

# **Family Members of the Mentally Ill and Their Experiences with Mental Health Professionals**

by

Suellen A. Evavold

Dissertation submitted to the Faculty of the Virginia Polytechnic Institute and State University in partial fulfillment of the requirements for the degree of

Doctor of Philosophy

In

Environmental Design and Planning

Committee:

James Bohland, Ph.D. Chair

Jo Ann Carmin, Ph.D. Chair

Carol A. Bailey, Ph.D.

Bonnie Billingsley, Ph.D.

Peggy de Wolf, Ph.D.

April 23, 2003

Blacksburg, Virginia

Keywords: Families, Family-Centered, Mental Health, Mental Illness, Qualitative

© 2003 by Suellen A. Evavold

## Suellen Evavold: Family Members of the Mentally Ill and Their Experiences with Mental Health Professionals

### **Abstract**

This qualitative research looks at the relationships between primary caregivers of mentally ill individuals and mental health professionals from the perspective of the caregivers. It reports the stories told to me by family members of mentally ill loved ones who were receiving mental health services in order to raise awareness of the challenges these caretakers face on a daily basis as they tried to support their loved ones in the community and the isolation they experienced because of current attitudes and practices of mental health professionals.

Although family members voiced their frustrations at the relationship between themselves and mental health professionals, they were not complaining as much as viewing this study as a forum to vocalize years of frustration and recount numerous personally unsatisfying interactions and relationships with mental health professionals.

I used four main research questions to guide the interviews in which I asked family members to share their experiences with mental health professionals. My investigation produced a general narrative of experiences rather than specific details about the treatment of family members.

The overall results of my interviews suggest that family members believe a family-centered care approach in the treatment of mentally ill individuals and the respect of mental health care professionals for family members can enhance a mental health professional's ability to treat individuals with mental illness. These results provide useful insights into the challenges that mental health professionals need to address and highlight some of the changes they need to make for community mental health care programs to work for both the mentally ill and their caregivers.

## **Dedication**

To Bert: Thank you for believing in me!

## **Acknowledgements**

Pursing a doctoral degree is the fulfillment that no words can describe. My friend and confidant, Robert, and my brother, Todd, and my good friend, Matt, encouraged me to pursue a doctoral degree and they supported me throughout the *entire* process. For this I am truly grateful. My committee members Dr. James Bohland, Dr. JoAnn Carmin, Dr. Carol A. Bailey, Dr. Bonnie Billingsley, and Dr. Peggy de Wolf all have helped me stay focused and served as wonderful models for academic rigor and integrity. All of these people have been a pleasure to work with. All the participants who entrusted me with their stories, I thank you for your time and willingness to share your lives. I greatly appreciate your generosity and I acknowledge your essential contributions to this study. I thank the National Alliance for the Mentally Ill (NAMI) for aiding me in this project. Sara, my editor, thank you for your time, services and all your valuable suggestions.

## Table of Contents

TITLE PAGE .....	i
ABSTRACT .....	ii
DEDICATION .....	iii
ACKNOWLEDGEMENTS .....	iii
PREFACE .....	1
CHAPTER ONE: Introduction .....	2
History .....	2
Scope of Disorder .....	5
History of Family Involvement .....	6
Community Support Movement .....	7
CHAPTER TWO: Literature Review and Theoretical Perspective .....	10
Literature Review .....	10
Theoretical Perspective .....	19
CHAPTER THREE: Methodology .....	23
Research Questions .....	24
Data Sources and Collection Procedures .....	30
Interview Guide and Questions .....	32
Interview Settings and Scheduling .....	32
Confidentiality and Informed Consent .....	33
Ethical Considerations .....	34
Data Analysis Approach .....	34
CHAPTER FOUR: Description of Services and Presentation of Family Members .....	37
Services .....	38
The Story .....	39
Family Member Profiles .....	41
CHAPTER FIVE: Participant Responses .....	46
Research Question # 1: What are the Experiences of Family Members? .....	47
Research Question # 2: How Involved Have Family Members Been? .....	52
Research Question # 3: How Would Family Members Like To Be Involved? .....	70
Research Question # 4: Do Family Members Receive Necessary Support? .....	76
CHAPTER SIX: Themes .....	82
Family-centered care .....	82
Respect and Recognition .....	87
Confidentiality .....	93
Coping Strategies .....	96
System versus Relationship Issues .....	97

CHAPTER SEVEN: Summary and Conclusions .....	101
Limitations and Strengths of the Study .....	101
Recommendations .....	103
Contributions .....	107
Suggestions for Future Research .....	109
Summary .....	111
Conclusions .....	113
REFERENCES .....	115
APPENDIX A .....	122
APPENDIX B .....	124
INTERVIEW GUIDE .....	124
APPENDIX C .....	127
VITA .....	128

## **Preface**

Completing this study has challenged my thoughts and feelings on many different levels. As a social worker who has worked in the field of mental health for ten years, I have always thought that I worked well with some family members and not so well with others. What I have learned from the family members<sup>1</sup> who participated in this study is that I did not do enough for or with even those with whom I thought I had worked with well. It was not because I did not respect and admire these people because of what they go through on a daily basis, but because I lacked the time, carried a large caseload, and did not think through what family members' input means to the success of the mentally ill individuals in living in the community. I truly believe it takes very special people to deal with the effects of mental illness on a daily basis and also have the courage to move forward.

I was touched by every family member story. I am touched by their overarching commitment to advocate, love and make a deep investment in caring for their mentally ill loved one, even while being misunderstood and unheard much of the time by mental health professionals. While conducting this study, I learned a valuable lesson for life. The participants have all encountered loss, but loss and still have the courage and the guts to go on with life, and not just go on with life, but also participate and live life to the fullest. They have helped me learn the value of perspective and the importance of humor, and have reinforced for me that a person really does choose to be happy.

### **To the family members in this study:**

Thank you for the valuable lessons you have taught me. And thank you for your time, and your willingness to share your personal and powerful stories.

---

<sup>1</sup> Names of family members and facilities have been given pseudonyms to protect the family members and facilities. Some of the details have also been altered to protect family members.

## **CHAPTER ONE**

### **An Introduction to the History, Family Involvement, and Community Support**

The purpose of this study is to examine more fully the experiences that family members with a mentally ill relative have had with mental health professionals in order to document for mental health professionals the role family members play in supporting their mentally ill loved one in the community. This study was undertaken with the expectation that it will demonstrate to mental health professionals the importance of involving family members more fully in the treatment process. For this study a family or family member will be defined as a parent, grandparent, spouse, sibling, child, aunt, uncle, or cousin who provides the care and support to the mentally ill person.

The family members who participated in this study have, for the most part, had years of experience with mental health professionals. Although they voice their frustration and anger at the relationship between themselves and mental health professionals, they are not complaining as much as viewing this study as a forum to vocalize years of frustration and recount numerous personally unsatisfying interactions and relationships with mental health professionals. They are pleased to have someone listen to them and record their observations in the hope that they might contribute to positive changes in the mental health care system. All the interviews contain a strain of hopefulness, especially because the interviewees seem to sense a shift for the better in the relationship between mental health professionals and family members. Perhaps this feeling arises from the newly educated mental health workers who are now entering the field with training that focuses on understanding and valuing the role family members play in treating the mentally ill individual. Or perhaps the introduction of the new model of care, PACT, has opened the doors for family members to be active participants with the mental health professionals in the care of their mentally ill loved one.

#### *History*

Although this study focuses on the current situation of community mental health care, the concept of community mental health care is not a new one. To better understand this concept, it is important to have some sense of the history of mental disorders. This history helps explain why family involvement is essential to successful community based

mental health care, and why mental health providers should take the experiences of the family members of a mentally ill person into consideration.

The treatment of mental disorders can be traced back to medieval times when a shaman attempted to drive them away with flogging or by drilling a hole in the skull to release the evil spirits. Until the 16<sup>th</sup> century, treatment techniques were cruel, and sometimes torturous, and all the treatments were aimed at attempting to balance the mind and the body. The 17<sup>th</sup> century marked the beginning of a semblance of humanitarian treatment, because the mentally ill were housed in institutions or hospitals. Confinement at this time was not only for those with a mental illness, but also for those who were homeless or poor, as well as for addicts or invalids (Gupta, 1993). Around 1745, the efforts of Phillippe Pinel, Dorothea Dix, and Jean-Baptiste Pussin led to concern for the treatment and well-being of the poor and disadvantaged (Gallager, 1995). Pinel came up with the idea of removing chains from the mentally ill patients. Dix became a crusader against inadequate and inhuman conditions in mental hospitals and jails. Her crusading led to millions of dollars being spent to improve the conditions in the hospitals. Finally in 1900-1905, Sigmund Freud discovered the link between psychological processes and mental illness. During World War II, military mental health services developed early interventions, and it was around this time that the concept of community mental health care was created.

By the 1950s, the treatment system began to make a transition, when the introduction of psychotropic medications to treat mental disorders revolutionized psychiatric treatment. These drugs, which help control hallucinations and delusions, created an opportunity for deinstitutionalizing many individuals with a mental illness. Consequently, the need for community-based mental health care arose.

This need became more pressing as increasing numbers of people seeking help began to alarm state authorities due to the high cost of maintaining mentally ill people in the institutions. This concern resulted in the passage of the Community Mental Health Service Act in 1954 to help subsidize rates, including those for outpatient care. In 1955, the Joint Commission on Mental Illness and Health was established and given the task of evaluating the conditions and needs of mentally ill people in order to make recommendations to Congress to develop a national mental health program (Tausig,



Michello & Subedi, 1999). In the 1960s, political and social activism brought attention to the inhuman conditions of mental institutions (Gallagher, 1995), which eventually led to further deinstitutionalization that heightened the need for community-based health care.

Since the objectives of the community mental health program are primary prevention and treatment, mental health programs were initially extended to various entities such as schools, social service agencies, and church programs. However, the Nixon administration cut community mental health programs, and the Reagan administration made severe budget cuts, because this administration decided that it was up to each state to fund and administer community health programs.

When deinstitutionalization took place in the 1950s and 1960s, it meant that mental health patients were transferred from mental institutions into the care of community mental health agencies. However, this transfer was not successful, because appropriate support systems for the mental health patients were not set up. Several problems, including poor monitoring of care, poor staffing and funding, public apathy, and homelessness resulted (Gupta, 1993). Many patients found life in the community frightening, largely because of negative community attitudes about deinstitutionalization. And due to all the negativity and the lack of coordinated and comprehensive services, these patients found themselves going in and out of the mental health wards of hospitals on a regular basis.

In the 1950s, the civil rights movement began to push community health to make social changes. Eventually the women's movement, the gay rights movement, anti-Vietnam War movement, and the disability rights movement (Minkler, 1999) all contributed to the evolution of community-based care. During the 1980s, homosexuality was removed as a diagnostic category from the Diagnostic and Statistical Manual (DSM) as a result of a social and political process, and its removal followed the gay rights liberation movement (Tausig et al., 1999, p. 133).

In 1975, the "community support" movement began as an outgrowth of the community mental health movement. Community support emphasizes an expanded vision of care and treatment to include assessing and providing for the social welfare needs of people with a mental illness in their local communities. Also, voluntary support networks emerged such as the National Alliance of the Mentally Ill (NAMI), which is a

nonprofit, grassroots, self-help, support and advocacy organization of consumers, families, and friends of people with severe mental illnesses (National Alliance for the Mentally Ill, [NAMI] 2002, Introduction ¶ 1) have expanded to advocate for individuals with a mental illness. This kind of advocacy has promoted the idea that mentally ill people have civil rights that need to be protected.

### *Scope of Disorder*

Since deinstitutionalization, it has been difficult to accurately measure just how many people are diagnosed with a mental disorder. According to current epidemiological estimates, at least one in five people has a diagnosable mental disorder during the course of a year. These estimates, however, have shifted over the years because of changes in the definitions and diagnosis of mental health and mental illness. Consequently, in the early 1950s, the rates of mental illness were far higher than they are today. The most complete and concise recent epidemiological studies (Robins & Reigier, 1990; Kessler et al., 1994) document the high levels of disorder in the community and low rates of psychiatric treatment for adults. Epidemiologic Catchment Area (ECA) and the National Comorbidity Survey (NCS) estimate that about 20% of the population of the United States is affected by mental disorder during a given year.

With the large number of people diagnosed with a mental disorder, costs become outrageously high, partly because they are divided among a fragmented system of mental health services. This fragmentation has occurred over the years because of the influence of factors that include financial arrangements, such as who pays for what service, and an increase in care costs.

Services for mental health have separate sectors for financing, length of care, and setting (U.S. Department of Health and Human Services, 1999). There are also four sectors of the community mental health services, which are medical/primary care, human services, mental health, and volunteer support networks. The system is further divided into the public and private sectors with government resources generally financing the public sectors, and private resources supporting the private sectors. The duration of care is also fragmented in that it is divided between services for the treatment of individuals with acute conditions and services for the care of individuals with chronic conditions.

The patterns of use of these services show about 15 % of the adult population of the United States uses the mental health system in any given year (Wang, Demler, & Kessler, 2002). Unfortunately, because the system is so fragmented and difficult for people to negotiate, those with the greatest needs often fall through the cracks. Many of these are the racial and ethnic minority populations. There are various reasons why these minorities do not seek services, and when they do, they are often given treatment that is inappropriate for their needs (Wang, et al, 2002).

### *History of Family Involvement*

Prior to the 1950s, families of mentally ill individuals found that accessing care was relatively easy. The mentally ill individual was taken, either voluntarily or involuntarily, to a hospital primarily to protect the individual from the “stressful, pathogenic elements of society” (Bernheim, 1989, p.561). In many cases, the patient remained in the hospital for many years, if not a lifetime, enduring treatments that rarely were successful. At this time, families and professionals had little contact with the patient and families were told to expect very little change and to resume their lives with the understanding that the patient might never return home.

Visiting the patient was also discouraged for several reasons. Among these was the belief that families often caused the patient to become agitated. Gradually, families became to be seen as the carriers of the still undefined societal pathogen (Rothman, as cited in Bernheim, 1989). At this time families grieved for the loss of their loved one and went about their lives without the burdens and ongoing caretaking responsibilities, which the hospital now undertook.

The advent of psychotropic medications in the middle 1950s, and deinstitutionalization of the 1960s have each had a large impact on the lives of patients and their families. It is estimated that approximately 65% of discharged mentally ill patients return to live with their families (Goldman, 1982), who are, as a result finding themselves more and more playing an integral role in caring for their mentally ill loved ones. Some of their tasks include: 1.) creating an environment that balances their needs with those of the mentally ill individual, 2.) learning to cope with the mentally ill person’s symptoms, 3.) locating services for the mentally ill individual. These roles and

responsibilities highlight the drastic changes that have occurred which involve families more directly in the care of their mentally ill loved one than they were when they placed these loved ones in hospitals where they had no contact and influence on the type of care and treatment that the mentally ill individual received.

### *Community Support Movement*

Since the 1970s, from about the same time that the community support movement began, consumer and family organizations have exerted a growing influence on the way mental health services are delivered. They have lobbied for new legislation and policy to direct the way in which mental health services are delivered (Tausig et al, 1999). They also promote self-help groups and address stigma issues. Up until this time, family members had not been involved in the care and treatment of their loved ones, because many health professionals believed family members were the cause of mental illness, and because treatment took place in institutions. Because of new understandings of the causes of mental illness and changes in treatment procedures, it is estimated that today about 75 percent of mentally ill persons maintain some type of contact with their family members (Holden & Lewine, 1982). With a mentally ill family member under family care, families are in a position to respond to a crisis, monitor medications, seek care, arrange social events, and apply for social security benefits and other services. Since families play such an integral role in the mentally ill person's life, it is all the more important that the professional-family collaboration ties be strengthened.

I believe that professionals can gain valuable insights by working with families to develop more effective methods of interventions for seriously mentally ill persons, because families are key service providers to their loved ones and, therefore, invaluable resources to professionals developing treatment plans. However, research reveals that professionals do not sufficiently include families in the treatment of their mentally ill relative, and much of the time families are confused and frustrated when left to sort out a very complex and confusing mental health system (Biegel, Sales, & Schulz, 1991; Sawa, 1992). A team approach involving families and professionals is needed to resolve these issues and provide for the care and rehabilitation of seriously mentally ill persons.

Although the important role the family plays in supporting a mentally ill member in the community is now emerging as a significant factor in mental health care, research has traditionally focused on the burden placed on the family. To demonstrate the need for full family involvement, this study reports the stories told by family members of mentally ill persons who are currently receiving mental health services. It goes beyond looking at the burden the family bears to highlight how the lack of family involvement in the treatment process can increase the burden. By compiling a detailed collection of family member perceptions and experiences, this study raises awareness of the challenges families have in trying to support their loved ones in the community. By listening to family members recount their experiences, it adds to the body of knowledge on the subject of families' experiences with mental health professionals so that the needs of caretakers and other family members can be taken into account when treatments are being devised for their mentally ill loved ones. Thus, it helps to decrease the isolation these family members experience.

To conduct this research, I asked for volunteers from a NAMI support group. NAMI is a nonprofit, grassroots, self-help, support and advocacy organization of consumers, families, and friends of people with severe mental illnesses, such as schizophrenia, major depression, bipolar disorder, obsessive-compulsive disorder, and anxiety disorders (NAMI, 2002, Introduction ¶ 1). Sixteen family members volunteered, and of these, four were couples. The interviews took place at the homes of some, at libraries, and at restaurants. I found that these participants readily shared their experiences and discussed their perceptions with me. In Chapter Two, I review the relevant literature, and in Chapter Three, I describe the methodology for this study. Chapter Four describes the services and provides an introduction of family members. Chapter Five is a discussion of each of the research questions. In Chapter Six, the various themes are discussed in detail. In this discussion, I summarize my findings and explore how they complement and augment previous research. Chapter Seven contains the limitations and strengths of the study, recommendations for family members, and suggestions for future research. The concluding sections are a summary of the findings and the conclusion.

Having learned from my interviews of the men and women who participated in the study how difficult it can be to find information about mental illness, I include in Appendix C definitions of some of the terminology used in this study. Appendix A provides a copy of the consent form the participants read and signed, and Appendix B provides the question I use to guide the interviews.

## **CHAPTER TWO**

### Literature Review and Theoretical Perspective

#### **Literature Review**

This review of literature concentrates on research relevant to family member experiences with mental health professionals. It consists of sections on mental illness and community health services, and family experiences with mental health services, as well as a section on the theoretical perspective that informs this study. Perhaps the most significant discovery of this section is the absence of a body of current research of family experiences with mental health professionals. This fact, in itself underscores the need for this study.

#### Mental Illness and Community Health Services

Mental illness is a disease that affects millions of people each year. Experts estimate that “one of every five Americans suffers from a mental disorder in any 6-month period, and that one of every three person suffers from a mental disorder in his or her lifetime” (Bourdon, Rae, Locke, Narrow, & Reiger, 1992, p. 663). Mental illness strikes without regard to age, gender, race, education, socioeconomic status, culture, or ideology. In many cases, mental illness brings suffering not only to the individual, but also to family and friends (NAMI, 2001).

The economic costs of mental illness are staggering. America spends over 69 billion dollars yearly on direct treatment costs. There are long waiting lists for community services. Many persons with severe mental illness are caught in a vicious circle. They enter a psychiatric hospital for treatment, are discharged back to their home community with no effective follow-up care, and end up homeless or back in the hospital. In addition, it is not unusual for those with private insurance to end up in public care once their limited coverage is exhausted (NAMI, 2001).

Today, with the focus on community care, when people experience mental health problems, they receive care from a wide range of people in the community—their family, friends, peers, physicians, and mental health specialists. According to Bourdon et al.

(1992), the results of the Epidemiological Catchment Area (ECA) project show that in 1990 about 53 million adults had a mental or addictive disorder, and 27 million received care. Mental health care was provided in various settings, where usually the largest segment of people was treated through outpatient services by mental health and substance abuse providers. Primary care physicians, social service providers, and self-help groups treated the second largest segment of people.

Much of what is known about the use of services focuses on specialized mental health care and general medical care. Specialized mental health care includes the services of psychiatrists, psychologists, psychiatric nurses, and social workers, and general medical care includes the services of primary care practitioners and community hospitals. All these together form community resources for dealing with mental health problems (Horwitz & Scheid, 1999).

Community mental health services differ from traditional mental health services in several ways. These include care provided in the home versus a clinic and home visits from social workers, nurses, and vocational rehabilitation professionals. One major characteristic that distinguishes community mental health from more traditional mental health-related activities is its emphasis on treatment in the community as opposed to treatment in institutional settings (Bloom, 1984).

Persons with mental illness and their families, who rely on community mental health services, prefer an array of services, such as family self-help programs, crisis intervention, and advocacy services to help them cope with the isolation and loss that often accompanies those with a serious mental illness (U.S. Department of Health and Human Services, 1999). However, mentally ill persons and their families in need of support and services are, in many instances, receiving fragmented care, or worse yet, no care at all (NAMI, 2001). Other aspects of community services, which are lacking, but are necessary to help avoid lifelong institutionalization of some people with serious mental illness, are continuity and consistency of quality care in order to avoid treatment gaps and care which varies from one health care professional to another. Several researchers point out that the need for this continuum of care also includes funding issues and decreasing monies for services (Bloom, 1984; Backer & Richardson, 1989).



The fundamental components of effective service delivery include integrated community-based services, continuity of providers, and family support services. Horwitz and Scheid (1999) argue that as the life expectancy of Americans continues to expand, the number of people affected by mental illness will also increase; therefore, it is necessary to confront the issues of delivery in the mental health system, including the recognition and support of the role that family members play in caring for and supporting their mentally ill family member and the effective treatment of people with mental illness living in the community. A comprehensive and integrated system of community-based services must exist to fill these needs (Bonjean, Coleman, & Iscoe, 1988).

