIS: Basic Facts***

The current form of the Family Burden Interview Schedule is revised based upon psychometric analyses of the instrument in the RWJ evaluation. During the three waves of interviewing we experimented in limited ways with item wording and different response categories, and for particular modules also added and deleted specific items. Thus while the FEIS holds much similarity to the version used in Ohio there have been some improvements. Our revised version of the earlier FBIS strives to keep open-ended questions to a minimum. However, researchers are free to add their own open-ended questions tailored for their specific needs.

The accompanying FEIS Quick Reference Guide in the Introduction and Overview introduces the basic characteristics of the FEIS. As was shown, it has been used with a variety of client populations, including but not limited to schizophrenia and the affective disorders. It has been administered to a variety of caregivers, including primary care givers as well as other family members. Virtually all types of family relations have been interviewed using the earlier FBIS, including some relationships that while not linked by blood or marriage are nonetheless considered by clients to be "like family." The FBIS has been used in exp[oratory and descriptive studies, as well as in program evaluations and randomized clinical trials. Thus it is robust with respect to research design. While it has not been formatted for use as a self administered questionnaire, it is recommended for use both as a personal interview and as a telephone interview. The latter is recommended particularly as a follow up to a personal interview. The

time frame for the burden modules is 30 days, while some related modules use 12 months or longer as the measurement period. Interviewers do not need to have a clinical background, but it is strongly recommended that they have background in conducting structured interviews, or that they receive intensive training. In either event, some training is required to familiarize interviewers with the FEIS.

Both the FBIS and the HIS incorporate a multidimensional approach to the family experience. Separate modules are included for: financial expenditures, the objective and subjective burdens associated with ADL care, the objective and subjective burdens associated with supervision, impact on daily routines, and emotional response worry and displeasure. The special rewards of caregiving are measured as benefits and gratifications.

Note: The FEIS has not been tested with caregivers to the elderly or to children with a serious emotional disorder. It has also not been used for studying families of persons with a primary diagnosis of substance abuse, families of forensic clients, and families of non-English speaking clients.

### **Modular Descriptions & Rationales**

The Family Experiences Interview Schedule lends itself to modular usage. Accordingly, the current section describes the protocol, one module at a time. For each module, a rationale is given for why it is relevant. The organization follows the format of the interview. Note that screeners are used throughout the interview that skip respondents out of items that are not applicable.

### ***Cover Page and Interviewer Observations***

The interview protocol included in the "toolkit" provides an illustrative cover page plus an end set of interviewer ratings to be filled out upon completing the interview. The cover page will of course need to be adapted by the investigators to their own individual study. Note that the interviewer observation module also includes provision for the interviewer's signature acknowledging that s/he will keep all information confidential.

### ***Module A: Respondent Background***

This group of items measures the respondent characteristics most often used as a basis for examining social differentiation: sex, age, marital status, religion, race/ethnicity, educational attainment, and household income (Fisher et al. 1990; Biegel et al. 1991). In addition, current school enrollment and/or current work status are included for the purposes of examining the effect of the mental illness on daily routines later on in the interview. (See Module I: Impact on Daily Routines). Household size is relevant to family burden because household size may be a proxy for crowding and as such contribute to strain for both the client, also referred to as (NAME), and other family members. Relatives with larger homes may have greater capacity to extend aid to their bin than those living in closer quarters.

### ***Module B: Family Enumeration***

This module records the respondent's relationship to the consumer and seeks to enumerate the potential as distinct from the actual caregiving network (Fisher and Tessler 1991). Without knowing the size, composition, and proximity of potential support networks, inferences about the representativeness of the sample of family members or about the caregiving associated with various family roles (e.g., siblings) cannot be made with confidence (Horwitz et al. 1992). There is also an enumeration of the adult children of parents with severe mental illness who may be asked to take on a caregiving role. In addition we ask for the number of (NAME)'s minor children who may represent an additional caregiving responsibility for some family members (Gamache, Tessler and Nicholson in press).

### ***Module C: Client Background***

This module provides background information about (NAME) that may be relevant to family burden. While some of these questions may also be part of a cheat interview, it has been our experience that it is worthwhile to also ask them in the family interview in order to guard against missing data and to assure timely availability of consumer variables. In addition to social and clinical characteristics, a global measure of continuity of care is included. This measure was used in the Robert Wood Johnson evaluation (Tessler and Gamache 1994). A key finding was

that under the condition of co-residence, continuity of care (as measured) reduced objective burden but not “worry.”

### ***Module D: Contact***

This module was designed to determine the current level of contact between the respondent and (NAME) including co-residence. Client residence is relevant to family burden because co-residence implies greater opportunity for caregiving (Tessler and Gamache 1994) and contributions (Greenberg et al. 1994). This module also includes screeners that determine whether the respondent has had contact with or knowledge of the client in the past 30 days and if not, then within the past 12 months. In addition, the respondent is asked whether or not the illness is associated with the lack of contact with (NAME). Whether the respondent has had recent contact with or knowledge of the client is important to establish early in the interview because many of the subsequent questions focus on the past 30 days (e.g., the measures of assistance and supervision), while selected modules are appropriate if there has been contact during the past 12 months (e.g., attitudes towards professionals). Even when there has been no contact during the past 12 months two modules are still appropriate: stigma and worry. Thus, the skip patterns embedded in the interview determine whether or not certain modules are asked. When the consumer is living with the respondent, it is assumed that contact and/or knowledge has occurred in the past 30 days.

### ***Module E: Benefits and Gratifications***

As previously noted, there has been until recently a lack of research attention to the worthwhile special rewards that may be involved in relationships between caregivers and their relatives with severe mental illness (Bulger et al. 1993; Schene et al. in press). Whereas mental illness may be disabling in certain ways, e.g. by restricting educational attainment and occupational performance, it does not necessarily rule out reciprocal and beneficial exchanges between consumers and their families.

Relatives with mental illness receive support to the extent that they can count on family members for help when the need arises. Support, however, is not a one way provision of care and

help. A relative with mental illness may be expected to reciprocate in some measure for the help received, at the very least by complying with the treatment regimen (Parsons and Fox 1952) and by correcting inappropriate behaviors (Stoneall 1983). To the extent that consumers can contribute to the functioning of the household, provide companionship or can fulfill other supportive familial obligations, the costs to the family caregiver may be offset. When expected exchanges do not occur, negative responses are likely to follow (Stoneall 1983). Kreisman and Joy (1974) noted that “when the patient contributed to the household rather than taxed its limited resources, there was significantly greater likelihood that the patient would remain out of the hospital (p. 48).”

### **Benefits**

The E1 - E5 series of items are derived from the National Surveys-of Families and Households (Sweet et al. 1988). Their purpose is to describe what, if anything, (NAME) has done recently to benefit the respondent. Greenberg, Greenley, and Benedict (1994) reported recently in a rural Wisconsin survey using many of the same items that between 50 and 80 percent contributed to their families

### **Gratifications**

Positive feelings derived from the relationship may be as strong or stronger as those engendered in “normal” family relationships. Caregivers may enjoy (NAME)’s company, feel he or she is an important part of their life, feel pride and experience happiness as a result of their continuing relationship. “Gratifications” is positively framed in contrast to the negative concept of “rejection” or “displeasure” which appears in Module K (Kreisman et al. 1987).

### ***Module F: Financial Expenditures***

Depending upon the financial resources of the potential donor, mental illness may lead to a substantial outlay of money over an extended period (Franks 1990; Clark and Drake 1994). Clark (1994) report that family members of persons with dual diagnoses indeed do provide significantly more financial support than a control sample of persons in the same neighborhood



whose relatives do not have a mental illness. At issue is the amount of economic resources family members expend to financially support their relative due to his or her psychiatric condition. Based upon a survey of the Alliance for the Mentally Ill in Massachusetts, and using a list of expense categories which included transportation, clothing, pocket money, food, shelter, recreation, medical/dental, medication, and mental health treatment, Franks (1990) estimated an average yearly expense of \$3,311. In interpreting economic expenditures, it is important to keep in mind what are the economic resources of the persons under study since generosity is conditioned at least in part by capacity. The relatively affluent with their greater discretionary income may have a larger capacity to extend aid to their kin while those whose income is closer to subsistence level may not have as much capacity.

We ask family members: “During the past 30 days, have you personally paid for, or given (NAME) money for any of the following for which (NAME) has not paid you back?” For any category in which expenditures did occur during the past 30 days, the respondent is asked how much money was given. The list which was informed by the earlier work of Franks (1987) includes such expenses as transportation, clothing, pocket money, medication, mental health treatment, other medical expenses, cigarettes, personal items, as well as an open ended other expenses category. For food and shelter expenses, if (NAME) lives with the respondent, the respondent is asked to estimate the consumer's share of the grocery bill and the rent or mortgage. A final item (QF3) is conceptualized as a global measure of perceived “economic burden” over the past year.

### ***Module G: Assistance in Daily Living***

Much of the “burden” experienced by relatives of persons with mental illness arises from caregiving (Creer et al. 1982). Even when florid symptoms of psychopathology are controlled by medication, persons with severe mental illness often experience residual impairments that prevent them from functioning without assistance in every day life. Many need help or reminding with such tasks as getting dressed, taking medication, doing laundry, preparing meats, shopping, getting places, managing money, and making use of their leisure time. Relatives living

in unsupervised settings or at home frequently rely on a family member to provide such assistance.

Our approach to measuring the burden associated with caregiving is to present the respondent with the broad list of areas described above, to determine whether the respondent gave help in each, how much was given, and who else, if anyone (including professionals) provided the help.

Module G includes measures to indicate the subjective burden associated with caregiving on an area by area, basis, e.g. the subjective burden directly related to helping (NAME) manage money. In every instance where the respondent provides care, either alone or in conjunction with others, the respondent is asked “How much did you mind helping (NAME) with...? Was it a lot, some, very little, or not at all? These items measure the respondent's subjective burden that directly links subjective burden to objective caregiving (Tessler et al. 1988).

#### ***Module H: Supervision or Control of Bothersome Behaviors***

Another burden associated with caregiving is dealing with behavior that is embarrassing or frightening (Creer et al. 1982). Very often one (or more) family member(s) is asked to do something about the client's bothersome behavior, leading them to take on the role of de facto guardians or controllers of the client. While incidents of threatened or actual violence to self or other(s) may occur only rarely, when they do occur they are matters of great concern to relatives of persons with mental illness.

We approach the burden associated with supervision or control in the same way as we approached the burden of caregiving associated with assistance in daily living. We selected embarrassing behavior, attention-seeking, disturbing behavior at night, threatening or violent behavior, talk or threats (or attempts) of suicide, excessive use of alcohol and the use of drugs such as marijuana, cocaine, amphetamines, or heroin. For each of the seven areas, respondents are asked whether during the past 30 days they had tried to prevent or stop the consumer from engaging in the behavior, how often they were involved, how much they minded having to deal with the problem, and who else, if anyone (including professionals) tried to prevent or stop the client.

Module H includes measures of the subjective burden associated with caregiving on an area by area basis, e.g. the subjective burden directly related to supervision or control such as preventing or stopping (NAME) from keeping anyone up at night. Thus, these items measure the respondent's subjective burden that is directly linked to objective caregiving (Tessler et al. 1988).

### ***Module I: Impact on Daily Routines***

The “impact” of mental illness on family members may include disruptions in social or work life or daily household routines (Platt et al. 1980). The disruption measures are adapted from the measures of Platt and colleagues, but in contrast to the use of interviewer ratings in their semi-structured Social and Behavior Interview Schedule, the FEIS uses fixed response categories and does not require interviewer ratings. We have also expanded slightly the item content to include disruption in attention given to other family members.

For those respondents who are working or who are students, the interviewer asks: “During the past 30 days, did you miss, or were you late for work or school because of your involvement with (NAME)? If the answer is yes, the respondent is asked how often this occurred. A similar format is used to inquire whether social and leisure activities were changed or disrupted, whether housework or domestic routine was disrupted, and whether taking care of the consumer prevented the relative from giving other family members as much time and attention as they needed.

### ***Module J: Attitudes Towards Professionals***

Prior to deinstitutionalization the family was viewed at best as inexperienced, and at worst as a causal agent in the development and maintenance of mental illness (Fisher et al. 1990). As families became more vocal, they began to express their attitudes towards mental health professionals. These expressed attitudes suggested a large gap between what families wanted and needed and what was provided. Although attitudes toward professionals appear to be becoming more positive (Tessler et al. 1992) there remains much basis for concern.

This module includes a series of items about attitudes toward mental health treatment professionals. In these attitudinal questions, conceptualized as alienation from professionals, respondents are asked to what extent seven statements reflect their experiences with mental health professionals during the past 12 months. The series begins with a screener so that persons who have not had contact with a professional during the past 12 months are skipped out of the sequence.

The items inquire about whether or not professionals were interested in what family members could tell them about (NAME)'s condition, discussed services and medication with them, took very seriously their problems in caring for (NAME), gave them useful practical advice, and were always available when needed. Two items were framed negatively to avoid response set bias. One asks whether professionals made them feel responsible for causing the illness, and the other inquires- whether professionals gave no information about (NAME)'s illness.

Note: We have been informed that one researcher has replaced the item concerned with whether professionals made family members feel responsible for causing the illness with an item that reads: "The professionals I have dealt with gave me the feeling I was overprotective." (Reinhard, personal communication). Researchers may want to add this item to those given in the FEIS and conduct their own psychometric analyses both with and without it. At this time we do not have psychometric information to report.

### ***Module K: Affective Response***

#### **Worry**

Possible costs of mental illness involve more than money (Hatfield 1978; Lefley 1987). The emotional distress caused by worrying may be a significant additional cost. Relatives worry about a range of issues that might affect the safety and well. being of the consumer. Even when relatives have not seen each other for a period of time, sometimes they worry anyway about the other person. Hence, we believe that worries can be measured whether or not there has been recent contact. Using a 5-point Likert scale (0 = constantly or almost constantly; 2 = often; 3 = sometimes; 4 = seldom; 5 = never), the interview protocol asks whether the respondent worries

about (NAME)'s safety, the kind of help and treatment that (NAME) is receiving, (NAME)'s social life, (NAME)'s physical health, (NAME)'s current living arrangements, about how (NAME) would manage financially if the respondent were not there to help, and about his or her future prospects.

### **Displeasure**

Seven items (QK8a-g) measure general emotional distress or displeasure (Gamache et al. 1991). Several items were taken from the rejection scale developed by Kreisman and colleagues in 1987. Responses include the family member's disappointment, anger, depression, irritation and embarrassment at the illness or the client's behavior and displeasure at organizing his or her life around (NAME). A final global measure (QK8h) asks for the respondent's perception of being overwhelmed by the intensity of the consumer's need for family care.

### ***Module L: Stigma***

Lefley (1989) has suggested that the stigma of mental illness generalizes from the consumer of mental health services to other family members. Hence the stigma arising from the mental illness of a relative may be expected to have a variety of adverse effects, coloring family interactions within the larger community. The FEIS views stigma as a negative outcome closely related to burden. We have adapted the stigma items from the Family Interview Schedule developed for a WHO study by Ezra Susser of the New York State Psychiatric Institute. These in turn were derived from stigma items developed for the general population by Bruce Link (1989).

As in the WHO interview protocol, the FEIS inquires about stigma since the onset of the mental illness. The lifetime window for response was chosen because stigma may be felt most keenly early in the history of the illness. Thus a 30 day time frame would miss some significant expressions of the stigma as experienced by family members.

The items include worry about: people finding out about the illness, neighbors treating them differently, friends and neighbors avoiding them, and being treated differently by even their best friends. Other items inquire about the need to hide the illness or keep it a secret, the avoidance of social events, not seeing friends and feelings of shame or embarrassment.

The measurement of stigma is also unique in the FEIS in that it employs a dichotomous yes-no format for response. The “yes-no” categories for response were chosen to simplify the respondent’s last task, but could be reformatted in future studies to include response categories such as 0 = not at all, 1 = a little, 2 = some, 3 = a lot. These were the response categories that are included in the WHO Family Interview Schedule.

Future studies should also explore factor analysis. Our analysis indicates that there are two factors represented in the stigma index.

### ***Global Measures***

#### **Module F**

Question F3 is a global assessment of the respondent's perception of financial burden over the past 12 months. Family members often feel that the 30 day framework does not adequately represent their experiences in this area. The 12 month time period allows the respondent to provide information about a financial burden over a longer time period (This item was adapted from a similar item developed by Greenberg and Greenley for their rural Wisconsin survey).

#### **Module I**

Question I9 is a global measure of the more or less permanent changes that family members have reported as a response to taking care of (NAME). A study of family members enrolled in a Massachusetts Family Support Program indicated that these changes may be missed in the measures of impact that are limited to the past 30 days (Gamache et al. 1991). For example, if a family member had previously retired early in order to take care of (NAME), there would be no disruption of a work schedule.

#### **Module K**

Question K8h although included with the displeasure items is not a part of that scale. It is a global measure of burden that is based on the self-reported perception of the respondent.

## **Modular Outline of Measures**

### **1. Module A: Background**

- Respondent age (A1)
- Respondent sex (A2)
- Respondent race/ethnicity (A3a)
- Client race/ethnicity (A3b)
- Respondent involvement with client (A4-A5)
- Respondent marital status (A6)
- Respondent religion (A7)
- Respondent education (A8)
- Respondent currently at work or school (A9-A10)
- Respondent household size (A11)
- Respondent total family income (A12)

### **2. Module B: Family Enumeration**

- Respondent relationship to client (B1)
- Client's living parents (B2)
- Client's living siblings (B3a-B3b)
  - Siblings living in same area (B3c)
- Client's living spouse (B4)
- Client's living children (B5a)
  - Number of minor children (B5b)

### **3. Module C: Client Background**

- Age (C1)
- Gender (C2)
- Education (C3)
- Marital Status (C4)
- Diagnosis (C5a-C5b)
- Respondent reported age at onset (C6)
- Continuity of Care (C7)
- Primary caregiver (C8-C9)
- Hospitalization history (C10-C11)
- History of homelessness (C12)

### **4. Module D: Contact**

- Client residence - where (D1)
- Client residence - with whom (D2)
- Contact in past 30 days (D3)
- Contact in past 12 months (D4)
- Perceptions of lack of contact (D5-D6)

5. **Module E: Benefits and Gratifications**
  - Benefits\* (E1-E5)
  - Gratifications\* (E6a-e)
6. **Module F: Financial Expenditures**
  - Areas of expenditures (F1a-k)
  - Total dollar amount (F2a-k)
  - Global financial burden (F3)
7. **Module G: Assistance in Daily Living: ADL Care**
  - Respondent objective ADL caregiving\* (G2, G7, G11, G15, G19, G23, G27, G31)
  - Respondent subjective ADL caregiving\* (G3, G8, G12, G16, G20, G24, G28, G32)
  - Others helped with ADL Care (G4, G9, G13, G17, G21, G25, G29, G33)
    - Another family member
    - Mental health program staff
    - Someone else
8. **Module H: Supervision**
  - Respondent objective Supervision. caregiving\* (H2, H6, H10, H14, H18, H22, H26)
  - Respondent subjective Supervision caregiving\* (H3, H7, H11, H15, H19, H23, H27)
  - Others helped Supervision (H4, H8, H12, H16, H20, H24, H28)
    - Another family member
    - Mental health program staff
    - Someone else
9. **Module I: Impact on Daily Routines**
  - Frequency of disruption of daily routines (I2, I4, I6, I8)
10. **Module J: Attitudes Toward Professionals**
  - Attitudes toward professionals scale\* (J2a-g)
11. **Module K: Affective Response**
  - Worry\* (K1-K7)
  - Displeasure\* (K8a-g)
  - Global measure (K8h)
12. **Module J: Stigma**
  - Perceived Stigma\* (L1a-i)

\* See Table 1: Summary of Family Experiences Measures for Cronbach's alpha.



## **Scale And Index Construction**

### ***Introduction***

This section of the Toolkit describes procedures for constructing scales and indices from the FEIS. We describe a total of 13 scales and indices which can be constructed and, where appropriate, report relevant psychometric information. Although researchers may choose to modify the scales somewhat based on their own psychometric analyses (e.g., to delete a given item if the corrected item-to-total correlation does not meet a chosen criterion), these are the scales which we recommend based on past analyses. An advantage of using them as recommended is that the results can be compared directly across studies.

Table 1, entitled Summary of Family Experiences Measures, shows the name of each scale or index, the module in which it appears, the number of items used to construct the measure, and the item numbers as they appear in the interview. Table 1 also shows Cronbach's alphas computed for two independent samples. One is from the study conducted in three cities in Ohio based on interviews with multiple respondents per client (305 family members related to 175 clients) as part of the evaluation of the Robert Wood Johnson Program for the Chronically Mentally Ill (Tessler and Gamache, 1994). Client identified primary caregivers were the respondents in another study in Connecticut conducted by Susan Essock and colleagues in which 176 family members were interviewed as part of an assessment of Assertive Community Treatment.

We assume that researchers will have their own methods for coding and entering missing data, i.e. refusals, don't knows, and interviewer errors. For many variables a “not applicable” (NA) code is also needed because of skip patterns built into the interview. NA's are relevant in two ways. First, NA's may signify that the item is not applicable in the sense that the amount of contact does not meet the requirement for asking the question. For example, attitudes toward treatment professionals is contingent upon there having been at least one contact with at least one professional during the past 12 months. Respondents with contact form a subsample for the analysis of this measure.

However, for other measures, no contact with (NAME) is assumed to be the equivalent of no “burden” associated with caregiving or “rewards” during the measurement period.

