

FAMILY MEMBERS' BEHAVIOURAL INTENTIONS TO ADVOCATE FOR
RESOURCES FOR COMMUNITY-BASED CARE, INCLUDING HOME CARE,
FOR INDIVIDUALS WITH A CHRONIC MENTAL DISORDER.

by

JANINE CUTLER

A Thesis
Submitted to the Faculty of Graduate Studies
in Partial Fulfillment of the Requirements
for the Degree of

DOCTOR OF PHILOSOPHY

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University of Manitoba
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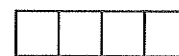
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Abstract

As a result of deinstitutionalization and community-based treatment, families are often primary caregivers for a family member with a chronic mental disorder (Pomeroy & Trainor, 1991). This study adopted Ajzen and Fishbein's (1980) Theory of Reasoned Action as its theoretical framework to examine family members' beliefs regarding and attitudes towards: community-based care, including home care; the adequacy of resources necessary for community-based care, including home care; and advocacy. The study also investigated family members' behavioural intentions to advocate for resources necessary for community-based care, including home care.

Consent was obtained from the sample of individuals with a CMD (n=100) to contact and interview their designated family member and mental health worker. Family members (n=100) were interviewed at their homes, using a structured questionnaire. The mental health workers (n=31) were interviewed with a structured questionnaire and requested to complete the Global Assessment Scale (Endicott, Spitzer, Fleiss, & Cohen, 1976) and the Role Functioning Scale (Georgia Department of Human Resources, 1984).

Twenty hypotheses regarding particular beliefs, attitudes, and behavioural intentions were tested, using correlational analyses (Pearson r correlations,

partial correlations and multiple regression procedures).

The results showed that family member respondents' attitudes toward the adequacy of resources and advocating for resources for community-based care predicted family member respondents' behavioural intentions to advocate for resources for community-based care. However, the model did not adequately predict family member respondents' behavioural intentions to advocate for better resources for home care. The results of the regression analyses and tests of hypotheses suggest that the inadequacy of the model stem from the lack of attention to affective components, a lack of correspondence between adjacent measures used to test the model, and the use of new measures.

Future research utilizing the Theory of Reasoned Action (Ajzen & Fishbein, 1980) could include scale development for some of the constructs utilized in the present study, the addition of self-efficacy and affective variables, and a measure of personal norm or moral obligation. Family member respondents' reported that having a family member with a CMD placed a burden on the family and a need for support. Future research also could examine family members support needs.

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Introduction

Deinstitutionalization

Deinstitutionalization emerged in the 1950s as a mental health policy to accommodate the needs and intentions of diverse groups in American society (Shadish, 1984). The National Institute of Mental Health defined three processes involved in deinstitutionalization, which Bachrach (1977) described as: prevention of inappropriate mental health admissions through the provision of community alternatives for treatment; release to the community of all institutional patients who had not been adequately prepared for living in the community; and establishment and maintenance of community support systems for non-institutionalized persons receiving mental health services.

Deinstitutionalization has fostered a great deal of controversy. Between 1950 and 1981, it brought about a 70% decline in patients in public mental hospitals in the United States (Borus, 1981). Toews (1986) noted that Canadian reports have indicated a similar decline (approximately 60%). In Canada, patients discharged from psychiatric hospitals accounted for 7.2 million days of hospital stay in 1982-83 as compared to 19.8 million in 1971, a 64% decrease. This decline in hospitals days was due to such factors as the reduction in the number of psychiatric hospitals and the number of beds in these hospitals; the decline of long stay patients through earlier discharges;

and the increasing utilization of general hospitals, residential care facilities, and community mental health services for the care and treatment of the mentally ill (Statistics Canada, 1983).

Dimirsky (1990) stated that in Canada, a lack of national leadership and coordination makes it difficult to even assess the magnitude of the population of individuals with a chronic mental disorder (CMD). A conservative estimate is thought to be approximately 180,000 individuals in Canada who have a CMD and need support to meet basic needs. This estimate does not include individuals presently institutionalized in mental health care facilities (Toews & Barnes, 1982).

Borus (1981) argued that deinstitutionalization not only brought about a decline in patients in public mental hospitals, but also demonstrated that, without sufficient resources, good care is not created simply by changing the locus of bad care. Over time, there has been a growing recognition of a discrepancy between the ideology that allegedly guided deinstitutionalization and the practice that actually emerged out of this policy (Felton & Shinn, 1981). Nursing homes, for example, have assumed a major role in deinstitutionalization (Lehmkuhl, Bosch, & Steinhart, 1987; Shadish, Straw, McSweeney, Koller, & Bootzin, 1981). This occurred despite the fact that nursing homes were just as likely as hospitals to promote chronic illness and hinder rehabilitation (Kunze, 1985).

One unfortunate outcome of deinstitutionalization is "dumping" (Lamb & Goertzel, 1971; Miller, 1985). Dumping is an administrative practice in which patients are discharged from psychiatric hospitals prematurely and with insufficient preparation of the patients or those who will be living and working with them (Miller, 1985). The results, in human terms, have been devastating. Evidence indicates that substantial numbers of individuals with a CMD are included in the ranks of the homeless (Appleby & Desai, 1985; Bachrach, 1984; Ball & Havassy, 1984; Dee Roth, Bean, & Hyde, 1986; Hagen, 1987; Lamb, 1984). Moreover, as Tessler & Goldman (1982) have pointed out, the many tragedies of deinstitutionalization have been vividly portrayed in mass media descriptions of ex-hospital patients sleeping outdoors on heating grates and in doorways, living in squalid single room occupancies, wandering the streets, and trying desperately to get back into institutions in which they could feel safe and secure.

One other outcome of depopulating public mental hospitals has been trans-institutionalization (i.e., the transfer of individuals from psychiatric institutions to the courts and jails). Hodgins (1990) reported that recent studies in the U.S.A. documented prevalence rates of mental disorders among prisoners that markedly exceeded the rates for the general male population. Hodgins evaluated a representative sample of 650 male inmates of

penitentiaries situated in Quebec, and found that 25% of the inmates suffered from major mental disorders, 57% presented a problem of drug or alcohol abuse and/or dependency, 13% suffered from less severe mental disorders, and only 4.7% of the inmates presented none of the disorders evaluated. The increasing numbers of mental disorder among the Canadian prison population has been the subject of much study.

While strong opposition to deinstitutionalization has arisen (Gralnick, 1985), some authors have cautiously applauded deinstitutionalization despite its many limitations and problems. These authors have suggested that alternative programs, such as development of comprehensive regional community support and rehabilitation services, and development of an integrated mental health system, have improved the care of individuals afflicted with a CMD (Carling, Miller, Daniels, & Randolph, 1987; Christenfeld, Toro, Brey, & Haveliwala, 1985; Kiesler, 1982; Kiesler & Sibulkin, 1987; Okin & Dolnick, 1985). Bachrach (1978) described the process of deinstitutionalization as a dynamic and continuing series of adjustments which involve all parts of the mental health system.

Deinstitutionalization greatly changed the role of families who had a member with a CMD. As a result of deinstitutionalization and the current trend towards community-based treatment for individuals with a CMD,

periods of hospitalization have shortened and a wide array of aftercare and rehabilitative services have been used (Spaniol, Jung, Zipple, & Fitzgerald, 1986a). Community-based treatment has resulted in large numbers of persons with a CMD returning to their families (Spaniol et al., 1986a). A number of studies have reported that from 25 to 60 percent of deinstitutionalized patients return to their families (Goldman, 1982; Lamb & Oliphant, 1978; Minkoff, 1979). Other studies have estimated that at least two-thirds of patients with a mental disorder return home immediately following a period of hospitalization (Davis, Dinitz, & Pasanick, 1974; Leaf, 1977; Michaux, Kratz, Kurland, & Gansereit, 1969; Reich & Seigel, 1973).

Turner, Avison, Noh, and Speechley (1983) reported that the available data suggest that patterns of hospitalization of individuals with a CMD in Ontario changed, with the number of patients being discharged into the community increasing dramatically between 1960 and 1971. They stated that a substantial proportion of patients returned to their families after their discharge from hospital.

It has become clear that families are often primary caregivers for family members afflicted with a CMD (Doll, 1976; Falloon, Boyd, & McGill, 1984; Goldman, 1982; Hatfield, 1978, 1979 1981; Holden & Lewine, 1982; Lamb & Oliphant, 1978; Seeman, 1988; Wasow & Wiklow, 1983). While families often maintain involvement with their relative even after long separations, they frequently do

not have the information, skills, or resources to adequately assist their family member with a CMD (Hatfield, Fierstein, & Johnson, 1982). Lefley (1986) pointed out that, not only is there very little research on the effects of deinstitutionalization on patients, but also there is virtually no research on how the social policy of deinstitutionalization has affected families. However, it is widely believed that many families have suffered because of their inability to cope adequately with the stress resulting from having a family member with a CMD living at home.

The movement toward community-based care for people with long-term mental illness was born out of the belief that long hospitalizations unduly isolate people with mental disorders and generally foster the very behaviours, dependencies, and difficulties in living in "normal" society that it is supposed to cure (Brown & Parrish, 1987). It also was hoped that a person's quality of life would be improved by virtue of returning the person to the community. Before discussing the quality of life afforded the individual with a CMD within the familial home, two other issues will be explored. A brief explanation of quality of life measures will first be offered, followed by discussions of quality of life in relation to non-familial and familial community-based living arrangements.

Quality of Life in Relation to Community-Based Residential Facilities

The trend towards community-based care fostered research regarding the quality of life of persons afflicted with a CMD living in the community. Baker and Intagliata (1982) as well as related studies (Lehman, Ward, & Linn, 1982; Lehman, 1983a & 1983b) reported that persons with a CMD are least satisfied with their economic situations, their use of leisure time, and their health. However, Baker and Intagliata (1982) pointed out that clients displayed greatest satisfaction with being out of the hospital. The most positive feelings were expressed about the place where the individual lived at the time of the interview compared with living at the state hospital.

Dimirsky (1990) reported that two studies of deinstitutionalized individuals (Tessler & Goldman, 1982; Hull, Keats, & Thompson, 1984) confirmed that economic dependency, social isolation, deficits in self-maintenance skills, and poor community re-integration abilities characterize persons with a CMD.

A socio-ecological model of coping described by Kearns, Taylor and Dear (1987) provided as a conceptual framework for research on factors influencing the quality of everyday life among persons with a CMD in the community. Their results suggested that more satisfied clients are generally older, able to identify several significant others, not living in board-and-care homes,

residentially stable, not on social assistance, and have enough to do in their spare time. These authors, along with Mueller and Hopp (1983), also commented on the potentially detrimental effect of boredom.

Dimirsky (1990) reviewed the quality of life literature and concluded that two different measurement strategies are well represented, namely social or objective indicators (e.g., unemployment rates) and psychological or subjective indicators (e.g., satisfaction). Subjective indicators can be further divided into global measures (e.g., overall measures of satisfaction) and domain-specific measures (e.g., measures of satisfaction in specific life domains such as family, education, work, and health). Dimirsky stated that objective or social indicators may point out circumstances that indirectly facilitate or attenuate quality of life, but individual cognitions and feelings directly affect satisfaction with life and global perceptions of psychological well-being. Dimirsky (1990) also indicated that social variables have been found to have a statistically significant but weak effect on self-reported quality of life.

Lehman (1983a) supported the proposition that, ultimately, quality of life is a subjective matter (i.e., it is based upon personal evaluation and experience) and is reflected in a sense of global well-being. Further, at least three types of variables are involved and act as

contributing factors in the formation of this evaluation or experience. The three types of variables involved are personal characteristics (e.g., age, sex); objective indicators in various domains of life (e.g., income level); and subjective indicators in these same life domains (e.g., satisfaction with income).

Lehman et al. (1982) stated that several researchers have investigated the quality of life afforded the residents of community-based residential care facilities (e.g., nursing facilities, group homes, personal care homes, foster homes, natural family placement, satellite houses).

Three studies (Lehman et al., 1982; Lehman, 1983a, 1983b) assessed the quality of life of residents living in board-and-care homes. Life satisfaction was assessed in eight domains: living situations, family relations, social relations, leisure activities, work, finances, safety, and health. Results suggested that the quality of life of board-and-care residents was affected mainly by social problems. They were dissatisfied with being poor, unemployed, victims of crime, socially isolated. Residents also reported being dissatisfied with health care services.

Lehman, Possidente, and Hawker (1986) examined objective and subjective quality of life indicators of four groups of chronic patients categorized according to (a) whether they were inpatients of a state hospital or

residents of a supervised community residence and (b) whether their current length of stay had been less than or greater than six months. Community residents, regardless of length of stay, perceived their living conditions more favourably, had more financial resources, and were less likely to have been assaulted in the past year than inpatients. The authors cautioned that the community residents studied had fewer psychiatric symptoms and a higher overall level of functioning than those in the state hospital. Since current living arrangements were dependent on individuals' clinical condition and not on random assignment, their level of functioning and psychiatric symptoms affected individuals' assessments of the quality of their living arrangements.

In most cases, those living in community-based facilities appeared to have a better quality of life than those living in hospital facilities. However, different community residential facilities have been shown to have differential effects upon the perceived quality of life of persons with a CMD. Lehman et al. (1982) assessed both objective conditions (e.g. living arrangements, family and social relationships) and subjective satisfaction in several life areas. They found that the board-and-care home characteristic most highly correlated with satisfaction with living arrangements was privacy.

Pepper and Ryglewicz (1982), Markson (1985), and Blake (1987) showed that, although board-and-care

facilities generally provide shelter and modest opportunity for social support, they do not provide services or a good therapeutic environment. Most importantly, they do not provide the aggressive outreach efforts needed for more effective community integration. Parks and Pilisuk (1984) confirmed these findings. They reported that residents of board-and-care facilities tended to be isolated from the general community, had minimal friendships with peers, and had little contact with people outside the facility or with family. As social isolation is an indicator of life dissatisfaction and a precursor to homelessness, most board-and-care facilities appear not to meet several needs of persons with a CMD.

Lamb and Goertzel (1971) measured the effects of high-expectation settings (e.g., halfway house, day-treatment center, rehabilitation workshop) and low-expectation settings (e.g., boarding homes) on discharged long-term mental patients. High-expectation settings demand much in the way of mobility, planning, and accepting responsibility. However, low-expectation settings value docility and expect little initiative from their residents. The high-expectation settings had a higher rehospitalization rate, but a longer time out of the hospital with a higher level of instrumental performance than did low-expectation settings. Lamb and Goertzel suggested that high-expectation settings

facilitate normalization, as patients are less segregated, experience less stigmatization, experience more normalization, and see themselves as functioning members of the community. If this is the case, high-expectation settings should promote higher life satisfaction.

Cantelon (1988) investigated some of the qualities of community-based residential facilities and their operators that contributed to the well-being and functioning of residents. Those found to be beneficial for external integration (the extent to which a resident's life focused outside the facility) included a family-like atmosphere, low operator expectations, and a moderate number of residents per facility. Internal integration (the extent to which a resident's life centered around and was mediated by the facility) was associated with operators who had a non-authoritarian belief system and with facilities that had medium to large numbers of residents.

Kruzich and Berg (1985) found that a family-like atmosphere, less restrictive rules, and operators with benevolent beliefs increased residents' performance of daily living tasks and raised levels of self-sufficiency.

Cantelon (1988) stated that if greater external integration, internal integration, and satisfaction in living arrangements are desirable goals, then family-like interactions and benevolent, non-authoritarian beliefs on the part of the operators are important. It also is

important to have operators who develop a nonrestrictive facility and who have low but realistic expectations of residents.

It is important to acknowledge that the particular type of residence determines the type of care provided to its residents. However, exclusively focusing on the type of residence and care provided to the residents of these facilities neglects the individual difference factor in the person-environment fit equation. It is important to consider the differential needs of different subpopulations of individuals with a CMD. Individuals who are multiply disabled (e.g., schizophrenic and having a substance abuse disorder or a physical disorder) have different needs than those who are not multiply disabled, and individuals who are younger have different needs than those who are older (Cutler, 1986; Pepper & Ryglewicz, 1985; Randolph, Lindenberg & Menn, 1986). People participate in settings because they can tolerate the demands and because they achieve something from participating (Perkins & Perry, 1985).

Different types of community-based residential care facilities have been outlined and discussed. One other type of community-based residential care facility is the familial home. As many individuals with a CMD live with their families, it is important to consider both the demands and benefits that come from living in the family home. In this way, the person-environment fit and the

appropriateness of this living arrangement for individuals with a CMD can be assessed. While home care falls under the rubric of community-based care, this study will focus on various aspects of this particular component of community-based care, separate and apart from the general discussion of community-based care for individuals with a CMD. Of course, the relationship between home care for individuals with a CMD and other aspects of community-based care also will be discussed and examined.

Quality of life In Relation to Home Care

Family Members' Beliefs Regarding and Attitudes Toward Individuals with a CMD. As families are often the caregivers for their family members with a CMD, it is important to understand their beliefs regarding and attitudes toward their relatives with a CMD.

Rabkin (1972) noted that only a few studies have documented the attitudes of family members toward mental illness or the changes that may occur in their attitudes over time. Kriesman and Joy (1974) suggested there is evidence that expectations about cure and homecoming are more pessimistic among family members than among the public at large.

In reviewing the literature, Kriesman and Joy (1974) suggested that although studies of the family's early reaction to the mental illness of a relative were enlightening and heuristic, they suffered from the shortcomings often found in the initial exploration of a

complex phenomenon. According to these researchers, most of the research has been impressionistic in nature, inconsistent, descriptive rather than explanatory, limited in scope and technique, and has failed to incorporate the type of controls that would permit clear conclusions to be drawn. Use of small samples and lack of rigorous sampling procedures also have made interpretation of results more difficult.

Kriesman and Joy (1974) suggested that a complex amalgam of responses probably best represents the family's evaluation, with variables such as length and number of hospitalizations, types of symptoms, pre-hospitalization family interaction, prognosis, and sociocultural status, to cite a few, determining the nature and intensity of such attitudes. They stated that there is an extremely complex set of interacting variables, and that it appears likely that important information is to be found in the interactions rather than in one or another main effect. These authors concluded that what seems to be needed is truly multivariate research.

More recent studies also have investigated family members' beliefs regarding and attitudes toward individuals with a CMD. Regarding etiology, Lefley (1985) surveyed 84 experienced mental health professionals from families with members suffering from long-term psychotic disorders. Lefley's findings indicated that these mental health professionals predominantly supported biogenetic

etiological models and directions for research. Further, regardless of the respondent's relationship to the individual with a CMD, models of family causation were seldom accepted. Respondents tended to perceive disturbed familial dynamics as reactive rather than systemic. Sixty-seven percent reported that at least one family member was affected psychologically, and 38% medically, by the experience of having an individual with a CMD in the family.

Pomeroy and Trainor (1991) asked families from across Canada to write and tell about their experiences. They reported that many families had embraced the biological explanations enthusiastically.

The severity of psychiatric symptoms exhibited by the individual with a CMD also contributed to family member's attitudes towards their family member with a CMD. Doll (1976) reported that family members who had a relative with a CMD at home were most troubled by the continued presence of psychiatrically severe symptoms, such as hallucinations and self-destructive behaviour. The least harmonious households were those in which a former patient was still seen by relatives as being plagued by clinical symptoms.

Doll, Thompson, and Lefton (1976) suggested that little is known about the affective response to actual mental patients. Standard measures tend to ask respondents about abstract, hypothetical mental patients,

rather than actual patients. Doll et al. suggested that a great deal was known about the reactions to and evaluations of the former, but not the latter. Their sample of relatives of actual mental patients displayed reactions that were multi-faceted, ambivalent, and at times contradictory. Behaviour that was either unmanageable because of the display of definite clinical symptoms or uncomfortably deviant consistently elicited the most negative feelings. However, the presence of acceptable behaviour did not, in and of itself, elicit a consistently accepting and sympathetic response. Content analyses of the data highlighted the many facets of the affective response. The authors suggested that disagreeable reactions of shame and social distance coexist with, interact with, and can be over-ridden by simultaneous feelings of sympathy, desire to include, understanding, and compassion.

Family members' beliefs regarding and attitudes toward their family member with a CMD have been shown to contribute to their overall evaluation of the return of their family member with a CMD to the household. Terkelsen (1986b) suggested that variations in the way relatives give meaning to illness arise from five main sources: the extent of the relative's involvement in the daily life of the patient; the relative's model of causation, symptoms, and outcomes; the phenomenology and natural history of the patient's illness; the relative's

personality and life history, including prior experiences with mental illness; and responses of other persons to the patient's illness. These factors all contribute to the relationship that develops between the family and the individual with a CMD. In turn, this relationship greatly affects the quality of life within the home.

Quality of Life of a Family Member with a CMD.

Although research exists which has examined the relationship between quality of life and residential facilities for individuals with a CMD, there has been little investigation of the relationship between quality of life and home care for individuals with a CMD.

More recently, studies have been conducted in an attempt to determine how the social policy of deinstitutionalization has impacted upon individuals with a CMD and their families. Doll (1976) studied a fairly representative sample of former mental patients who were returned to their homes. While they were physically accepted in the home and were not rehospitalized, many were socially and affectionally rejected by their families. He suggested that more attention must be paid to the meaning of the term discharge and to the quality of the situation to which former patients are sent.

Doll further suggested that increasing numbers of families are being forced into dangerously unendurable situations. Interviews with many of the respondents revealed strong feelings of pain and bitterness, being

trapped, and antagonism towards their relative with a CMD. Feelings of sympathy were mixed with feelings of anger, frustration, and resignation. Doll (1976) suggested that the reassuring findings that families show little shame and avoidance of their relative with a CMD obscures much of the reality of coping with the individual with a CMD. Doll concluded that the failure to monitor family-patient conditions at home and to provide the necessary mechanisms for support and relief may cripple the community movement.

Cohen and Sokolovsky (1978) pointed out that the sole social network available to people with a CMD may be their family. However, there is some evidence that family bonding may not facilitate social adjustment because it is often conflictual and overprotective. Vaughn and Leff (1976) found that close family ties with critical parents or spouses may be associated with a decrease in functioning and relapse, even for persons with a mental disorder who remain on psychotropic medication. Two studies (Brown, Birley, & Wing, 1972; Vaughn & Leff, 1976) investigated expressed emotion. The expressed emotion score is the composite of three separate scores: the number of comments made by a family member referring in a critical way to any aspect of the patient's behaviour, the number of openly hostile comments (i.e., deprecating statements about the patient), and a global estimate of the family member's degree of emotional involvement with the patient. The results from these two studies showed

that expressed emotion correlates strongly with relapse rates in schizophrenics (high expressed emotion is positively related to greater chance of relapse). Vaughn and Leff (1976) stated that most persons with a CMD are supersensitive to the manner in which they are treated and the respect they are accorded by family, friends, and others they encounter.

Studies investigating ethnicity and mental illness and family tolerance for family members with a CMD (Fabrega & Wallace, 1970-71; Clausen & Huffine, 1975) suggested that close family ties could serve to isolate or overprotect family members with a CMD, discourage independent living, and retard personal adjustment. The results from these studies indicated that both family ethnicity and family tolerance for family members with a CMD were micro-level features (e.g., demographic, structural) which contributed to the relationship between families and their member with a CMD. The particular demographic (i.e., ethnicity) and structural (i.e., degree of tolerance) features of the family network appeared to determine the effects of family relationships for the personal and community adjustment of the member with a CMD. Grusky et al. (1985) and Mueller (1980), based upon their research on schizophrenia and depressive disorders, respectively, and concluded that social networks must be carefully examined with regard to their particular structural and demographic features.

More recently, Atkinson (1986) reported that there is little research on problems that arise from living in the family for schizophrenic patients. She suggested that many adult family members with a CMD continue to be treated as children. She also speculated that, although a married individual with a CMD is not placed immediately in a child role, this could easily come about. If the individual with a CMD is not the family wage earner, or if that individual is not able to take care of household duties and other familial stress, he or she may be placed in a dependent position. Atkinson suggested that patients may also be placed in caregiving roles for their elderly parents which they may not be able to handle or, in a few cases, may be neglected or even exploited by the family.

Anthony (1989) and Hatfield (1989) noted that psychiatric patients living in the community preferred to live on their own or with their families, as opposed to a supervised community residence. However, Hatfield (1989) indicated that nearly one-half of the families in her sample preferred to have their family member with a CMD living in a residence, as they believed that their relative with a CMD required a supervised residence. One unexpected finding was the number of respondents who felt that their relative with a CMD could live out of the home with only personal care assistance provided (27%). Similarly, in his discussion of the housing preferences of individuals with a CMD living in the community, Anthony

(1989) stated that professionals preferred supervised residences. Grosser and Vine (1991) reported that a survey which assessed family members's perceptions of service needs for their family members with psychiatric disabilities, indicated that family members also preferred supervised residences. Hatfield (1989) stated that, although professionals and families may be in close agreement on this issue, a poll of individuals with a CMD would probably indicate that fewer of them prefer such residential living.

Doll (1976) and Thompson and Doll (1982) addressed the quality of life issue in regard to home care for both families and their family member with a CMD. They concluded that, although patients remain in the community, they are often in home environments marked by relatives' feelings of despair, resentment, and at times, social isolation. The quality of patients' home care must be assessed or patients and families may suffer.

Quality of Life of Families Living with a Member with a CMD. Caring for a member with a CMD can be a dreadful experience for families. Thompson and Doll (1982) separated the impact on the family into two types of burden, objective and subjective. Objective burden is defined in terms of the disruptions the former patient causes in the family's everyday life (e.g., financial burden; role strains due to relatives having to neglect other responsibilities; interruptions in the family's

normal routines; supervision that would otherwise be unnecessary; and problems with neighbours). Subjective burden is defined as the emotional costs the patient's presence and behaviour have on the family (e.g., feelings of embarrassment, overload, being trapped, and resentment).

Two early studies, Grad and Sainsbury (1963a) and Hoenig and Hamilton (1966), reported that many families experience at least some form of objective burden. With the member afflicted with a CMD at home, families suffer financial loss, disruption of domestic routines, and interference in social and work lives. Hoenig and Hamilton (1966) also investigated subjective burden. They found that the proportion of families reporting objective burden (81%) was greater than the number reporting subjective burden (60%). Hoenig and Hamilton suggested that disruptions in everyday life are not necessarily subjectively experienced by families as unduly burdensome.

Similar findings have been reported more recently. Hatfield (1978) reported that families experienced objective burden in the form of disturbed family life and disrupted interpersonal relationships and leisure activities. Families also reported experiencing severe stress, anxiety, grief, and depression, all indicators of subjective burden. Hatfield indicated that feelings of guilt, resentment, and anger were rarely expressed. Families saw their relative with a CMD as ill and unable

to behave differently and, therefore, felt that he or she merited sympathy rather than rejection. Some families felt their member with a CMD suffered a great deal more than they did. Hatfield suggested that many families felt resentment but expressed it only in terms of their fate in life, the lack of understanding and resources for them in the community, and the way they had been treated by professionals. Hatfield's observations differ somewhat from those of Hoenig and Hamilton (1966), who suggested that disruptions in everyday living are not necessarily subjectively experienced by families as a burden.

Thompson and Doll (1982) assessed the relationship among the subjective dimensions of burden and families' objective burden, certain sociodemographic characteristics of the family, and the psychiatric characteristics of the member with a CMD. Three major findings emerged. First, when both objective costs and subjective burdens are considered together, it appears that many families are placed in an emotionally demanding, often untenable situation and feel psychologically burdened by it.

The second major finding was evidence for the "universality" of subjective burden across families of different composition, social class, and race. The only exception was that lower socioeconomic families experienced greater financial burden. Thompson and Doll (1982) reported that their findings were consistent with those of other studies (Angrist, Lefton, Dinitz, & Pasamanick,

1968; Lefton, Angrist, Dinitz, & Pasamanick, 1962).

Third, Thompson and Doll (1982) suggested that, at a minimum, the burdens of coping need to be separated into objective and subjective components. Objective costs do not necessarily imply subjective costs and it appears that the underlying causes of each may be quite different.

In a Canadian study, Noh and Turner (1987) examined the association among the two dimensions of family burden and psychological well-being of family members. They found that only subjective burden was significantly related to psychological well-being. Noh and Turner suggested that the variability in objective burden that is related to distress is shared with subjective burden. Therefore, difficulties associated with the presence and behaviour of individuals with a CMD seem to be relevant to the psychological well-being of their family members only to the extent that they are perceived as sources of subjective burden.

In a more recent Canadian study, Noh & Avison (1988) suggested that little is known about the factors that influence or condition the extent of burdens experienced by family members. Noh and Avison examined variations in the experience of burden among a sample of men and women who were married to individuals with a CMD who had been formerly hospitalized. They investigated the extent to which psychiatric characteristics of the individual with a CMD and aspects of family structure affect the perception

of burden, and how other factors such as stressful life events and psychosocial resources influence the process.

Noh and Avison discussed their findings in the context of the stress process model developed by Pearlin, Lieberman, Menaghan, and Mullan (1981). The process model delineates the interplay among three major components: sources of stress, mediators of stress, and manifestations of stress. Multiple sources of stress are thought to interact to produce elevated levels of emotional problems. According to Pearlin et al. (1981) this relationship may be mediated by various psychosocial resources and coping behaviours.

The results from the study by Noh and Avison (1988) indicated that the current level of symptoms of the discharged individual with a CMD was the only psychiatric variable significantly related to spouse's experience of burden, and that psychosocial factors (i.e., life stress and mastery) are importantly related to the perception of burden. In examining the various interactions (mastery and symptomatology, mastery and stressful life events, social support and symptomatology, social support and stressful life events, and symptomatology and stressful life events), the authors determined that they interacted in a way consistent with what might be expected from the stress process model. The impact of patient's symptomatology on burden increased as the number of stressful life events reported by the spouse increased.

The data for the life events-social support interaction indicated that the effect of stressful life events on experienced burden diminishes as social support increases. Therefore, Noh and Avison concluded that it was reasonable to suggest that the experience of strain on the part of the spouse of individuals with a CMD is conditioned both by eventful stressors and by psychosocial resources.

According to Hatfield (1986a), the degree to which having a family member with a CMD is a negative experience depends on three factors. First, the objective burden is invariably heavier when families care for their relative directly and continuously. Second, the degree of subjective or emotional burden depends upon the meaning the illness has for the family. As mentioned previously, many factors determine this meaning. One such factor is the family's beliefs regarding etiology. Hatfield pointed out that the beliefs about etiology once espoused by clergymen and now by mental health professionals have historically added to the family's anguish about the mental illness. Family traits were claimed to be the cause of mental illness for over four decades. Hatfield indicated that, as a result of scientific research, these beliefs partially have lost their credibility over time. Nevertheless, many families have been devastated by iatrogenic guilt. Finally, how well families manage depends upon the adequacy of community supports available to them.

Terkelsen (1986a) suggested that due to such factors as the incomprehensibility of mental illness and the stigmatization attached to it, the adjustment process is prolonged in nature. He indicated that the process is usually characterized by many different and conflicting attitudes within and among family members, by dramatic forward strides in understanding and equally dramatic reversals, and always by a wide range of negative emotions (e.g., anger, frustration, entrapment). Terkelsen concluded that families faced with unremitting, prolonged, or fluctuating levels of disability in an affected family member eventually experience a collapse of therapeutic optimism and the sorrows of letting go of the dreams of unattainable futures.

Terkelsen (1986a) suggested further that, in the present era of community-based care, the aim of many families is to achieve an accommodation through which the welfare of the member with a CMD is brought into balance with the welfare of other members. He suggested that most families support the move away from total institutions. However, they are just now in the process of learning how to find the appropriate balance between retaining meaningful involvement with the member who has a CMD and at the same time preserving or resurrecting the capacity for involvement in other pursuits. Terkelsen indicated that most families are having difficulty setting up and maintaining this balance. For this reason, families of

individuals with a CMD have become increasingly vocal about restoration of long-term hospital services, provision of community residences in adequate numbers, and increases in funding for day programming and case management services.

Terkelsen (1986a) suggested that future research should focus on the family's struggle to come to terms with mental illness and the impact this struggle has on the family's other responsibilities and interests.

Resources for Families and Home Care

Although families have frequently become primary caregivers for family members with a CMD, they often do not have the information, skills, and support necessary to adequately assist their member with a CMD (Hatfield, Fierstein, & Johnson, 1982). Doll (1976) reported that there was a lack of community supports available to help families with the care of their member with a CMD. They did not have the benefit of adequate numbers of trained staff to manage the family member with a CMD. Families also were not prepared to provide constant home-based psychiatric treatment.

Social (Familial and Extrafamilial) Support. It is usually the immediate family that experiences most directly the incapacities in the person with a CMD. Terkelsen (1986b) described the family dynamics that often result from having a member with a CMD living at home. He suggested that one member within the immediate family,

most often the mother, sister, or wife, generally assumes the role of daily caregiver. The daily caregiver carries the main burden of the illness in the family. Other members may be less influenced by the daily routines of the family member with a CMD. The family's pre-existing cohesiveness may be threatened by the differential responsiveness to the illness by the primary caregiver and other family members. Other members of the family may not only erect barriers against involvement with the person who has a CMD, but also may resist involvement with the primary caregiver. The primary caregiver has no choice but to care for the family member with a CMD. Other family members, however, have the option of escaping the pressures of caregiving involvement. They often choose to do this in an attempt to limit the intrusion of illness-related concerns into their lives and daily activities.

Members outside of the nuclear family may attempt to restrict the impact of the illness on their own lives. However, as they are not exposed as directly and intensively to the illness, the patient, or the concerns of the primary caregiver, they may be more accessible to the person with a CMD and to the caregiver. Although this accessibility would be in a less constant manner than members of the immediate family, these relatives may be able to provide both caregiving help and emotional support (Terkelson, 1986b).

It has frequently been observed that families who

have a member with a CMD are socially isolated (Beels, 1975). As previously mentioned, the social life of many family members is often disrupted and socializing becomes minimal due to concentrated attention on the new problem (Hatfield, 1978; Thompson & Doll, 1982). Terkelsen (1986b) suggested that families with a member who has a CMD often experience a special isolation, as their problem is uncommon and, thus, not understood and often feared.

Very few families with a member who has a CMD have a natural network with enough diversity and density of resources to respond to all the needs created by ongoing caregiving. As a result, a new type of network develops that is tied to the principle caregiver's new status (Terkelsen, 1986b).

Encounters with care-givers from other families constituted one of the two main aspects of the new network that Terkelsen (1986b) suggested developed as a result of the burden experienced by families when caring for a family member with a CMD.

Hatfield (1986) reported that the emergence of self-help groups has provided new ways to solve difficult problems in living. Katz and Bender (1976) defined self-help as:

voluntary small group structures for mutual aid in the accomplishment of a specific purpose. They are usually formed by peers who have come together for mutual assistance

in satisfying a common need, overcoming a common handicap or life- disrupting problem, and bringing about desired social and/or personal change. The initiators and members of such groups perceive that their needs are not or cannot be met by or through existing social institutions (p.9).

Katz and Bender reported that the number and types of self-help groups have grown in the last two decades to the point of attracting the attention of social scientists and alerting human service organizations to their potential value in care and treatment.

Hatfield (1981) suggested that the development of mutual support groups began as a way of getting and giving the emotional support that had been missing in relationships with mental health professionals. Hatfield (1986) also suggested that the uniqueness of these groups was in their focus on peer support; on education regarding mental disorders, treatment approaches, and drug management; and on decreased reliance on professionals and agencies. She likened these groups to the old concept of neighbour helping neighbour.

Lieberman and Borman (1976) observed that most self-help groups tend to fit into one of two types: support groups that devote their time to giving service, information, and comfort to their members; and advocacy groups whose primary mission is to change the mental

health system. Lieberman and Borman, and Hatfield (1981, 1986b), also suggested that although many groups begin with a support function, over time they expand to include advocacy. It became apparent to families that, if life was to improve for themselves and for their relatives with a CMD, they would have to become sophisticated advocates for change in the mental health system.

During the 1970s, support and advocacy groups of families who have relatives with a CMD began forming independently of each other in different areas across the United States and Canada. In the U.S.A., local groups gradually discovered each other's existence and began forming affiliate relations. This led to a meeting of 100 local groups in Madison, Wisconsin, in September, 1979, and the formation of the National Alliance for the Mentally Ill (NAMI). By 1985, NAMI had nearly 500 affiliates in all 50 states and had a mailing list of 50,000 persons nationwide. NAMI has become well-known among organizations of mental health professionals.

NAMI was formed in response to numerous social problems resulting from the deinstitutionalization of persons with a CMD, such as lack of community resources for treatment and care, patients' rights to refuse treatment, family stress and burnout because of the burden of family care, and mental health professions ill-equipped to work with families (Hatfield, 1978). Advocacy is now one of the top priorities of NAMI and its various

affiliates. Hatfield suggested that, like many other reform movements, NAMI is a product of its period in history and can best be understood within the socio-cultural context of that period.

In 1978, a group called the Friends of Schizophrenics was organized in Toronto, Ontario. The group's first efforts were directed to self-help through the exchange of practical advice and moral support and to mutual cooperation with health professionals involved in the care of schizophrenics (Belford, 1984; Neufeldt, 1981). Belford (1984) reported that the objectives of Friends of Schizophrenics in Canada are to speak for the rights of schizophrenics; to assist in providing suitable accommodation on leaving hospital; to provide sheltered work when the patient is not well enough to hold a regular job; to provide social recreation when the patient is isolated; to assist in providing training where life skills are disordered; to bring families together in order to share their problems and mitigate loneliness; through education, to foster more insight into the nature of schizophrenia; to provide information of the services and facilities that can help; to collect and disseminate information on developments in the treatment of schizophrenia; to assist in educating the public about the nature and extent of the problem in society; to raise funds to assist in the carrying out of these objectives; and to establish and raise funds for a Schizophrenic

Research Foundation which will assign funds as determined by a medical advisory board.

Pomeroy and Trainor (1991) suggested that The Schizophrenia Society of Canada (still referred to as the Friends of Schizophrenia in some areas) is possibly the most significant player amongst the family organizations in the country. Other Canadian family groups include such groups as The Society of Depression and Manic Depression, The Families Association for Mental Health in Etobicoke, and a number of family organizations in Saskatchewan, including Friends and Relatives of the Mentally Ill (Pomeroy & Trainor, 1991).

Organizations of mental health advocates and family members have joined together to exchange information about mental disorder, to reduce blame and stigma, to share experiences and advice, and to gain mutual support. They also fight for improvements in services, civil rights, and benefits for persons with a CMD (Goldman, 1982). Goldman indicated that relatives' groups are a broad-based, inexpensive approach to coping with some of the major sources of family burden. He suggested that widespread adoption of self-help groups could facilitate the work of mental health professionals, who must conserve scarce resources for crisis intervention. Effective advocacy activities could expand available resources and further strengthen the network of community support.

Mental Health System Resources. Terkelsen (1986b) stated that a new type of network developed for the primary caregivers of family members with a CMD. There were two aspects to this network, encounters with other family caregivers and encounters with the mental health system. Kriesman and Joy (1974), when reviewing the literature, noted the findings regarding family responses to encounters with the mental health system. Kriesman and Joy concluded that the needs of families are often poorly assessed and, consequently, that mental health professionals do not respond effectively to them.

A study by Hatfield (1979) revealed that families reported needing respite and community support programs to relieve some of the burden placed upon them. Her survey results indicated that families need advice concerning appropriate expectations for patients; specific techniques for managing disturbed behaviour; and information about the common forms of treatment of, and practical management techniques for, the major mental disorders. Families wanted assistance with management and coping strategies (Bernheim & Lehman, 1985; Hatfield, 1979, 1981). As Bernheim and Lehman (1985) pointed out, families need help with handling life on a day-by-day basis.

Research in the area of family coping (Vaughn & Leff, 1976, 1981) has shown that some families are more successful in promoting a rehabilitation environment than are others. In families where there was respect for the

patient's desire for social distance, a greater degree of emotional control (i.e., less criticism and hostility expressed toward the member with a CMD), an acceptance and recognition of the legitimacy of the disorder, and a greater tolerance of disturbed behaviour and long-term social impairment, the individuals with a CMD were less at risk of relapse. The most intrusive and conflictual family environments provided the greatest risk of relapse (Vaughn & Leff, 1981). Bernheim and Lehman (1985) suggested that even though these more successful families have intuitively learned some skills on their own, educational methods could be employed to increase the coping skills of numerous others.