So far, the attempts to integrate services successfully have been fair at best. Although there is a belief that community-based care could prevent the development of more serious mental breakdowns, the community mental health systems have failed to develop plans for the difficult-to-treat patient. Consequently, community treatment for this kind of patient consists of loosely constructed programs divided among various service providers. Such programs are inaccessible to individuals with serious mental illness, because they have problems negotiating service bureaucracies (U.S. Department of Health and Human Services, 1999).

Many of the issues concerning integrating services began with deinstitutionalization, a process which requires the release of many seriously mentally ill individuals, institutionalized in state facilities for years, into either nursing homes or directly into the community. Goldman and Taube (1989), therefore, argue that the mental health system needs to expand and move from a primarily inpatient to a primarily outpatient service. This change benefits those in need of immediate care, but not those suffering from a serious long-term mental illness. Consequently, the needs of many people with mental illness in the community have yet to be adequately met. Unforeseen problems continue to plague both the vision of deinstitutionalization and the effectiveness of community health care services.

While living in the community, many people with serious mental illness experience very stressful lifestyles that include homelessness or living in unsuitable or substandard housing. There has also been a shift in how these people receive services. Geller (cited in Cook & Wright, 1995 and Goldman (1982) present evidence that

hospitalizations have grown shorter in duration, although not in frequency, while community care emphasizes case management services and psychopharmacological treatment, rather than psychotherapy.

Many people with a serious mental illness receive their services from case managers, social workers or psychiatric nurses, who may or may not be part of a community support program. Unfortunately, the treatment continuum necessary to maintain these individuals successfully in the community has not been sufficient. Mechanic and Aiken (1987) point out that a lack of adequate care and treatment has resulted in many inappropriate admissions to hospitals, the overuse of emergency rooms, an undue burden on families, homelessness, and repeated encounters with the correctional system. Other existing challenges are problems with financing mental health services, rehabilitation efforts, employment opportunities, access to health care, the impossible role of the case manager, and the burdens faced by the families of the seriously mentally ill (Aviram, 1990).

As Bachrach (1986) points out, “comprehensive services have several dimensions with many of them overlapping” (p.172). Since many within the mentally ill population are in need of immediate assistance, services must be available around the clock to accommodate those in crisis (Hatfield, 1979). Also, for seriously mentally ill persons to prosper in the community, there must be an array of varied residential alternatives should be available (Hatfield, 1979).

Providing treatment also means bringing services to the people in their homes, on the streets or in homeless shelters. The treatments need to vary from social and vocational rehabilitation services, psychotherapy services, and physical health services to a whole range of outreach services. Comprehensive services must also include social and leisure opportunities and assist with supportive services. Bachrach (1986) explains that “with residential and treatment services being spread out, people need to have access to transportation to receive the care that is available to them as well” (p.171).

When all the dimensions of comprehensive care are in place, efforts must be undertaken to coordinate the formal services and integrate the family, who provides much of the care to those with mental illness, into this comprehensive care system. Families comprise a group of persons requiring integration into the system of care, because they

represent a vital resource in the treatment and rehabilitation of the mentally ill person (Lamb & Oliphant, 1978).

A consistent theme highlighting this need for integrated and comprehensive community services runs through this literature on mental health and community health services. It argues for the need to include families and family support programs in these services to help balance and even alleviate the burden of care a mentally person places on health care professionals and families.

### Family Experiences with Mental Health Services

The philosophy and concept of family support, as well as actual resources and services for families, are developing more slowly for mental health care than for other disabilities. Although the current emphasis in mental health care is on providing a broad array of services to those people with a serious mental illness, almost nowhere is family identified as an important part of the treatment team. This lack of inclusion is a serious limitation, because more than 65% of mentally ill persons are discharged from the hospital and return home to their families (Goldman, 1982), who may not be emotionally, physically or financially prepared for this burden. The lag in the development of family support services in mental health is related to a number of factors that include the consequent stigma of mental illness, the lack of public and professional understanding and support for family concerns, and, until relatively recently, organized and effective advocacy (Friesen, 1993). Because of a lack of family support services, very little literature explains existing family support programs or reports the findings of family support research in the mental health field. Although the need for family support is clearly reflected in the conceptual literature and preferences of family members who have mental disorders (Biegel, Sales, & Schulz, 1991; Hatfield, 1987; Sawa, 1992), very little research directly asks families about their experiences. According to Friesen, (1993), since the 1990s, only a small number of studies have been designed to elicit family members' points of view and find out what services they receive and whether they are helpful.

Bloom (1984) provides a reminder that originally families were the sole providers of care of the mentally ill loved ones, while the community took little responsibility, but in the 19<sup>th</sup> and 20<sup>th</sup> centuries, a movement to institutional care removed most mentally ill persons from the home. Then, in the 1950s, family and community became places where mentally ill persons were to be cared for and they were rapidly deinstitutionalized.

The deinstitutionalization movement has profoundly affected the lives of families who are involved with the care of a relative who has a serious mental illness, because they must now not only respond to the relative's symptoms, but also as negotiate the complex mental health and social services agencies. Families now must also cope with how they are to balance their own needs and the needs of other children in the home with the needs of the mentally ill person (Hatfield, 1979).

Currently, there are several family groups who both advocate for the seriously mentally ill and provide mutual support for their family members. Many of the original ones formed in response to the inhumane conditions that existed within the state-operated mental hospitals. Levine and Spaniol (1985) report that during the 1970s, family groups continued to expand due to the families' needs for mutual support and education about mental illness. They have grown into advocacy groups and a consumer movement (Hatfield, 1987). The most prominent one is the NAMI. Among its goals is the education of the professional community about the needs and perspectives of families. At the same time, these groups have expanded their efforts to reform and improve the fragmented system of community-based care (Backer & Richardson, 1989).

These efforts reflect the change in treatment philosophy from favoring institutionalization to favoring community care, because many more seriously mentally ill people live with or near their families. According to Goldman and Gatozzi (1981), approximately 800,000 severely mentally ill people are living in the community, and up to 500,000 of these people are living at home, which means that families now play an integral role in taking care of a relative with a serious mental illness. Among the family responsibilities are: creating an environment that balances the needs of the mentally ill person and the well being of other family members; finding and accessing services; learning to cope with the residual symptoms of a relative's illness; learning to recognize

symptoms of relapse; coping with family conflict; and finding ways to resolve negative feelings (Bernheim, 1989).

According to Litman (1974), social scientists have long recognized that the family is the most important social group within which illness occurs and is resolved. The family defines and validates whether or not an individual is sick, and then determines the use of health care services. Finally, the family has a major influence on compliance with suggested treatment regimes and the recovery process. Thus, the family is the basic unit of care (Litman, 1974). This is also true in cases of mental illness. Family members play a vital role in whether the mentally ill individual is compliant with medications and whether the mentally ill individual seeks treatment. They are crucial to creating an environment in which the mentally ill individual can thrive. Family members do this by creating and sustaining an internal environment to reduce stress.

Mental health professionals, however, have long overlooked responsibilities family members undertake to support their mentally ill loved one. One of the points that Sawa (1992) makes is family members provide an enormous amount of resources and support to the mentally ill individual. Families not only provide material resources such as food, clothing, shelter, and money; they are also instrumental in assisting the mentally ill individual to access medical care and community resources.

When asked about their satisfaction with mental health professionals, a high percentage of parents report dissatisfaction with the help they receive from the mental health professionals (Bernheim, 1989; Hatfield, 1979). The major problems they cite are lack of information about the illness, lack of help with practical management issues, and inadequate help during crises. Besides feeling neglected by mental health professionals, parents think that current models of family therapy are guilt-inducing, demoralizing, and generally non-supportive of their role as parents. Several researchers (Hatfield, 1979; Holden & Lewine, 1982; Hatfield & Lefley, 1987; Bernheim, 1989) have found that families are dissatisfied with both the nature and the quality of their involvement with the mental health professionals, because they were typically ignored and left out of the treatment process for their mentally ill family member and, as a result, feel frustrated and powerless.

Since families play a significant role in the mentally ill individual's stability and integration into the community, the professional community needs to give them more recognition (Spaniol, Zipple, & FitzGerald, 1984). Lash, (1991) demonstrates that families have important information and expertise that can be useful to professionals in understanding the needs of families and improving both the content and the delivery of services. This situation requires that professionals work with families in new and different ways to promote an effective collaborative relationship.

Stewart (1984) stresses the importance of developing a collaborative working relationship with families who provide housing and care on a daily basis for their mentally ill loved one. Since families are with the mentally ill person continuously, while the mental health workers see the person for limited times, the families are the real source of information. They can provide pertinent information about medication compliance, symptoms, and adjustment to community. Family members also cope with the mentally ill person when he or she is irrational at times with hallucinations, delusions, and paranoia (Arnhoff & Goldman, as cited in Hatfield & Lefley, 1987).

As the primary caregivers, families suffer from such stress factors as financial burdens, the neglect of other siblings, and the interruption of family routines. Berheim (1989) reports that the demands of providing care can also socially isolate families from formal and informal social supports in the community. When studying the adjustment of families to formerly hospitalized relatives, Doll (1976) found that families feel hopelessly burdened or trapped by the former patients' problems. When Dincin, Selleck and Streicker, (1978) studied a support group for parents of mentally ill persons, they found that parents often bear the burden of guilt and feelings of responsibility for their child's mental condition.

Families frequently do not have the information, skills or resources to assist their mentally ill family member adequately (Spaniol et al., 1984). They need information pertaining to the nature of the mental illness, available treatment options, and goals for the mentally ill person (Goldman, 1982). Not only must family members need to learn how to cope with their mentally ill family member, they must also learn how to work with mental health providers. Collins and Diego (2000) point out that potential negative

outcomes, such as unresolved grief and depression, can occur when families do not have the support and services of mental health professionals.

How well a family with a seriously mentally ill family member manages under the exigencies of mental illness depends on the kinds of services and qualities of services provided to them. Families have reported that service providers are not always helpful and can be negligent in encouraging families to be part of the treatment process (Hatfield, 1979). Several researchers have examined the degree of dissatisfaction expressed by families who received professional services (Creer & Wing, 1974; Holden & Lewine, 1982; Wasow & Wikler, 1983). Creer and Wing (1974) conducted extensive interviews with families about difficulties they encountered in the care of their mentally ill loved one. These families report problems at every stage, from getting an early diagnosis and prompt treatment to obtaining information about medications and being able to keep in close contact with a professional who can ensure rapid treatment at the time of a relapse. Creer and Wing also point out that families consider social work services unreliable as well as unsympathetic. Hatfield & Lefley (1987) reveals that families seek out friends, relatives, and individual therapy (in that order) for support and help.

D.L. Johnson (1985) compares perceptions of families' needs to the perceptions of mental health professionals. The results reveal that families and professionals do not view families in similar ways. Professionals view services rendered to families in a more favorable light than do families whose dissatisfaction is high. The families are dissatisfied with treatment coordination, practical advice, information about the illness, emotional support, and referral assistance. Professionals often misunderstand families having difficulties locating services in a complex service delivery system and do very little to prepare families for their role as caretakers. Furthermore, professionals often perceive the frustration expressed by families as misplaced reactions to their loved ones' mental health condition and label families as resistant (Lash, 1991). These perceived responses of mental health professionals suggest the need for additional knowledge and training to prepare them to work more closely and cooperatively with family members (Spaniol et al., 1984).

Since close relatives of mentally ill persons have a store of experience and knowledge that is important for mental health professionals to tap into, I believe that

community care will not work effectively without the inclusion and cooperation of families. In working to support families and successfully integrate and sustain persons with a serious mental illness in the community, there must be a balance between the demands facing families and their capabilities for managing them. This delicate balance can only be achieved by improving the collaborative working process between families and mental health professionals.

The family systems theory (as described in the following section) provides a theoretical model that addresses the need for this balance.

### **Theoretical Perspective**

Although there is no central, dominant family theory, family systems theory has emerged from a collection of theories focusing on different aspects of family relationships as the dominant theoretical model for developing and maintaining such a balance. A review of the literature not only supports this theory as the best currently available framework to address the issues related to mental health, but, also shows that it is particularly significant when the questions have to do with issues of family and professional interactions.

Different theories, for example, focus on issues such as how families function in the larger society, how families create shared meanings, and how families react to crisis. Each of these theories represents different views and approaches to the family science field. For instance, the family health and illness cycle is a way to look at the family's longitudinal experience with health and illness. The family health promotion and risk reduction refers to family beliefs and behavior patterns of families, and the family illness appraisal perspective refers to family beliefs about a family member's illness and the family's decisions on how to deal with the illness.

The family systems theory informs this study, because it focuses on interactional processes of family life, rather than on viewing children and parents in isolation. This theory interprets family life in terms of an ecological pattern where the many thoughts, feelings, and actions of the members directly and indirectly influence the thoughts, feelings, and actions of others in the environment. As a family-centered approach to service delivery, it adopts a philosophy "in which families are recognized as having



unique concerns, strengths and values” (Connard & Novick, 1996, p. 1), and “represents a paradigm shift away from deficit-based, medical models that discover, diagnose and treat ‘problems’ in families to an ecological mode” (p.1). Central ideas in a family ecology model include, “...creating partnerships and helping relationships...building the community environment, [and] linking families and community support” (p.2). Families are crucial participants in the prevention and treatment of illness. Doherty and Baird (as cited in Sawa, 1992) refer to the “therapeutic triangle” in all health care. This is notion that family is always a “third party” to health care encounters between patients and health professionals. Empirical evidence supports that families have been found to be the primary source of health-related behavior patterns, of the decision to seek medical care, of health beliefs and attitudes influencing compliance with medical care, and of social support for chronic health problems (Christie-Seely, 1984a (as cited in Sawa, 1992); Doherty & Campbell, 1988; (as cited in Sawa, 1992); Litman, 1974). These ideas, which argue for comprehensive community involvement in the care of a mentally ill individual, highlight the need for mental health care professionals to develop a better understanding of the needs of the caretakers.

The family systems theory is relevant when examining family factors as they relate to the onset and course of mental illness. Sawa (1992) addresses these factors in health care from three different perspectives that validate the essential role family members can and must play in a collaborative treatment process and reinforce the need for the type of research conducted in this dissertation. The following overview of these three perspectives illustrates how they impact the treatment process of ill individuals:

*1. The family as a resource for the individual coping with the medical illness:*

This perspective presumes that the family may have no role in the onset of the illness, but often the family decides whether or not a particular set of symptoms warrants medical attention and participates in the decision-making about treatment options. Nursing care, economic support, arranging for health care options, and negotiating with employers are all practical support activities that families may engage in on behalf of members who have become ill. Family support can also be important in implementing

particular medical regimens and is a critical component in determining successful compliance with medical treatment regimens (Sawa, 1992).

*2. Family characteristics as they influence relationships with health care delivery systems:*

This perspective looks at the interface between the family and health care providers. Of interest here are questions about the utilization of health care services can be attributed to the family characteristics (Sawa, 1992). The assumption is that family characteristics do contribute to the variability in utilization of health care services.

*3. Family factors as determinants of differential clinical courses of specific illnesses:*

This perspective, which addresses the response patterns of families to the challenges of chronic illness, suggests that the inclusion of the family unit in the delivery of primary care permits implementation of more effective prevention, diagnosis, treatment, and rehabilitation plans (Sawa, 1992).

These three perspectives support the notion that family members and mental health professionals working collaboratively can enhance and expedite the recovery process for the mentally ill individual and how family systems theory pertains to this dissertation.

A systems approach applied to interactions between the systems of mental health professionals and families has begun to gain some attention, especially as more indicators point to the essential nature of partnerships between these two groups in creating healthy living conditions in the community for those individuals with chronic mental illness.

Even though family involvement can provide a wide range of support and material resources that no other individuals or services can, almost no literature on how to best utilize this resource exists. There is little written about how health care professionals work with families. Some family theorists assume that health care professionals work with individuals in the same way family therapists do without taking into consideration the differences between these fields. Clearly, there is a need for documented evidence regarding the nature of patient, health care professional and family relationships. Doherty and Baird (1983) concept of the therapeutic triangle addresses the

issue that the health professional does not have a relationship with just the individual, but with the whole family.

In recent years there has been an insufficient amount of research into the family and professional support team and their interaction and cooperation in a comprehensive collaborative effort. The sparseness of research in this area supports the need for this study. I have, therefore, developed four questions that will provide the information necessary to ascertain the essence of family member experiences with mental health professionals.

After examining other research articles and based on my own experience working with family members who have mentally ill loved ones, I expect family members will view their experience as frustrating and before that they feel alienated from the process of treatment for their mentally ill loved one.

## **CHAPTER THREE**

### Methodology

This study reports the experiences of family members of mentally ill relatives with mental health professionals. It is undertaken with the expectation that it will provide these professionals with a perspective, which will move them to involve family members more fully in the treatment of their mentally ill relative.

This chapter includes four sections. The first section, “ Research Questions,” provides the foundation for the methodology of this study. The second section includes participant selection procedures, participant selection, and a description of the participants. The third section explains the data sources and collection procedures, Finally, the fourth section, which is titled “Data Analysis Approach,” describes the methods used to analyze data as well as how the problem of validity is addressed.

## **Research Questions**

This study's research questions emerged from the literature review of family member experiences with mental health professionals and my own experiences as a mental health social worker and are:

### *Main Research Question:*

How do members of families whose mentally ill loved ones are currently under the care of the community mental health system view their experiences with mental health professionals?

### *Subsequent Questions:*

- What are the experiences of family members with mental health professionals?
- How involved are family members been in the care and treatment of their mentally ill loved one?
- How would family members like to be included in the treatment of their mentally ill loved one?
- From the point of view of the family members in this study, are mental health professionals providing the support services necessary to help them cope effectively with their mentally ill loved one?

I examined how 16 family members view their experiences with mental health professionals. These 16 people who are parents, aunts and uncles are the primary caretakers of a mentally ill person. The mental health professionals who treat each of the mentally ill persons include, psychologist, psychiatrists, social workers, and vocational rehabilitation counselors.

Before discussing the results of my research, it is important to introduce myself and discuss my paradigm. The term "paradigm" refers to a systematic set of assumptions or beliefs about fundamental aspects of reality. Paradigms represent how "we organize our thoughts about the world. Our actions in the world, including the actions we take as

inquirers cannot occur without reference to those paradigms: “As we think, so do we act.” (Lincoln & Guba, 1985, p. 15). Our paradigms are a “basic set of beliefs that guides action” (Guba, 1990, p. 17).

Constructionism is the paradigm in which I locate myself. In this study, I used a constructivist theoretical framework to guide my examination of family experiences with mental health professionals. Denzin & Lincoln (1998) explain that the “constructivist paradigm assumes a relativist ontology (multiple realities), a subjectivist epistemology (knower and subject create understandings), and a naturalistic (in the natural world) set of methodological procedures” (p. 27). A constructivist paradigm attends to the process of how people make sense and give meaning to the experiences in their lives (White, 1995). The constructivist framework in qualitative research accepts the possibility of, and search for, multiple realities or worldviews (Blaikie, 2000). Gergen (1985) adds that constructivism is principally concerned with the processes by which people come to describe, explain, or otherwise account for the world in which they live.

Stewart (1994) explains that collaborative inquiry is a central feature of the constructivist’s perspective in qualitative research. By examining the perceptions and issues surrounding families’ collaborative attempts with the community mental health system, I hoped to gain an understanding of the holistic reality of the families’ experiences in the mental health system. A constructivist framework in qualitative research neither searches for truth nor holds the researcher up as a source of truth (Hoffman, 1993). Rather it sets the stage for a collaborative discourse with study participants.

As a qualitative researcher I was concerned with the meaning people attach to things in their lives, and attempt to understand families from their own frames of reference. A constructivist focus is non-judgmental and non-control oriented, but employed on a lateral rather than hierarchical plane (Hoffman, 1993).

While using a constructivist framework in my qualitative research project, it was important that I, as the researcher, acknowledged that research is an interactive process shaped by my personal history, biography, gender, social class, race, and ethnicity (Patton, 1990). My prior employment as a social worker has shaped my perception of family members’ experiences. My personal experiences and my insights are, therefore, a

part of the relevant data, even though I take a neutral nonjudgmental stance toward whatever content may emerge (Patton, 1990).

Because my experience enhances my awareness, knowledge, and sensitivity to many of the challenges and issues encountered by family members, it has assisted me in working with family members in my study. My personal experiences and insights are an important part of this inquiry and critical to understanding the challenges that families face (Patton, 1990).

*A social worker perspective:* About nine years ago I was working as a social worker with mentally individuals who were residing in the community. I knew John<sup>2</sup>, who had been diagnosed with bipolar disorder very well, because he had been a patient approximately six years. John had cancer for which he underwent chemotherapy, which made him physically ill for days after each treatment. This meant he often threw up the medications for his mental illness. Consequently, John became mentally unstable and was hospitalized several times to be stabilized and then released to begin the whole cycle again.

One Sunday evening I happened to be watching the local news and there was a report about a murder at one of the local apartment complexes. I immediately ran my caseload through my head to think about whether any of my patients living at that complex were unstable enough to be capable of committing such a heinous act. In my estimation, none was. However, the following morning as I was on my way to my standing Monday 8:00 am appointment with another patient, Ed<sup>2</sup>, the radio announcer gave a few more details about the man arrested for the murder at the apartment complex. I immediately froze.

To this day I have no idea how I was able to turn my car around and get myself back to the agency where I was employed to find out all the details about the man and the situation just described on the radio. When I reached the agency, my supervisor took me into the back conference room to tell me the news that it was John who had brutally stabbed a woman to death. A wave of immense sadness, disbelief, and shock took over my entire being. I wondered how a man whom I thought I had known so well could have done something like this and what had I missed.

---

<sup>2</sup> Names have been changed to protect the identity of patients

Through the whole legal, media and professional flurry, I was also dealing with my own personal and professional loss of a friend, and a patient. I had never known anyone that had committed a murder. As I was able to think through the days before and after this tragic event, time after time I kept thinking back to John's family. I had never met John's family until the funeral. I have often wondered what this whole system we call the "mental health system" looked like to John's family, and what their experiences were when they attempted to contact a mental health professional. I never got the chance to ask them. I never got the chance to talk through this whole situation with John, because 3-months after he murdered the woman in the parking lot he killed himself. In trying to make sense out of what happened to John, I tried to give meaning to this experience by imaging the responses of John's family to his illness and their experiences with mental health workers and how different these must have been from mine. Consequently, I am drawn to the constructivist paradigm, because it accepts the possibility of multiple realities and supports the search for them.