Respondents who have not had contact with (NAME) during the past 30 days should not be eliminated from analyses but their scores should be recoded to zero burden associated with caregiving or zero rewards (See Table 2). When the sample is chosen on the basis of primary caregiving to (NAME) it will be rare to find such cases.

Second, “not applicable” codes are also used following the screeners in section G, section H, and section I, when the response to the screener is “no.” These screeners skip the respondent out of the questions that inquire about the frequency of help and the subjective feelings related to the area (Sections G and H). The method we recommend is that the raw data from the other items in these sequences be coded “not applicable” because the respondent gave no assistance. However, these “not applicable” codes represent no burden associated with caregiving or no rewards to the respondent, and as such will need to be recoded to zero as part of the process of scale construction.

All scales and indices (other than financial expenditures which are summary totals) involve computing an average. Depending on the researcher's preference there are several options for handling missing data in the averaging process. The method used by the authors is to create a score for every individual for which there is a response to at least one item. The summative score is divided by the number of items over which the sum is calculated. An alternative is to choose a criterion, a priori, for the number of valid responses per observation that are required. For example, one may choose to exclude cases for which less than half of the items have valid responses. Other options are mean or mode substitution for missing data.

It is clearly beyond the scope of this section to include command files for the scale/index instructions which appear in narrative form. Researchers will have a variety of statistical programs with which they work including SPSS, SAS and STATA. The authors have worked largely using STATA and include for the researcher's convenience a sample file for a single scale. Thus, Attachment A contains a sample do file written for STATA that constructs the “worry” scale from items E1 – E7. It assumes that missing values are coded as 7 (“don't know”) and 8 (“interviewer error”).

Below we describe each set of scales and indices. For the reader's convenience we also reproduce the reliability coefficients when relevant based on the Ohio study.

## ***Module E: Benefits and Gratifications***

### **Benefits (Cronbach's alpha = .819)**

Benefits are measured in Module E, items E1 -E5. There are five items, each of which needs to be recoded so that higher scores signify more “benefits” received by the family member. Respondents without 30 day contact will have their items recoded to 0 (zero). The assumption is that if there was no contact (including seeing, talking to or having knowledge of (NAME) during the past 30 days) there could be no benefits. To produce a total score with a range of 0-4, recode items E1, E2, E3, E4, and E5 such that 5 = 0, 4 = 1, 3 = 2, 2 = 3, 1 = 4. The responses can then be averaged (as discussed above) to produce a total score, where values are now equal to:

- 0 = not at all
- 1 = less than once a week
- 2 = once or twice a week
- 3 = 3 to 6 times a week
- 4 = every day

### **Gratifications (Cronbach's alpha = .87)**

Gratifications are measured in Module E, items E6a-e. Note that the “Q by Q” instructs interviewers not to read the answer category “AMBIVALENT”, but to circle code 3 if R is unable to give one of the other responses and then to make a marginal note if the response can affect the way in which the data are interpreted. Items coded 3 should be carefully examined by the coder to make sure that “ambivalent” is the best representation of the respondent's feelings.

The five items need to be recoded such that higher scores signify more “gratification.” To produce a total score with a range of 1-5, recode items E6a, E6b, E6c, E6d, and E6e, such that 5 = 1, 4 = 2, 3 = 3, 2 = 4, 1 = 5. The responses can then be averaged (as discussed above) to produce a total score, where values are now equal to:

- 1 = strongly disagree
- 2 = disagree
- 3 = ambivalent

4 = agree

5 = strongly agree

### ***Module F: Financial Expenditures***

Two summary scores are constructed from Module F. The first is the number of areas for which the respondent has paid for or given (NAME) money (areas = Fla + Flb + Flc + Fld + Fle + Flf + Flg + Flh + Fli + Flj + Flk). Codes should be changed from 1 = yes and 2 = no to 1 = yes and 0 = no. The “other expenses” category may be eliminated if the frequencies are negligible.

The second measure is the total number of dollars paid over the 11 areas (dollars = F2a + F2b + F2c + F2d + F2e + F2f + F2g + F2h + F2i + F2j + F2k). Our experience in the Ohio study indicates that respondents are clear about giving money in a particular area but may have difficulty providing a dollar figure. If interviewer probes fail to elicit a dollar amount the researcher can substitute the mode on an item by item basis. Where the dollar amounts that are reported seem non-credible, we advise checking the respondent's reported income and the interviewer ratings of truthfulness that appear at the end of the interview. If the contribution is not consistent with the respondent's income and the truthfulness rating (See Module I, IO4) is greater than 2 (i.e., “about half and half” truthful or “mainly untruthful”), the item should be considered to be missing.

### ***Module G: Assistance in Daily Living (ADL Care)***

#### **Objective ADL (Cronbach's alpha = .777)**

Constructing the ADL care measures involves 3 recoding procedures before the averaging takes place.

Items G2, G7, G11, G15, G19, G23, G27, and G31 need to be recoded such that the values are:

1 = less than once a week

2 = once or twice a week

3 = 3 to 6 times a week

4 = everyday

(x<sub>1</sub>) = not applicable code for no burden associated with caregiving

(x<sub>2</sub>) = not applicable code for no contact

The next step is to take items G1, G6, G10, G14, G18, G22, G26 and G30 and convert them into variables having values of 0 (no help given) and 1 (help given). The 0 values are used to replace the x<sub>1</sub> values in G2, G7, G11, G15, G19, G23, G27, and G31.

The third step is to replace the x<sub>2</sub>, not-applicable codes (by virtue of no contact with (NAME), with zeros (using the assumption of no burden associated with caregiving) for items G2, G7, G11, G15, G19, G23, G27, and G31. Respondents whose relative does not take medication for the illness are also recoded to zero burden associated with caregiving. The final values are:

0 = never (no contact or no help given)

1 = less than once a week

2 = once or twice a week

3 = 3 to 6 times a week

4 = everyday

Based on items G4, G9, G13, G17, G21, G25, G29, and G33, caregiving burden scales can distinguish various permutations of respondent caregiving, e.g. whether caregiving burden is shouldered by the respondent alone, by the respondent and another family member, or by the respondent and a program staff member. Measures can also be constructed of care given by others even if the respondent has not assisted (NAME).

### **Subjective ADL (Cronbach's alpha = .741)**

This measure is constructed from items G3, G8, G12, G16, G20, G24, G28, and G32. Items need to be recoded such that 4 = 0, 3 = 1, 2 = 2, and 1 = 3. Where the objective burden measure associated with ADL caregiving described above is equal to 0, the values of subjective ADL caregiving burden, (originally coded as x<sub>1</sub> and x<sub>2</sub>) are also recoded to 0, indicating no subjective burden associated with ADL caregiving. The final values are:

0 = not at all

- 1 = very little
- 2 = some
- 3 = a lot

### ***Module H: Supervision/Control of Bothersome Behaviors***

#### **Objective Control (Cronbach's $\alpha = .65$ )**

The low internal consistency coefficient (.65) reported in the table was not unexpected since issues of control occur much more sporadically than problems in daily living, especially within a 30 day time frame. This measure is more properly viewed as an index rather than a scale.

Constructing the supervision/control measures involves 3 recoding procedures before the averaging takes place.

Items H2, H6, H10, H14, H18, H22 and H26 need to be recoded such that the values are:

- 1 = less than once a week
- 2 = once or twice a week
- 3 = 3 to 6 times a week
- 4 = everyday

(x<sub>1</sub>) = not applicable code for no ADL assistance

(x<sub>2</sub>) = not applicable code for no contact

The next step is to take items H1, H5, H9, (H13a and H13b), (H17a, H17b and H17c), H21 and H15 and convert them into variables having values of 0 (no help given) and 1 (help given). Note that the areas of suicide (H13a-b) and violence (H17a-c) have multiple screeners which need to be combined as indicated by the skip patterns of the FEIS. A “yes” on any one of the screeners indicates that the respondent is asked the entire sequence relating to that area. One screener variable should be constructed from the multiple screeners before proceeding to the next step. As with the burden associated with ADL caregiving, the not-applicable values will need to be replaced with zero (0) values in H2, H6, H10, H14, H18, H22 and H26.

The third step is to replace the  $x_2$  not-applicable codes (by virtue of no contact with (NAME) with zeros (using the assumption of no caregiving burden associated with supervision) for items H2, H6, H10, H14, H18, H22 and H26. The final values are:

0 = never (no contact or no help given)

1 = less than once a week

2 = once or twice a week

3 = 3 to 6 times a week

4 = everyday

As with assistance around ADL caregiving, various supervision indices can be constructed based on items H4, H8, H16, H20, H24, and H28. Indices can distinguish various permutations of respondent caregiving, e.g. whether caregiving is shouldered by the respondent alone, by the respondent and another family member, or by the respondent and a program staff member. Supervision can also be indicated for persons other than the respondent.

#### **Subjective control/supervision (Cronbach's $\alpha = .638$ )**

This measure is constructed from items H3, H7, H11, H15, H19, H23, and H27. As in objective control, the low alpha suggests the sporadic nature of this aspect of caregiving. Items need to be recoded such that 4 = 0, 3 = 1, 2 = 2, and 1 = 3. Where the objective burden measure associated with supervision or control caregiving described above is equal to 0, the values of the subjective burden measure associated with supervision or control, originally coded as not applicable, are recoded to 0. The final values are:

0 = not at all

1 = very little

2 = some

3 = a lot

#### ***Module I: Impact on Daily Routines (Cronbach-'s $\alpha = .568$ )***

Impact is considered an index measure of the quantitative impact on family respondents' daily routines. The low alpha indicates that disruption in one area does not necessarily imply

disruption in another area. An additional factor is that respondent backgrounds also differ by virtue of their current employment and other caregiving responsibilities.

Impact is measured in Module I and constructed from items I1-I8. Constructing the impact measures involves 3 recoding procedures designed to make higher scores represent greater impact before the averaging takes place.

Items I2, I4, I6, and I8 need to be recoded such that the values are:

1 = less than once a week

2 = once or twice a week

3 = 3 to 6 times a week

4 = everyday

(x<sub>1</sub>) = not applicable code for no ADL assistance

(x<sub>2</sub>) = not applicable code for no contact

The next step is to take items I1, I3, I5 and I7 and convert them into variables having values of 0 (no disruption) and 1 (disruption in that area). The 0 values are used to replace the x<sub>1</sub> values in I2, I4, I6, and I8.

The third step is to replace the x<sub>2</sub> not-applicable codes (by virtue of no contact with (NAME) during the past 30 days), with zeros (using the assumption of no burden associated with disruption of the caregiver's routine) for items I2, I4, I6, and I8. The final values are:

0 = never (no contact or no help given)

1 = less than once a week

2 = once or twice a week

3 = 3 to 6 times a week

4 = everyday

### ***Module J: Attitudes Towards Professionals (Cronbach's alpha = .815)***

Attitudes towards professionals is measured in Module J, items J2a-g. This scale is computed only for the subsample of respondents who have had contact with (NAME)'s doctor, social worker, case manager, or other mental health professional during the past 12 months. In



order to generate an index of alienation based on question Ja-g, items b and d should be reverse scored before computing *an* average so that higher scores indicate greater alienation on all items.

### ***Module K: Affective Response***

#### **Worry (Cronbach's alpha = .891)**

Worry is measured in module K, items K1 - K7. There are seven items, each of which needs to be recoded so that higher scores signify more “worry.” To produce a total score with a range of 0 - 4, recode items K1, K2, K3, K4, K5, K6 and K7 such that 5 = 0, 4 = 1, 3 = 2, 2 = 3, 1 = 4. The responses can then be averaged (as discussed above) to produce a total score, where values are now equal to:

0 = never

1 = seldom

2 = sometimes

3 = often

4 = constantly or almost constantly

#### **Displeasure (Cronbach's alpha= .852)**

Displeasure is measured in module K, items K8a-g. Factor analysis indicates that these 7 items comprise a single factor that represents the respondent's displeasure with (NAME) and (NAME)'s behavior.

Note that the “Q by Q” instructs interviewers not to read the answer category “AMBIVALENT,” but to circle code 3 if R is unable to give one of the other responses and then to make a marginal note if the response can affect the way in which the data are interpreted. Items coded 3 should be carefully examined by the coder to make sure that “ambivalent” is the best representation of the respondent's feelings.

The seven items need to be recoded so that higher scores signify more “displeasure.” To produce a total score with a range of 1 - 5, recode items K8a, K8b, K8c, K8d, K8e, K8f, and K8g, such that 5 = 1, 4 = 2, 3 = 3, 2 = 4, 1 = 5. The responses can then be averaged (as discussed in the introduction) to produce a total score, where values are now equal to:

1 = strongly disagree

2 = disagree

3 = ambivalent

4 = agree

5 = strongly agree

***Module L: Stigma (Cronbach.' s alpha = .851)***

Stigma is measured in Module L and includes 9 items: L1a, L1b, L1c, L1d, L1e, L1f, L1g, L1h, and L1i. The raw data values of 1 (yes) and 2 (no) will need to be recoded to 1 (yes) and 0 (no). The variable that results from the averaging procedure will range from 0 - 1 where 0 = no stigma and 1 = a yes response to all 9 items. Intervening values represent the proportion of valid responses that are affirmative, e.g., .22 means that the respondent answered “yes” to 2 out of 9 items and .89 means that the respondent answered “yes” to 8 out of 9 items. Thus as the score goes from 0 to 1, the perceived stigma increases.

### Attachment A: Sample STATA Command File

- This series of commands creates a “worry” scale using the f13 items.

- These commands recode 7 and 8 to STATA missing value codes.

```
mvdecode K1, mv(7)
```

```
mvdecode K2, mv(7)
```

```
mvdecode K3, mv(7)
```

```
mvdecode K4, mv(8)
```

```
mvdecode K5, mv(7)
```

```
mvdecode K6, mv(8)
```

```
mvdecode K7, mv(7)
```

- These commands reverse and rescore the “worry” variables.

```
recode K1 5=0 4=1 3=2 2=3 1=4
```

```
recode K2 5=0 4=1 3=2 2=3 1=4
```

```
recode K3 5=0 4=1 3=2 2=3 1=4
```

```
recode K4 5=0 4=1 3=2 2=3 1=4
```

```
recode K5 5=0 4=1 3=2 2=3 1=4
```

```
recode K6 5=0 4=1 3=2 2=3 1=4
```

```
recode K7 5=0 4=1 3=2 2=3 1=4
```

- This command constructs an average worry scale and produces a Cronbach's alpha coefficient.

```
alpha K1 K2 K3 K4 K5 K6 K7, generate(worry)
```

```
label variable worry “(avg worry score)”
```

<b>Table 1. Summary of Family Experiences Measures</b>					
<b>Name of Scale or Index</b>	<b>Module</b>	<b>Cronbach's Alpha</b>		<b>Number of Items</b>	<b>Item Numbers</b>
		<b>CT (176)</b>	<b>OH (305)</b>		
<b>Benefits</b>	E	NA	0.819	5	E1-E5
<b>Gratifications</b>	E	NA	0.87	5	E6a-e
<b>Financial expenditures: Areas</b>	F	NA	NA	11	F1a-k
<b>Financial expenditures: Dollars</b>	F	NA	NA	11	F2a-k
<b>Objective ADL care</b>	G	0.791	0.777	8	G2, G7, G11, G15, G19, G23, G27, G31
<b>Subjective ADL care</b>	G	0.761	0.741	8	G3, G8, G12, G16, G20, G24, G28, G32
<b>Objective supervision</b>	H	0.612	0.65	7	H2, H6, H10, H14, H18, H22, H26
<b>Subjective supervision</b>	H	0.676	0.638	7	H3, H7, H11, H15, H19, H23, H27
<b>Objective impact</b>	I	0.564	0.568	4	I2, I4, I6, I8
<b>Attitudes toward professionals*</b>	J	0.799*	0.815*	7	J2a-g
<b>Worry</b>	K	0.798**	0.891	7	K1-K7
<b>Displeasure</b>	K	NA	0.852	7	K8a-g
<b>Stigma</b>	L	NA	0.851	9	L1a-i
*Only measured for respondents who had contact with a professional during the past 12 months.					
**CT based on 5 items.					

<b>Table 2. Recoding of Measures by Contact Pattern</b>				
<b>Name of Scale or Index</b>	<b>Module</b>	<b>Required Contact Period</b>	<b>Items</b>	<b>Recodes for R's w/o 30 day contact</b>
<b>Benefits</b>	E	Past 30 days	E1-E5	0 (zero benefits)
<b>Gratifications</b>	E	Past 30 days	E6a-e	0 (zero gratifications)
<b>Financial expenditures: Total areas</b>	F	Past 30 days	F1a-k	0 (zero areas)
<b>Financial expenditures: Total dollars</b>	F	Past 30 days	F2a-k	0 (zero dollars)
<b>Objective ADL care</b>	G	Past 30 days	G2, G7, G11, G15, G19, G23, G27, G31	0 (zero objective burden)
<b>Subjective ADL care</b>	G	Past 30 days	G3, G8, G12, G16, G20, G24, G28, G32	0 (zero subjective burden)
<b>Objective supervision</b>	H	Past 30 days	H2, H6, H10, H14, H18, H22, H26	0 (zero objective burden)
<b>Subjective supervision</b>	H	Past 30 days	H3, H7, H11, H15, H19, H23, H27	0 (zero subjective burden)
<b>Objective impact</b>	I	Past 30 days	I1, I4, I7, I10	0 (zero impact)
<b>Attitudes toward professionals*</b>	J	Past 12 months	J2a-g	None (This is a subsample analysis*.)
<b>Worry</b>	K	None	K1-K7	None
<b>Displeasure</b>	K	None	K8a-g	None
<b>Stigma</b>	L	None	L1a-i	None
*Based on the subsample of respondents who had contact with a professional during the past 12 months.				

## THE FAMILY EXPERIENCES INTERVIEW SCHEDULE

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*By Richard Tessler, Ph.D. and Gail Gamache, Ph.D.*

Respondent ID#: \_\_\_\_\_

Date of Interview: \_\_\_\_\_

Time Began: \_\_\_\_\_ AM PM

Time Ended: \_\_\_\_\_ AM PM

Interviewed by Telephone: \_\_\_\_\_

1

Interviewed in Person: \_\_\_\_\_ 2

Name: \_\_\_\_\_  
(first) (middle) (last)

Address: \_\_\_\_\_  
(number and street) (apt.)

\_\_\_\_\_  
(city) (state) (zip)

Phone: \_\_\_\_\_  
(area code) (telephone number)

Interviewer: \_\_\_\_\_

ID#: \_\_\_\_\_

*-This item and the Interview Schedule text on disk-*

Respondent ID#: \_\_\_\_\_

**Section A: Background**

I would like to begin by asking you some questions about yourself and your relationship with (NAME).

**A1. How old are you now?**

Age (SPECIFY BELOW)

\_\_\_\_\_

**A2. (CODE RESPONDENT SEX)**

Male.....1

Female.....2

**A3a. Which of these groups best describes you:**

Asian.....1

Black.....2

Hispanic.....3

White.....4

Something else? (SPECIFY BELOW).....5

\_\_\_\_\_

**A3b. Is (NAME) also (INSERT RESPONDENT RACE FROM QA3a)?**

Yes (SKIP TO QA4).....1

No.....2

**A3c. Which of these groups best describes (NAME):**

- Asian.....1
- Black.....2
- Hispanic.....3
- White.....4
- Something else? (SPECIFY BELOW).....5
- 

**A4. How deeply are you involved with (NAME)?**

- Very involved.....1
- Somewhat involved.....2
- Slightly involved.....3
- Not involved?.....4

**A5. Would you say that your involvement in (NAME)'s life during the past 30 days was more than, less than, or about the same as it was during the past 12 months? Was it:**

- More.....1
- Less.....2
- About the same?.....3



**A6. Are you currently: (CIRCLE THE FIRST CODE THAT APPLIES)**

- Married.....1
- Living with a partner.....2
- Widowed.....3
- Separated.....4
- Divorced.....5
- Have you never married?.....6

**A7. What is your religious preference? Is it Protestant, Catholic, Jewish or something else?**

- Protestant.....1
- Catholic.....2
- Jewish.....3
- Other (SPECIFY BELOW).....4
- \_\_\_\_\_
- No religion.....5

**A8. What is the highest grade of school or year of college you have completed? (CIRCLE ONLY ONE CODE)**

- No schooling 00
- Elementary 01 02 03 04 05 06 07 08
- High school 09 10 11 12
- College 13 14 15 16
- Graduate/ 17+  
Professional

- A9. Are you currently enrolled in school or college?**
- Yes.....1
- No.....2
- A10. Are you currently working for pay:**
- Full time.....1
- Part time.....2
- Are you not working at  
all?.....3
- A11. What is the total number of people, including yourself, presently living in your household? Please include everyone who lives here at least half the time.**
- # of people (SPECIFY BELOW)
- 
- A12. Please tell me the letter on this card that represents your (INSERT LAST YEAR) total family income, before taxes, from all sources.**
- A less than \$10,000.....1
- B between \$10,000 and \$19,999.....2
- C between \$20,000 and \$29,999.....3
- D between \$30,000 and \$39,999.....4
- E between \$40,000 and \$49,999.....5
- F between \$50,000 and \$59,000.....6
- G or more than \$60,000.....7

## Section B: Family Enumeration

The next questions have to do with (NAME)'s family.