Holden and Lewine (1982) surveyed families, all of whom had a family member with a psychiatric history either living with them, in independent housing, or in hospital. Thirty-eight percent found professionals frustrating, another 33% described professionals as not helpful, and only 26% were very or generally satisfied with professional services. Problems identified were lack of involvement in the treatment planning for their family member with a CMD; lack of information about diagnosis, treatment, and medication; lack of support during transition back to the community; and lack of help in connecting with community resources and in dealing with difficult behaviour on the patient's part. However, Holden and Lewine (1982), as well as Stein and Test

(1980), found that in instances when community treatment and support services had been provided, families perceived them as helpful in relieving the burden caused by the relative's mental illness.

Spaniol et al. (1986a) investigated the needs and coping strengths of families with a member who has a CMD. They also examined the perceptions of mental health professionals regarding the service needs of families, and families' level of satisfaction with the mental health services.

The study utilized a survey research design. It is important to note that the family respondents in Spaniol et al.'s (1986) study were not representative of all families who had members with a CMD. Those who responded belonged to the National Alliance of the Mentally Ill (NAMI), a family organization. They were primarily white, female, over 50 years of age, highly educated, employed in professional or managerial occupations, and had family incomes over \$25,000. Spaniol et al. suggested that, due to these limitations, it seems most prudent to consider the respondents as a large and unique group of individuals who were highly motivated to participate in the study.

Mental health professionals were sampled by randomly selecting one community mental health centre from each of the 48 continental states. Of the 48 centres invited to participate, 12 (25%) agreed to participate. There were centres from each region of the country represented.

There also was an even split between rural and urban centers. Each centre was asked to provide names of practitioners who worked with families that had psychiatrically disordered members. Two hundred and forty-five names were submitted. All 245 were sent questionnaires, and 93 subjects (38%) of the professional sample returned usable questionnaires. Although response rates were low, the authors suggested that the study reveals some interesting findings that deserve further investigation.

Spaniol et al. (1986a) assessed family perceptions of mental health professionals. Families' reported overall dissatisfaction (45%) with mental health services. Spaniol et al. stated that families strongly desired more contact with professionals. More specifically, families wanted professionals to assist with treatment coordination and referrals, to provide practical advice and information about the illness, and to provide information regarding medication management. Other studies (Hatfield, 1978, 1979, 1981, 1984, 1986b; NAMI, 1982) supported the finding that families desired many types of information from professionals. Spaniol et al. (1986a) suggested that these needs reflected the primary service concerns of families and that they confirmed the findings of other, more geographically limited, needs assessments. Frequently, families did not feel supported by professional services and were critical of their quality.

Moreover, the availability of these services was limited.

Spaniol et al. (1986a) also found that families especially wanted emotional support from professionals. Families voiced concern about their own stress. The symptoms reported by families included anxiety, worry, frustration, sense of burden, depression, grief, and fear. These researchers found that the sources of stress appeared to be both internal (family attitudes and coping skills) and external (caring for a disabled family member and the frustrations of dealing with what family respondents saw as a frequently unreceptive and, at times, disregarding and disparaging mental health system).

Families who coped well had relatives who were effectively managed on medication that diminished their symptoms, making home care possible. This group also felt supported by professionals and had been adequately prepared to respond to the specific tasks associated with home management of a recovering family member. Families who did not cope were dissatisfied with many professional practices and services. They reported a lack of information about the illness, possessed few resources, and experienced little emotional support. These families also had not developed effective coping strategies necessary for home management of a member with a CMD. They had not developed strategies which increased their options for dealing with specific problems. They were not able to distance themselves from "bizarre" behaviours that

do not harm anyone, rather than trying to control these behaviours, and they did not take the opportunity to call upon proven resources when needed. Feelings of severe burden also were reported by these families (Spaniol et al., 1986a).

When Spaniol et al. (1986a) compared the results from the family need survey with those from the professional survey, it became clear that professionals do not see families the same way that families see themselves. Professionals do not appear to be in tune with the needs of families. Professionals consistently view families as being more satisfied with mental health services than families themselves.

Solomon, Beck, & Gordon (1988) surveyed families regarding their satisfaction with hospital staff. Approximately 80% of the families in this study did not feel that they were given emotional support or practical advice on how to cope, and around two-thirds of the families felt that the hospital did not do well in terms of discussing future plans, keeping them informed of their relatives' progress, or providing information about their relatives' illness. Solomon and Marcenko (1992) investigated family satisfaction with inpatient and outpatient treatment. The results of the study showed that families evaluated community-based intensive case managers and mental health agencies more positively than they had evaluated services provided by the hospital.

Families were most satisfied with information and communication provided by case managers. They also tended to be more satisfied with services to their relative than with services for themselves. Families were most dissatisfied with assistance in areas of skill building (e.g., teaching about medication, and teaching how to motivate their relative. Solomon and Marcenko (1992) commented that the results of their study are relatively consistent with prior research investigating what families want and need.

The participants in most of the above studies were mainly females of above-average education and income, who were members of a family organization. In most cases, the participants also were likely to be the primary caregiver. Therefore, the results cannot be generalized to all families or all family members. However, because the same concerns are raised in several studies, they appear to be broadly-based.

Birchwood & Smith (1990) stated that greater resources must be directed toward supporting families with members who had a CMD. They suggested, however, that this is not likely to be effective unless applied in the context of a rational, comprehensive system of community rehabilitation services with the long-term goal of assisting patients in reaching maximum feasible independence.

Community Based Care Resources for Individuals with
a CMD

It has been suggested that the association among chronic mental disorder and factors such as social class, ethnicity, stress, marginality, and distorted communication patterns, may be mediated by the quantity and quality of supportive social relationships (Hammer, Makiesky-Barrow, & Gutwirth, 1978).

Grusky et al. (1985) suggested that the personal and community adjustment of chronic schizophrenics depends greatly on the micro-level features (e.g., degree of intrusiveness, level of conflict) of their relationships with relatives and friends. Their findings do not support the assumption that social affiliations have uniformly positive effects on either personal and community adjustment or the service utilization of adults with a CMD. However, they indicated that personal networks and social activities are sources of information, material assistance, and social support during times of stress.

Earls and Nelson (1988) stated that social networks act as a buffer against stress. Their investigation of the interaction between housing concerns and social support on client's self-reported affect (i.e., sense of well-being), both positive and negative, indicated that a positive correlation between network size and positive affect was found only for clients with a high level of housing concerns. Similarly, an inverse correlation

between network size and negative affect was found only for clients who reported a high level of housing concerns. Although there was some concern about the representativeness of their sample, Earls and Nelson suggested that comparison of different samples (e.g., higher-functioning individuals in the community, long-term psychiatric clients presently hospitalized) may add further insight into the relationship among housing and social support, psychological well-being, and community integration.

Grusky et al. (1985) reported that social ties also can provide individuals with a CMD with opportunities for appropriate behaviour, nondependent relationships, and reciprocal social exchange. These authors concluded, in a review, that psychosocial treatment approaches can have positive consequences. Stein and Test (1976) indicated that, in addition to other treatments and services, persons with a CMD need assistance in developing and maintaining meaningful social relationships and activities that help them become part of the community.

Many treatment approaches acknowledge the importance of social support and it is often included as a major component of these approaches. The Training in Community Living model (TCL), for example, offers an alternative to hospitalization by teaching independent living and recreational skills (Grusky et al., 1985). The heart of the TCL system is a core team that serves as a fixed point

of responsibility for a defined group of patients (Test, 1979). The community serves as the primary locus of care in order to promote growth and community living. In-hospital treatment is minimized. Treatment focuses primarily on teaching and helping patients to learn and use coping and living skills. The work done with families and significant others is directed primarily toward lessening excessive dependence. When relating to patients, staff members always treat them as responsible individuals. The approach taken by staff members is an assertive one, using a great deal of outreach to prevent dropout as well as communicating a positive, supportive attitude to patients.

Stein and Test (1976) reported that those who take part in the TCL program have lower rates of subsequent hospitalization, greater chances of employment, improved life satisfaction, and decreased family burden compared to controls. Stein and Test (1985) found that, by providing individuals with a CMD with special supports and direct assistance in community-living skills, they could help them not only to survive in the community but also to make gains in psychosocial areas (e.g., work, social activities). When the researchers extended these principles and techniques to patients seeking in-hospital admission, they found that TCL served as a highly effective and economical alternative.

Paquin and Perry (1990) reviewed techniques for

promoting the durability of interventions designed to address the return to the community of clients who have a CMD. They focused on social-skills training in general and, more specifically, on job training, rehabilitation, and community adaptation. These authors emphasized the need for social-network enhancement and self-help groups. Self-help groups provide clients with a forum in which they can discuss and work on problems. Ex-members of skill training groups often can maintain their gains in this way and, in addition, benefit from contacts with new social networks.

Tutty (1990) suggested that self-help groups also may be considered as an adjunct to professional treatment. A promising approach was presented by Pratt and Gill (1990). This approach involves psychoeducation and direct member involvement in program evaluation and teaching others about mental illness. Pratt and Gill speculated that programs which encourage member involvement and self-help assist individuals to become more self-reliant.

Over the past 20 years, there has been an emerging grass-roots self-help movement of present and former mental patients. This has resulted in the development of numerous self-help groups to provide support and services (National Mental Health Consumer Self-Help Clearing House, 1989). Such groups are growing rapidly, at the local, statewide, and national levels. Also, many groups are developing innovative drop-in centres, housing programs,

anti-stigma campaigns, and other activities. In 1985, The National Mental Health Consumer Self-Help Clearing House was established to promote and assist the development of consumer-run self-help groups across the nation.

In Canada, a group of "ex-psychiatric patients" founded the Ontario Mental Patients' Association, which was renamed in 1981, and is now known as On Our Own (Neufeldt, 1981). The group's underlying message is basic rights for everyone. On Our Own advocates for its members' right to make their own choices about issues (e.g., treatment, guardianship) and for its members' legal rights as human beings. On Our Own offers friendship, understanding, and support.

Leete (1988) stated that she sees comprehensive psychosocial rehabilitation as one means by which the lives of individuals with a CMD can be improved. Rehabilitation can provide assistance with social, psychological, educational, financial, residential, and vocational problems. She used the term psychosocial rehabilitation to refer to a comprehensive array of ongoing services offered to persons with a CMD to develop, or enhance, independent living skills to the maximum extent possible. Leete indicated that such services need to incorporate continuity of care, provide interpersonal support, and encourage individual growth in all aspects of life.

Leete (1988) stated that individuals with a CMD

could successfully adapt and normalize their lives only by actually living in the community. She stated that individuals with a CMD can and need to be active agents in managing their own illnesses, as well as partners in the design and implementation of their own treatment.

Leete (1988) summarized what helped her own recovery process. She progressed through a community-based psychosocial treatment program. Professionals who recognized and respected her individual needs and wishes were vital to her recovery. It was important for her to be treated with dignity as an individual with strengths and weaknesses, instead of as a mental patient who could never improve. Acceptance and reassurance were more helpful than confrontation. The acquisition of social skills enabled her to successfully reintegrate with her community and vocational skills led her to employment. Leete stated that the continuing support and encouragement she received gave her the strength and faith in herself to fight against her disabilities, minimize her vulnerabilities, and work effectively with her individual assets. She believes that it is possible for those who have a CMD to overcome handicaps, live independently, learn skills, and contribute to society.

Many families have indicated a desire to be included in the treatment planning for their member with a CMD (Holden & Lewine, 1982). There is a growing consensus that psycho-education programs which involve the families

of persons with a CMD as resources and as collaborators is the strategy of choice (Falloon, 1988; Falloon & Pederson, 1985; Falloon, Pederson, & Al-Khayyal, 1986; Hatfield, 1988; Reiss, 1988; Rosenson, 1987; Tunnell, Alpert, Jacobs, & Osiason, 1988; Zipple & Spaniol, 1986).

Gruenbaum and Freedman (1988) reported that educational programs aimed at helping families deal with a member who has a CMD can reduce patient relapse rates and improve family coping. Considering that the family often provides the most, if not the only, social support to its member with a CMD, it would seem especially important to involve family members in treatment and rehabilitation programs.

Zipple, Langle, Spaniol, and Fisher (1990) suggested that without ongoing contact with loved ones, individuals with a CMD might easily become homeless. Therefore, in a service system that relies on providers who have short job expectancies, it is even more important to assist the client to preserve his/her natural caregivers and advocates. These researchers state that this must entail informing and involving the families in the service planning and delivery process.

Birchwood and Smith (1990) suggested that an effective service delivery system should engage family members proactively, through a multiplicity of contact points. It should also ensure that family needs are adequately assessed and responded to sympathetically within a framework of willing alliance among patients,

family members, and mental health professionals. Moreover, it should be integrated with existing treatment systems, be linked closely with community agencies, and provide ongoing training and supervision of rehabilitation staff.

Researchers also have evaluated community-based programs through investigations of service utilization. Hatfield (1989) conducted a study to determine utilization of rehabilitation services and their adequacy through a questionnaire survey of families. Families reported that less than one-fifth of their relatives afflicted with a CMD were in community rehabilitation programs. Their family members with a CMD had dropped out of programs that were perceived as having uninteresting programs, poorly trained staff members, and wide variations in levels of member functioning. The families indicated that nearly one-half of the consumers who had never entered a program were negative toward all mental health programs.

Hatfield (1989) also stated that people with a CMD who are seriously impaired, suffering frequent symptom exacerbation, or who have severe substance abuse problems or behavioural disorders are usually most in need of well-constructed programs to meet their special needs. However, they are the ones most likely to be excluded from residential and rehabilitative programs. Further, individuals with a CMD who exhibit high levels of

functioning also tend to be excluded, thus leaving them without assistance which could possibly help them achieve independence from the mental health system.

Mueller and Hopp (1987) described a model of case management, focusing on various types of barriers encountered in the implementation of case-management services and the major factors that led to rehospitalization. The site of the demonstration study described by Mueller and Hopp is a state psychiatric facility located in upstate New York. The facility provides inpatient care and provides services for outpatients, including a day hospital and family care and transitional living arrangements. The demonstration project was located in the education and training unit of the facility so that case-management services staff would not be aligned with either the inpatient or the outpatient services.

Within this model, the principle functions of a case manager are to provide information; to make and follow up on referrals; to provide means of access where there are social, psychological, economic, or bureaucratic obstacles to obtaining needed services; to serve as an advocate if services to which a patient is entitled are withheld or denied; and to offer short-term counseling as appropriate. Mueller and Hopp argued that case managers should provide entry into a system of service and monitor their clients to ensure that the level of support is appropriate as the

patients' social competencies wax or wane. The goal is to provide the lowest level of intervention and the least restrictive environment compatible with the patient's changing needs.

Mueller and Hopp (1987) found that the attitudes of discharged patients, at times when they did not want to be involved with the mental health system, posed considerable obstacles to case management. For many patients, being in the community meant they were well and they wanted no reminders of not being well. Understandably, patients typically view mental health professionals as representatives of the institutional system. Staff had to overcome patient resistance in order to maintain contact during periods when patients were not in crisis or experiencing loneliness.

Roberts & Kurtz (1987) stated that mental health has been a major concern in the 1980s, as cutbacks in funding, coupled with the necessity of providing expensive support services to a population of people with a CMD, have presented policy makers with conflicting demands. Recent appraisal indicates that due to differing client responses to treatment, both community and institutional care are needed (Guedeman & Shore, 1984). Due to the scarcity of resources, institutional and community care compete for the same funds. Therefore, Roberts and Kurtz (1987) stated that use of families as resource personnel and collaborators in treatment programming, along with the use

of self-help support groups and organizations, helps to keep the community-based care movement alive.

Spaniol et al. (1986a) reported that because of the importance of the family and the home environment in the rehabilitation of the individual with a CMD, mental health administrators, mental health practitioners, and legislators need to listen to what families have to say and to take their concerns seriously.

Family Advocacy for Resources for Community-Based Care

The development of advocacy models and practices is a recent phenomenon in the history of human services. It has been only in the last two decades that advocacy has been conceptualized as a key element in the area of mental health (Evaluation Committee for the Psychiatric Patient Advocate Office, 1987). This committee stated that there appears to be little consensus to date on either the definition or the purpose of advocacy. Advocacy traditionally meant "to plead the case of another," but it also has come to mean "speaking for oneself."

The four different types of advocacy documented in the literature are self-advocacy, individual or case advocacy, agency advocacy, and collective advocacy (Evaluation Committee for the Psychiatric Patient Advocate Office, 1987). Self-advocacy is when a person speaks on his or her own behalf, and individual or case advocacy is when one person represents or speaks on behalf of another person (e.g., a patient's advocate or ombudsman).

Wolfensberger (1973) defined agency advocacy as agency administration of a protective service provision. Finally, collective advocacy is when a group of individuals undertake among themselves to represent the interests of an entire category of persons (e.g., individuals with a CMD) (Wolfensberger, 1973).

The Evaluation Committee for the Psychiatric Patient Advocate Office (1987) stated that self-advocacy and individual or case advocacy often is useful for solving individual dilemmas. However, they rarely produce systemic change because these types of advocacy focus only on the needs of individuals. Agency advocacy, more than other types of advocacy, is hampered by conflict of interest because when a professional person provides protective services as part of his or her agency-defined duties, it is almost inevitable that he or she will experience conflicts of interest. Wolfsenberger (1973) stated that due to the way in which the system works, the interests of the client must be expected occasionally to be at variance with the interests of the agency. When this occurs, the professional is placed in the middle, and the professional more commonly internalizes the interests of the agency than of the client. Of the four types of advocacy, collective advocacy is most free from conflict of interest and, because of its collective nature, tends to have the most impact on systemic and policy change (Evaluation Committee for the Psychiatric Patient Advocate

Office, 1987).

Roberts and Kurtz (1987) reported that, in the history of mental illness and its treatment over the centuries, people with a CMD have had few advocates except each other. Hatfield (1986b) stated that no patient or family can by itself gather the resources necessary even for minimal care and, unfortunately, appropriate care is not one of society's priorities. She indicated that collective advocacy was going on in many localities and states in the USA, as well as on the national level, in hopes of achieving supervised housing, increased access to constructive day programs, case management, and crisis care for persons with a CMD. Hatfield (1986b) reported that there are now advocacy organizations, composed of patients and their families, that pressure for continued reform, public education, and research. The National Alliance for the Mentally Ill (NAMI) is one such group. The Schizophrenia Society of Canada (Friends of Schizophrenics) is one such group in Canada (Belford, 1984; Pomeroy & Trainor, 1991).

Bernheim (1986) suggested that as members of governmental advisory boards at state and local levels, NAMI affiliates have begun to influence the allocation of funds, so as to ensure that the needs of individuals with a CMD are addressed. She also reported that, at the national level, NAMI has a full-time lobbyist and that many statewide affiliates daily grow more adept at using

lobbying and other political strategies to achieve their goals.

Bernheim (1986) argued that pressure also has been applied by ex-patients' groups that have their own issues and agendas. Neufeldt (1981) investigated parent groups and ex-patient groups in Canada. Neufeldt suggested that both groups want to know about what happens in psychiatric treatment, want to have a chance to make decisions, and want to take responsibility for what occurs. The immediate objectives of self-help groups of ex-patients or present patients differ from parent-to-parent groups. Self-help groups of ex-patients or present patients with mental disorders are determined to make their way "on their own". Parent groups have as their immediate concern supporting each other in their struggles to understand and support a member of the family who has a psychiatric disorder. Bernheim (1986) stated that the goals of the patients' rights movement are sometimes consistent with, and sometimes opposed to, those of the family consumer movement. Bernheim also argued that although both groups advocate for a wider range of services and oppose discrimination against persons with a CMD, they diverge sharply on issues of enforced treatment, legal responsibility of persons with mental illness, and whether or not disordered behaviour should be considered an illness at all. For example, some militant ex-patient groups adhere to the "mental illness is myth" model

espoused by Szasz (1976).

Bernheim (1986) suggested that although the tension between family and ex-patient groups will never be completely resolved, increased communication, greater dissemination of knowledge, and efforts to reduce stigma, can help to make the conflict creative and constructive. Meanwhile, professionals must struggle with the dilemma of how to meet the needs of families for information and assistance while protecting patients' rights to privacy and autonomy (Bernheim, 1986; Zipple et al., 1990).

Some researchers have suggested the need for consumers, families, friends, and professionals to join forces and to work in a collaborative fashion (Cromwell, Howe, & O'Rear, 1988; Rosenson, 1987). Cromwell et al. (1988) suggested that, without citizen strength and unity, administrators and politicians who may want to maintain the status quo will be able to play one interest group against another and avoid progressive change, as they have too often done. These authors stated that citizens who are organized, unified, and politically sophisticated, have the power to overcome these obstacles.

Tefft (1987) suggested that advocacy by coalition should be heavily oriented toward forging alliances with dominant elements of society or pre-existing institutions and interest groups, such as the opposition political parties, government Ministers, and community opinion makers (e.g., individual legislators, private funders, and

media representatives). Alliances with powerful elites serve two important functions: to magnify the impact of social movement organization action and, to shelter it from repression by the target group. Tefft stated that the task of forging alliances is equally as important as articulating a coherent program of mental health reform.

Davis (1989) suggested that consumers, providers, family members, and other concerned citizens are not going to agree on every issue. Therefore, the different groups must focus on areas of agreement while tolerating disagreements. He indicated that it is necessary to support and accept help from each other, while helping our own group. Davis suggested that branching out, sharing information, and expanding the community of people involved will help to find answers. In addition, combining forces will help move the system toward positive change.

Purpose of Proposed Study

In summary, deinstitutionalization and community-based care have brought forth several issues of concern for families with a member who has a CMD. As family members are greatly affected by the policies and practices of deinstitutionalization, it is important to understand their beliefs regarding, and attitudes toward, various aspects of this social policy.

It has been suggested that collective advocacy may be effective in bringing about systemic and policy change

(The Evaluation Committee for the Psychiatric Patient Advocate Office, 1987). Intuitively, whether or not families embrace the advocacy role depends to a large extent on their beliefs regarding, and attitudes toward the following: (a) community-based care, including home care, for individuals with a CMD; (b) the importance and adequacy of resources necessary for community-based residential facilities and programs for individuals with a CMD; (c) the importance and adequacy of resources for families; and (d) families' role in advocacy. Also, as suggested earlier, a number of factors, such as the characteristics of individuals with a CMD and perceived support, may help determine people's beliefs and attitudes. The proposed study investigated these relationships.

Finally, the proposed study investigated family members' behavioural intentions to advocate for resources for community-based care, including home care, for individuals with a CMD. In Canada, there are social and mental health services provided to handicapped and disadvantaged persons which are extant in the U.S.A. However, despite the presence of these services, the effects of deinstitutionalization have brought forth concern regarding the quality of these services (Tanguay, 1987). This concern has given rise to the formation of family advocacy groups in Canada. However, family advocacy in Canada is still in its developmental stage.

Neufeldt (1981) explained that, only recently, there has been an increasing recognition by professionals that the family continues to be the best single ongoing resource for individuals with a CMD. This altered viewpoint, along with the accumulated evidence that most people with schizophrenia (and other chronic mental disorders) return to live with their families after discharge, has led to a re-evaluation of old research evidence on theories of family causation and contribution to patient pathology. Neufeldt postulated that the development of patient and family self-help groups in Canada is a product of the zeitgeist, the spirit of our times; rights and reciprocal responsibilities of clients, parents, and professionals are being taken with greater seriousness than previously. At the same time, Neufeldt suggested that a gradually accumulating body of evidence demonstrates that there is a change that results not only from a change in "belief", but also one which empirically demonstrates benefits to all parties concerned.

Over the last decade, many family members and family groups have been sorting through their beliefs regarding and attitudes toward community-based care for their member with a CMD. As well, they have been determining for themselves when, where, and how they want to be involved with their member who has a CMD, with the mental health system, and with other family caregivers. Therefore, at this point, it seems most relevant to examine families'

behavioural intentions regarding advocacy behaviour, rather than the actual behaviour itself. Previous research has substantiated that behavioural intentions serve as an accurate predictor of behaviour (Sejwacz, Ajzen, & Fishbein, 1980; Sperber, Fishbein & Ajzen, 1980).

Theoretical Model

The model to be utilized in this study is the Theory of Reasoned Action (Fishbein & Ajzen, 1975; Ajzen & Fishbein, 1980), a theoretical model based upon attitude-behaviour consistency. This model attempts to account for the multiple factors that determine social behaviour.

A basic assumption of the Theory of Reasoned Action is that individuals engage in a systematic reasoning process prior to acting. This process involves cognitive and/or emotional appraisal of certain behavioural options, which results in an intention to perform a particular behaviour, followed by the act itself. It postulates that, as a general rule, people intend to behave in favorable ways with respect to things and people they like, and to display unfavorable behaviours toward things and people they dislike (Ajzen, 1988). People translate their intentions into action, unless other factors intervene.

Ajzen (1988) stated that the Theory of Reasoned Action posits a linear causal sequence of events. Figure 1 is a general diagram of the Theory of Reasoned Action as

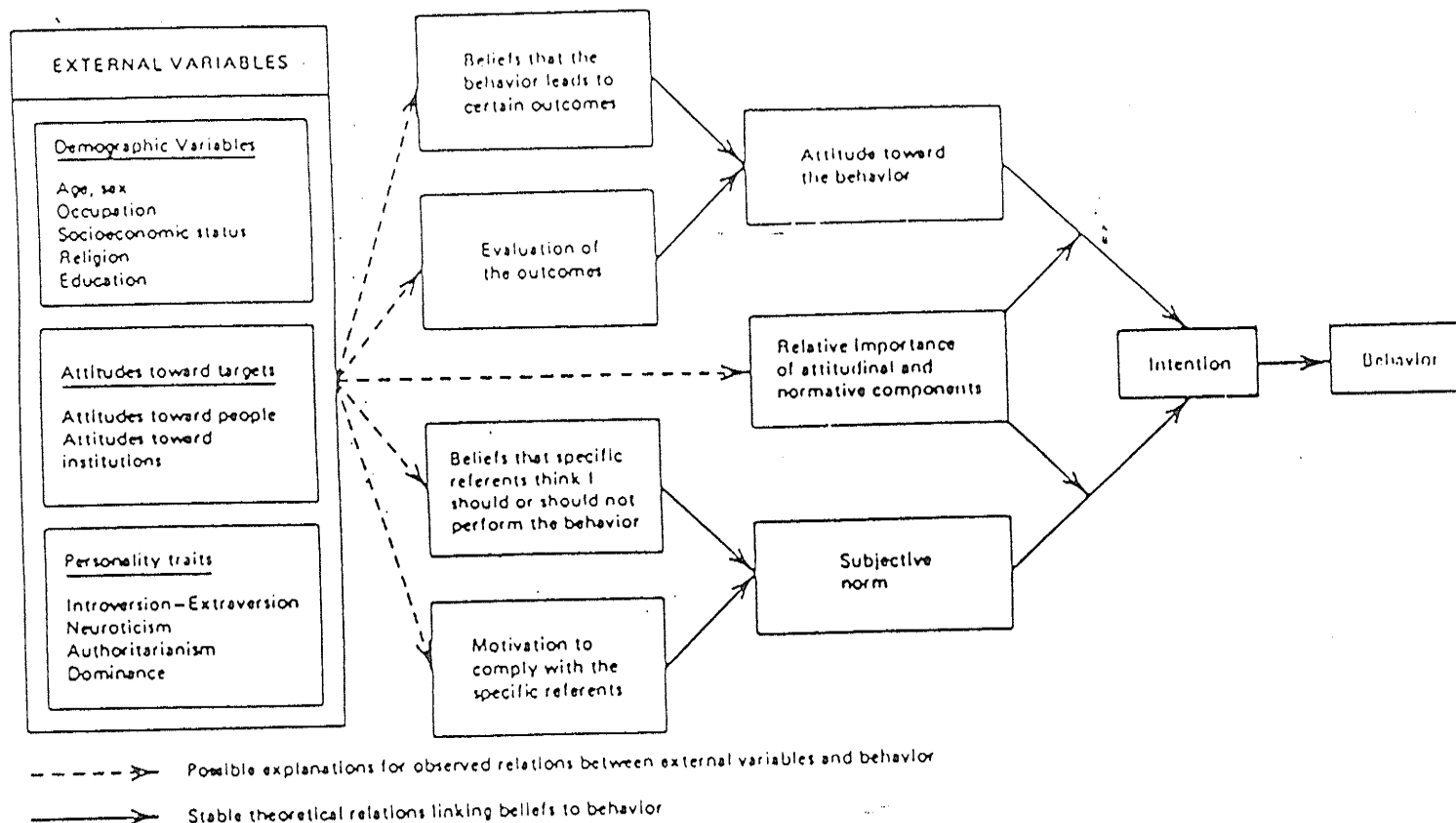


Figure 1. A model of behaviour prediction

Note. From Understanding Attitudes and Predicting Social Behaviour (p. 84)
by I. Ajzen and M. Fishbein, 1980, Englewood Cliffs, NJ: Prentice-Hall.

postulated by Ajzen and Fishbein (1980). The figure depicts five sets of variables. The linear sequence begins on the extreme left hand side of the diagram and proceeds towards the extreme right hand side. The sequence is as follows: (a) external variables; (b) behavioural and normative beliefs; (c) attitude and subjective norm; (d) behavioural intention; and (e) behaviour.

External variables are general characteristics distinct and separate from the behaviour in question. However, external variables usually affect the formation of beliefs. Figure 1 presents examples of external variables which could be predictive of beliefs. They include demographic variables such as age, sex, and socioeconomic status; traditional measures of attitudes towards targets (people, institutions); and personality traits such as neuroticism and authoritarianism.

The beliefs portion of the Theory of Reasoned Action includes both beliefs about behaviours and normative beliefs. Beliefs about behaviours are generally formed by associating the belief with various characteristics, qualities, and attributes. However, a person can only attend to a relatively small number of beliefs at any given time. According to the Theory of Reasoned Action, these salient beliefs are the immediate determinants of the person's attitude. In order to understand why a person holds a certain attitude toward a behavioural

intention, it is necessary to assess his or her salient beliefs about the consequences of performing that behaviour. The Theory of Reasoned Action predicts that the more positive the beliefs about the consequences of performing a behaviour, the more favorable will be the attitude towards performing it.

The second set of beliefs is related to the individual's estimation of the normative expectations of significant others (i.e., referents) in his or her environment. In other words, an individual considers whether specific individuals and groups think he or she should or should not engage in the behaviour and then uses this information in deciding whether to comply with these social demands. The individual's belief that referents think he or she should or should not perform the behaviour is a normative belief. Not every possible referent will be relevant or important; only salient referents will influence the person's normative beliefs.

Attitude toward a behaviour and subjective norm are both considered to be a function of the sum of the salient beliefs. The attitudinal component refers to the person's attitude toward performing the behaviour under consideration. According to the Theory of Reasoned Action, an attitude toward any behaviour is simply a person's general feeling of favourableness or unfavourableness toward that behaviour. Generally, the more favorable a person's attitude toward a behaviour, the

more he or she would intend to perform that behaviour.

Subjective norm refers to a specific behavioural prescription attributed to a generalized social agent. The subjective norm refers to the person's perception that important others desire the performance or nonperformance of a specific behaviour. This perception may or may not reflect what the important others actually think he or she should do. According to the Theory of Reasoned Action, the more a person perceives that others who are important to him or her think he or she should perform a behaviour, the more he or she will intend to do so. In addition to measuring the person's attitude toward the behaviour, it also is necessary to assess his or her subjective norm in order to predict and understand intention.

Ajzen and Fishbein (1980) suggested that, in most instances, it is likely that people hold favourable attitudes toward behaviours their important others think they should perform and negative attitudes toward behaviours their important others think they should not perform. When this is the case, the attitude and the subjective norm are in agreement and prediction of intention is relatively straightforward. However, there are times when the two components may not be in agreement. A person may hold a favourable attitude toward performing a behaviour and yet believe that his or her important others think he or she should not perform it. In this instance, the person's intention will depend on the

relative importance of the two components.

Behavioural intentions are assumed to be the immediate antecedents of behaviour. Behavioural intentions refer to the person's assessment of the likelihood of his or her performing the future behaviour under consideration. When an appropriate measure of intention is obtained, it most accurately predicts behaviour. However, behavioural intentions only predict behaviour if the person has control over the behaviour and the intention remains stable prior to its performance. Behaviour is found at the extreme right-hand side (i.e., at the end) of the model. Behaviour refers to overt behaviour and can involve a single act performed by an individual (e.g., buying a package of cigarettes), or behavioural categories involving sets of actions rather than a single action (e.g., dieting, health maintenance).

According to Ajzen & Fishbein (1980), there needs to be correspondence in measurement between the different links in the causal chain. More specifically, each component of the model must be defined at the same level of specificity. When measures of beliefs, attitudes, intentions, and behaviours correspond in their levels of specificity, they correlate more highly. For example, a general attitude will predict a multiple-act criterion better than a single-act criterion, and a specific attitude will predict a single-act criterion better than a multiple-act criterion. Ajzen and Fishbein (1977)

reported that studies which had high correspondence between elements, in terms of specificity, showed strong relationships between attitude and behaviour. In contrast, studies which had low correspondence between elements, in terms of specificity, showed little or no relationship between attitude and behaviour.

Chaiken and Stangor (1987), and Cooper and Croyle (1984), indicated that a great deal of thoughtful and productive research had been conducted on the relation between attitudes and behaviour utilizing the Theory of Reasoned Action. Liska (1984) stated that it has been by far the most prominent and influential of the attitude-behaviour consistency models.

Tefft, Segall, and Trute (1988) adopted the Theory of Reasoned Action as the theoretical framework for their investigation of public beliefs, attitudes, and behavioral intentions concerning persons with a CMD and community mental health facilities. These researchers reported that every major linkage hypothesized by the theory was substantially confirmed.

Tesser and Shaffer (1990) recently reviewed the literature on attitudes and attitude change. They outlined the more recent research utilizing the Theory of Reasoned Action, discussing the various refinements implemented and the relative success of these alterations. They reported that this model has been extremely fruitful and continues to attract attention. Tesser and Shaffer

concluded that it is likely that the theory will undergo further refinements and will remain an influential approach in the future. Two recent studies support these statements (Meissen, Mason, & Gleason, 1991; Pancer, George, & Gebotys, 1992).

Ajzen and Fishbein's model could be adapted to predict family members' behavioural intentions to advocate for resources for community-based care, including home care, for individuals with a CMD and their families. The model utilized in this study, investigated beliefs regarding and attitudes toward a behaviour (advocacy behaviour). It also investigated other types of beliefs and attitudes (i.e., beliefs regarding and attitudes toward particular types of care and resources for these types of care) that do not represent beliefs regarding and attitudes toward a behaviour. Figure 2 and 3 are diagrams of the model, based upon Ajzen and Fishbein (1980), utilized in the study.

In each component of the model, the particular sets of variables that were examined were based upon the existing information in the empirical research and the research questions posed in the present study.

External Variables

The model begins at the extreme left-hand side with the external variables. There were two sets of external variables, perceived supports and characteristics of individuals with a CMD. Sociodemographic material was

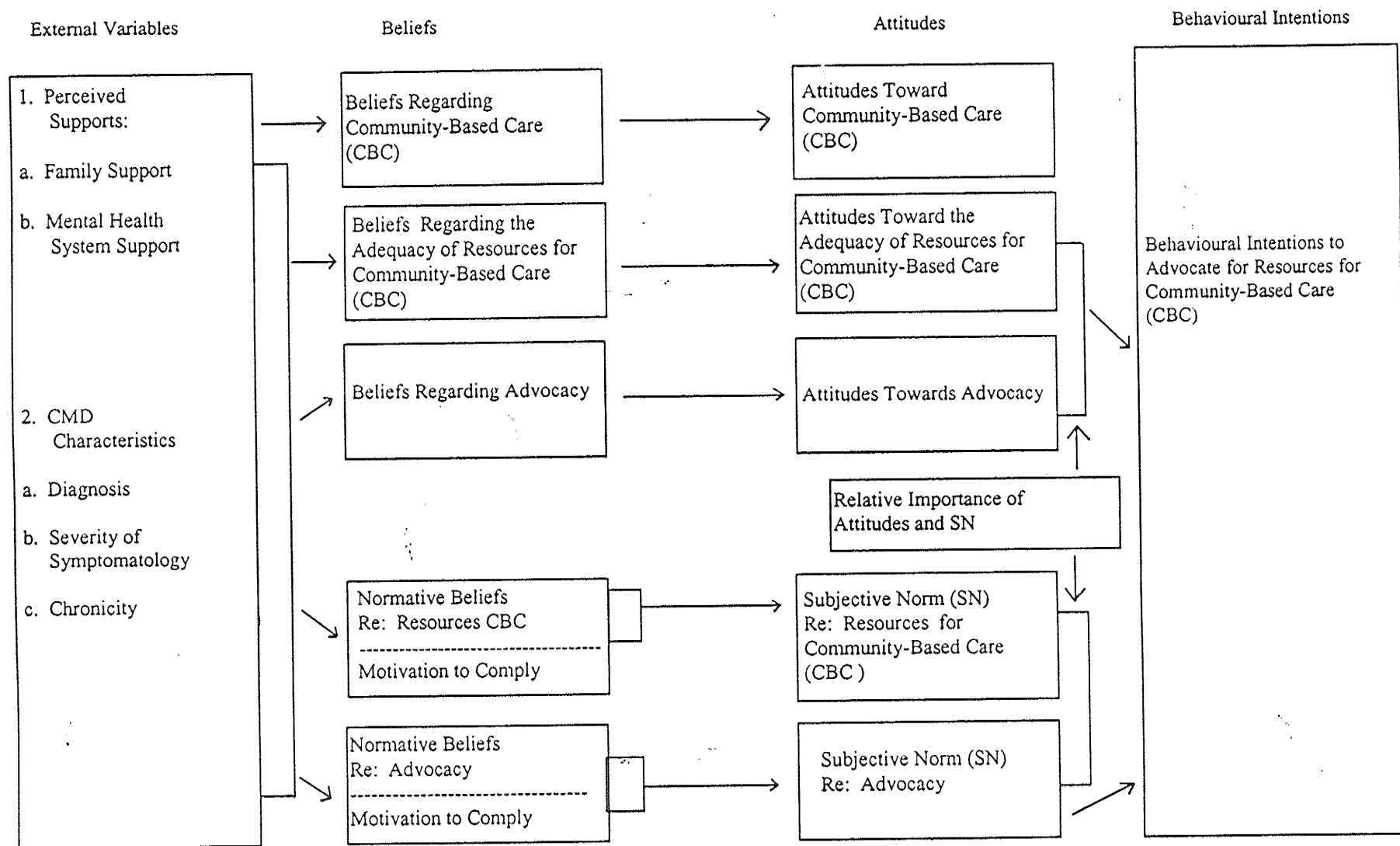


Figure 2. A model predicting family member's behavioural intentions to advocate for resources for community-based care for individuals with a CMD

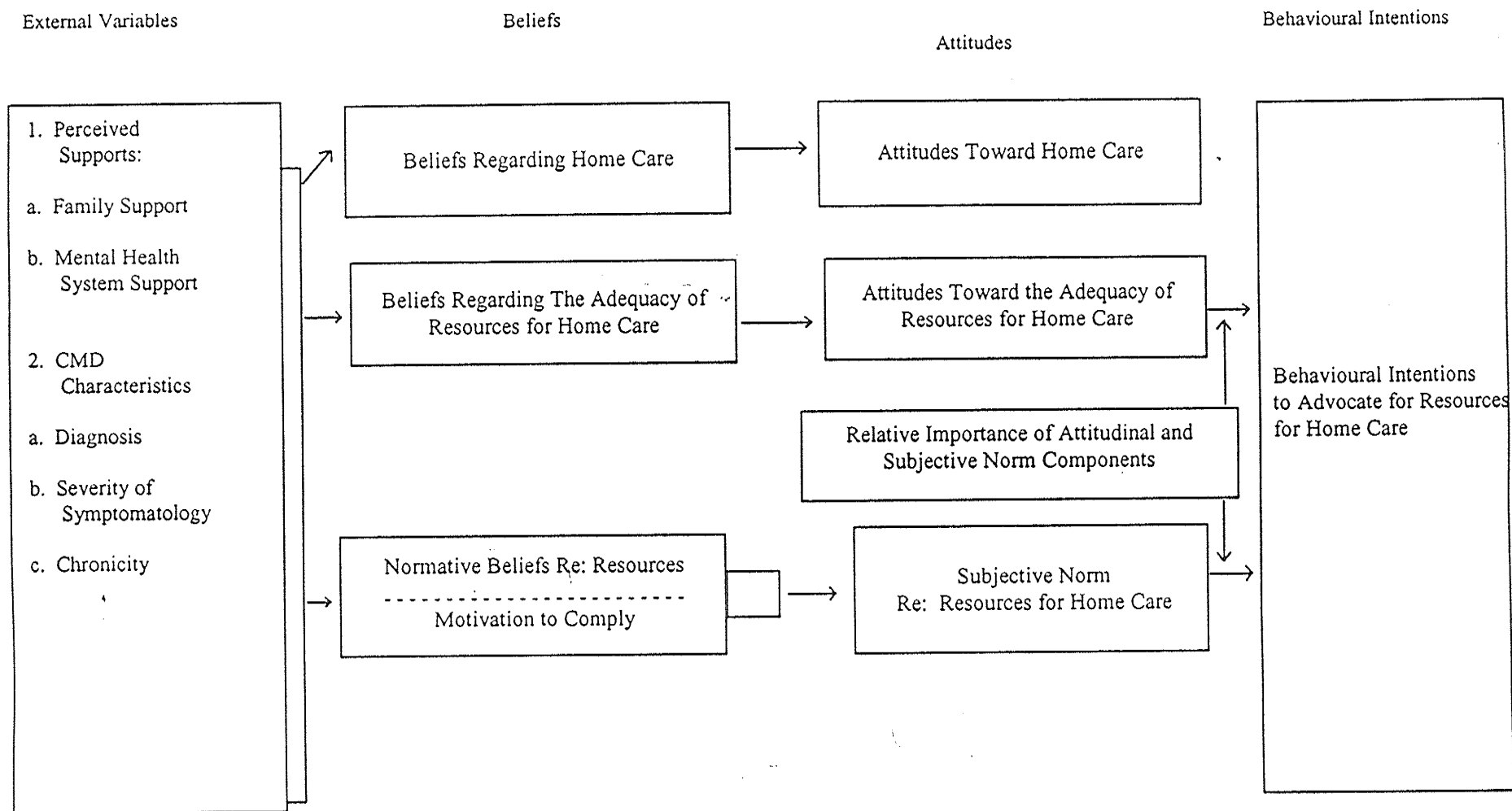


Figure 3. A model predicting family members behavioural intentions to advocate for resources for home care for individuals with a CMD and themselves.

obtained for both the family respondents and for the sample of individuals with a CMD. These sociodemographic variables were correlated with the belief measures. If any significant relationships existed, the variables in question were used as control variables.