My experiences with the family members I interviewed made it clear that families of the mentally ill and the health care professionals who work with these same mentally ill people often have very different perceptions, understandings, and viewpoints of the same situations and interactions with one another. The realization of these different responses to the same issues and situations certainly highlighted for me a constructionist point of view.

#### *Role as a social worker and a researcher*

As the researcher, I am deeply interested and sincere about the research I conduct. I am a good listener and ask tactful questions gather information. I acknowledge that the formulation of the questions I asked were a reflection of the experiences I have had as a social worker in the mental health field. Since I am aware of this bias, I was flexible during the interview process to allow for a unique discussion of experiences from each family member's point of view. From my many years as a social worker, I know that patients, doctors, nurses, co-workers, and family members all have different and unique perspectives. As a social worker and a person, I have learned to acknowledge and accept these different perspectives. While conducting each interview, I took note about what I



had learned from each family member, and I tried to place myself in each family member's shoes to clearly understand what he or she was trying to convey. Furthermore, the role of social worker and researcher combined to allow for a situation in which I was able to move from the perspective of an outsider to one of an insider in the situations family members discussed with me. Gaining this insider perspective is essential to credible qualitative research.

### *Bias*

I entered the interview process with the biased assumption that family members would dismantle any credibility that social workers might have. Therefore, I went into my first couple of interviews wearing an invisible suit of armor and with my guard up, because I expected to find myself in a situation where I had to support my field. To my surprise, I heard these family members speak generously, but perceptively about social workers. Actually I found myself a bit embarrassed by the profession and at some level felt I should apologize for the entire field of mental health. After my first few interviews, I let my guard down and was able to really listen to the criticism that was cast upon social workers. During this research process monitoring personal emotions kept me aware of my researcher role.

### *Qualitative Research*

My research questions dictated the design and use of a qualitative research study. Qualitative research is a descriptive, systematic, multi-method examination of the experiences of others expressed in their own words that results in detailed information on behaviors, attitudes, and motivations (Creswell, 1994). It is important to locate a qualitative study in one of the several choices of traditions. Creswell (1998) identifies five of the most used traditions: biography, phenomenology, grounded theory, ethnography and case study. I have situated my research in the biography tradition, because as Creswell (1998) points out, although "biographical forms of research vary and the terms reflect different disciplines perspectives, all forms represent an attempt to construct the history of a life" (p. 49). I have used oral history as my approach to gather personal recollections from family members about their experiences with mental health

professionals, because I wanted the families to take me into the world of their experiences with mental health professionals so that I could understand what they have encountered, what they expect, and how they feel about their relationship with mental health providers. I aimed to understand more fully the meanings that they give to their experiences. I intended to simply “seek to discover and understand a phenomenon, a process, or the perspectives and worldviews of the people involved” (Merriam, 1998, p. 11). As a mental health professional, I understand the aspects of providing care to a mental health consumer and his or her family, but I do not fully understand the issues that family members experience with mental health providers. I am empathic to the situations that family members deal with when trying to work with a mental health provider, but I have strived to fully understand what the issues are, how family members want to be included, and how they feel when attempting to work with a mental health provider.

#### *Participant Selection Procedure*

The procedure used to select the cases for this study consisted of several steps. I met with a woman who was knowledgeable about NAMI and explained to her my proposed study, the people I needed to interview, and the participant selection criteria. I attended a family member group meeting where I explained my research project and what I was looking for in potential participants in this study. I invited people from the family member group meeting to contact me if they were interested in participating. The woman to whom I initially had spoken about my study also assisted me by contacting additional family members and briefly explaining my study. If the family members expressed an interest, she asked their permission for me to contact them with more information.

When I contacted interested family members, I gave them additional information about the study over the telephone and what their involvement would entail. All family members who were contacted agreed to participate in the study. One participant who scheduled an appointment with me called to reschedule it. I attempted to reschedule the appointment, but was unable to reach her. I left two messages on her answering machine, but she did not return my call. I gave family members assurances of confidentiality, informed them that all audiotapes would be given to a transcriber for transcribing, and assured them after the transcription was complete the transcripts would remain in my sole

possession. Only first names were used during the interviews and each participant was given a pseudonym before each audiotape was given to the transcriber.

### *Participant Selection*

Since this study sought information from specific participants, family members were chosen using purposeful sampling. These family members had to meet three criteria. First, these family members are the primary caregivers to a relative who has a serious mental illness, and for this study a serious mental illness is defined as any disorder of the brain that disrupts a person's thinking, feeling, moods, and ability to relate to others. Secondly, the relatives whom these family members are caring for had to be adults in need of current mental health services to sustain him or her in the community. Thirdly, the family members must have experience dealing with mental health professionals.

As it turned out, all family members whom I interviewed have had some experience with NAMI. I did not specifically ask participants if they are NAMI members, but all participants mentioned during the interview that they have had contact with NAMI.

### *Description of Participants*

The participants consisted of family members with a mentally ill loved one. They live in Virginia and in all cases, have a mentally ill loved one who is a son or a daughter or a close family member. In all, I interviewed members of 12 families, eight individuals for four couples for a total of 16 people.

Of the mentally ill loved ones, seven individuals lived at home with their families and five lived in the community. The ages of the participants ranged from the mid-thirties to eighty years old. All participants had experiences with both the private and public sectors of mental health care.

### **Data Sources and Collection Procedures**

Data sources for this study include the interviews with family members, observations, my field notes, and my personal journal. Data collection for this study consisted of one face-to-face semi-structured interview with each of the sixteen

individual family members. I conducted interviews between June 2002 and August 2002 each of which lasted one and a half to two and a half hours. Throughout the data collection process, I kept a journal to record my reactions to the interviews and the responses of individual participants, and my observations about nonverbal communication and emotional intensity. The journal has proved a useful tool for each interview, because my notes have helped me direct my questions more specifically toward themes that most participants share. In this way, as is consistent with qualitative research techniques, I became an instrument of data collection (Sprenkle & Moon, 1996).

My interest in the study increased as it progressed, because prior to returning to school, I had worked with several families of mentally ill individuals, and from this experience, I had assumed that the partnership between families and mental health professionals was strengthening. Although my research forced me to modify this assumption, it has made me more aware of the passion family members have and the interests and desires families have, if only they can gain access to mental health professionals and be a part of the treatment team.

### *Observations*

I observed my surroundings before, during and after each interview so that I could note how people entered the room, how comfortable they seemed to be, and how passionate they seemed to be when answering questions. After each interview, I spent a few minutes making post-interview observations. I then recorded these notes in my journal.

### *Audio-taping*

All interviews were audiotaped, because personal observations alone cannot capture all the dialogue and nuances of the conversations. As Patton (1990) states, “No matter what style of interviewing is used, and no matter how carefully one words interview questions, it all comes to naught if the interviewer fails to capture the actual words of the person being interviewed” (p. 347). Before each interview began, I placed the recorder in the middle of the table between the participant and myself to make certain it would capture all the dialogue.

### *Field Notes and Personal Journal*

Throughout the study, I recorded field notes before, during, and after the interviews. I took field notes during interviews, because they helped me formulate additional questions to explore participants' answers further during the interview. Also taking notes can help locate important points later in the transcript analysis (Patton, 1990). I made every effort to keep my notes brief enough not to interrupt the conversation or cause me to be inattentive to the participant.

In addition to field notes, I kept a personal journal to chronicle my daily experiences, thoughts, and reflections. It has served, in part, as an organizational tool to keep track of tasks that needed to be completed throughout the study. The journal and the field notes have both helped me make sense of the data.

### **Interview Guide and Questions**

An open-ended set of questions was developed to use as a guide in all interviews (see Appendix B). Having the questions open-ended encouraged family members to expand on their thoughts and opinions about their experiences with mental health professionals. The interview format was flexible, relaxed, and conversational in tone. For example, sometimes questions were phrased differently and asked in a different order, depending on participants' comments. Other times, participants answered more than one question in their responses; therefore other questions were set aside. Sometimes, participants answered in a way that introduced other topics not central to the study, but these were explored so that I could better understand the participants' thinking. Since the interview guide encouraged flexibility and spontaneity, it allowed for more in-depth probing into personal experiences and stories.

### **Interview Settings and Scheduling**

The only criteria for site selection were that the locations were places where the participants felt comfortable and free to talk with me. All interviews took place at times and places convenient to the participants. I allowed the participant to decide where he or

she preferred to meet with me, and I met him or her at the specified location. Consequently, interviews took place at libraries and restaurants and in participants' homes, during day and evening hours during the week and on the weekends. After placing the recorder between the participant and myself, I began each interview with "small talk" in order to give me a way to connect with the participant and begin to build rapport. I made an effort to match the language level of each participant and refrained from using any social worker jargon. My goal during the interviews was to encourage participants not to view me primarily as social worker but as a person who genuinely cared about what they had to say and, therefore, feel comfortable enough to speak openly to me.

The rapport I established with family members results from my understanding of mental health professionals and many of the issues these families addressed. That understanding is evidenced in my ability to ask questions which less experienced interviewers would not have been able to address, because they would have lacked the knowledge that comes from working for many years in the field of mental health. Even though I tried to remain neutral, at times it was difficult, because I was often ashamed that as a mental health professional, I have not done a better job working with family members. I also found myself frustrated by not being able to give suggestions as to the direction toward which people should focus their efforts. I found it astonishing that some people do not have the basic information that they need to guide their decisions on the care of their mentally ill loved ones.

### **Confidentiality and Informed Consent**

To fulfill my responsibilities as a researcher, I fully informed participants that I would respect their wishes regarding the confidentiality of disclosures, and I would not print anything that he or she did not want to be made public. No family member asked me to refrain from printing any of the information that he or she provided. I have kept all tapes and transcripts in my possession, except when the professional transcriber had them for no more than five days.

Before the interviews began, I read the entire informed consent form out loud with each participant. I explained the scope of the study and gave each participant an

informed consent form (Appendix A) describing the study's basic purpose and design, confidentiality, and his or her right to discontinue the interview and/or withdraw from the study at any time. After each participant read and signed the informed consent, I once again asked each one to refrain from using last names to help protect people's identity. I also gave each participant a copy of the informed consent form.

### **Ethical Considerations**

During each interview I was mindful of the often painful and frustrating times these family members have gone through. At no time did any of the participants seem to become overwhelmed with emotion. Voice intonations revealed some participants to be more tense than others, but no one asked to have the interview terminated early.

### **Data Analysis Approach**

To assess how family members experienced the relationship with mental health professionals, I employed Holloway's (1997) strategy for analyzing data. Since analysis involves breaking down the data and searching for codes and categories which are then turned into themes, Holloway's (1997) strategy has several steps:

Ordering and organizing the collected material, re-reading the data, breaking the material into manageable sections, identifying and highlighting meaningful phrases, building, comparing and contrasting categories, looking for consistent patterns of meanings, searching for relationships and grouping categories together, recognizing and describing patterns, themes and typologies, and interpreting and searching for meaning (p.44).

To begin the process of ordering and organizing the collected data, I had the audiotaped data converted to print. A third party transcriber not connected to or familiar with the participants was used to assist with transcribing the interviews. She listened to the audiocassette tapes and transcribed them into a computer file for each participant interview. As she submitted each transcript, I carefully reviewed it, checking for accuracy. After all the transcripts were completed and corrected, I read each piece of datum collected for a case (i.e., family member interviews, observations, documents,

field and journal notes) several times and marked information by underlining relevant words or phrases and making notes in the margins for the purpose of creating a summary of the paraphrased or marked information of each piece of datum.

Next, I placed the highlighted phrases of information into Microsoft Project 98 as summary tasks and inserted the answers as sub-tasks so that it was possible for me to organize and display the answers to my research questions in useful way. The use of Microsoft Project 98 has allowed me to compare participants' responses and develop a sense of the range of their experiences. With the answers to the survey questions put into Microsoft Project 98, I was able to transfer them to a complimentary tool, Critical Tools-Work Breakdown Structure (WBS), which displays my questions and answers in a graphic form, which shows the overall study as an integrated totality and also displays individual questions and their answers. While these tools are not designed to organize qualitative research, they work well for this purpose. Then, I compared all the summaries of each piece of datum within each question to identify themes by determining similarities or patterns among them. The final step involved searching for relationships and grouping categories together, recognizing and describing patterns and themes, and interpreting and searching for meaning.

### *Quality Assurance*

As an alternative to the quantitative criterion of internal validity, Lincoln and Guba (1985) coined the term trustworthiness to be the standard by which to judge qualitative research. According to Lincoln and Guba, there is "still a major gulf between theoretical definitions of the trustworthiness criteria and the means of operationalizing them" (p. 329) and those who use natural inquiry should show "humility in asserting that a 'new and truer (more natural?) path to knowledge' has been found" (p. 331).

To ensure validity, I provide a rich, detailed description of my research and an analysis of my interviews. I also used three techniques, as recommended by Denzin and Lincoln, (1998) and Creswell (1994), who encourage the use of multiple techniques (triangulation) to ensure validity. These multiple data sources consist of interviews, observations, transcripts, field notes, and journal entries. I also provide a detailed account of the focus of the study, my role as the researcher, the family member's position and



basis for selection, and the context in which data was gathered. To contribute to validity still further, I kept an organized file of field notes and observations to supplement the interviews. For instance, my observations include descriptions of the setting, of the participants' comfort level, my feelings at the time of the interview, as well as my thinking about emerging themes and unique qualities of the interviews. The field notes are part of a reflexive journal detailing my responses, thoughts, and concerns, as well as the problems I encountered, and describing any methodological decisions made during the course of the research. The journal has helped to locate possible researcher bias and also to evaluate how decisions were made during the research process. This process has helped shape future interviews and has also contributed to an audit trail, which documents the process involved in collecting and interpreting data (Lincoln & Guba, 1985).

Since people have different interpretations of truth, it was my responsibility to present other interpretations. To improve validity I also include prolonged engagement, persistent observation, and triangulation. I had a prolonged engagement with each family member, meeting each of them once for an extended period of time and speaking with each of them over the telephone at least once before the interviews began. This allowed me to build trust with family members and to clear up any misinformation. By using persistent observation, I was able to identify interchanges during observations to pursue and focus on greater detail with participants.

## CHAPTER FOUR

### Description of Services and Presentation of Family Members

In this study, I explore how family members experience their relationship with mental health professionals. All 16 participants, who share a strong commitment to their mentally ill loved one, have stated they appreciate the opportunity to be involved in this research project. In their interviews, they discuss a wide range of personal reactions to the experiences they have had when trying to work with mental health professionals. It was disconcerting to hear most of family members echo similar experiences of not being respected or heard by mental health professionals. Katherine explains, “I was told by a mental health professional that I was not his guardian nor was I power of attorney. I was only his mother, which didn’t count.” Her words express the perception most of the participants have about the attitude of mental health professionals toward family members.

I appreciate the variety of views I heard from these family members, as well as their problem-solving abilities, their insight into the issues mental health professionals face, and the high regard in which they hold their mentally ill loved ones during often frustrating and unpredictable times. Lori explained, “I often say that he is the bravest of my children in that he has to handle this illness in such a courageous way.” She then went on to say how she includes him in all family functions and respects his decision to attend or not to attend. Excerpts from these interviews tell an interesting story about the relationship the family members have had and will continue to have with mental health professionals until they can be persuaded that family members are the primary caretakers of mentally ill loved ones living in the community and, therefore, need to be included in the decision-making and treatment processes.

As I interviewed participants’ and read over the transcripts, I noted that these family members had experiences with several different types of mental health professionals. Therefore, a description of the mental health services that were being provided to their mentally ill loved one when family members came in contact with the mental health professionals they were speaking about follows. Several of the family

members had contact with mental health professionals from at least of two of these services.

### *Hospitals*

The hospital is considered the locus for acute care as well as rehabilitation. Once discharged, the patient also receives outpatient follow-up care.

### *Outpatient Clinics*

Outpatient services provide an important link between the hospital and the community. In outpatient clinics, professionals from all the fields of mental health care provide the clinical management.

### *Day Treatment*

The aim of day treatment is to provide all the resources of an inpatient stay from 9:00AM to 5:00PM during weekdays for acutely mentally ill people. The treatment focuses on working with people on their living skills, including self-care, social care, social skills, and work skills.

### *Program of Assertive Community Treatment (PACT)*

The PACT rehabilitation team focuses on integrating those with mental illness into programs within the community. These programs may involve leisure, recreation, work, education, housing or community service. (Falloon & Fadden, 1993).

In their interviews for this study, family members discuss their hopes that someday mental health professionals will decide to embrace the concept of family-centered care. Within the family-centered care concept family members would like to be able to experience open and honest communication, mutual respect for their skills and knowledge, and shared planning and decision making. They would also like to receive information about diagnosis, medications, and prognosis, and, in return, provide the mental health professionals with information they believe to be useful and relevant to the care of their mentally ill loved one. In other words, they want to have ongoing communication throughout all phases of treatment and ongoing input throughout all phases of the decision-making process. Family members would also like advice on the

skills they need to cope with a mentally ill loved one and support for logistics, such as arranging for transportation and financial assistance. They would like to see mental health professionals involved in community care learn to recognize and respect the pivotal role families play in the lives of their mentally ill loved ones, and also learn to value family member judgments.

Since the purpose of my study has been to discover how members of families whose loved ones are currently under the care of the community mental health system view their experiences with mental health professionals, I include in this chapter a succinct generic description of the “story” this study examines, as well as a brief profile of each of the 16 family members interviewed. Then I discuss the information each of the research questions I devised for this study elicited from the participants, and finally, I examine five themes identified through analysis of the data.

### *The Story*

The story is about how selected family members of mentally ill loved ones perceive their experiences with mental health professionals. Although the family members in this study all perceive their experiences with mental health professionals in unique ways, they share a desire for family-centered care that actively includes them with mental health professionals in the treatment process of their loved one. They see their inclusion as the most effective way to ensure that their mentally ill loved one will be able to live in the community successfully. However, they report that mental health professionals regularly ignore them, even though they are the primary care givers for mentally ill loved individuals. Many of the professionals have not taken the time to hear from family members what is happening in the lives of their mentally ill patients. Mental health professionals turn down attempts by family members to communicate with them through various ways, such as phone calls, faxes, e-mails, and even face-to-face meetings. Because family members have received so much resistance from mental health professionals, they have attempted in very creative ways to involve themselves in the care and treatment of their mentally ill loved one.

The actions of mental health professionals limit the impact family members can have in trying to deliver or receive critical information from mental health providers.

Family members have encountered rude and busy mental health professionals, who will not attempt to receive information that family members have about their mentally ill loved ones. As a result, they cannot fathom how these professionals can assemble a treatment plan or prescribe medications based on only half of the information available to them. Family members feel that, because they live with these mentally ill people 24 hours a day, seven days a week, they have vital information that could assist professionals in making better decisions in the way they provide treatment.

Family members are also been confronted with other issues that limit their involvement in the treatment process of their mentally ill loved one. The policy of restricting the exchange of information is still operative in most agencies, and family members believe this to be one of the problems discouraging the implementation of family-centered care. Mental health professionals more often than not use the confidentiality law as a reason not to include family members. Because of this issue of confidentiality, limited or no communication takes place between family members and mental health professionals. However, even in cases where the mentally ill individual has signed the release of confidentiality form allowing his or her family member to have access to treatment information and to be part of the treatment team, many professionals continue to overlook this invitation and negate collaborating with family members, even when the family member is most certainly capable of using the information provided to benefit a mentally ill loved one.

Logistical issues are still another way family members are kept from being included as active participants with mental health professionals in treating mentally ill individuals. On occasion, family members have not been able to make critical court hearings due to lack of transportation or funds. If mental health professionals were committed to including family members in the treatment of their mentally ill loved one, they would arrange transportation or provide funding to make sure all family members have every opportunity to participate.

Because of their unenthusiastic attitude toward the inclusion of family caregivers in the various aspects of a mentally ill person's treatment plan, mental health professionals are not taking advantage of an important and useful resource. They are also driving family members to be incredibly creative in their efforts to provide them with

information vital to assessing their patient's condition and prescribing treatment, as my interviews with family members reveal.

### **Family Member Profiles**

Before proceeding with the two major themes that have arisen from my research, it is important to learn more about the family members I interviewed to provide a personal context for their experiences. I will also present the discussion of the highlights from each research question.

**Lori** is a mother of four children, one of whom is a son who has schizophrenia. Since Lori has had dealings with mental health professionals from the early 1970s, she is very knowledgeable about the system and able to communicate clearly what has worked well and what has not worked well. I met with Lori, who is well spoken and well educated, at her home. The number of people who called while I was there, as well as a visitor at the door, emphasized that she is well connected in the community.

During our interview, Lori spoke of several frustrating problems that she has encountered through the years. These include everything from being able to understand schizophrenia to locating safe and affordable housing for her son. One of the major adjustments Lori spoke about was trying to understand what her role as a mother is now that her son has been diagnosed with a mental illness. She did not want to consume his life with attempts to keep him safe, but she did not know how hard to push him either. Lori also spoke directly about how angry she sometimes is at mental health professionals, because they do not notice her pain, and that services that she feels her son needs are not available to him. She also spoke about having to fight an inadequate system that does not have enough money to provide the services and has too often dismissed her son's illness as not worth putting money into because it is hopeless. Lori responded that over the years she has developed a greater understanding of schizophrenia and how to communicate, problem solve, adapt, and cope with the pressures and the family burden. She stressed the importance of developing relationships with mental health providers, partnering, and information sharing. Although Lori feels that over the years the

relationships between families and mental health professionals have improved, she was unable to give specifics about the improvements.