### B1. What is your relationship to (NAME)?

Parent.....	1
Child.....	2
Sibling.....	3
Spouse/Partner.....	4
Other kin.....	5
Nonkin/Friend.....	6

### B2. Does (NAME) have [another] living parent?

Yes living parent.....	1
No living parent.....	2
Don't know.....	7

### B3a. What about [any other] living brothers and sisters?

Yes living sibling(s).....	1
No living sibling(s) (SKIP TO QB4).....	2
Don't know.....	7

### B3b. How many brothers and sisters [including yourself]?

# of brothers and sisters (SPECIFY BELOW):

---

**B3c. How many live in the same area as (NAME)?**

# live in same area (SPECIFY BELOW)

---

(SKIP TO QB5a IF R IS SPOUSE)

**B4. Does (NAME) have a living spouse?**

Yes living spouse.....1

No living spouse.....2

Don't know.....7

**B5a. How many [other] living children, if any, does (NAME) have? Include natural, adopted, step and foster children. (Please include yourself.)**

Number of children (SPECIFY BELOW)

---

Don't know.....97

**B5b. How many of (NAME)'s children are under the age of 18?**

Number of children (SPECIFY BELOW)

---

Don't know.....97

### Section C: Client Background

Next I would like to ask you some questions about (NAME).

**C1. How old is (NAME) now?**

Age (SPECIFY BELOW)

---

Don't know.....97

**C2. (ASK IF UNKNOWN)**

**Is (NAME) male or female?**

Male.....1

Female.....2

**C3. What is the highest grade of school or year of college (NAME) has completed?  
(CIRCLE ONLY ONE CODE)**

No schooling 00

Elementary 01 02 03 04 05 06 07 08

High school 09 10 11 12

College 13 14 15 16

Graduate/ 17+  
Professional

**C4. Is (NAME) currently: (CIRCLE THE FIRST CODE THAT APPLIES)**

Married.....	1
Living with a partner.....	2
Widowed.....	3
Separated.....	4
Divorced.....	5
Has (he/she) never been married?.....	6

**C5a. Do you know what (NAME)'s diagnosis is?**

Yes.....	1
No (SKIP TO QC6).....	2
Don't know.....	7

**C5b. What is it? (What do you think it is?)  
(SPECIFY BELOW)**

---

**C6. At about what age did (NAME) first receive help for mental health problems?**

Age (SPECIFY BELOW)

---

Don't know.....	97
-----------------	----

- C7. Does (NAME) have a primary therapist, case manager, or social worker who sees (NAME) on a regular basis?**
- Yes.....1
- No.....2
- Don't know.....7
- C8. Are you the family member who provides the most support for (NAME)?**
- Yes (SKIP TO QC10).....1
- No.....2
- C9. Which family member, relative or friend provides the greatest amount of care to (NAME)?**
- Relationship to name (SPECIFY)
- \_\_\_\_\_
- No one.....1
- Don't know.....7
- C10. Has (NAME) ever been in the hospital for (his/her) emotional or mental problems?**
- Yes.....1
- No (SKIP TO QC12).....2
- Don't know.....7
- C11. How many times has (he/she) been in the hospital for emotional or mental problems?**
- # of times (SPECIFY BELOW)
- \_\_\_\_\_
- Don't know.....7

**C12. Has (NAME) been homeless at any time during the past 12 months?**

Yes.....1

No.....2

Don't know.....7



## Section D: Contact

**D1. In what type of housing has (NAME) been living the majority of the past 30 days? (Where has [he/she] spent the majority of overnights?)**

House/Apartment.....	1
Supervised group home.....	2
Mental health hospital.....	3
Homeless.....	4
Other (SPECIFY BELOW).....	5
<hr/>	
Don't know.....	7

**D2. With whom has (NAME) been living the majority of the past 30 days? (Where has [he/she] spent the majority of overnights?)**

Respondent (SKIP TO QE1).....	1
Other family member(s).....	2
Friend(s).....	3
Spouse/partner.....	4
Unrelated others.....	5
Alone.....	6
Don't know.....	7

**D3. Have you seen or talked to (NAME) in the past 30 days?**

Yes (SKIP TO QE1).....	1
No.....	2

- D4. Have you seen, talked to, or had knowledge of (NAME) within the past 12 months?**
- Yes.....1
- No (SKIP TO QJ1).....2
- D5. Did (NAME)’s illness have anything to do with your not being in contact all this time?**
- Yes.....1
- No.....2
- D6. If (NAME) wanted to re-establish contact, would you be:**
- Opposed.....1
- In favor.....2
- (DO NOT READ)** Ambivalent.....3

**(ALL SKIP TO QK1)**

## Section E: Benefits and Gratifications

Here is a list of things that family members sometimes do for one another. Please tell me how often during the past 30 days (NAME) has done the following for you.

**E1. During the past 30 days, how often has (3) helped you with meal preparation, shopping or other household chores? Was it:**

- Every day.....1
- 3 to 6 times a week.....2
- Once or twice a week.....3
- Less than once a  
week.....4
- Not at all?.....5

**E2. During the past 30 days, how often has (NAME) helped you out financially? Was it:**

- Every day.....1
- 3 to 6 times a week.....2
- Once or twice a week.....3
- Less than once a  
week.....4
- Not at all?.....5

**E3. During the past 30 days, how often has (NAME) listened to your problems and offered advice? Was it:**

- Every day.....1
- 3 to 6 times a week.....2
- Once or twice a week.....3
- Less than once a  
week.....4

Not at all?.....5

**E4. During the past 30 days, how often has (NAME) given you news about mutual friends and the family? Was it:**

Every day.....1

3 to 6 times a week.....2

Once or twice a week.....3

Less than once a week.....4

Not at all?.....5

**E5. During the past 30 days, how often has (NAME) given you companionship? Was it:**

Every day.....1

3 to 6 times a week.....2

Once or twice a week.....3

Less than once a week.....4

Not at all?.....5

**E6. As I read each of the following statements, tell me how you have felt during the past 30 days. Do you strongly agree, agree, disagree, or strongly disagree with what these statements say about (NAME)?**  
**(READ STATEMENTS a.-e. REPEAT THE ANSWER CATEGORIES AS NEEDED)**

	Strongly Agree	Agree	(DO NOT READ) Ambivalent	Disagree	Strongly Disagree
a. I have enjoyed being with (NAME).	1	2	3	4	5
b. (NAME) has been an important part of my life.	1	2	3	4	5
c. I have been very proud of (NAME).	1	2	3	4	5
d. It has made me happy to do things for (NAME).	1	2	3	4	5
e. (NAME) has made me happy.	1	2	3	4	5

## Section F: Financial Expenditures

**F1. During the past 30 days, have you personally paid for, or given (NAME) money for any of the following for which (NAME) has not paid you back? (IF YES, IMMEDIATELY ASK QF2)**

**F2. How much money was that?**

		QF1		QF2
		Yes	No	Amount in past 30 days
a.	Transportation expenses, carfare, gas, taxi, etc.?	1	2	\$ _____
b.	Clothing?	1	2	\$ _____
c.	Pocket money?	1	2	\$ _____
d.	Food? (IF [NAME] LIVES WITH R, ASK R TO ESTIMATE [NAME]'S SHARE OF GROCERY BILL.)	1	2	\$ _____
e.	Shelter (rent, mortgage)? (IF [NAME] LIVES WITH R, ASK R TO ESTIMATE [NAME]'S SHARE OF RENT/MORTGAGE.)	1	2	\$ _____
f.	Medication?	1	2	\$ _____
g.	Mental health treatment?	1	2	\$ _____
h.	Other medical expenses?	1	2	\$ _____
i.	Cigarettes?	1	2	\$ _____
j.	Personal items?	1	2	\$ _____
k.	Other expenses? (SPECIFY BELOW)	1	2	\$ _____
_____				
_____				

**F3. Was (NAME) a financial burden to you during the past 12 months? Was it:**

- Constantly or almost constantly.....1
- Often.....2
- Sometimes.....3
- Seldom.....4
- Never?.....5

## Section G: Assistance in Daily Living

It frequently happens that persons who are mentally ill need help or need to be reminded to do everyday things. The next questions are about that. All of them may not apply to (NAME), but please try to answer them to the best of your knowledge.

**G1. During the past 30 days, did you help or remind (NAME) to do things like grooming, bathing, or dressing?**

- Yes.....1
- No (SKIP TO QG4).....2

**G2. During the past 30 days, how often did you help (NAME) with, or remind (NAME) to do things like grooming, bathing, or dressing? Was it:**

- Every day.....1
- 3 to 6 times a week.....2
- Once or twice a week.....3
- Less than once a week?.....4

**G3. How much did you mind helping (NAME) with or reminding about these things? Was it:**

- A lot.....1
- Some.....2
- Very little.....3
- Not at all?.....4

- G4. During the past 30 days, did anyone else help or remind (NAME) to do things like grooming, bathing, or dressing?  
(PLEASE CIRCLE AS MANY AS APPLY)**
- Another family member.....1
- Mental health program staff.....2
- Someone else.....3
- No other person.....4
- Don't know.....7
- G5. Is (NAME) supposed to be taking medication for (his/her) condition?**
- Yes.....1
- No/Don't Know (SKIP TO QG10).....2
- G6. During the past 30 days, did you help, remind, or encourage (NAME) to take (his/her) medicine?**
- Yes.....1
- No (SKIP TO QG9).....2
- G7. During the past 30 days, how often did you help, remind, or encourage (NAME) to take (his/her) medicine?**
- Every day.....1
- 3 to 6 times a week.....2
- Once or twice a week.....3
- Less than once a week?.....4



- G8. How much did you mind helping, reminding, or encouraging (NAME) to take (his/her) medicine? Was it:**
- A lot.....1
- Some.....2
- Very little.....3
- Not at all?.....4
- G9. During the past 30 days, what other persons, if any, helped, reminded, or urged (NAME) to take (his/her) medicine? (PLEASE CIRCLE AS MANY AS APPLY)**
- Another family member.....1
- Mental health program staff.....2
- Someone else.....3
- No other person.....4
- Don't know.....7
- G10. During the past 30 days, did you help (NAME) with, or remind (him/her) to do (his/her) housework or laundry?**
- Yes.....1
- No (SKIP TO QG13).....2
- G11. During the past 30 days, how often did you help (NAME) with, or remind (NAME) to do (his/her) housework or laundry? Was it:**
- Every day.....1
- 3 to 6 times a week.....2
- Once or twice a week.....3
- Less than once a week?.....4

- G12. How much did you mind helping (NAME) with or reminding (him/her) about these things? Was it:**
- A lot.....1
- Some.....2
- Very little.....3
- Not at all?.....4
- G13. During the past 30 days, what other persons, if any, helped (NAME) with, or reminded (NAME) to do (his/her) housework or laundry? (PLEASE CIRCLE AS MANY AS APPLY)**
- Another family member.....1
- Mental health program staff.....2
- Someone else.....3
- No other person.....4
- Don't know.....7
- G14. During the past 30 days, did you help (NAME) with, or remind (him/her) to do shopping for groceries, clothes, and other things?**
- Yes.....1
- No (SKIP TO QG17).....2
- G15. During the past 30 days, how often did you help (NAME) with, or remind (NAME) to do shopping for groceries, clothes, and other things? Was it:**
- Every day.....1
- 3 to 6 times a week.....2
- Once or twice a week.....3
- Less than once a week?.....4

- G16. How much did you mind helping (NAME) with or reminding (him/her) about these things? Was it:**
- A lot.....1
- Some.....2
- Very little.....3
- Not at all.....4
- G17. During the past 30 days, what other persons, if any, helped (NAME) with, or reminded (NAME) to do shopping for groceries, clothes, and other things? (PLEASE CIRCLE AS MANY AS APPLY)**
- Another family member.....1
- Mental health program staff.....2
- Someone else.....3
- No other person.....4
- Don't know.....7
- G18. During the past 30 days, did you cook for (NAME) or help (him/her) prepare meals?**
- Yes.....1
- No (SKIP TO QG21).....2
- G19. During the past 30 days, how often did you cook for (NAME) or help (him/her) prepare meals? Was it:**
- Every day.....1
- 3 to 6 times a week.....2
- Once or twice a week.....3
- Less than once a week?.....4

- G20. How much did you mind cooking for (NAME) or helping (him/her) prepare meals? Was it:**
- A lot.....1
- Some.....2
- Very little.....3
- Not at all?.....4
- G21. During the past 30 days, what other persons, if any, cooked for (NAME) or helped (him/her) prepare meals? (PLEASE CIRCLE AS MANY AS APPLY)**
- Another family member.....1
- Mental health program staff.....2
- Someone else.....3
- No other person.....4
- Don't know.....7
- G22. During the past 30 days, did you give (NAME) a ride or help (him/her) to use public transportation?**
- Yes.....1
- No (SKIP TO QG25).....2
- G23. During the past 30 days, how often did you give (NAME) a ride or help (him/her) to use public transportation? Was it:**
- Every day.....1
- 3 to 6 times a week.....2
- Once or twice a week.....3
- Less than once a week?.....4

**G24. How much did you mind helping (NAME) with (his/her) transportation needs? Was it:**

- A lot.....1
- Some.....2
- Very little.....3
- Not at all?.....4

**G25. During the past 30 days, what other persons, if any, gave (NAME) a ride or helped (NAME) to use public transportation?  
(PLEASE CIRCLE AS MANY AS APPLY)**

- Another family member.....1
- Mental health program staff.....2
- Someone else.....3
- No other person.....4
- Don't know.....7

**G26. During the past 30 days, did you help (NAME) to manage (his/her) money?**

- Yes.....1
- No (SKIP TO QG29).....2

**G27. During the past 30 days, how often did you help (NAME) to manage (his/her) money, or manage it for (him/her)? Was it:**

- Every day.....1
- 3 to 6 times a week.....2
- Once or twice a week.....3
- Less than once a week?.....4

- G28. How much did you mind helping (NAME) manage (his/her) money? Was it:**
- A lot.....1
- Some.....2
- Very little.....3
- Not at all?.....4
- G29. During the past 30 days, what other persons, if any, helped (NAME) to manage (his/her) money, or managed it for (him/her)?  
(PLEASE CIRCLE AS MANY AS APPLY)**
- Another family member.....1
- Mental health program staff.....2
- Someone else.....3
- No other person.....4
- Don't know.....7
- G30. During the past 30 days, did you help, remind or urge (NAME) to make use of (his/her) time, such as going to work, or school, or aftercare, or visiting with friends?**
- Yes.....1
- No (SKIP TO QG33).....2
- G31. During the past 30 days, how often did you help, remind, or urge (NAME) to make use of (his/her) time? Was it:**
- Every day.....1
- 3 to 6 times a week.....2
- Once or twice a week.....3
- Less than once a week?.....4

**G32. How much did you mind helping (NAME) make use of (his/her) time? Was it:**

- A lot.....1
- Some.....2
- Very little.....3
- Not at all?.....4

**G33. During the past 30 days, what other persons, if any, helped, reminded, or urged (NAME) to make use of (his/her) time?  
(PLEASE CIRCLE AS MANY AS APPLY)**

- Another family member.....1
- Mental health program staff.....2
- Someone else.....3
- No other person.....4
- Don't know.....7

## Section H: Supervision

**H1. During the past 30 days, did you try to prevent or stop (NAME) from doing something embarrassing in public or before company?**

Yes.....1

No (SKIP TO QH4).....2

**H2. During the past 30 days, how often did you try to prevent or stop (NAME) from doing something embarrassing? Was it:**

Every day.....1

3 to 6 times a week.....2

Once or twice a week.....3

Less than once a week?.....4

**H3. How much did you mind dealing with (NAME)'s embarrassing behavior? Was it:**

A lot.....1

Some.....2

Very little.....3

Not at all.....4

**H4. During the past 30 days, what other persons, if any, tried to prevent or stop (NAME) from doing something embarrassing?  
(PLEASE CIRCLE AS MANY AS APPLY)**

Another family member.....1

Mental health program staff.....2

Someone else.....3

No other person.....4

Don't know.....7



- H5. During the past 30 days, did you try to prevent or stop (NAME) from making excessive demands for attention?**
- Yes.....1
- No (SKIP TO QH8).....2
- H6. During the past 30 days, how often did you try to prevent or stop (NAME) from making excessive demands for attention? Was it:**
- Every day.....1
- 3 to 6 times a week.....2
- Once or twice a week.....3
- Less than once a week?.....4
- H7. How much did you mind dealing with (NAME)'s attention-seeking behavior? Was it:**
- A lot.....1
- Some.....2
- Very little.....3
- Not at all.....4
- H8. During the past 30 days, what other persons, if any, tried to prevent or stop (NAME) from making excessive demands for attention?  
(PLEASE CIRCLE AS MANY AS APPLY)**
- Another family member.....1
- Mental health program staff.....2
- Someone else.....3
- No other person.....4
- Don't know.....7

- H9. During the past 30 days, did you try to prevent or stop (NAME) from keeping anyone up at night for any reason?**
- Yes.....1
- No (SKIP TO QH12).....2
- H10. During the past 30 days, how often did you try to prevent or stop (NAME) from keeping anyone up at night for any reason? Was it:**
- Every day.....1
- 3 to 6 times a week.....2
- Once or twice a week.....3
- Less than once a week?.....4
- H11. How much did you mind having to deal with (NAME)'s disturbing behavior? Was it:**
- A lot.....1
- Some.....2
- Very little.....3
- Not at all?.....4
- H12. During the past 30 days, what other persons, if any, tried to prevent or stop (NAME) from keeping anyone up at night?  
(PLEASE CIRCLE AS MANY AS APPLY)**
- Another family member.....1
- Mental health program staff.....2
- Someone else.....3
- No other person.....4
- Don't know.....7

**H13. During the past 30 days, did you try to prevent or stop (NAME):**

a. from striking or injuring anyone, including yourself?

Yes.....1

No.....2

b. from threatening to strike or injure anyone, including yourself?

Yes.....1

No.....2

**(IF NO TO BOTH a AND b, SKIP TO QH16. IF ANY YES, ASK QH14.)**

**H14. In the past 30 days, how often did you try to prevent or stop (NAME) from injuring or threatening to injure anyone? Was it:**

Every day.....1

3 to 6 times a week.....2

Once or twice a week.....3

Less than once a week?.....4

**H15. How much did you mind doing that? Was it:**

A lot.....1

Some.....2

Very little.....3

Not at all?.....4

**H16. During the past 30 days, what other persons, if any, tried to prevent or stop (NAME) from injuring or threatening to injure anyone?  
(PLEASE CIRCLE AS MANY AS APPLY)**

Another family member.....1

Mental health program staff.....2

Someone else.....3

No other person.....4

Don't know.....7

**H17. During the past 30 days, did you try to prevent or stop (NAME):**

	Yes	No
a. from talking about committing suicide?	1	2
b. from making threats to commit suicide?	1	2
c. from actually attempting to commit suicide?	1	2

**(IF NO TO a, b AND c, SKIP TO QH20. IF ANY YES, ASK QH18.)**

**H18. In the past 30 days, how often did you try to prevent or stop (NAME) from talking about, threatening, or attempting suicide? Was it:**

Every day.....1

3 to 6 times a week.....2

Once or twice a week.....3

Less than once a week?.....4

- H19. How much did you mind dealing with (NAME)'s suicidal (talk/threats/attempts)? Was it:**
- A lot.....1
- Some.....2
- Very little.....3
- Not at all?.....4
- H20. During the past 30 days, what other persons, if any, tried to prevent or stop (NAME) from talking about, threatening, or attempting suicide? (PLEASE CIRCLE AS MANY AS APPLY)**
- Another family member.....1
- Mental health program staff.....2
- Someone else.....3
- No other person.....4
- Don't know.....7
- H21. During the past 30 days, did you try to prevent or stop (NAME) from having too much to drink?**
- Yes.....1
- No (SKIP TO QH24).....2
- H22. During the past 30 days, how often did you try to prevent or stop (NAME) from drinking too much? Was it:**
- Every day.....1
- 3 to 6 times a week.....2
- Once or twice a week.....3
- Less than once a week?.....4

- H23. How much did you mind having to deal with (NAME)'s drinking? Was it:**
- A lot.....1
- Some.....2
- Very little.....3
- Not at all?.....4
- H24. During the past 30 days, what other persons, if any, tried to prevent or stop (NAME) from drinking too much?  
(PLEASE CIRCLE AS MANY AS APPLY)**
- Another family member.....1
- Mental health program staff.....2
- Someone else.....3
- No other person.....4
- Don't know.....7
- H25. During the past 30 days, did you try to prevent or stop (NAME) from using drugs or pills such as marijuana, cocaine, amphetamines or heroin?**
- Yes.....1
- No (SKIP TO QH28).....2
- H26. During the past 30 days, how often did you try to prevent or stop (NAME) from using drugs? Was it:**
- Every day.....1
- 3 to 6 times a week.....2
- Once or twice a week.....3
- Less than once a week.....4

**H27. How much did you mind having to deal with (NAME) using drugs? Was it:**

- A lot.....1
- Some.....2
- Very little.....3
- Not at all?.....4

**H28. During the past 30 days, what other persons, if any, tried to prevent or stop (NAME) from using drugs?  
(PLEASE CIRCLE AS MANY AS APPLY)**

- Another family member.....1
- Mental health program staff.....2
- Someone else.....3
- No other person.....4
- Don't know.....7

## Section I: Impact of Daily Routines

(IF R IS NOT IN SCHOOL [QA9 is coded 2] AND NOT WORKING [QA10 is coded 2], SKIP TO Q13.)