Perceived supports included the following: (a) family support from spouse, children, siblings, parents, and extended family; (b) extra-familial support from friends, colleagues or co-workers, and church; and (c) mental health system support from programs/services for individuals with a CMD, ongoing consultation/interaction, education and information, respite care, emergency service, and financial aid. In this study, family support and extra-familial support together constituted social support. As a result of a factor analysis, extra-familial support was dropped as a support variable.

Characteristics of individuals with a CMD included diagnosis, perceived severity of psychiatric symptoms, and chronicity (length of time since the disorder was first diagnosed).

More negative mental health characteristics of individuals with a CMD included: (a) more severe psychiatric symptomatology; (b) longer chronicity and (c) a psychiatric diagnosis of schizophrenia.

Beliefs

Several sets of beliefs were investigated. The first set of beliefs involved beliefs regarding community-

based care, including home care, for individuals with a CMD. Included in this set of beliefs were: (a) beliefs regarding the importance of providing living arrangements and treatment in the least restrictive environment possible; (b) beliefs regarding the importance of living arrangements that encourage both high internal and external integration; (c) beliefs regarding the importance of improving and maintaining the quality of life of individuals with a CMD in selected domains (e.g., living arrangements); and (d) beliefs regarding the burden experienced by families as a result of having a family member with a CMD living at home. Familial burden encompassed subjective burden (emotional burden) and objective burden (social and financial burden).

Positive beliefs regarding community-based care, including home care included: (a) beliefs that living arrangements and treatment should be provided in the least restrictive environment possible; (b) beliefs that living arrangements for individuals with a CMD should encourage normal functioning; (c) beliefs that community-based care improves the quality of life of individuals with a CMD; (d) beliefs that the familial home provides the most appropriate and natural environment; (e) beliefs that the familial home encourages normal functioning; (f) beliefs that living in the familial home improves the quality of life of the individual with a CMD and; (g) beliefs that home care is not a burden on the family.

The second set of beliefs involved beliefs regarding: (a) the importance and adequacy of resources for community-based care for individuals with a CMD; and (b) the importance and adequacy of resources for home care for individuals with a CMD.

Resources for community-based care were divided into five areas: housing programs, social support programs, education programs, employment programs, and financial aid.

Resources for home care were divided into social support (self-help groups, other support groups) and mental health system supports (education and information, ongoing consultation/interaction, respite care, emergency service, and financial aid).

More positive beliefs regarding the adequacy of resources for community-based care, including home care, included: (a) beliefs that the adequacy of the services provided to individuals with a CMD meet the needs of these individuals; and (b) beliefs that the adequacy of resources provided to families meet the needs of the families.

The third set of beliefs involved beliefs regarding advocacy. For the purpose of this study, advocacy was defined as taking certain actions, such as signing a petition or attending a meeting. Beliefs regarding advocacy on behalf of individuals with a CMD included the following: (a) beliefs regarding family responsibility to advocate for resources necessary for community-based care,

including home care; (b) beliefs regarding family ability to advocate; and (c) beliefs regarding family influence to change governmental mental health spending policies.

Positive beliefs about advocacy included: (a) the belief that it is the family's responsibility to advocate for resources for community-based care, including home care; (b) a belief in one's ability to advocate; and (c) a belief that family advocacy would be influential in bringing about governmental changes in mental health spending.

Normative beliefs were investigated in relation to family members' beliefs regarding resources/supports for community-based care, including home care, for individuals with a CMD and family members' beliefs regarding advocacy. Ajzen and Fishbein's model postulates a positive correlation between a normative belief and a subjective norm. The researcher chose to investigate two of these relationships, one because it related to beliefs regarding and attitudes toward a behaviour and the other because it seemed relevant to the other sets of beliefs and attitudes. If family members did not have positive beliefs regarding and positive attitudes toward resources for community-based care, including home care, they probably would not have behavioural intentions to advocate for these resources. Based upon the rationale provided, for practical purposes (e.g., length of questionnaire), the researcher investigated only the two sets of normative

beliefs referred to above.

Ajzen & Fishbein (1980) stated that normative beliefs involve specific individuals or groups, rather than a generalized important other. When asking about "beliefs regarding referents", the relevant referent inquired about was a significant person within one of the groups referred to under the area of perceived support. Therefore, the specific referent was the most important individual within the respondent's social network (i.e., family, friends, coworkers, colleagues, church) or the most important individual within the respondent's mental health network (i.e., the mental health professionals working with the family member with a CMD). Each respondent determined for him/herself who the most significant individual was from the two groups of people, and he or she was asked to answer the questions regarding referents with that individual in mind.

Respondents' motivation to comply with their referents' wishes also was examined. The respondents' perceptions of their referents' beliefs regarding the relevant issues were assessed. This was followed by an assessment of the respondents' wishes to comply with the specific referents.

As stated, this study investigated normative beliefs in regard to two sets of attitudes. The relative weights that the belief components and the normative beliefs

components contributed to the proposed relationship between beliefs and attitudes also were explored.

Attitudes

Several sets of attitudes were investigated. The first set of attitudes involved attitudes toward community-based care, including home care, for individuals with a CMD. Included in this set of attitudes was: (a) attitudes toward the importance of providing living arrangements and treatment in the least restrictive environment possible; (b) attitudes toward the importance of living arrangements that encourage normal functioning; (c) attitudes toward the importance of improving the quality of life of individuals with a CMD ; (d) attitudes toward home care for individuals with a CMD; and (e) attitudes toward the burden experienced by families as a result of having a member with a CMD living at home.

Positive attitudes toward community-based care included: (a) attitudes that living arrangements and treatment should be provided in the least restrictive environment possible; (b) attitudes that living arrangements for individuals with a CMD should encourage normal functioning; (c) attitudes that community-based care improves the quality of life of individuals with a CMD; (d) attitudes that the familial home provides the most appropriate and natural environment; (e) attitudes that the familial home encourages normal functioning; (f) attitudes that living in the familial home improves the

quality of life of the individual with a CMD and (g) attitudes that home care is not a burden on the family.

The second set of attitudes involved attitudes toward: (a) the importance and adequacy of resources for community-based care for individuals with a CMD; and (b) the importance and adequacy of resources for home care for individuals with a CMD.

More positive attitudes toward the adequacy of resources for community-based care, including home care, included: (a) attitudes that better resources for community-based care for individuals with a CMD would be desirable and; (b) attitudes that better resources for home care for individuals with a CMD and their families would be desirable.

The third set of attitudes involved attitudes towards advocacy. Attitudes toward advocacy were assessed by the family member respondents stated desirability to advocate for better community-based care.

Positive attitudes toward advocacy were indicated through a desirability by the family member respondent to advocate for better community-based care.

It has been suggested that the contribution of attitudes is generally greater than that of norms (Cialdini, Petty, & Cacioppo, 1981). Following from the discussion on normative beliefs, this study investigated subjective norms in regard to two sets of attitudes. The relative weights that the attitude components and the

subjective norm components contributed to the proposed relationship between attitudes and behavioural intentions was explored.

The same referents applied in this part of the inquiry. Respondents were asked their perception about whether their referent thought they should perform the behaviour (advocate) or support an increase in resources for a particular type of care (community-based care, including home care).

Behavioural Intentions

For the purpose of the proposed study, behavioural intentions served as the dependent variable. There were two sets of behavioural intentions. The first set involved the behavioural intentions of the family member to advocate for resources for community-based care for individuals with a CMD. The resources referred to were the same as mentioned previously (housing programs, social support programs, education programs, employment programs, financial aid).

The second set of behavioural intentions involved the behavioural intentions of the family member to advocate for mental health system resources for home care for individuals with a CMD. The resources referred to were the same as mentioned previously (information and education, ongoing consultation/interaction with mental health professionals, respite care, emergency service, financial aid).

Greater behavioural intentions were indicated by stated willingness to partake in advocacy activities. For the purposes of this study, advocacy activities included the following actions: signing a petition, attending a meeting, joining an organization/action group (family, consumer, advocacy), forming an organization/action group (family, consumer, advocacy), writing to a newspaper, contacting a politician, and volunteering some time to help improve services.

Hypotheses

Based upon the empirical literature to date and the theoretical model presented earlier, the following hypotheses were proposed. All the hypotheses refer to the family member respondents.

External Variables and Beliefs

1. Perceived social support will be directly related to positive beliefs regarding community-based care (home care).
2. Perceived social support will be directly related to positive beliefs regarding the adequacy of resources for community-based care (home care).
3. Perceived social support will be directly related to positive beliefs regarding advocacy.
4. Perceived mental health system supports will be directly related to positive beliefs regarding community-based care (home care).
5. Perceived mental health system supports will be

directly related to positive beliefs regarding the adequacy of resources for community-based care (home care).

6. Perceived mental health system supports will be directly related to positive beliefs regarding advocacy.
7. Negative mental health characteristics associated with individuals with a CMD will be inversely related to positive beliefs regarding community-based care (home care).
8. Negative mental health characteristics associated with individuals with a CMD will be inversely related to positive beliefs regarding the adequacy of resources for community-based care (home care).
9. Negative mental health characteristics associated with individuals with a CMD will be inversely related to negative beliefs regarding advocacy.

Beliefs-Attitudes

10. Positive beliefs regarding community-based care will be directly related to positive attitudes toward community-based care (home care).
11. Negative beliefs regarding the adequacy of resources for community-based care will be inversely related to negative attitudes toward better resources for community-based care (home care).
12. Positive beliefs regarding advocacy will be directly related to positive attitudes toward advocating for

better community-based care.

Normative Beliefs-Subjective Norm

13. The belief that their referents think they should support better resources for community-based care will be directly related to the perception that their referents favour them supporting better resources for community-based care (home care).
14. The belief that their referents think they should advocate for better resources for community-based care will be directly related to the perception that their referents favour them advocating for better resources for community-based care.

Attitudes-Behavioural Intentions

15. Positive attitudes toward (a) better resources for community-based care and (b) advocating for better community-based care will be directly related to positive behavioural intentions to advocate for better resources for community-based care.
16. Positive attitudes toward better resources for home care will be directly related to positive behavioural intentions to advocate for better developed resources for home care.

Subjective Norm-Behavioural Intentions

17. The perception that their referents favour them supporting better resources for community-based care will be directly related to positive behavioural intentions to advocate for better resources for

community-based care (home care).

18. The perception that their referents favour them advocating for better community-based care will be directly related to positive behavioural intentions to advocate for better resources for community-based care.

Attitudes, Subjective Norm, and Behavioural Intentions

19. The perception that their referents favour them supporting better resources for community-based care, the perception that their referents favour them advocating for better community-based care, and positive attitudes toward (a) better resources for community-based care and (b) advocating for better community-based care, all will be directly related to positive behavioural intentions to advocate for better resources for community-based care.
20. The perception that their referents favour them supporting better resources for home care, and positive attitudes toward better resources for home care, will be directly related to positive behavioural intentions to advocate for better resources for home care.

Method

Respondents

Three groups of people participated in this study. However, only two of the three groups acted as respondents. The respondent groups were community mental

health and other mental health workers (n=31) and family members of individuals with a CMD (n=100). The non-respondent group consisted of individuals with a CMD (n=100). This latter group of individuals was sampled for the purpose of obtaining their permission to gather information regarding their clinical history (e.g., diagnosis, severity of symptomatology, chronicity of the disorder), as well as to gather some sociodemographic information from their community mental health or other mental health workers. Further, individuals with a CMD were asked for their consent to approach a family member about participating in this study as a respondent.

The sample was drawn from the Winnipeg area (96%) and vicinity (4%). Winnipeg is located in the Canadian prairies and is the largest urban centre in the province of Manitoba (Tourism Winnipeg, 1993). Winnipeg has a population of 615,187 (Statistics Canada, 1991). The latest census data indicates that Manitoba is Canada's most ethnically diverse province, as well as home to the largest percentage of aboriginal peoples in the country. Despite its relative geographic isolation from other major centres, Winnipeg is known to have a plethora of cultural activities (Tourism Winnipeg, 1993).

Very few mental health system or other supports exist outside urban centres in Manitoba. Therefore, individuals with a CMD generally live in urban centres. In addition, there are differences in the types and

availability of supports in different urban centres. To control for these differences, the sample of individuals with a CMD was drawn exclusively from the Winnipeg area.

A non-probability (i.e., non-random) sample was utilized. In such a sample, respondents are chosen deliberately for certain characteristics believed to be relevant to the study (Backstrom & Hursh-Cesar, 1981). More specifically, a combination of purposive and volunteer sampling was utilized. In purposive sampling, respondents are chosen deliberately, by knowing the type of people they are or where they are located. On the other hand, volunteer sampling is utilized when it may be necessary to let respondents volunteer themselves to participate.

Purposive sampling was chosen due to the low prevalence rate of the target (CMD) group in the general population (bipolar disorders, 0.4% - 1.2%; depression, 2.3% - 9.3%; schizophrenia, 0.2% - 1.0%) (American Psychological Association, 1987). It would have been prohibitively costly to identify the desired sample of individuals with a CMD (n=100) from a random sample of households within the city. Furthermore, many individuals with a CMD live in large residential facilities or group homes rather than individual households. In addition, purposive sampling was utilized because family members and community mental health and other mental health workers could be interviewed only if the individuals with a CMD

gave the researcher permission to do so.

Volunteer sampling was chosen for three reasons. First, for ethical reasons, the researcher received the names of individuals with a CMD only through their community mental health or other mental health workers. The researcher received the names of those individuals who agreed beforehand to speak with the researcher regarding the study. Second, the community mental health and other mental health workers had to be willing to take the time to contact their clients and to be interviewed by the researcher. Third, volunteer sampling was chosen due to the sensitivity of the subject matter for family members. It often is difficult for families to discuss their situation and their relative who has a CMD. Although theories of family causation have been largely dispelled, families remain very aware of the stigma that still is attached to mental disorders and the prejudice experienced by their relatives with a CMD. Families also have had to defend the role the family has played in the life of the family member with a CMD, as well as the life style of their family member with a CMD. Therefore, many family members are intensely skeptical of any investigation that focuses in part on their involvement with their relative with a CMD and the mental health system.

Backstrom and Hursh-Cesar (1981) commented on the problems connected with using a non-probability, purposive sample. The present samples were biased in that they were

not necessarily representative of the target populations. Therefore, generalizability is limited. The findings of the current study are generalizable only to individuals with a CMD, family members, and community mental health and other mental health workers with the same characteristics as those of the samples utilized in the study.

Sample of individuals with a CMD. In the current study, the definition of the sample of individuals with a CMD was partially derived from A National Plan for the Chronically Mentally Ill (NP/CMI) (Tessler & Goldman, 1982). The Plan was developed by a coalition of federal agencies within the United States Department of Health and Human Services in response to the President's Commission on Mental Health (1978). The NP/CMI included an operational definition of the target population based on diagnosis, disability, and duration:

The chronically mentally ill population encompasses persons who suffer certain mental and emotional disorders (organic brain syndrome, schizophrenia, recurrent depressive and manic-depressive disorders, and paranoid and other psychoses, plus other disorders that may become chronic) that erode or prevent the development of their functional capacities in relation to three or more primary aspects of daily life--personal hygiene and self-care, self-

direction, interpersonal relationships, social transactions, learning, and recreation--and that erode or prevent the development of their economic self sufficiency.

Most of these individuals have required institutional care of extended duration, including intermediate-term hospitalization (90 days to 365 days in a single year), long-term hospitalization (one year or longer in the preceding five years), or nursing home placement because of a diagnosed mental condition or a diagnosis of senility without psychosis. Some of these individuals have required short-term hospitalization (less than 90 days); others have received treatment from a medical or mental health professional solely on an outpatient basis, or-despite their needs-have received no treatment in the professional service system. Thus included in the target populations are persons who are or were formerly residents of institutions (public and private psychiatric hospitals and nursing homes) and persons who are at high risk of institutionalization because of persistent mental disability (Tessler & Goldman, 1982, p. 5).

Dimirsky (1990) reported that, although attempts to define individuals with a CMD have traditionally followed

a medical model and used diagnosis as the primary criterion, this view has been slowly replaced by a multi-axial (i.e., multi-dimensional) definition of the population. Such a definition recognizes many factors as contributing to long-term psychiatric disabilities (e.g., signs and symptoms of illness, skill or coping level, and financial and/or employment disadvantage).

Therefore, the present study specified four inclusion criteria for the sample of individuals with a CMD. Three of these criteria, adapted from Dimirsky (1990), are as follows:

- 1) The individual with a CMD must have been diagnosed within the past two to five years as suffering from schizophrenia or from recurrent depressive or manic-depressive disorders that have become chronic.

- 2) The individual with a CMD must have had serious difficulties in functioning (either due to erosion or prevention of skill development) over a period of at least two years. In addition, the difficulties must have involved at least three of the following areas: personal hygiene or self-care, self-direction, social transactions, interpersonal relations, economic self-sufficiency, learning, and recreation.

- 3) The individual with a CMD must have received institutional and/or supervised community care at least once a month for at least two consecutive years.

Eligible programs include those that are hospital-based, community facilities sanctioned to provide services to mental health patients (such as group or family placement homes), and service programs designed to provide supervision to individuals formally admitted to the program but still living either independently or with family.

The fourth criterion specified that for inclusion in the study, the individuals with a CMD must be at least 18 years of age. This is the age at which individuals are considered to be adults and, therefore, able to provide informed consent.

In order to ensure that the sample of individuals with a CMD met the inclusion requirements, they were recruited through their community mental health workers or other mental health workers. The individuals with a CMD determined which member(s) of their family were to be contacted by the researcher.

One hundred and twelve (112) individuals with a CMD were recruited, in order to obtain the required 100 family member respondents. A sample size of 100 family members was required in order to conduct the appropriate statistical analyses (Tabachnick & Fidell, 1983). The 12 individuals with a CMD whose family members declined to participate were not included in the study.

Sample of community mental health and other mental health workers. The study design called for at least 10 community mental health workers to be recruited in order to control for possible mental health worker bias in client selection. In total, 31 community mental health and other mental health workers were interviewed. Nineteen of the 31 workers were from the Mental Health Division of the Manitoba Department of Health.

As it did not prove feasible to recruit a sufficient number of individuals with a CMD through community mental health workers, other referral sources also were utilized. Staff in four housing programs (n=5), one sheltered workshop (n=5), and one life skills program (n=2) were approached and their aid solicited. Three of the housing programs agreed to cooperate, as did the sheltered workshop and life skills program.

In order to be eligible for the study, each of the community mental health and other mental health workers had to be the primary worker for the individual with a CMD he or she was referring. The community mental health and other mental health workers also had to have access to data on their clients' clinical histories and present treatment programs.

The researcher conducted all interviews with the community mental health and other mental health workers. Spot checks of client files were conducted by the researcher to ensure that accurate data were being

obtained from all community mental health and other mental health workers. The researcher reviewed at least one of each community mental health or other mental health worker's client files. These reliability checks were conducted to ensure that all data provided by the community mental health or other mental health workers were consistent with the information documented in the client files.

Sample of family member respondents. For inclusion in the study, family member respondents had to have been designated by the individual with a CMD and had to have at least minimal involvement with their family member who has a CMD. Minimal involvement was defined as at least one telephone conversation every two weeks, on a regular basis, in which the family member respondent and the relative with a CMD discuss issues pertinent to the life of the person with a CMD (e.g., living arrangements, financial situation, education or employment situation, rehabilitation and support program involvement, treatment concerns, friendships, leisure activities, and health). In order to be able to answer the interview questions, the family member respondents had to be aware of their relative's past and present life situation. In over 90% of the cases, family member respondents spent at least one hour per week with their relative who had a CMD. While there were instances where contact was less frequent, neither the individual with the CMD nor the family member

respondent felt that the contact was so infrequent that the family member respondent would not be able to answer the questions in the interview.

All family member respondents were required to be 18 years of age or older. An upper cut-off age of 70 years was set to help ensure mental competence. Structural, physiological, neurochemical, and psychological deficits of a brain-related nature have been shown to occur in the aging process (Reitan & Wolfson, 1985). As old age generally is considered to begin between 60 and 65 years old, and the aging process is usually gradual, 70 years old was thought to be an appropriate ceiling to help ensure mental competence. However, as many individuals with a CMD were older, so were their family members. Therefore, the researcher evaluated, on a case by case basis, the ability of family member respondents who were over 70 years of age to complete the questionnaire. If a family member respondent was unable to understand the questions because of language or comprehension difficulties, the interview was terminated.

Family members included parents or spouses of individuals with a CMD, as well as other family members. The researcher originally planned to interview only parents and spouses of individuals with a CMD. However, it was not always possible to interview a parent or spouse for a number of reasons. First, the individual with a CMD did not always want to give a parent or spouse as the

contact person. Second, a few parents did not want to, or feel able to, complete the interview. Third, as some of the individuals with a CMD were older themselves, their parents were deceased. Finally, many of the individuals with a CMD were not married and, therefore, did not have spouses. Therefore, equal priority was given to other family members.

Whenever possible, the individual with a CMD was asked to provide the names of two family members whom he or she was willing to have the researcher approach for inclusion in the study. As indicated to the individual with a CMD, the researcher contacted the preferred person first, and only contacted the second person if the former was unreachable or refused to participate in the study. The researcher reviewed the consent form with the individual with a CMD and explained when she would contact the individual's specified family members. Prior to having the individual with a CMD sign the consent form, the researcher wrote the name(s) of the family member(s) in the appropriate space(s) on the consent form.

Recruiting family member respondents through individuals with a CMD helped to control for possible selection bias by the researcher. Selection bias also was controlled by application of the inclusion criterion for family member respondents.

The families of 112 individuals with a CMD were approached to participate in this study. Not all family

members who were approached agreed to be a respondent. One hundred and twenty-two family members were approached to participate in the study. Of these, 19 family members (15.6%) refused to participate in the research. Fifteen individual family members and two couples (both members of each couple) refused to be interviewed. In addition, three family members were not able to complete the questionnaire. Some reasons for not participating included having had a bad experience with being involved in a research study in the past; feeling that this issue was a private one; and feeling unable to participate at the time, because the family member with a CMD was experiencing serious difficulties. Ten of the 15 individual family members who refused to participate in the study were women. The beliefs, attitudes, and behavioural intentions expressed by those who volunteered may be different from non-volunteers and, therefore, may not be representative of all family members.

Procedure

The researcher sent a personalized letter (Appendix A) to the Director of Clinical Programs, Mental Health Division, Manitoba Department of Health, explaining the purpose of the study and the potential usefulness of the results. The letter also included information regarding study procedures and background of the researcher. This was followed by a telephone contact for the purpose of requesting a meeting with the Director to discuss the

study and to ask for his co-operation in connecting the researcher with community mental health workers.

The researcher obtained the co-operation of the Director, who then set up a meeting and introduced the researcher to contact people in the community mental health program, as well as to contact people associated with some of the residential facilities for individuals with a CMD. The researcher scheduled separate meetings with each contact person.

The researcher sent a personalized letter to the community mental health workers in the Winnipeg Region (Appendix B). This letter contained the same information as was provided in the letter to the Director. This was followed by a telephone contact for the purpose of arranging a meeting with each of the community mental health workers to ask for his or her co-operation. Two meetings with the team of community mental health workers working out of the main office also were held to provide additional information regarding the purpose of the study, the procedure utilized in the study, and the proposed use for the results of the study. A similar meeting was held with the team of community mental health workers working out of the satellite community mental health offices.

The researcher asked the community mental health workers to identify clients they believed may meet the inclusion criteria and to provide the information necessary to assess each case. Once the researcher and

the community mental health worker determined the eligibility of each individual with a CMD, the community mental health worker was asked to contact his or her clients to arrange individual meetings among a client, his or her worker, and the researcher. Alternatively, many community mental health workers contacted their clients initially to ask if the researcher could approach them directly. If the person agreed, the name of the client was provided to the researcher, who contacted the person and requested a meeting to discuss the research.

At meetings with clients, the researcher provided all the necessary information regarding the study and her background. The researcher also gave the individual with a CMD an information sheet (Appendix D) on the study. Finally, the researcher asked for permission from the individual with a CMD to include him or her, and appropriate family members, in the study. If permission was granted, the individual with a CMD was requested to sign a release of information and consent form (Appendix F). This allowed the researcher to interview the community mental health worker of the individual with a CMD, and to interview his or her family member. All participants were assured of anonymity and confidentiality. Names were removed from all documentation once the clinical, sociodemographic, and family data were merged.

The researcher also held meetings at four

residential facilities, a sheltered workshop, and a life skills training program. The researcher met with the staff and provided the pertinent information regarding the study. The same recruitment procedure was carried out with the mental health workers at these facilities and programs as with the community mental health workers. The procedure for contacting and meeting with clients was the same as the one used for contacting and meeting with the clients of the community mental health workers.

Once the name(s) of the family member(s) were received, the researcher contacted the preferred family member. As with the community mental health workers, a letter (Appendix C) was sent first, providing all the pertinent information. This letter was followed by a telephone contact for the purpose of arranging an appointment for the interview.

All family members were requested to sign a consent form, indicating their willingness to participate in the study (Appendix G). A structured interview (Appendix K) was conducted with each respondent. Each respondent was interviewed individually. Due to the sensitive nature of this study, in-person interviewing was employed. Interviews were conducted by the researcher (n=58) or by her trained research assistant (n=42). If the researcher was not going to be the interviewer, she arranged with the respondent, during the initial telephone call, to have the assistant call the respondent to set up an appointment.

The research assistant was an undergraduate student majoring in psychology, who had completed a volunteer training course at a community agency, where she worked as a peer counselor. Regarding additional training, the researcher went through the questionnaire with the assistant, thoroughly explaining how each item was to be asked and how each answer was to be recorded. Interviewing techniques and protocol also were explained. The assistant underwent three practice sessions, as well as watched a demonstration interview conducted by the researcher, before going into the field. After each interview was conducted, the assistant returned the questionnaire to the researcher. The researcher conducted an ongoing quality check of each questionnaire to ensure accuracy and consistency across interviews, and to monitor any difficulties the interviewer was experiencing.

Interviews were conducted in private in the family member respondent's residence. Every attempt was made to arrange an appointment time that was convenient for the respondent. Other individuals present, if any, were most often asked to leave the room. However, in 14% of the cases, respondents were parents or sisters of the individual with a CMD and requested that their spouse/partner be allowed to remain in the room. In these cases, the parents consulted each other regarding issues pertaining to their family member with a CMD. In another 5% of the cases, the respondent was the spouse of the

individual with a CMD, and felt that the individual should be present to hear the questions and answers. These couples had very open relationships and did not want to violate this value. In another 2% of the cases, the individual with a CMD lived with the family member respondent, and these two people also felt that the former had the right to hear their responses to the questions. Finally, in one case, the family member respondent was a brother of the individual with a CMD. While he agreed to be the family member respondent, he felt that his father and sister had the right to hear his responses. This family was very close and all members had contact with the family member with a CMD. The family member with a CMD supported his brother's request.

The presence of another person during the interview process could be considered to violate the research protocol and good interviewing practice. However, due to the sensitive nature of the subject matter, and an awareness of the frequent exclusionary practice of the formal mental health system, the researcher determined that to not allow the presence of others during the interview process would have been detrimental to the process and a violation of personal principles. Moreover, the researcher felt that the presence of significant others assisted in establishing rapport, provided support to the respondent, and helped to counteract the often exclusionary practice of the mental health system. In her

judgment, the quality of the interviews was not affected adversely, but rather enhanced. Many respondents indicated they were pleased to be involved in the study and to have the opportunity to express their views.

In order to maximize candid, truthful responding by family members (i.e., to encourage openness and a willingness to disclose), several procedures were implemented (Backstrom & Hursh-Cesar, 1981). All respondents were assured that the information received would remain strictly confidential. Respondents were told that their names would be removed from the questionnaire once the questionnaire identification number was matched with the identification number assigned to that family member's relative with a CMD. The interviews with the family member respondents generally were conducted prior to the interviews with the community mental health and other mental health workers.

In addition, because the researcher conducted all the community mental health and other mental health worker interviews, the research assistant never saw the data from these interviews. Therefore, except for the few cases in which the researcher conducted the community mental health or other mental health worker interviews were prior to her interviewing the family member respondents, the interviewer would not know the particulars of the clinical history, present level of functioning, current place of residence, or have any other information about the family

member respondent's relative who has a CMD, at the time of the interview with the family member. Thus, the interview would be done blind (i.e., without the interviewer having any information, beyond knowing that the individual with a CMD met the inclusion criteria for the study).

Response booklets were prepared, so that respondents were able to see the response categories of selected questions. Respondents were encouraged to be as open as possible by emphasizing the importance of their participation in the study. Respondents also were informed that they could refuse to answer any questions they did not wish to answer, and that their participation in the study could be terminated at any point if they wished to do so.

Once the family member respondents had been interviewed, the researcher contacted the community mental health and other mental health workers who had not yet been interviewed, to arrange a time to meet with them and conduct the interviews regarding their clients. The researcher conducted a structured interview (Appendix H) with each community mental health or other mental health worker and also requested that he or she complete two brief scales, detailed below. The community mental health and other mental health workers also were asked to complete a consent form (Appendix E) for their participation in the study.

Measures

Three measures comprised the interview with the community mental health and other mental health workers. First, the Data Questionnaire for Individuals with a CMD (Appendix H) covers sociodemographic information and clinical information (e.g., diagnosis) regarding the individual with a CMD referred by the community mental health or other mental health worker. The researcher adapted the questions from Spaniol et al. (1986b).

The purpose of the study conducted by Spaniol et al. (1986b) was to identify family needs and coping strengths, as well as perceptions of mental health professionals. These researchers reported that the survey instrument was based on models available in the literature and on innovations and modifications made by themselves. The initial draft of the instrument was developed by the research staff. The draft was then reviewed and critiqued by family members, professionals in the field, and other researchers, in order to evaluate the relevance of the items to the research objectives. The reviewers were potential users of the data and individuals who represented the populations assumed to be in need, that is, family members and mental health professionals. The feedback received from these family members and mental health professionals supported the basic approach and content of the instruments. Suggestions regarding ambiguous items and unnecessary items were incorporated into the final

draft of the instruments.

Following the review, appropriate changes were incorporated into the final draft of the instrument. A pilot test was then conducted. The subjects' responses indicated that they were able to understand and complete the questionnaire and that they found the items relevant to their own personal experience. Spaniol et al. (1986b) stated that additional comments frequently were written into the margins of the questionnaires, indicating that the respondents were well motivated by the items and were eager to communicate with the researchers.

The results of both expert review and field testing supported the assumption that the instrument was relatively stable as well as valid in content vis-a-vis the purpose of the study. Spaniol et al. also reported that the overall simplicity of the instrument minimized problems concerning its validity. However, they did not report test-retest reliability or internal consistency data.

The remaining two measures were used recently with mental health caregivers in an investigation of the Oregon Quality of Life Theory (Dimirsky, 1990). These two measures are the Global Assessment Scale and the Role Functioning Scale.

Global Assessment Scale. The Global Assessment Scale (GAS) (Endicott, Spitzer, Fleiss, & Cohen, 1976) (Appendix I) evaluates the overall functioning of a person

during a specified time period, on a continuum from psychological or psychiatric sickness to health. It focuses on overt illness patterns along three dimensions: subjective distress, behavioural disturbances, and disturbances of reality (e.g., behaviour is considerably influenced by delusions). A single rating of the person's overall functioning is obtained. A 100 point rating scale is divided into ten equal intervals, each interval (e.g., 1-10, 11-20) having its own rating guidelines. A rating of 1 indicates the hypothetically most pathological (ill) person, and a rating of 100 indicates the least pathological (healthiest) person.

Endicott et al. (1976) did not report any test-retest data on the GAS. However, they did report that the inter-rater reliabilities for ratings of inpatients and aftercare patients ranged from .61 to .91.

Endicott et al. (1976) also provided concurrent validity data for the GAS. They found that concurrent validity correlations among the GAS, and the overall severity score on the Mental Status Examination Record (Endicott, Spitzer, & Fleiss, 1975) and the Family Evaluation Form (Spitzer, Gibbon, & Endicott, 1971) are moderate at six months following admission ($r = -.62$ and $r = -.52$, respectively). Endicott et al. (1976) noted that, as the GAS was the only measure scaled so that higher values represent health, correlations between the GAS and the other measures were expected to be negative. Higher

GAS scores correlated positively with lower amounts of intervention planned by clinicians, providing a measure of concurrent validity.

The researcher chose the GAS because it provides a measure of psychopathology that has been standardized on populations comparable to that in the present study (e.g., psychiatric inpatients; patients attending after-care clinics at state psychiatric institutes) and is based on a time-limited sample of behaviour (Dimirsky, 1990).

Dworkin, Friedman, Telschow, Grant, Moffic, and Sloan (1990) found the GAS to be an easy, reliable, clinically relevant rating of patient functioning, useful in a multiple caregiving setting, where communication among clinicians is critical for good treatment.

Role Functioning Scale. The Role Functioning Scale (Georgia Department of Human Resources, 1978) (Appendix J) is used to assess patient functioning in four life areas or roles: work, independent living, immediate social network, and extended social network. The rating scale ranges from 1 (severely limited) to 7 (optimal). Each score is accompanied by a description of that level of skill development and functioning. For example, a score of 1 concerning work indicates "productivity severely limited; often unable to work or adapt to school or homemaking; virtually no skills or attempts to be productive." At the other end of the scale, a score of 7 indicates "optimally performs homemaking, school tasks or

employment-related functions with ease and efficiency." The rater renders a judgment of the patient's functioning in each role. The summary role functioning scores are added together to provide a global role functioning index ranging from 4 (severely limited) to 28 (optimal).

This scale was obtained from Dimirsky (1990). He reported that no reliability or validity data are available.

Family Member Questionnaire. Appendix K contains the family member questionnaire (FMQ). For clarity, section headings have been included. These headings were removed before the final questionnaire was prepared for use in the field.

This questionnaire, developed by the researcher, was organized generally in the following manner. Basic sociodemographic questions were presented first. Sociodemographic variables are considered to be external variables in Ajzen and Fishbein's (1980) theoretical model. Following these questions is a section on perceived supports. Perceived supports represent one of the external variables in the theoretical model utilized in the present study.

Next, the FMQ assesses beliefs regarding and attitudes toward community-based care in one section, beliefs regarding and attitudes toward home care in a second section, and beliefs regarding and attitudes toward advocacy in a third section.

Sections on behavioural intentions regarding both community based care and home care are found near the end of the questionnaire. The FMQ ends with a few questions regarding the interview itself. Family member respondents' are asked if they would be willing to provide their telephone number, in case the researcher wants to contact them again with some follow-up questions.

Respondents also are told that they will be sent a summary copy of the results once the study is completed, unless they specify they do not want one. Finally, family member respondents are asked if they have any further comments they would like to offer prior to concluding the interview.

The specific measures are discussed below within the framework of the theoretical model used in this study. There are no reliability or validity data for the measures devised by the researcher.

The first 12 questions (Section I) of the FMQ are basic socio-demographic questions regarding both the family member and the relative with a CMD. Questions on age, marital status, and family income are standardized measures used previously in the Winnipeg Area Study (WAS) (Tefft et al., 1989), an annual survey of the general population in that city. Tefft et al. reported that the WAS routinely collects detailed information on a broad range of socioeconomic and social-demographic variables for every respondent. These measures were judged to be

more than adequate for the present research.

Continuing with Section I, four questions regarding the family member with a CMD (time spent in the familial home, amount of contact with the respondent, relationship to the respondent, and who provides the primary caregiving within the home) are adapted from Spaniol et al. (1986b). In addition, included in this section are two questions devised by the researcher. These two questions asked (a) what is the composition of the family and (b) what is the number of family members currently living with the respondent? The family was defined as comprising grandparents, parents, siblings, spouse, and children. These two questions provided an indication of family members who may be a source of emotional and/or instrumental support to the family member respondents. The next section in the FMQ addresses the issue of family member respondents' perceptions regarding the supports available to them.

Section II is composed of seven questions concerning family support, extra-familial support, and mental health care system support. These questions were devised by the researcher, and based on her investigation of the empirical research. As families have indicated the need for family, peer, and various mental health system supports (e.g., Bernheim, 1986; Hatfield, 1978, 1986, Spaniol et al., 1986a, Terkelsen, 1986b), it is important to know their perceived needs for support relative to the

support perceived by families as actually available.

A factor analysis was conducted utilizing the seven support questions. Based on this analysis, factor scores were computed for two separate constructs labeled family supports (comprised of two items) and mental health system supports (comprised of four items). Each question asked how much support the family member respondent had received from particular people, groups, or services. Subscale scores were computed by summing responses to individual items in each factor. A seven-point response scale was used, ranging from 1 (no support) to 7 (a great deal of support). The theoretical range for each of the measures is: family supports (2 - 14); mental health system supports (4 - 28). The higher the score, the greater the support.

Beliefs regarding care for individuals with a CMD were investigated through the use of two measures: beliefs regarding community-based care, in general, for individuals with a CMD (Section III) and beliefs regarding home care for individuals with a CMD (Section IX).

The questions in Section III were devised by the researcher and based upon the quality of life research (Baker & Intagliata, 1982; Lehman, 1983a, 1983b; Lehman et al., 1986; Lehman et al., 1982) concerning persons with a CMD in institutional and community-based care facilities. This quality of life research has assessed life satisfaction along such domains as living situation,

family relations, social relations, leisure activities, work, finances, safety, and health.

A factor analysis identified one factor representing the construct labeled beliefs regarding community-based care. Therefore, a factor score was computed. Family member respondents were asked to indicate how much they agreed or disagreed with some statements. Subscale scores were computed by summing the responses to individual items. A five-point response scale was used, ranging from 1 (strongly agree) to 5 (strongly disagree). The questions were counterbalanced to control for possible response set bias. Therefore, some questions were reverse scored for analysis. The theoretical range for this scale is 5 - 25. A higher score indicates more positive beliefs regarding community-based care for persons with a CMD.