**Cindy**, a soft-spoken woman, was very passionate about telling her story. She has a son who has been diagnosed with schizophrenia who lives with her and her husband. Cindy quit her job several years ago to stay at home to care for her son. She and I met in a conference room at a local library. It was a cold room with white walls, several chairs, and a large brown rectangular table in the middle. Since there was a large square window, which brought in an abundance of light, no overhead lights were turned on. The sterility of the room seemed to reflect Cindy's experiences, as she explained how she has gotten "virtually nothing from mental health professionals over the years," and that mental health professionals have provided no support to her family.

**Paul and Grace** are an articulate couple who I met in a small conference room at a local library. Both were passionate about telling their story. Each gave the other generous opportunity to speak openly and honestly about the experiences that they have encountered with mental health professionals when trying to seek help for their daughter who has been diagnosed with schizophrenia. They spoke about their experiences of having little information provided by mental health professionals about diagnosis, prognosis, and medications. This couple talked openly about how hard families work for the information they feel is essential and how hard they work to provide mental health professionals information that they may need to make an informed decision about what direction treatment should take.

**Elon**, an expressive woman, met with me at her home. She seemed very relaxed during our conversation, almost as if she was relieved to be talking with someone about her experiences with mental health professionals. Elon is able to obtain information about her daughter who has a mental illness, because her daughter has signed a confidentiality release form. However, even with this form, professionals do not ask her about her observations or involve her in the treatment process. Elon believes that mental health

professionals leave the search for information up to the families, even though they could be more upfront with the knowledge and expertise that they have at their fingertips.

**Katherine**, a very thoughtful, reflective, humorous woman, who invited me to her home, has gone through several challenges in life and still remains positive, upbeat, and hopeful about the future. Katherine has been given little to no direction from mental health professionals. Her son has been in and out of the correctional institutions and state mental institutions with little change in symptoms. There have been no intense community support services for this individual other than seeing a psychiatrist. Katherine had little knowledge of how to access appropriate services for her child. She has pleaded with mental health professionals to locate care for her son and has had to rely on support groups to provide her with information about mental illness, medications and resources.

**Jerome and Gloria** are an active couple in their community. They invited me to their home and were very welcoming and eager to present their experiences. Jerome is very disappointed with mental health professionals' willingness to have contact with the family, especially because he knows that the family can provide vital feedback to mental health professionals so that they can make an informed decision about how to treat their child. Gloria stated that NAMI has provided her with information about mental illness and resources.

**Lisa**, whom I met at a local coffee shop which, at times, was noisy with endless chatter, is a well-educated, successful career woman who has spent many years in the mental health system seeking appropriate services for her mentally ill daughter. She is so disheartened and frustrated about being able to locate services or information about her daughter's illness that she has little energy to fight anymore. Lisa has sought out several professionals trying to get information only to have the door closed on her because of confidentiality. What is even more frustrating for Lisa is that even though her daughter has signed the release of confidentiality forms, her daughter's social worker still does not include her in the treatment process.



**Abby**, who is a well-spoken woman, was forthcoming with information and eager to tell her story about her experiences with mental health professionals. I met with her at the library of a local school where I learned that she has had years of experience with mental health professionals, because she had an uncle who had a mental illness for as long as she can remember, and she was left to care for him. Abby had located a doctor who was willing to work with her as a family member years ago, but today it is a different story. Now she has a mentally ill daughter and has made several attempts to get vital information to the mental health professionals who are treating her daughter to no avail. Because of her experience with her uncle, she is very aware of the benefits of sharing and cooperation between family caregivers and professional care providers.

**Terry** is a quiet, college-educated woman in the field of mental health. I met with her at home on her sunny porch. Her experience with mental health professionals has been satisfactory, although she has received very little information about her daughter's illness and how to manage some of the behaviors that her daughter displays at times. Terry explained that since her daughter is doing exceptionally well at this time, she does not need much from mental health professionals. However, when her daughter's mental health declines she, as a family member, needs more information and skills training from professionals.

**Ross and Carol** are a professional couple who knew nothing about mental illness before their daughter became ill. When I met with Ross and Carol in their kitchen of their home, I learned that they rely on the Internet to find information about their daughter's mental illness. NAMI proved helpful to them in locating information and resources after mental health professionals left it up to them to find their way around a confusing mental health system. Ross and Carol would appreciate feedback from mental health professionals on their daughter's progress or weaknesses, and would like to learn what they, as family members, can do to help their daughter move forward in her life.

**Jeff and Jennifer** are a busy couple who juggle many obligations with regards to children, work and family. I met them at home in their kitchen. They too turned to

NAMI, which initially directed them in the right direction. They have tried several ways to get important information to mental health professionals about their loved one with little to no avail. Consequently, they have concluded that mental health professionals do not want or value their input. Ideally, they would like mental health professionals to reach out to them and acknowledge the value of the information that they have to provide, but at this juncture, they believe that this kind of collaboration will never be reality.

**Amy** is a retired dietician who would like a partnership role with mental health professionals. I met with Amy in a conference room at a small local library. She would like mental health professionals to be in regular contact with family members and provide follow-up written reports to the families about their mentally ill loved one. Along with written reports, she would like to have face-to-face meetings with mental health professionals on a regular basis so that she can pass on information to mental health professionals.

## **CHAPTER FIVE**

### **Participant Responses**

The discussion of each research question is organized into the following four sections. Each section begins with the research question followed by a discussion of the most significant information from the participants.

The purpose of these interviews is to explore the experiences that family members have with mental health professionals. Many of the issues family members raise in these interviews are related to individual health care professionals and arise from their own beliefs about the role of family members play in care and treatment of mentally ill. Some of these issues may well point to overall system issues, such as high caseloads, which leave little time for specific mentally ill patients and thus for family members of these patients. Some of the issues raised may point to other causes all together. These are views from the family member perspective. I report the “story” of the relationship between the family member and the mental health professional.

Another point that is important to keep in mind, especially when family members are discussing their first encounters with the mental health system, is that family members have encountered individuals who are part of the total mental health system, but are not classified as “mental health professionals.” Many times these are professionals who have had little to no training in mental health. They include police officers who, in many cases, initially transfer mentally ill individuals to the hospital. They also include hospital staff not trained in mental health issues at all and still are often the first “health care professionals” family members encounter during the process of entering into the mental health system. These people can leave a lasting and powerful impression, positive or negative, that the family members carry with them, in some cases, for years.

## **Research Question # 1**

*What are the experiences of family members with mental health professionals?*

### *First encounter with mental health system*

Initially, I asked family members to describe the process of entering into the mental health system just after their family member was diagnosed with a mental illness. When I worked in the mental health system, I witnessed that family members attempting to gain access to the system often find the experience daunting and frustrating. The family members I interviewed have had involvement with their loved one with the mental health system anywhere from 1975 to 2002. Each family member tells a similar story of a crisis that eventually forced him or her to intervene and access the care for his or her loved one. In several families, the onset of the illness did not occur for their loved one until early adulthood; in others, it was around the age of 16 years old. Those whose loved ones were involved in mental health services as a child had no easier access to care than those whose loved ones experienced later onset of illness. Lori reports her son was in his 20s and attending college, while Cindy's son was 20 years old and working a full time job when he became ill. Katherine's son first exhibited signs of mental illness in 1970 when he was in his 20s and based in Vermont in the armed forces. Both Terry and Jerome's loved ones began exhibiting unusual behaviors when they were in their late teens, and still in high school.

These family members reported that they either had to telephone the police or take their mentally ill loved ones to a clinic or the hospital where their loved one was then admitted for psychiatric care. Cindy related the story of her son's entry in to the mental health system. She knew something was terribly wrong when her son was catatonic for 8-12 hours. She called the police and the rescue squad picked him up and took him to the emergency room where he was evaluated and then admitted to the psychiatric center. Grace described her initial encounter with her child's mental illness and initial visit to the hospital as a very frightening situation:

It was really scary, because when she first just kind of freaked out, of course, the police were called because we couldn't control her, and then

we had to go to the police station and had to be interviewed there...and then she finally rode in a police car to the hospital.

After a year of her daughter displaying strange behaviors such as moving several times in a short period of time, lack of interest in things she use to have a strong desire for, and changing jobs frequently or getting fired, Abby arranged a family meeting to persuade her daughter to go the hospital.

We approached her and told her she needed to go get help and at the end if 31/2 hours she put her head down and she said she would go. She got in the car and went to the hospital with her sister.

Ross and Carol's daughter came home from school depressed and telling bizarre stories about being watched and webcammed. Since Ross and Carol recognized this was odd and unusual behavior, they used the phone book to search for help. Carol contacted a local non-profit agency and made an appointment for their daughter to see a counselor the following day. The counselor suggested that Ross and Carol's daughter be hospitalized.

Although there are several strategies that family members have used to persuade their loved ones to seek mental health treatment, family members often are disheartened with the means they feel they have to use to receive help. Grace's frustration with the manner in which her loved one was able to get help initially from the mental health system highlights the contrast between finding help for a physical illness and a mental illness. When a person has a physical illness, he or she is able to quickly access a doctor and information regarding a diagnosis. In the case of a mental health issue, it is often necessary to contact a police officer in order to get mentally ill individuals connected to mental health services. Once the mentally ill individual arrives at a care facility, there is very little information given to the family members about the process of admissions or how long they should expect their loved one to stay. Saddened and angered by the way in which mental health patients encounter their first experience with the mental health system, Grace states:

When the individual presents no danger to self or others, the police should not have to be called to have their loved one admitted to the hospital. My daughter has had such bad experiences riding off in the police car. The

police officers actually chained her feet together as well as her hands while riding in the police car.

Cindy, describes similar experiences and points to another related issue: the need for better training for police officers in how to better deal with mentally ill individuals.

Cindy believes that:

police officers need training on how to approach a mentally ill person, and they need to be taught something about the medications and the illness, because what has happened more than once is that families have called the police because their mentally ill family member is out of control, and the mentally ill family member winds up shot dead.

Recalling a frustrating time when his daughter was admitted to the hospital for two days, Paul commented on one of the initial encounters into the mental health system: “they couldn’t verify that she had medical insurance so they released her, still in bad shape.” There will always be situations when police officers need to be called to assist with the transfer of mentally ill individuals to the hospital. The manner in which mentally ill persons are dealt with in the community by police officers is an issue that has drawn some concern in many communities. Enhanced training for police officers is beginning to take place in many communities. These training sessions are aimed at educating police officers on how to deal more compassionately and effectively with mentally ill individuals.

#### *Information prior to onset of illness*

It is common that people do not learn about an illness until they are faced with it, and this seems to be the case with the amount of knowledge family members have about mental illness prior to their loved one becoming ill. In this study, the information that family members have about mental illness ranges from having no knowledge about mental illness to having worked in the field of psychiatry for many years and being privy to the current information about the illness. Jerome is a family member who had almost no knowledge of mental illness. “My mother had what I understood to be a nervous breakdown and she was confined to an institution. I always thought counseling would take care of everything. I had no idea.” Ross, another family member, explained, “My

knowledge was nil. I used to see news broadcasts of people that they really never call it a mental illness, but they will say they exhibit hearing voices and things like that when crimes are committed.” Grace acknowledged, “I didn’t know a lot about mental health, because I had never had or seen anyone in the family who had mental illness.” Other family members interviewed had siblings or other loved ones with a mental illness. Although Jeff has a brother who has a mental illness, Jeff did not have much knowledge regarding the illness that his brother has. Jennifer had experience with mental illness with an ex-husband. “I had been through the process with my ex-husband so I know the different facilities for help.” Amy also has had first hand experience with mental illness, because her sister has been diagnosed with depression. Terry had prior employment that gave her access to the latest information about mental illness: “It was part of my career, so I had a good feel for what was going on.” Lori also had the latest information about mental illness, because she too worked in the field of psychiatry for many years. Information family members had prior to their loved one becoming ill differed due to the experiences each has had in the past. Some had worked in the field of psychiatry and knew about the different diagnoses, medications and their side effects. Some had family members with a mental illness, while others had no knowledge of mental illness.

### *Locating help*

When they did not need the assistance from law enforcement officers to access care for their loved ones, family members found other resourceful ways to search for resources to locate help for their loved one. Tracking down information regarding help for their mentally ill loved one came from several different sources such as support groups, general practitioners, the Internet, telephone book and other family members. Ross reported,

We looked in the phone book and we found a crisis line number and they could see her later that afternoon, and we took her down and she was interviewed by a counselor, I guess apparently Bonnie [daughter] was asked some questions and the counselor felt that she potentially could be a harm to herself, so she suggested that Bonnie stay and be admitted to the psychiatric ward.

Not until after the police brought Grace's daughter to the hospital and she was admitted to the psychiatric unit did Grace have contact with hospital staff regarding where to locate outpatient services for her daughter. Amy was able to obtain information about mental health services from her sister, who had also sought services in the past. Jeff found help on the Internet and then it was through NAMI that he was connected to resources for help. Jeff stated,

I contacted the crisis line and they didn't give me any information and then I happened to find NAMI on the Internet. When someone from NAMI called me back it was like thank God we found you. So it took quite some time to actually get in touch with the right people to help us.

In addition to the difficulty of locating help for their mentally ill loved ones, many family members have encountered numerous other frustrations with mental health professionals: they have not been provided counseling sessions for themselves; they have not been included in the treatment planning process; and mental health professionals spend no time with them explaining to them their roles and responsibilities as family members. These frustrations are detailed in the discussions of the following research questions.



## **Research Question # 2**

*How involved have family members been in the care and treatment of their mentally ill loved one?*

All of the participants are involved one way or another in the care of their mentally ill loved one. If this individual does not live with them, they must check regularly (sometimes several times a day) on such mundane things as whether their loved one is eating, attending to housekeeping chores, going to work, taking prescribed medications, and keeping appointments. If the mentally ill individual cannot drive, and cannot manage public transportation, the family caregiver must take him or her to shop for groceries, to work, and to treatment appointments.

### *Confidentiality Statements & Acknowledgement of Family Members Role as Care and Treatment Team Members*

Confidentiality is an important issue in the treatment and care of mentally ill adults. Once presumed only for physicians, the rule of confidentiality is a universal ethical requirement for those who work in health care settings, including psychologist, social workers and others who provide mental health services. Nearly all states have discrete statutes addressing the confidentiality of mental health records and information. While the laws make it comfortable for the mentally ill individual to communicate freely with the mental health professional, the confidentiality law constrains the information exchange and cooperation between mental health professionals and family members of the mentally ill adults. Information gained during this study reflects how many mental health professionals use confidentiality as a tool to discourage family members from becoming valuable members of the overall treatment and care team.

For some family members, having their loved ones sign release of confidentiality forms, which are legal forms that, if signed by the mentally ill individual, can allow information to be passed onto family members, has been the most successful way of obtaining treatment information from mental health professionals. Family members have been allowed to sit in on psychiatric appointments, as long as their mentally ill loved one has signed a release of confidentiality form allowing them to be a part of the treatment.

However, even with confidentiality forms signed, mental health professionals still direct questions solely to the mentally ill individual and make treatment decisions without requesting family members input or accessing valuable information that they possess. Elon's daughter signed a release of confidentiality form allowing Elon to be part of the treatment process, but Elon still feels left out of the treatment process and notes, "There have been no problems with me sitting in on my daughter's appointment as long as she signs the consent forms; however, they don't show much concern for how I am feeling." Jerome states that working with his daughter to have her sign a release of information from has made a world of difference.

The professions want to exclude the family all together, and I have had to tell some of them up front if I come in and want to be a part of the treatment, I don't want to know all the intricacies of your counseling, I want to know what's going on. I mean I have never known anybody who really wanted to know all the particulars about the counseling and the other things. You just want to be able to get help.

Carol echoes Jerome's feelings about information family members need to know about their mentally ill loved ones.

Their [mentally ill individuals'] sense of awareness isn't very good, and their decision-making abilities aren't very good, but they [mental health professionals] leave all the decision making to them, because there is nothing a parent can do or say. It's not that we want to hear anything confidential, but you can give us an idea of what is going on. It just seems like there should be some sort of compromise made where the family has a little bit of rights to find out stuff without this breach of confidentiality.

Her remarks also express her disillusionment with the confidentiality law.

Jennifer, who is frustrated and disappointed with the laws, offers her opinion of the confidentiality laws: "Now things have gotten worse because of confidentiality laws. They [mental health professionals] are afraid to give you anything." Abby reports

I would try to call and was told they could not talk to me, because my daughter is 34 years old, and she needs to sign a release. I started in every way in the world to get information to them so I could help her. I typed

letters and sent them to the professionals. I sent e-mails, I faxed, and finally I showed up at the clinic and stood there until someone listened to me.

Jeff shares a story about a time when he was encouraged to document behaviors his daughter was displaying and then share that list with his daughter's counselor. He followed through with the documentation and attempted to share the information with his daughter's counselor, but the counselor advised him, not to document and submit information to her any more. His assessment of the situation is: "Now the one thing I would say is they [mental health professionals] don't necessarily seem to want our input." Lisa says, "I feel that to help the patient they [mental health professionals] have got to communicate with the family. So far I haven't met with anybody face-to-face." According to Grace,

The first time I talked with her [daughter's] social worker she was saying, well, I can't tell you that, because Lucy didn't give me permission. And she was asking me questions. And I said you know maybe I shouldn't tell you anything, because I didn't get permission from Lucy to tell you anything. So, you know, this works both ways

Since her daughter asks her to attend doctor appointments with her, Terry is able to maintain current information on her daughter's treatment:

At times my daughter will request me to go with her to the doctor, and she will go in and tell him that I have asked my Mom to come, and I would like for you to talk with her too. And that is working well, and usually I am able to sort of fill in the gaps when my daughter is having a difficult time. Prior to my daughter doing that, it was tough. He [doctor] was like you stay out, this kind of approach.

However, prior to attending appointments with her daughter, Terry felt as if the doctors wanted her to stay out of the treatment process.

Terry, Jerome, Carol, and Jennifer hold similar views that the confidentiality law prohibits them from having communication with their mentally ill loved ones' treatment providers. Family members whose loved ones have signed a release of information form share the notion that the confidentiality law ingrains a mindset into mental health

professionals that family members need not be included as part of the treatment and care team. They feel that the confidentiality law prohibits families from having communication with treatment providers that could enhance the decisions made about treatment and the actions and medications stemming from those decisions.

Those who care for, but have not been included in the treatment of their mentally ill loved one, believe mental health providers use the confidentiality law as a crutch for not including family members in the treatment process. Paul explains,

I will be the first to say that the mental health profession hides behind the confidentiality. I have since learned that yes, doctors know you can't discuss your treatment with me, but I can tell you plenty of things that will help you in your treatment of the patient.

He goes on to say,

We were in the waiting room and the doctor didn't even acknowledge us. We [the family] continuously get the stiff-arm approach, meaning, we are the professionals. We know how to treat, and if you get intrusive we'll throw the confidentiality issue at you.

The frustration these family members express with the confidentiality laws and the ways mental health professionals use them are valid. Since family members spend a majority of their time with the mentally ill individual, they do have crucial expert advice and information that is necessary for the psychiatrist in diagnosing and prescribing medications. Mental health professionals should not use confidentiality to block them from providing this information.

### *Courtesy, Involvement, and Collaboration*

Confidentiality is not the only issue family members raise. Other issues are courtesy, involvement of family members, a strong collaborative relationship between families and mental health professionals, and general communication between families and mental health professionals.

Cindy whose son is currently in the public system, describes the services her son receives and her involvement and general communication with mental health professionals treating her son,

We see a psychiatrist every two to three months, and its like 10 minutes and that's it. I mean other than that I am the treatment tool. There is supposed to be a follow-along social worker that is supposed to contact us from time to time and see if there is anything that we want to talk about or to do updates. She has not contacted us for over a year. So, I am going to contact her or whoever it is pretty soon and see about doing updates. I know there are forms in my son's files that have to be updated, and I am sure that this is not being done.

Cindy has made attempts to be more involved with the social worker and notes,

It just doesn't happen. They [social workers] are overloaded and they are in the public system, and they are busy, busy, busy, busy, busy. The social workers tend to turn over rather fast. We have gone through I don't know three or four social workers easily.

Cindy's comment highlights the issue of social worker retention and the problems it creates for patients and their families. This is an issue that is being addressed at many agencies around the United States. Cindy's comment also brings up the issue of high caseloads, which contribute to the inability of many mental health professionals to dedicate quality time to families, and also to the rapid turnover of social workers, who are unable to sustain the burden.

Ross opines about the services that his loved one received at a mental health residential program, how communication happened and how the program involved him, "It was a waste of money. They let her off her medications and didn't tell me about it, and no one informed me about payment of services when she was admitted, and no one

informed me about my responsibilities.” If this were a single incidence of a lack of courtesy and communication, it could perhaps be overlooked or forgiven. However, other family members have similar complaints.

Lisa explained how frustrating it has been not being communicated with or involved as part of the treatment team,

I have not been informed of my daughter’s progress or what is going on. I need to know if progress is made, and what she is working on this week, and what they are trying to accomplish with her. Have they changed the medicines this week? If so, what are these medicines supposed to do to make a difference? What should I be looking for as far as behavioral changes? I have not been informed of any of this. How can I help my daughter if I don’t know what is going on? I would like to see more interaction with families. I don’t see how they can help somebody if they don’t really know what is going on. My daughter’s perception of what is going on is not even close to being real. The professionals need to sit down with the families separately, because in my situation, knowing my daughter and how fragile she is, I don’t want to say anything in front of her that is going to demean her or make her feel bad about herself. But there are things that need to be said that I don’t want to say in front of my daughter that they need to hear and nobody has.

Like Lisa, Jeff would appreciate it if mental health professionals would provide just a grain of information so that family members can have an inkling of what the status of their mentally ill loved one is: “If my daughter’s counselor would just pick up the phone and say hey, she is doing great or she is not doing great. However, I just don’t think that is ever going to be reality.” The courtesy of a telephone call ought to be a reality, even if the counselor can only provide a grain of information, because it can help the caretaker in his or her role.