- I1. During the past 30 days, did you miss, or were you late for (school/[and] work) because of your involvement with (NAME)?**

Yes.....1

No (SKIP TO Q13).....2

- I2. (During the past 30 days), how often did you miss, or were you late for (school/[and] work) because of your involvement with (NAME)? Was it:**

Every day.....1

3 to 6 times a week.....2

Once or twice a week.....3

Less than once a week?.....4

- I3. During the past 30 days, were your social and leisure activities changed or disrupted because of (NAME)?**

Yes.....1

No (SKIP TO Q15).....2

- I4. (During the past 30 days), how often were your social and leisure activities changed or disrupted because of (NAME)? Was it:**

Every day.....1

3 to 6 times a week.....2

Once or twice a week.....3

Less than once a week?.....4



- I5. During the past 30 days, was your usual housework or domestic routine disrupted or changed because of (NAME)?**
- Yes.....1
- No (SKIP TO QI7).....2
- I6. (During the past 30 days), how often was your usual housework or domestic routine disrupted or changed because of (NAME)? Was it:**
- Every day.....1
- 3 to 6 times a week.....2
- Once or twice a week.....3
- Less than once a week?.....4
- I7. During the past 30 days, did taking care of (NAME) prevent you from giving (other) family members as much time and attention as they needed?**
- Yes.....1
- No (SKIP TO QI9).....2
- I8. (During the past 30 days), how often did taking care of (NAME) prevent you from giving other family members as much time and attention as they needed? Was it:**
- Every day.....1
- 3 to 6 times a week.....2
- Once or twice a week.....3
- Less than once a week?.....4
- I9. Has (NAME)'s illness caused you to make more or less permanent changes in your daily routine, work, or social life?**
- Yes.....1
- No (SKIP TO QJ1).....2

**I10. IF YES: How did your routine change?**

Worked less/quit job.....	1
Retired earlier than planned.....	2
Have no social life.....	3
Lost friendships.....	4
Take no vacations.....	5
Other (SPECIFY BELOW).....	6

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## Section J: Attitudes Toward Professionals

- J1.** Next, I want to ask you about treatment professionals you may have turned to for help and advice in caring for (NAME). During the past 12 months, did you meet or talk with (his/her) doctor, social worker, case manager, or any other mental health professional on any matter pertaining to (NAME)'s care?

Yes.....1

No (SKIP TO QK1).....2

- J2.** To what extent do the following statements reflect your experiences with mental health treatment professionals over the past 12 months? As I read each statement, tell me whether you strongly agree, agree, disagree, or strongly disagree. The professionals I have dealt with:  
(READ a-g. REPEAT THE ANSWER CATEGORIES AS NEEDED)

	Strongly Agree	Agree	Disagree	Strongly Disagree
a. were extremely interested in what I could tell them about (NAME)'s condition or problems.	1	2	3	4
b. gave me no information about (NAME)'s illness.	1	2	3	4
c. discussed with me the services and medication they planned for (NAME).	1	2	3	4
d. gave me the feeling that I am responsible for causing (NAME)'s illness.	1	2	3	4
e. took very seriously the problems I faced in caring for (NAME).	1	2	3	4
f. gave me useful, practical advice in caring for (NAME).	1	2	3	4
g. were always available when I needed them.	1	2	3	4

## Section K: Affective Response

(Even when people have not seen each other for a period of time, sometimes they worry anyway about the other person.) I would like to ask you about concerns or worries you may have about (NAME).

### K1. Do you worry about (NAME)'s safety:

Constantly or almost constantly.....	1
Often.....	2
Sometimes.....	3
Seldom.....	4
Never?.....	5

### K2. Do you worry about the kind of help and treatment (NAME) is receiving:

Constantly or almost constantly.....	1
Often.....	2
Sometimes.....	3
Seldom.....	4
Never?.....	5

### K3. Do you worry about (NAME)'s social life:

Constantly or almost constantly.....	1
Often.....	2
Sometimes.....	3
Seldom.....	4
Never?.....	5

**K4. Do you worry about (NAME)'s physical health:**

Constantly or almost constantly.....	1
Often.....	2
Sometimes.....	3
Seldom.....	4
Never?.....	5

**K5. Do you worry about (NAME)'s current living arrangements:**

Constantly or almost constantly.....	1
Often.....	2
Sometimes.....	3
Seldom.....	4
Never?.....	5

**K6. Do you worry about how (NAME) would manage financially if you were not there to help (him/her):**

Constantly or almost constantly.....	1
Often.....	2
Sometimes.....	3
Seldom.....	4
Never?.....	5

**K7. Do you worry about (NAME)'s future prospects:**

- Constantly or almost constantly.....1
- Often.....2
- Sometimes.....3
- Seldom.....4
- Never?.....5

**K8. People who have (relatives/friends) with mental health problems often have mixed feelings about them. As I read each of the following statements, tell me how you feel right now. Do you strongly agree, agree, disagree, or strongly disagree with what these statements say about (NAME)?  
(READ STATEMENTS a-g. REPEAT THE ANSWER CATEGORIES AS NEEDED.)**

	Strongly Agree	Agree	(DO NOT READ) Ambivalent	Disagree	Strongly Disagree
a. I am very disappointed in (NAME).	1	2	3	4	5
b. I am tired of having to organize my life around (NAME).	1	2	3	4	5
c. I get more irritated with (NAME) as time goes by.	1	2	3	4	5
d. I feel critical of the things (NAME) does.	1	2	3	4	5
e. I am very angry with (NAME).	1	2	3	4	5
f. I get depressed when I think about (NAME).	1	2	3	4	5
g. (NAME)'s behavior embarrasses me.	1	2	3	4	5
h. Taking care of (NAME) is a heavier burden than I can bear.	1	2	3	4	5

## Section L: Stigma

**L1. Was there ever a time when, because of (NAME)'s mental health problems:  
(READ a-i)**

	Yes	No
a. you worried whether people would find out about (NAME)'s condition	1	2
b. you worried that your neighbors would treat you differently?	1	2
c. you sometimes felt the need to hide (NAME)'s illness?	1	2
d. you kept (his/her) illness a secret?	1	2
e. you worried that friends and neighbors would avoid you after they found out about it?	1	2
f. you didn't see some of your friends as often as you did before?	1	2
g. you avoided going to large parties or social events with (NAME)?	1	2
h. you worried that even your best friends would treat you differently?	1	2
i. you felt ashamed or embarrassed about (NAME)'s illness?	1	2

**THANK RESPONDENT. RECORD TIME HERE AND ON THE COVER. TURN TO THE NEXT PAGE AND COMPLETE THE INTERVIEWER OBSERVATION QUESTIONS IMMEDIATELY. DO NOT DISCUSS THEM WITH THE RESPONDENT.**

Time Ended: \_\_\_\_\_ AM PM

### **Interviewer Observation Questions**

ANSWER THESE QUESTIONS IMMEDIATELY AFTER THE INTERVIEW. DO NOT DISCUSS THEM WITH THE RESPONDENT.

**IO1. During the interview, was the respondent generally:**

Very interested.....	1
Somewhat interested.....	2
Indifferent.....	3
Somewhat bored.....	4
Very bored?.....	5

**IO2. In general, how quickly did the respondent respond to questions?**

Responded quickly, without hesitation.....	1
Deliberated, but responses were not too slow.....	2
Was often slow to respond.....	3
Usually very slow, needed much urging.....	4

**IO3. What is your perception of R's intelligence?**

Very high.....	1
Above average.....	2
Average.....	3
Below average.....	4
Very low.....	5



**IO4. How truthful did R seem?**

- Completely truthful.....1
- Mainly truthful.....2
- About half and half.....3
- Mainly untruthful; evasive.....4

**IO5. Was the interview conducted:**

- in total privacy.....1
- with anyone else present?.....2

**IO6. Which questions, if any, did R have difficulty understanding?**

- .....
- None.....1

**IO7. What else, if anything, will help us interpret the data or give us a better understanding of the interview situation?**

- .....
- .....
- .....
- Nothing.....1

**IO8. I CERTIFY THAT I ADMINISTERED THIS INTERVIEW WITH THE DESIGNATED RESPONDENT, THAT I FOLLOWED ALL QUESTIONNAIRE SPECIFICATIONS, AND THAT I WILL KEEP ALL INFORMATION OBTAINED DURING THE INTERVIEW CONFIDENTIAL.**

Interviewer's Signature: \_\_\_\_\_

ID#: \_\_\_\_\_

## **PUTTING A FAMILY STUDY INTO THE FIELD**

### **Introduction**

Our recommendation is that a professional survey organization handle the process of tracing and interviewing respondents. The main reason is to assure the quality of the collected data. Quality control procedures are routinely used by established survey research organizations. These include established procedures for tracing respondents and informing them in advance about the study, and much experience in training and supervising interviewers. As part of this training, interviewers are required to successfully complete a mock interview, to take and pass quizzes, and to role play difficult initial contact situations. When actual interviewing begins, the initial interviews are monitored very closely in order to detect problems, e.g., failure to follow a required skip pattern, or high refusal rate. If crucial items are missing, or if the amount of missing data exceeds a minimum level, respondents are routinely called or re-visited as quickly as possible.

However, for those researchers who prefer to manage this process themselves, we include some general guidelines and materials that may be helpful. The authors wish to thank the Institute for Survey Research, Temple University, and Ellin Spector, Study Director, for granting permission to reproduce or adapt materials used in the National Institute of Mental Health sponsored Continuity of Care, Residence and Family Burden Study (RO1 MH44683).

### **Tracing Guidelines**

Because human subjects concerns and sampling procedures often necessitate that clients provide the names and addresses of family members, it has been our experience that extra effort may be required to obtain some respondent addresses and telephone numbers.

As a first step, we recommend sending out informational letters describing the study and what would be involved to the respondent at the address provided by the client (see sample letter in appendix). Arrange for the post office to notify you if there is a change of address, and not to forward such letters. If the letter is not returned by the post office, it can usually be assumed that the given address is valid.

When the address for a family member (given by the client) cannot be verified, the following points may be helpful to both interviewers and researchers:

1. If the address does not exist, it is possible that numbers were transposed or a street name was recorded incorrectly. For example, 1368 Milton St. could be 1638 Milton St. or 1368 Hilton St. Try likely possibilities.
2. Use the address given by the consumer as a starting point. Ask the present occupants and neighbors if they have any information about the respondent or the family. Apartment managers and landlords may also have relevant information.
3. Some sources may be unwilling to give you information until they obtain permission from the respondent. Leave your name and number with these sources, so that they or the respondent can get in touch with you.
4. Follow all leads. In-person tracing is best. People are more likely to give you information face-to-face than if you are an anonymous voice on the telephone.
5. Utilize all appropriate sources, including telephone directories, directory assistance, cross directories organized by addresses rather than alphabetically, the city directory, voter registration lists, and other available public records.
6. Do not trust your memory. Record every bit of information as soon as you obtain it. (Professional survey organizations utilize special tracing forms to organize this material).

The need for tracing is not necessarily limited to the first interview. When more than one interview is planned, a tracing form should be included in the protocol and administered at the end of the interview. The tracing form should ask for the names, addresses and telephone numbers of three close friends or relatives (not living with the respondent) who will know how to get in touch with the respondent in case R moves or the telephone number is changed.

Obviously every interviewer should have copies of the interview protocol. Various methods are available for assuring confidentiality of the protocol once it is completed, including sealing it in an envelope or using special confidentiality seals on the interview itself. All methods require sealing in the presence of the respondent. A set of General Instructions for interviewers as well as a set of Question by Question Specifications is included in the Manual.

Each Interviewer should be given an identification card to present at each contact with each respondent.

Researchers may find that it is worthwhile to prepare the following materials, some of which are required to satisfy human subjects concerns.

Samples of these materials are included in the appendix.

1. Call Report Form - Each interviewer should receive one of these forms (for illustration, see appendix) for each case assigned to him or her. The Call Report Form provides a full record of efforts to contact the respondent and space to record the result. Numeric result codes allow the analysis of the results of calls.
2. Introductory Letter - Prior to being contacted, each respondent should receive an introductory letter describing the study. The interviewer should bring a copy of this letter along to show to the respondent. .
3. Information Sheet - This sheet describes the purpose of the study and provides basic information in written form about how the respondent's name was obtained and what participation will involve.
4. Informed Consent Form - This form acknowledges that the respondent understands the purpose of the study, what it will involve, and that all information will be kept confidential. Verbal consent is usually sufficient when the interview is conducted by telephone.
5. Pledge of Confidentiality - It is important to talk with each interviewer about respecting and preserving the confidential nature of information to be obtained. Every interviewer should be asked to sign a pledge of confidentiality to be kept on file.

## **Interviewer's Instruction Manual**

### ***What You Will Need***

You will need copies of the Family Experiences Interview Schedule (FEIS). You should become thoroughly familiar with the Schedule and study it along with this manual. You will also need Call Report Forms to fully record your efforts to contact each respondent (R). You should bring to each interview a copy of the Introductory Letter which each respondent should have received prior to being contacted that describes the study. You should also bring to the interview a copy of the Information Sheet that describes the purpose of the study and provides, basic information in written form about how the respondent's name was obtained and what participation will involve. Finally you should have the Informed Consent Form. This form acknowledges that the respondent understands the purpose of the study, what will be involved, and that all information will be kept confidential. (Verbal consent is usually sufficient when the interview is conducted by telephone). Note that a card with precoded categories is required for the question about income QA12.

### ***The Initial Contact***

Your first contact with the respondent is the most important contact you make. One of four outcomes should be expected:

1. A completed interview
2. If not a completed interview, a firm appointment for an interview
3. If not that, then a clear idea of why the respondent does not want to cooperate now
4. If not that, then a graceful retreat and information about the respondent that will help in future attempts

Prepare yourself for the first contact by packaging your materials and yourself in an organized, professional way. Have positive feelings about yourself as an interviewer and the study. Have a full understanding of the study-its goals, its importance-and be able to convey this understanding to the respondent. Take a genuine interest in respondents and let them know that their participation, opinions, and experiences are valued. Also, let each one know that he or she is irreplaceable-that no one else can be a substitute for him or her.

Although the majority of your contacts will result in completed interviews, there may be times when informants and respondents are either not at home or not cooperative. Obviously, if only the most available and willing people are interviewed, they will not be representative of the total population being studied and the study results may be different from those that would be obtained if every respondent participated. Our goal, therefore, is to interview every respondent.

To gain cooperation, you should have a positive attitude, wear or present your ED card, be appropriately dressed, show regard for people's properties and homes, be pleasant and courteous, and assure the person who answers the door that you are not selling anything and that you are not from welfare, any government agency, or a collection agency. To gain cooperation, you should not wear dark glasses, chew gum, wear visible religious jewelry or political buttons, or smoke in the respondent's presence.

### **Overcoming Objections and Avoiding Refusals**

Even the best interviewers receive refusals to participate in a survey. Most respondents do not refuse outright: rather they express some hesitancy, reservation, or initial hostility. In a short time you will become sensitive to the firmness of the "NO" conveyed by the tone and wording of the respondent's comments. There is a fine line between a wavering, hesitant person and a firm refuser. Very often, you will make the difference and be able to skillfully move the person into the respondent role on the spot. At other times, your sixth sense will guide you to leave before you get an adamant refusal, knowing that other actions can be taken to help you convert the refusal on your next contact.

A high response rate is essential. We count on your motivation and persuasive skills to make this a successful endeavor. The Project Director will work with you to convert reluctant respondents by sending letters and making calls, if appropriate. However, it is you, the interviewer, in direct personal contact with refusers, whose efforts are decisive.

Always listen very carefully to what the respondent has to say. Be attuned to "hidden" concerns which may be behind initial reluctance or refusal. Some of the most common reasons respondents give for refusing are:

- Too busy; don't have the time
- Not interested in the study
- Don't want to be bothered or involved
- Waste of time and money
- Nothing in it for me

These reasons reflect two broad types of concerns respondents may have: concern about the time you are asking them to give and concern about the study itself or about surveys in general. You can respond to the first concern in several ways: by emphasizing the importance of the study, by persuading respondents that we do appreciate their contribution to the project, and by indicating your willingness to be as flexible as possible in arranging an appointment at the respondent's convenience. You can address the second type of concern by explaining how the project is worthwhile, that for a survey's results to be useful, they must include information from a representative sample.

Additional considerations to keep in mind for overcoming respondent refusals include the following:

- Make your respondents feel important. They are valuable to the study.
- Make your respondents feel needed. Be empathetic—you do care about their time, their experience, etc.
- Make your respondent feel respected. Each is a human being, not just another interview.
- Focus on your respondent—maintain eye contact, be trusting and interested.
- Make sure your respondent knows exactly who you are, who you represent, and why you are there.
- Be confident, reassuring, and ready to react promptly to a respondent's cues. Don't get into a “set interviewing routine” that keeps you from dealing with each respondent's individual concerns.
- Above all, be thoroughly familiar with all study materials so that you can readily answer a respondent's questions about the survey.

If you find that you are not getting anywhere with a respondent, try to end the contact before you get a final “NO.” However gruff or rude a respondent may be, always maintain a pleasant courteous manner. Above all, do not antagonize or alienate the respondent. Try to keep the door open for future contacts, the Study Director may ask you to go back or assign the case to another interviewer. If you can leave on a pleasant note, the respondent may be more receptive to follow-up efforts.

Some possible reasons for not being interviewed and suggested responses follow:

REASON: I'm too busy. I don't have time.

RESPONSE: I understand how valuable your time is. I'll be glad to see you at a more convenient time. Would it be convenient for me to call you Wednesday at 8:00 P.M., or would you prefer Friday evening?

COMMENT: Always suggest two times so the respondent can choose one of them. Avoid asking for an appointment in a way that will elicit a negative response.

REASON: I have so many problems doing things for (NAME) that I don't have time.

RESPONSE: I understand your situation. Because you do so much for (NAME), it is very important that we interview you. I will be glad to do it at any time and place that is convenient. It is very important that you participate so that people know about the problems you and others in your situation have to deal with. This may lead to better services for caregivers in the future.

COMMENT: Some R's will have heavy responsibilities assisting (NAME). Make sure they understand you recognize the demands on their time.



REASON: You should interview (SOMEONE ELSE) instead of me. She/he is more available/more involved with R/more interested.

RESPONSE: You are the special person whose name has been given by (NAME). Yours are the opinions and answers we want and need. No one else can take your place.

COMMENT: Explain that you can only conduct interviews with the people whose names were given by the consumer.

REASON: I'm not interested in the study. I don't want to be bothered.

RESPONSE: I can understand that you might feel that way. I think it's because I haven't explained how important the study is and how important you are to its success. I'd like to show you this letter (show introductory letter) and information sheet that give more information about the study and your part in it. Very little is known about the problems that relatives of persons with mental illness may experience. Your experiences and opinions represent those of many others in similar situations across the country.

COMMENT: Emphasize the respondent's vital role and the study's importance. Sometimes this reason may be given by a respondent who is simply fearful. Be sure to present your ID and to reassure R that he/she can call the Project Director to verify that you are who you say you are.

REASON: I don't want to have anything to do with (NAME).

RESPONSE: It is important that we interview those who are closely involved with (NAME) as well as those who aren't. Everything you say will be confidential. (NAME) will never know what you tell us during the interview.

COMMENT: Emphasize confidentiality and importance of the study.

REASON: (NAME) is doing fine now, so there's no need to interview me.

RESPONSE: I'm glad (NAME) is doing well. The fact that we want to interview you does not mean that we think (NAME) has problems now. We are interviewing over (INSERT NUMBER OF RESPONDENTS) people; many are relatives of former patients who are now doing well. We must interview everyone whose name was given. If we interviewed only the relatives of clients who are still ill, we would not get an accurate picture of what happens after clients are discharged. We cannot substitute anyone else for you, so your participation is important for the overall success of the project.

COMMENT: Emphasize how valuable each respondent is and how important it is to talk with people with many different kinds of experiences.

REASON: This isn't going to help me in any way.

RESPONSE: I really hope that you will get the satisfaction of participating in an important greatly needed study which may lead to more support for those caring for relatives with mental illness. In that way, it will be helpful to many relatives who have a family member with mental illness in the long run.

COMMENT: Emphasize the contribution respondents can make to our knowledge of the special problems faced by caregivers of relatives with mental illness, and how this knowledge provides the basis for improving services.

REASON: I don't feel well enough to do this.

RESPONSE: I'm sorry. Of course I understand that you wouldn't want to be interviewed.

May I call you in a day or two or would it be better if I waited a week?

COMMENT: Be understanding but also set up an appointment by giving the person two options.

In summary, you need to be prepared for a variety of situations which threaten to lead to a non-interview. When a respondent refuses an interview, treat the refusal as a situation that needs probing. Do not panic. Stay calm and remain pleasant. Listen attentively and probe for the “why” of the refusal. Remember not to lose your sense of humor. The more in control you are, the more likely it is that you will pick up clues to the reason for the refusal and ways to creatively convert it into an interview. Experienced interviewers regularly transform initial refusals into complete interviews even though initially respondents claim to be too busy, scared, or uninterested. Gatekeepers who attempt to refuse on behalf of the respondent need to be convinced of the respondent's right to speak for himself or herself. Say good-bye gracefully, and leave the way open for future contacts.

### **General Interviewing Instructions**

The following are general instructions that apply to conducting a face-to-face or telephone interview using The Family Experiences Interview Schedule. Examples or references to the interview are given in brackets below, as appropriate.

- a. All interviewing should be done in privacy and the confidentiality of the information should be strictly respected. Information provided should not be shared with anyone outside the research group including your family members, friends, or any other respondents.
- b. Read each question slowly and distinctly, exactly as it is worded and in the order in which it appears in the questionnaire. Emphasize underlined words.
- c. Interviewer instructions are in capital letters, enclosed by parentheses or brackets, and are not to be read to the respondent.

[See QA11 in the questionnaire. The interviewer instruction here indicates that you are to record the total number of people on the line.]