The six questions in Section IX investigate beliefs regarding home care. There are two sets of three questions each in this section. A factor analysis of these six questions identified two separate factors, each factor representing one of the sets of questions. The first factor measures the construct labeled beliefs regarding home care. The items composing this factor are based upon the quality of life research referred to above, as well as upon the research on home care (e.g., Doll, 1976; Grusky et al., 1985; Kriesman & Joy, 1974; Vaughn & Leff, 1976). The research on home care for individuals with a CMD indicates that, although many families have

their family member living at home, many appear to do so with great reluctance. Family members' beliefs regarding home care for their relative with a CMD is affected by the particular structural and social-demographic features of the home environment.

Family member respondents were asked the extent to which they agreed or disagreed with some statements. A factor score was computed. Subscale scores were computed by summing responses to individual items. A five-point response scale was used, ranging from 1 (strongly agree) to 5 (strongly disagree). The questions were again counterbalanced to control for possible response set bias and some questions were reverse scored. The theoretical range for this measure is 3 - 15. A higher score indicates more positive beliefs regarding home care for persons with a CMD.

Questions about beliefs regarding family burden comprise the second set of questions in Section IX. In this study, family burden refers to both objective burden, defined as the disruptions the individual with a CMD causes in the family's everyday life (e.g., financial burden, interruptions in the family's normal routines), and subjective burden, defined as the emotional costs experienced by the family as a result of the presence and the behaviour (e.g., symptomatology) of their relative with a CMD. These questions were devised by the researcher and based upon the family burden research (e.g., Hoenig &

Hamilton, 1966; Noh & Avison, 1986; Doll et al., 1976; Thompson & Doll, 1982; Terkelsen, 1986).

Although family burden scales already exist (e.g., Noh & Avison, 1988; Thompson & Doll, 1982; Zarit, 1986), the format and some of the content of these scales were not appropriate for use in the present study. For example, the scale by Zarit (1986) is based upon research conducted with family members of patients with dementia. While there are many similarities between this group of family members and family members of individuals with a CMD, the first group is mainly composed of spouses and the second group is mainly composed of parents. Also, the first group may be somewhat older in age and, therefore, have greater immediate physical health concerns. Therefore, these two groups may not have identical concerns or experience burden in the same manner.

As mentioned above, the definition of burden and the general areas of inquiry utilized in previous research guided the content of the questions comprising the family burden scale. The second factor which emerged from the factor analysis conducted on the six items in Section IX is comprised of three items relating to family burden. Family member respondents were asked to what extent they agreed or disagreed with some statements. Once again, a factor score was computed. Subscale scores also were computed by summing responses to individual items. A five-point response scale was used, ranging from 1

(strongly agree) to 5 (strongly disagree). As before, the questions were counterbalanced and some questions were reverse scored. The theoretical range for this measure is 3 - 15. A higher score indicates more burden.

Two sets of questions come under the heading beliefs regarding the importance and adequacy of resources for community-based care for persons with a CMD. The first set (Section V) includes questions regarding resources for community-based care, in general, and the second set (Section XI) pertains to resources for families, and for home care.

Section V is comprised of a measure adapted by the researcher from a scale used by Tefft et al. (1989) to investigate behavioural intentions regarding support for several helping services (e.g., housing, financial assistance, job training, recreation). As stated previously, the quality of life research suggests that the more satisfied individuals with a CMD in specific life domains are, the greater their quality of life will be within the community (Lehman et al., 1982; Lehman, 1983a, 1983b; Lehman et al., 1986). The services mentioned above are investigated as they focus on improving the quality of life of individuals with a CMD in the life domains (e.g., shelter, income, education, work, family and health) referred to in the quality of life literature.

The scale used by Tefft et al. (1989) was adapted from Weiner, Perry, and Magnusson (1988). In addition,

Tefft et al. included three programs and services (housing programs, recreation programs, training in interpersonal skills) not included previously but which are especially relevant to persons with a CMD.

The wording of the current questions was changed so that they could be used to investigate beliefs rather than behavioural intentions. For example, instead of asking "how much support" individuals would give to specific services, the adapted scale asks respondents their opinion regarding the "importance of" and "adequacy of" these services. Two questions are asked for each type of service or resource (e.g., job training). The first question asks how important the family member respondent thinks that particular resource is for individuals with a CMD. The second question asks how adequate the respondent thinks that particular resource is at the present time. If respondents rated a service as minimally important (i.e., 6 or 7 on a 7-point scale), then the second question was skipped. The rationale for this skip logic is that, if a respondent does not think that a resource is important, then he or she is not going to be concerned about the adequacy of it.

The questions regarding the importance of specific resources were factor analyzed. Two separate factors emerged, representing two constructs labeled beliefs regarding the importance of supplemental resources and beliefs regarding the importance of essential resources.

Factor scores were computed for each factor. The theoretical ranges for the factors are 4 - 28 for beliefs regarding the importance of supplemental resources, and 2 - 14 for beliefs regarding the importance of essential resources. Subscale scores were computed by summing responses to individual items in each measure. A seven-point response scale was used, ranging from 1 (very important; very adequate) to 7 (not at all important; not at all adequate). Based upon the results of the factor analysis for the importance questions, separate composite scores were computed based upon the two sets of items that corresponded to the items in the importance factors. The theoretical ranges for these measures are the same as for the corresponding importance measures. Once again, subscale scores were computed by summing responses to individual items. The response scale used for the importance questions also was used for the adequacy questions. A lower score indicates greater importance or greater adequacy.

The measure utilized to investigate beliefs regarding the importance and adequacy of resources for home care for individuals with a CMD also was devised by the researcher. The resources addressed in this section were chosen on the basis of research on family needs (e.g., Hatfield, 1978; Spaniol et al., 1986a). These researchers found that families desired emotional support from their peers, as well as a variety of mental health

system supports. For example, families wanted more contact with mental health professionals, more information about the illness and medication management, and more assistance with coping strategies and techniques for the home management of their relative with a CMD.

The questions regarding the importance of specific resources were factor analyzed. Two separate factors emerged, representing two constructs labeled beliefs regarding the importance of family resources and beliefs regarding the importance of family education. Factor scores were computed for each factor. The theoretical ranges for the factors are 5 - 35 for beliefs regarding the importance of family resources, and 2 - 14 for beliefs regarding the importance of family education. Subscale scores were computed by summing responses to individual items in each measure. A seven-point response scale was used, ranging from 1 (very important; very adequate) to 7 (not at all important; not at all adequate).

Based upon the results of the factor analysis for the importance questions, separate composite scores were computed based upon the two sets of adequacy items that corresponded to the items in the importance factors. The theoretical ranges for these measures are the same as for the corresponding importance measures. Once again, subscale scores were computed by summing responses to individual items. The same seven-point response scale was used as with the importance questions, and the skip logic

referred to above also was used in this section. A lower score indicates greater importance or greater adequacy.

Prior to the first set of normative belief questions (Section VI), family member respondents were asked to identify a significant referent regarding mental health issues. When answering all questions that pertained to significant referents (i.e., the normative belief and subjective norm items), respondents were asked to refer to the individual identified as their significant referent. As stated previously, Ajzen & Fishbein (1980) stated that normative beliefs involve specific individuals or groups. Respondents were asked to identify a specific person rather than a specific group because family members may receive support from some family members or other members of their social support network, but not receive support from other members of this support network (Terkelsen, 1986b). Family members also may interact with more than one mental health professional within the mental health system. Several studies investigating family members' perceptions of mental health professionals indicated that family members may have received support from a mental health professional, but may have received little or no support from other mental health professionals or the mental health system (Holden & Lewine, 1982; Spaniol et al., 1986a).

Two items relating to normative beliefs regarding resources for community-based care are found in Section

VI. The first question reads, "Keeping your important referent in mind, please indicate the degree to which he or she believes you should support the development of better resources for community-based care for _____ (name of disordered family member)." The second question reads, "Given the belief of your referent, how much do you want to comply with his or her wishes so as to satisfy him or her)." Two similar questions regarding resources for home care are found in Section XII. All four questions follow the format recommended by Ajzen and Fishbein (1980) in their discussion of normative beliefs. Results of the correlational analysis indicated that the two normative belief questions were unrelated. Therefore, each question formed a separate scale of one item. As a seven-point response scale was used, ranging from 1 (not at all) to 7 (totally), the theoretical range for both scales also is 1 - 7. The higher the score, the stronger the normative belief.

Section XV is comprised of questions concerning beliefs regarding advocacy. Recent literature on families who have relatives with a CMD indicates that family groups have taken on the role of advocacy (Bernheim, 1986;

Hatfield, 1986b). Lieberman and Borman (1976) and Hatfield (1981, 1986b) suggested that, although many family groups began with a support function, they changed over time. It became apparent that, if life was to improve for themselves and for their relatives with a CMD, they

would have to become sophisticated advocates for change in the mental health system.

Based upon the family advocacy literature, the researcher devised questions regarding people's beliefs about their own role, as well as the role of families and family groups, in advocating for resources for community-based care. The questions regarding advocacy were factor analyzed. One factor emerged, representing a construct labeled beliefs regarding advocacy. A factor score was computed. The theoretical range for the factor is 3 - 21. Subscale scores were computed by summing responses to individual items in each measure. A seven-point response scale was used, ranging from 1 (none at all or not at all influential) to 7 (totally or very influential). The higher the score, the more positive the belief regarding advocacy.

Section XVI asks about the normative beliefs associated with advocacy. Two questions are asked, based on Ajzen and Fishbein (1980). The respondents are reminded to keep in mind their important referent concerning mental health issues, when answering the two questions. The first question asks that the family member respondent "please indicate the degree to which he or she believes you should advocate for better, more effective community-based care." The second question asks "given the belief of your referent, how much do you want to comply with his or her wishes so as to satisfy him or

her." The results of the correlational analysis showed that the two normative belief questions regarding advocacy were related but separate questions. Therefore, each question formed a separate scale of one item each. As a seven-point response scale was used, ranging from 1 (not at all) to 7 (totally), the theoretical range for both scales also is 1 - 7. The higher the score, the stronger the normative belief.

Several attitude measures form part of the family member questionnaire. As with beliefs regarding community-based care for persons with a CMD, attitudes toward community-based care for persons with a CMD involve two measures: attitudes toward community-based care, in general, for persons with a CMD (Section IV) and attitudes toward home care for the persons with a CMD (Section X).

The items in Section IV (attitudes toward community-based care, in general, for persons with a CMD) were devised by the researcher, based upon the quality of life literature referred to previously. These items investigate the respondent's attitudes associated with his or her beliefs regarding community-based care. Family member respondents are not asked if they believe in community-based care, but rather whether they feel it is accomplishes what it sets out to do. For example, the family member respondent was asked "In your opinion, how effective is community-based care for providing living arrangements and treatment to _____ (name of

disordered family member) in as natural a setting as possible". This specific question was asked because the quality of life literature often examines the relationship among the type of living arrangements and/or treatment settings and the degree of life satisfaction experienced by the individual with a CMD (e.g., Blake, 1987; Cantelon, 1988; Kruzich & Berg, 1985; Markson, 1985; Pepper & Ryglewicz; 1982).

The three attitudes toward community-based care questions were factor analyzed. One factor emerged representing a construct labeled attitudes toward community-based care. A factor score was computed. Subscale scores were computed by summing responses to individual items in the measure. The theoretical range is 3 - 15. A five-point response scale was used, ranging from 1 (very ineffective) to 5 (very effective). The higher the score, the more positive the attitudes toward community-based care for persons with a CMD. There are no reliability or validity data available on this measure.

The six questions in Section X pertaining to attitudes toward home were factor analyzed. Two factors emerged, representing the constructs attitudes toward home care and attitudes toward family burden.

The first three questions pertain specifically to attitudes toward home care for the individual with a CMD. The first question was adapted from Spaniol et al. (1986b). The other two questions were devised by the

researcher. The questions in this section follow from the questions about the respondent's beliefs regarding home care and measure his or her corresponding attitudes. For example, one of the questions asks, "In your opinion, how effective is home care for providing living arrangements and treatment to _____ (name of disordered family member) in as natural a setting as possible." This question was asked for the same reason as the equivalent question regarding community-based care in Section V.

A factor score was computed. Subscale scores were computed by summing individual responses to items in the scale. The theoretical range is 3 - 15. A five-point response scale was used, ranging from 1 (very ineffective) to 5 (very effective). The higher the score, the more positive the attitudes toward home care. There are no reliability and validity data available for the questions devised by the researcher or for the specific question adapted from Spaniol et al. (1986b).

The second part of Section X investigates attitudes toward family burden. These questions were devised by the researcher. The items in this part again follow from the questions on beliefs regarding family burden. They assess the family member respondent's attitudes toward family burden, both objective and subjective. For example, one question asks "How much stress have you experienced as a result of practical problems (e.g., financial, disruption in daily routine) that have developed as a result of

having _____ (name of disordered family member) living at home."

A factor score was computed. Subscale scores were computed by summing responses to individual items in the scale. The theoretical range was 3 - 21. A seven-point response scale was used, ranging from 1 (very little) to 7 (very much). The higher the score, the greater the feelings of burden.

Section VII and Section XIII inquire about family members' attitudes toward the importance and adequacy of resources for community-based care for individuals with a CMD. The first measure (Section VII) investigates the importance and adequacy of resources for community-based care for the individual with a CMD, in general. The second measure (Section XIII) investigates the importance and adequacy of resources specifically for families and for home care.

The questions in Section VII and Section XIII follow from the corresponding belief sections (Section V and XI) of the questionnaire. The question posed in both Section VII and Section XIII provides a measure of the respondent's attitudes toward his or her beliefs. Section V asks questions regarding the family member respondent's beliefs regarding the importance and adequacy of specific resources for community-based care. The question in Section VII follows from this question, and asks the family member respondent "...how desirable it

would be to better develop those community-based resources that you indicated were important but inadequate."

Similarly, the questions in Section XI pertain to family member respondents' beliefs regarding the importance and adequacy of resources for home care. The question in section XIII is the same as the question in Section VII except that the question refers to resources for home care rather than for community-based care.

In both Section VII and Section XIII, a seven-point response scale was used, ranging from 1 (not at all desirable) to 7 (totally desirable). The higher the score, the more positive the attitudes.

Section VIII and Section XIV look at the subjective norms which relate to Section VII (attitudes toward resources for community-based care) and Section XIII (attitudes toward resources for home care). Each of these sections consists of only one question. These questions are based on Ajzen & Fishbein (1980). The question in Section VIII asks the family member respondent to "please indicate to what extent your referent wants you to support the development of better resources for community-based care for _____ (name of disordered family member). Section XIV asks the same question except that instead of referring to resources for community-based care, the question refers to resources for home care.

In both Section VIII and Section XIV, a seven point scale was used, ranging from 1 (not at all) to 7

(totally). The higher the score, the stronger the subjective norm.

The question in Section XVII (attitude toward advocacy) follows from the questions in Section XV (beliefs regarding advocacy). The question posed follows from the questions about the family member respondent's beliefs regarding advocacy, and provides a measure of the respondent's feelings about advocating for better community-based care. The question asks the family member respondent to "please tell me how desirable it is for you to advocate for better, more effective community-based care."

A seven-point response scale was used, ranging from 1 (not at all desirable) to 7 (very desirable). The higher the score, the more positive the attitude toward advocacy.

Section XVIII examines the subjective norm associated with Section XVII (attitudes toward advocacy). The one question in this section is based on the format suggested by Ajzen and Fishbein (1980). It asks the family member respondent "to what extent does your important referent want you to advocate for better, more effective community-based care. A seven point response scale was used, ranging from 1 (not at all) to 7 (very much). The higher the score, the stronger the subjective norm.

The measure for investigating behavioural intentions

to advocate for resources for community-based care for individuals with a CMD (Section XIX) consisted of eight actions (e.g., sign petition, attend meeting, write to newspaper, contact politician) that a person may take in support of resources for community-based care for individuals with a CMD. It was adapted from a measure used by Tefft et al. (1989) to assess the actions respondents would likely take in support of, or opposition to, a particular mental health facility in their neighbourhood. Respondents may answer "yes" to more than one behavioural intention. The more actions respondents say they are likely to take, the more positive the intention toward advocacy.

This same scale, with one minor adaptation, was used to assess intentions regarding advocating for resources for home care for individuals with a CMD (also located in Section XIX). The wording of the seventh item was changed from "support and volunteer some of your time to help improve services/programs for individuals with a CMD" to "support and volunteer some of your time to help improve services/programs for family members."

Tefft et al. (1987) analyzed their original nine item measure and found that it was a Guttman scale of increasing intensity. From lowest to highest intensity, the scale consisted of sign petition, attend meeting, join neighbourhood action group, contact politician, write newspaper, and form neighbourhood action group. Tefft et

al. found that the three lowest intensity actions involved group participation characterized by relatively little effort, and the three highest intensity actions involved relatively more visible and/or sustained individual effort. The three remaining items (contact another government official, consider moving, take no action) did not load on the action intensity scale. Subsequently, Tefft et al. (1989) dropped two of the non-loading items (contact another government official, consider moving) and added one positive action item (support and volunteer some of your time to help improve facility services). As a result, the current version of the scale is comprised of six actions. The Guttman scale score obtained by a respondent indicates the most intense action likely to be taken by that respondent and, thus, subsumes all the less difficult actions the respondent is likely to take.

While there are no reliability or validity data available on the most recent version of their scale, Tefft et al. (1989) reported that statements of intention correlate significantly with past actions. This indicates a valid relationship between the intentions expressed by people and actions they have performed in the past.

The researcher pretested the family member questionnaire, by obtaining 5 interviews prior to the actual data collection period. Five family members of individuals with a CMD were recruited for the pretest. Based upon the feedback received from the pretest, minor

adjustments were made to a few of the instructions in the portion of the questionnaire pertaining to home care.

Results

Characteristics of sample of individuals with a CMD.

The sample of 100 individuals with a CMD was comprised of 49 males and 51 females. As stated previously, they were all 18 years or older ($M = 37.9$, $S.D. = 12.1$).

Seventy-seven individuals had diagnoses of schizophrenia and 23 individuals had diagnoses of affective disorder. While some individuals barely met the minimum requirement of two years since first diagnosis, thirty-eight individuals had been first diagnosed over 15 years ago. Therefore, the sample was diverse in terms of duration ($M = 5.8$, $S.D. = 1.3$).

The number of hospitalizations also varied greatly. Two individuals had never been hospitalized, 51 people had been hospitalized between 1 and 5 times, and 33 individuals had been hospitalized over 5 times ($M = 3.0$, $S.D. = .89$). Forty-seven people received treatment services primarily at a hospital, and 41 individuals received treatment primarily at their place of residence (group home) or at a community agency. Only 11 individuals indicated that they were treated primarily by a private psychiatrist or other physician.

Over half of the sample of individuals with a CMD (52) lived in a group home and 24 individuals lived with

family (parents or spouse). Nineteen people in the sample lived either semi-independently or independently.

Individuals in the CMD sample varied in terms of educational level. Although two individuals had no schooling, seven individuals had some college and eight had a college degree. The majority of individuals had either completed junior high (31) or high (27) school. The majority of individuals (72) were not involved in any type of work activity. Twenty-three individuals worked in a sheltered workshop, and four individuals were employed competitively (3 full-time and 1 part-time).

Table 1 summarizes the social-demographic and diagnostic characteristics of the sample of individuals with a CMD.

Characteristics of community mental health and other mental health worker interviews. Nineteen out of 25 community mental health workers approached agreed to participate in the study. Fifty-nine client interviews were conducted with the 19 community-mental health workers. The remaining 41 client interviews were conducted with 12 other mental health workers. Of the 100 interviews conducted regarding the sample of individuals with a CMD, the largest number conducted with any one worker was eight interviews.

The interviews with the community mental health and other mental health workers varied in time from 5 to 40

Table 1

Social-Demographic and Diagnostic Characteristics of
Individuals with a CMD

Characteristic (n = 100)	Study Sample
Gender	
Male	49
Female	51
Age	
Range (years)	20 - 76
Mean	37.9
S.D.	12.1
Diagnosis	
Schizophrenia	77
Affective Disorder	23
Duration (of Diagnosis)	
< 2 years	01
2 years	07
3 - 5 years	10
6 - 10 years	17
11 - 15 years	24
> 15 years	38
Unknown	03
Global Assessment Scale and Role Functioning Scale (Severity)	
Range	06 - 36
Mean	22.2
S.D.	06.6
Education	
None	02
Grade School	14
Junior High	31
Senior High	27
Post High Tech	06
Some College	07
College	06
Unknown	01

Table 1 (continued)

Social-Demographic and Diagnostic Characteristics of
Individuals with a CMD

Characteristic (n = 100)	Study Sample
Employment	
Full Time	03
Part Time	01
Workshop	23
Unemployed Not Look	12
Unemployed Looking	60
Unknown	01
Living Arrangements	
Psychiatric Ward	02
Group Home	51
Personal Care Home	01
Parent(s)/Spouse	24
Semi Ind. or Indep.	19
Other	03

minutes ($M = 13.5$; $S.D. = 7.3$). The time an interview took depended on the availability of the information sought, the worker's familiarity with the information, and the degree to which the individual worker discussed the information with the researcher.

Characteristics of family member respondents and family member respondent interviews. Sixty-seven of the family member respondents were female and 33 were male. Forty-four of these family members were mothers, 13 were fathers, 9 were spouses, 4 were daughters, 28 were siblings, and two were some other family member.

The ages of the family member respondents ranged from 20 years of age to 83 years of age ($M = 54.9$; $S.D. = 14.3$). As mentioned previously, although a ceiling of 70 years of age was established as an entrance criterion, the researcher assessed each situation on a case by case basis. While 3 older family member respondents were not able to complete the interview, many were very capable of doing so.

Almost two-thirds (63) of the family member respondents lived with a spouse/partner, and the other one-third (37) lived on their own. The education level of family member respondents varied from elementary school (3) to a Master's degree (1). Thirty-six individuals had completed junior high school, and 19 individuals had completed high school. Twenty-four family member respondents had either a non-university diploma or some

university courses, and seven had graduated with a B.A.

The total household income in the past year of family member respondents ranged from under \$6,000 to over \$80,000. The median household income was approximately \$25,000. Sixteen respondents were either not able or unwilling to provide their total household income for the past year.

The number of days/week the individual with a CMD lived at the home of the family member respondent varied from none to seven days. The hours of face-to-face contact per week that family member respondents had with their family member with a CMD also varied from no time to 70 hours or more. The median hours per week family member respondents spent in face-to-face contact with their family member with a CMD was 13 hours.

The family interviews varied in length from 30 to 120 minutes ($M = 61.9$ minutes). There were several reasons for the wide variations in length. As many of the family member respondents had not been provided adequate opportunity by the mental health system to offer their opinions and express their feelings on the topic areas covered in the interview, many people seized the opportunity to do so by elaborating on, and explaining, the reasons for their responses. For some family member respondents, the interview brought back painful memories and highlighted their frustrations. Due to the sensitive nature of the subject matter covered in the interview, it

was important for the interviewers to be aware of, and responsive to, the needs of the respondents throughout the interview, and to allow respondents to take whatever time they required to answer each question.

Table 2 summarizes the major social-demographic characteristics for the sample of family member respondents.

Data Preparation

In preparation for analyses, the data from a random 10% of the cases in the computerized data file were compared to the questionnaires from which they were taken. No errors were discovered in this examination, indicating a high level of coding/keypunching accuracy. Regarding the total sample, descriptive statistics were obtained for all variables. The variance for some variables was quite little. For example, the variance in each of the items in the measure of beliefs regarding community-based care is quite small (from a S.D. = .67 to S.D. = 1.03). The attitudes toward resources for community-based care measure only consisted of one measure, and the variance for this item also is very small (S.D. = .722).

All variables also were examined for missing values and outliers. The use of mean substitutions was determined on an individual variable basis. Mean substitutions were utilized in instances where a summative score was computed and one item was missing. The

Table 2

Social-Demographic Characteristics of Family Member Respondents

Characteristic (n = 100)	Study Sample
Gender	
Male	33
Female	67
Age	
Range (years)	20-83
Mean	54.9
S.D.	14.3
Marital Status (Living Arrangements)	
Married	61
Common Law	02
Single	07
Separated	07
Divorced	07
Widowed	16
Household Income	
Sample Range	\$6,000.00 - \$80,000+
Median	\$25,000.00
Education	
Elementary	13
Junior High	36 (complete)
High School	19 (complete)
Non University/ Diploma/Some University	24
B.A.	07
M.A.	01

Table 2 (continued)

Social-Demographic Characteristics of Family Member Respondents

Characteristic (n = 100)	Study Sample
Relationship to Family Member with a CMD	
Mother	44
Father	13
Spouse	09
Daughter	04
Son	00
Sibling	28
Other	02

distribution for each variable was examined visually to detect any outliers (i.e., points suspiciously different from the others). For all variables, the distribution was examined for skew. None of the distributions were highly skewed.

A more conservative significance criterion (alpha level) of .025 was utilized in this study. The more conservative significance criterion was chosen as a compromise, because of the numerous comparisons conducted, despite the following reasons for using a more liberal significance criterion. First, some adjustment in the significance criterion was warranted, as this was an exploratory study. Exploratory studies are usually less stringent than other studies. Second, a more liberal significance criterion is often used for a relatively small sample size. Third, many of the measures had unknown psychometric properties. They were new measures and did not have great reliability. Therefore, the tests were biased in favour of non-significance.

A retrospective power analysis also was conducted because of the numerous comparisons made in this study. Cohen (1988) outlined four types of power analyses. One type determines power as a function of significance criterion, effect size, and sample size. Such analyses are generally performed as part of research planning. However, Cohen (1988) stated that the power which a given statistical test had can also be determined by performing

such analyses on completed studies. Power analyses for correlations with a significance criterion of .025, an effect size of .29 (which had been significant) and .18 (which had not been significant), and a sample of 100 were conducted. The results of these power analyses indicated that any analysis with an effect size of .196 or above would be significant at the .025 alpha level for a sample size of 100. A similar test was conducted for regression analyses. This retrospective power analysis indicated that the power was high for all regression analyses that were significant at the .025 alpha level.

All statistical analyses for the study were conducted using SPSS-X software (SPSS Inc., 1986). Several statistical procedures were utilized in this study. These statistical procedures are detailed, along with the results of those analyses, in the following sections.

Description of Statistical Analyses

The statistical analyses were conducted in two stages. Prior to testing the specific hypotheses and examining the predictive validity of the theoretical model utilized in the study, several statistical analyses were conducted for the purpose of preparing the data for hypothesis testing. Several steps were involved in this first stage of statistical analysis.

Relationships Between External Variables. The relationships between external variables relating to the

sample of individuals with a CMD and the sample of family member respondents were examined. One-way analysis of variance was utilized to examine the relationship between discrete and continuous variables, chi square analysis was utilized to examine the relationship between discrete variables, and a Pearson r was utilized to examine the relationship between continuous variables. These analyses were conducted to test for confounding social-demographic variables.

An examination of the chi square analyses showed there were too few cases in some cells. For this reason, the categories for some variables were collapsed. The chi square and one-way analysis of variance procedures were conducted a second time for those variables where categories had been collapsed.

The one-way analysis of variance and Pearson r analyses showed that gender and age of the sample of individuals with a CMD were significantly related ($p < .025$) to several other external variables, indicating that they may act as confounding variables in subsequent analyses. The one-way analysis of variance showed that gender and age of the sample of individuals with a CMD also were significantly related [$F(1, 98) = 12.1, p < .001$] to each other. Based upon the results of these analyses, it was decided that subsequent analyses examining the relationships between external variables and beliefs would control for gender and age of the sample of

individuals with a CMD.

The correlation between the two disorder severity indexes (Global Assessment Scale Score and the Role Functioning Scale Score) was significant ($r = .72$, $N = 100$, $p = .01$). The correlations between The Global Assessment Scale score and the total severity score, and the Role Functioning Scale score and the total severity score also were both significant ($r = .84$, $p < .000$; and $r = .98$, $p < .000$ respectively). Therefore, although the theoretical range for the Global Assessment Scale (coded as 1 - 10) and the Role Functioning Scale (4 - 28) differed, the sum of the two scores were computed, producing a composite score for a single severity index variable.

Relationships Between External Variables and Beliefs.

Partial correlation and analysis of covariance procedures were utilized to examine relationships between each of the various external variables not investigated within the hypotheses (social-demographic variables) and each of the belief factors in the model. The partial correlation coefficient is a measure of linear association between two continuous variables, while adjusting for the linear effects of one or more additional variables. Partial correlation is a useful technique for uncovering spurious relationships, detecting hidden relationships, and identifying intervening variables (Norusis, 1990). Similarly, analysis of covariance provides a measure of linear association between a discrete variable and a

continuous variable, while adjusting for the linear effects of one or more additional variables (Tabachnick & Fidell, 1989).

For the reasons mentioned above, the control variables in these analyses were gender and age of the sample of individuals with a CMD. The results of the partial correlation and analysis of covariance procedures also indicated that none of the other external variables correlated significantly with several other external variables. Therefore, it was not necessary to treat any other external variables as control variables.

Factor Analysis of Measures Developed for the Study.

Principal components analysis is considered an appropriate technique for empirically summarizing data (Gorsuch, 1983). Therefore, groups of items on measures developed by the researcher or adapted from other measures were combined into interpretable factors by conducting principal components analysis.

The Family Member Questionnaire contained many such measures, including: a) perceived support; b) beliefs regarding community-based care; c) beliefs regarding the importance of resources for community-based care; d) beliefs regarding home care; e) beliefs regarding the importance of resources for home care; f) beliefs regarding advocacy; g) attitudes toward community-based care; and h) attitudes toward home care. Correlations in excess of .30 were revealed in the matrix for each set of

variables, suggesting that factor analysis was appropriate (Tabachnick and Fidell, 1989).

The extraction of principal components was accompanied by a varimax rotation producing an orthogonal solution. As varimax rotation allows for relatively easy identification, description, and interpretation of the variables making up a factor, it is the type most frequently used in social science research (Tabachnick & Fidell, 1989).

The Kaiser-Guttman Rule suggests that the factors in the final solution should have eigenvalues greater than 1.0. In the present study, the number of factors in the final solution was based on this rule and on the interpretability of factors (Gorsuch, 1983). Only those variables loading highly on just one factor were retained, following the principle of simple structure (Tabachnick and Fidell, 1989; Thurstone, 1947). Loadings in excess of .45 were considered salient and usable for interpretability (Comrey, 1973). All factor loadings in this study were in excess of .50.

Results of the Factor Analyses

Perceived Supports

An initial principal components analysis of the seven perceived support items revealed that one item, measuring extra-familial support, did not load on either of two factors. This item was dropped from the analysis. A second principle components analysis of the remaining

six items identified two factors, with eigenvalues of 2.4 and 1.4. Therefore, a two-factor solution was selected. This two-factor solution accounted for 63.5% of the common variance. Table 3 presents the solution, with items in each factor, factor loadings, percentage of variance accounted for by each factor, and communalities. Factor 1 is interpreted as perceived support from the mental health system. The four items in this factor reflect family members' perceptions of mental health system supports. Factor 2 reflects family members' perceptions of support from other family members.

Beliefs Regarding Community-Based Care

Principal components analysis of the five belief items regarding community-based care identified only one factor, with an eigenvalue of 2.2. This factor represents family member respondents' beliefs regarding community-based care versus hospitalization. Table 4 presents the factor loadings, percentage of variance accounted for, and communalities of items in the solution.

Beliefs Regarding the Importance of Resources for Community-Based Care

Principle components analysis of the six belief items regarding the importance of resources for community-based care for individuals with a CMD identified two factors with eigenvalues of 2.6 and 1.2. This two-factor solution served as the final solution. Table 5 presents

Table 3

Perceived Supports: Items, Factor Loadings, Variance Explained, and Communalities of Factors

	Factor Loading	Variance Explained	Communality
<hr/>			
Factor 1: Mental Health Care System Supports		40.3%	
How much support have you received from the mental health care system in terms of education and information?	.85		.72
How much support have you received from the mental health care system in terms of ongoing consultation and interaction?	.84		.72
How much support have you received from the mental health care system in terms of emergency (i.e., crisis care)?	.75		.71
Finally, how much support have you received from the mental health care system in terms of financial assistance?	.52		.33
<hr/>			
Factor 2: Family Supports		23.2	
How much support have you received from members of your immediate family (i.e., spouse, children, siblings, parents, and grandparents)?	.79		.63
How much support have you received from other family members (e.g., uncles, aunts, cousins)?	.83		.69

Table 4

Beliefs Regarding Community-Based Care: Items, Factor Loadings, Variance Explained, and Communalities of the Factor

Factor/Item	Factor Loading	Variance Explained	Communality
Factor 1: Beliefs Regarding Community-Based Care		44.5	
The quality of life of _____ (name of family member with disorder) is greater when s/he is being treated in the hospital than when s/he is being treated in the community.	.77		.60
Hospital care encourages more frequent interactions between _____ (name of member with disorder) and members of his/her social network than community-based care.	.74		.55
Treatment and other rehabilitation (e.g., social skills or job training) programs are less restrictive for _____ (name of member with disorder) when offered in the community than when offered in hospitals.	.68		.47
Community-based residential facilities provide a more natural living environment than hospitals and, therefore, encourage more normal functioning for _____ (name of member with disorder).	.56		.31
Hospitalization should only be used if community treatment is ineffective for _____ (name of member with disorder).	.55		.30

Table 5

Beliefs Regarding the Importance of Resources for
Community Based Care: Items, Factor Loadings,
Variance Explained, and Communalities of Factors

Factor/Item	Factor Loading	Variance Explained	Communality
Factor 1: Beliefs regarding the importance of community- based supplemental resources.		43.2%	
How important do you think job training is for _____?	.84		.71
How important do you think training in interpersonal or social skills is for _____?	.76		.58
How important do you think higher education programs are for _____?	.75		.58
How important do you think recreational programs are for _____?	.63		.42
Factor 2: Beliefs regarding the importance of essential resources.		20.4%	
How important do you think social assistance is for _____?	.88		.77
How important do you think housing programs are for _____?	.63		.42

the solution, with items in each factor, factor loadings, percentage of variance accounted for by each factor, and communalities.

As shown in Table 5, Factor 1 consists of four items tapping into beliefs which emphasize the importance of specific community-based programs: job training, higher education, recreation, and social skills training programs. This factor appears consistent with beliefs regarding supplemental resources for individuals with a CMD as outlined in the literature (Leete, 1988).

Factor 2 consists of two items representing beliefs regarding essential resources. Housing and financial assistance are considered basic requirements for living and, therefore, as Factor 2 consists of two items relating to these resources, it is labeled beliefs regarding essential resources.

Beliefs Regarding Home Care

Principal components analysis of the six belief items regarding home care identified two factors with eigenvalues of 3.1 and 1.4. As both these factors were judged to be interpretable, a two-factor solution was adopted as the final solution. This solution is presented in Table 6, with items in each factor, factor loadings, percentage of variance accounted for by each factor, and communalities. Factor 1 consists of items regarding the impact of home care on the life of the individual with a CMD.

Table 6

Beliefs Regarding Home Care: Items, Factor Loadings, Variance Explained, and Communalities of Factors

Factor/Item	Factor Loading	Variance Explained	Communality
Factor 1: Beliefs regarding home care.		52.0	
In theory, home care provides/ would provide the most family-like atmosphere and, therefore, the most natural living arrangements for _____?	.92		.85
In theory, the quality of life of _____ is/would be greatest when s/he lives at home with other family members?	.88		.82
In theory, home care does not/would not provide an environment which best encourages normal functioning by _____?	.86		.77
Factor 2: Beliefs regarding family burden.		23.8%	
Social and interpersonal relationships are not/would not become limited or strained as a result of having _____ living at home.	.83		.73
It is/would be difficult to live with the psychiatric symptoms and behaviour displayed by _____.	.82		.67
As a result of having _____ living at home, practical problems such as financial strain occur/ would occur and daily routines are/would be disrupted.	.78		.69

Factor 2 is made up of three items representing beliefs regarding the impact (degree of burden) home care has on the life of the family member respondent. It is consistent with beliefs concerning burden that have been expressed by families who have a family member with a CMD (Thompson & Doll, 1982).

Beliefs Regarding the Importance of Resources for Home Care.

Principal components analysis of the eight belief items regarding the importance of resources for home care identified two factors with eigenvalues greater than 1.0.

One variable had salient loadings on two factors and was dropped. A second principal components analysis produced a two-factor solution, with eigenvalues of 2.8 and 1.2 respectively, as the final solution. Table 7 presents the final solution, with items in each factor, factor loadings, percentage of variance accounted for by each factor, and communalities.

As indicated in Table 7, Factor 1 consists of items regarding family resources. It includes self-help and support groups, home management training, respite care, emergency care services, and financial aid for families who have a member with a CMD. This factor is consistent with family members' beliefs regarding the types of resources families require if they have a relative with a CMD living at home (Spaniol et al., 1986a).

Factor 2 is made up of two items representing

Table 7

Beliefs Regarding the Importance of Resources for Home Care:
Items, Factor Loadings, Variance Explained, and Communalities
of Factors

Factor/Item	Factor Loading	Variance Explained	Communality
Factor 1: Beliefs regarding the importance of family supports.		40.3%	
How important is/would it be for you to receive respite care?	.75		.59
How important is/would it be for you to receive financial aid to cover the costs of home care for _____?	.72		.55
How important do you think it is/ would be to have 24 hours a day emergency care available?	.70		.51
How important is/would it be for mental health professionals to assist you to develop the skills and strategies that may help you to better cope with and manage _____?	.67		.52
How important is/would it be for you to belong to a self- help or support group?	.54		.42
Factor 2: Beliefs regarding the importance of family education.		17.3%	
How important is/would it be for you to be included in the treatment planning, including medication management for _____?	.86		.75
How important is/would it be for you to be informed and educated about mental disorders?	.81		.69

beliefs regarding family education. It also reflects some of the needs expressed by families who have a member with a CMD (Spaniol et al., 1986).

Beliefs Regarding Advocacy

Principal components analysis of the three belief items regarding advocacy identified one factor with an eigenvalue of 1.7 that formed the final solution. This factor represents family member respondents' beliefs regarding their responsibility and ability to advocate for better resources for community-based care. Table 8 presents the factor loadings, percentage of variance accounted for, and communalities of items in the solution.

Attitudes Toward Community-Based Care

Principal components analysis of the three attitude items regarding community-based care identified one factor, with an eigenvalue of 2.5, that formed the final solution. This factor represented family member respondents' beliefs regarding the effectiveness of community-based care. Table 9 presents the factor loadings, percentage of variance accounted for, and communalities of items in the solution.

Attitudes Toward Home Care

Principal components analysis of the six attitudes toward home care items identified two factors with eigenvalues of 3.2 and 1.7, respectively.

As both the factors were judged to be interpretable,

Table 8

Beliefs Regarding Advocacy: Items, Factor Loadings,
Variance Explained, and Communalities of the Factor

Factor/Item	Factor Loading	Variance Explained	Communality
Factor 1: Beliefs regarding advocacy.		56.8%	
Please indicate how influential you think you can be as an advocate for better, more effective community-based care.	.83		.69
Please indicate to what extent you possess the skills that are necessary for advocacy.	.77		.59
Please indicate to what extent you think it is your personal responsibility, as a relative of someone with a mental disorder, to advocate for better, more effective community-based care with those responsible for mental health care (e.g., mental health professionals, Manitoba Department of Health).	.65		.42

Table 9

Attitudes Toward Community-Based Care: Items, Factor Loadings, Variance Explained, and Communalities of the Factor

Factor/Item	Factor Loading	Variance Explained	Communality
Factor 1: Attitudes toward community-based care.		84.0%	
In your opinion, how effective is/would be community-based care for helping _____ to function normally?	.94		.89
In your opinion, how effective is/would be community-based care for improving the quality of life of _____?	.93		.87
In your opinion, how effective is/would be community-based care for providing living arrangements and treatment to _____?	.87		.76

a two-factor solution was adopted as the final solution. Table 10 presents the factor loadings, percentage of variance accounted for, and communalities of items in the solution. Factor 1 consists of three items relating to how home care impacts on the lives of individuals with a CMD.

Factor 2 is made up of three items representing feelings about the burden experienced by families as a result of having a family member with a CMD living at home. It is consistent with the feelings of burden experienced by other families who have a family member with a CMD living at home (Thompson & Doll, 1982).