These observations, and the ones to follow, highlight the professionals’ lack of interest in useful and valuable information the family member may have that can help refine treatment procedures, as well as an inexcusable disregard for the feelings of the

person bearing the burden of care. Abby describes how her situation changed after her daughter became ill:

It's been a burden for us because we had to become caretakers and create a life for her, because all of a sudden she is by my side all the time, and I know she doesn't want that. I know she wants to have friendships and relationships again, and that is the hardest part for me.

Recognizing the toll mental illness takes on the entire family is an issue that mental health professionals need to address. Educating and communicating with family members not only lessens the family member burden, but also makes them better caregivers.

Paul describes his and his wife's situation as a desperate one in which they were looking for answers and getting no feedback or support from mental health professionals:

We were excluded from the system for about eight years. We were out there floundering around trying to get help, pleading for help. Both of us went to the doctor and pleaded for help and asked what can we do? The doctors didn't mention anything about support groups or any other resources in the community or point us in any direction--our pleas were basically ignored.

During this time Paul and his wife felt very alone and wondered if there was ever going to be help for their daughter. Paul feels the doctors do not get involved with their patients like they should, because doctors do not spend enough time getting to know their patients well. Regarding the level of involvement and communication with her daughter's mental health professionals, Grace adds,

They [patient and mental health professional] have a 30-minute session, but they don't keep them in there for 30 minutes. We see the doctor for a short time. He asks my daughter how she's doing, she says she's fine, he renews the prescription, and he says see you in 3-months.

During this shortened appointment there is not enough time for the mental health professional to accurately assess what changes in medication need to be made. It is perplexing how mental health professionals can make an accurate diagnosis and prescribe effective medications based on very little information or feedback from the mentally ill individual or their family members.

Ross and Carol also feel a collaborative relationship between family members and mental health professionals are essential for the success of the mentally ill individual. And their experience with mental health professionals is similar to Paul's in that there is little time and recognition given to family members when they attend appointments with their mentally ill loved one. As Ross explains,

Our experience has been that we go to an hour session; the doctor asks the patient if the pills are helping, you get an appointment for the next one, and you come home. I don't mean to be derogatory, because they [mental health professionals] are concerned people. They are in it for more than just the money, but if they would just stop and take the time to answer some questions. They are just so busy. The office is packed and it's get in and get out.

This dissertation again points out that mental health professionals often do not take the time to gather necessary information and input from the mentally ill individual and their family members to accurately assess if the medications the mentally ill individual is on are beneficial. Although Ross notes that the doctor is busy, it is impossible not to notice the subtext of Ross's comments—the frustration at the seemingly superficial evaluation and lack of interest in the concerns of the family caregivers.

These stories emphasize the desperation and frustration family members experience when health professionals are not willing to work with them in the treatment of their mentally ill loved one. In fact, it is hard to understand how doctors can prescribe medication effectively if they are not making decisions based on all the information that can be available to them about their patient.

Although family members continually show up at clinics, hospitals, and courts with their mentally ill loved one, they still are not recognized as valuable resources when the mental health professional is designing a treatment plan for their mentally ill relative. Katherine explains what happened when she showed up for a meeting at the hospital regarding her son's inpatient stay:

They [mental health professionals] did not discuss the medication at all, and just how long he should stay there. They have asked me to the meetings, but seldom do I get to say anything. I have talked to a social



worker, but all she wanted to know was everything that happened to him since he was a small child.

The mental health professionals directed the care without any regard for Katherine being in the room and without asking her opinion about the type of treatment her son should receive. Katherine says of a situation when her son was hospitalized, “ I don’t know anything, because they [mental health professionals] don’t tell me anything. You don’t have the right to know, because you are not guardian or power of attorney.” Paul too voices the frustrations of trying to communicate with doctors, but from a slightly different perspective:

When we try to talk to the doctors, they don’t listen. We tell them we have the right to tell them and they don’t have to tell us a thing. There is no law that says you can’t tell them whatever you want to.

In Paul’s case, the doctors did not have the decency to listen to the family members, who can offer information useful to making treatment decisions. As these observations confirm, families are desperately attempting to present mental health providers information that may be key in treating the mentally ill individual. In their desperation, they have tried faxing, e-mailing, telephoning and visiting mental health professionals.

These stories also support family members’ claims that there is a lack of respect and recognition when they attempt to provide the mental health professional with potentially valuable information about the mentally ill person. This is a puzzling situation, because mental health professionals ought to welcome any information that might be useful in deciding treatment options. Instead, mental health professionals are not involving them in the treatment of their ill family members even when there is a signed informed consent form. Listening to information families can provide and drawing on any of it that is pertinent should be an integral part all treatment and care programs for the mentally ill. Mental health professionals must also respond to the family’s desire to be involved. Even if they are restricted by confidentiality laws, mental health professionals should include family members in the treatment process at an early stage by providing a list of readily accessible resources and support groups.

Most family members have had experiences with both public and private agencies and feel both entities treat families in a similar manner. Lori has had many years of involvement with her loved one in both the private and public sectors, explains,

There is no system in the public or private mental health system to provide the help to families to be involved in a therapeutic, helpful way. The kind of care is so important for the community, and the facilities that provide care both private and public go in and get out and dump on the family.

That is not family involvement.

Terry, who has worked in the mental health profession for several years, believes the same problems involving families in the treatment process exist with both the public and private systems:

There is a long way to go before providers start including families. I feel there is still so much of that school of thought that it is your family background and your childhood that causes these mental illnesses. While working with psychiatric patients, I saw some providers make light of ‘Well he brought his Mom today’, you know the kind of remarks that are still present today. I don’t think it’s much different anywhere else, whether working for the government or the private sector, because I have heard a lot of people talk about the same issue.

Many of the family members give specific examples of how they are not recognized and respected by mental health professionals. Gloria observes that, “there needs to be a realization that we need one another and in fact, family members are the expert.” Agreeing, Jerome says, “Family members are the experts. No one knows the mentally ill person more than the family member. That’s why professionals should listen.” Gloria adds, “Family is around the patient 24/7 and is certainly aware of how they are doing.” Family members also want mental health professionals to reach out to them, instead of family members having to reach out to mental health professionals all the time.

Grace speaks with anger about the rudeness and disrespect she encountered from a health professional at an emergency room when she brought her daughter, who was actively symptomatic, there to be treated:

We need more health care professionals that really enjoy their jobs. I mean a lot of them have an attitude and that's the truth about it. They really have an attitude. There was a nurse over at Mennings Heights Hospital. Lucy was delusional and was calling the nurse by some other name, and she [nurse] stood there and said that's not my name. I am like come on lady give me a break. I mean arguing with a psychotic patient, that is rather stupid in my opinion.

Grace also describes other disrespectful situations such as doctors who do not return telephone calls and inappropriate crisis call workers. Grace is not the only family member in this study with the problem of telephone calls not being returned. Grace also tells about a crisis line staffer who responded to her call by asking if the patient would be okay until the following day. Grace replied, "If she [daughter] was going to be okay, why would I be calling you tonight?" This is a lack of recognition from mental health professionals that family members are capable of assessing a situation and then reaching out for help at the appropriate times is cause for complaint as are other unfathomable practices that can make the relationship with mental health professionals "antagonistic" at times. Cindy relates one such incident:

Something started to happen [with her son], so I called the clinic and explained what the problem was and that we needed to see him [psychiatrist] and he [psychiatrist] would not speak to us, because it was only two weeks since he had seen our son, so our son must be all right.

When I asked Katherine about support and recognition for her as a family member, she explained that she feels discounted by mental health professionals and not listened to. Mental health professionals ignore her need to understand her role as a family member and do not provide guidance. She says,

I don't know whether they [mental health professionals] would even listen to what I had to say. It's just come to the point that you know this has been going on since 1974, you get to the point you don't know which way to turn or who to ask.

Family members would like mental health professionals to see them as important and key players in the treatment of the mentally ill individual. Many times family

members are seen by mental health professionals as a hindrance and are often overlooked as key witnesses to the mentally ill individuals behaviors.

Overall, family members' comments point out that the level of involvement, the communication regarding care and treatment, and the overall collaboration in providing effective care and treatment for their mentally ill loved ones provided by publicly or privately funded community services programs are insufficient. Throughout the responses to this research question, issues of a poor relationship between families and mental health professionals recur. Lori sums up the relationship between families and mental health professionals as one where there is a "lack of a trusting relationship between families and professionals," and she feels that there needs to be a "long term relationship between families and professionals, and many times case managers come and go so quickly a relationship cannot be developed." On the whole, the family members interviewed for this study have found and continue to find their experiences with mental health professionals frustrating and even negative.

There are also positive comments, even though mental health professionals, for the most part, persist in refusing to recognize that the burden of care falls on family members. Lori notes that she sees the beginnings of a partnership between family members and mental health professionals: "I have seen an evolution through the years. There have been more changes in the last 3-4 years than ever before." Despite the changes she is seeing, Lori says that family members still have to fight to define their roles in the treatment and care process. As is the case with any system entrenched in tradition, change comes slowly.

The family members, however, make especially positive observations and comments regarding services provided by mental health professionals when the mentally ill individual was receiving Program of Assertive Community Treatment (PACT). PACT is:

a service-delivery model that provides comprehensive, locally based treatment to people with serious and persistent mental illnesses. Unlike other community-based programs, PACT provides highly individualized services directly to consumers. PACT recipients receive the multidisciplinary, round-the-clock staffing of a psychiatric unit, but within

the comfort of their own home and community. PACT team members are trained in the areas of psychiatry, social work, nursing, substance abuse, and vocational rehabilitation and these team members provide necessary services 24 hours a day, seven days a week, 365 days a year (www.nami.org, 2002).

Lori reports some success working with the PACT team:

The PACT team is available and is there continually. The PACT program has made the greatest difference in my son's health and my burden. I meet with the professional face-to-face if it is necessary, and I have met with the entire PACT team. If things are going OK, I can just call or e-mail. The important thing is that I can give the staff any signs that I see of stress level increasing. It is a very therapeutic situation, because they are able to help my son with issues such as medication, life issues, and life goals, and I can be there in a healthy parental role working towards all the same goals.

One of the key features of a PACT program is collaboration with families. However, very few mentally ill individuals whose family members were interviewed for this study receive or have knowledge about this service or how to access it. This discovery astounded me, because I have worked on a PACT team and every person I interviewed who described their loved one seemed to fit the profile of someone who should be involved in a PACT program.

With the exception of those family members who are involved with the PACT program, it can be asked if these issues that frustrate family members are due to a lack of sensitivity, lack of creativity, training, high caseloads, time or individual worker ethic on the part of mental health professionals, or if they arise from the system's structure, which expects mental health professionals to perform their work in such a way that all they can do each day is attend to crises and allows no time for preventative or planning measures. It is possible these issues arise because mental health professionals are given more and more cases to work with without sufficient resources to support their efforts. It is possible they result from a combination of individual mental health work issues and system issues.

*Accessing Information About Mental Illness, Support Groups, and Community Resources.*

For family members, learning about the facts of mental illness and how to cope with the effects has been difficult. Abby states that she “would try to call, and they would say they couldn’t talk to me. So I never got any information.” Abby is not alone; family members have recounted that not receiving information about mental illness is something they have come to expect from mental health professionals. Ross compares a situation when he tried to access information about his mother who was hospitalized for a physical illness to the situation with his mentally ill daughter:

When my mother was in the hospital dying, I asked the doctor what her condition was and he read off all the facts to me, and with my daughter who has a mental illness, I can’t call the doctor and ask what her status is because he says he can’t talk about that to me. How are we supposed to help as parents if we don’t know what is what? As a parent you have to do your own research on mental illness and thank God for the Internet. You know I found out things on the Internet and there are different kinds of web sites to learn about these mental illnesses and symptoms and signs and what you can do and what you shouldn’t do. That has been very helpful, and NAMI has been a big help too, but that is after the fact, but when you are just getting into it, you are just totally lost.

Ross’ comments highlight the situation most families find themselves up against.

Once a mental illness diagnoses is made, family members are left to seek out information on their own with little information provided by mental health professionals about the illness itself, about medications, treatment or resources. Help is usually drawn from the surrounding family and friends. Gloria says, “I receive information indirectly from people other than professionals, specifically NAMI,” while Abby explains, “I had to search things out on my own. My sister-in-law got stuff off the Internet for me. We didn’t hear about it from the doctor.” Other family members have also used various resources at their disposal to gather whatever information they can find about mental illness. These resources include family, friends, Internet searches, the resources located in the public library, and support groups, especially NAMI. Grace even stated she saw a newspaper

advertisement for a person coming to town to speak about his or her time in a mental hospital. When Cindy's son became ill, her husband looked for information any way he could, and eventually was connected with NAMI. Cindy reports, "It was through NAMI we found out the information on medications and not through the psychiatrist." When asked if the psychiatrist gave her information about diagnosis, side effects and prognosis, Cindy answered, "Oh no, absolutely not. They have given us nothing." Cindy tries to attend all appointments with her son, and when I asked her if she is unable to attend the meeting with her son how she receives the information about the session she replied, "Well, I think there was only one time when that actually happened, and I never got the information." Since Cindy is very dedicated to attending each psychiatric appointment with her son, she is well apprised of the changes in treatment.

Paul reports that when his daughter became ill, mental health professionals never provided him with information such as diagnosis, what a mental illness is, what prognosis is, what types of medications are used to treat mental illness or what the family is supposed to look for. Grace says the doctor told her, "It is Schizophrenia, and there was no hope." All the information Gloria and Jerome have received about their daughter's illness has come from sources other than the direct mental health professionals who are providing the care. Gloria says NAMI has provided her with all the information that she has acquired. Amy, who says has obtained all her information about mental illness from either her sister or NAMI, "I can't give NAMI enough credit, because they have been just wonderful. I have found out so much from going to the different meetings." Jeff and Jennifer's main source of obtaining information about mental illness is through the Internet and NAMI. According to Jeff, they "are very fortunate to have found NAMI. Getting knowledge to the folks is probably the most helpful, and it relieves stress and helps people understand." Carol also praises NAMI:

NAMI has been a big help. It's really a Godsend that they have that, because parents are pretty much left on their own to do the work, to do the research. It made such a big difference when you know and understand a little bit about what the diseases are, because then they don't seem so foreign to you.

Abby reports, “I had to search out things on my own, and the only reason I found NAMI is because my sister went on the Internet and found it.” Elon, who has received no information from mental health professionals about medication, diagnosis, financial resources, and crisis or respite services, states,

To tell you the truth, I really haven’t gotten that much from mental health professionals. I got most of my information from people who are going through the same thing. I have gotten most of my information and support from groups like NAMI or from Cope and Hope. I really haven’t gotten that much from the mental health professionals.

Like those of the other participant’s in this study, Elon’s experiences demonstrate the interest they all have in becoming educated about mental illness and resources available to patients and their families.

These participant observations emphasize the reluctance of mental health professionals to communicate useful information to the caregivers and, therefore, the importance of being able to access other sources for information. Ross feels being able to have access to information on medications that have been prescribed would make working with his daughter more successful. He explains, “When she [our daughter] was put on medication, it would have been nice to have information about what the medication is, its potential side effects, and what it is supposed to do for her. We didn’t get any of that information, so my wife searched it out on the Internet.”

A support group was the main source of information for Terry and her husband, Terry says, “Families in Touch was a tremendous help, especially for my husband because he still feels like she [daughter] can do better.” When I asked Terry if mental health professionals referred her to Families in Touch she replied, “No, I believe when I called the NAMI number I got a real sweetheart, and she told me about Families in Touch.” Amy also credits NAMI for the information about medications, treatment, and other resources. “I can’t give NAMI enough credit, because they have just been wonderful. I have found out so much from going the different meetings.”

According to Abby, mental health professionals have provided her with no information about mental illness. She explains that she has found information about mental illness through the Internet, friends, and family members:



We have pretty much done it all through the Internet and through friends and family members, because the information wasn't provided to us. Somebody just didn't sit down with us and say, you know these are some avenues you can take; this is what is available to you. We searched all those things out. It's just awful. We come up against so many things that you just never think you are going to have to deal with, just so many obstacles. Right now I am not even sure about her [daughter] diagnosis. I am living in the dark all the time. Every day I get up, I don't go through a day without questioning something. I wish Dr. Riley would just see me and not release any of my daughter's information, but coach me on how to live with it. Maybe he could teach me not to worry so much.

These comments reiterate the lack of support families receive from mental health professionals. Even when families actively seek out information from the professionals, they rarely receive it in any sufficient quality or quantity. For example, family members did not receive from mental health professionals a clear explanation of the patient's illness, practical help concerning how to handle patient behavior, or referrals to appropriate community resources. In fact, family members find other sources of assistance more effective than the help of professionals.

The PACT program exemplifies the different ways communication between family members and mental health professionals is managed. Most of the family members' comments to this question show that the family members of loved ones under the broad based care of the community mental health system do not receive direct information from mental health professionals. However, the family members whose loved ones are participating in the PACT program receive information regularly from mental health professionals. PACT is designed to provide family members with abundant information and solicit information from them as part of the overall care and treatment of the mentally ill individual. Family members who have experience with the PACT program have welcome access and input to treatment information about their loved one. They are invited to regular treatment planning meetings and are kept abreast of any treatment changes made with the mentally ill individual. Family members are also allowed to have input into the treatment planning process.

Although family members overwhelmingly conveyed their frustration with how little information and guidance they receive from mental health professionals and told of the creative searches they have undertaken to find the information they needed to effectively work together with their mentally ill loved one, they also praised the efforts of NAMI and the PACT program, which is providing a valuable resource for the family members who are participating in the program.

### **Research Question # 3**

*How would family members like to be included in the treatment of their mentally ill loved one?*

#### *Ideal Relationship*

As part of my effort to find out how family members would like to be included in the treatment of their mentally ill loved one, I asked about the frequency of contact that they have had with mental health professionals. Most family members feel the frequency of contact is not enough. Again, only those who are involved with the PACT program feel as if the contact is sufficient. Cindy has not seen her son's social worker in a year. As Lori and Lisa points out, family members want the contact with mental health professionals to occur more often. Both feel the contact needs to be more fluid, so that it can move wherever the illness is. Lori notes that "parents need more feedback and need to feel more involved in the healing and not so much treated as an outsider."

When asked about their "ideal" level of contact with mental health professionals, the responses indicate that family members want more of a family-centered care approach to treatment and more respect and recognition of the strengths they bring to the treatment process.

When I asked family members what their ideal relationship with a mental health professional would be, Grace described her ideal relationship as an "open door policy with professionals. I am a strong believer in protecting people's rights, but when it interferes with treatment and well-being, I think you have to make a bit of a compromise." Jeff would like to see, "integration and greater flow of communication among family members and mental health professionals." Carol explains her ideal is to have more feedback:

I would like some feedback on progress or weaknesses, or is there something we can do at home to help her [daughter] to get to the point where he [doctor] wants her to get. I mean, is there something we can do at home like getting her involved in things to get her motivated. I really think we need to work as a team. I think things may move along better

instead of us [family members and mental health professionals] being separate entities.

Although an ideal relationship comes in many different forms for family members, all agree that there needs to be more partnering between mental health professionals and family members. Also, an ideal relationship means offering services such as hotlines, more upfront information from mental health professionals on how to address certain behaviors and overall, opening up the communication lines. For whatever reason, be it confidentiality laws, lack of time, high caseloads, lack of concern for family member input, there seems to be a breakdown in what both mental health professionals and family members need to be effective when dealing with mentally ill individuals.

Interestingly, none of the ideals the family members seek is impossible to fulfill. Abby simply wants the health professionals to give the family more information upfront:

I would have liked to have had in the very beginning them [mental health professionals] sit down with me and my daughter in the room and say this is what happened to your daughter and you are going to encounter things that are different and these are the places that can help you with information.

Part of an ideal relationship for Jeff is an established 24-hour hotline for families that can assist with situations, which occur that are over and beyond what families know how to handle. Jeff states, "I think it would be helpful if there was a 24-hour emergency hotline where you can actually ask someone that has some credentials, give them a situation and get some educated and hopefully unbiased feedback." Jennifer would like someone on the other end of the 24-hour line who can give facts on mental illness that would allow family members to be able to make an informed decision on what action to take with a certain situation, because, as Jeff explains, "It is the immediate situations that arise. You don't know what is the right thing to do and that is tough." Family members need to be able to have information at hand so that they know how to handle situations appropriately.

An ideal relationship for Elon is a partnering relationship with professionals where family members are given the opportunity to discuss openly with professionals the information they have and are able to actively make decisions about the treatment

direction for their mentally ill loved one. She believes if family members have the information about treatment decisions, they will be more effective when dealing with the mentally ill person and supporting treatment decisions. She also believes it would be beneficial if family members and mental health professionals would get to know each other and be aware of the issues and situations that arise. Elon describes her view:

I would like professionals to collaborate more, partnership with us [family members], understand that how we feel has a lot to do with how the patient is going to do and how the family is going to do. I would also like to have a professional that comes into the home and talks to you, gets to know your situation and they are aware of your environment. I'd like to have a professional that I can contact and ask about what to do in a certain situation. And if the mental health professionals could avail themselves not just for the crisis, but that I could call at any time and get the information I need or the support that I need.

Elon adds that an ideal system would involve those family members who are willing to be involved as part of the care and treatment team from their entrance into the mental health system:

The mental health professionals need to have programs that involve the family and also have more communication with the family. If somehow they could co-counsel or require counseling as a family as part of the program for the patients. They are asking the family members to do the questioning, to ask for help. The family needs to be educated about the illness, and educated about what services are out there. Mental health professionals need to become partners with us in care. The help needs to be offered to families, not asking them to seek out all the help on their own.

Terry's wishes for an ideal relationship are similar to Elon's. Terry, who believes because she lives with her daughter, she has information that no one else is privy to, states,

I would like to be part of her [daughters] treatment plan and [have] my concerns be addressed, because I feel like I know my daughter in a

different way. I live with her 24/7, and I think how can these providers feel so confident that they know it all and just leave you out of it.