- d. When interviewer instructions are underlined, that means to substitute a word, usually a person's name for the word or phrase in capital letters.  
[See QA4. When you see “(NAME)” in this interview, substitute the name of the client. You should insert the client's name preceded by Mr., Mrs., Ms., or Miss. You may also use the client's relationship to the respondent (your son, your mother, etc.) or the name used by the respondent when referring to the client.]
- e. When a question ends with a question mark (?), stop at that point without reading any of the categories that might follow.  
[See QA7 and QA8. Answer choices are not read to the respondent in either of these questions.]
- f. When the stem or lead-in question ends with a colon (:) read all of the answer categories, pausing briefly between them, up to the question mark. If the respondent gives you a response before you finish reading all of the choices, explain that you must read all of the categories, and continue reading.  
[QD6 would be read: “If (NAME) wanted to re-establish contact, would you be opposed, or in favor?” Note that you would stop at the question mark and not read aloud to the respondent the third answer choice, “Ambivalent.”]
- g. We expect the respondent to answer in terms of the precoded answer choices given, unless we have provided an “Other (SPECIFY BELOW)” category.
- h. When the response given does not fit into any of the precoded answer choices and no “Other” category is provided, repeat the precoded choices and say, “Which of these comes closest to how you feel?” If the respondent is unable to choose a category, do not circle a code, but record the respondent's answer word-for-word in the space to the left of the answer categories.
- i. When alternative wording is given (words or phrases enclosed in parentheses, sometimes separated by a slash), choose the appropriate wording to use with each respondent.  
[In QC11 for example, say “...for his emotional or mental problems?” if the client you are asking about is male. Say her if the client is female.]

- j. When the respondent asks you to define a term or clarify a question, you may not do so, unless a specific definition or explanation is provided either in the interview or in the Question-by-Question Specifications. The standard interviewer's response when a respondent asks what a word or question means is, "Whatever it means to you." However, you will often find that repeating the question, perhaps more slowly than the first time, gives the respondent the needed clarification.
- k. When one question has a series of parts, the stem or lead-in to the question is usually repeated the first two times, then only the parts are read. Repeat the lead-in as often as necessary to make sure the respondent remains focused on the point of the question.

*For example, in QF1 you would read:*

**"During the past 30 days, have you personally paid for, or given (NAME) money for which you were not paid back for transportation expenses, carfare, gas, taxi, etceteras?"**

*After waiting for the respondent to answer and recording the answer (including the dollar amount if appropriate), next you would read:*

**"During the past 30 days, have you personally paid for, or given (NAME) money for clothing for which you have not been paid back?"**

*After recording the answer(s), you could then just read:*

**"Pocket money?"**

*You could continue to read most of the rest of the parts of this question in the same way, leaving off the lead-in, as long as you were certain that the respondent remembered the important parts of the lead-in, "during the past 30 day" and "personally paid for or given (NAME) money for" and "for which the respondent has not been paid back."*

- l. Interviewing is not a simple matter of just asking questions and recording answers. Probing is the technique interviewers use to keep the respondent on the right track and to get the precise information. Never suggest an answer. Let the respondent tell you. The basic probes are pausing, rereading the question, and repeating the response.

Probes can also be simple, short phrases like “Please be more specific” or “What else?”

m. Respondents have various reasons for answering, “I don't know.” Here are some of them:

- R really doesn't know
- R hasn't thought about it
- R doesn't feel like thinking about it
- R can't give you an exact answer
- R is afraid his/her answer will seem stupid
- R doesn't want to talk about it
- Many people use “I don't know” just to gain a little thinking time. A pause can be an extremely effective probe in these cases. just give them time, and they will usually come through with an answer.

n. Please encourage the person who does not want to make the effort to remember.

Probe gently to help him or her think through an answer. Remember to be neutral in your probes.

### **Recording Responses**

- Record everything in blue or black ink; do not use pencil.
- Circle the numerical codes (not the words) when recording responses, unless instructed to do otherwise.

**A9. Are you currently enrolled in school or college?**

Yes.....1

No.....2

- To make a change, cross out what you previously recorded and then circle or write in the correct response. Never erase or use white-out or other correction fluid or tape.

**G5. Is (NAME) supposed to be taking medication for (his/her) condition?**

Yes (SKIP TO QG10).....~~1~~

No.....2

- d. Show that you skipped questions. When you are instructed to skip one or more questions, circle the skip instruction and slash through the skipped questions with a diagonal line. Then ship to the next appropriate question.

**G6.      During the past 30 days, did you help, remind, or encourage (NAME) to take (his/her) medicine?**

Yes (SKIP TO QG9).....1

No.....2

**G7.      During the past 30 days, how often did you help, remind, or encourage (NAME) to take (his/her) medicine?**

Every day.....1

3 to 6 times a week.....2

Once or twice a week.....3

Less than once a  
week.....4

**G8.      How much did you mind helping, reminding, or encouraging (NAME) to take (his/her) medication? Was it:**

A lot.....1

Some.....2

Very little.....3

Not at all.....4

**G9.      During the past 30 days, what other persons, if any, helped, reminded, or uged (NAME) to take (his/her) medicine?**

**(PLEASE CIRCLE AS MANY AS APPLY)**

Another family member.....1

Mental health program staff.....2

Someone else.....3

No other person.....4

Don't know.....7

- e. Record in the left margin any comments the respondent makes about his or her answers to a question whenever the comment could change the way a response will be interpreted and coded. Try not to waste time recording irrelevant remarks, but in general, the rule is, "When in doubt, write it out." If the respondent refuses or is unable to answer a question, record what he or she says word-for-word in the left margin, and leave the question uncoded.

**C12. Has (NAME) been homeless at any time during the past 12 months?**

Yes.....	1	Well, I don't know how
No.....	2	to answer that - he was
Don't know.....	7	living in a group home,
		but he was disoriented
		and got lost and slept
		on the street for a

- f. Show when you probe. If you are unable to code an answer the respondent gives, record the answer verbatim, that is, word-for-word. Then probe, recording an "X" each time you probe. Record everything the respondent says, until a codeable answer has been given. If necessary, slow the respondent by repeating what you are writing. That will allow you the time needed to record verbatim and it will relieve the tension that your silence may produce for the respondent.

**H25. During the past 30 days, did you try to prevent or stop (NAME) from using drugs or pills such as marijuana, cocaine, amphetamines or heroin?**

Yes.....	1	He doesn't use drugs
No (SKIP TO QH28).....	2	anymore. X

- g. If the respondent gives a range in response to a question requiring a numerical answer, record the first response, then probe for one answer, and record an X to show that you probed. Then record the next response, continuing to probe until you have received one response, or until the respondent has said that he or she cannot give a more specific answer.



**C6. At about what age did (NAME) first receive help for mental health problems?**

Age (SPECIFY)

In his teens. X 15 or 16. X

15.

Don't know.....97

- h. Record everything in the questionnaire at the time of the interview. Do not edit or add comments later.
- i. Only two abbreviations may be used: DK for "Don't know," and R for "Respondent."

**Question by Question Specifications**

These instructions explain what is intended by particular questions and how you are to administer specific questions. Explanations have been provided only for those questions that are not self-explanatory.

Remember that throughout this schedule, (NAME) refers to the client whose relative is being interviewed. Before the interview note the client's name and whenever you see "(NAME)" in this interview, substitute the name of the client. You should insert the client's name preceded by Mr., Mrs., Ms., or Miss. You may also use the client's relationship to the respondent (your son, your mother, etc.) or the name used by the respondent when referring to the client. For example, you could say, "your daughter," "your son," etc.

**Module A: Background**

- QA2 Circle the appropriate code for respondent sex.
- QA3a - QA3b Ask about race or ethnicity. The answers may be redundant but they need not be. For example, in the case of an adoption, the race of the respondent and (NAME) may differ.
- QA4 Asks about involvement. If the respondent asks what do you mean by "involvement," the appropriate answer is "whatever it means to you."

## Module B: Family Enumeration

QB1 – QB5b The purpose of these questions is to enumerate all members of the client's immediate family. Some will be currently involved with the client. Others will not. It is important to probe for the number of all living relatives, in the kinship categories used, regardless of their current or past involvement with the client. Each question requires that you remember the relationship of the respondent to (NAME) and include the material in brackets as appropriate. For example, if you are interviewing (NAME)'s mother, in QB2 you would ask if NAME has another living parent.

QB2 If the respondent asks if he or she should include a step parent or a foster parent, the answer is yes. Please so note in the margin.

QB3a If the respondent asks if he or she should include a step sister or brother, or a half or foster brother or sister, the answer is yes. Please so note in the margin.

QB3c The phrase "lives in the same area" is defined as within 25 miles or a ½ hour drive.

QB4 Please note that living spouse refers to people who are currently married. Ex-spouses are not meant to be included in the enumeration.

## Module C: Client Background

QC2 If you already know the sex of (NAME) you may circle the appropriate code without asking the question.

QC5a If the respondent gives a diagnosis such as diabetes, probe for a mental health diagnosis or category. Probe for the diagnosis in words rather than a DSM number code. If the respondent states that (NAME) has received multiple diagnoses, probe for the most recent diagnosis.

QC6 is designed, to measure the age of onset of the illness. If the respondent is uncertain, circle don't know and write down what was said.

- QC7 If the respondent answers that a general physician is the client's primary therapist, and that (NAME) sees this physician on a regular basis, circle yes.
- QC8 The key word here is "most." If more than one person is identified, probe to determine who provides the greatest amount of care.
- QC12 Use a literal definition of homelessness as involving at least some nights with no place to sleep other than the streets or a public shelter.

#### **Module D: Contact**

- QD1 – QD2 are asked of everyone in order to determine where and with whom (NAME) has been living the past 30 days. If the type of housing does not fit into one of the precoded categories, probe for housing characteristics and record the response in the margin.
- QD3 – QD4 are meant to sort respondents into 3 groups:
1. Those respondents who have had contact during the past 30 days.
  2. Those respondents who have had contact during the past 12 months but not within the past 30 days.
  3. Those respondents who have had no contact for more than 12 months; skip patterns are based on these items.
- QD5 – QD6 are asked only of those respondents who have had no contact for more than 12 months (D4 = NO).

#### **Module E: Benefits and Gratifications**

- QE1 – QE5 These questions inquire about things the client has done recently for the respondent. Emphasize “you.” These questions are relevant whether or not the client currently lives with the respondent, since a client can live elsewhere but still help out in a variety of ways as these questions indicate. For example, a client can live elsewhere but still help the respondent with household chores.

QE6a – QE6e Note that the time frame for the questions in this sequence is the past 30 days. If a respondent states that his or her feelings are variable, say that you want to know how they feel right now. Do not read the "ambivalent" category to the respondent—it is for your recording use if that describes the respondent's answer.

### **Module F: Financial Expenditures**

QF1 – QF2 Ask each part of QF1a-k. If the response is yes, immediately ask QF2 (How much money was that?). These questions ask whether the respondent has personally paid for things for which he/she has not been paid back. Again, the emphasis is on the word “you.” Note that if (NAME) lives with R, there are instructions to be followed in and after items d and e.

QF3 Note that the time frame here is the last year. Thus it is possible that no expenditures were reported in the past 30 days, but that (NAME) represented a financial burden during the past 12 months. If the respondent asks what is meant by financial burden, the recommended answer is "whatever that means to you."

### **Module G: Assistance in Daily Living**

QG1 – QG33 The introduction to QG1 introduces a series of questions about the kinds and amount of care in daily living the respondent and others have given to the client during the past 30 days. The series consists of a total of 8 different areas for which help or support might be given, with skip patterns for those who have not helped in the past 30 days. The format of the questions is basically the same for each of the 8 areas, with some slight changes in wording to reflect differences among areas. Note that the final question in each area invites multiple responses, if appropriate. For example, in QG4 both another family member and someone else may have helped with grooming, bathing, or dressing.

### Module H: Supervision

QH1 – QH28 Beginning here the questions focus on the supervision or control of difficult and troublesome behaviors by the respondent and/or others. There are 7 areas which come into focus. The format is similar to Module G.

### Module I: Impact on Daily Routines

QI1 – QI10 Refer back to the questions that tell you if R is in school and/or working so that you will know which questions are to be asked and which parenthetical words are to be included in QI1-2. Again, skip patterns are provided to skip over inappropriate questions.

### Module J: Attitudes Toward Professionals

QJ1 This question serves to screen out respondents who have not had contact with mental health professionals during the past 12 months. Do not include general medical practitioners unless the contact was prompted by the client's mental health problem.

QJ2a-g Encourage R to choose between the available alternatives, if at all possible.

### Module K: Affective Response

QK1 – QK7 The introduction will vary depending on how recently R has seen the client. The words contained within the parentheses are to be read only if there has been no contact within the past 12 months. Otherwise skip over the parenthetical statements. If a respondent who has seen the client in the past year but not in the past month questions the appropriateness of the items, draw on the rationale contained in the parenthesis to justify the series.

QK8a-g Circle a code for each part of this question a-h. Do not read the answer category "AMBIVALENT," but circle code 3 if R is unable to give one of the responses. Make a marginal note if the response can affect the way in which the data are interpreted. Item QK8h is detached from items QK8a-g because it is a separate global measure.

### Module L: Stigma

QL1a-i All respondents, including those who reported no contact with the client in the past year (see QD4) will be asked this and subsequent questions. Note that this series asks whether "there was ever a time when..." Emphasize ever. These items should go quickly since they use a yes-no response format.

## APPENDIX

## Call Report Form

---

**Respondent ID#:**

**Interviewer:**

**Address:**

**Interviewer ID#:**

**Telephone #:**

**Record All Changes Below:**

**Mother of:**

---

---

---

Call #	Day	Date	Time	Result Code	Interviewer Comment
1			AM PM	P T	
2			AM PM	P T	
3			AM PM	P T	
4			AM PM	P T	
5			AM PM	P T	
6			AM PM	P T	

### CODES FOR RESULTS OF CALLS

---

**01. Completed Interview**

**10. R Refused (2<sup>nd</sup> Refusal)**

**02. Appointment Made**

**11. Someone Else Refused for R**

**03. Broken Appointment**

**12. Wrong Phone #/Disconnected/Unlisted**

**04. R Not Home (No Appointment)**

**13. R Too Ill**

**05. No One Home/No Answer**

**14. Message Left on Machine**

**06. R Moved; Address Obtained**

**15. R Away for Study Duration**

**07. R Moved; Obtained Lead**

**16. Other: Explain In Comments**

**08. R Moved; Cannot Locate**

**P Personal Interview**

**09. R Refused (1<sup>st</sup> Refusal)**

**T Telephone Interview**



## OFFICIAL LETTERHEAD

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### [Name of Study] Introductory Letter

Date:

Name:

Address:

Dear Respondent:

The [NAME OF YOUR ORGANIZATION] is conducting a study of family experiences when a relative suffers from a mental illness. Your relative has agreed to participate in this study and has given us your name as someone whom we could interview. We are interested in learning about how this person's illness is affecting your life, if at all.

This study is strictly voluntary. If you decide not to participate, it will in no way affect your relative's treatment program. We hope, however, that you will participate, because by doing so you will be helping to improve services for persons with mental illness and for those who care for them.

The interview takes about an hour. It will be conducted in privacy, either in your home, or at some other location-whatever you prefer. I want to emphasize that all information collected is confidential, and will not be shared with anyone. No one unconnected with the research will ever or in any way have access to the information you provide. Reports from the study will only present information for groups of people. It will be impossible to identify individuals from these reports.

If you have any questions about the study, please call me collect at [YOUR TELEPHONE NUMBER), weekdays between 8:30 AM and 4:30 PM.

Sincerely,

[Name]

Study Director

## OFFICIAL LETTERHEAD

---

### [Name of Study] Information Sheet

1. **Purpose** The purpose is to study the roles of family members and significant others in caring for persons with mental illness. We are particularly interested in the difficulties and rewards families may experience when asked to care for a relative with mental illness. We need the benefit of your experience and hope you will help us.
2. **How we got your name** We asked persons in the hospital to name family members who we could interview. Your name was among those given.
3. **Interview** A personal interview of approximately one hour will be scheduled at a convenient time and place. Participation is voluntary. You may choose not to answer specific questions. In addition, you may end the interview at any time.
4. **Confidentiality** All the results are confidential and will be used for statistical purposes only. Only the researchers will have access to the information you give.
5. **Benefit** The benefit is that you will contribute to research that may help improve services for persons with mental illness and their families.
6. **Sponsorship** The study is being conducted by [INSERT NAME OF SPONSOR]. Interviews are being conducted by [INSERT INTERVIEWER ORGANIZATION]. An [INTERVIEWER ORGANIZATION] interviewer will be contacting you [INSERT TIME PERIOD, E.G., IN THE FALL) to schedule the interview.

## OFFICIAL LETTERHEAD

---

### A Study of [Insert Study Purpose], [Insert Date]

#### Informed Consent Form

The study being conducted by [INSERT ORGANIZATION NAME] has been explained to my satisfaction. I understand that it will involve a structured interview of about one hour and that the questions will focus on my relationship to the relative who provided my name and the impact of that client's mental illness on my life.

I agree to be interviewed with the understanding that the information will be kept confidential, used only for research purposes, and that I have the right not to participate at any time.

**Respondent's Signature:** \_\_\_\_\_

**Date:** \_\_\_\_\_

**(Interviewer: Print the Information Below)**

---

**Case #:** \_\_\_\_\_

**Respondent's Name:** \_\_\_\_\_

**Interviewer:** \_\_\_\_\_

**ID#:** \_\_\_\_\_

## OFFICIAL LETTERHEAD

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### **Pledge of Confidentiality**

I hereby guarantee that I will faithfully execute my obligations and responsibilities as an interviewer to fully respect and preserve the confidential nature of information obtained during the Study of [INSERT STUDY NAME HERE] interviews.

**Interviewer's Signature:** \_\_\_\_\_

**ID#:** \_\_\_\_\_

**Date:** \_\_\_\_\_

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**Addendum to Toolkit for Evaluating Family  
Experiences With Severe Mental Illness:**  
*New Measures of Family Member Evaluations of Mental  
Health Professionals, Client Services, and Systems*

**Richard Tessler, Ph.D.  
& Gail Gamache, Ph.D.**

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## **MODULE M**

### **Statement of Purpose**

This Addendum, entitled New Measures of Family Member Evaluations of Mental Health Professionals, Client Services and Systems, is intended to be used as Module M in conjunction with the Toolkit for Evaluating Family Experiences with Severe Mental Illness (Tessler and Gamache, 1995). The current Module M provides the same information (in a similar but self-contained format) for the new measures that we provided in the Toolkit for Modules E (Benefits and Gratifications), F (Financial Expenditures), G (Assistance in Daily Living), H (Supervision), I (Impact on Daily Routines), J (Attitudes Toward Professionals), K (Affective Response) and L (Stigma). Module M. specifically extends the study of family experiences with severe mental illness to include family member evaluations of mental health professionals, consumer services and systems. Although this new module may be used alone, the authors recommend that it be added to the end of the Family Experiences Interview Schedule (FEIS) presented in the Toolkit.

Module M contains four major sections:

1. An introduction to the measures.
2. The background and significance of family member experiences with mental health professionals, services and systems.
3. A narrative history of the new measures including how they were derived, information about the study used to test the properties of the measures, a description of the study sample, psychometric properties and rules for scale construction.
4. The 25 items comprising the measures are presented in a manner consistent with the formatting of the interview protocol included in the Toolkit along with other related measures that provide basic information about the preferences of family members as to their wishes to be involved in the consumer's treatment.
5. Interviewer instructions and question by question specifications.

## **Introducing the Measures**

Four measures are presented in this Addendum: Family Member Evaluations of 1) Mental Health Professionals/Providers; 2) Client Services; 3) Mental Health Systems and 4) a summary Global Evaluation of Mental Health Professionals, Services and Systems. We conceptualize the first three measures as representing: 1) family member preferences for their own roles in treatment and their involvement with professionals, 2) ratings of the services provided to their relatives, and 3) satisfaction with the formal system of care. The central issues addressed by the measures are how family members evaluate their own involvement as partners in treatment, the quality of services provided directly to their relatives with mental illness and how they perceive the adequacy of the mental health system with respect to its response to them rather than to their relatives.

The measures are useful for describing and analyzing how family member evaluations of mental health services and preferences for their own role in treatment may shift over time in response to changes in the public system of mental health care. They may also be viewed as providing a family-based source of data relevant to the assessment of quality of care for the consumer. These measures were designed to address issues important to the triad of mental health professionals, family members and consumers of mental health services (Haug, 1994).

Although the original Toolkit included a module on Attitudes Towards Professionals (see Module J in the Toolkit), the 4 measures in this addendum are new in the following respects:

- they are broader in scope than the Attitudes Towards Professionals measure;
- the items are relevant whether or not there has occurred recent contact (or any contact) with mental health professionals;
- response categories are sensitive to differences in family member preferences and variations in client use of services;
- the measures are not just about family member satisfaction but include added information about preferences and needs;
- an item specifically designed to address the issue of sensitivity to cultural diversity is included;
- each item asks about the past 6 months; and
- the items were derived in close collaboration with a state Department of Mental Health.

## **Background and Significance**

Current mental health policy takes the perspective that a system of care will be more effective when family caregivers play a role in its design, implementation, and evaluation. In an era of community care for consumers of mental health services, building mental health systems importantly involves family members (Fisher, Benson and Tessler, 1990). Two recent developments point to the need for new ways to conceptualize family member attitudes toward the mental health system (as well as toward individual mental health professionals). One positive development is the belated recognition by mental health providers of family members as major providers of the informal support which may be vital to the consumer's quality of life in the community. In response, state mental health authorities nationwide are implementing plans to include family representation on state planning committees, advisory boards, and as speakers and panelists in conferences. Family members are also being seen as partners in treatment.