Derivation of Factor Scores. The regression method was used to compute factor scores based on the final solutions described above. This method is the most broadly used procedure for estimating factor scores (Gorsuch, 1983). A major advantage of this approach over others is that it produces the highest correlations between factors and factor scores (Tabachnick & Fidell, 1989). The distribution of each factor score is standardized, with a mean of zero and a standard deviation of one.

For each respondent, missing values on individual items were estimated before calculating factor scores. This estimation was accomplished by using the mean of the other items making up that factor for the respondent. Items were left as missing if all other items making up

Table 10

Attitudes Toward Home Care: Factor Loadings, Variance Explained, and Communalities of Factors

Factor/Item	Factor Loading	Variance Explained	Communality
<hr/>			
Factor 1: Attitudes toward home care.		52.9%	
In your opinion, how effective is/would home care be for helping _____ function normally?	.94		.90
In your opinion, how effective is/would home care be for improving the quality of life of _____?	.93		.87
In your opinion, how is/would home care be for providing living arrangements and treatment to _____ in as natural a setting as possible?	.90		.83
<hr/>			
Factor 2: Attitudes toward family burden.		28.4%	
How much stress do you/would you experience as a result of practical problems (e.g., financial, disruption in daily routine) that develop/might develop as a result of having _____ living at home?	.89		.81
How much stress do you/would you experience due to a strain on, or loss of social and interpersonal relationships as a result of having _____ living at home?	.85		.73
How much stress do you/would you experience as a result of having to live with the psychiatric symptoms and behaviour displayed by _____ who is/would be living at home?	.82		.74

the factor in question were missing.

An examination of the covariance matrix for estimated factors showed them to be orthogonal to each other for all of the measures with two-factor solutions.

Internal Reliabilities of Measures. Internal reliabilities were calculated for items in the final factors. Cronbach's alpha for these measures ranged from .56 to .92. These alpha levels are considered adequate for representing unidimensional constructs. Table 11 shows Cronbach's alpha for all multiple-item measures.

Normative Beliefs and Subjective Norm. Normative beliefs regarding community-based care, home care, and advocacy were investigated in this study. Two items made up each of the three measures of normative beliefs. One question asked family member respondents the degree to which they believe their significant referents think they should take an action (e.g., support better resources for community-based care, support better resources for home care, advocate for better community-based care), and the other question investigated the degree to which family member respondents would comply with the wishes of their significant referents. The subjective norm question which corresponded to each set of normative beliefs asked about family member respondents' feelings regarding their significant referents favouring them taking the action in

Table 11

Cronbach's Alpha for Multiple Item Measures

Variable	Alpha Coefficient
Mental health system supports	.75
Family supports	.56
Beliefs regarding community-based care	.68
Attitudes toward community-based care	.90
Beliefs regarding the importance of supplemental resources (community-based care)	.73
Beliefs regarding the importance of essential resources (community-based care)	.68
Beliefs regarding home care	.89
Beliefs regarding family burden	.77
Attitudes toward home care	.92
Attitudes toward family burden	.82
Beliefs regarding the importance of family resources	.73
Beliefs regarding the importance of family education	.65
Beliefs regarding advocacy	.62

question. Table 12 presents the frequency with which different referents were named. Thirty percent of the family member respondents chose either a psychiatrist or medical doctor as their significant referent. Another 18% chose either a community mental health worker or another mental health professional. Therefore, one-half of the respondents chose someone within the mental health system as their most significant referent regarding mental health issues. Twenty-two percent of family member respondents named another family member, and 25% identified some other person (e.g., a friend) as their significant referent in this area.

Tests of Hypotheses

The next stage of the statistical analyses, hypotheses testing, involved partial correlations between sets of variables representing the first step in the theoretical model, and a series of Pearson correlations between sets of variables representing successive steps in the theoretical model. In all cases in which factor scores were computed, these were the variables used to test hypotheses. Partial correlation procedures were used to examine relationships between external variables and beliefs because gender and age for the sample of individuals with a CMD correlated significantly with several other external variables.

Therefore, as discussed previously, all analyses involving external variables controlled for these two

Table 12

Significant Referents of Family Member Respondents

Label	Frequency (n=100)	%	Cumulative %
MD/Psychiatrist	30	30.0	31.6
Community Mental Health Worker or other Mental Health Professional	18	18.0	50.5
Other Family Member	22	22.0	73.7
Friend/Other	25	25.0	100.0
No Response	5	5.0	

variables. One-tailed tests of significance are reported for all partial correlations and correlations, as it is the appropriate test of significance when the direction of the relationship between pairs of variables can be specified in advance of the analysis.

The final stage of the analyses involved standard multiple regressions. Where more than one independent variable correlated significantly with a dependent variable, a multiple regression analysis was conducted to measure the relative strength of the relationships, and to examine the predictive validity of the model utilized in the present study. The theoretical model for the study was based on Ajzen and Fishbein's (1980) theory of reasoned action, which delineates a chain of variables that ultimately predicts behaviour. The major objective of the present study was to investigate the behavioural intentions of family members to advocate for better resources for community-based care, including home care, for their family members with a CMD and for themselves.

Results of the tests of hypotheses and investigation of the theoretical model are presented in the following sections. As stated previously, all tests of significance were set at an alpha of .025.

External Variables and Beliefs

Hypothesis 1

Hypothesis 1 postulates that perceived social support by families will be directly related to positive

beliefs regarding community-based care (home care).

The partial correlations indicated that perceived social support by families was not significantly related to either positive beliefs regarding community-based care or positive beliefs regarding home care.

Hypothesis 1 was not supported.

Hypothesis 2.

Hypothesis 2 predicts that perceived social support by families will be directly related to positive beliefs regarding the adequacy of resources for community-based care (home care).

Family member respondents were asked about their beliefs regarding both the importance and adequacy of resources for community-based care. Skip logic was used such that the adequacy question regarding an individual resource was asked only if the respondent indicated that specific resource in question was important. The adequacy questions were grouped together to reflect the factor structure of the importance questions, and mean composite scores for each of two factors were computed. The same procedure was followed for family member respondents' beliefs regarding both the importance and adequacy of resources for home care.

The partial correlations showed that perceived family support was not significantly related to respondents' beliefs regarding the adequacy of resources for either community-based care or home care.

Hypothesis 2 was not confirmed.

Hypothesis 3

Hypothesis 3 predicts that perceived social support by families will be directly related to positive beliefs regarding advocacy.

The partial correlations showed no significant relationship between perceived social support by families and positive beliefs regarding advocacy.

Hypothesis 3 was not supported.

Hypothesis 4

Hypothesis 4 postulates that perceived mental health system supports will be directly related to positive beliefs regarding community-based care (home care).

Results of the partial correlation indicated that perceived mental health system supports were not significantly related to positive beliefs regarding either community-based care or home care.

Hypothesis 4 was not confirmed.

Hypothesis 5

Hypothesis 5 predicts that perceived mental health system supports will be directly related to positive beliefs regarding the adequacy of resources for community-based care (home care).

The partial correlations showed that perceived mental health system supports were not significantly related to respondents' beliefs regarding the adequacy of essential resources for community-based care. However, partial

correlation results did show that perceived mental health system supports were significantly related to positive beliefs regarding the adequacy of supplemental resources for community-based care ($r = .26, p < .01$). That is, the higher the perceived mental health system supports, the more positive the beliefs regarding the adequacy of supplemental resources for community-based care.

The partial correlations also showed that perceived mental health system supports were significantly related to positive beliefs regarding the adequacy of family resources ($r = .43, p < .001$); and positive beliefs regarding the adequacy of family education ($r = .45, p < .001$). That is, the higher the perceived mental health system supports, the more positive the beliefs regarding family resources and family education.

Hypothesis 5 was partially supported.

Hypothesis 6

Hypothesis 6 postulates that perceived mental health system supports will be directly related to positive beliefs regarding advocacy.

The partial correlation showed no significant relationship between perceived mental health system supports and positive beliefs regarding advocacy.

Hypothesis 6 was not confirmed.

Hypothesis 7

Hypothesis 7 postulates that negative mental health characteristics associated with individuals with a CMD

will be inversely related to positive beliefs regarding community-based care (home care).

The partial correlations indicated that diagnosis was not significantly related to family member respondents' beliefs regarding community-based care. However, the partial correlations indicated that both chronicity and severity were significantly related to family member respondents' beliefs regarding community-based care (chronicity: $r = .27$, $p < .01$; severity: $r = .25$, $p = .01$).

The shorter the time since the individual with a CMD was first diagnosed, and the lower the severity index, the more positive the beliefs regarding community-based care.

In relation to home care, the partial correlations indicated that neither diagnosis, chronicity nor severity were significantly related to family member respondents' beliefs regarding home care.

Hypothesis 7 was partially supported.

Hypothesis 8

Hypothesis 8 predicts that negative mental health characteristics associated with individuals with a CMD will be inversely related to positive beliefs regarding the adequacy of resources for community-based care (home care).

The partial correlation analyses showed no significant relationships between negative mental health characteristics associated with individuals with a CMD and

family member respondents' beliefs regarding the adequacy of resources for either community-based care or home care.

Hypothesis 8 was not confirmed.

Hypothesis 9

Hypothesis 9 postulates that negative mental health characteristics associated with individuals with a CMD will be inversely related to negative beliefs regarding advocacy.

The partial correlation showed no significant relationship between negative mental health characteristics associated with individuals with a CMD and family member respondents' beliefs regarding advocacy.

Hypothesis 9 was not supported.

Summary of External Variable-Belief Relationships and Examination of the Model. Significant correlations between the external variables and beliefs are outlined in Table 13. In evaluating the strength of relationships among variables in their theory, Ajzen & Fishbein (1980) interpret correlations less than .30 as low, in the .30 to .50 range as moderate, and greater than .50 as relatively strong.

As shown in Table 13, perceived mental health system supports as an external variable only correlated significantly with family member respondents' beliefs regarding the adequacy of resources for community-based care and for home care. Similarly, characteristics associated with the sample of individuals with a CMD only

Table 13

Significant Relationships Between External Variables and Beliefs

External Variables	Belief Factor	r
Higher perceived mental health system supports	Positive beliefs re: adequacy of supplemental resources for community-based care	.26**
Higher perceived mental health system supports	Positive beliefs re: adequacy of family resources	.43***
Higher perceived mental health system supports	Positive beliefs re: adequacy of family education	.45***
Fewer years since individual with a CMD was first diagnosed	Positive beliefs re: community-based care	.27**
Less severe symptoms (higher functioning)	Positive beliefs re: community-based care	.25**

*p < .025, **p < .01, ***p < .001

correlated significantly with family member respondents' beliefs regarding community-based care. The strength of these relationships ranged from .25 to .45, indicating low to moderate relationships.

The external variables which correlated significantly with a specific belief factor were utilized for further analyses. Multiple regression analyses were performed to determine which of these external variables (independent variables) were the best predictors of the specific belief factor (dependent variable).

The partial correlations indicated that in only one case did two external variables correlate significantly with the same belief factor. Both chronicity and severity (characteristics of individuals with a CMD) correlated significantly with family member respondents' beliefs regarding community-based care. Results of the multiple regression indicated that only severity entered the equation predicting family member respondents' beliefs regarding community-based care ($r = .35$, $\beta = .35$, $p < .001$).

Beliefs-Attitudes

Hypothesis 10

Hypothesis 10 postulates that positive beliefs regarding community-based care will be directly related to positive attitudes toward community-based care (home care).

Although correlation results did not show a significant relationship between family member

respondents' beliefs regarding community-based care and their attitudes toward community-based care, the results did approach significance ($r = .18$, $p < .05$).

Turning to home care, the correlational analyses also indicated that family member respondents' positive beliefs regarding home care correlated significantly with family member respondents' positive attitudes toward home care ($r = .77$, $p < .001$). Similarly, family member respondents' positive beliefs regarding family burden correlated significantly with family member respondents' positive attitudes towards family burden ($r = .69$, $p < .001$).

Hypothesis 10 was partially confirmed.

Hypothesis 11

Hypothesis 11 predicts that negative beliefs regarding the adequacy of resources for community-based care will be inversely related to negative attitudes toward better resources for community-based care (home care).

Family member respondents' beliefs regarding the adequacy of supplemental resources for community-based care correlated significantly with family member respondents' attitudes toward better supplemental resources ($r = -.29$, $p < .01$). The more negative the beliefs, the more positive the attitudes. In contrast, family member respondents' beliefs regarding the adequacy of essential resources for community-based care did not

correlate significantly with family member respondents' attitudes toward better essential resources. However, the results of the correlation analysis did approach significance ($r = -.19$, $p < .05$).

Family member respondents' beliefs regarding the adequacy of family resources for home care significantly correlated with family member respondents' attitudes toward better family resources ($r = -.32$, $p = .001$). The more negative the beliefs, the more positive the attitudes. However, family member respondents' beliefs regarding the adequacy of family education for home care did not correlate significantly with respondents' attitudes toward better family education.

Hypothesis 11 was partially supported.

Hypothesis 12

Hypothesis 12 predicts that positive beliefs regarding advocacy will be directly related to positive attitudes toward advocating for better community-based care.

The results showed that family member respondents' beliefs regarding advocacy correlated significantly with family member respondents' attitudes toward advocating for community-based care ($r = .46$, $p < .001$). The more positive the beliefs, the more positive the attitudes.

Hypothesis 12 was confirmed.

Summary of Belief-Attitude Relationships. The significant correlations between beliefs and attitudes are summarized in Table 14. The strength of the relationships range from a low of $-.29$ to a high of $.77$.

Normative Beliefs-Subjective Norm

Hypothesis 13

Hypothesis 13 postulates that the belief that their referents think they should support better resources for community-based care will be directly related to the perception that their referents favour them supporting better resources for community-based care (home care).

Results of the correlation analyses indicated that the belief that their referents think they should support the development of better resources for community-based care significantly correlated with the perception that their referents favour them supporting better resources for community-based care ($r = .66, p < .001$).

Similarly, the belief that their referents think they should support better resources for home care significantly correlated with the perception that their referents favour them supporting better resources for home care ($r = .75, p < .001$).

Hypothesis 13 was supported.

Hypothesis 14

Hypothesis 14 predicts that the belief that their referents think they should advocate for better community-

Table 14

Significant Relationships Between Beliefs and Attitudes

Belief	Attitude	r
Positive beliefs re: home care	Positive attitudes toward home care	.77***
Positive beliefs re: family burden	Positive attitudes toward family burden	.69***
Negative beliefs re: adequacy of supplemental resources for community-based care	Positive attitudes toward supplemental resources for community-based care	-.29**
Negative beliefs re: adequacy of family resources	Positive attitudes toward family resources	.32***
Positive beliefs re: advocacy	Positive attitudes toward advocacy	.46***

*p < .025, **p < .01, ***p < .001

based care will be directly related to the perception that their referents favour them advocating for better community-based care.

The results indicated that the belief that their referents think they should advocate for better community-based care significantly correlated with the perception that their referents favour them advocating for better resources for community-based care ($r = .80$, $p < .001$).

Hypothesis 14 was confirmed.

Summary of Normative Belief-Subjective Norm

Relationships and Examination of the Model. The significant correlations between normative beliefs and subjective norms are summarized in Table 15. The strength of the correlation was high for each of the three relationships, ranging from .66 to .80.

It is important to reiterate that Ajzen and Fishbein's (1980) theoretical model delineates two components which comprise normative beliefs: the normative belief itself, and the individual's motivation to comply with his or her significant referent's belief. Both components were investigated separately in relation to the subjective norm, an aspect of attitudes. Results of the correlational analyses investigating the relationship between the normative belief component and subjective norm have been reported previously.

Results of the correlational analyses examining the relationship between the motivation to comply component of

Table 15

Significant Relationships Between Normative Beliefs and Subjective Norm

Normative Beliefs	Subjective Norm	r
Belief that referents think respondents should support the development of resources for community-based care	Perception that referents favour respondents supporting the development of resources for community-based care	.66***
Belief that referents think respondents should support the development of resources for home care	Perception that referents favour respondents supporting the development of resources for home care	.75***
Belief that referents think respondents should advocate for better resources for community-based care	Perception that referents favour respondents advocating for better resources for community-based care	.80***

*p < .025, **p < .01, ***p < .001

normative beliefs and subjective norm indicated that the motivation to comply with the wishes of their referents regarding family member respondents supporting the development of better resources for community-based care correlated significantly with the perception that their referents favour them supporting the development of better resources for community-based care ($r = .39$, $p < .001$).

Family member respondents' motivation to comply with the wishes of their referents regarding family member respondents advocating for better community-based care correlated significantly with the perception that their referents favour them advocating for better community-based care ($r = .34$, $p < .001$).

Regarding home care, the motivation to comply with the wishes of their referents regarding family member respondents supporting the development of better resources for home care correlated significantly with the perception that their referents favour them supporting the development of better resources for home care ($r = .33$, $p < .01$).

The significant correlations between the motivation to comply component of normative beliefs and subjective norm are outlined in Table 16. The strength of the correlation was moderate for each of the relationships, ranging from .33 to .34.

Table 16

Significant Relationships Between Motivation to Comply
Component of Normative Beliefs and Subjective Norm

Motivation to Comply	Subjective Norm	r
Given your referent's belief, how much do you want to comply with his or her wishes so as to satisfy him or her?	Perception that referents favour respondent supporting the development of resources for community-based care	.39***
Given your referent's belief, how much do you want to comply with his or her wishes so as to satisfy him or her?	Perception that referents favour respondent supporting the development of resources for home care	.33**
Given your referent's belief, how much do you want to comply with his or her wishes so as to satisfy him or her?	Perception that referents favour respondent advocating for better resources for community-based care	.34***

*p < .025, **p < .01, ***p < .001

Multiple regression analyses were conducted to determine whether the normative belief itself or the individual's motivation to comply with his or her referent best predicted the subjective norm. The results of the multiple regressions indicated that, in each of the three analyses examining the relationship between normative beliefs and subjective norm (resources for community-based care, resources for home care, and advocating for resources for community-based care), only the normative belief itself predicted the subjective norm ($r = .66$, $B = .66$, $p < .000$; $r = .75$, $B = .75$, $p < .000$; $r = .80$, $B = .80$, $p < .000$ respectively).

Attitudes-Behavioural Intentions

Hypothesis 15

Hypothesis 15 postulates that positive attitudes toward better resources for community-based care and advocating for better community-based care will be directly related to positive behavioural intentions to advocate for better resources for community-based care.

The correlational analysis showed that positive behavioural intentions to advocate for better resources for community-based care were directly related to both positive family member respondents' attitudes toward better resources for community-based care ($r = .27$, $p < .01$) and positive family member respondents' attitudes toward advocating for better community-based care ($r = .41$, $p < .001$).

Hypothesis 15 was supported.

Hypothesis 16

Hypothesis 16 postulates that positive attitudes toward better resources for home care will be directly related to positive behavioural intentions to advocate for better resources for home care.

The results of the correlational analysis indicated that family member respondents' attitudes toward better resources for home care did not correlate significantly with family member respondents' behavioural intentions to advocate for better resources for home care.

Hypothesis 16 was not confirmed.

Summary of Attitude-Behavioural Intentions Relationships and Examination of the Model. As stated above, the results indicated significant relationships between both attitudes (i.e., toward better resources, toward advocating) regarding community-based care and behavioural intentions to advocate for resources for community-based care. A multiple regression analysis was conducted to determine which of these attitudes best predicted behavioural intentions to advocate for resources for community-based care. The results of the multiple regression showed that both family member respondents' attitudes toward better resources for community-based care, and family member respondents' attitudes toward advocating for better community-based care, predicted family member respondents' behavioural intentions to

advocate for better resources for community-based care.

Family member respondents' attitudes toward advocating for better community-based care was the more salient predictor of family member respondents' behavioural intentions to advocate for better resources for community-based care. Table 17 shows the Multiple R, R^2 , beta weights, and F (change) for the multiple regression analysis. The strength of these relationships were in the low to moderate range.

Subjective Norm-Behavioural Intentions

Hypothesis 17

Hypothesis 17 predicts that the perception that their referents favour them supporting better resources for community-based care (home care) will be directly related to positive behavioural intentions to advocate for better resources for community-based care (home care). Neither of the correlations was significant.

Hypothesis 17 was not supported.

Hypothesis 18

Hypothesis 18 predicts that the perception that their referents favour them advocating for better community-based care will be directly related to positive behavioural intentions to advocate for resources for community-based care.

The correlation was not significant. Hypothesis 18 was not confirmed.

Table 17

Significant Relationships Between Attitudes and Behavioural Intentions

Attitudes	Behavioural Intentions	R	R ²	B	F (change)
Attitudes toward advocating for better community-based care	Behavioural intentions to advocate for better resources for community-based care	.41	.17	.41	19.7***
Attitudes toward better resources for community-based care	Behavioural intentions to advocate for better resources for community-based care	.46	.22	.22	5.8***

* $p < .025$, ** $p < .01$, *** $p < .001$

Attitudes, Subjective-Norm, and Behavioural IntentionsHypothesis 19

Hypothesis 19 postulates that the perception that their referents favour them supporting better resources for community-based care, the perception that their referents favour them advocating for better community-based care, and positive attitudes toward (a) better resources for community-based care and (b) advocating for better community-based care all will be directly related to behavioural intentions to advocate for better resources for community-based care.

Both attitudes and both subjective norms previously were correlated with family member respondents' behavioural intentions to advocate for better resources for community-based care. A multiple regression analysis also was conducted to determine which of the two attitudes best predicted behavioural intentions. Hypothesis 19 predicts an additive effect between attitudes and subjective norms. Therefore, the next step would have been to conduct a multiple regression analysis utilizing both attitudes and both subjective norms to predict behavioural intentions. However, previous analyses showed that neither subjective norm was significantly related to behavioural intentions to advocate for resources for community-based care. Therefore, this next step would not have been appropriate statistically.

Hypothesis 19 was not tested.

Hypothesis 20

Hypothesis 20 predicts that the perception that their referents favour them supporting better resources for home care, and positive attitudes toward better resources for home care, will be directly related to positive behavioural intentions to advocate for better resources for home care.

Both the perception that their referents favour them supporting better resources for home care, and respondents attitudes toward better resources for home care, were investigated previously in relation to respondents' behavioural intentions to advocate for resources for home care. Hypothesis 20 predicts an additive effect between attitudes and subjective norms. Therefore, the next step would have been to conduct a multiple regression analysis utilizing both the attitude and subjective norm to predict behavioural intentions. However, as the perception that their referents favour them supporting better resources for home care did not correlate significantly with their behavioural intentions to advocate for better resources for home care, a multiple regression analysis would not have been appropriate statistically.

Hypothesis 20 was not tested.

Summary of Attitudes, Subjective-Norm, and Behavioural Intentions Relationships and Examination of the Model.

The two hypotheses investigating the relationships among attitudes, subjective norm, and behavioural intentions

(#19 and #20) were included for the purpose of examining this portion of the theoretical model, and determining whether attitudes or subjective norm would best predict behavioural intentions. The results of these analyses suggested that no new information would be gained from further analyses, because there was not a significant relationship between subjective norm and behavioural intentions in either instance.

Family member respondents' attitudes toward advocating for better community-based care best predicted family member respondents' behavioural intentions to advocate for better resources for community-based care. Family member respondents' attitudes toward community-based care, and the perception that their referents favour them advocating for better resources for community-based care, were not analyzed to determine whether attitudes and subjective norms provided an additive effect in predicting behavioural intentions, as subjective norms were not significantly related to behavioural intentions.

Overall Examination of the Model

The major objective of the present study involved investigating family respondents' behavioural intentions to advocate for better resources for community-based care, including home care, for their family member with a CMD and for themselves. The theoretical model for the study, developed from Ajzen and Fishbein's (1980) theory of reasoned action, delineates a chain of variables that

ultimately predict behavioural intentions (see figure 4 and 5). Individual hypotheses were generated from this model. The previous section presented the results of the tests of these hypotheses and an examination of the ability of independent variables at one step of the model to predict a dependent variable at the next step of the model.

A further examination of the predictive validity of the model utilized in this study was conducted through a series of multiple regression analyses investigating the relationship between external variables and behavioural intentions; beliefs and behavioural intentions; and attitudes and behavioural intentions. The purpose of these analyses was to investigate which variables best predicted behavioural intentions.

Two multiple regressions were conducted to investigate the relationship between external variables and behavioural intentions to advocate for better resources for community-based care (home care). For both analyses, seven external variables were entered into the regression in a stepwise fashion. The first five external variables related to the sample of individuals with a CMD, namely age, gender, diagnosis, chronicity, and severity. The other two external variables were perceived family supports and perceived mental health system supports. The results of the regressions showed no significant relationships among the external variables utilized in the

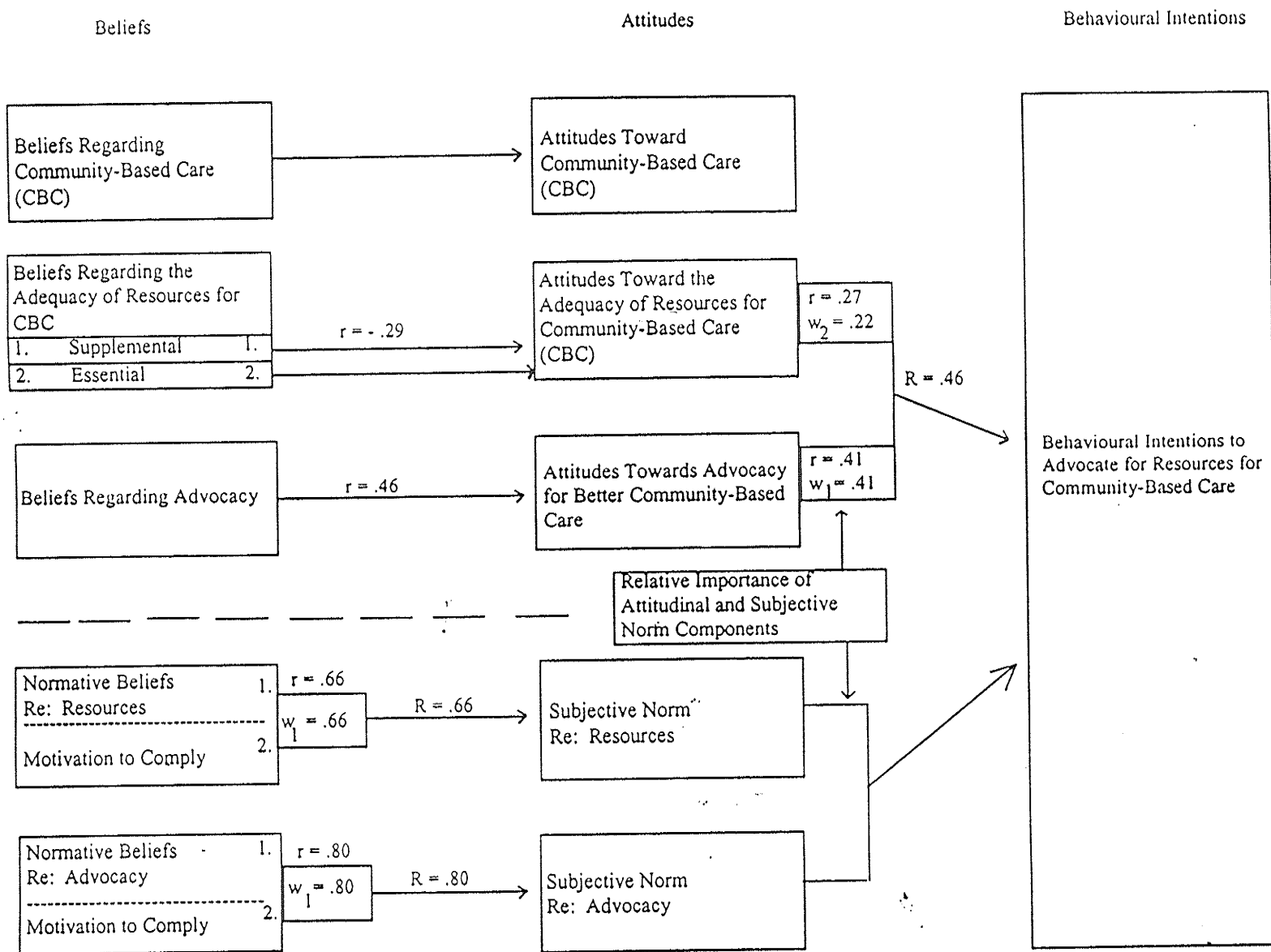


Figure 4. Model for family member respondents' behavioural intentions to advocate for resources for community-based care

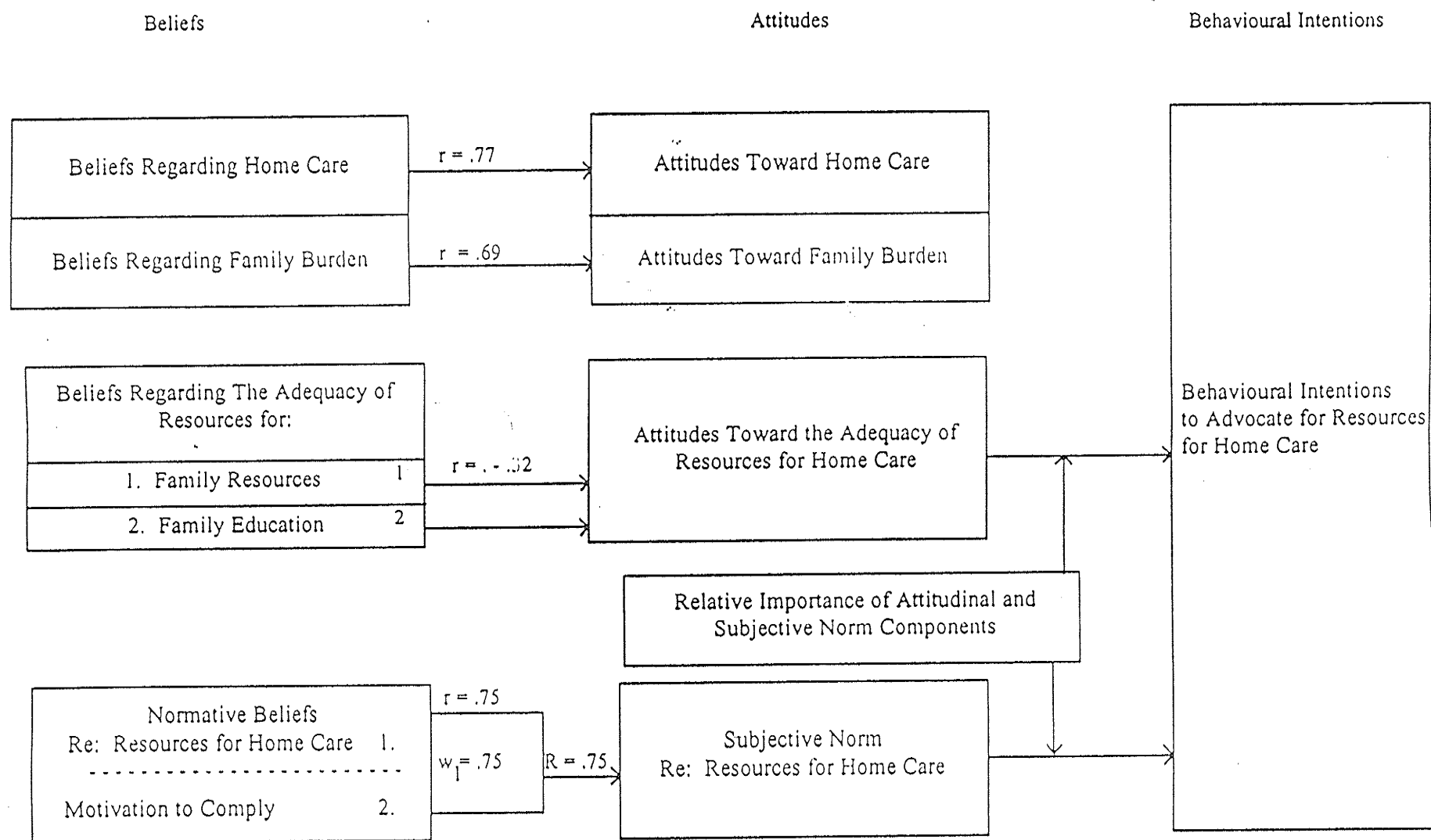


Figure 5. Model for family member respondents' behavioural intentions to advocate for resources for home care.

present study and behavioural intentions. However, in several of these analyses, gender, age, or gender and age together were found to be predictors of family member respondents' beliefs.

Next, two stepwise regression analyses were conducted to investigate the relationships among all belief factors regarding community-based care (home care) and behavioural intentions to advocate for resources for community-based care (home care). The following beliefs regarding community-based care were entered into the first regression analysis: beliefs regarding community-based care; beliefs regarding the adequacy of supplemental resources for community-based care; beliefs regarding the adequacy of essential resources for community-based care; and beliefs regarding advocacy. The following beliefs regarding home care were entered into the second regression analysis: beliefs regarding home care; beliefs regarding family burden; beliefs regarding the adequacy of family resources; and beliefs regarding the adequacy of family education.

The results of the first multiple regression indicated that both family member respondents' beliefs regarding advocacy and respondents' beliefs regarding the adequacy of necessary resources for community-based care predicted their behavioural intentions to advocate for better resources for community-based care ($r = .49$, $B = .49$, $p < .001$; and $r = -.21$, $B = -.20$, $p < .001$

respectively). Family member respondents' beliefs regarding advocacy was the more salient predictor. Table 18 shows the Multiple R, R^2 , beta weights, and F (change). The strength of these relationships were in the low to moderate range.

The results of the second multiple regression did not indicate any significant relationships among family member respondents' beliefs regarding home care and their behavioural intentions to advocate for better resources for home care.

Finally, two multiple stepwise regression analyses investigated the relationships among all attitude factors/variables toward community-based care (home care) and behavioural intentions to advocate for resources for community-based care (home care). The following attitudes toward community-based care were entered into the first regression analysis: attitudes toward community-based care; attitudes toward the desirability of better resources for community-based care; and attitudes toward advocating for better community-based care. The following attitudes toward home care were entered into the second regression analysis: attitudes toward home care; attitudes toward family burden; and attitudes toward the desirability of better resources for home care.

The results of the first multiple regression indicated that both family member respondents' attitudes toward advocating for better community-based care and

Table 18

Significant Relationships Between Beliefs and Behavioural Intentions

Beliefs	Behavioural Intentions	R	R ²	B	F (change)
Beliefs regarding advocacy	Behavioural intentions to advocate for better resources for community-based care	.49	.24	.49	29.0***
Beliefs regarding necessary resources for community-based care	Behavioural intentions to advocate for better resources for community-based care	.53	.28	-.21	17.5***

*p < .025, **p < .01, ***p < .001

respondents' attitudes toward the desirability of better resources for community-based care predicted their behavioural intentions to advocate for better resources for community-based care ($r = .41$, $B = .41$, $p < .001$; and $r = .27$, $B = .22$, $p < .001$ respectively). Family member respondents' attitudes toward advocacy was the more salient predictor. Table 19 shows the Multiple R, R^2 , beta weights, and F (change). The strength of these relationships were in the low to moderate range.

The results of the second multiple regression did not indicate any significant relationships among family member respondents' attitudes toward home care and respondents' behavioural intentions to advocate for better resources for home care.

In summary, the overall examination of the model utilized in this study showed that family member respondents' beliefs regarding advocacy ($r = .50$, $p < .000$); beliefs regarding the adequacy of necessary resources ($r = -.21$, $p < .000$); attitudes toward the desirability of advocating for better community-based care ($r = .41$, $p < .000$); and attitudes toward the desirability of better resources for community-based care ($r = .30$, $p < .000$); all predicted respondents' behavioural intentions to advocate for better resources for community-based care. Family member respondents' beliefs regarding advocacy and the adequacy of necessary resources were stronger predictors of family member respondents' behavioural intentions to

Table 19

Significant Relationships Between Attitudes and Behavioural Intentions

Attitudes	Behavioural Intentions	R	R ²	B	F (change)
Attitudes toward advocacy	Behavioural intentions to advocate for better resources for community-based care	.41	.17	.41	19.7***
Attitudes toward the desirability of better resources for community-based care	Behavioural intentions to advocate for better resources for community-based care	.46	.22	.22	5.8***

*p < .025, **p < .01, ***p < .001

advocate for better resources for community-based care than were respondents' attitudes toward advocating for better resources for community-based care and the desirability of better resources for community-based care.

Family member respondents' beliefs regarding advocacy were the most salient predictor of respondents' behavioural intentions to advocate for resources for community-based care. In regard to home care, none of the external variables, beliefs, or attitudes predicted behavioural intentions.

Discussion

The purpose of the present study was to investigate several hypotheses relating to community-based care, including home care, for individuals with a CMD and their families. The study also examined a model based upon Ajzen and Fishbein's (1980) Theory of Reasoned Action. The model utilized in the present study provided the framework for the hypotheses.

The discussion is organized into two major sections. The first section discusses the theoretical implications of the findings, and the second section addresses the practical implications of the findings for system and program planning.

Theoretical Implications of the Study

Community-Based Care. Family member respondents' beliefs regarding community-based care did not correlate significantly with their attitudes toward community-based

care, although the relationship did approach significance. The most obvious explanation is that family member respondents answered belief questions more "in principle" and attitude questions based on actual services and their effectiveness.

Besides the explanation offered above, concerning family member respondents' beliefs and attitudes regarding community-based care, there also are four possible methodological explanations as to why family member respondents' beliefs did not correlate with their attitudes, in this instance. First, a more stringent than normal alpha level (.025) was selected due to the sample size and the numerous comparisons made in this study. The relationship would have been significant at the .05 alpha level.

Second, as shown previously, the variance in each of the belief items in the measure of beliefs regarding community-based care was very small. When the variance of an item is very small, the range of responses is restricted, and this attenuates the correlation coefficient. The result is a much weaker linear relationship (Tabachnick & Fidell, 1989).

Third, the Theory of Reasoned Action (Ajzen & Fishbein, 1980) makes reference to a person's beliefs regarding and attitudes toward a behaviour. It does not include such traditional attitudes as attitudes toward objects, people, or institutions. Beliefs regarding

community-based care in the present study do not refer to a person's beliefs regarding performing a certain behaviour. This could have reduced the accuracy of the relationship.

Finally, this theory states that a lack of correspondence between components on any of four dimensions (action, target, context, and time) can reduce the accuracy of prediction. Although the items in the beliefs regarding community-based care factor compared community-based care to hospitalization, the items in the attitudes toward community-based care factor did not compare community-based care to hospitalization, but only addressed the effectiveness of community-based care. This lack of correspondence in regard to context may also have reduced the accuracy of the predictive relationship.

Although family member respondents' beliefs regarding supplemental resources were significantly related to their attitudes toward resources for community-based care, respondents' beliefs regarding necessary resources were not related to their attitudes toward resources for community-based care. However, as indicated previously, the variance for the attitudes toward resources for community-based care measure is very small. Therefore, as this relationship did approach significance, it is possible that the lack of variability in responding contributed to this finding.

One essential component of community-based care is

comprehensive services and supports for individuals with a CMD. With the exception of higher education, at least 75% of family member respondents believed that both supplemental and essential resources for community-based care were very important. Between one-third and one-half of family member respondents also believed these resources were very inadequate, and another 10 - 15% believed that they were not sufficiently adequate. As a result, 90% of family member respondents indicated that they felt it was very desirable to have better resources for community-based care. It seems logical that if family member respondents believed in community-based care, but also believed that resources were inadequate and that community-based care could be more effective, they also would feel it was desirable to have better resources for community-based care. Although family member respondents' responses suggest this is the case, the results of the correlational analyses do not support this argument.

Seventy-five percent of family member respondents believed that it was their personal responsibility to advocate on behalf of their family member with a CMD and themselves with those responsible for mental health care. Family member respondents varied in their beliefs regarding their ability to advocate, however, and over 50% believed they would not be very influential as advocates. These belief items comprised the beliefs regarding advocacy factor. Family member respondents' beliefs

regarding advocacy were significantly related to their attitudes toward advocacy. Family member respondents' attitudes toward advocacy also were significantly related to their behavioural intentions to advocate for better resources for community-based care.