Both Terry and Elon strongly advocate for a partnering relationship with mental health professionals. They believe family members have very important and pertinent information for mental health professionals.

Other family members voice this similar concern. Carol reports feeling sad sometimes about the confidentiality laws and wishes they could have more feedback and feel more involved in the recovery process of their mentally ill daughter. Carol states, “sometimes I feel like a criminal and, my gosh, we have known our daughter longer than the mental health professionals have.” It is difficult to understand how mental health professionals can prescribe medications and develop treatment plans when they are receiving only a part of the information and persist in ignoring insights family members can supply.

For Jerome and Gloria, building relationships between families and mental health professionals is very important. Gloria points out, “Families are the experts. Nobody knows more about the family member than they [families] do and that is why the professionals should listen.” Amy would appreciate being included in treatment planning sessions. “I don’t want to, you know, be overbearing. I would like to have some input, because I live with him and I have known him longer than they [mental health professionals] certainly will.” Amy also states she would like to be active in the decision making process, and if she cannot attend a meeting, she would like written details about the meeting from a mental health professional or else a telephone call. When I asked Abby how it would be helpful if mental health professionals partnered more with family members, she responded, “It would just relieve a lot of stress.” Abby went on to say,

It would help if there were more interaction with mental health professionals and the family even though my daughter is an adult. I know that there are laws preventing all of that, but the government and people who make the laws do not realize the situations that you come into contact with when dealing with a person with a mental illness.

Abby continues that she gathers information about her daughter where she can. It would lessen the stress of caregiving if she could receive information from mental health

professionals that indicates if her daughter is improving, because the way it is now Abby just relies on her own instincts.

For family members, an ideal relationship with mental health professionals is one that actively involves them in the decision making process when deciding what treatment modality will be used with their mentally ill loved one. Family members would like access to professional advice, information about medications that are being prescribed, input on treatment plans, and recognition and respect from mental health professionals that they are vital to the overall well-being of the mentally ill individual.

### *Earlier Information*

When mental illness develops in a family, the physical, emotional, and financial strain of the illness disrupts the quality of their life together. Marital stress escalates, social life often diminishes, and life in general can become bleak for the entire family under the overwhelming cloud of sadness. Communities that tend to be judgmental and aloof surround these families. Family members are trapped with few tools and little knowledge to help them handle the task ahead of them.

When family members were asked what would have been more helpful if they had known about it earlier, they responded by saying they would have liked mental health professionals to work with them from the beginning, and they would have liked information about the illness, the available resources, and some guidance on how the family is supposed to react to the behaviors that mentally ill individuals display. Lori would have appreciated more information about the illness and what the family would go through, as well as the resources that can help families handle situations.

Carol spoke about the issues that arise within a marriage when one member has a mental illness. She would have liked more information about what happens to the dynamics of a family and where to go for help when mental illness strikes the family:

I would have liked to know what the families are going to be in for, because you just don't have a clue, but you still need a life, and the life you used to have just does not exist anymore. I mean the disease, the mental illness, is an all-consuming situation. It's every day, every minute, and it's like having a handicapped child. It's just constant. It can zap your

energy and it can cause strife in your home, and it can cause problems in a marriage, and problems with other children. Families really need a lot of support and understanding.

Ross would benefit from information about how to react to some of the behaviors:

How do I react to my daughter when she says someone is talking to her through that light fixture? We were never given any instructions so I just winged it. For the first few months I just didn't know how to react with her anymore. It was almost like this foreigner had walked into our house, and we couldn't communicate anymore.

In the future, Amy will search out mental health professionals based on their view of what role family members play in the treatment process. Amy says, "Upfront, I wish I knew if the professional was willing to include me or not." She went on to say that if she knew up front that the professional was not willing to include her, she would have kept searching for a professional who would include her.

When I asked family members if there was any information they could have used less of, I was answered with a one-word consensus...NO! As Ross notes, "We have gotten very little. No."



#### **Research Question # 4**

*From the viewpoint of the family members in this study, have mental health professionals provided the support services necessary to help these family members cope effectively with their mentally ill loved one?*

#### *Support Needed*

Family members of the mentally ill shoulder a significant amount of caregiving responsibilities, often with inadequate assistance from mental health professionals. The burdens of such caregiving are multiple and pervasive. This question is designed to find out what mental health professionals have done to help ease the burdens of caring for a mentally ill loved one. Jerome simply states, “Mental health professionals have provided very little, period. I don’t know how else to say that,” while Gloria declares, “Mental health professionals have provided very little, NAMI has.” Elon adds, “To tell you the truth, I really haven’t gotten much from mental health professionals. I have gotten most of my information [about support] from people who are going through the same thing or from support groups such as NAMI.” These observations reflect the opinions of all participating family members, who state that mental health professionals do little to help ease the burdens of caring for a mentally ill loved one.

When I asked family members what adequate support for family members would be, Cindy matter-of-factly said, “Adequate support is someone to replace what Mom does.” Lori believes that “adequate support is what is necessary each day. It needs to deal with the emotional, physical, financial, social and spiritual needs. We need to look at this as a holistic approach.” Amy believes that adequate support is “for them [mental health professionals] to include me. He [son] went alone [to the psychiatry appointment] and it was a waste of money, because he [psychiatrist] didn’t tell us anything. I would have liked to be included.” Carol thinks the service that NAMI provides is one that mental health providers should provide. Jerome firmly believes that the support NAMI provides is needed, and Gloria agrees with him. Ross shares their sentiments:

NAMI and Cope and Hope, is just a place to be able to go that the family can talk, because this is very stressful. It’s draining on families and we sometimes need a place to go to vent and express our frustrations, as well

as any successes that we have to share. We thought we are unique and have this child that has gotten into all this trouble and has all these problems, but the next family member said that they have almost exactly the same situation.

Carol adds,

A little bit of education or briefing and then let you know about the resources that are available. We looked in up in the yellow pages and we found it on our own, but it would be nice if they [mental health professionals] would give you some sort of referral information that you could go and call or you know if you have a problem call this number.

Ross continues, “More feedback from the professional specifically to the family as to how the patient is doing.” Mental health professionals provide most family members with few support services and little in education, emotional or financial support.

Terry, Paul, and Grace report they have received minimal assistance or support from mental health professionals. Mental health professionals seldom provide support for Terry as a family member. She does state that in 1986 they [mental health professionals] did provide financial resources at that time. After several encounters with different providers, Paul and Grace did receive pamphlets from one institution. This institution also is good at making sure the family receives some support, such as family counseling. Paul and Grace would like to see more education directed to family members. They also suggested that respite services be offered to family members, because as Grace points out,

Family members get very tired. There is nowhere that you can go to get someone to actually relieve you of caring for that [mentally ill individual]. There is really no place to go unless you have relatives close by and the relatives are willing to participate. [It would be nice] if I needed to go out of town or on vacation there would be someone to just go by and see if she’s okay and if she has taken her medications.

Lori believes times are changing and mental health professionals are beginning to take a look at the role family members play in the mentally ill loved one’s life:

In the beginning they [mental health professionals] blamed us. There has been a change as time has gone on, and there is a great deal of support for getting on with our life. However, there are some contradictions. They miss the point of saying well the only housing that we have is in a drug infested neighborhood so it's obvious we cannot meet that need. So you take him back home and take care of him yourself. So it's a mixed bag. Sometimes it's lip service, you know take care of yourself, but families then have to go out and find the housing that is affordable.

Elon has not received support from mental health professionals. She would prefer mental health professionals to be more accessible for her. Elon describes what adequate support means to her,

In a perfect world...at 10:00 or 11:00pm and I am sitting here scared to death and I feel like I have to call the police, and instead I would have a professional to contact and he or she knows what to do.

All these observations make it clear that family members need some assurances from mental health professionals that there is help for family members. For instance, family members need to know there is assistance to obtain adequate housing for their mentally ill loved one that is not located in a run down part of town, that money management help is available for the mentally ill person, and they need guidance in finding respite services. Grace believes providing education about respite services would be beneficial, "because family members get very tired. There is nowhere that you can go to get someone to actually relieve you of caring for that individual." Cindy thinks receiving help connecting to services, help with payee [money management of the mentally ill loved one's personal finances], and shopping would be an enormous help to families. Family members would also feel more secure in their role as a caretaker if they could reach out to a mental health professional who can offer some guidance on how to get through a particular situation. Elon's feelings are, "If mental health professionals could avail themselves not just for the crisis, but as an avenue for the family to call when they are at their breaking point." Paul would like "someone to talk to that knew a lot about mental illness." Jeff would "appreciate the continuity of support with a mental health professional so support is within reach when you need to get in touch with

someone.” This comment brings up another need, more advice on how to react to particular behaviors.

Family members overwhelmingly agree that there are times when they need more support than others. All family members would appreciate more support at times when the mentally ill individual is not emotionally stable. Lori explains, “Yes, specifically when stress levels for me increase, I need more support. This means understanding my feelings, my stress level and to be able to talk about it.” Lori also states she would like to see “mental health professionals during times of increased stress for me. I would like them to understand my feeling, my needs, partner with me, and recognize my strengths.” Several family members say they would appreciate more support from mental health professionals when their mentally ill loved one is going through a rough spot, and when important decisions need to be made. Gloria describes what support means to her, “listening or talking...I also understand that mental health professionals are understaffed, and their budgets have been cut so they do not have a lot of time.” Elon appreciates group support but thinks it is important to have a mental health professional available to provide daily support, for family services if needed during the rough times:

when you need someone to talk to professionally who knows the situation, who knows what you are dealing with, you can call and you can talk to this mental health professional to figure out what you need to do to get through that crisis. If mental health professionals could avail themselves for not just the crisis, but also as an avenue for the family to call when they are just about to the breaking point.

Cindy seemed taken aback when I asked her if she felt there were times when she needed more support than others and replied, “Of course. Our son has gone missing two or three times. That was rather scary for us. We didn’t know what happened to him.” For Cindy, mental health professionals could have been supportive to her and her husband at a very frightening and uncomfortable time.

Lori feels family members could use more support from mental health professionals when stress levels increase during good or bad events. She believes family members need extra support not only for major stress events, such as marriages, death, and Christmas, but also for everyday situations that can cause enormous stress for family

members. Terry notes that family members need more support when their mentally ill loved ones are going through an “episode.” She also echoes Lori’s thoughts that family members need more support during high stress times such as a marriage breakup. Terry reports that after 9-11 her daughter went through a rough time and needed more support from her family and, therefore, the family members could have used extra support from mental health professionals.

When I asked what support means to Terry, she answered that support would be in the form of emotional support. For Jerome, support means giving the family members rest. Jerome thinks extra support should be offered to family members “anytime there is a big change. At the times when they [mentally ill individual] are worse, you [family member] need more support.” For Lori, support means that

mental health professionals need to understand my feelings, understand my needs and listen and partner with me. Professionals should not treat families as inadequate and do for the family. They should empower the family with the strengths that are within families to do something about it and partner with the family. A few [mental health professionals] have, but some do not.

Abby would like more support from mental health professionals when

I reach those points of frustration, I would like to be able to call somebody and have them advise me. I would like somebody that I could turn to [to] get answers for questions, so I don’t have to live with worry. I would like to be able to communicate with her [daughter] counselor or doctor.

Grace, who also believes there are times when she could use extra support from mental health professionals, explains she needs more support when “her [daughter] condition is worse, and she is psychotic and just aggressive and her medication has been off or it is not working.” Carol believes family members need more support when their loved one is going through a:

bad spot, or when they [mentally ill individual] make a decision, like for example to go back to school or get an apartment. You know we [family members] do not know everything and you just don’t know what the right thing is to do, so there are times when you need a little more support.

Amy shares Carol's concern about knowing when to be involved in a decision that the mentally ill individual has made, such as getting a job. Amy does not know if she should intervene, because she does not know if it is the best thing for his recovery.

Family members want mental health professionals to recognize the toll caring for a mentally ill loved one exacts from the caregivers and provide help and support to them during stressful periods. Katherine would like mental health professionals to sit down and talk with her, although she feels whatever she has to say is not going to be heard: "They [mental health professionals] are going to do what they want to do. Just a little bit of kindness would go a long way."

## CHAPTER SIX

### Themes

Although accurately depicting the experiences of the family members with mental health professionals is a challenge, my responsibilities as a researcher extend beyond that. Qualitative research also entails making the findings “discernible to the diverse audiences...including researchers and practitioners” (Sandelowski & Barroso, 2002, p. 219). Family member experiences have a broad appeal, especially related to social work, psychiatry, counseling, medical care, academia, nursing, and patients. Therefore, a discussion of the findings in thematic form is appropriate.

The analysis of the information provided by each family member for each research question produced five themes:

- 1) family-centered care that takes into account the desire of family members for information sharing, coping skills training and support for logistics;
- 2) recognition and respect for family members and their knowledge of the patient;
- 3) the confidentiality law and how it restricts, according to the family members interviewed, the information between mental health professionals and family members;
- 4) coping strategies family members have developed to function within a system that does not allow for fluid collaboration with mental health professionals;
- 5) the system versus the relationship between family members and individual mental health professionals.

Throughout the literature, there is a litany of labels used to discuss the idea of collaboration between parents and professionals. I have chosen to use the concept, family-centered care, which is discussed extensively in the literature about school personnel working collaborating with parents and which is discussed minimally in mental health literature.

#### **Family-centered care**

Family-centered care was the theme which was most prominent throughout the interviews. Many of the other themes that arose during these interviews are all

encompassed by family-centered care. A family-centered care approach to the planning, delivery, and evaluation of health care is grounded in mutually beneficial partnerships of patients, families, and professionals. Family members in this study believe partnering will improve the well-being of mentally ill individuals and their families, as well as the working relationships for all involved.

Family members in this study feel that mental health professionals need to begin seeking out family members for input on services they plan to develop. And they feel it is necessary to be involved along with their mentally ill loved one with making decisions about what and how treatment will be delivered.

Paul believes his daughter would be much healthier if, from the beginning, his daughter, family members, and mental health professionals had worked together to build a treatment plan: “if we were allowed to have input and access to the mental health professional, we would have been at a better point sooner.” He then elaborates on the frustrating situations family members encountered when trying to provide mental health professionals with vital information.

Family members believe health care professionals need to instill the importance of family member input into the current health care system, because health care places too much emphasis on the science of medicine, focusing only on the disease, and thus, failing to treat the patient holistically, within the context of family and community. Family members would like mental health professionals to treat family members as allies.

As the families in this study point out, the role of family members is not always clearly defined in community-based care. Family members in this study are very seldom provided education about the nature of mental disorders and the vulnerability of their mentally ill loved one, and even fewer programs actively engage families in the rehabilitation program, preferring to employ professional resources instead. A strong emphasis has often been placed on assisting the mentally ill individual, instead of the family, to seek out a mental health professional. Two disadvantages to this approach, as Falloon and Fadden (1993) point out, are that family members have vital information to assist with the treatment process that the mentally ill individual does not always reveal to the mental health professional and the mentally ill individual becomes dependent on the



professional. Since many mental health professionals do not stay in their jobs for long, the absence of this professional can prove catastrophic to the mentally ill individual.

The family members interviewed for this study report that mental health professionals do not involve family members in the treatment of their ill relative or help address the needs of the caregiving family member. Furthermore, these participants never mention attending any educational programs developed by mental health professionals. All participants agree that these programs would be appreciated. They also report that NAMI arranged the majority of the support they have received and educational seminars they have attended. In my study, family members report that seldom has the information they have received been delivered directly from the mental health professionals.

Family members interviewed for this study would like mental health professionals to educate them about the etiology, treatment, and prognosis of the illness and be available to answer questions. Many family members do not know what the diagnosis of their mentally ill loved is nor do they know what medications their loved one is taking and what side effects these may have. They also do not know what changes they should be looking for when their loved one is put on certain medications. Grace opines, “If we had an accurate diagnosis and assessment we would have known what she can and cannot do. We had no idea that she is so fragile.” This family member explains further that perhaps they pushed their daughter too hard, because they did not understand the whole impact of the mental illness.

These family members are likely to get their information from support groups or other family members and friends, or from their mentally ill loved one. Elon, in frustration, notes,

It hasn't been from mental health professionals that I have obtained my information. I have obtained my information from family and friends, and it's been through my initiation that services have been found for my daughter, and I've done all the leg work to get my daughter into these services.

Other participants report that they gathered all their information from the “library” and from “support groups.” Cindy, Gloria, Ross, and Carol all confirm the information that they have found has come from people other than professionals and all

mention that information has come directly from NAMI. Abby is disgusted by the fact that,

We've pretty much gotten all of our information about mental illness through the Internet, and friends. Mental health professionals have not sat us down to say these are some of the avenues you can take, and these are some of the avenues available to you. We've searched that all out on our own.

Carol's exclamation, "Thank goodness for the Internet, and NAMI has been a big help too," summarizes the participant's frustrations at not being included by professional caregivers in the process of sharing information vital to understanding their family members' illnesses.

Abby explains, "We've searched all of this out on our own; we didn't hear about it from the doctor. It's been a struggle for me to get her help, without having any contact with the doctor, while the father of a mentally ill daughter states, "We don't know how to treat our daughter if we don't know if she's getting any better or not." Family members interviewed feel that the more informed they are about what is happening with their mentally ill loved one in treatment, the better able they are to support efforts assisting their mentally ill loved one in successfully living in the community.

Both mental health professionals and families agree that the goal of providing effective services to mentally ill individuals is to enhance their efficiency of stress management and their immediate support network to enable them to achieve full and productive lives in the community with minimal risk of major episodes of mental disorder (Falloon & Fadden, 1993). However, the concept is not always well defined between family members and mental health professionals.

With the exception of those family members who are involved with the PACT program and feel well supported and understood, family members who participated in this study are receiving very little support or assistance with developing coping skills from mental health professionals.

The family members who were interviewed for this study feel that many times they have to guess at what is the proper way to interact with their mentally ill loved one and when it is time to intervene in a situation. Many say that they do not have the

necessary skills, information, and training to perform their role as a caregiver effectively. Lisa explains. “I need more communication from mental health professionals, because I need to understand how to handle situations that come up.” And family members add that since the illness changes so often, the information and training they need depends on the situation. For family members to develop their skills, they need information training and resources. “There needs to be a long term relationship between families and mental health professionals”, Lori noted after explaining the frustrations she has encountered over the years with mental health professionals.

All these people have vital information to add, and it is clear that the mental health professionals have as much to learn from family members as they have to offer in terms of specialized knowledge and skills. It seems essential to form a working family-centered care partnership, not merely with the primary care professionals, but above all with the patients and their families, who represent the greatest resource for any community-based service. A primary consideration in collaboration is not just “consulting” or “educating” family members; they should be brought actively into the process. Family members need to be included in such a way that they have power, resources, and control, as well as the ability to set priorities. This is key for a family-centered relationship.

Some family members also feel logistics such as travel, meeting times, and money can affect the extent of the commitment a family member can make to care for a mentally ill loved one. The way in which each mental health professional accommodates these logistics will determine the role family members can play in decision making, and truly becoming an active, important member of the treatment team. In many instances, some family members could not attend important meetings or court hearings, because they did not have a ride or they did not have adequate funds to pay for a ride. Katherine voices her frustrations about being unable to see her son when he is hospitalized, “Nobody’s invited me to the meetings. They’ve told me the days he can have visitors at the hospital, but I have no one that can go with me.” Family members also feel that the meetings and appointments should be flexibly organized and scheduled so that they can participate, and meetings where decisions need to be made should not be held unless family members are present.

Family members interviewed in this study believe effectively treating mentally ill individuals so that they can successfully live in the community involves collaboration between the patient, the family members, and the mental health professionals.

In summary, family members participating in this study would like mental health professionals to recognize that health services need to be delivered to those who are seriously ill in a way that acknowledges the central role families play in the lives of ill persons, including those who are mentally ill. The family knows and loves the ill individual as no one else can, while recognizing that there are times when a family must seek and depend upon expertise it does not have.

When family-centered care is practiced in a psychiatric setting, the family, the mentally ill person, the psychiatrist, the social workers, and the support staff bring their skills, knowledge, experiences, and individual perspectives together on behalf of the ill person. In family-centered care, the mentally ill person, the family, and the mental health professionals share a goal regarding the ill person's health care, which they have explored, talked about, and negotiated together.

### **Respect and Recognition**

The second theme that arises from of this study is the way mental health professionals relate to family members. One of the key elements of family-centered care is mutual respect for skills and knowledge, and this is an area in which family members feel mental health professionals fail them. "Respect is a virtue. It's a way to care about others, ourselves, and our world. Respect means believing that every person on earth has value" (Care Notes for Kids). Family members report their observations go unheard, or are dismissed, by mental health professional. This report is consistent with other reports from family members who indicate frustration with the absence of effective collaboration (Turnball & Turnball, 1986). On the whole, both family members and professionals have difficulty engaging in communication behaviors considered important as indicators of constructive communication.

Even though families of people with chronic illness have many more interactions with professionals than do typical families, research on family stress suggests that all too often these interactions are a source of distress (Hatfield, 1987). In order to change this

situation, parents and professionals have asserted the importance of collaboration and mutually respectful relationships (Patterson, 1991). Embedded in a system of care philosophy that encourages a family-centered approach to service delivery is the belief that the family should be recognized and respected as the primary caretaker who helps his or her mentally ill relative achieve success in the community. By incorporating family member input into their thinking about how to plan services, mental health professionals can increase their helpfulness to families by increasing the amount of information and discussion they provide families regarding their own perspective about their mentally ill loved one. Mental health professionals must embrace basic relationship values and attitudes. Lisa notes, “ I know many professionals have their degrees, but if they really cared they would work with the family.” This essential set of values includes: equality, cooperation, partnership, and the incorporation of a family-centered focus in family member-professional relationships (Walker & Singer, 1993).