Another more ambiguous development is the move toward managed care in the area of public mental health services. David Mechanic has noted that this latter trend holds uncertain implications for family members (1994). This trend whose main beneficiaries are intended to be primary consumers is also likely to affect family members. One implication for families flows from the fact that housing for persons with mental illness is not Medicaid reimbursable and it may tend to be a scarce resource. There is also reason to be concerned that managed care programs may encourage family involvement as an alternative to hospitalization. On the other hand, improvements in crisis services which are sometime anticipated as part of managed care are likely to benefit families who have long advocated for 7 day a week, 24 hour a day, emergency services. In the past, family attitudes toward mental health services and professionals have, for the most part, been negative. Some empirical evidence indicates “near-universal dissatisfaction” with services (Grella and Grusky, 1989, p. 831). More recently, a study in Vermont using focus groups to explore family attitudes, reported that Family members saw themselves as disregarded by the mental health system and often blamed for their relatives mental illness (Pulice, McCormick and Dewees, 1995). The authors of a study of 250 family members in New York state reported how the relatives of consumers viewed mental health professionals during the 1980s:

Family members have complained that they have lacked information about the patient's illness, that they have received inadequate advice on management issues, and the availability of services during times of crisis has been poor. They have reported coming away from interactions with professionals feeling guilty, frustrated, and helpless. They place mental health workers at the bottom of their list of useful supports (Bernheim and Switalski, 1989).

Biegel and his colleagues recently reported similar complaints among family members in Cleveland, although Black caregivers expressed higher overall satisfaction when compared to white caregivers (Biegel, Song, and Milligan, 1995).

On the other hand, some research on family attitudes toward professionals indicates improvement on some issues but not on others. A majority of family members in the Robert Wood Johnson family study reported in the Toolkit felt that professionals were interested in what the family members could tell them. Most also agreed that professionals assured them they were not to blame and showed that they understood the problems faced by the family. However, the results also revealed that a majority believed that professionals did not give detailed information or include family members in treatment planning (Tessler et al., 1991).

Thus, family member evaluations are valuable from two perspectives. When family members are perceived as part of the treatment team, an evaluation would be incomplete without their input. A comprehensive evaluation of the impact of the mental health component of a system change over to a managed care entity also needs to include outcomes for family caregivers. We emphasize that family members, consumers, and professionals are, or should be, part of a "health care triad" (Haug, 1994). All three parties form a triangle which is important to the success of long term care in the community. Mental illness poses dilemmas for each of them, but the family perspective is most often the view that is ignored when evaluating system changes. To ignore the perspective of any one of the parties may adversely affect the client's quality of life, cause distress for the family caregiver, and lead to frustration for the professional.



## **Narrative History of the Study and the Measures**

The Family Member Evaluation Measures were developed to study how changes in the system effect family member evaluations of mental health professionals, client services and systems. The measures were originally designed for a three wave study of how family members would be effected when a state system of mental health care converted to a system of managed care for the provision of public mental health services. When the state of Ohio declined to adopt the managed care model after receiving a Medicaid waiver, the study continued on the assumption that nevertheless system changes were taking place about which family members had strong feelings, and that it was valuable to record these family sentiments (Dee Roth, personal communication).

The measures (and the other relevant items included here) also have as one of their primary objectives the collection of basic information about both the preferences of family members as to their wishes to be involved in building the system of mental health care and in treatment and the preferences of consumers as regards the involvement of their relatives. Some family members may want to be involved while their relatives with mental illness may prefer that they not be. Some consumers may want a lot of family involvement, while others may want as little as possible. Some consumers might feel strongly that family members should not be involved at all in building a system of care. Other consumers might feel positively about a family member being involved in system design issues but not in his or her treatment.

### ***How the Measures Were Derived***

The items were developed in collaboration with the Ohio Department of Mental Health (ODMH). Input was particularly sought from the ODMH Family/Consumer advocate. ODMH has been a leader in recognizing the importance of families in the informal system of care, their potential burden, as well as their involvement in system and treatment planning and their evaluations of the public system of care.

The authors worked closely with the Ohio staff in constructing the items around issues important to ODMH as well as to family members (as reported to the consumer/family advocate staff member). These issues include family member evaluations of accessibility, integration among different service delivery systems, that crisis response be timely and convenient that family members have the opportunity to be involved in the treatment plan, that clients have

options from which to choose, and that in general the system of care be responsive to what clients and family members need and want

Response categories were modeled after those used in a study of family satisfaction with services in a northwestern state by Grella and Grusky (1989). The basic strategy was to make the response category labeled all that you wanted (or needed) indicate the highest level of satisfaction. The response categories were chosen in order to quantify level of satisfaction, while taking account of variation in client needs and family member preferences for specific services and desires for involvement.

A related issue for mental health systems and providers is the recognition that treatment should also mirror cultural preferences. Future choices may include culturally specific treatment services that consumers believe are appropriate to their ethnic background. The consumer and family advocate in Ohio has provided state of the art examples including drumming and other types of culturally specific music therapy such as rap music, as well as acupuncture and herbal medicine, and an Afrocentric case management team which uses a kinship or tribal model of therapy. (Wilma Townsend, personal communication)

### ***The Study From Which The Sample Was Drawn***

The data used in the analyses come from the study entitled, Evaluating Family Experiences with Clients and Services in Ohio funded by the Ohio Department of Mental Health (ODMH). (It should be noted that the sample of 147 Ohio family members is not the same sample of 305 Ohio family members described in the Toolkit.) The client sample is an extension of the Longitudinal Study of Mental Health Services and Consumer Outcomes in a Changing System study (LCO) initiated by the ODMH in 1989. Criteria for this sample were that the client had to meet ODMH 508 criteria for serious mental illness, and be receiving publicly funded mental health services. The sample was drawn from 4 county board sites and stratified on patterns of service delivery, and in 2 of the sites further stratified by race.

The original LCO sample consisted of 457 individuals and ODMH continued the longitudinal study with a fourth wave of interviews in spring 1995 when they re-interviewed 323 clients. Of these 323 clients, 188 consented to have family members interviewed. This is a 58.2 percent LCO client consent rate for the family study described in this Addendum. Family

members were nominated by clients and interviewed by telephone in late 1995 using a structured Computer Assisted Telephone Interview (CATI) format.

Clients who refused to name a family member had significantly fewer family members that they could count on compared to consenters. In general, consenters reported receiving more help from family members. There were no differences between consenters and refusers in respect to sex, education, diagnosis of schizophrenia, or whether they live with a family member. However, there were significant differences with older clients being more likely to refuse and non-whites and currently married consumers being less likely to refuse. There was also a trend indicating that consenters were more symptomatic at the time of their interview as measured by a Brief Symptom Index than were refusers.

Of the 188 clients who gave permission, we succeeded in obtaining a telephone interview with 147 family members conducted by a professional survey firm. This is a 78.2 percent response rate. Most of the time when we could not obtain a family interview it was because we were unable to reach or locate a family member (even after extensive help from ODMH). Twenty-two family members (about 12 percent) could not be reached because of telephone disconnects, wrong addresses or telephone numbers, or were never available, and in one case an eligible respondent had died. When family members were reached by telephone, the cooperation rate was almost 90 percent.

In general the 147 clients for whom we were successful in obtaining a family interview did not differ from the clients who consented but for whom we did not obtain a family interview. There were two notable exceptions. Clients with diagnoses of schizophrenia were less likely to have a family member interviewed. Also, clients who reported less contact with family were less likely to have a family member interviewed.

The 147 consumers for whom a family interview was obtained averaged 47 years of age; 11 years of education; 27 percent were minorities; and 45 percent had a diagnosis of schizophrenia. More than one-third had never been married and 56 percent were female. Family respondents averaged 51 years of age; 28 percent were minorities and 81 percent were female. More than one-third were parents of the consumer; 18 percent were adult children; 8 percent were spouses; and 18 percent were siblings. Uncles, aunts, grandmothers, fiancées and partners were also represented. A small number of fictive kin such as a good friend and a legal guardian were also interviewed. However, the majority were not only primary kin but considered

themselves to be the primary caretakers of their relative (84.4% said they provided the most support for the client).

## **Psychometrics and Scale Construction**

### ***Factor Analysis***

As noted above, the 25 items were originally chosen to operationalize six important dimensions of evaluations by family members. In order to sort among the 25 items, we first attempted to construct subscales based on the a priori categories of accessibility, involvement of family member in treatment plan, integration of service delivery systems, crisis response, client choice among options, and adequacy of system of care for relatives with mental illness. However, neither the number of factors or, perhaps more seriously, the item loadings, corresponded to the a priori framework. Therefore we decided to use an a posteriori framework based on a 3 factor varimax solution, which appeared to fit the data best. Factor analysis indicates two robust factors and a third significant but less interpretable one.

Please note that all items listed below are preceded by the phrase “During the past 6 months.” Each is also followed by the same (or comparable) response categories, where: 1 = none (not) at all; 2 = very little; 3 = don't know/ambivalent; 4 = some, but not as much as you wanted and 5 = all that you wanted or needed.

### **Factor 1**

#### **Family Member Evaluations of Their Involvement with Mental Health**

**Professionals/Providers** consists of the following 9 items: 1.) How much information did you receive from mental health service providers about (NAME)'s illness? 2.) How much information did you receive from mental health professionals about what to do if there were to be a crisis involving NAME? 3.) How much information did you receive from mental health professionals about whom to call if there were to be a crisis involving (NAME)? 4.) How much were you encouraged by mental health professionals to take an active role in (NAME)'s treatment? 5.) How much did mental health professionals respond to your concerns about (NAME)? 6.) How much did mental health professionals take into account your ideas and opinions? 7.) How much did mental health professionals involve you in (NAME)'s treatment? 8.) How much did mental health providers who were helping (NAME) recognize the burdens that family members like you face? 9.) How much contact did you have with any mental health professional on any matter pertaining to (NAME)'s care?

### **Factor 2**

**Family Member Evaluations of Client Services** consists of the 12 items: 1.) How many mental health services were available for (NAME) that you thought were needed? 2.) How much help did (NAME) receive from mental health professionals in finding other services, such as housing, legal aid, vocational programs or transportation? 3.) How available to (NAME) were general health services, such as treatment for a cold or the flu, injuries, or chronic physical conditions such as diabetes? 4.) How available to (NAME) were dental services? 5.) How much opportunity was there for you to complain to the agency about the treatment (NAME) received? 6.) How much opportunity did (NAME) have to choose between different service options? 7.) How much opportunity did (NAME) have to choose a particular case manager or therapist? 8.) How convenient was it for (NAME) to use mental health services? 9.) How much say did (NAME) have in the services that (he or she) received? 10.) If (NAME)'s needs had changed, how much flexibility would there have been in the treatment plan? 11.) How much satisfaction did you feel about the services (NAME) received? 12.) How many culturally specific treatment services were offered to (NAME) that you were aware of?

### **Factor 3**

**Evaluations of System Response to Family Members** consists of the 4 items: 1.) How much help was available to you at night or on weekends when (NAME) had a crisis? 2.) How much did you feel that the mental health system was responding to the wishes of family members like yourself? 3.) How much say did you have in the services that (NAME) received? 4.) How much satisfaction did you feel about your role in (NAME)'s treatment?

## **Reliability Coefficients for the Four Measures**

The reliability coefficients (Cronbach's alphas) for the three factors (treated not as factor scores but as summated indices) are as follows:

1. Family Member Evaluation of Their Involvement with Mental Health Professionals and Providers = .928;
2. Family Member Evaluation of Client Services = .812; and
3. Family Member Evaluation of System = .739.

A Summary Measure incorporating all 25 items yields a reliability coefficient of .922.

## **Validity**

The focus in this section is on criterion-related validity (also called predictive validity). We report here the bivariate correlations of the Summary Measure with a variety of measures of family burden (See the Toolkit) and contextual variables such as co-residence and client symptoms.

The summary measure of Family Evaluations was correlated negatively with feelings of hardship when giving money to the consumer and with providing supervision for behavior problems such as violent threats and alcohol abuse. The more the family member perceived an economic hardship or needed to control problem behaviors, the less likely he or she was to evaluate professionals, services and systems in a positive way. On the other hand, family members who lived with the consumer or who provided assistance to the consumer with the activities of daily living were more likely to believe that they were getting all that they wanted or needed. Family members who reported that the consumer had a case manager were also more likely to report receiving all that they wanted or needed.

## **Scale Construction**

This section of the Addendum describes procedures for constructing four family evaluation measures from the 25 items. Although researchers may choose to modify the scales somewhat based on their own psychometric analyses (e.g., to delete a given item if the corrected item-to-total correlation does not meet a chosen criterion), these are the scales which we recommend based on our analyses. A major advantage of using them as recommended is that the results can be compared directly across studies.

The responses of family members whose client-relative did not need a particular service during the 6 month period in question should be coded as all that you wanted or needed. This is the rationale for including needed in the response categories. An example is crisis services, which may not have been needed because as a family member would explain – there had been no crisis situation in the past 6 months. A response of don't know is considered to be ambivalent and coded to the mid-point. Other responses that may be termed ambivalent, e.g., I'm not sure, are also coded to the midpoint of the scale.

Constructing the evaluation measures involves computing an average. As in the Toolkit, we assume that researchers will have their own methods for coding and entering missing data, i.e., refusals and interviewer efforts. Depending on the researcher's preference there are several options for handling missing data in the averaging process. The method suggested by the authors is to create a score for every observation for which there are responses to at least half the items. Other options are mean or mode substitution for missing data. The summary score is divided by the number of items over which the sum is calculated. (It is clearly beyond the scope of this Addendum to include command files for the scales. Researchers will have a variety of statistical programs with which they work including SPSS, SAS and STATA.)

Average scores for the 4 scales are constructed from the 25 items as shown in the previous sections using the following response categories:

none (not) at all.....	1
very little.....	2
don't know/ambivalent.....	3
some, but not as much as you wanted, or.....	4
all that you wanted or needed?.....	5

Items included in Evaluations of Mental Health Professionals/Providers are Questions 1-9; items included in Evaluations of Client Services are Questions 10 - 21; and items included in Evaluations of Mental Health Systems are Questions 22-25. All 25 items are included in the summary Global Evaluation of Mental Health Professionals, Services and Systems.



## **Preliminary Findings**

Preliminary findings from the first wave of data collection in our new Ohio study indicate that the different factors have somewhat different determinants.

- For example, when we looked at spouses (compared to other family roles) we saw that spouses were less likely to feel that they received all that they wanted or needed from professionals. There was also a tendency ( $p < .10$ ) for spouses to give lower evaluations of client services and lower summary measure evaluations.
- Being an adult child showed a similar pattern except that it was not a significant predictor of either factor 2 or factor 3.
- Family member education predicted only factor 2 (Evaluations of Client Services), where the greater the family member's educational attainment the more favorable were his or her evaluations of client services.
- Co-residence was a significant predictor of all three factors, with sharing a residence associated with more positive evaluations. But living with the client appeared to be most important with respect to factors 1 and 3.
- Financial contributions, a dimension of the family burden, was as expected associated with more negative evaluations and was significant across all three factors. That is, the more areas family members contributed to financially for the consumer, the less likely they were to feel that they were receiving some or all of what they wanted or needed.
- Another dimension of the family burden, (Worry about the client, module K in the Toolkit) was also related to less positive evaluations of client services and the summary measure. The more family members worried about such things as the client's safety and living arrangements, the less they reported getting all that they wanted or needed.
- We had anticipated that when family members received information primarily from a case manager or other provider that they would evaluate the system more positively. To the contrary, the results show that more positive evaluations occur when it was the client who was the family's primary source of information. This was an across the factors finding.

- When the interviewed family member also helped with medication, this was associated with more positive evaluations. This finding fits with some of the other significant variables already noted such as co-residence and the client being the primary source of information.
- If the family member reported that the client had a case manager, then evaluations of professional interactions and client services tended to be more favorable, as one might expect.
- Interestingly, clients being older and being female were not predictive of factor 1 (professionals) but were predictive of factor 2 (client services); sex (being female) also predicted more favorable summary evaluations.
- The only clinical measure that was significant in predicting family evaluation was a diagnosis of schizophrenia; being diagnosed with schizophrenia was associated with more negative evaluations of client services and with more negative summary evaluations, but not with family evaluations of professionals.
- We also considered indicators of desired family member involvement in treatment planning. How much involvement family members wanted made no discernable difference once we controlled for how much they thought the client wanted them to be involved. The belief that the client desired family member involvement was strongly associated with more favorable evaluations of professionals and more weakly with the summary evaluation.

## Items for the Family Evaluation Measures

*Interviewer lead-in to items:* "Next, I would like to ask you about your opinions of mental health services. In choosing the answer that best reflects how you feel, please remember to answer "none or not at all" if you are dissatisfied and "all that you wanted" if you are satisfied."

**1. During the past 6 months, how much information did you receive from mental health service providers about (NAME)'s illness:**

- none at all.....1
- very little.....2
- don't know/ambivalent (DO NOT READ).....3
- some, but not as much as you wanted.....4
- all that you wanted or needed?.....5

**2. During the past 6 months, how much information did you receive from mental health professionals about what to do if there were to be a crisis involving (NAME):**

- none at all.....1
- very little.....2
- don't know/ambivalent (DO NOT READ).....3
- some, but not as much as you wanted.....4
- all that you wanted or needed?.....5

**3. During the past 6 months, how much information did you receive from mental health professionals about whom to call if there were to be a crisis involving (NAME):**

- none at all.....1
- very little.....2
- don't know/ambivalent (DO NOT READ).....3
- some, but not as much as you wanted.....4
- all that you wanted or needed?.....5

4. **During the past 6 months, how much were you encouraged by mental health professionals to take an active role in (NAME)'s treatment:**
- none at all.....1
- very little.....2
- don't know/ambivalent (DO NOT READ).....3
- some, but not as much as you wanted.....4
- all that you wanted or needed?.....5
5. **During the past 6 months, how much did mental health professionals respond to your concerns about (NAME):**
- none at all.....1
- very little.....2
- don't know/ambivalent (DO NOT READ).....3
- some, but not as much as you wanted.....4
- all that you wanted or needed?.....5
6. **During the past 6 months, how much did mental health professionals take into account your ideas and opinions:**
- none at all.....1
- very little.....2
- don't know/ambivalent (DO NOT READ).....3
- some, but not as much as you wanted.....4
- all that you wanted or needed?.....5

7. **During the past 6 months, how much did mental health professionals involve you in (NAME)'s treatment:**
- none at all.....1
- very little.....2
- don't know/ambivalent (DO NOT READ).....3
- some, but not as much as you wanted.....4
- all that you wanted or needed?.....5
8. **During the past 6 months, how much did mental health professionals who were helping (NAME) recognize the burdens that family members like you face:**
- none at all.....1
- very little.....2
- don't know/ambivalent (DO NOT READ).....3
- some, but not as much as you wanted.....4
- all that you wanted or needed?.....5
9. **During the past 6 months, how much contact did you have with any mental health professional on any matter pertaining to (NAME)'s care:**
- none at all.....1
- very little.....2
- don't know/ambivalent (DO NOT READ).....3
- some, but not as much as you wanted.....4
- all that you wanted or needed?.....5

10. **During the past 6 months, how many mental health services were available for (NAME) that you thought were needed:**
- none at all.....1
- very little.....2
- don't know/ambivalent (DO NOT READ).....3
- some, but not as much as you wanted.....4
- all that you wanted or needed?.....5
11. **During the past 6 months, how much help did(NAME) receive from mental health professionals in finding other services, such as housing, legal aid, vocational programs or transportation:**
- none at all.....1
- very little.....2
- don't know/ambivalent (DO NOT READ).....3
- some, but not as much as you wanted.....4
- all that you wanted or needed?.....5
12. **During the past 6 months, how available to (NAME) were general health services, such as treatment for a cold or the flu, injuries, or chronic physical conditions such as diabetes:**
- none at all.....1
- very little.....2
- don't know/ambivalent (DO NOT READ).....3
- some, but not as much as you wanted.....4
- all that you wanted or needed?.....5

13. **During the past 6 months, how available to (NAME) were dental services:**
- none at all.....1
- very little.....2
- don't know/ambivalent (DO NOT READ).....3
- some, but not as much as you wanted.....4
- all that you wanted or needed?.....5
14. **During the past 6 months, how much opportunity was there for you to complain to the agency about the treatment (NAME) received:**
- none at all.....1
- very little.....2
- don't know/ambivalent (DO NOT READ).....3
- some, but not as much as you wanted.....4
- all that you wanted or needed?.....5
15. **During the past 6 months, how much opportunity did (NAME) have to choose between different service options:**
- none at all.....1
- very little.....2
- don't know/ambivalent (DO NOT READ).....3
- some, but not as much as you wanted.....4
- all that you wanted or needed?.....5

16. **During the past 6 months, how much opportunity did (NAME) have to choose a particular case manager or therapist:**
- none at all.....1
- very little.....2
- don't know/ambivalent (DO NOT READ).....3
- some, but not as much as you wanted.....4
- all that you wanted or needed?.....5
17. **During the past 6 months, how convenient was it for (NAME) to use mental health services:**
- none at all.....1
- very little.....2
- don't know/ambivalent (DO NOT READ).....3
- some, but not as much as you wanted.....4
- all that you wanted or needed?.....5
18. **During the past 6 months, how much say did (NAME) have in the services that (he or she) received:**
- none at all.....1
- very little.....2
- don't know/ambivalent (DO NOT READ).....3
- some, but not as much as you wanted.....4
- all that you wanted or needed?.....5



19. **During the past 6 months, if (NAME)'s needs had changed, how much flexibility would there have been in the treatment plan:**
- none at all.....1
- very little.....2
- don't know/ambivalent (DO NOT READ).....3
- some, but not as much as you wanted.....4
- all that you wanted or needed?.....5
20. **During the past 6 months, how much satisfaction did you feel about the services (NAME) received:**
- none at all.....1
- very little.....2
- don't know/ambivalent (DO NOT READ).....3
- some, but not as much as you wanted.....4
- all that you wanted or needed?.....5
21. **During the past 6 months, how many culturally specific treatment services were offered to (NAME) that you were aware of:**
- none at all.....1
- very little.....2
- don't know/ambivalent (DO NOT READ).....3
- some, but not as much as you wanted.....4
- all that you wanted or needed?.....5

22. **During the past 6 months, how much help was available to you at night or on weekends when (NAME) had a crisis:**
- none at all.....1
- very little.....2
- don't know/ambivalent (DO NOT READ).....3
- some, but not as much as you wanted.....4
- all that you wanted or needed?.....5
23. **During the past 6 months, how much did you feel that the mental health system was responding to the wishes of family members like yourself (NAME):**
- none at all.....1
- very little.....2
- don't know/ambivalent (DO NOT READ).....3
- some, but not as much as you wanted.....4
- all that you wanted or needed?.....5
24. **During the past 6 months, how much say did you have in the services that (NAME) received:**
- none at all.....1
- very little.....2
- don't know/ambivalent (DO NOT READ).....3
- some, but not as much as you wanted.....4
- all that you wanted or needed?.....5

25. **During the past 6 months, how much satisfaction did you feel about your role in (NAME)'s treatment:**

- none at all.....1
- very little.....2
- don't know/ambivalent (DO NOT READ).....3
- some, but not as much as you wanted.....4
- all that you wanted or needed?.....5

**Other Relevant Items**

[The following item is not a part of the scale but provides an opportunity for family members to express opinions about what services are lacking for their relative.]