Beliefs regarding, attitudes toward, and behavioural intentions regarding advocacy all refer to performing a behaviour and, thus, adhere more strictly to the Ajzen and Fishbein's (1980) theoretical model. There also was correspondence between adjacent steps of the model, in the sense that each step referred to advocacy in relation to better community-based care. Perhaps as a consequence, each step correlated significantly with the step adjacent to it. These findings provide more support for the Theory of Reasoned Action and for the model proposed in this study.

Unexpectedly, however, family member respondents' beliefs regarding advocacy better predicted family member respondents' behavioural intentions to advocate for better resources for community-based care than did respondents' attitudes toward advocacy. The beliefs regarding advocacy factor was the most salient predictor of the behavioural intention (community-based care) factor. In other words, family member respondents' beliefs regarding advocacy best predicted their behavioural intentions to advocate for resources for community-based care.

The finding that family member respondents' beliefs

regarding advocacy better predicts their behavioural intentions to advocate for resources for community-based care than their attitudes towards advocacy is contrary to the model. Recent research based on this theory offers a possible explanation for this finding. Meyerowitz & Chaiken (1987) and Ronis & Kaiser, (1989) investigated self-breast examination behaviour, and found that self-efficacy was an independent determinant of behavioural intentions.

van Ryn & Vinokur (1992) also found self-efficacy to be an independent determinant of behavioural intentions. They examined the mediating effects of job search self-efficacy, attitudes, norms and intentions on job search behaviour. Their results demonstrated the primary role of self-efficacy as the sole cognitive mediator of intervention effects on job-seeking adaptive coping behaviour following the stressful life events of job loss and unemployment. The results showed that job-search self-efficacy had relatively durable effects on intention to job-seek over time, despite repeated failures to get a job. van Ryn and Vinokur (1992) suggested that self-efficacy generates expectancies that one can perform the behaviour successfully, which in turn are likely to increase the intention to perform the behaviour. Conversely, having little confidence in one's ability to execute a behaviour is likely to undermine the intention regardless of attitudes or subjective norms toward the

behaviour.

It is feasible that because the questions comprising the beliefs regarding advocacy factor included not only beliefs regarding advocacy but also beliefs regarding ability to perform the behaviour and to be influential, this factor also provided an independent determinant of behavioural intention. If this is the case, the model utilized in this study also lends credence to self-efficacy acting as an independent determinant of behavioural intentions.

The second best predictor of family member respondents' behavioural intentions to advocate for better resources for community-based care was their beliefs regarding essential resources (housing, welfare/social assistance). Family member respondents' attitudes toward advocacy and resources for community-based care also were directly related to their behavioural intentions to advocate for better resources for community-based care, but were less salient predictors than respondents' beliefs regarding essential resources for community-based care. Once again, this finding is contrary to the model. However, Ajzen and Fishbein (1980) hypothesized that the effects of prior behaviour would be mediated entirely through beliefs, by shaping and changing beliefs and attitudes. Behavioural intention is the immediate determinant of behaviour. Therefore, prior behaviour would not be expected to have an effect on actual

behaviour separate from its mediation through beliefs.

Several studies have found that past behaviour has the ability to independently predict later behaviour. Granberg and Holmberg (1990) found prior voting behaviour separately predicted behavioural intentions to vote and voting behaviour in later elections. Prior behaviour was a more powerful predictor than behavioural intentions of shoplifting, cheating, and lying (Beck & Ajzen, 1991), computer equipment and software purchasing (McQuarrie & Langmeyer, 1987), donating (Manfredo & Shelby, 1988), and prior smoking (Godin & Le Page, 1988).

Keulker (1993) reviewed the recent literature in this area and found that the studies reviewed consistently indicate that past behaviour, whether frequent or infrequent, predicts later behaviour. Perhaps past advocacy behaviour might be the best predictor of behavioural intentions to advocate for resources for community-based care. If prior behaviour is mediated entirely through beliefs, it seems plausible that beliefs might be a more salient predictor of behavioural intentions than are attitudes.

The advocacy attitude measure consisted of only one item which asked family member respondents' a general attitude question regarding the desirability of advocating for resources for community-based care. The beliefs regarding advocacy factor was comprised of three items. Each of these items referred to beliefs regarding a

specific aspect of advocacy (responsibility, ability, and influence). If the attitude measure had consisted of items corresponding to the specific items in the beliefs regarding advocacy factor, there would have been greater specificity within the measure, which may have allowed for greater predictability. Family member respondents' may feel it is desirable to advocate for resources for community-based care, but not feel they have the ability to advocate and/or feel that they can have any influence. In fact, over 50% of family member respondents do not believe they could be influential as advocates. If they also do not feel that they can be influential, this could affect their behavioural intentions to advocate, and be an indication of a lack of self-efficacy.

In both instances where a normative belief was correlated with its corresponding subjective norm, the relationship was found to be significant. If a family member respondent believed his or her significant referent thought he or she should support the development of better resources for community-based care, then the respondent also felt that the referent favoured him or her supporting these initiatives. The same was true for advocacy for community-based care. However, neither of the subjective norm components associated with community-based care correlated significantly with family member respondents' behavioural intentions to advocate for better resources for community-based care.

Ajzen & Fishbein (1980) suggested that it is likely that people hold favourable attitudes toward behaviours their significant referents think they should perform and negative attitudes toward behaviours their referents think they should not perform. When this is the case, the attitude and subjective norm are in agreement and the prediction of intention is relatively straightforward. However, if a person holds a favourable attitude toward performing a behaviour and yet believes that his or her important referent thinks he or she should not perform it, the person's intention will depend on the relative importance of the two components. It appears that, in the present study, only family member respondent's attitudes toward community-based care correlated significantly with family member respondents' behavioural intentions to advocate for community-based care.

As stated above, neither of the subjective norm components correlated significantly with family member respondents' behavioural intentions to advocate for resources for community-based care. Keulker (1993) reported that a variable that has been investigated as an addition to the Theory of Reasoned Action is personal norm or moral obligation towards performing a behaviour. Keulker, in his review of the current research on the Theory of Reasoned Action, found that in the five reports which indicated personal norm or moral obligation was a separate construct from intention, it also predicted

intention and/or behaviour.

The Theory of Reasoned Action is a cognitive and rational model, and normative variables are considered to be cognitive variables (Ajzen & Fishbein, 1980). The present study investigated issues that are very personal and sensitive to the family member respondents. The use of a cognitive, rational model constrains the way in which questions and answers may be posed, and creates an artificial situation divorced from what people may feel. The model may not be appropriate when examining emotionally charged and very personal issues.

Two studies which investigated whether affective variables predict behavioural intentions or behaviour indicated that affective variables aid in the prediction of behavioural intentions and behaviour. Boyd and Wandersman (1991) found that fear of aids predicted condom use separately from intention, and the results of a study conducted by Welsh and Gordon (1991) investigating aggressive behaviour in a role-play situation in a prison setting, showed that arousal and trait anger predicted both behavioural intentions and behaviour.

Home Care. With one exception, all hypotheses examining the relationships between belief factors and attitude factors/variables, in relation to home care, were supported. Family member respondents' beliefs regarding home care were significantly related to their attitudes toward home care and respondents' beliefs regarding family

burden were significantly related to their attitudes toward family burden. Family member respondents' beliefs regarding family resources were significantly related to their attitudes toward better resources for home care, but respondents' beliefs regarding family education were not related to their attitudes toward better resources for home care. Family members may be more concerned about having concrete resources (e.g., respite care, emergency services, financial aid) available to assist them and relieve them of some of the burden they experience as a result of caring for their family member with a CMD, rather than having more information about chronic mental disorders and more involvement in their family member's treatment plan.

Family member respondents indicated a need for resources for home care. While 72% of respondents believed that respite care was important, at least 75% believed that information/education, involvement in treatment planning, ongoing consultation with mental health professionals, home management training, and emergency care also were important resources. Depending on the particular resource, 25 - 55% of family member respondents believed these resources were very inadequate, and another 7 - 14% believed they were not adequate enough. Not surprisingly, eighty-five percent of family member respondents felt it would be desirable to have better resources for home care.

Following from this, a large percentage (76 - 87%) of family member respondents indicated they would advocate for better resources for home care. However, the relationship between family member respondents' attitudes toward better resources for home care and their behavioural intentions to advocate for better resources for home care only approached significance.

Methodologically, the use of a more stringent alpha level than is traditional may account for the non-significant relationship. While respondents were asked about their beliefs regarding and attitudes toward advocacy, the belief factor and attitude variable both were concerned with advocacy regarding community-based care. Family member respondents were not asked about their beliefs regarding and attitudes toward advocacy in relation to home care. The behavioural intentions regarding home care factor refers specifically to advocating for resources for home care. As family member respondents were not asked about their beliefs regarding and attitudes toward advocating for resources for home care, there was a lack of correspondence between adjacent steps in the model. If family member respondents did not believe in advocacy and/or did not have favourable attitudes towards advocacy in regard to home care, they may not be willing to advocate for better resources for home care, even if they thought it was important to have resources for home care and were in favour of having these

resources. Separate scales examining beliefs regarding advocacy and attitudes toward advocacy in relation to home care would have provided relevant data and allowed for a more adequate test of the hypotheses.

Following from this argument, family member respondents' were requested to answer questions regarding the importance and adequacy of resources for home care, whether or not they personally supported home care for their family member with a CMD. At this point in the interview, numerous respondents felt it was necessary to mention that they did not want, or could not have, their family member living at home. At the end of the interview, family member respondents were asked if they would like to make any further comments. Although many respondents had commented on this previously in the interview, 18 of 75 (24%) who did not have their family member living with them again specifically mentioned that they either did not believe in home care, or were not able to have their family member with a CMD live with them.

As previously suggested, many family member respondents who stated that resources for home care were important and inadequate, and also stated that these resources were desirable, may not have been as willing to advocate for them, if they were not committed personally to home care. Once again, questions on beliefs regarding and attitudes toward advocacy in relation to home care were not included in the interview. An understanding of

family member respondents' beliefs regarding and attitudes toward advocacy in relation to home care may also have assisted in clarifying this issue.

One other methodological issue relates to the use of cognitive variables and the rational nature of the Theory of Reasoned Action (Ajzen & Fishbein, 1980). Many family member respondents believed that having a family member living at home placed a heavy burden on the family. As indicated, some family members also mentioned that they either did not believe in home care, or were not able to have their family member with a CMD live with them. For these reasons, the portion of the interview that addressed issues of home care brought forth the greatest emotional response from family member respondents. The overall issue is a sensitive one for them. They often have experienced great pain, anguish, and frustration both for their family member with a CMD and for themselves. The model utilized in this study determined the way in which questions were posed. The questions may not have addressed family member respondents ambivalent feelings around home care or the emotionality associated with some of the issues. As mentioned in the section on community-based care, a couple of studies have found that affective variables aid in the prediction of intention and/or behaviour. Issues as personal and sensitive as the ones addressed in the present study may not be adequately addressed by such a cognitive model.

As with community-based care, normative beliefs were significantly related to the subjective norm. However, the subjective norm was not significantly related to family member respondents' behavioural intentions to advocate for resources for home care. Home care affects family members in a much more direct way than community-based care, as they are more intimately involved in the day to day life and care of their family member with a CMD. Therefore, family member respondents may be even less influenced by their significant referents in this area. The inclusion of a measure of personal norm or moral obligation may have provided important additional information. It could be hypothesized that it is a family member respondent's own personal norm or moral obligation towards performing a behaviour that determines his or her behavioural intentions to advocate for resources for home care, rather than the subjective norm.

Characteristics of the Sample of Individuals with a

CMD. In the present study, diagnosis did not correlate significantly with any of the belief factors. One possible explanation for the non-significant relationship between diagnosis of the sample of individuals with a CMD and family member respondents' beliefs may be related to the sample itself. Seventy-seven percent of the sample of individuals with a CMD had a diagnosis of schizophrenia. Since over three-quarters of the sample of individuals with a CMD had the same

diagnosis, and they all were functionally classified as having a serious, chronic disorder, these factors may have combined to produce little variability operationally. This could account for the fact that diagnosis was not related to respondents' beliefs.

Only chronicity and severity correlated significantly with family member respondents' beliefs regarding community-based care. The longer the time since the individual with a CMD had been first diagnosed and the more severe the symptomatology, the more negative were family member respondents' beliefs regarding community-based care. Many of the sample of individuals with a CMD had been diagnosed many years ago (38% over 15 years ago; 24% over 10 years ago) and were now older. Respondents may not have believed that their family member with a CMD would benefit from community-based care at this point. Many of the individuals with a CMD had been hospitalized for quite some time and had difficulty adjusting to community life, particularly without adequate supports. Many family member respondents, themselves, were older. These family members identified increased concerns about the well-being of their family member with a CMD when they are not around to support them in the community (Grosser & Vine, 1991).

While many family member respondents' view community-based care as preferable to hospitalization in principle, they may have grave concerns about its

effectiveness and the ability of their family member with a CMD to function in the community without adequate supports. The longer individuals with a CMD have been out of the community, the more supports they require to assist them in adjusting to community-life. The more severe the illness, the more supports the individual with a CMD requires. If a respondent does not believe supports are available in the community, but knows that his or her family member has been cared for previously in a hospital, it is not surprising that severity would be directly related to perceiving a hospital as the best locus of care.

Chronicity and severity did not correlate significantly with any of the other beliefs held by family member respondents. Chronicity and severity may influence family members beliefs regarding home care and family burden. However, as indicated previously, beliefs regarding home care and family burden also are affected by many other factors, such as financial concerns, interference with day to day living, and lack of resources.

Family member respondents, in general, believed that resources for community-based care, including home care, were important and inadequate. Chronicity and severity may have affected the number and types of supports family member respondents believed were necessary for their family member with a CMD. However, regardless of the

chronicity or severity of the problem, family member respondents' believed that better resources were required for their family member with a CMD and themselves.

Finally, in general, the linkage between external variables and beliefs tended to be the weakest in the model. As suggested in the sections above, a combination of factors influence family member respondents' beliefs in relation to community-based care and home care. All individuals with a CMD met the inclusion criteria for the study and, therefore, were considered to have a serious, chronic disorder. Ajzen and Fishbein (1980) do not include external variables as a formal part of the Theory of Reasoned Action because of their inconsistent relationship with behaviour.

Ajzen and Fishbein point out that there is no necessary relationship between any given external variable and behaviour, because they have no consistent effects on the beliefs underlying these behaviours. Some external variables may bear a relation to the behaviour under investigation and others may not, and even when a relationship is discovered, it may change over time and from one population to another. Although investigation of the effects of external variables can enhance our understanding of a given behavioural phenomenon, the theory deals mainly with the factors that intervene between external variables and behaviour. Previous research using the Theory of Reasoned Action also has not

found strong relationships between external variables and beliefs, and where relationships did exist, they tended to be weak (Aubrey, 1992, Tefft et al., 1988).

Perceived Supports The social (family) support factor was not significantly related to any of the belief factors. One possible explanation for the above finding relates to the multidimensionality of social support (Barrera, 1986). Tausig (1992) stated that some of the definitional and operational variation in the social support research is due to a failure to distinguish among the structure of networks (e.g., support networks), the mobilization of supports within these networks, and the effects of support on health outcomes. Studies that measure network structural properties and attempt to relate these properties directly to a health outcome (or distress) should be expected to show small or even insignificant effects (Tausig, 1992). While the questions concerning perceived support in this study introduced one of the dimensions of support (emotional), they did not include other dimensions of support (e.g., instrumental). Therefore, it is possible to speculate that one reason why perceived family support did not correlate with any of the belief factors may have been due to a failure to take into account the multidimensionality of social support. The lack of a more sophisticated measure may have contributed to the non-significant relationships between perceived support and respondents' beliefs.

The mental health system supports factor was significantly related to three of the four belief factors which pertained to resources for community-based care (home care). However, the mental health system supports factor was not significantly related to the belief factors which pertained to community-based care, home care, family burden, or advocacy. The mental health system supports factor was directly related to three of four belief factors which corresponded to it in terms of specificity. The mental health system supports factor consisted of concrete resources (e.g., education and information, crisis care, financial assistance). This factor was directly related to only those belief factors which were concerned with specific resources. According to Ajzen and Fishbein (1980), there must be correspondence in measurement between the different links in the causal chain. More specifically, each component of the model must be defined at the same level of specificity. When measures correspond in terms of specificity, they correlate more highly. The mental health system supports factor was directly related to the beliefs regarding resources (supports) factors. As well, in regard to community-based care, family member respondents' attitudes toward resources were directly related to family member respondents' behavioural intentions to advocate for community-based care. The model utilized in this study has supported, at least in part, Ajzen & Fishbein's (1980)

argument for correspondence and specificity between adjacent steps of the model.

Once again, the same argument as articulated earlier regarding the role of external variables in the model applies. The linkages between external variables and beliefs tend to be the weakest in the model. Previous research using the Theory of Reasoned Action also has not found strong relationships between external variables and beliefs, and where relationships did exist, they tended to be weak (Aubrey, 1992, Tefft et al., 1988).

Summary of Methodological Limitations of the Study.

An important limitation of the present study was the inability to examine the model as effectively as would have been desirable. In some instances, the lack of a significant relationship or the existence of weak relationships was due to the relatively small sample size in relation to the numerous comparisons made in the study. A more stringent alpha level than normal was utilized to compensate for the numerous comparisons.

There also was no examination of family member respondents' beliefs regarding and attitudes toward advocacy in relation to home care. As a result, there was a lack of adequate correspondence for some linkages.

Some of the beliefs and attitudes investigated in the present study did not refer to beliefs regarding and attitudes toward performing a behaviour. In relation to home care, family member respondents' beliefs regarding

home care and family burden were directly related to their attitudes toward home care and family burden. These relationships were strong. However, family member respondents' beliefs regarding community-based care were not directly related to their attitudes toward community-based care. The beliefs regarding community-based care items compared community-based care to hospitalization. However, the attitudes toward community-based care factor items did not make this comparison. The attitude items asked only about the effectiveness of some aspects of community-based care. It is difficult to know whether it is the lack of correspondence and specificity, or the use of beliefs and attitudes that do not refer to beliefs regarding and attitudes toward a behaviour or both, that account for the non-significant relationship between family member respondents' beliefs regarding community-based care and their attitudes toward community-based care. It also could be due to a lack of power.

Another limitation of the present study was the use of newly developed scales. Due to the lack of standardized instruments and the need to use scales which would allow for an examination of constructs at each step of the model utilized in the study, several scales had to be either devised by the researcher or adapted from pre-existing scales. While many of these scales appear to be accurate measures of the construct in question, at least one proved to be inadequate. The measure used to

investigate social (family) support did not take into account the complexity of the construct. A more sophisticated, multidimensional scale would have measured more than one aspect of social support.

As mentioned previously, the range of responses for some measures was quite small (e.g., the measure of family member respondents' attitudes toward better resources for community-based care). The lack of variation in responses could have contributed to the non-significant or weak relationship between family member respondents' beliefs regarding essential resources and their attitudes toward better resources for community-based care and their corresponding beliefs regarding community-based care. This attitude measure consisted of only one question. A longer scale with additional, and more specific, questions may have provided a better measure and allowed for greater variability in responding than the limited one used in this study.

None of the subjective norm components correlated significantly with family member respondents' behavioural intentions to advocate for resources for community-based care (home care). The Theory of Reasoned Action is a cognitive and rational model, and normative variables are considered to be cognitive variables (Ajzen & Fishbein, 1980). As the present study investigated issues considered to be very personal and sensitive to family members who have a member with a CMD, the use of a

cognitive, rational model may provide a framework which constrains the way in which questions and answers may be posed, and creates an artificial situation divorced from family members' feelings. The model may not be appropriate or adequate when examining emotionally charged and very personal issues.

One final methodological limitation of the present study relates to the exclusive use of quantitative data in the analyses. At the end of the interview, family member respondents were asked if they had any further comments. As mentioned earlier, eighty-six percent offered additional qualitative information. Many family member respondents also stopped at different points in the interview and offered supplementary comments. These individuals had so much to say and, at times, felt frustrated by the structure of the questionnaire, which called for specific, numerical responses. Although an attempt was made to provide family member respondents with an opportunity to provide additional information, this information was not gathered in a systematic manner. Therefore, it was not possible to utilize it in a meaningful way.

Jayaratne and Stewart (1991) stated that one frequent source of enthusiasm for qualitative methods stems from their potential to offer a more human, less mechanical relationship between the researcher and the "researched." The inclusion of qualitative methods would

have provided a mechanism for family member respondents' to express their perceptions and knowledge of events and issues, as well as their own personal experiences. The inclusion of qualitative methods allows for greater opportunity to represent the lived experience of research participants as the central concern. This validation of individuals' experiences and knowledge empowers people. There is no doubt from the information received in this study and from other research cited here (Bernheim, 1990; Lefley, 1989) that the adoption of a new collaborative model of professional-family relationships has done much to destigmatize a formerly negatively valued group. It is important to adopt a collaborative model for gathering research data. Qualitative methodology provides the opportunity to utilize this type of model.

Many family members had not been given the opportunity to talk about their experiences, frustrations, and pain. Many family members felt that they had been ignored or neglected by the mental health system. They felt excluded, uninformed, angry, or frightened. On the other hand, some family member respondents had found some people in the mental health system to be responsive to them and/or to their family member with a CMD. They also wanted to have the opportunity to talk about these positive experiences and to indicate in what ways they had been beneficial. Some family member respondents have been involved with the mental health system for years and/or

are actively involved in a support/self-help group. They have a wealth of knowledge and experience from which mental health professionals could benefit.

Another way of understanding the utilization of qualitative methodology is from a feminist perspective. A feminist perspective often advocates the use of a combination of quantitative and qualitative approaches. It could have provided the methodological framework for this research because, as Thurer (1983) indicated, deinstitutionalization is a feminist issue. Thurer (1983) has defined deinstitutionalization as a feminist issue because care of the chronically mentally disordered has historically been assigned to women. In the present study, 67% of family member respondents were women. Therefore, it would seem particularly appropriate to have taken a feminist approach to research with this target group.

Suggestions for Future Research. Future research utilizing the Theory of Reasoned Action (Ajzen & Fishbein, 1980) should adhere more closely to the model's framework. Future studies examining the beliefs, attitudes, and behavioural intentions of family members who have a member with a CMD should pay special attention to the issues of correspondence between adjacent steps in the model and specificity, when devising or adapting pre-existing scales.

Another future research endeavour might be in the

area of scale development. There is a need for standardized scales to measure some of the constructs utilized in the present study. The development of more sophisticated instruments to examine the constructs would improve research in the area.

The Theory of Reasoned Action may not provide an adequate framework for examining personal and sensitive issues, as it may not adequately take into account affect. Future studies in the area of the present research, particularly in the area of home care, should expand on the present theory. The addition of self-efficacy and affective variables may also contribute greatly to the theory's ability to predict family member's behavioural intentions to advocate for resources for both community-based care and home care. The addition of a measure of personal norm or moral obligation also may prove to be more useful than a measure of subjective norm, in predicting family members' behavioural intentions.

Finally, the addition of qualitative methods used in a systematic manner would greatly enhance research in this area.

Practical Implications of the Study

Community-Based Care. A large majority of family member respondents believed community-based care was preferable to hospitalization. However, they varied in their attitudes toward community-based care. Although family member respondents believed in the concept of

community-based care, they varied in their attitudes

toward its effectiveness in providing living arrangements and treatment in as normalized a setting as possible, in helping their family member with a CMD to function normally, or in improving their family members' quality of life.

The interviews conducted with family member respondents varied in length from 30 minutes to two hours. Many respondents wanted to talk about their experiences and their frustrations with various aspects of the mental health system. At the end of the interview, each family member respondent was asked if he/she would like to make any further comments. Eighty-six of 100 family member respondents chose to provide additional information or to expand on a topic that had been referred to in the interview. Many respondents spoke about the lack of services, the poor quality of services, and the lack of ongoing care for their family member with a CMD. Therefore, it is not surprising that, although most respondents believe community-based care is preferable to hospitalization, they vary more in their attitudes toward the effectiveness of that care.

Bachrach (1991) reported that the complexity of patients' clinical and other programmatic needs requires that an array of viable comprehensive services be made available. She suggested that comprehensive services presuppose, at a minimum, the provision of adequate crisis

stabilization services; an array of residential settings; an array of psychiatric, medical, and supportive treatment settings within which a variety of therapeutic interventions are offered; and adequate occupational, recreational, and leisure activities for members of the patient population. Bachrach commented that in the early years of deinstitutionalization, the difficulty of caring for chronic mental patients in fragmented systems of care was underestimated. She suggested that it is not enough to provide an array of treatment interventions; efforts to insure and enhance continuity of care are at least as important as the structural components. Respondents were very aware of the gaps in the service system and the fragmented care received by their family members with a CMD.

The second best predictor of family member respondents' behavioural intentions to advocate for better resources for community-based care was their beliefs regarding essential resources (housing, welfare/social assistance). Beliefs regarding supplemental resources did not predict behavioural intentions to advocate for resources for community-based care. Family member respondents' attitudes toward advocacy and resources for community-based care also were directly related to their behavioural intentions to advocate for better resources for community-based care, but were less salient predictors. It is possible that despite their beliefs

regarding and attitudes toward the importance and inadequacy of supplemental resources, family member respondents may be more willing to expend their energy to advocate for resources which are regarded as the "right" of all people, namely welfare/social assistance and housing. A recent survey (Grosser & Vine, 1991) assessed perception of service needs of family members of individuals with psychiatric disabilities. Housing needs emerged as the primary concern of these family members.

More family member respondents were willing to participate in what Tefft et al. (1989) classified as group actions (e.g., signing a petition, attending a meeting) rather than in individual actions (e.g., writing to a newspaper, contacting a politician). The former are actions that involve group participation characterized by relatively little effort, as opposed to actions that involve visible and/or sustained individual effort (Tefft et al., 1989). One explanation for this may be that because over 50% of family member respondents do not believe they could be influential as advocates, these family members may only be willing to partake in actions which involve relatively little effort. Pomeroy and Trainer (1991) reported that, despite the courageous and dedicated work of many people, the voice of families has not been clearly heard by government and policy makers. If family members believe that they can only be somewhat influential, they also might focus on essential resources

(welfare/social assistance, housing) first and, once headway has been made in these areas, move on to other issues.

Home Care. While most family member respondents believed in community-based care, they varied in their beliefs regarding and attitudes toward home care. A number of family member respondents commented that adult children generally do not live with their family of origin. These family member respondents believed that if their family member with a CMD was to function normally, and experience a better quality of life, it was important that he or she live in a supervised residence, semi-independently, or independently within the community.

Many family member respondents also believed that having a family member with a CMD living at home placed a heavy burden on the family. This is consistent with the literature on family burden (Hatfield, 1978; Thompson & Doll, 1982; Noh & Turner, 1987). Many family member respondents felt that having a family member with a CMD living in the familial home created stress for the family. This finding supports the literature on caregiving for an individual who has a disability. Tausig (1992) stated that providing care to a disabled family member is generally viewed as a stressful situation. There also is substantial documentation that the caregiver is subject to increased risk of physical and emotional distress as a result of being the primary support person (Brody, 1985;

George & Gwyther, 1986). In a study conducted by Lefley (1987) involving mental health professionals who had a family member with a CMD, she found that despite the fact that respondents were predominantly involved in the practice of psychotherapy, they considered affiliation with a self-help group and residential separation from the patient more effective coping strategies than individual or group therapy.

Family member respondents also indicated they had very little social support. Thirty-seven percent of respondents indicated they had little or no support from their immediate family, 75% indicated they had little or no support from extended family, and 60% indicated they had little or no support from other sources (e.g., friends, work, church). Tausig (1992) suggests that caregivers may well require moral support or material support from others to maintain the caregiving relationship. It has already been noted that the caregiving situation represents a continuing stressor. Therefore, Tausig points out that it makes sense to suggest that the caregiver would benefit from the acquisition of support as one mechanism that might offset any personal consequences of dealing with this stressor.

In the present study, it was hypothesized that the more family member respondents perceived that they had social (family and extended family) support, the less they believed having a family member with a CMD living at home

placed a high degree of burden on the family and the less they experienced burden. However, although respondents' beliefs regarding family burden correlated significantly with their attitudes toward family burden (feelings of stress), perceived support did not correlate significantly with respondents' beliefs regarding family burden.

At this point, it is important to note that only 50% of family member respondents believed that support/self-help groups were important. Perhaps some family member respondents either do not know how to, or are not able to, avail themselves of social networks which can provide both emotional and instrumental support.

Gidron, Guterman, and Hartman (1990) investigated the stress and coping patterns of participants and non-participants in self-help groups for parents of the mentally ill. They found that participants tended to come from a higher socio-economic status than non-participants. The former reported greater stress related to more psycho-social burdens (e.g., accepting the situation, guilt feelings about their child, relations to their spouses) and more frequent utilization of active and interactive coping strategies. Non-participants, on the other hand, tended to come from lower socio-economic status, were burdened by more basic survival issues (e.g., financial problems) and tended to use less active forms of coping. Gidron et al. (1990) concluded that self-help frameworks as they exist today, with primarily a psycho-social focus,

may have difficulties attracting persons with lower socio-economic status.

Family members of individuals with a CMD experience a great deal of stress and need support in dealing with this stress. The emotional support received from others who have shared a common experience often is extremely helpful (Hatfield, 1986; Terkelson, 1986b). Previous research (e.g., Spaniol et al., 1986b) has shown that other types of support (e.g., emotional support from professionals, advice and information about mental illness and medication management, assistance with treatment coordination and referrals) also are required to ease the burden of families who have a family member with a CMD.

The issue of "mental illness in the family" evokes strong emotion for families who have a family member with a CMD. Home care is a particularly sensitive issue for family members. They often have experienced great pain, anguish, and frustration both for their family member with a CMD and for themselves. Unfortunately, in the face of adversity, they have not received the support they required and desired.

Normative beliefs-Subjective Norm. Family members have a difficult time accepting that a member of their family has a CMD. Moreover, family members often have felt unsupported, have experienced the stigma attached to having a family member with a CMD and, at times, even have been made to feel by mental health professionals that they

are to blame for the condition of their family member with a CMD (Terkelson, 1986b, Lefley, 1989; Pomeroy & Trainer, 1991). Thus, family members more and more have come to rely upon themselves for support and to see themselves as advocates for their family member with a CMD and for themselves (Hatfield, 1987; Sommer, 1990). For this reason, family member respondents' may not have placed much importance on the attitudes of their significant referents when making decisions regarding advocating for resources for either community-based care or home care.

Characteristics of the Sample of Individuals with a CMD. In the present study, diagnosis did not correlate significantly with family member respondents' beliefs. Lefley (1989) pointed out that, regardless of diagnostic category, there are cycles of exacerbation and remission of symptoms with concomitant patterns of hope and disappointment in family members. The diagnosis itself may become somewhat irrelevant to family members once it has been determined that a family member has been diagnosed as having a chronic mental disorder. Finding out that he or she has a chronic mental disorder of any type is devastating for all family members (Lefley, 1989, Pomeroy and Trainer, 1991).

In a study conducted by Riebschleger (1991), siblings discussed their emotional responses to the mental illness of their brother or sister. Sibling emotional responses were categorized into grief and loss, phases of

denial, anger, bargaining, depression, relief/respite, and acceptance. Siblings believed that their expressions of grief and loss were impaired by characteristics of mental illness and mixed messages from the mental health system. The characteristics of mental illness that affected these siblings were the special difficulties of adult-phase onset and the cyclical illness pattern. Siblings must learn to adjust to the rapid deterioration of their sister or brother, who is still alive, but ill. The cyclical nature of a chronic mental disorder created further barriers to grief resolution for siblings as the loss occurred over and over (Riebschleger, 1991). Pomeroy and Trainer (1991) reported that knowing the diagnosis allowed family members to gather information about their family members' illness. However, the diagnosis itself was not what was important. What they mainly wanted was some information regarding their family members illness, some understanding of their experience with the situation, and support to deal with the problem.

Suggestions for future research. The relationships among the mental health system, family members who have a relative with a CMD, and the individuals with a CMD is complicated. Mental health professionals see themselves as the bearers of expert knowledge about chronic mental disorders. While they do possess this expertise, professionals often fail to see that there are other crucial types of knowledge in which family members are

expert (Pomeroy & Trainor, 1991). Pomeroy and Trainor reported that family members have extensive expertise with regard to how to live with and support a mentally ill person. The family consumer movement arose as a response to deinstitutionalization and the removal of stigma from parents of mental health clients (Hatfield, 1987; Pomeroy & Trainor, 1991; Sommer, 1990).

Families are becoming a dynamic force in mental health policymaking. Sommer (1990) suggests that, if mental health professionals are to collaborate in support and advocacy programs, they should be aware of the origins and goals of the movement. He also stated that if the system is unable to meet familial expectations, it is likely that families will place themselves in competition with existing agencies for available resources. Bernheim (1990) reported that genuine collaboration with families is widely advocated in principle, but elusive in practice. Bernheim suggested that if a real partnership is to exist, a thoughtful, systemic approach to change is needed.

Individuals with a CMD also have their own issues and agendas (Bernheim, 1986). Bernheim stated that the goals of the patients' rights movement are sometimes consistent with, and sometimes opposed to, those of the family consumer movement. Neufeldt (1981) reported that the immediate objectives of self-help groups of individuals with a CMD differ from parent-to-parent groups.

This study investigated the beliefs regarding, attitudes toward, and behavioural intentions of family members regarding community-based care and home care. It also is important to investigate the beliefs regarding, attitudes toward, and behavioural intentions of both the individuals with a CMD and mental health professionals, in regard to community-based care and home care. If true collaboration is to exist and progress is to be made, the concerns, needs, and expertise of all involved need to be acknowledged. It is only with the co-operation and support of all three groups that a collaborative, systemic approach can be applied to the area of mental health.

A final suggestion for future research focuses on the issue of self-help. Many individuals in this study and, as mentioned previously, in other studies, have indicated a lack of, but need for support. Only 50% of family member respondents in this study indicated that support/self-help groups were important, despite their lack of, and need for, support. One other future research endeavour would be to investigate family members needs and wishes in regards to support from other family members and family organizations. If self-help support and advocacy groups are to exist and thrive, they must find ways to welcome and work co-operatively with all family members, so that the needs of different groups of family members can be met. Family members are very aware and willing to articulate their needs. They simply need to be asked.

In conclusion, family members who have a relative with a CMD have undergone a vast array of experiences which have provided them with a large base of knowledge and expertise. They too often have been a neglected and unappreciated group. It is time that the mental health system joined forces with family members and individuals with a CMD in the pursuit of mental health reform.

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Appendix A

Personalized letter of introduction to the
Director of Clinical Programs, Mental Health Division,
Manitoba Department of Health

January 17, 1991

Dr. Rudy Ambtman
Director of Clinical Programs
Mental Health Division
Manitoba Department of Health
305-1200 Portage Avenue
Winnipeg, Manitoba
R3G 0T5

Dear Dr. Ambtman:

I am conducting research intended to clarify the beliefs, attitudes, and behavioural intentions of families with a chronically mentally disordered member regarding advocacy for resources for community-based care, including home care, for their disordered member. The study is being conducted as part of my Ph.D. program in the Department of Psychology, University of Manitoba and will be approved by the Human Ethical Review Committee of the Department.

This letter is to request that you assist me in this research by introducing me to community mental health workers who have clients with a chronic mental disorder. The community mental health workers will be requested to refer disordered clients who meet the study's inclusion criteria. They also will be asked to provide certain socio-demographic (e.g., gender, age) and clinical (e.g., diagnosis, chronicity) information concerning the clients they refer.

I will meet individually with referred clients to solicit their brief participation in the study. After being introduced by the client's community mental health worker, I will explain the study and request his or her cooperation in two respects. First, the client will be asked to grant permission for me to obtain socio-demographic and clinical information from his or her community mental health worker. Second, he or she will be asked to grant permission for me to contact the family member (i.e., parent or spouse) with whom the client is most closely involved to request his or her participation in the study.

Family members who agree to participate will be interviewed individually in their homes, using a structured questionnaire and at a time convenient to them, either by me or by another trained interviewer.

Enclosed is an information sheet which, with your approval, will be sent to each community mental health worker, along with an introductory letter. The information sheet outlines the purpose of the study, time

required of participants, client inclusion criteria, procedures, feedback, and my qualifications.

I would be pleased to discuss my proposed research with you. I will phone you within a few days of your receiving this letter to arrange an appointment at your earliest convenience. Thank you very much for your prompt attention to, and consideration of, this matter.

Sincerely

Janine Cutler, M.A.

Bruce Tefft, Ph.D., Head
(Research Supervisor)

Encl. Information Sheet

INFORMATION SHEET: FAMILY ADVOCACY STUDY

Purpose of the study

There is very little research on the effects of community-based care for individuals with a chronic mental disorder and their families. Some of these individuals live with their families and others live apart from their families. In either case, it is important to understand the needs of those involved and the ways in which their living arrangements influence their quality of life. It is also important to know about critical resources such as emergency care and family support groups in terms of their availability and effectiveness. The purpose of this study is to investigate families views on these issues, as well as their behavioural intentions to advocate for resources for community-based care, including home care, for persons with a chronic mental disorder.

The reasons for involving community mental health workers are twofold. It is important that appropriate clients and families participate in the study, so that the results are as representative of these groups as possible. Therefore, workers who are involved with individuals who have a chronic mental disorder, and who are aware of their clinical characteristics, are being asked to refer qualified clients to the researcher. As part of the study, the effects of clinical characteristics (e.g., diagnosis, severity of disorder, chronicity of disorder) on family members' opinions and feelings about various

aspects of community-based care, including home care, will be investigated. Once again, community mental health workers would be the most appropriate people to provide clinical information.

Time required of participants

Interviews with clients will usually take no longer than 15-30 minutes. They will involve explaining to clients the purpose of the study and requesting their permission to obtain socio-demographic and clinical information from their community mental health worker. Clients will be asked to give permission to contact a family member (i.e., parent or spouse) to solicit their participation in the study.

Only one interview with the community mental health worker will be necessary. This interview will take approximately 15 minutes. In addition, the community mental health worker will be requested to introduce the researcher to his or her client, at the start of the meeting between the researcher and the client.

Inclusion Criteria

The criteria for including people in the population of persons with a CMD are important. All three listed below must be satisfied.

1. Diagnosis within last five years of schizophrenia or recurrent depressive or manic-depressive disorder.
2. A history of hospitalization and/or treatment within the mental health system for the past two years

(consecutively).

3. Major difficulties (in the opinion of the community mental health worker) in the patient's functional capacities in at least three of the following areas of life:

- A. Personal hygiene and self-care
- B. Self-direction
- C. Interpersonal relationships
- D. Learning
- E. Recreation
- F. Economic self-sufficiency

Procedures

As indicated above, separate interviews will be conducted with the community mental health worker, the individual with a chronic mental disorder, and the family member. A file check for confirmation of eligibility for inclusion of the individuals with a chronic mental disorder also will be conducted. All data will be kept strictly confidential. Names and any other identifying information will be removed from all materials.

Feedback

A summary of study results will be communicated in writing to all participants upon completion of the study.

Qualifications of Principal Investigator

I have an M.A. in Clinical Psychology. I am a Ph.D. candidate in Clinical Psychology at the University of Manitoba, working under the supervision of Dr. Bruce Tefft, Head, Department of Psychology.

Appendix B

Letter of Introduction to
Community Mental Health Workers

Dear

I am conducting research intended to clarify the beliefs, attitudes, and behavioural intentions of families with a chronically mentally disordered member regarding advocacy for resources for community-based care, including home care, for their disordered member. The study is being conducted as a part of my Ph.D. program in the Department of Psychology, University of Manitoba and will be approved by the Human Ethical Review Committee of the Department. I also have met with Dr. Rudy Ambtman, Director of Clinical Programs, Mental Health Division of the Manitoba Department of Health, to discuss the study, and he has given his endorsement and support of it. It is from Dr. Ambtman that I received your name.

This letter is sent with the hope that you may be able to refer clients you think meet the study's inclusion criteria, as well as participate in the study yourself. The reasons for involving community mental health workers are twofold. It is important that appropriate clients and families participate in the study, so that the results are as representative of these groups as possible. Therefore, workers who are involved with individuals who have a chronic mental disorder, and who are aware of their clinical characteristics, are being asked to refer qualified clients to the researcher. As part of the study, the effects of clinical characteristics (e.g., diagnosis, severity of symptomatology, chronicity of disorder) on family members' opinions and feelings about various aspects of community-based care, including home care, will be investigated. Once again, community mental health workers would be the most appropriate people to provide clinical information.