Mental health professionals are beginning to recognize families as valuable partners and allies in the care and treatment of the mentally ill individual; however, professionals have much to learn and gain from this alliance. Recognizing the fundamental role that a family plays in the life of a family member means that professionals must learn to respect and value family member judgment, and ensure that their efforts are designed to support each family in its caring giving role (Gasching, Vohs, & Weaver, 1995). Many family members who were interviewed for this study felt mental health professionals do not recognize and respect the pivotal role that families play in the lives of their mentally ill loved ones and most do not value family member assessments. Family members believe mental health professionals need to work together with families as partners, learn to value family members for their expertise regarding their loved one’s disability, and regard their participation as crucial to planning for services. Lori explains the importance of family involvement, “ It is absolutely important for the community to involve the family in care and treatment. There needs to be recognition of the importance of understanding and supporting families.” Family members note they live with the daily reality of mental illness and, consequently, are able to speak with a kind of authenticity and authority that is not available from others. Also, their knowledge is embedded in “real-life” conditions that they can describe in everyday language. The fact that family

members experience the day-to-day details of life with their mentally ill loved one means that they have a tremendous amount of practical knowledge and expertise about their ill member's strengths and weaknesses to offer professionals. Therefore, although mental health professionals have a body of knowledge as well as their expertise and experience to draw from, they can make better decisions about treatment by using the information provided by collaboration with the daily caregivers.

Two of the Cornell Empowerment Group's (1989) elements to an empowering relationship are mutual respect and trust, defined as the "belief that diversity is positively valued...that relations among [stakeholders] should be organized to provide an equal balance of power...and play an important role in developing strategies...[to] gain control over [their lives]" (as cited in Singer, Powers, & Olson, 1996, p.2). The family members in this study also feel that mental health professionals do not demonstrate that they respect the diversity and varied experience of all families, and they do not develop opportunities to learn about the perspectives of families and work together with parents as equals at all levels of care. All families have strengths and capabilities, and many family members who were interviewed believe it is critical that mental health professionals ensure that they reinforce these family strengths which make it possible to individualize care for each mentally ill adult and their family. Lori explains, "Professionals need to look for the strength within each family and encourage what their role is and provide counseling if necessary." Lori continues, "Professionals should not treat families as inadequate, but instead sense the strengths and empower the family." Family members think professionals need to take the time to develop a relationship with the family in which he or she becomes a trusted confidant, and then through each contact with the family, helps with developing a partnership. Lori observes, "There needs to be a long-term relationship between family members and professionals. Community health services at times, lacks [*sic*] a trusting relationship between families and professionals." Trusting, working relationships rarely emerge out of an initial encounter. They unfold over time. Also, by developing relationships and identifying the strengths of families, instead of focusing on the weaknesses, families will be more likely to respond by being able to make significant positive impacts on the entire family unit.

Mental health professionals must hold the belief that families have capabilities and strengths, as well as the capacity to become more competent, before they are likely to enter into partnership with families. As noted by Clifford and Warner (1987), “the most important attribute of any shared business is the competence of the co-owners and the trust they have in one another” (p. 10). Recognition of the mutual strengths and trust of partners in a partnership is essential if the working relationship is going to start off in the right direction and continue on a successful path (Dunst, Trivette, & Deal, 1994). Meeting the individualized needs of families requires a shift and expansion in the roles professionals assume in interactions with families.

According to Rappaport (1981), the ability to strengthen families in a way that makes them more capable requires a change in the way professionals interact with families. Mental health professionals will be the most effective if they place major emphasis on helping families identify and prioritize their needs from their own, and not a professional’s, point of view, if they encourage active participation as part of the process of mobilizing resources for the mentally ill individual, and if they provide families with the necessary information to make informed decisions about their mentally ill loved ones’ needs and the courses of action to take to meet these needs. If professionals employ these techniques, family members will be able to manage the day-to-day situations that occur with their mentally ill loved one more effectively.

During their interviews, several family members mention that over the years the relationship between family members and mental health professionals has changed, but not one of them is able to give specifics on how the relationship has changed. When I asked Lori who has almost 30 years of experience with mental health professionals how the relationship has changed over the years, she said, “It has evolved, but I still have to fight to define my role.” How things have changed became apparent to me during my fourth interview, when I realized family members are beginning to develop a voice and are taking a more assertive stance in obtaining proper and quality care for their loved ones. I was appalled to hear what these family members have to say about their experiences with mental health professionals. Since most of the participants are middle class, well connected socially, and able to fight for services on their own, I thought to myself “This is as good as it gets?” It was not difficult for me to imagine what it must be

like for those who are underprivileged, and have to cope with a mentally ill loved one, have no social network with NAMI, have no transportation to get to places, and have no telephones or access to computers. At the very least, they must find life as a family member with a mentally ill loved one overwhelming.

Many family members mention mental health professionals do not want them involved. When I asked what those mental health professionals say to them to make them believe this, they replied it was not in the words, but in the actions of the professionals. This observation is significant, because, as Day (1972) points out, non-verbal behavior plays an important part in the interaction between the family member and the mental health professional. For example, Cindy tried to talk with a mental health professional about her son being on many different medications, one of which she does not believe he needs, because she is concerned about the side effects many of the medications can cause. And yet the mental health professional did not pay any attention to her concern. This action conveys a subtle message that what the family member has to say has no impact or importance to the professional. Terry experienced a similar situation when she attended a clinic appointment with her daughter. She explains, “ He didn’t verbally say he didn’t want me involved, but he indicated with all his actions, and the way he handled our conversation that he didn’t want me involved.” Describing their experience in the waiting room of a mental health clinic with their mentally ill loved one, Grace and Paul report that when the doctor walked out to call their daughter back to his office, “ the doctor didn’t even acknowledge us.”

Singer and Powers (1993) refer to these non-verbal or interpersonal interactions as “meta-communication,” which “consists of what we say or imply by body language about our values, perspectives, and roles” (p.296). Professionals convey a great deal about their interests, beliefs, attitudes, and intentions through a variety of meta-messages, and these affect the relationship between the family member and the professional. One of the things meta-messages reveal about a professional is their understanding and acceptance of the value of flexible partnering. An important key to the development of collaborative family member-professional relationships involves the ability and willingness of the professionals to adapt their roles according to family member role preferences and abilities. From the outset, professionals who value family input and



empowerment tend to convey a positive orientation toward flexibility in their relationships with family members. These professionals cultivate and communicate openly their interest in understanding the family's perspective on the mentally ill individual. Dunst and Paget (1991) believe that in the balance of power in the relationship between mental health professionals and family members, the power ought to lie with family members, because they rightfully possess decision-making power concerning their own children.

Effective communication is essential when working with families. Without effective communication between family members and mental health professionals there is inadequate assessment of the problem and limited or ineffective treatment or both. Many family members believe that they have important information that will help mental health professionals make better and more informed treatment decisions for their mentally ill loved one. The listening problem mental health professionals have is best exemplified by Katherine's description of going to court with her mentally ill child. "I stood up to try to tell him he tried to commit suicide, and the judge told me, 'I don't have time for this,' and the judge made his own decision." Like this judge, many mental health professionals use their power to make absolute decisions. Instead, for the benefit of the patient, they need to use their communication skills in a way that treats the patient's family with respect, dignity, and trust to establish a partnership with the patient's family. Emphasis should be placed on active listening techniques as a way of understanding and supporting families (Dunst, Trivette & Deal, 1994). Ross expresses frustration at not being listened to: "It doesn't matter if I contact them because they won't listen to anything." Katherine comments, "I don't know if they would listen to what I have to say. This has been going on since 1974 and you get to the point when you don't know which way to turn, or who to ask and you're wondering what is going to happen to him." Through the use of good listening skills, professionals can improve collaboration and show their respect for family members. Good listening skills enhance collaboration and also increase family input during meetings. Used effectively, listening provides a context in which family members can clarify and express their thoughts and feelings; professionals can gain useful and accurate information (Singer & Powers, 1993). Weick and Saleebey (1995) report that listening to families has demonstrated that most families,

despite turmoil and numerous problems, have resources which they can and do draw on, and that when working with families, the professional should take into account their internal strengths and external resources (p.144).

Honesty is also another essential requirement for effective communication and partnerships between mental health professionals and families. In every interaction mental health professionals must make clear statements about the purpose of the meetings. Mental health professionals need to be up front with families, and forthcoming with information, because, as research has found, this kind of behavior sends a message of caring for and respecting families. Carol sums it up all so well: “ Most parents are left in the dark and they don’t have a clue, they have no idea what’s going on. It’s pretty devastating for parents, because you have lost your child, the one you used to know, and it’s not that they are going to be worse, it’s just that now they are a different person, and as a family member it’s pretty hopeless and we feel very alone.” For family members to survive and draw on strengths they may not know they have, they need the compassion and support a partnership with the mental health professionals can provide.

### **Confidentiality**

The third theme that emerges from this study is the legal barrier to more effective relationships, the confidentiality law. At present no national standard for the confidentiality in mental health information exists. Rather, each state has laws that establish confidentiality. There often are significant differences among states, which can create problems for those providing care for people with mental illness. In some states, the mental health confidentiality statute applies only to information gathered when a state facility provides care; in others, it applies to mental health treatment regardless of the auspice of care. ([www.surgeongeneral.gov](http://www.surgeongeneral.gov)).

Each state law creates exceptions to confidentiality. Many state laws permit some types of disclosures without client consent, raising questions regarding the adequacy of these laws.

An issue of some controversy in mental health is whether families should be provided information regarding their adult child. While many family members believe mental health professionals frequently use the confidentiality law as a way to keep them

out of the treatment process, family members must recognize that the confidentiality law is a very important law and one that mental health professionals must abide by and perhaps sometimes err on the side of caution simply to protect themselves from a legal situation.

Many of the family members interviewed believe that because they are the primary caregiver to their mentally ill loved one they need information about the diagnosis, prognosis, and treatment, and they would like to be included in treatment planning sessions so that they can provide consistent care that parallels what mental health professionals are trying to accomplish, instead of finding out that what they have done or what they have not done is completely opposite of what the mental health provider may be doing. Abby reports,

I grab pieces of information where I can get them. It would be nice to get reports from them [mental health professionals] to know that she is doing well and what the plan is for her. That would relieve a lot of our stress, but we don't get any kind of connection from any of them [mental health professionals] to know if things are moving forward or if she [daughter] is doing better. For now I just use my instincts to know if things are getting better or not.

Family members also believe that they have fundamental information and advice which is necessary for mental health professionals to have access to in order to effectively diagnosis and treat their mentally ill love one. In many cases both parties have the same goal in mind, such as wanting the mentally ill patient to be successful in living in the community, but each party goes about trying to accomplish that in different ways and many times are in conflict with one another. Jeff states, "You know it would certainly help if there were a greater flow of communication. I understand the confidentiality issues, but that really hinders, I think, the family member's role with the person with the mental illness." Family members firmly believe that having factual information from a mental health professional would assist them in providing improved care for their mentally ill loved one. Many times family members do not know or understand the illness that their mentally ill loved one has and, therefore, simply do what they think is the best thing for their loved one, only to find out later the way they have

been responding to behaviors is entirely wrong. For many family members, mental illness is new and mysterious and having access to information and being able to be active participants in the treatment process would greatly reduce the fear and apprehension that many have at some point. Abby elaborates,

It would help if there were more interaction with mental health professionals and the family even though my daughter is an adult. I know that there are laws preventing all of that, but the government and people who make the laws do not realize the situations that you come into contact with when dealing with a person with a mental illness.

Confidentiality laws in some states provide that parents acting in the role of caregiver may be given information, but this is usually limited to diagnosis, prognosis, and medications used to treat the illness. The states with these provisions, some permit the disclosure of this information without the consent of the ill individual, while others require consent, with some requiring administrative review, if consent is given at all. Most of the reform proposals that have been introduced before Congress provide for the disclosure of limited information regarding an individual's current health status to family or next of kin. Consent generally is not required, although most provide the patient with the opportunity to request that information not be released to their families ([www.surgeongeneral.gov](http://www.surgeongeneral.gov)).

In mental health treatment, there is much disagreement regarding the issue of confidentiality ([www.surgeongeneral.gov](http://www.surgeongeneral.gov)). Family advocates believe that a family in a caregiving role should have access to some types of information, even without patient consent, because the information is necessary for them to provide quality care (Lefly, 2000, as cite in [www.surgeongeneral.gov](http://www.surgeongeneral.gov)). Advocates for patients argue that consent should be required, because the right to confidentiality belongs to the recipient of services, and because there may be intrafamily conflicts that could develop by the release of information to family members ([www.surgeongeneral.gov](http://www.surgeongeneral.gov)).

Since family-centered care is essential to providing complete care to those individuals with a mental illness, mental health professionals need to include family members more. This means that a confidentiality law, which accommodates the criteria of family-centered care for mentally ill individuals, needs to be enacted at the national

level or states need to amend their existing laws. Neither will be an easy task, because such laws will also need to safeguard the patient's right to privacy. And until that time, family members and mental health professionals need to work with the patient to understand the importance of family involvement and the critical role family members can play in helping the mentally ill individual maintain himself or herself successfully within the community. On the one hand, mental health professionals need to look for other ways to provide information to family members without breaching the confidentiality law, such as providing general factual information on mental illness, medication, and coping skills. On the other hand, family members need to understand that in some instances mental health professionals are bound by law. Therefore, family members may need to work within those constraints to find ways to provide valuable information to mental health professionals and to persuade their loved ones to sign informed consent forms allowing family member involvement. Family members can join a support group and consider supportive counseling for themselves to help deal with the burdens of caring for a mentally ill loved one.

### **Coping Strategies**

The fourth theme that comes out of this study is coping strategies. Family members have developed excellent coping strategies after years of trying to negotiate a mental health system that does not give them easy access to information about mental illness, medications, treatment, and that does not encourage their inclusion in the care and treatment of their mentally ill loved one. Many of the strategies these families have developed have proved to be outstanding strategies to manage the system. The strategies that family members have reported are contacting mental health professionals and not asking for information from the professional but simply stating what their concerns are and e-mailing and faxing information to mental health professionals.

Abby's strategy has been to e-mail, fax and make a personal visit to the clinic in the hope of relaying information to the mental health professional:

I started in every way in the world to get information to them so I could help her. I typed letters and sent them to the professionals. I sent e-mails, I

faxed, and finally I showed up at the clinic and stood there until someone listened to me.

Other family members have continued to strategize by working with their mentally ill loved one to have them sign an informed consent allowing his or her family members to actively participate in the care and treatment with mental health professionals and their mentally ill loved one. Jerome is one family member whose working relationship with mental health professionals has improved since he asked his mentally ill daughter to sign an informed consent so that he too can be part of the treatment team. Jerome professes, "I want to know what's going on. I mean I have never known anybody who really wanted to know all the particulars about the counseling and the other things. You just want to be able to get help." The strategies Abby and Jerome have developed are similar to the strategies other family members have used when trying in some small way to communicate to mental health professionals what they believe is information that the professionals need to have to make informed decisions about the care and treatment that they will recommend to the mentally ill individual. These small strategies are letting mental health professionals know that family members would like to be able to play a significant role in providing care and treatment to their mentally ill loved one. Unfortunately, due to system issues and perhaps attitudes of some mental health professionals, the process of being able to be an active participant in the care and treatment along with mental health professionals is often a slow and frustrating road. For now, until system issues can be revamped and attitudes of mental health professionals change, family members may need to resort to these types of strategies to be a part of the treatment process.

### **System versus Relationship Issues**

The fifth theme that has arisen from this study is system versus relationship issues. Numerous times during this study, family members raise issues about problems in the way mental health professionals interact with family members of the mentally ill. They point out how some mental health professionals avoid involving family members as part of the care and treatment team, that many mental health professionals fail to communicate important information to family members, such as information about

mental illness in general, information about medication and treatment options in general and specifics of these for the family members' loved ones.

The failure of mental health professionals to communicate effectively and often enough with family members, the lack of involvement of family members as part of the overall care and treatment team, the issues of respect and recognition that family members in this study have raised, the lack of information given to family members and resistance to receiving information from family members point to the fifth theme that emerges from in this study, the underlying theme of system issues versus individual mental health professional issues.

Family members in this study tend to focus on the individual mental health professional and their interactions and relationships with him or her without making any distinction between individual mental health professionals and mental health systems. Since individual and systems issues are very closely intertwined, the perception of these family members that the individual mental health professional is the problem is a common one. Albrecht and Zemke (1985) define the interaction which an individual customer of a system (such as a family member) has with an individual representing that system (such as a mental health professional) as "moments of truth." During a "moment of truth" the family member is interacting with the mental health professional who is a representative of a larger system, but at that moment the family member does not conceptualize a larger system. During that interaction, the mental health professional and the system are one-in-the-same for the family member (Albrecht & Zemke, 1985).

This dissertation makes no distinction between system problems and individual mental health professional issues pertaining to their relationships with family members; it only reports what family members have shared in their interviews. While this study does not address whether issues raised are system issues or individual mental health professional issues, many of the family members' comments and issues they identify as important raise questions about whether various problems with family member involvement as an integral partner in the care and treatment team are system or individual issues.

There is always the question of whether a mental health professional has the time and inclination to work with families and communicate with them. This issue is common

to the management of systems and people in all fields including mental health, and raises the questions of whether people can do what is required and whether people will do what is required (Hersey and Blanchard, 1988). The question of whether people will do what is required is a personal issue and includes: motivation, self-esteem, correct job matching, human interaction skills, and much more. The question of whether people can do what is required encompasses both individual and system issues. Individual issues include: task skills required for the job, personal time management skills, tools to do the required tasks, specialized training for specific tasks, and more.

Contributing factors to system issues include: support from the overall organizational culture, support from top management, support from direct managers, support from clients, support from regulatory and legal bodies, correct and supportive organizational policies, supportive organizational structures, tools, materials and supplies, proper funding, and much more. These are mostly outside of the control of the mental health professional and contribute to creating the environments and the systems in which mental health professionals must operate on a daily basis.

Many mental health professionals have impossible caseloads to manage. They, therefore, prioritize their time and usually find they do not have enough time to dedicate to the care and treatment of everyone on their case list. Since family members are a lower priority than the mentally ill clients themselves, family members and their need to interact with and develop effective relationships with mental health professionals often suffer. This becomes an issue for individuals that Covey (1989) addresses in his discussion of time management in terms of distinguishing between issues which are important and issues which are urgent. Covey argues that people spend most of their time addressing urgent issues at the expense of issues which may be more important. They address issues which are both urgent and important first, and issues that are urgent and less important second. Often people never deal with the less urgent yet highly important issues they face (Covey, 1989). An example of an urgent and important issue is a crisis with a mentally ill patient; this type of issue will be dealt with by the mental health professional first. An urgent but not highly important issue in the mental health system could be meetings with mentally ill individuals conducted simply to satisfy regulatory or policy requirements. These meetings are often urgent for mental health professionals



because frequency of visits required for each patient and the raw numbers of meetings with people overall are closely tracked by regulatory agencies, but these meetings may not always be important because some of these individuals are doing well and don't require a personal meeting. Finally, discussing long-term care with family members and their role in that care may be important to a mental health professional but certainly not urgent; therefore, may not get done.

Mental health professionals also have to cope with the issues of "doing things right" and "doing the right things." Mental health professionals all want to "do things right" but it is often more difficult to focus on "doing the right things."

For example, mental health workers have individuals on their caseloads who require varying degrees of time, care, and energy. It is often easier to focus on the mentally ill individuals who need less. Dealing with those who need less counts on the tally sheets of cases dealt with for the organization just the same as dealing with the more difficult mentally ill individuals. When dealing with family members wanting time, interaction, and communication is added to the mental health professional's workload it becomes even more seductive to work with the less demanding mentally ill individual because a better job can be done with them; when working with these individuals a mental health professional may be better able to "do things right". However, working with the mentally ill patients that are currently doing well at the expense of working with the more difficult patients may not be "the right thing to do" at a given time.

Although there are many reasons why mental health professionals do not have, find, or make the time to work in a collaborative partnership with family members of the mentally ill, it is beyond the scope of this study to determine these reasons. No matter what the reasons - whether they are system issues or relationship issues with individual mental health professionals - family members in this study emphasize that they do not feel included enough in the care and treatment of their mentally ill loved ones, even though they often are the primary care mechanism and spend by far the greatest amount of time with the mentally ill person.

## CHAPTER SEVEN

### Summary of Findings, Limitations, Recommendations, Future Research, Summary & Conclusions

So far, this study has explored how family members perceive their experiences with mental health professionals. The participants who volunteered eagerly shared their experiences and discussed their perceptions with me. In Chapter Four, the detailed discussions of the various themes are supplemented with verbatim quotations from the interview transcripts. I also summarize my findings and explore how they complement and augment previous research. This chapter begins with a summary of the findings, which is followed by a description of the limitations of the study. It then provides recommendations for family members and suggestions for future research. The concluding section contains a brief summary and conclusion of my study.

#### **Limitations and Strengths of the Study**

Five factors limit the findings of this study. First, the methodology of in-depth interviewing is a limitation, because it is susceptible to interviewer bias, which can influence the outcomes of the collected data. Also, the quality of the interview relies on the ability and willingness of the family members to articulate perceptions and to share accounts of experiences, which are personal and confidential. These, in turn, depend on the ability of the interviewer to establish and maintain a rapport with the family members.

Second, as a social worker who worked with mentally ill individuals for 10 years, my bias regarding family member involvement is a limitation for this study. I have had the opportunity to work with some of the finest and most challenging families and working with those families has helped shape my opinions that I have about family involvement. Even though I openly acknowledged the fact that these experiences have shaped my attitudes about family involvement, these experiences do play a role in my ideas about having family members and mental health professionals working together. I also acknowledge that the formulation of the questions I asked is a reflection of the experiences I have had as social worker in the mental health field.

Third, the participants also pose inherent limitations, because they offer a subjective account that cannot be verified without additional observations. For example, a

participant may describe the encounter with a mental health professional, but this could not be checked against the perceptions of another family member or a friend. The interpretation of the interviews is also limited by the lack of member checking in this study.