**During the past 6 months, was there any particular service which (NAME) needed that was not available?**

- yes.....1
- no.....2

What service is that? (SPECIFY)

---

[The following item is not a part of the scale but may be asked following Q1: During the past 6 months, how much information did you receive from mental health service providers about (NAME)'s illness? If the response is negative.]

**Was this because the information was confidential?**

- yes.....1
- no.....2

[The following items while not part of the scales are useful in determining how family members receive information about their relative.]

**Who is your primary source of information about (NAME)'s mental health services? Is it:**

- (NAME).....1
- (his/her) case manager.....2
- (his/her) therapist.....3
- the staff at (his/her) mental health agency.....4
- somebody else (SPECIFY).....5

---

no one?.....6

**Have you ever learned anything about (NAME)'s illness or treatment by overhearing conversations between mental health professionals?**

- yes.....1
- no.....2

[The following items are useful as confirmations of both the family member's preference for involvement and the family member's view of consumer preferences for family member involvement.]

**During the past 6 months, how much involvement did you want to have in (his/her) treatment plan? Was it:**

- a lot.....1
- some.....2
- very little.....3
- not at all.....4

**During the past 6 months, how much involvement did (NAME) want you to have in (his/her) treatment plan? Was it:**

- a lot.....1
- some.....2
- very little.....3
- not at all.....4

## **Interviewer Instructions**

The Toolkit includes detailed instructions for interviewers. We repeat here a brief review of some general points relevant to Module M.

All interviewing should be done in privacy and the confidentiality of the information should be strictly respected. Information provided should not be shared with anyone outside the research group including your family members, friends, or any other respondents.

Read each question slowly and distinctly, exactly as it is worded and in the order in which it appears. Interviewer instructions are in capital letters, enclosed by parentheses or brackets, and are not to be read to the respondent. When interviewer instructions are underlined, that means to substitute a word, usually a person's name for the word or phrase in capital letters. When you see “(NAME)” in this interview, substitute the name of the client. You should insert the client's name preceded by Mr., Mrs., Ms., or Miss. You may also use the client's relationship to the respondent (your son, your mother, etc.) or the name used by the respondent when referring to the client.

When a question ends with a question mark (?), stop at that point without reading any of the categories that might follow. When the stem or lead-in question ends with a colon (:), read all of the answer categories, pausing briefly between them, up to the question mark. If the respondent gives you a response before you finish reading all of the choices, explain that you must read all of the categories, and continue reading. You should not read aloud to the respondent the answer choice, "Ambivalent."

We expect the respondent to answer in terms of the precoded answer choices given, unless we have provided an "Other (SPECIFY)" category. When the response given does not fit into any of the precoded answer choices and no "Other" category is provided, repeat the precoded choices and say, "Which of these comes closest to how you feel?" If the respondent is unable to choose a category, do not circle a code, but record the respondent's answer word-for-word in the space to the left of the answer categories.

When the respondent asks you to define a term or clarify a question, you may not do so, unless a specific definition or explanation is provided either in the interview or in the Question-by-Question Specifications. The standard interviewer's response when a respondent asks what a word or question means is, "Whatever it means to you." However, you will often

find that repeating the question, perhaps more slowly than the first time, gives the respondent the needed clarification.

### **Question by Question Specifications**

Q1-26. These questions are meant to assess the family member's evaluations of mental health services for (NAME). Mental health services are help and information that assist (NAME) to live in the community. Examples of mental health services are therapy, medication, and help with daily living. Examples of mental health service providers are: psychiatrist, psychologist, psychiatric nurse, case manager, social worker, counselor, and therapist. Please note that all of the questions in this module use a 6 month time frame.

Our response categories are designed to measure the level of satisfaction of the family member toward mental health services. For example, a family member who receives no information and is dissatisfied should be coded "none at all." A family member who receives no information but is satisfied should be coded "all that you wanted or needed." Questions 1-25 contain a response category that you are not to read when asking each question. This code is to be used if the respondent cannot make up his or her mind or stresses that he or she really doesn't know how to answer the question. You will code these responses as 3. Please note that when an item is not-applicable, as for example when no services were needed or no crisis occurred, that these responses qualify as an all that you wanted or needed response.

QJ25. In this question, "culturally specific treatment services" refers to services that family members believe are appropriate to their ethnic background. Examples that you may use if asked by the respondent include drumming and other types of culturally specific music therapy including rap music, acupuncture and herbal medicine, and an Afrocentric case management team which uses a kinship or tribal model of therapy.

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# Evaluating Family Experiences with Severe Mental Illness

*To be used in conjunction with*

*The Family Experiences Interview Schedule (FEIS)*

## **SUPPLEMENTARY DOCUMENTS**

**Addendum to Toolkit for Evaluating Family  
Experiences With Severe Mental Illness:**  
*New Measures of Family Member Evaluations of Mental  
Health Professionals, Client Services, and Systems*

**Richard Tessler, Ph.D.  
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## **MODULE M**

### **Statement of Purpose**

This Addendum, entitled New Measures of Family Member Evaluations of Mental Health Professionals, Client Services and Systems, is intended to be used as Module M in conjunction with the Toolkit for Evaluating Family Experiences with Severe Mental Illness (Tessler and Gamache, 1995). The current Module M provides the same information (in a similar but self-contained format) for the new measures that we provided in the Toolkit for Modules E (Benefits and Gratifications), F (Financial Expenditures), G (Assistance in Daily Living), H (Supervision), I (Impact on Daily Routines), J (Attitudes Toward Professionals), K (Affective Response) and L (Stigma). Module M. specifically extends the study of family experiences with severe mental illness to include family member evaluations of mental health professionals, consumer services and systems. Although this new module may be used alone, the authors recommend that it be added to the end of the Family Experiences Interview Schedule (FEIS) presented in the Toolkit.

Module M contains four major sections:

1. An introduction to the measures.
2. The background and significance of family member experiences with mental health professionals, services and systems.
3. A narrative history of the new measures including how they were derived, information about the study used to test the properties of the measures, a description of the study sample, psychometric properties and rules for scale construction.
4. The 25 items comprising the measures are presented in a manner consistent with the formatting of the interview protocol included in the Toolkit along with other related measures that provide basic information about the preferences of family members as to their wishes to be involved in the consumer's treatment.
5. Interviewer instructions and question by question specifications.

## **Introducing the Measures**

Four measures are presented in this Addendum: Family Member Evaluations of 1) Mental Health Professionals/Providers; 2) Client Services; 3) Mental Health Systems and 4) a summary Global Evaluation of Mental Health Professionals, Services and Systems. We conceptualize the first three measures as representing: 1) family member preferences for their own roles in treatment and their involvement with professionals, 2) ratings of the services provided to their relatives, and 3) satisfaction with the formal system of care. The central issues addressed by the measures are how family members evaluate their own involvement as partners in treatment, the quality of services provided directly to their relatives with mental illness and how they perceive the adequacy of the mental health system with respect to its response to them rather than to their relatives.

The measures are useful for describing and analyzing how family member evaluations of mental health services and preferences for their own role in treatment may shift over time in response to changes in the public system of mental health care. They may also be viewed as providing a family-based source of data relevant to the assessment of quality of care for the consumer. These measures were designed to address issues important to the triad of mental health professionals, family members and consumers of mental health services (Haug, 1994).

Although the original Toolkit included a module on Attitudes Towards Professionals (see Module J in the Toolkit), the 4 measures in this addendum are new in the following respects:

- they are broader in scope than the Attitudes Towards Professionals measure;
- the items are relevant whether or not there has occurred recent contact (or any contact) with mental health professionals;
- response categories are sensitive to differences in family member preferences and variations in client use of services;
- the measures are not just about family member satisfaction but include added information about preferences and needs;
- an item specifically designed to address the issue of sensitivity to cultural diversity is included;
- each item asks about the past 6 months; and
- the items were derived in close collaboration with a state Department of Mental Health.

## **Background and Significance**

Current mental health policy takes the perspective that a system of care will be more effective when family caregivers play a role in its design, implementation, and evaluation. In an era of community care for consumers of mental health services, building mental health systems importantly involves family members (Fisher, Benson and Tessler, 1990). Two recent developments point to the need for new ways to conceptualize family member attitudes toward the mental health system (as well as toward individual mental health professionals). One positive development is the belated recognition by mental health providers of family members as major providers of the informal support which may be vital to the consumer's quality of life in the community. In response, state mental health authorities nationwide are implementing plans to include family representation on state planning committees, advisory boards, and as speakers and panelists in conferences. Family members are also being seen as partners in treatment.

Another more ambiguous development is the move toward managed care in the area of public mental health services. David Mechanic has noted that this latter trend holds uncertain implications for family members (1994). This trend whose main beneficiaries are intended to be primary consumers is also likely to affect family members. One implication for families flows from the fact that housing for persons with mental illness is not Medicaid reimbursable and it may tend to be a scarce resource. There is also reason to be concerned that managed care programs may encourage family involvement as an alternative to hospitalization. On the other hand, improvements in crisis services which are sometime anticipated as part of managed care are likely to benefit families who have long advocated for 7 day a week, 24 hour a day, emergency services. In the past, family attitudes toward mental health services and professionals have, for the most part, been negative. Some empirical evidence indicates “near-universal dissatisfaction” with services (Grella and Grusky, 1989, p. 831). More recently, a study in Vermont using focus groups to explore family attitudes, reported that Family members saw themselves as disregarded by the mental health system and often blamed for their relatives mental illness (Pulice, McCormick and Dewees, 1995). The authors of a study of 250 family members in New York state reported how the relatives of consumers viewed mental health professionals during the 1980s:

Family members have complained that they have lacked information about the patient's illness, that they have received inadequate advice on management issues, and the availability of services during times of crisis has been poor. They have reported coming away from interactions with professionals feeling guilty, frustrated, and helpless. They place mental health workers at the bottom of their list of useful supports (Bernheim and Switalski, 1989).

Biegel and his colleagues recently reported similar complaints among family members in Cleveland, although Black caregivers expressed higher overall satisfaction when compared to white caregivers (Biegel, Song, and Milligan, 1995).

On the other hand, some research on family attitudes toward professionals indicates improvement on some issues but not on others. A majority of family members in the Robert Wood Johnson family study reported in the Toolkit felt that professionals were interested in what the family members could tell them. Most also agreed that professionals assured them they were not to blame and showed that they understood the problems faced by the family. However, the results also revealed that a majority believed that professionals did not give detailed information or include family members in treatment planning (Tessler et al., 1991).

Thus, family member evaluations are valuable from two perspectives. When family members are perceived as part of the treatment team, an evaluation would be incomplete without their input. A comprehensive evaluation of the impact of the mental health component of a system change over to a managed care entity also needs to include outcomes for family caregivers. We emphasize that family members, consumers, and professionals are, or should be, part of a "health care triad" (Haug, 1994). All three parties form a triangle which is important to the success of long term care in the community. Mental illness poses dilemmas for each of them, but the family perspective is most often the view that is ignored when evaluating system changes. To ignore the perspective of any one of the parties may adversely affect the client's quality of life, cause distress for the family caregiver, and lead to frustration for the professional.

## **Narrative History of the Study and the Measures**

The Family Member Evaluation Measures were developed to study how changes in the system effect family member evaluations of mental health professionals, client services and systems. The measures were originally designed for a three wave study of how family members would be effected when a state system of mental health care converted to a system of managed care for the provision of public mental health services. When the state of Ohio declined to adopt the managed care model after receiving a Medicaid waiver, the study continued on the assumption that nevertheless system changes were taking place about which family members had strong feelings, and that it was valuable to record these family sentiments (Dee Roth, personal communication).

The measures (and the other relevant items included here) also have as one of their primary objectives the collection of basic information about both the preferences of family members as to their wishes to be involved in building the system of mental health care and in treatment and the preferences of consumers as regards the involvement of their relatives. Some family members may want to be involved while their relatives with mental illness may prefer that they not be. Some consumers may want a lot of family involvement, while others may want as little as possible. Some consumers might feel strongly that family members should not be involved at all in building a system of care. Other consumers might feel positively about a family member being involved in system design issues but not in his or her treatment.

### ***How the Measures Were Derived***

The items were developed in collaboration with the Ohio Department of Mental Health (ODMH). Input was particularly sought from the ODMH Family/Consumer advocate. ODMH has been a leader in recognizing the importance of families in the informal system of care, their potential burden, as well as their involvement in system and treatment planning and their evaluations of the public system of care.

The authors worked closely with the Ohio staff in constructing the items around issues important to ODMH as well as to family members (as reported to the consumer/family advocate staff member). These issues include family member evaluations of accessibility, integration among different service delivery systems, that crisis response be timely and convenient that family members have the opportunity to be involved in the treatment plan, that clients have



options from which to choose, and that in general the system of care be responsive to what clients and family members need and want

Response categories were modeled after those used in a study of family satisfaction with services in a northwestern state by Grella and Grusky (1989). The basic strategy was to make the response category labeled all that you wanted (or needed) indicate the highest level of satisfaction. The response categories were chosen in order to quantify level of satisfaction, while taking account of variation in client needs and family member preferences for specific services and desires for involvement.

A related issue for mental health systems and providers is the recognition that treatment should also mirror cultural preferences. Future choices may include culturally specific treatment services that consumers believe are appropriate to their ethnic background. The consumer and family advocate in Ohio has provided state of the art examples including drumming and other types of culturally specific music therapy such as rap music, as well as acupuncture and herbal medicine, and an Afrocentric case management team which uses a kinship or tribal model of therapy. (Wilma Townsend, personal communication)

### ***The Study From Which The Sample Was Drawn***

The data used in the analyses come from the study entitled, Evaluating Family Experiences with Clients and Services in Ohio funded by the Ohio Department of Mental Health (ODMH). (It should be noted that the sample of 147 Ohio family members is not the same sample of 305 Ohio family members described in the Toolkit.) The client sample is an extension of the Longitudinal Study of Mental Health Services and Consumer Outcomes in a Changing System study (LCO) initiated by the ODMH in 1989. Criteria for this sample were that the client had to meet ODMH 508 criteria for serious mental illness, and be receiving publicly funded mental health services. The sample was drawn from 4 county board sites and stratified on patterns of service delivery, and in 2 of the sites further stratified by race.

The original LCO sample consisted of 457 individuals and ODMH continued the longitudinal study with a fourth wave of interviews in spring 1995 when they re-interviewed 323 clients. Of these 323 clients, 188 consented to have family members interviewed. This is a 58.2 percent LCO client consent rate for the family study described in this Addendum. Family

members were nominated by clients and interviewed by telephone in late 1995 using a structured Computer Assisted Telephone Interview (CATI) format.

Clients who refused to name a family member had significantly fewer family members that they could count on compared to consenters. In general, consenters reported receiving more help from family members. There were no differences between consenters and refusers in respect to sex, education, diagnosis of schizophrenia, or whether they live with a family member. However, there were significant differences with older clients being more likely to refuse and non-whites and currently married consumers being less likely to refuse. There was also a trend indicating that consenters were more symptomatic at the time of their interview as measured by a Brief Symptom Index than were refusers.

Of the 188 clients who gave permission, we succeeded in obtaining a telephone interview with 147 family members conducted by a professional survey firm. This is a 78.2 percent response rate. Most of the time when we could not obtain a family interview it was because we were unable to reach or locate a family member (even after extensive help from ODMH). Twenty-two family members (about 12 percent) could not be reached because of telephone disconnects, wrong addresses or telephone numbers, or were never available, and in one case an eligible respondent had died. When family members were reached by telephone, the cooperation rate was almost 90 percent.

In general the 147 clients for whom we were successful in obtaining a family interview did not differ from the clients who consented but for whom we did not obtain a family interview. There were two notable exceptions. Clients with diagnoses of schizophrenia were less likely to have a family member interviewed. Also, clients who reported less contact with family were less likely to have a family member interviewed.

The 147 consumers for whom a family interview was obtained averaged 47 years of age; 11 years of education; 27 percent were minorities; and 45 percent had a diagnosis of schizophrenia. More than one-third had never been married and 56 percent were female. Family respondents averaged 51 years of age; 28 percent were minorities and 81 percent were female. More than one-third were parents of the consumer; 18 percent were adult children; 8 percent were spouses; and 18 percent were siblings. Uncles, aunts, grandmothers, fiancées and partners were also represented. A small number of fictive kin such as a good friend and a legal guardian were also interviewed. However, the majority were not only primary kin but considered

themselves to be the primary caretakers of their relative (84.4% said they provided the most support for the client).

## **Psychometrics and Scale Construction**

### ***Factor Analysis***

As noted above, the 25 items were originally chosen to operationalize six important dimensions of evaluations by family members. In order to sort among the 25 items, we first attempted to construct subscales based on the a priori categories of accessibility, involvement of family member in treatment plan, integration of service delivery systems, crisis response, client choice among options, and adequacy of system of care for relatives with mental illness. However, neither the number of factors or, perhaps more seriously, the item loadings, corresponded to the a priori framework. Therefore we decided to use an a posteriori framework based on a 3 factor varimax solution, which appeared to fit the data best. Factor analysis indicates two robust factors and a third significant but less interpretable one.

Please note that all items listed below are preceded by the phrase “During the past 6 months.” Each is also followed by the same (or comparable) response categories, where: 1 = none (not) at all; 2 = very little; 3 = don't know/ambivalent; 4 = some, but not as much as you wanted and 5 = all that you wanted or needed.

### **Factor 1**

#### **Family Member Evaluations of Their Involvement with Mental Health**

**Professionals/Providers** consists of the following 9 items: 1.) How much information did you receive from mental health service providers about (NAME)'s illness? 2.) How much information did you receive from mental health professionals about what to do if there were to be a crisis involving NAME? 3.) How much information did you receive from mental health professionals about whom to call if there were to be a crisis involving (NAME)? 4.) How much were you encouraged by mental health professionals to take an active role in (NAME)'s treatment? 5.) How much did mental health professionals respond to your concerns about (NAME)? 6.) How much did mental health professionals take into account your ideas and opinions? 7.) How much did mental health professionals involve you in (NAME)'s treatment? 8.) How much did mental health providers who were helping (NAME) recognize the burdens that family members like you face? 9.) How much contact did you have with any mental health professional on any matter pertaining to (NAME)'s care?

### **Factor 2**

**Family Member Evaluations of Client Services** consists of the 12 items: 1.) How many mental health services were available for (NAME) that you thought were needed? 2.) How much help did (NAME) receive from mental health professionals in finding other services, such as housing, legal aid, vocational programs or transportation? 3.) How available to (NAME) were general health services, such as treatment for a cold or the flu, injuries, or chronic physical conditions such as diabetes? 4.) How available to (NAME) were dental services? 5.) How much opportunity was there for you to complain to the agency about the treatment (NAME) received? 6.) How much opportunity did (NAME) have to choose between different service options? 7.) How much opportunity did (NAME) have to choose a particular case manager or therapist? 8.) How convenient was it for (NAME) to use mental health services? 9.) How much say did (NAME) have in the services that (he or she) received? 10.) If (NAME)'s needs had changed, how much flexibility would there have been in the treatment plan? 11.) How much satisfaction did you feel about the services (NAME) received? 12.) How many culturally specific treatment services were offered to (NAME) that you were aware of?

### **Factor 3**

**Evaluations of System Response to Family Members** consists of the 4 items: 1.) How much help was available to you at night or on weekends when (NAME) had a crisis? 2.) How much did you feel that the mental health system was responding to the wishes of family members like yourself? 3.) How much say did you have in the services that (NAME) received? 4.) How much satisfaction did you feel about your role in (NAME)'s treatment?

## **Reliability Coefficients for the Four Measures**

The reliability coefficients (Cronbach's alphas) for the three factors (treated not as factor scores but as summated indices) are as follows:

1. Family Member Evaluation of Their Involvement with Mental Health Professionals and Providers = .928;
2. Family Member Evaluation of Client Services = .812; and
3. Family Member Evaluation of System = .739.

A Summary Measure incorporating all 25 items yields a reliability coefficient of .922.