I have enclosed a brief summary of the purpose of the study, time required of participants, client inclusion criteria, procedures, feedback, and my qualifications. This type of research provides pertinent information that could aid in influencing government policy, funding, and practice. This hopefully would lead to better developed community-based programs and services for individuals with a chronic mental disorder and their families.

I would be pleased to discuss my proposed research with you. I will phone you within a few days of your receiving this letter to arrange an appointment at your earliest convenience. Thank you for your prompt attention to, and consideration of, this matter.

Sincerely,

Janine Cutler, M.A.

Bruce Tefft, Ph.D., Head
(Research Supervisor)

Encl. Information sheet

INFORMATION SHEET: FAMILY ADVOCACY STUDY

Purpose of the study

There is very little research on the effects of community-based care for individuals with a chronic mental disorder and their families. Some of these individuals live with their families and others live apart from their families. In either case, it is important to understand the needs of those involved and the ways in which their living arrangements influence their quality of life. It is also important to know about critical resources such as emergency care and family support groups in terms of their availability and effectiveness. The purpose of this study is to investigate families views on these issues, as well as their behavioural intentions to advocate for resources for community-based care, including home care, for persons with a chronic mental disorder.

The reasons for involving community mental health workers are twofold. It is important that appropriate clients and families participate in the study, so that the results are as representative of these groups as possible. Therefore, workers who are involved with individuals who have a chronic mental disorder, and who are aware of their clinical characteristics, are being asked to refer qualified clients to the researcher. As part of the study, the effects of clinical characteristics (e.g., diagnosis, severity of disorder, chronicity of disorder) on family members' opinions and feelings about various

aspects of community-based care, including home care, will be investigated. Once again, community mental health workers would be the most appropriate people to provide clinical information.

Time required of participants

Interviews with clients will usually take no longer than 15-30 minutes. They will involve explaining to clients the purpose of the study and requesting their permission to obtain socio-demographic and clinical information from their community mental health worker. Clients will be asked to give permission to contact a family member (i.e., parent or spouse) to solicit their participation in the study.

Only one interview with the community mental health worker will be necessary. This interview will take approximately 15 minutes. In addition, the community mental health worker will be requested to introduce the researcher to his or her client, at the start of the meeting between the researcher and the client.

Inclusion Criteria

The criteria for including people in the population of persons with a CMD are important. All three listed below must be satisfied.

1. Diagnosis within last five years of schizophrenia or recurrent depressive or manic-depressive disorder.
2. A history of hospitalization and/or treatment within the mental health system for the past two years

(consecutively).

3. Major difficulties (in the opinion of the community mental health worker) in the patient's functional capacities in at least three of the following areas of life:

- A. Personal hygiene and self-care
- B. Self-direction
- C. Interpersonal relationships
- D. Learning
- E. Recreation
- F. Economic self-sufficiency

Procedures

As indicated above, separate interviews will be conducted with the community mental health worker, the individual with a chronic mental disorder, and the family member. A file check for confirmation of eligibility for inclusion of the individuals with a chronic mental disorder also will be conducted. All data will be kept strictly confidential. Names and any other identifying information will be removed from all materials.

Feedback

A summary of study results will be communicated in writing to all participants upon completion of the study.

Qualifications of Principal Investigator

I have an M.A. in Clinical Psychology. I am a Ph.D. candidate in Clinical Psychology at the University of Manitoba, working under the supervision of Dr. Bruce Tefft, Head, Department of Psychology.

Appendix C

Letter of introduction to family members

Dear

I am conducting research intended to clarify the beliefs, attitudes, and behavioural intentions of families with a chronically mentally disordered member regarding advocacy for resources for community-based care, including home care, for their disordered member. The study is being conducted as a part of my Ph.D. program in the Department of Psychology, University of Manitoba and will be approved by the Human Ethical Review Committee of the Department.

I have met with (name of member with a CMD) community mental health worker, as well as with (name of member with a CMD). I obtained your name from (name of member with a CMD), after I explained to him or her the purpose of this study.

The purpose of this letter is to request your participation in this study. Your participation is vital, as it is family members such as yourself who are most able to identify the needs of families and their member with a chronic mental disorder. This type of research provides pertinent information, and aids in influencing government policy, funding, and practice. There is not likely to be any changes in the funding provided for the care of individuals with a chronic mental disorder and their families, unless those in charge of mental health care are convinced that there is the need for change, and that it would be cost-effective to introduce those changes. Families who have a family member with a chronic mental disorder living in the community can be an important source of information and eventually persuasion. Hopefully, this leads to an improved quality of life for individuals with a chronic mental disorder and their families.

I have included a brief summary of the purpose of the study, time required by participants, procedures, feedback, and my qualifications.

I would be pleased to discuss my proposed research with you. I will phone you within a few days of your receiving this letter to arrange a meeting time with you, at your earliest convenience. Thank you for your prompt attention to, and consideration of, this matter.

Sincerely,

Janine Cutler, M.A.
Bruce Tefft, Ph.D., Head
(Research Supervisor)

Encl. Information Sheet

INFORMATION SHEET: FAMILY ADVOCACY STUDY

Purpose of the study

There is very little research on the effects of community-based care for individuals with a chronic mental disorder and their families. Some of these individuals live with their families and others live apart from their families. In either case, it is important to understand the needs of those involved and the ways in which their living arrangements influence their quality of life. It is also important to know about critical resources such as emergency care and family support groups in terms of their availability and effectiveness. The purpose of this study is to investigate families views on these issues, as well as their behavioural intentions to advocate for resources for community-based care, including home care, for persons with a chronic mental disorder.

As families often are intimately involved in the care of their member who has a chronic mental disorder, regardless of whether their member with a chronic mental disorder lives with them, family members are a vital resource. Families are aware of the impact a chronic mental disorder has upon a person and a person's family. Therefore, they can provide important information concerning the needs of families and their member with a chronic mental disorder. More and more families are voicing their concerns about the quality of life experienced by their member who has a chronic mental

disorder and themselves. The more these concerns are expressed by those most aware of the problems facing those individuals with a chronic mental disorder living in the community and their families, the more the mental health professionals and the government officials involved in mental health will become aware of these problems and the need for change. In this way, families have the opportunity to impact upon mental health policies, funding, and practices.

Time required of participants

Family members (i.e., parents or spouses) partaking in the study will be interviewed in person by Janine Cutler, the principal investigator of the study, or her research assistant. Unless otherwise requested by the individual being interviewed, the interview will take place in that individual's place of residence. The interview will take approximately 30 to 45 minutes.

Procedures

Separate interviews will be conducted with the community mental health worker for the individual with a chronic mental disorder, the individual with a chronic mental disorder, and the family member. The interviews with the community mental health workers will be to obtain the socio-demographic and clinical information regarding their clients. The interviews with the clients will be conducted in order to explain the purpose of the study to

them, to ask their permission to obtain the necessary information from the community mental health worker, and to ask their permission to contact a family member. The interviews with family members will be conducted for the purpose of obtaining their opinions and feelings regarding a variety of issues concerning community-based care, including home care, for their family member with a chronic mental disorder. Information will be collected through the interviews. All information will be kept strictly confidential. Names and any other identifying information will be removed from all materials.

Feedback

A summary of study results will be communicated in writing to all participants upon completion of the study.

Qualifications of Principal Investigator

I have an M.A. in Clinical Psychology. I am a Ph.D. candidate in Clinical Psychology at the University of Manitoba, working under the supervision of Dr. Bruce Tefft, Head, Department of Psychology.

Appendix D

Client Information Sheet

INFORMATION SHEET: FAMILY ADVOCACY STUDY

Purpose of the study

There is very little research on the effects of community-based care for individuals with a chronic mental disorder and their families. Some of these individuals live with their families and others live apart from their families. In either case, it is important to understand the needs of those involved and the ways in which their living arrangements influence their quality of life. It is also important to know about critical resources such as emergency care and family support groups in terms of their availability and effectiveness. The purpose of this study is to investigate families views on these issues, as well as their behavioural intentions to advocate for resources for community-based care, including home care, for persons with a chronic mental disorder.

While it would be possible to contact family members through other means (e.g., family groups), it seemed most appropriate to contact them through their family member involved with the mental health system. It is important to have accurate information, and the most accurate clinical information can be obtained from your community mental health worker. It also is important to interview a family member who is involved in your life, as he or she is the most likely person, other than yourself, to be aware of your service needs and general life concerns.

Your family member also will be able to identify the needs of families who have a member with a chronic mental disorder living at home. For these reasons, your participation in this study is very important.

More and more family members are voicing their concerns about the quality of community-based living and about the quality and adequacy of services for their family members involved with the mental health system. Family members also are expressing the need for more resources for families who have a member with a mental disorder. The more families are able to make the mental health professionals and the government officials aware of mental health issues and the problems facing individuals with a chronic mental disorder, the more likely they will be able to influence some changes in mental health policy, funding, and practices.

Time required of participants

There is no other time required.

Procedures

Separate interviews will be conducted with the community mental health workers of persons with a chronic mental disorder, the individuals with a chronic mental disorder, and the family member. The interviews with the community mental health workers will be to obtain the socio-demographic and clinical information regarding their clients. The interviews with the clients will be conducted in order to explain the purpose of the study to

them, to ask their permission to obtain the necessary information from the community mental health worker, and to ask their permission to contact a family member. Interviews with family members will be conducted in order to obtain their opinions and feelings about a variety of issues regarding community-based care, including home care, for individuals with a chronic mental disorder. Information will be collected through the interviews. All information will be kept strictly confidential. Names and any other identifying information will be removed from all materials.

Feedback

A summary of study results will be communicated in writing to all participants upon completion of the study.

Qualifications of Principal Investigator

I have an M.A. in Clinical Psychology. I am a Ph.D. candidate in Clinical Psychology at the University of Manitoba, working under the supervision of Dr. Bruce Tefft, Head, Department of Psychology.

Appendix E

Community Mental Health Worker Consent Form

CONSENT TO PARTICIPATE: COMMUNITY MENTAL HEALTH WORKERS

I, _____, agree to participate in a research study intended to clarify the beliefs, attitudes, and behavioural intentions of families with a chronically mentally disordered member regarding advocacy for resources for community-based care, including home care, for their disordered member. The principal investigator of this study is Janine Cutler, who is supervised by Dr. Bruce Tefft, the Head of the Department of Psychology at the University of Manitoba. The study has been approved by the Manitoba Department of Health.

I agree to introduce the researcher to my clients who meet the inclusion criteria for the study. For each client who permits me to provide the necessary information to the researcher, I agree to be interviewed by the researcher and complete the two client questionnaires being used in this study. I understand that I will receive no direct benefit from participating in this study.

I have been assured that the confidentiality of my client and myself will be maintained at all times. I also have been informed that I will receive a summary of the results once the study has been completed.

Community Mental Health Worker: _____

Principal Investigator: _____

Date: _____

Appendix F

Client Consent Form

CONSENT TO PARTICIPATE

I, _____, agree to participate in a research study with families who have a chronically mentally disordered (mentally ill) family member. The study is trying to find out about the ideas, thoughts, and action plans of those families, regarding getting care for their disordered member. The researcher for this study is Janine Cutler, who is supervised by Dr. Bruce Tefft, the Head of the Department of Psychology at the University of Manitoba. The study has been approved by the Manitoba Department of Health.

I agree to permit my community mental health worker, or other mental health worker involved with me on an ongoing basis, _____ to release all information regarding my diagnosis, history of mental health treatment, education and work situation, and present living arrangements to Janine Cutler. I also agree to let Janine Cutler look at my medical record to make sure that the information in the medical record is the same as the information given by my mental health worker. I am allowing Janine Cutler, or her research assistant, to contact _____, my parent/spouse to ask him or her to take part in this family study. If for some reason _____ does not take part in the study, then _____ my other parent or, in the case where a spouse was contacted first,

_____, my parent can be asked to take part in the study.

I have been assured that all information will be kept strictly confidential.

Client Participant: _____

Principal Investigator: _____

Date: _____

Appendix G

Family Member Consent Form

CONSENT TO PARTICIPATE

I, _____, agree to participate in a research study with families who have a chronically mentally disordered (mentally ill) family member. The study tries to find out about the ideas, thoughts, and action plans of those families, regarding getting care for their disordered family member. The principal investigator of this study is Janine Cutler, who is supervised by Dr. Bruce Tefft, the Head of the Department of Psychology at the University of Manitoba. The study has been approved by the Manitoba Department of Health.

I understand that I am being asked to participate in a research study on family advocacy (action plans). I agree to be interviewed in my home or in another mutually-agreeable location by Janine Cutler, the principal investigator, or her research assistant.

I have been assured that all information will be kept strictly confidential.

Family Participant: _____

Principal Investigator: _____

Date: _____

Appendix H

Questionnaire

Regarding Individuals with a CMD

Questionnaire

Regarding Individuals With A CMD

1. Questionnaire Number _____ (1-3)

2. Date of Interview: Month _____ (4)

Date _____ (5-6)

Time (24 Hr. clock) _____ (7-10)

3. Length of Interview: (minutes) _____ (11-12)

I would like to ask some questions regarding your patient's (client's) past and present clinical status. I also would like to ask a few sociodemographic questions regarding your patient (client) as well.

To make things easier, I have prepared a Response Booklet (GIVE TO RESPONDENT). I will let you know every time you need to use the Booklet by giving you the correct scale number to refer to.

First, some sociodemographic questions.

1. Name of patient or client (to be removed after assigned a number).

_____ (13-14)

2. Gender of patient or client.

Male _____ 1
Female _____ 2 (15)

3. Age of patient or client.

_____ (16-17)

4. This question uses Scale 4 on page 1 of your response booklet. Please look at Scale 4, and indicate the current employment status of your patient (client).

Employed full time _____ 1
Employed part time _____ 2
Sheltered workshop _____ 3
Homemaker _____ 4
Unemployed and looking for work _____ 5
Unemployed and not looking for work _____ 6
DK _____ 8 (18)

5. (Scale 5) In terms of education, how much formal schooling has your patient (client) completed.

None _____ 01
Grade school _____ 02
High school or equivalent _____ 03
Post-high school technical training _____ 04
Some college _____ 05
College degree _____ 06
Some graduate study _____ 07
Graduate degree _____ 08
DK _____ 98 (19-20)

6. (Scale 6) Present living arrangements of client:

Mental hospital/institution_____	01
General hospital's psychiatric ward__	02
Nursing facility_____	03
Group home_____	04
Personal care home_____	05
Foster home_____	06
With parents_____	07
With spouse_____	08
Apartment with family support and supervision_____	09
Semi-independent living_____	10
Independent living_____	11
Other_____	12
DK_____	98 (21-22)

7. What is your patient's (client's) most recent diagnosis?

Schizophrenia_____	1
Schizophrenia (acute)_____	2
Schizophrenia (chronic)_____	3
Paranoid schizophrenia_____	4
Depressive_____	5
Bipolar disorder_____	6
Mania_____	7
Other (specify)_____	8
DK_____	98 (23-24)

8. How long ago was your patient (client) first diagnosed?

Less than 6 months ago_____	1
7 months to 1 year ago_____	2
1-2 years ago_____	3
3-5 years ago_____	4
6-10 years ago_____	5
11-15 years ago_____	6
More than 15 years ago_____	7
DK_____	8 (25)

9. Would you please tell me the number of hospitalizations your patient (client) has experienced since he or she was first diagnosed.

_____ (26-27)

10. How much time has your patient (client) spent in the hospital, in total, since he or she was first diagnosed? Please answer in terms of total number of months of hospitalization.

_____ (28-29)

11. What was the length of your patient's (client's) last hospitalization? Please answer in terms of number of days.

_____ (30-32)

12. What was the date of your patient's (client's) last hospital admission?

_____/_____/_____ (33-38)
DD MM YY

13 Using Scale 7, where is your patient (client) primarily receiving treatment services?

Psychiatric service in general hospital_01
Provincial mental hospital_____02
Provincial mental health center_____03
Rehabilitation agency_____04
Social work agency_____05
University clinic_____06
Halfway house (group home)_____07
Private psychiatrist_____08
Private psychologist_____09
Regular medical doctor_____10
Other (please specify):_____11
DK_____12 (39-40)

14. What is your patient's (client's) present treatment status? (READ RESPONSES)

In-patient_____1
Out-patient_on_regular_basis_____2
Occasional_contact_on_out-patient_basis_3
Discharged_with_no_further_treatment____4
Other (specify):_____5
DK_____8 (41)

I have two short questionnaires I would like you to answer. However, it would be easier if you read the questions yourself. I would appreciate it if you would respond to these questionnaires now. It should only take 5 to 10 minutes of your time.

GIVE RESPONDENT GLOBAL ASSESSMENT SCALE AND ROLE FUNCTIONING SCALE.

When the questionnaires are returned, thank the person for their help and co-operation.

Appendix I

Global Assessment Scale (GAS)

Global Assessment Scale

Patient's Name: _____ Date: _____

Community Mental Health Worker's Name: _____

Rate the subject's lowest level of functioning in the last week by selecting the lowest range which describes his functioning on a hypothetical continuum of mental health-illness. For example, a subject whose "behaviour is considerably influenced by delusions" (range 21-30) should be given a rating in that range even though he has "major impairment in several areas" (range 31-40). Use intermediate levels when appropriate (e.g., 35, 58, 63). Rate actual functioning independent of whether or not subject is receiving and may be helped by medication or some other form of treatment.

PLEASE WRITE YOUR RATING IN THE SPACE PROVIDED AT THE END SCALE.

91-100

No symptoms, superior functioning in a wide range of activities, life's problems never seem to get out of hand, is sought out by others because of his warmth and integrity.

81-90

Transient symptoms may occur, but good functioning in all areas, interested and involved in a wide range of activities, socially effective, generally satisfied with life, "everyday" worries that only occasionally get out of hand.

71-80

Minimal symptoms may be present but no more than slight impairment in functioning, varying degrees of "everyday" worries and problems that sometimes get out of hand.

61-70

Some mild symptoms (e.g., depressive mood and mild insomnia) OR some difficulty in several areas of functioning, but generally functioning pretty well, has some meaningful interpersonal relationships and most untrained people would not consider him "sick".

51-60

Moderate symptoms OR generally functioning with some difficulty (e.g., few friends and flat affect, depressed mood, and pathological self-doubt, euphoric mood and pressure of speech, moderately severe antisocial behaviour).

41-50

Any serious symptomatology or impairment in functioning that most clinicians would think obviously requires treatment or attention (e.g., suicidal preoccupation or gesture, severe obsessional rituals, frequent anxiety attacks, serious antisocial behaviour, compulsive drinking).

31-40

Major impairment in several areas, such as work, family relations, judgment, thinking, or mood (e.g., depressed woman avoids friends, neglects family, unable to do housework), OR some impairment in reality testing or communication (e.g., speech is at times obscure, illogical or irrelevant), OR single serious suicide attempt.

21-30

Unable to function in almost all areas (e.g., stays in bed all day), OR behaviour is considerably influenced by either delusions or hallucinations, OR serious impairment in communication (e.g., sometimes incoherent or unresponsive) or judgment (e.g., acts grossly inappropriately).

11-20

Needs some supervision to prevent hurting self or others, or to maintain minimal personal hygiene (e.g., repeated suicide attempts, frequently violent, manic excitement, smears feces), OR gross impairment in communication (e.g., largely incoherent or mute).

1-10

Needs constant supervision for several days to prevent hurting self or others, or makes no attempt to maintain minimal personal hygiene.

Rating: _____

Signature: _____

*Spitzer, Gibbon & Endicott. Archives of General Psychiatry, 33, June, 1976.

Appendix J

Georgia Department of Human Resources
Role Functioning Scale
Adults and Independent Adolescents

Georgia Department of Human Resources
Role Functioning Scale
Adults and Independent Adolescents

THE IDENTIFYING INFORMATION PORTION IS TO BE COMPLETED BY
THE INTERVIEWER. THE REMAINDER OF THE QUESTIONNAIRE IS TO
BE COMPLETED BY THE COMMUNITY MENTAL HEALTH WORKER.

Community Mental Health Worker: _____

Date: _____

Client's Name: _____

I.D. # _____

INSTRUCTIONS: Score each scale by circling the appropriate number to the left of the scale description you think best describes the client.

Score WORKING: PRODUCTIVITY

Rate the client primarily in the most appropriate expected role (i.e. homemaker, student, wage earner).

1	Productivity severely limited; often unable to work, adapt to school or homemaking; virtually no skills or attempts to be productive.
2	Occasional attempts at productivity unsuccessful; productive only with constant supervision in sheltered work, home or special classes.
3	Limited productivity; often with restricted skills/abilities for homemaking, school, independent employment (e.g., requires highly structured routine).
4	Marginal productivity (e.g., productive in sheltered work or minimally productive in independent work; fluctuates at home, in school; frequent job changes).
5	Moderately functional in independent employment, at home or in school. (Consider very spotty work history or fluctuations in home, in school with extended periods of success).
6	Adequate functioning in independent employment, home or school; often not applying all available skills/abilities.
7	Optimally performs homemaking, school tasks or employment-related functions with ease and efficiency.

Comments:

Score INDEPENDENT LIVING, SELF CARE
 (Management of household, eating, sleeping,
 hygiene care)

1	Lacking self-care skills approaching life endangering threat; often involves multiple and lengthy hospital services; not physically able to participate in running a household.
2	Marked limitations in self-care/independent living; often involving constant supervision in or out of protective environment (e.g. frequent utilization of crisis services).
3	Limited self-care/independent living skills; often relying on mental/physical health care; limited participation in running household.
4	Marginally self-sufficient; often uses REGULAR assistance to maintain self-care/independent functioning; minimally participates in running household.
5	Moderately self-sufficient; i.e. living independently with ROUTINE assistance (e.g. home visits by nurses, other helping persons, in private or self-help residences).
6	Adequate independent living and self-care with MINIMAL support (e.g. some transportation, shopping assistance with neighbours, friends, other helping persons).
7	Optimal care of health/hygiene; independently manages own personal needs and household tasks.

Comments:

Score IMMEDIATE SOCIAL NETWORK RELATIONSHIPS
(Close friends, Spouse, Family)

1	Severely deviant behaviours within immediate social networks (i.e. often with imminent physical aggression or abuse to others or severely withdrawn from close friends, spouse, family; often rejected by immediate social network).
2	Marked limitations in immediate interpersonal relationships (e.g. excessive dependency or destructive communication or behaviours).
3	Limited interpersonally; often no significant participation/communication with immediate social network.
4	Marginal functioning with immediate social network (i.e. relationships are often minimal and fluctuate in quality).
5	Moderately affective continuing and close relationship with at least one other person.
6	Adequate personal relationship with one or more immediate member of social network (e.g. friend or family).
7	Positive relationships with spouse or family and friends; assertively contributes to these relationships.

Comments:

Score EXTENDED SOCIAL NETWORK RELATIONSHIP
 (Neighbourhood, community church, clubs,
 agencies, recreational activities)

1	Severely deviant behaviours within extended social networks (i.e. overtly disruptive, often leading to rejection by extended social network).
2	Often totally isolated from extended social networks, refusing community involvement or belligerent to helpers, neighbours, etc.
3	Limited range of successful and appropriate interactions in extended social networks (i.e. often restricts community involvement to minimal survival level interactions).
4	Marginally effective interactions, often in a structured environment; may receive multiple public system support in accord with multiple needs.
5	Moderately affective and independent in community interactions; may receive some public support in accord with need.
6	Adequately interacts in neighborhood or with at least one community or other organization or recreational activity.
7	Positively interacts in community, church or clubs, recreation activities, hobbies or personal interests, often with other participants.

Comments:

Score GLOBAL PERSONAL DISTRESS SCALE
(Subjective, self-reported/observed feelings-situational/symptomatic or combination thereof).

1	Non-communicative or unaware of apparent personal, symptomatic distresses.
2	Constant and pervasive awareness of markedly painful symptoms; often vaguely described as "nerves" and "depression", "anxiety".
3	Bothered for major portions of day and evening by painful symptoms or very negative feelings about self/others.
4	Experiences periodic symptomatic or situational distress; generally dissatisfied with self/others.
5	Moderately impacted by distress from symptoms or situations; some dissatisfaction with self/others.
6	Experiences mild, infrequent personal distress; adequate self-image and satisfaction with others.
7	Positive self-image and much satisfaction with others with no apparent or reported personal distress.

Comments:

Signature: _____

THIS PORTION OF THE QUESTIONNAIRE WILL BE COMPLETED BY THE INTERVIEWER.

SUMMARY ROLE FUNCTIONING SCORES

Score	1	2	3	4	5	6	7
WORKING (Productivity)
INDEPENDENT LIVING/Adults or age Appropriate/Child
IMMEDIATE RELATIONSHIPS
EXTENDED RELATIONSHIPS

GLOBAL ROLE FUNCTIONING INDEX: _____
(Total of Role Functioning Scores)

GLOBAL ROLE FUNCTIONING SCALE:

0-4	Severely Limited
5-8	Markedly Limited
9-12	Limited
13-16	Marginal
17-20	Moderate
21-24	Adequate
25-28	Optimal

Comments:

Appendix K

Family Questionnaire

Family Questionnaire

1. QUESTIONNAIRE NUMBER _____ (1-3)
2. INTERVIEWER NAME _____ (4-5)
3. GENDER OF RESPONDENT MALE 1 FEMALE 2 (6)

CONTACT

- | | DATE | TIME | 1
NONE | 2
RESPDT | 3
OTHER | |
|-------------------------------------------|---------------------------|------|-----------|-------------|------------|---------|
| 4. INITIAL CALL _____ | | | 1 | 2 | 3 | (7) |
| 5. CALL BACK (1) _____ | | | 1 | 2 | 3 | (8) |
| (2) _____ | | | 1 | 2 | 3 | (9) |
| (3) _____ | | | 1 | 2 | 3 | (10) |
| (4) _____ | | | 1 | 2 | 3 | (11) |
| 6. DATE OF INTERVIEW: MONTH _____ | | | | | | (12) |
| | DATE _____ | | | | | (13-14) |
| | TIME (24 hr. clock) _____ | | | | | (15-18) |
| 7. LENGTH OF INTERVIEW: (minutes) _____ | | | | | | (19-21) |
| 8. (IF RE-CONTACT) APPOINTMENT TIME _____ | | | | | | |
| 9. REASON NO INTERVIEW _____ | | | | | | |
-

There are several topics to this survey. Before starting, I would like to assure you that all responses are kept strictly confidential, and that this questionnaire will be completely anonymous. Your address and phone number will be removed from the questionnaire, as soon as the questionnaire is received at the research site, and the questionnaire number is recorded. I am aware of the sensitive nature of some of the questions. You may, of course, refrain from answering any questions that you feel are too personal, and you are free to terminate this interview at any time.

At the end of the interview, I will be pleased to hear any comments you may wish to make about any of the issues we covered in the questionnaire.

SECTION I

FIRST OF ALL, I WOULD LIKE TO ASK SOME QUESTIONS ABOUT YOUR PERSONAL STATUS AND PRESENT LIFE SITUATION.

1. First, would you please tell me your present age?

_____ (22-23)

NOW A COUPLE OF QUESTIONS ABOUT YOUR LIVING ARRANGEMENTS.

2. What is your current living arrangement? (READ RESPONSES, CODE LOWEST NUMBER)

Now married and living with spouse	1
Common-law relationship, or live in partner	2
Single - never married	3
Divorced	4
Separated	5
Widowed	6
NR	9

 (24)

3. How many people, beside yourself, are there in your immediate family (including grandparents, parents, spouses, children, and siblings)?

None	0 (if 0 go to q. 5)
One	1
Two	2
Three	3
Four	4
Five	5
Six or more	6
NR	9

 (25)

4. How many of these family members live with you?

None_____0
 One_____1
 Two_____2
 Three_____3
 Four_____4
 Five_____5
 Six or more_____6
 NA_____7
 NR_____9

(26)

To make things easier, we have prepared a Response Booklet (GIVE TO RESPONDENT). I will let you know every time you need to use the Booklet by giving you the correct scale number to refer to. The next question uses scale 5 on page 1 of the Response Booklet. Please indicate which answer applies to you.

5. (Scale 5) What is the current living arrangement of _____ (NAME OF DISORDERED FAMILY MEMBER)?

Mental hospital/institution_____01
 General hospital's psychiatric ward_____02
 Nursing facility_____03
 Group home_____04
 Personal care home_____05
 Foster home_____06
 With parents_____07
 With spouse_____08
 Apartment with family support
 and supervision_____09
 Semi-independent living_____10
 Independent living_____11
 Other_____12
 DK_____98
 NR_____99

(27-28)

6. Sometimes when a relative with a chronic mental disorder lives outside of the family home, he or she might spend some time at home. How many days per week, if any, does _____ (NAME OF DISORDERED FAMILY MEMBER) live at home?

None	_____	01
One	_____	02
Two	_____	03
Three	_____	04
Four	_____	05
Five	_____	06
Six	_____	07
Seven	_____	08
DK	_____	98
NR	_____	99

(29-30)

7. On average, about how many hours per week are you in face to face contact with _____ (NAME OF DISORDERED FAMILY MEMBER)?

_____ (31-33)

8. What is your relationship to _____ (NAME OF DISORDERED FAMILY MEMBER)?

Father	_____	1
Mother	_____	2
Spouse	_____	3
Daughter	_____	4
Son	_____	5
Sibling	_____	6
Other (e.g., stepfather)	_____	7
NR	_____	9

(34)

9. When _____ (NAME OF DISORDERED FAMILY MEMBER) is at your home, who has the primary responsibility for taking care of him/her?

You	_____	1
Your Spouse	_____	2
A Sibling	_____	3
Another Relative	_____	4
Responsibility is shared by adult members of household	_____	5
Other	_____	6
No One	_____	7

(35)

I WOULD LIKE TO GET SOME INFORMATION ABOUT YOUR EDUCATIONAL BACKGROUND.

10. Looking at Scale 10, what is the highest level of education that you (and your spouse/partner) have completed?

	You	Spouse/ Partner
No Schooling_____	01	01
Elementary School		
Incomplete_____	02	02
Complete_____	03	03
Junior High School		
Incomplete_____	04	04
Complete_____	05	05
High School		
Incomplete_____	06	06
Complete (GED)_____	07	07
Non-University (Voc/Tech, Nursing Schools)		
Incomplete_____	08	08
Complete_____	09	09
University		
Incomplete_____	10	10
Diploma/Certificate (Hygienists)_____	11	11
Bachelor's Degree_____	12	12
Medical Degree (Vets Drs. Dentists)_____	13	13
Master's Degree_____	14	14
Doctorate_____	15	15
NO SPOUSE_____	--	97
DK_____	--	98
NR_____	99	99 (36-39)

NOW A QUESTION ABOUT YOUR PERSONAL FINANCES. The information you give will be kept strictly confidential. Of course, if you prefer not to answer this question, you are free not to do so.

11. Looking at Scale 11, please tell me which number comes closest to the total income for this past year, before tax and deductions of all members living in this household? (CIRCLE NUMBER)

No income_____00	
Under \$6,000_____01	34,000 - 35,999__16
6,000 - 7,999_____02	36,000 - 37,999__17
8,000 - 9,999_____03	38,000 - 39,999__18
10,000 - 11,999____04	40,000 - 44,999__19
12,000 - 13,999____05	45,000 - 49,999__20
14,000 - 15,999____06	50,000 - 54,999__21
16,000 - 17,999____07	55,000 - 59,999__22
18,000 - 19,999____08	60,000 - 64,999__23
20,000 - 21,999____09	65,000 - 69,999__24
22,000 - 23,999____10	70,000 - 74,999__25
24,000 - 25,999____11	75,000 - 79,999__26
26,000 - 27,999____12	80,000+_____27
28,000 - 29,999____13	DK_____98
30,000 - 31,999____14	NR_____99
32,000 - 33,999____15	

(40-41)

SECTION II: PERCEIVED SUPPORTS

Using Scale 12, please indicate how supportive you feel the following people, groups, or programs have been to you, since you found out that _____ (NAME OF DISORDERED FAMILY MEMBER) had a chronic mental disorder.

No
Support

A Great Deal NA DK NR
of Support

1 2 3 4 5 6 7 0 8 9

12. How much support have you received from members of your immediate family (i.e., spouse, children, siblings, parents, and grandparents)? _____ (42)
13. How much support have you received from other family members (e.g., uncles, aunts, cousins)? _____ (43)
14. How much extra-familial support have you received from other sources (e.g., friends, co-workers, colleagues, church)? _____ (44)
15. How much support have you received from the mental health care system in terms of education and information? _____ (45)

16. How much support have you received from the mental health care system in terms of ongoing consultation and interaction? _____ (46)
17. How much support have you received from the mental health care system in terms of emergency (i.e., crisis) care? _____ (47)
18. Finally, how much support have you received from the mental health care system in terms of financial assistance? _____ (48)

SECTION III: BELIEFS REGARDING COMMUNITY-BASED CARE

I would now like to ask you some questions regarding community-based care for _____ (NAME OF DISORDERED FAMILY MEMBER). However, before doing so, I would like to read you a few definitions that may be helpful to you when answering some of the questions.

COMMUNITY-BASED CARE: Treatment or care outside of a hospital. For example, community-based care includes community residences, outpatient clinics, and rehabilitation programs.

LEAST RESTRICTIVE ENVIRONMENT: The environment which gives a person as much physical freedom and decision-making power as possible.

QUALITY OF LIFE: The degree of satisfaction a person experiences either overall or in the different areas of his or her life (e.g., work, family, social relationships, health).

Using Scale 19, please indicate how much you AGREE OR DISAGREE with the following statements.

Strongly Agree Undecided Disagree Strongly Disagree DK NR

1 2 3 4 5 8 9

19. Hospitalization should only be used if community treatment is ineffective for _____ (NAME OF DISORDERED FAMILY MEMBER). _____ (49)

20. Community-based residential facilities provide a more natural living environment than hospitals and, therefore, encourage more normal functioning for _____ (NAME OF DISORDERED FAMILY MEMBER)? _____ (50)
21. Hospital care encourages more frequent interactions between _____ (NAME OF DISORDERED FAMILY MEMBER) and members of his/her social network than community-based care. _____ (51)
22. Treatment and other rehabilitation (e.g., social skills or job training) programs are less restrictive for _____ (NAME OF DISORDERED FAMILY MEMBER) when offered in the community than when offered in hospitals. _____ (52)
23. The quality of life of _____ (NAME OF DISORDERED FAMILY MEMBER) is greater when s/he is being treated in the hospital than when s/he is being treated in the community. _____ (53)

SECTION IV: ATTITUDES TOWARD COMMUNITY-BASED CARE

Please use Scale 24 when answering the following questions.

Very ineffective _____ 1
 Ineffective _____ 2
 Moderately effective _____ 3
 Effective _____ 4
 Very effective _____ 5
 DK _____ 8
 NR _____ 9

24. In your opinion, HOW EFFECTIVE is community-based care for providing living arrangements and treatment to _____ (NAME OF DISORDERED FAMILY MEMBER) in as natural a setting as possible? _____ (54)
25. In your opinion, HOW EFFECTIVE is community-based care for helping _____ (NAME OF DISORDERED FAMILY MEMBER) function normally? _____ (55)

26. In your opinion, HOW EFFECTIVE is community-based care for improving the quality of life of _____ (NAME OF DISORDERED FAMILY MEMBER)? _____ (56)

SECTION V: BELIEFS REGARDING THE IMPORTANCE AND ADEQUACY OF RESOURCES FOR COMMUNITY-BASED CARE

Another issue I would like to explore with you is the availability of certain community-based programs or services (e.g., job training programs, welfare).

I would now like to ask your opinion regarding what types of PROGRAMS OR SERVICES should be available to help _____ (NAME OF DISORDERED FAMILY MEMBER) lead a more satisfactory life.

TO THE INTERVIEWER: PLEASE NOTE THE SKIP PATTERN USED IN THIS SECTION. PLEASE ALSO NOTE THAT IF THE ADEQUACY QUESTION IS ASKED, THE RESOURCE IS CONSIDERED TO BE ADEQUATE ONLY IF THE RESPONDENT ANSWERS 1 OR 2 TO THE ADEQUACY QUESTION. PLEASE MAKE A NOTE, ON A SMALL SEPARATE PIECE OF PAPER, OF ALL THE RESOURCES THAT ARE CONSIDERED TO BE IMPORTANT AND INADEQUATE. YOU WILL NEED TO REFER TO THESE RESOURCES IN QUESTIONS 36 AND 69.

27. JOB TRAINING PROGRAMS

- a. (Scale 27a) How IMPORTANT do you think job training is for _____ (NAME OF DISORDERED FAMILY MEMBER)?

Very
Important

Not At All DK NR
Important

1 2 3 4 5 6 7 8 9 (57)

(IF RESPONDENT RATES IMPORTANCE AS 6 - 9, GO TO 28)

- b. (Scale 27b) How ADEQUATE do you think all job training programs in Winnipeg are for _____ (NAME OF DISORDERED FAMILY MEMBER)?

Very
Adequate

Not At All NA DK NR
Adequate

1 2 3 4 5 6 7 0 8 9 (58)

28. SOCIAL ASSISTANCE (welfare)

- a. (Scale 27a) How IMPORTANT do you think social assistance is for _____ (NAME OF DISORDERED FAMILY MEMBER)?

Very
Important

Not At All DK NR
Important

1 2 3 4 5 6 7 8 9 (59)

(IF RESPONDENT RATES IMPORTANCE AS 6 - 9, GO TO 29)

- b. (Scale 27b) How ADEQUATE do you think social assistance allowances are for _____ (NAME OF DISORDERED FAMILY MEMBER)?

Very
Adequate

Not At All NA DK NR
Adequate

1 2 3 4 5 6 7 8 9 (60)

29. HIGHER EDUCATION PROGRAMS (post-secondary education)

- a. (Scale 27a) How IMPORTANT do you think higher education programs are for _____ (NAME OF DISORDERED FAMILY MEMBER)?

Very
Important

Not At All DK NR
Important

1 2 3 4 5 6 7 8 9 (61)

(IF RESPONDENT RATES IMPORTANCE AS 6 - 9, GO TO 30)

- b. (Scale 27b) How ADEQUATE do you think higher education programs are for _____ (NAME OF DISORDERED FAMILY MEMBER)?

Very
Adequate

Not At All NA DK NR
Adequate

1 2 3 4 5 6 7 8 9 (62)

30. HOUSING

- a. (Scale 27a) How IMPORTANT do you think housing programs are for _____ (NAME OF DISORDERED FAMILY MEMBER)?

Very
Important

Not At All DK NR
Important

1 2 3 4 5 6 7 8 9 (63)

(IF RESPONDENT RATES IMPORTANCE AS 6 - 9, GO TO (31))

- b. (Scale 27b) How ADEQUATE do you think housing programs are for _____ (NAME OF DISORDERED FAMILY MEMBER)?

Very
Adequate

Not At All NA DK NR
Adequate

1 2 3 4 5 6 7 8 9 (64)

31. RECREATIONAL PROGRAMS (organized social and leisure-time activities and programs)

- a. (Scale 27a) How IMPORTANT do you think recreational programs are for _____ (NAME OF DISORDERED FAMILY MEMBER)?

Very
Important

Not At All DK NR
Important

1 2 3 4 5 6 7 8 9 (65)

(IF RESPONDENT RATES IMPORTANCE AS 6 - 9, GO TO 32)

- b. (Scale 27b) How ADEQUATE do you think recreational programs are for _____ (NAME OF DISORDERED FAMILY MEMBER)?

Very
Adequate

Not At All NA DK NR
Adequate

1 2 3 4 5 6 7 8 9 (66)

32. INTERPERSONAL OR SOCIAL SKILLS TRAINING (i.e., organized training in such areas as personal hygiene, work habits, and social interactions).

- a. (Scale 27a) How IMPORTANT do you think training in interpersonal or social skills is for _____ (NAME OF DISORDERED FAMILY MEMBER)?

Very
Important

Not At All DK NR
Important

1 2 3 4 5 6 7 8 9 (67)

(IF RESPONDENT RATES IMPORTANCE AS 6 - 9, GO TO 33)

- b. (Scale 27b) How ADEQUATE do you think interpersonal or social skills training programs are for _____ (NAME OF DISORDERED FAMILY MEMBER)?