## **Validity**

The focus in this section is on criterion-related validity (also called predictive validity). We report here the bivariate correlations of the Summary Measure with a variety of measures of family burden (See the Toolkit) and contextual variables such as co-residence and client symptoms.

The summary measure of Family Evaluations was correlated negatively with feelings of hardship when giving money to the consumer and with providing supervision for behavior problems such as violent threats and alcohol abuse. The more the family member perceived an economic hardship or needed to control problem behaviors, the less likely he or she was to evaluate professionals, services and systems in a positive way. On the other hand, family members who lived with the consumer or who provided assistance to the consumer with the activities of daily living were more likely to believe that they were getting all that they wanted or needed. Family members who reported that the consumer had a case manager were also more likely to report receiving all that they wanted or needed.

## **Scale Construction**

This section of the Addendum describes procedures for constructing four family evaluation measures from the 25 items. Although researchers may choose to modify the scales somewhat based on their own psychometric analyses (e.g., to delete a given item if the corrected item-to-total correlation does not meet a chosen criterion), these are the scales which we recommend based on our analyses. A major advantage of using them as recommended is that the results can be compared directly across studies.

The responses of family members whose client-relative did not need a particular service during the 6 month period in question should be coded as all that you wanted or needed. This is the rationale for including needed in the response categories. An example is crisis services, which may not have been needed because as a family member would explain – there had been no crisis situation in the past 6 months. A response of don't know is considered to be ambivalent and coded to the mid-point. Other responses that may be termed ambivalent, e.g., I'm not sure, are also coded to the midpoint of the scale.

Constructing the evaluation measures involves computing an average. As in the Toolkit, we assume that researchers will have their own methods for coding and entering missing data, i.e., refusals and interviewer efforts. Depending on the researcher's preference there are several options for handling missing data in the averaging process. The method suggested by the authors is to create a score for every observation for which there are responses to at least half the items. Other options are mean or mode substitution for missing data. The summary score is divided by the number of items over which the sum is calculated. (It is clearly beyond the scope of this Addendum to include command files for the scales. Researchers will have a variety of statistical programs with which they work including SPSS, SAS and STATA.)

Average scores for the 4 scales are constructed from the 25 items as shown in the previous sections using the following response categories:

none (not) at all.....	1
very little.....	2
don't know/ambivalent.....	3
some, but not as much as you wanted, or.....	4
all that you wanted or needed?.....	5

Items included in Evaluations of Mental Health Professionals/Providers are Questions 1-9; items included in Evaluations of Client Services are Questions 10 - 21; and items included in Evaluations of Mental Health Systems are Questions 22-25. All 25 items are included in the summary Global Evaluation of Mental Health Professionals, Services and Systems.

## **Preliminary Findings**

Preliminary findings from the first wave of data collection in our new Ohio study indicate that the different factors have somewhat different determinants.

- For example, when we looked at spouses (compared to other family roles) we saw that spouses were less likely to feel that they received all that they wanted or needed from professionals. There was also a tendency ( $p < .10$ ) for spouses to give lower evaluations of client services and lower summary measure evaluations.
- Being an adult child showed a similar pattern except that it was not a significant predictor of either factor 2 or factor 3.
- Family member education predicted only factor 2 (Evaluations of Client Services), where the greater the family member's educational attainment the more favorable were his or her evaluations of client services.
- Co-residence was a significant predictor of all three factors, with sharing a residence associated with more positive evaluations. But living with the client appeared to be most important with respect to factors 1 and 3.
- Financial contributions, a dimension of the family burden, was as expected associated with more negative evaluations and was significant across all three factors. That is, the more areas family members contributed to financially for the consumer, the less likely they were to feel that they were receiving some or all of what they wanted or needed.
- Another dimension of the family burden, (Worry about the client, module K in the Toolkit) was also related to less positive evaluations of client services and the summary measure. The more family members worried about such things as the client's safety and living arrangements, the less they reported getting all that they wanted or needed.
- We had anticipated that when family members received information primarily from a case manager or other provider that they would evaluate the system more positively. To the contrary, the results show that more positive evaluations occur when it was the client who was the family's primary source of information. This was an across the factors finding.



- When the interviewed family member also helped with medication, this was associated with more positive evaluations. This finding fits with some of the other significant variables already noted such as co-residence and the client being the primary source of information.
- If the family member reported that the client had a case manager, then evaluations of professional interactions and client services tended to be more favorable, as one might expect.
- Interestingly, clients being older and being female were not predictive of factor 1 (professionals) but were predictive of factor 2 (client services); sex (being female) also predicted more favorable summary evaluations.
- The only clinical measure that was significant in predicting family evaluation was a diagnosis of schizophrenia; being diagnosed with schizophrenia was associated with more negative evaluations of client services and with more negative summary evaluations, but not with family evaluations of professionals.
- We also considered indicators of desired family member involvement in treatment planning. How much involvement family members wanted made no discernable difference once we controlled for how much they thought the client wanted them to be involved. The belief that the client desired family member involvement was strongly associated with more favorable evaluations of professionals and more weakly with the summary evaluation.

## Items for the Family Evaluation Measures

*Interviewer lead-in to items:* "Next, I would like to ask you about your opinions of mental health services. In choosing the answer that best reflects how you feel, please remember to answer "none or not at all" if you are dissatisfied and "all that you wanted" if you are satisfied."

**1. During the past 6 months, how much information did you receive from mental health service providers about (NAME)'s illness:**

- none at all.....1
- very little.....2
- don't know/ambivalent (DO NOT READ).....3
- some, but not as much as you wanted.....4
- all that you wanted or needed?.....5

**2. During the past 6 months, how much information did you receive from mental health professionals about what to do if there were to be a crisis involving (NAME):**

- none at all.....1
- very little.....2
- don't know/ambivalent (DO NOT READ).....3
- some, but not as much as you wanted.....4
- all that you wanted or needed?.....5

**3. During the past 6 months, how much information did you receive from mental health professionals about whom to call if there were to be a crisis involving (NAME):**

- none at all.....1
- very little.....2
- don't know/ambivalent (DO NOT READ).....3
- some, but not as much as you wanted.....4
- all that you wanted or needed?.....5

4. **During the past 6 months, how much were you encouraged by mental health professionals to take an active role in (NAME)'s treatment:**
- none at all.....1
- very little.....2
- don't know/ambivalent (DO NOT READ).....3
- some, but not as much as you wanted.....4
- all that you wanted or needed?.....5
5. **During the past 6 months, how much did mental health professionals respond to your concerns about (NAME):**
- none at all.....1
- very little.....2
- don't know/ambivalent (DO NOT READ).....3
- some, but not as much as you wanted.....4
- all that you wanted or needed?.....5
6. **During the past 6 months, how much did mental health professionals take into account your ideas and opinions:**
- none at all.....1
- very little.....2
- don't know/ambivalent (DO NOT READ).....3
- some, but not as much as you wanted.....4
- all that you wanted or needed?.....5

7. **During the past 6 months, how much did mental health professionals involve you in (NAME)'s treatment:**
- none at all.....1
- very little.....2
- don't know/ambivalent (DO NOT READ).....3
- some, but not as much as you wanted.....4
- all that you wanted or needed?.....5
8. **During the past 6 months, how much did mental health professionals who were helping (NAME) recognize the burdens that family members like you face:**
- none at all.....1
- very little.....2
- don't know/ambivalent (DO NOT READ).....3
- some, but not as much as you wanted.....4
- all that you wanted or needed?.....5
9. **During the past 6 months, how much contact did you have with any mental health professional on any matter pertaining to (NAME)'s care:**
- none at all.....1
- very little.....2
- don't know/ambivalent (DO NOT READ).....3
- some, but not as much as you wanted.....4
- all that you wanted or needed?.....5

10. **During the past 6 months, how many mental health services were available for (NAME) that you thought were needed:**
- none at all.....1
- very little.....2
- don't know/ambivalent (DO NOT READ).....3
- some, but not as much as you wanted.....4
- all that you wanted or needed?.....5
11. **During the past 6 months, how much help did(NAME) receive from mental health professionals in finding other services, such as housing, legal aid, vocational programs or transportation:**
- none at all.....1
- very little.....2
- don't know/ambivalent (DO NOT READ).....3
- some, but not as much as you wanted.....4
- all that you wanted or needed?.....5
12. **During the past 6 months, how available to (NAME) were general health services, such as treatment for a cold or the flu, injuries, or chronic physical conditions such as diabetes:**
- none at all.....1
- very little.....2
- don't know/ambivalent (DO NOT READ).....3
- some, but not as much as you wanted.....4
- all that you wanted or needed?.....5

13. **During the past 6 months, how available to (NAME) were dental services:**
- none at all.....1
- very little.....2
- don't know/ambivalent (DO NOT READ).....3
- some, but not as much as you wanted.....4
- all that you wanted or needed?.....5
14. **During the past 6 months, how much opportunity was there for you to complain to the agency about the treatment (NAME) received:**
- none at all.....1
- very little.....2
- don't know/ambivalent (DO NOT READ).....3
- some, but not as much as you wanted.....4
- all that you wanted or needed?.....5
15. **During the past 6 months, how much opportunity did (NAME) have to choose between different service options:**
- none at all.....1
- very little.....2
- don't know/ambivalent (DO NOT READ).....3
- some, but not as much as you wanted.....4
- all that you wanted or needed?.....5

16. **During the past 6 months, how much opportunity did (NAME) have to choose a particular case manager or therapist:**
- none at all.....1
- very little.....2
- don't know/ambivalent (DO NOT READ).....3
- some, but not as much as you wanted.....4
- all that you wanted or needed?.....5
17. **During the past 6 months, how convenient was it for (NAME) to use mental health services:**
- none at all.....1
- very little.....2
- don't know/ambivalent (DO NOT READ).....3
- some, but not as much as you wanted.....4
- all that you wanted or needed?.....5
18. **During the past 6 months, how much say did (NAME) have in the services that (he or she) received:**
- none at all.....1
- very little.....2
- don't know/ambivalent (DO NOT READ).....3
- some, but not as much as you wanted.....4
- all that you wanted or needed?.....5

19. **During the past 6 months, if (NAME)'s needs had changed, how much flexibility would there have been in the treatment plan:**
- none at all.....1
- very little.....2
- don't know/ambivalent (DO NOT READ).....3
- some, but not as much as you wanted.....4
- all that you wanted or needed?.....5
20. **During the past 6 months, how much satisfaction did you feel about the services (NAME) received:**
- none at all.....1
- very little.....2
- don't know/ambivalent (DO NOT READ).....3
- some, but not as much as you wanted.....4
- all that you wanted or needed?.....5
21. **During the past 6 months, how many culturally specific treatment services were offered to (NAME) that you were aware of:**
- none at all.....1
- very little.....2
- don't know/ambivalent (DO NOT READ).....3
- some, but not as much as you wanted.....4
- all that you wanted or needed?.....5



22. **During the past 6 months, how much help was available to you at night or on weekends when (NAME) had a crisis:**
- none at all.....1
- very little.....2
- don't know/ambivalent (DO NOT READ).....3
- some, but not as much as you wanted.....4
- all that you wanted or needed?.....5
23. **During the past 6 months, how much did you feel that the mental health system was responding to the wishes of family members like yourself (NAME):**
- none at all.....1
- very little.....2
- don't know/ambivalent (DO NOT READ).....3
- some, but not as much as you wanted.....4
- all that you wanted or needed?.....5
24. **During the past 6 months, how much say did you have in the services that (NAME) received:**
- none at all.....1
- very little.....2
- don't know/ambivalent (DO NOT READ).....3
- some, but not as much as you wanted.....4
- all that you wanted or needed?.....5

25. **During the past 6 months, how much satisfaction did you feel about your role in (NAME)'s treatment:**

- none at all.....1
- very little.....2
- don't know/ambivalent (DO NOT READ).....3
- some, but not as much as you wanted.....4
- all that you wanted or needed?.....5

**Other Relevant Items**

[The following item is not a part of the scale but provides an opportunity for family members to express opinions about what services are lacking for their relative.]

**During the past 6 months, was there any particular service which (NAME) needed that was not available?**

- yes.....1
- no.....2

What service is that? (SPECIFY)

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[The following item is not a part of the scale but may be asked following Q1: During the past 6 months, how much information did you receive from mental health service providers about (NAME)'s illness? If the response is negative.]

**Was this because the information was confidential?**

- yes.....1
- no.....2

[The following items while not part of the scales are useful in determining how family members receive information about their relative.]

**Who is your primary source of information about (NAME)'s mental health services? Is it:**

- (NAME).....1
- (his/her) case manager.....2
- (his/her) therapist.....3
- the staff at (his/her) mental health agency.....4
- somebody else (SPECIFY).....5

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no one?.....6

**Have you ever learned anything about (NAME)'s illness or treatment by overhearing conversations between mental health professionals?**

- yes.....1
- no.....2

[The following items are useful as confirmations of both the family member's preference for involvement and the family member's view of consumer preferences for family member involvement.]

**During the past 6 months, how much involvement did you want to have in (his/her) treatment plan? Was it:**

- a lot.....1
- some.....2
- very little.....3
- not at all.....4

**During the past 6 months, how much involvement did (NAME) want you to have in (his/her) treatment plan? Was it:**

- a lot.....1
- some.....2
- very little.....3
- not at all.....4

## **Interviewer Instructions**

The Toolkit includes detailed instructions for interviewers. We repeat here a brief review of some general points relevant to Module M.

All interviewing should be done in privacy and the confidentiality of the information should be strictly respected. Information provided should not be shared with anyone outside the research group including your family members, friends, or any other respondents.

Read each question slowly and distinctly, exactly as it is worded and in the order in which it appears. Interviewer instructions are in capital letters, enclosed by parentheses or brackets, and are not to be read to the respondent. When interviewer instructions are underlined, that means to substitute a word, usually a person's name for the word or phrase in capital letters. When you see “(NAME)” in this interview, substitute the name of the client. You should insert the client's name preceded by Mr., Mrs., Ms., or Miss. You may also use the client's relationship to the respondent (your son, your mother, etc.) or the name used by the respondent when referring to the client.

When a question ends with a question mark (?), stop at that point without reading any of the categories that might follow. When the stem or lead-in question ends with a colon (:), read all of the answer categories, pausing briefly between them, up to the question mark. If the respondent gives you a response before you finish reading all of the choices, explain that you must read all of the categories, and continue reading. You should not read aloud to the respondent the answer choice, "Ambivalent."

We expect the respondent to answer in terms of the precoded answer choices given, unless we have provided an "Other (SPECIFY)" category. When the response given does not fit into any of the precoded answer choices and no "Other" category is provided, repeat the precoded choices and say, "Which of these comes closest to how you feel?" If the respondent is unable to choose a category, do not circle a code, but record the respondent's answer word-for-word in the space to the left of the answer categories.

When the respondent asks you to define a term or clarify a question, you may not do so, unless a specific definition or explanation is provided either in the interview or in the Question-by-Question Specifications. The standard interviewer's response when a respondent asks what a word or question means is, "Whatever it means to you." However, you will often

find that repeating the question, perhaps more slowly than the first time, gives the respondent the needed clarification.

### **Question by Question Specifications**

Q1-26. These questions are meant to assess the family member's evaluations of mental health services for (NAME). Mental health services are help and information that assist (NAME) to live in the community. Examples of mental health services are therapy, medication, and help with daily living. Examples of mental health service providers are: psychiatrist, psychologist, psychiatric nurse, case manager, social worker, counselor, and therapist. Please note that all of the questions in this module use a 6 month time frame.

Our response categories are designed to measure the level of satisfaction of the family member toward mental health services. For example, a family member who receives no information and is dissatisfied should be coded "none at all." A family member who receives no information but is satisfied should be coded "all that you wanted or needed." Questions 1-25 contain a response category that you are not to read when asking each question. This code is to be used if the respondent cannot make up his or her mind or stresses that he or she really doesn't know how to answer the question. You will code these responses as 3. Please note that when an item is not-applicable, as for example when no services were needed or no crisis occurred, that these responses qualify as an all that you wanted or needed response.

QJ25. In this question, "culturally specific treatment services" refers to services that family members believe are appropriate to their ethnic background. Examples that you may use if asked by the respondent include drumming and other types of culturally specific music therapy including rap music, acupuncture and herbal medicine, and an Afrocentric case management team which uses a kinship or tribal model of therapy.

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# Evaluating Family Experiences with Severe Mental Illness

*To be used in conjunction with  
The Family Experiences Interview Schedule (FEIS)*

## **SUPPLEMENTARY DOCUMENTS**



## Call Report Form

RESPONDENT ID #:

INTERVIEWER:

ADDRESS:

*(Jane Doe  
1123 Main St.  
Anywhere, USA)*

INTERVIEWER ID #:

RECORD ALL CHANGES BELOW

TELEPHONE #:

MOTHER OF:

*(John Doe)*

CALL #	DAY	DATE	TIME	RESULT CODE	INTERVIEWER COMMENT
1			AM PM	P T	
2			AM PM	P T	
3			AM PM	P T	
4			AM PM	P T	
5			AM PM	P T	
6			AM PM	P T	

### CODES FOR RESULTS OF CALLS

- |   |  |
|---|--|
| <ul style="list-style-type: none"> <li>01. COMPLETED INTERVIEW</li> <li>02. APPOINTMENT MADE</li> <li>03. BROKEN APPOINTMENT</li> <li>04. R NOT HOME (NO APPOINTMENT)</li> <li>05. NO ONE HOME/NO ANSWER</li> <li>06. R MOVED; ADDRESS OBTAINED</li> <li>07. R MOVED; OBTAINED LEAD</li> <li>08. R MOVED; CANNOT LOCATE</li> <li>09. R REFUSED (1ST REFUSAL)</li> </ul> | <ul style="list-style-type: none"> <li>10. R REFUSED (2ND REFUSAL)</li> <li>11. SOMEONE ELSE REFUSED FOR R</li> <li>12. WRONG PHONE #/DISC/UNLISTED</li> <li>13. R TOO ILL</li> <li>14. MESSAGE LEFT ON MACHINE</li> <li>15. R AWAY FOR STUDY DURATION</li> <li>16. OTHER: EXPLAIN IN COMMENTS</li> </ul> <hr/> <p><i>P    Personal Interview</i></p> <p><i>T    Telephone Interview</i></p> |
|---|--|

## *Official Letterhead*

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### **[NAME OF STUDY] Introductory Letter**

Date: \_\_\_\_\_

Name: \_\_\_\_\_

Address: \_\_\_\_\_

#### **Dear Respondent:**

The [NAME OF YOUR ORGANIZATION] is conducting a study of family experiences when a relative suffers from a mental illness. Your relative has agreed to participate in this study and has given us your name as someone whom we could interview. We are interested in learning about how this person's illness is affecting your life, if at all.

This study is strictly voluntary. If you decide not to participate, it will in no way affect your relative's treatment program. We hope, however, that you will participate, because by doing so you will be helping to improve services for persons with mental illness and for those who care for them.

The interview takes about an hour. It will be conducted in privacy, either in your home, or at some other location—whatever you prefer. I want to emphasize that all information collected is confidential, and will not be shared with anyone. No one unconnected with the research will ever or in any way have access to the information you provide. Reports from the study will only present information for groups of people. It will be impossible to identify individuals from these reports.

If you have any questions about the study, please call me collect at [YOUR TELEPHONE NUMBER], weekdays between 8:30 AM and 4:30 PM.

Sincerely,

[NAME]  
Study Director

## *Official Letterhead*

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### [NAME OF STUDY] Information Sheet

1. **Purpose** The purpose is to study the roles of family members and significant others in caring for persons with mental illness. We are particularly interested in the difficulties and rewards families may experience when asked to care for a relative with mental illness. We need the benefit of your experience and hope you will help us.
2. **How we got your name** We asked persons in the hospital to name family members who we could interview. Your name was among those given.
3. **Interview** A personal interview of approximately one hour will be scheduled at a convenient time and place. Participation is voluntary. You may choose not to answer specific questions. In addition, you may end the interview at any time.
4. **Confidentiality** All the results are confidential and will be used for statistical purposes only. Only the researchers will have access to the information you give.
5. **Benefit** The benefit is that you will contribute to research that may help improve services for persons with mental illness and their families.
6. **Sponsorship** The study is being conducted by [INSERT NAME OF SPONSOR]. Interviews are being conducted by [INSERT INTERVIEWER ORGANIZATION]. An [INTERVIEWER ORGANIZATION] interviewer will be contacting you [INSERT TIME PERIOD, *E.G.*, IN THE FALL] to schedule the interview.

## *Official Letterhead*

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**A STUDY OF [INSERT STUDY PURPOSE] Fall 1994**

### **Informed Consent Form**

The study being conducted by [INSERT ORGANIZATION NAME] has been explained to my satisfaction. I understand that it will involve a structured interview of about one hour and that the questions will focus on my relationship to the relative who provided my name and the impact of that client's mental illness on my life.

I agree to be interviewed with the understanding that the information will be kept confidential, used only for research purposes, and that I have the right not to participate at any time.

**Respondent's Signature:** \_\_\_\_\_

**Date:** \_\_\_\_\_

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#### **(INTERVIEWER: PRINT THE INFORMATION BELOW)**

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**CASE #:** \_\_\_\_\_

**RESPONDENT'S NAME:** \_\_\_\_\_

**INTERVIEWER:** \_\_\_\_\_

**ID#:** \_\_\_\_\_

## ***Official Letterhead***

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### **Pledge of Confidentiality**

I hereby guarantee that I will faithfully execute my obligations and responsibilities as an interviewer to fully respect and preserve the confidential nature of information obtained during the Study of [INSERT STUDY NAME HERE] interviews.

**Interviewer's signature:** \_\_\_\_\_

**ID#:** \_\_\_\_\_ **Date:** \_\_\_\_\_