Very
Adequate

Not At All NA DK NR
Adequate

1 2 3 4 5 6 7 0 8 9 (68)

69-80 Blank
1-3 ID

SECTION VI: NORMATIVE BELIEFS REGARDING RESOURCES FOR COMMUNITY-BASED CARE

At different times throughout the interview, I am going to ask you a few questions about your most significant referent concerning mental health issues or questions. By referent, I mean a person whose opinion is very important to you. While we may have more than one person whose opinion is important to us, I am interested in the person whose opinion is most important to you in this specific area.

33. Who is your most significant referent regarding mental health issues or questions? Once again, by referent, I mean a person whose opinion is very important to you in the area of mental health.

(4)

INTERVIEWER: ONCE THE RESPONDENT HAS PROVIDED YOU WITH THE NAME OF THE REFERENT, PLEASE USE EITHER HE AND HIM OR SHE AND HER (DEPENDING ON WHICH COMBINATION IS APPROPRIATE) IN THE REMAINDER OF THE QUESTIONS REGARDING THE REFERENT.

34. (Scale 34) Keeping your important referent in mind, please indicate the degree to which he or she believes you should support the development of better resources for community-based care for _____ (NAME OF DISORDERED FAMILY MEMBER).

Not At All					Totally					DK	NR	
1	2	3	4	5	6	7	8	9				(5)

35. Still using Scale 34, given the belief of your referent, how much do you want to comply with his or her wishes so as to satisfy him or her?

Not At All					Totally					DK	NR	
1	2	3	4	5	6	7	8	9				(6)

SECTION VII: ATTITUDES TOWARD THE IMPORTANCE AND ADEQUACY OF RESOURCES FOR COMMUNITY-BASED CARE

Next, I would like to know your opinion regarding the impact the development of better and more effective community-based services and programs would have on _____ (NAME OF DISORDERED FAMILY MEMBER).

I asked you some questions about the importance and adequacy of different resources (i.e., programs and services) for community-based care for _____ (NAME OF DISORDERED FAMILY MEMBER). You indicated that you thought that (LIST THE RESOURCES HERE) were important resources to have but that they were inadequate at the present time.

36. Using Scale 36, please tell me how desirable it would be to better develop those community-based resources that you indicated were important but inadequate?

Not At All					Very					DK	NR		
Desirable					Desirable								
1	2	3	4	5	6	7	8	9				(7)	

SECTION VIII: SUBJECTIVE NORM REGARDING RESOURCES FOR COMMUNITY-BASED CARE

I am now interested in finding out to what extent the person most important to you (i.e., your referent) favours your supporting development of better resources for community-based care for _____ (NAME OF DISORDERED FAMILY MEMBER).

37. Using scale 37, please indicate to what extent your referent wants you to support the development of better resources for community-based care for _____ (NAME OF DISORDERED FAMILY MEMBER).

Not At All

Totally DK NR

1 2 3 4 5 6 7 8 9 (8)

SECTION IX: BELIEFS REGARDING HOME CARE FOR INDIVIDUALS WITH A CHRONIC MENTAL DISORDER

Before continuing, I would like to remind you that at the end of the interview you will be asked for any comments you may wish to make about any of the issues covered in this questionnaire.

Following discharge from hospital, many individuals with a chronic mental disorder either live at home, or spend considerable time at the family home. For this reason, regardless of whether or not _____ (NAME OF DISORDERED FAMILY MEMBER) is living with you at the present time, I would now like to ask your opinion on some issues relating to home care for _____ (NAME OF DISORDERED FAMILY MEMBER).

Allow me to explain what I mean by home care. HOME CARE is one type of community-based care. The individual with a chronic mental disorder lives with his or her parent(s) or with his or her spouse. One or more of these family members generally take on the role of primary caregiver.

INTERVIEWER: IF _____ (NAME OF DISORDERED FAMILY MEMBER) NORMALLY LIVES WITH THE RESPONDENT, CONTINUE WITH SECTIONS IX(A) - XI(A) BELOW. IF _____ (NAME OF DISORDERED FAMILY MEMBER) DOES NOT NORMALLY LIVE WITH THE RESPONDENT, SKIP TO SECTION IX(B) ON PAGE 22.

SECTION IX(A)

Looking at Scale 38, please indicate the extent to which you agree or disagree with the following statements.

Strongly Agree	Agree	Undecided	Disagree	Strongly Disagree	DK	NR
----------------	-------	-----------	----------	-------------------	----	----

1	2	3	4	5	8	9
---	---	---	---	---	---	---

38. In theory, home care provides the most family-like atmosphere and, therefore, the most natural living arrangements for _____ (NAME OF DISORDERED FAMILY MEMBER). _____ (9)
39. In theory, home care does not provide an environment which best encourages normal functioning by _____ (NAME OF DISORDERED FAMILY MEMBER). _____ (10)
40. In theory, the quality of life of _____ (NAME OF DISORDERED FAMILY MEMBER) is greatest when he or she lives at home with other family members. _____ (11)

I have just asked you some questions regarding the impact home care has on the life of _____ (NAME OF DISORDERED FAMILY MEMBER). Now, I would like to ask your opinion regarding some issues which may arise as a result of having _____ (NAME OF DISORDERED FAMILY MEMBER) living at home with you.

Once again, still using scale 38, please indicate to what extent you agree or disagree with the following statements.

41. As a result of having _____ (NAME OF DISORDERED FAMILY MEMBER) living at home, practical problems such as financial strain occur and daily routines are disrupted. _____ (12)
42. Social and interpersonal relationships do not become limited or strained as a result of having _____ (NAME OF DISORDERED FAMILY MEMBER) living at home. _____ (13)
43. It is difficult to live with the psychiatric symptoms and behaviour displayed by _____ (NAME OF DISORDERED FAMILY MEMBER). _____ (14)

SECTION X(A): ATTITUDES TOWARDS HOME-CARE FOR INDIVIDUALS
WITH A MENTAL DISORDER

Please use Scale 44 when answering the following questions.

Very ineffective_____	1
Ineffective_____	2
Moderately effective_____	3
Effective_____	4
Very effective_____	5
DK_____	8
NR_____	9

44. In your opinion, HOW EFFECTIVE is home care for providing living arrangements and treatment to _____ (NAME OF DISORDERED FAMILY MEMBER) in as natural a setting as possible? _____ (15)
45. In your opinion, HOW EFFECTIVE is home care for helping _____ (NAME OF DISORDERED FAMILY MEMBER) function normally? _____ (16)
46. In your opinion, HOW EFFECTIVE is home care for improving the quality of life of _____ (NAME OF DISORDERED FAMILY MEMBER)? _____ (17)

Using Scale 47, please answer the following questions by indicating HOW MUCH STRESS you feel as a result of having _____ (NAME OF DISORDERED FAMILY MEMBER) living at home with you.

Very Little						Very Much	DK	NR
1	2	3	4	5	6	7	8	9

47. How much stress have you experienced as a result of practical problems (e.g., financial, disruption in daily routine) that have developed as a result of having _____ (NAME OF DISORDERED FAMILY MEMBER) living at home? _____ (18)

48. How much stress have you experienced due to a strain on, or loss of, social and interpersonal relationships as a result of having _____ (NAME OF DISORDERED FAMILY MEMBER) living at home? _____ (19)
49. How much stress have you experienced as a result of having to live with the psychiatric symptoms and behaviour displayed by _____ (NAME OF DISORDERED FAMILY MEMBER) who is living at home? _____ (20)

SECTION XI(A): BELIEFS REGARDING THE IMPORTANCE AND ADEQUACY OF RESOURCES FOR HOME CARE

I would like to ask your opinion about the importance of, as well as the adequacy of, certain resources for home care for your family member with a chronic mental disorder and yourself. I am interested in your opinion regarding these resources whether or not you personally support home care for _____ (NAME OF DISORDERED FAMILY MEMBER).

RESOURCES FOR HOME CARE include services and supports for families and their family member with a chronic mental disorder which help them to provide home care (e.g., respite care for family caregivers, emergency care services for the family member with a chronic mental disorder).

TO THE INTERVIEWER: PLEASE NOTE THE SKIP PATTERN USED IN THIS SECTION. PLEASE ALSO NOTE THAT IF THE ADEQUACY QUESTION IS ASKED, THE RESOURCE IS CONSIDERED TO BE ADEQUATE ONLY IF THE RESPONDENT ANSWERS 1 OR 2 TO THE ADEQUACY QUESTION. PLEASE MAKE A NOTE, ON A SMALL SEPARATE PIECE OF PAPER, OF ALL RESOURCES THAT ARE CONSIDERED TO BE IMPORTANT AND INADEQUATE. YOU WILL NEED TO REFER TO THESE RESOURCES IN QUESTIONS 60 AND 70.

50. SELF-HELP AND SUPPORT GROUPS (e.g., groups which provide emotional support, and information and education on issues relating to mental disorder.

- a. (Scale 50a) How IMPORTANT is it for you to belong to a self-help or support group?

Very
Important

Not At All DK NR
Important

1 2 3 4 5 6 7 8 9 (21)

(IF RESPONDENT RATES IMPORTANCE AS 6 - 9, GO TO 51)

- b. (Scale 50b) At present, how ADEQUATE are such groups in Winnipeg as sources of support for you?

Very
Adequate

Not At All NA DK NR
Adequate

1 2 3 4 5 6 7 8 9 (22)

51. INFORMATION AND EDUCATION REGARDING MENTAL DISORDERS
(i.e., mental illness)

- a. (Scale 50a) How IMPORTANT is it for you to be informed and educated about mental disorders?

Very
Important

Not At All DK NR
Important

1 2 3 4 5 6 7 8 9 (23)

(IF RESPONDENT RATES IMPORTANCE AS 6 - 9, GO TO 52)

- b. (Scale 50b) How ADEQUATE is the information and education about _____'s (NAME OF DISORDERED FAMILY MEMBER) mental disorder provided to you by mental health professionals in Winnipeg?

Very
Adequate

Not At All NA DK NR
Adequate

1 2 3 4 5 6 7 8 9 (24)

52. TREATMENT PLANNING INCLUDING MEDICATION MANAGEMENT

- a. (Scale 50a) How IMPORTANT is it for you to be included in the treatment planning, including medication management, for _____ (NAME OF DISORDERED FAMILY MEMBER)?

Very
Important

Not At All DK NR
Important

1 2 3 4 5 6 7 8 9 (25)

(IF RESPONDENT RATES IMPORTANCE AS 6 - 9, GO TO 53)

- b. (Scale 50b) At present how ADEQUATE is your involvement in the treatment planning, including medication management, for _____ (NAME OF DISORDERED FAMILY MEMBER)?

Very Adequate						Not At All Adequate	NA	DK	NR	
1	2	3	4	5	6	7	0	8	9	(26)

53. ONGOING CONSULTATION AND INTERACTION WITH MENTAL HEALTH PROFESSIONALS

- a. (Scale 50a) How IMPORTANT is it for you to have ongoing consultation and interaction with the mental health professional(s) working with _____ (NAME OF DISORDERED FAMILY MEMBER)?

Very Important						Not At All Important	DK	NR	
1	2	3	4	5	6	7	8	9	(27)

(IF RESPONDENT RATES IMPORTANCE AS 6 - 9, GO TO 54)

- b. (Scale 50b) How ADEQUATE is the ongoing consultation and interaction with the mental health professional(s) in Winnipeg working with _____ (NAME OF DISORDERED FAMILY MEMBER) for you?

Very Adequate						Not At All Adequate	NA	DK	NR	
1	2	3	4	5	6	7	0	8	9	(28)

54. HOME MANAGEMENT SKILLS TRAINING (i.e., the development of coping strategies, stress management, and behaviour management techniques)

- a. (Scale 50a) How IMPORTANT is it for mental health professionals to assist you to develop the skills and strategies that may help you to better cope with and manage _____ (NAME OF DISORDERED FAMILY MEMBER)?

Very Important						Not At All Important	DK	NR	
1	2	3	4	5	6	7	8	9	(29)

(IF RESPONDENT RATES IMPORTANCE AS 6 - 9, GO TO 55)

- b. (Scale 50b) How ADEQUATE do you believe this type of assistance is for you in Winnipeg, at the present time?

Very
Adequate

Not At All NA DK NR
Adequate

1 2 3 4 5 6 7 8 9 (30)

55. EMERGENCY CARE SERVICES (i.e., 24 hour a day crisis care for individuals with a chronic mental disorder).

- a. (Scale 50a) How IMPORTANT do you think it is to have 24 hour a day emergency care available?

Very
Important

Not At All DK NR
Important

1 2 3 4 5 6 7 8 9 (31)

(IF RESPONDENT RATES IMPORTANCE AS 6 - 9, GO TO 56)

- b. (Scale 50b) How ADEQUATE are emergency care services in Winnipeg?

Very
Adequate

Not At All NA DK NR
Adequate

1 2 3 4 5 6 7 8 9 (32)

56. RESPITE CARE (i.e., time-limited care by outside professionals to give the primary caregiver a break)

- a. (Scale 50a) How IMPORTANT is it for you to receive respite care?

Very
Important

Not At All DK NR
Important

1 2 3 4 5 6 7 8 9 (33)

(IF RESPONDENT RATES IMPORTANCE AS 6 - 9, GO TO 57)

- b. (Scale 50b) How adequate is the respite care provided to you at the present time?

Very
Adequate

Not At All NA DK NR
Adequate

1 2 3 4 5 6 7 8 9 (34)

57. FINANCIAL ASSISTANCE

- a. (Scale 50a) How IMPORTANT is it for you to receive financial aid to cover the costs of home care for _____ (NAME OF DISORDERED FAMILY MEMBER)?

Very
Important

Not At All DK NR
Important

1 2 3 4 5 6 7 8 9 (35)

(IF RESPONDENT RATES IMPORTANCE AS 6 - 9, GO TO 58)

- b. (Scale 50b) How adequate is the financial assistance provided to you to help cover the costs of caring for _____ (NAME OF DISORDERED FAMILY MEMBER) at home?

Very
Adequate

Not At All NA DK NR
Adequate

1 2 3 4 5 6 7 0 8 9 (36)

INTERVIEWER PLEASE GO TO THE BOTTOM OF PAGE 28 AND
CONTINUE WITH SECTION XII.

SECTION IX(B)

Looking at Scale 38, please indicate the extent to which you agree or disagree with the following statements.

Strongly Agree	Agree	Undecided	Disagree	Strongly Disagree	DK	NR
----------------	-------	-----------	----------	-------------------	----	----

1	2	3	4	5	8	9
---	---	---	---	---	---	---

38. In theory, home care would provide the most family-like atmosphere and, therefore, the most natural living arrangements for _____ (NAME OF DISORDERED FAMILY MEMBER). _____ (9)
39. In theory, home care would not provide an environment which would best encourage normal functioning by _____ (NAME OF DISORDERED FAMILY MEMBER). _____ (10)
40. In theory, the quality of life of _____ (NAME OF DISORDERED FAMILY MEMBER) would be greatest when he or she lives at home with other family members. _____ (11)

I have just asked you some questions regarding the impact home care would have on the life of _____ (NAME OF DISORDERED FAMILY MEMBER). Now, I would like to ask your opinion regarding some issues which may arise as a result of having _____ (NAME OF DISORDERED FAMILY MEMBER) living at home with you.

Once again, still using scale 38, please indicate to what extent you agree or disagree with the following statements.

41. As a result of having _____ (NAME OF DISORDERED FAMILY MEMBER) living at home, practical problems such as financial strain would occur and daily routines would be disrupted. _____ (12)
42. Social and interpersonal relationships would not become limited or strained as a result of having _____ (NAME OF DISORDERED FAMILY MEMBER). _____ (13)

43. It would be difficult to live with the psychiatric symptoms and behaviour displayed by _____ (NAME OF DISORDERED FAMILY MEMBER). _____ (14)

SECTION X(B): ATTITUDES TOWARDS HOME-CARE FOR INDIVIDUALS WITH A MENTAL DISORDER

Please use Scale 44 when answering the following questions.

Very ineffective	_____	1
Ineffective	_____	2
Moderately effective	_____	3
Effective	_____	4
Very effective	_____	5
DK	_____	8
NR	_____	9

44. In your opinion, HOW EFFECTIVE would home care be for providing living arrangements and treatment to _____ (NAME OF DISORDERED FAMILY MEMBER) in as natural a setting as possible? _____ (15)
45. In your opinion, HOW EFFECTIVE would home care be for helping _____ (NAME OF DISORDERED FAMILY MEMBER) function normally? _____ (16)
46. In your opinion, HOW EFFECTIVE would home care be for improving the quality of life of _____ (NAME OF DISORDERED FAMILY MEMBER)? _____ (17)

Using Scale 47, please answer the following questions by indicating HOW MUCH STRESS you would feel as a result of having _____ (NAME OF DISORDERED FAMILY MEMBER) living at home with you..

- | | Very
Little | | | | | | Very
Much | DK | NR |
|--|----------------|---|---|---|---|---|--------------|----|----|
| | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 |
47. How much stress would you experience as a result of practical problems (e.g., financial, disruption in daily routine) that might develop as a result of having _____ (NAME OF DISORDERED FAMILY MEMBER) living at home? _____ (18)
48. How much stress would you experience due to a strain on, or loss of, social and interpersonal relationships as a result of having _____ (NAME OF DISORDERED FAMILY MEMBER) living at home? _____ (19)
49. How much stress would you experience as a result of having to live with the psychiatric symptoms and behaviour displayed by _____ (NAME OF DISORDERED FAMILY MEMBER) who would be living at home? _____ (20)

SECTION XI(B): BELIEFS REGARDING THE IMPORTANCE AND ADEQUACY OF RESOURCES FOR HOME CARE

I would like to ask your opinion about the importance of, as well as the adequacy of, certain resources for home care for your family member with a chronic mental disorder and yourself. I am interested in your opinion regarding these resources whether or not you personally support home care for _____ (NAME OF DISORDERED FAMILY MEMBER).

RESOURCES FOR HOME CARE include services and supports for families and their family member with a chronic mental disorder which help them to provide home care (e.g., respite care for family caregivers, emergency care services for the family member with a chronic mental disorder).

TO THE INTERVIEWER: PLEASE NOTE THE SKIP PATTERN USED IN THIS SECTION. PLEASE ALSO NOTE THAT IF THE ADEQUACY QUESTION IS ASKED, THE RESOURCE IS CONSIDERED TO BE ADEQUATE ONLY IF THE RESPONDENT ANSWERS 1 OR 2 TO THE ADEQUACY QUESTION. PLEASE MAKE A NOTE, ON A SMALL SEPARATE PIECE OF PAPER, OF ALL RESOURCES THAT ARE CONSIDERED TO BE IMPORTANT AND INADEQUATE. YOU WILL NEED TO REFER TO THESE RESOURCES IN QUESTIONS 60 AND 70.

50. SELF-HELP AND SUPPORT GROUPS (e.g., groups which provide emotional support, and information and education on issues relating to mental disorder.
- a. (Scale 50a) How IMPORTANT would it be for you to belong to a self-help or support group?

Very
Important

Not At All DK NR
Important

1 2 3 4 5 6 7 8 9 (21)

(IF RESPONDENT RATES IMPORTANCE AS 6 - 9, GO TO 51)

- b. (Scale 50b) At present, how ADEQUATE would such groups be in Winnipeg as sources of support for you?

Very
Adequate

Not At All NA DK NR
Adequate

1 2 3 4 5 6 7 0 8 9 (22)

51. INFORMATION AND EDUCATION REGARDING MENTAL DISORDERS (i.e., mental illness)

- a. (Scale 50a) How IMPORTANT would it be for you to be informed and educated about mental disorders?

Very
Important

Not At All DK NR
Important

1 2 3 4 5 6 7 8 9 (23)

(IF RESPONDENT RATES IMPORTANCE AS 6 - 9, GO TO 52)

- b. (Scale 50b) How ADEQUATE would the information and education about _____'s (NAME OF DISORDERED FAMILY MEMBER) mental disorder provided to you by mental health professionals be in Winnipeg?

Very
Adequate

Not At All NA DK NR
Adequate

1 2 3 4 5 6 7 0 8 9 (24)

52. TREATMENT PLANNING INCLUDING MEDICATION MANAGEMENT

- a. (Scale 50a) How IMPORTANT would it be for you to be included in the treatment planning, including medication management, for _____ (NAME OF DISORDERED FAMILY MEMBER)?

Very
Important

Not At All DK NR
Important

1 2 3 4 5 6 7 8 9 (25)

(IF RESPONDENT RATES IMPORTANCE AS 6 - 9, GO TO 53)

- b. (Scale 50b) At present how ADEQUATE would your involvement be in the treatment planning, including medication management, for _____ (NAME OF DISORDERED FAMILY MEMBER)?

Very
Adequate

Not At All NA DK NR
Adequate

1 2 3 4 5 6 7 0 8 9 (26)

53. ONGOING CONSULTATION AND INTERACTION WITH MENTAL HEALTH PROFESSIONALS

- a. (Scale 50a) How IMPORTANT would it be for you to have ongoing consultation and interaction with the mental health professional(s) working with _____ (NAME OF DISORDERED FAMILY MEMBER)?

Very
Important

Not At All DK NR
Important

1 2 3 4 5 6 7 8 9 (27)

(IF RESPONDENT RATES IMPORTANCE AS 6 - 9, GO TO 54)

- b. (Scale 50b) How ADEQUATE would the ongoing consultation and interaction with the mental health professional(s) in Winnipeg working with _____ (NAME OF DISORDERED FAMILY MEMBER) be for you?

Very
Adequate

Not At All NA DK NR
Adequate

1 2 3 4 5 6 7 0 8 9 (28)

54. HOME MANAGEMENT SKILLS TRAINING (i.e., the development of coping strategies, stress management, and behaviour management techniques)

- a. (Scale 50a) How IMPORTANT would it be for mental health professionals to assist you to develop the skills and strategies that may help you to better cope with and manage _____ (NAME OF DISORDERED FAMILY MEMBER)?

Very
Important

Not At All DK NR
Important

1 2 3 4 5 6 7 8 9 (29)

(IF RESPONDENT RATES IMPORTANCE AS 6 - 9, GO TO 55)

- b. (Scale 50b) How ADEQUATE do you believe this type of assistance would be for you in Winnipeg, at the present time?

Very
Adequate

Not At All NA DK NR
Adequate

1 2 3 4 5 6 7 0 8 9 (30)

55. EMERGENCY CARE SERVICES (i.e., 24 hour a day crisis care for individuals with a chronic mental disorder).

- a. (Scale 50a) How IMPORTANT do you think it would be to have 24 hour a day emergency care available?

Very
Important

Not At All DK NR
Important

1 2 3 4 5 6 7 8 9 (31)

(IF RESPONDENT RATES IMPORTANCE AS 6 - 9, GO TO 56)

- b. (Scale 50b) How ADEQUATE would emergency care services be in Winnipeg?

Very
Adequate

Not At All NA DK NR
Adequate

1 2 3 4 5 6 7 0 8 9 (32)

56. RESPITE CARE (i.e., time-limited care by outside professionals to give the primary caregiver a break)

- a. (Scale 50a) How IMPORTANT would it be for you to receive respite care?

Very
Important

Not At All
Important DK NR

1 2 3 4 5 6 7 8 9 (33)

(IF RESPONDENT RATES IMPORTANCE AS 6 - 9, GO TO 57)

- b. (Scale 50b) How adequate would the respite care provided to you be at the present time?

Very
Adequate

Not At All NA DK NR
Adequate

1 2 3 4 5 6 7 8 9 (34)

57. FINANCIAL ASSISTANCE

- a. (Scale 50a) How IMPORTANT would it be for you to receive financial aid to cover the costs of home care for _____ (NAME OF DISORDERED FAMILY MEMBER)?

Very
Important

Not At All DK NR
Important

1 2 3 4 5 6 7 8 9 (35)

(IF RESPONDENT RATES IMPORTANCE AS 6 - 9, GO TO 58)

- b. (Scale 50b) How adequate would the financial assistance provided to you be to help cover the costs of caring for _____ (NAME OF DISORDERED FAMILY MEMBER) at home?

Very
Adequate

Not At All NA DK NR
Adequate

1 2 3 4 5 6 7 8 9 (36)

SECTION XII: NORMATIVE BELIEFS REGARDING RESOURCES FOR HOME CARE

I would once again like to ask you a few questions about the person whose opinion is most important to you (i.e., your referent) concerning mental health issues.

58. (Scale 58) Keeping your important referent in mind, please indicate the degree to which he or she believes you should support the development of better resources for home care for you and _____ (NAME OF DISORDERED FAMILY MEMBER)?

Not At All					Totally		DK	NR	
1	2	3	4	5	6	7	8	9	(37)

59. Once again using Scale 58, given the belief of your referent, how much do you want to comply with his or her wishes so as to satisfy him or her?

Not At All					Totally		DK	NR	
1	2	3	4	5	6	7	8	9	(38)

SECTION XIII: ATTITUDES TOWARDS THE IMPORTANCE AND ADEQUACY OF RESOURCES FOR HOME CARE FOR INDIVIDUALS WITH A MENTAL DISORDER AND THEIR FAMILIES

I am interested in your feelings about the resources and services you have received from the mental health care system.

I asked you some questions about the importance and adequacy of different resources for you and _____ (NAME OF DISORDERED FAMILY MEMBER) which would help you to provide home care for _____ (NAME OF DISORDERED FAMILY MEMBER). You indicated that you thought that (LIST THE RESOURCES HERE) were important resources to have but that they were inadequate at the present time.

60. Using Scale 60, please tell me how desirable you feel it would be to have those home care resources that you indicated were important but inadequate?

Not At All Desirable					Very Desirable		DK	NR	
1	2	3	4	5	6	7	8	9	(39)

SECTION XIV: SUBJECTIVE NORM AND RESOURCES FOR HOME CARE

61. (Scale 61) Once again, considering the views of your referent, please tell me the extent to which your referent wants you to support the development of better resources for home care for you and _____ (NAME OF DISORDERED FAMILY MEMBER).

Not At All					Totally		DK	NR	
1	2	3	4	5	6	7	8	9	(40)

SECTION XV: BELIEFS REGARDING ADVOCACY

The final portion of this questionnaire addresses the issue of advocacy.

ADVOCACY refers to speaking out on behalf of another person or on behalf of oneself. In this specific instance, advocacy refers to families speaking out on behalf of their members who have a chronic mental disorder and themselves regarding mental health care issues.

62. (Scale 62) Please indicate to what extent you think that it is your personal responsibility, as a relative of someone with a mental disorder, to advocate for better, more effective community-based care with those responsible for mental health care (e.g., mental health professionals, Manitoba Department of Health).

Not At All					Totally		DK	NR	
1	2	3	4	5	6	7	8	9	(41)

63. Still using Scale 62, please indicate to what extent you possess the skills that are necessary for advocacy?

Not At All					Totally		DK	NR	
1	2	3	4	5	6	7	8	9	(42)

64. Once again, using Scale 62, please indicate how influential you think you can be as an advocate for better, more effective community-based care?

Not At All					Totally		DK	NR	
1	2	3	4	5	6	7	8	9	(43)

SECTION XVI: NORMATIVE BELIEFS REGARDING ADVOCACY

I would ask that you once again keep in mind your important referent concerning mental health issues, when answering the following questions.

65. (Scale 65) Please indicate the degree to which he or she believes you should advocate for better, more effective community-based care.

Not At All					Totally		DK	NR	
1	2	3	4	5	6	7	8	9	(44)

66. Still using Scale 65, given the belief of your referent, how much do you want to comply with his or her wishes so as to satisfy him or her?

Not At All					Totally		DK	NR	
1	2	3	4	5	6	7	8	9	(45)

SECTION XVII: ATTITUDES TOWARD ADVOCACY

67. Using Scale 67, please tell me HOW DESIRABLE it is for you to advocate for better, more effective community-based care.

Not At All Desirable					Very Desirable		DK	NR	
1	2	3	4	5	6	7	8	9	(46)

SECTION XVIII: SUBJECTIVE NORM REGARDING ADVOCACY

This is the last time that I will ask you to please keep your referent in mind when answering the following question.

68. (Scale 68) To what extent does your important referent want you to advocate for better, more effective community-based care.

Not At All					Totally		DK	NR	
1	2	3	4	5	6	7	8	9	(47)

SECTION XIX: BEHAVIOURAL INTENTIONS

Earlier in the interview, you were asked your opinions regarding several community-based programs and services.

I would now like to know whether or not you would take certain actions in support of those community-based programs and services that you believed were important and inadequate (LIST THE RESOURCES THE RESPONDENT INDICATED WERE IMPORTANT AND INADEQUATE).

69. Please tell me which of the actions listed in Scale 69 you would be LIKELY TO TAKE ON YOUR OWN without anyone asking you to by answering YES or NO. (READ EACH CATEGORY)

	ACTIONS LIKELY TO TAKE			
	YES 1	NO 2	DK 8	NR 9
Support and sign petition	_____	_____	_____	_____ (48)
Support and attend meeting	_____	_____	_____	_____ (49)
Support and join action group	_____	_____	_____	_____ (50)
Support and form action group	_____	_____	_____	_____ (51)
Support and write to newspaper	_____	_____	_____	_____ (52)
Support and contact politician	_____	_____	_____	_____ (53)
Support and volunteer some of your time to help improve services	_____	_____	_____	_____ (54)
Support but not take any action	_____	_____	_____	_____ (55)

You also were asked your opinions regarding various home care programs and services.

I would now like to know whether or not you would take certain actions in support of those home care programs and services that you believed were important and inadequate (LIST THE RESOURCES THE RESPONDENT INDICATED WERE IMPORTANT AND INADEQUATE).

70. Still looking at Scale 69, please indicate which of the actions listed in Scale 69 you would be LIKELY TO TAKE ON YOUR OWN without anyone asking you to by answering YES or NO. (READ EACH CATEGORY)

ACTIONS LIKELY
TO TAKE

	YES	NO	DK	NR	
Support and sign petition	_____	_____	_____	_____	(56)
Support and attend meeting	_____	_____	_____	_____	(57)
Support and join action group	_____	_____	_____	_____	(58)
Support and form action group	_____	_____	_____	_____	(59)
Support and write to newspaper	_____	_____	_____	_____	(60)
Support and contact politician	_____	_____	_____	_____	(61)
Support and volunteer some of your time to help improve services	_____	_____	_____	_____	(62)
Support but not take any action	_____	_____	_____	_____	(63)

I JUST HAVE A COUPLE OF GENERAL QUESTIONS BEFORE
CONCLUDING THE INTERVIEW.

71. If we want to talk to you again with some follow-up questions, may I have your phone number?

Yes.....1

Home _____

Work _____

No.....2

(64)

72. After the study is completed, a summary of the results will be sent out to all participants. If you do not wish to receive a copy of the summary, please tell me, so that one will not be sent out to you.

Does not want a copy of the summary.....1 (65)

INTERVIEWER PLEASE NOTE: IF THE RESPONDENT DOES NOT WISH A COPY OF THE RESULTS, PLEASE RECORD THEIR NAME ON THE SUMMARY SHEET IN YOUR INTERVIEWER'S KIT.

This ends the interview. I would like to thank you for taking the time to complete this questionnaire. If you have any questions, I would be pleased to answer them for you. Any comments or feedback you may have for me would be most appreciated. Are there any comments you would like to offer?

COMMENTS _____

TO BE COMPLETED BY INTERVIEWER:

73. Quality of interview:

High quality_____1
 Adequate_____2
 Questionable_____3 (66)

74. Respondent's cooperation:

Cooperative_____1
 Indifferent_____2
 Uncooperative_____3 (67)

75. Did you ask spouse/partner or others for privacy?

Yes_____1
 No_____2 (Go to 112)
 NA_____7 (Go to 112) (68)

76. Did the person(s) comply?

Yes_____1
 No_____2
 NA_____7 (69)

70-80 Blank
 1-3 ID

77. Sources of interview interference, if any: (CHECK AS MANY AS APPLY)

	YES 1	NO 2	
Alcohol.....	_____	_____	(4)
Language.....	_____	_____	(5)
Age.....	_____	_____	(6)
Illness.....	_____	_____	(7)
Noise.....	_____	_____	(8)
Presence of spouse.....	_____	_____	(9)
Presence of children.....	_____	_____	(10)
Presence of others.....	_____	_____	(11)
Phone calls.....	_____	_____	(12)
Other.....	_____	_____	(13)

THUMBNAIL SKETCH

78. Was there anything about the respondent or the interview situation that seems important?

(14)

I declare that this interview was conducted in accordance with the instructions given by the Researcher. I agree that the content of all the respondent's responses will be kept confidential.

(Interviewer's Signature)

APPENDIX L

FOLLOW-UP LETTER TO RESEARCH PARTICIPANTS

Dear Research Participant:

In the spring-summer of 1991, I met with you in relation to the study I was conducting as part of my Ph.D. program in the Department of Psychology, University of Manitoba. The purpose of the study was to investigate the beliefs, attitudes, and behavioural intentions of families who had a family member with a chronic mental disorder, regarding advocacy for resources for community-based care, including home care.

I recently have completed this study. The purpose of this letter is to thank you for your participation and to provide you with the enclosed summary of the study's results. If you have any questions regarding the study, please feel free to contact me through the Department of Psychology, University of Manitoba, Winnipeg, Manitoba, R3B 1Y4.

Before closing, I would like to take this opportunity to once again thank the community and other mental health workers for introducing me to their clients and for being participants in this study. I also would like to thank the individuals who have experienced a chronic mental disorder for meeting with me and allowing me to contact and interview one of their family members. Finally, I would like to thank all the family members who not only agreed to be interviewed, but who also willingly shared their knowledge and experiences with me and my research assistant.

Sincerely

Janine Cutler, M.A.

Encl.

Research Summary

RESEARCH SUMMARY

INTRODUCTION:

This study examined family members' beliefs regarding and attitudes toward: community-based care, including home care; the adequacy of resources necessary for community-based care, including home care; and advocacy. The study also investigated family members' behavioural intentions to advocate for resources for community-based care, including home care.

A summary of the frequency of responses received from the 100 family member respondents interviewed, to various portions of the interview is provided, along with a brief discussion of the practical implications for system and program planning.

SUMMARY OF RESPONSES (RESULTS):

A. PERCEIVED SUPPORT

The number of family member respondents who indicated they had received little or no support from the following sources is:

1. Immediate family	37
2. Extended family	75
3. Other sources	60
4. Mental Health Care System	
Information/Education	70
Ongoing consultation	77
Financial assistance	87
Crisis care	57

B. BELIEFS REGARDING COMMUNITY-BASED CARE

A large majority of family member respondents believed community-based care was preferable to hospitalization.

C. ATTITUDES TOWARD COMMUNITY-BASED CARE

Family member respondents believed that community-based care was preferable to hospitalization. However, they varied in their beliefs regarding the effectiveness of such care.

D. BELIEFS REGARDING THE IMPORTANCE AND ADEQUACY
OF RESOURCES FOR COMMUNITY-BASED CARE

The number of family member respondents who indicated they believed the following resources were very important is as follows:

1. Job training	75
2. Welfare	86
3. Higher education	50
4. Housing	87
5. Recreation	75
6. Social skills	76

The number of family member respondents who indicated they believed the following resources were not at all or not very adequate is as follows:

1. Job training	66
2. Welfare	67
3. Higher education	38
4. Housing	58
5. Recreation programs	64
6. Social skills training	55

E. ATTITUDES TOWARD THE DESIRABILITY OF RESOURCES FOR
COMMUNITY-BASED CARE

Ninety family member respondents indicated it was desirable to have better developed resources for community-based care.

F. BELIEFS REGARDING HOME CARE FOR INDIVIDUALS WITH A
CHRONIC MENTAL DISORDER

Family member respondents' beliefs regarding home care for their family member with a chronic mental disorder varied.

G. BELIEFS REGARDING FAMILY BURDEN

Many family member respondents believed that having a family member with a chronic mental disorder living at home placed a heavy burden on the family.

H. ATTITUDES TOWARD HOME CARE FOR THE INDIVIDUALS WITH A
CHRONIC MENTAL DISORDER

Family member respondents varied in their attitudes toward the effectiveness of home care in helping to improve the functioning and quality of life of their family member with a chronic mental disorder.

I. ATTITUDES TOWARD FAMILY BURDEN

Many family member respondents' indicated that as a result of having a family member with a chronic mental disorder living at home, they experienced a heavy burden.

J. BELIEFS REGARDING THE IMPORTANCE OF RESOURCES FOR HOME CARE

The number of family member respondents who indicated they believed that the following resources for home care were important is:

1. Support/self-help groups	51
2. Information/Education	84
3. Involvement in treatment planning	79
4. Ongoing consultation	90
5. Home management training	75
6. Emergency care	89
7. Respite care	72
8. Financial aid	71

The number of family member respondents who indicated they believed that resources for home care were not at all or not very adequate is as follows:

1. Support/self-help groups	41
2. Information/Education	70
3. Involvement in treatment planning	51
4. Ongoing consultation	72
5. Home management training	68
6. Emergency care	61
7. Respite care	54
8. Financial aid	65

K. ATTITUDES TOWARD THE DESIRABILITY OF RESOURCES FOR HOME CARE

Eighty-five family member respondents indicated it was very desirable to have better developed resources for home care.

L. BELIEFS REGARDING AND ATTITUDES TOWARD ADVOCACY

Between 75 and 80 family member respondents believed it was their personal responsibility to advocate on behalf of their family member with a chronic mental disorder and themselves with those responsible for mental health care. Respondents varied in their beliefs regarding their own ability to advocate, and over one-half believed they would not be very influential as advocates.

Seventy-three respondents indicated it would be desirable to advocate for better resources for community-based care.

M. BEHAVIOURAL INTENTIONS TO ADVOCATE FOR RESOURCES FOR COMMUNITY-BASED CARE AND HOME CARE

The number of family member respondents who indicated they would take the following actions in support of better resources for community-based care and home care is as follows:

<u>ADVOCACY ACTIONS</u>	<u>CBC</u>	<u>HOME CARE</u>
1. Sign petition	94	87
2. Attend meeting	88	77
3. Join action group	58	51
4. Form action group	14	15
5. Write to newspaper	41	39
6. Contact politician	52	48
7. Volunteer time	85	76

All family member respondents were asked if they wished to make any comments at the end of the interview. Eighty-six respondents provided additional comments.

DISCUSSION:

A large majority of family member respondents believed community-based care was preferable to hospitalization. However, they varied in their attitudes toward community-based care. Although family member respondents believed in the concept of community-based care, they varied in their attitudes toward: its effectiveness in providing living arrangements and treatment in as normalized a setting as possible, in helping their family members with a chronic mental disorder function normally, and in improving the quality of life of their family member with a chronic mental disorder. Many respondents spoke about the paucity of services, the poor quality of services, and the lack of ongoing care for their family member with a chronic mental disorder. Therefore, it is not surprising that, although family member respondents believed community-based care is preferable to hospitalization, they varied in their attitudes toward the effectiveness of that care.

Family member respondents also varied in their beliefs regarding and attitudes toward home care. A number of the respondents commented that adult children generally do not live with their family of origin. These respondents believed that if their family member with a chronic mental disorder was to function normally and experience a better quality of life, it was important that he or she live in a supervised residence, semi-independently, or independently

within the community. Family member respondents also believed that having a family member with a chronic mental disorder living at home placed a heavy burden on the family.

Family member respondents believed that resources for both community-based care and home care were important, but generally inadequate. If community-based care is to be effective, and if families who have a member with a chronic mental disorder are to feel less burdened, then better resources need to be provided for both community-based care and home care. Family member respondents did report that it would be desirable to have better resources for community-based care and home care. They also showed a willingness to advocate in some manner for these resources. Family member respondents indicated they were somewhat more willing to advocate for resources for community-based care than for home care.

Family member respondents also reported that they had very little social support. However, only 50% of these respondents believed that support/self-help groups were important. Perhaps some respondents either do not know how to, or are not able to, avail themselves of social networks which can provide both emotional and instrumental support. A future research endeavour would be to investigate family members' needs and wishes in regard to support from other family members and family organizations. If self-help support and advocacy groups are to exist and thrive, they must find ways to welcome and work co-operatively with all family members, so the needs of different groups of family members can be met. Family members are very aware and willing to articulate their needs. They simply need to be asked.

In conclusion, the relationships between the mental health system, family members who have a relative with a chronic mental disorder, and the individuals with a chronic mental disorder is complicated. Family members who have a relative with a chronic mental disorder have undergone a vast array of experiences which have provided them with a large base of knowledge and expertise. They too often have been a neglected and unappreciated group. It is time that the mental health system joined forces with family members and with individuals who have a chronic mental disorder in the pursuit of mental health reform.