Fourth, as a researcher entering into these family members' worlds, I also created some limitations for this study. Since I have worked in the field of mental health for ten years, I have experience working face-to-face with families who have a mentally ill loved one, but I myself have never experienced a mental illness nor do I have a loved one who is mentally ill. Although this created some distance from the issues studied, thereby minimizing the chances of bias, at times it was a challenge for me to enter into the participant's experiences. I worked at bridging that gap, but am aware of the limitations my own experience imposed on understanding family members experiences with mental health professionals.

Finally, another limitation is that all family members interviewed for this study have been involved with NAMI, whether it was a one-time attendance at NAMI meeting or a current on-going membership with NAMI. This membership does help shape their attitudes and actions toward mental health professionals. While this is a limitation, it also is important to point out that this group is concerned about their mentally ill loved ones, is working hard to be involved in their care and treatment, is informed on key elements of mental illness and mental health, and is working hard to be a valuable element in the care and treatment system. This may well be the most included, communicated with, respected, active group of family members available for this study. The problems they encounter are very likely worse for other populations of family members.

One of the strengths of this study is the use of the semi-structured interview protocol. It allowed me to ask each family member a core set of questions while giving me the flexibility to navigate down different paths in pursuit of confirmation, new insights, and more illustrative information. A strictly unstructured format does not always allow for qualitative comparisons to be made or themes to emerge, especially with only 16 participants. On the other hand, a strictly structured format prevents the researcher from investigating the broader set of issues people bring with them.

Another strength of this study is that I was a mental health social worker. The experience of being a mental health professional allowed me to fully understand the system within which family members are trying to work. My experience also allowed me the ability to ask the right questions, to be able to probe more deeply into the answers the participants were relying to me and my experience also gave me the opportunity to more completely understand the answers that family members were telling me.

### **Recommendations**

During the course of these interviews, several suggestions occurred to me that I wanted to make to the family members, but did not because I did not want my ideas and biases to taint the interviews. I was taken aback that many of the family members do not have the basic information that they need to guide their decisions on the care of their mentally ill loved ones.

Although I guaranteed the family members confidentiality, I knew some of the family members knew each other, because they all have had involvement with the same NAMI support group to varying degrees, and feared someone I had already interviewed might say to someone I had not yet talked to that the researcher suggests we do this or that thing. Now that this interview process is completed, I can make my recommendations not only to those who participated in this study, but also to all those who cope on a daily basis with a mentally ill individual or have had to cope. I urge them all to be pro-active by educating themselves, staying involved, advocating for changes and staying open to mental health professional involvement in mental health care and better treatment and services for those individuals with mental illness and their families.

#### *Educate Themselves*

Not only do I encourage family members to continue caring for their mentally ill loved one; I also urge them to educate themselves about the community services that are available to their mentally ill loved one. This not only means learning about the new medications on the market and their side effects, but also finding out about the intensive services that are available and how to access these services.

As pointed out in the discussion of *Locating Help* included under Question #1(pp.50-51). And in *Earlier Information* under Question #3 (pp. 74-75), many of the family members interviewed report they are not receiving adequate information about mental illness or the services available for treatment and care of a mentally ill loved one. They also report, as highlighted in *Support Needed* under Question #4 (pp. 76-81), that case management services are not providing adequate services to either the family or the mentally ill individual. The most important resource that most family members had no knowledge about is the PACT program. Even though the National Institute of Mental Health (2002) has confirmed the repeated success of this program, its introduction into the public health system continues at an agonizingly slow pace. There are many people who could benefit from PACT who have no access to the services that can help them to live successfully in the community. It is important for family members to find out from their local community services agency how a mentally ill person is referred to PACT and what the details of the program are.

#### *Stay Involved*

Another recommendation is to encourage family members to stay active and involved with their mentally ill loved one. As a former mental health professional, I cannot begin to explain how appreciative I was of families who are willing to be involved. Yes, sometimes motives were questioned and communication was difficult, but through time and patience a productive and workable situation arose out of each and every situation. Family members and mental health professionals have the same goal, but come at it a bit differently. All too often these different approaches and poor communication obscure the desire for the same results, and the family members are left feeling rebuffed and useless, even though the success of the treatment program may depend on them as primary caretakers. Throughout the interviews, families express their belief that collaborative partnering with mental health professionals would make the treatment of their mentally ill loved one more effective. This theme is highlighted in the “Ideal Relationship” section under Question #3 (pp. 70-74). In this section they also report family members desire partnering, but this goal is not often attained because of the resistance to including family members as a key part of the care and treatment team. I

urge family members to set aside their feelings of not being heard and their frustration at not attaining the collaborative partnering they are working toward as rapidly as they would like to attain it and persist in their efforts.

### *Advocate*

I encourage family members to involve themselves in the push for legislative changes where changes need to be made. I also urge them to advocate for full collaboration between themselves and mental health professionals. All the families in this study repeatedly mention their desire for this collaboration and it is especially highlighted in “Ideal Relationship” under Question #3 (pp. 70-74).

I also encourage family members to advocate for the enhancement of community-based programs to help integrate mentally ill individuals into the community. Most family members in this study remark about the need for collaboration and an overall “holistic” approach to care and treatment of their mentally ill loved ones that would include the mental health professionals along with family members. Few families ever mention a comprehensive approach to care and treatment that goes beyond the collaboration between mental health professionals and families to become an overall community-based effort. Current literature on community-based programs, discussed under “Mental Illness and Community Health Services” in Chapter 2 (pp. 10-14), along with my own experiences in community-based mental health treatment bring me to the realization that many of the specific issues the family members raise in this study could at least be somewhat addressed by a comprehensive community-based mental health system. I urge them to continue to do their part in educating the public about mental illness and its effects on individuals and families.

### *Stay Open to Mental Health Professional Involvement*

While many families are open to the idea of mental health professionals working with their mentally ill loved ones, some are not. Mental health professionals contribute knowledge, skills, and expertise acquired from many years of education and training that family members may not have. Mental health professionals may also have access to information about medications and their side effects, and to resources available in the

community that may benefit the mentally ill individual. Since family members expect mental health professionals to listen, respect, and collaborate with them, it is, therefore, important that family members do the same in return. The family members interviewed in this study all feel there should be a stronger collaboration between mental health professionals and families and they overwhelmingly state (see question #3 “Ideal Relationship,” pp.70-74) that the mental health professionals were the ones who need to do more to strengthen this collaboration and need to include family members as integral members of a comprehensive care and treatment team, but none of the family members in this study said mental health professionals are not needed. In “Ideal Relationship” under Question #3, Gloria speaks for everyone when she comments, “...we need each other...” From a mental health professional’s standpoint, several obstacles may stand in the way of improved relationships between families and mental health professionals. These can be large caseloads that do not leave mental health professionals much time to work with families, crisis-oriented work that makes preventative work with families difficult, patient’s rights to confidentiality that may prevent the release of information to family members, mental health reimbursement elements that may not support work with families. Additional barriers noted by Marsh (1992) are remnants of the past history of families being blamed by mental health professionals for their loved ones mental illness and insufficient knowledge and training for mental health professionals about the needs family members have when caring for their mentally ill loved one. It is important for family members to understand that mental health professionals have the same objective in mind for the mentally ill individual, but may approach treating and understanding the individual from a different perspective. Family members and mental health professionals truly do “need each other”.

## **Contributions**

This study makes four important contributions to the field of community based mental health care:

1.) The information gathered for this study adds information to the current body of literature about the relationship between family members and mental health professionals. It enhances existing information, because it provides material on the perspective of primary caregivers. As I have stated several times in this paper, there is a lack of current information about the relationship between family members and mental health professionals. Specifically, this study contributes to the family systems theory by enriching and expanding the information that already exists.

2.) This study contributes by offering some hope that change is beginning to take place as far as including families in the treatment of their mentally ill loved one. Family members in this study believe change is taking place within programs such as PACT, where mental health professionals accept family members as active participants in the care and treatment of their mentally ill loved one and work closely with them in making decisions regarding the care of the mentally ill individual. Even though, when specifically asked, family members could not explicitly say how mental health care is changing or why, it may be that with the introduction of the PACT program one avenue by which family members can have access to mental health professionals and be active participants in the care and treatment of their mentally ill loved one has opened.

3.) Another contribution of this study is that it shows family members using available resources to inform themselves about their loved one's mental illness and voicing a strong and informed opinion on what their role should be in the care and treatment of their mentally ill loved one. The overwhelming response from one NAMI support group of family members reveals caregivers who are confident in their roles and the impact that they could have if mental health professionals would acknowledge their importance in the treatment plan. This willingness to come forward and talk about the frustrations encountered working with mental health professionals and voice their opinions about



how and why they should be an active part of care and treatment of their mentally ill loved one represents a crucial change from the past when families were not willing to acknowledge and talk about mental illness in their families so openly. Family members understand the pivotal role they play in the care and treatment of their mentally ill loved one. They are clear in explaining what it is that they benefit from when involved with mental health professionals, and they also know what important information they can offer to assist mental health professionals in devising care and treatment plans for their loved one.

4.) The fourth important contribution this study makes is it points out that family members voice their willingness to be flexible to meet mental health professionals half way. Family members in this study make a concerted effort to acknowledge and empathize with the limitations placed on mental health professionals and express their willingness to work within limitations, which include limited resources, restricted monies, time constraints, high caseloads, and privacy issues. As a social worker, I have often wondered whether family members understood these limitations. It is clear that family members in this study are very knowledgeable about these issues and are willing to make adjustments to accommodate mental health professionals. It is also clear that, in return, they would like mental health professionals to recognize them as valuable members of the treatment team.

## **Suggestions for Future Research**

The research in this study brings to mind several ideas for follow-up studies. Again, the underlying theme of system versus individual issues is important. My ten years of experience as a mental health professional give me an in depth understanding and appreciation for the obstacles mental health professionals face on a daily basis. My research has given me an understanding and appreciation for the barriers family members of the mentally ill face. Many of the suggestions for further research, whether undertaken from the mental health professional viewpoint or from the family member viewpoint, could be approached from either perspective: system or individual. While this dissertation makes no distinction between system and individual issues, further research should be done in this important area.

Qualitative and quantitative research complements each other. The qualitative research conducted for this dissertation points the way to further qualitative research and also defines areas for valuable quantitative research. A researcher can conduct a study that investigates family members who are not connected with a support group. The family members interviewed for this study had an advantage in that they have a support network, specifically NAMI, which provides most participants with some level of direction and support. However, even with this support network, these family members do not have a mutually beneficial relationship with mental health professionals. A study specifically focusing on family members with no support networks would be of interest in order to find out what happens with family members and mentally ill individuals when no one has any advice or direction to offer.

The absence of a body of current research on family experiences with mental health professionals points to the need not only for this study, but also for continued efforts to investigate the relationship between family members and mental health professionals. With the growing use of PACT programs, it would be of use to examine whether or not PACT programs are showing improved outcomes for partnering with family members.

Another suggestion is to examine the relationship between family members and mental health professionals, and have the mental health professional perspective be the major focus of the research. An investigation into the perspectives of the relationship

between mental health professionals and family members would yield insights into how mental health professionals approach their work and how they attempt or do not attempt to accommodate family members in the treatment process.

One last suggestion that I have for future research projects is a study addressing whether the inclusion of families improves the effectiveness of treatment and if inclusion in the treatment process increases or decreases the burden of stress for family members.

Other suggestions for further research come from family members I interviewed. One family member suggests studying the role of siblings in caring for and supporting the mentally ill person. The patient's illness affects not only the patient and the parents, but also the entire family unit, especially siblings and other family members living in the same household. Research and service delivery needs to examine the impact of illness on the needs of all family members. Another family member suggests researching the concept of spirituality and its importance to family members for living a fulfilled life with all the pressures and stresses of caring for a mentally ill loved one in a system that does not support family efforts well. Others suggest a study that inquires how family members can promote a collaborative relationship with professionals. It seems the research conducted on the relationship between family members and health care professionals discusses the changes that professionals need to make in order to accommodate families in the collaboration process, but neglects to address some of the sacrifices and changes families need to make when it comes to working with professionals.

## Summary

As previously stated, I expect the research conducted for this dissertation to provide a fresh perspective to mental health professionals regarding the value of including family members in a comprehensive care and treatment plan for mentally ill individuals. The information gathered from my research highlights the perceptions and feelings of family members who have mentally ill loved ones and points out how these family members can contribute to a collaborative treatment process that focuses on keeping the mentally ill loved one in the community.

Although the important role the family plays in supporting a mentally ill member in the community is now emerging as a significant factor in mental health care, research has traditionally focused on the burden placed on the family instead of on the need to recognize the value of family input to designing a comprehensive treatment plan. This study reports the stories told by family members of mentally ill loved ones who are currently receiving mental health services in order to raise the awareness of health care professionals of this neglected asset. The literature review examines the relevant research on family member experiences with mental health professionals. The absence of a body of current research on family experiences with mental health professionals points to a need for this study.

By compiling a detailed collection of family member perceptions and experiences, this study attempts to raise awareness of the challenges families have in trying to support their loved ones in the community and, at the same time, decrease the isolation experienced by those family members. Sixteen people from twelve families were interviewed. Those interviewed consisted of eight individuals and four couples from a NAMI support group. My research plan was to listen to family members recount their experiences. My report and analysis of their stories add to the body of knowledge on the subject of families' experiences with mental health professionals and remind mental health professionals that the needs of family members must be taken into account when treatments are being devised for their mentally ill loved ones.

The family members in this study were asked to share their experiences with mental health professionals. Interviews were conducted in a semi-structured format using broad-based questions that allowed for a free range of response. My investigation was

intended to produce a general narrative of experiences rather than specific details about treatment of individuals with whom family members interacted. The general focus of this summary is on the response to experiences with mental health professionals that family members share. After data collection, organization, and analysis, the research questions are answered and five themes are derived from them.

In summary, most family members do not receive their initial information about mental illness, care and treatment, prognosis, medications, their roles as caregivers and members of the care and treatment system, or ongoing information in these areas from mental health professionals. They mostly receive their information from support groups or other family members and friends. Several family members state that their relationship with mental health professionals has changed for the better over the years, although when specifically asked how it has changed none of the participants were able to give concrete examples. Family members feel mental health professionals are excluding them from the planning and treatment process. Few mental health professionals have worked hard at including family members in the treatment process. Even with informed consent forms signed by the patient permitting family member involvement, many mental health professionals are still persistent about not including family members in the treatment process. Several family members have learned how to maneuver their way into mental health professionals' offices, and they have used many ways to get pertinent information to the professionals, such as faxing information, e-mailing, telephoning, and, of course, showing up at office doors. Family members believe if mental health professionals learn to respect the critical role that family members play when working with the mentally ill individuals and value with family members during the treatment process, this will help to improve the recovery process for the mentally ill individual.

## **Conclusions**

Because of the connection between mental illness and life experience, mental health professionals need to look beyond the individual patient to his or her family in the diagnostic and treatment processes. (Waggoner & Carek, 1964). Mental health professionals need to pay attention to the whole individual, which also includes the individual's family.

The family has a powerful influence on the individual patient. The family is a logical and accessible tool for gaining additional information about the patient beyond the clinic visit. The family can be helpful in two ways: first, they can provide a full and detailed picture of the individual that can help with diagnosis, and secondly, the family can be more than helpful with assisting with monitoring and supporting the treatment effort. In either situation, establishing a partnering relationship with family members is the cornerstone of successfully treating a person with mental illness. If mental health professionals can be successful in partnering with family members, the family members can be essential and powerful allies.

If the premise of partnering with family members is essential, this means mental health professionals need to be talking with family members more. It means the issue of confidentiality will need some careful consideration and perhaps need to be revisited at a higher legal level. And until that time, it means that family members and mental health professionals need to be working closely with the patient to gain the trust and understanding necessary for them to sign informed consent forms and be willing to have family members be an active participant in treatment. Family members need clear and consistent feedback so that they too are helping treatment, not hindering it because they do not have all the information.

Community-based care depends heavily on family members who look over the mentally ill individuals. Family members help with practical tasks of everyday life. Policies for health gain need to be knowledgeable about the significant role played by family members and to find ways of involving them more directly in health policy-making (Curtis & Taket, 1996).

Collaboration between family members and mental health professionals needs to consist of three key elements.

Respect: Mental health professionals must recognize and respect the pivotal role that families play in the lives of their mentally ill loved ones, and learn to value family member judgments and ensure that their efforts are supported. Professionals must develop more opportunities, both formal and informal, to learn about the perspectives of families and to work together with family members as equals at various levels of care. Mental health professionals also need to reinforce family strengths and make it possible to individualize care for each mentally ill adult and their family.

Logistics: Sometimes logistics such as travel, meeting times, and money affect the extent of commitment a family member can make to any task. The extent to which mental health professionals accommodate these issues will determine the role family members can play.

Sharing Information: The sharing of information between family members and professionals is integral to collaboration. In order to participate fully in the decision-making process, family members must have complete and ready access to information. This means they need information specific to their loved one, and also information about community resources, support groups, and treatment choices. Family members who are well informed about what is happening with their mentally ill loved one in treatment are better able to support the efforts assisting their mentally ill one in successfully living in the community. Family members will need more comprehensive and higher quality information and training to perform their role as a caregiver effectively. The amount and the nature of the information and training will depend on each situation and for each family member this information and training may need to take place often throughout the entire duration of care and treatment because the nature of the illness often changes.

## References

- Albrecht, K.A., & Zemke, R. (1985). *Service american: Doing business in the new economy*. New York: McGraw-Hill.
- Aviram, U. (1990). Community care of the seriously mentally ill: Continuing problems and current issues. *Community Mental Health Journal*, 26 (1), 69-87.
- Bachrach, L. (1981). Continuity of care for chronic mental patients. *American Journal of Psychiatry*, 138, 1449-1456.
- Bachrach, L. (1986). The challenge of service planning for the chronically mentally ill patient. *Community Mental Health Journal*, 22, 170-173.
- Backer, T.E. & Richardson, D. (1989). Building Bridges. *American Psychologist*, 44 (3), 546-549.
- Bernheim, K.F. (1989). Psychologists and Families of the Severely Mentally Ill. *American Psychologist*, 44 (3), 561-563.
- Biegel, D.E. Sales, E. & Schulz, R. (1991). *Family caregiving in chronic illness*. London: Sage.
- Blaikie, N. (2000). *Designing social research: The logic of anticipation*. London: Polity Press.
- Bloom, B.L. (1984). *Community Mental Health*. San Francisco: Brooks/Cole.
- Bonjean, C.M., Coleman, M.T., & Iscoe, I. (1989, September). Community care of the chronically mentally ill. In L. I. Stein (chair). *The community as the primary locus of care for persons with serious long-term mental illness*. Symposium conducted at the seminar of the Robert Lee Sutherland, Austin, Texas.
- Bourdon, K.H., Rae, D.S., Locke, B.Z., Narrow, W.E. & Regier., D.A. (1992). Estimating the prevalence of mental disorders in U.S. adults from the epidemiologic catchment area survey. *Public Health Reports*, 107(6), 663-668.
- CareNotes for Kids (2001). *Respect: Dare to care, share and be fair* [Brochure]. St. Meinrad: Abbey Press.
- Clifford, D., & Warner, R. (1987). *The partnership book*. (3<sup>rd</sup> ed.). Santa Cruz: Nolo Press.
- Collins, A.M., & Diego, L. (2000). Mental health promotion and protection. *Journal of Psychosocial Nursing*, 38, 27-32.



- Cook, J.A., & Wright, E.R. (1995). Medical sociology and the study of severe mental illness: Reflections on past accomplishments and directions for future research. *Journal of Health and Social Behavior*, 95-114.
- Connard, C., & Novick, R. (1996, February). The ecology of the family. A background paper for a family-centered approach to education and social service delivery. ED395373.
- Covey, S.R. (1989). *The 7 habits of highly effective people: Powerful lessons in personal change*. New York: Simon & Schuster.
- Creer, C., & Wing, J. (1974). *Schizophrenia at home*. London: Institute of Psychiatry.
- Creswell, J.W. (1994). *Research design: Qualitative & quantitative approaches*. Thousand Oaks: Sage.
- Creswell, J.W. (1998). *Qualitative inquiry and research design: Choosing among five traditions*. Thousand Oaks: Sage.
- Curtis, S., & Taket, A. (1996). *Health and Societies*. London: Arnold.
- Day, P. (1972). *Communication in Social Work*. New York: Pergamon Press.
- Denzin, N.K., & Lincoln, Y.S. (1998). *Handbook of Qualitative Research*. Thousand Oaks: Sage.
- Dincen, J., Selleck, V., & Streicker, S. (1978). Restructuring parental attitudes-working with parents of the adult mentally ill. *Schizophrenia Bulletin*, 4, 597-608.
- Doherty, W.J., & Baird, M.A. (1983). *Family therapy and family medicine: Toward the primary care of families*. New York: Guilford.
- Doll, W. (1976). Family coping with the mentally ill: An unanticipated problem of deinstitutionalization. *Hospital and Community Psychiatry*, 27, 183-195.
- Dunst, C., & Paget, K.D. (1991). Parent-professional partnerships and family empowerment. In M. Fine (Ed), *Collaborative involvement with parents of exceptional children* (pp. 25-44). Brandon: Clinical Psychology Publishing.
- Dunst, C. J., Trivette, C.M., & Deal, A.G. (1994). *Supporting and Strengthening Families*. Boston: Brookline Books.
- Falloon, I.R.H., & Fadden, G. (1993). *Integrated Mental Health Care*. Cambridge: Cambridge University Press.

- Friesen, B. J. (1993). As cited in Singer, G.H.S. & Powers, L. E. (1993). *Families, Disability, and Empowerment: Active coping skills and strategies for family intervention*. Baltimore: Paul H. Brookes.
- Friesen, B.J., & Osher, T.W. (1996). Involving families in change: Challenges and opportunities. *Special Services in the Schools 11,1/2*, 187-207.
- Gallagher, B.J., III. (1995). *The sociology of mental illness*. Upper Saddle River: Prentice Hall.
- Gasching, M., Vohs, J., & Weaver, P. (1995). Family/professional collaboration: Strategies for empowerment. *Focal Point, 9,1*, 11-12.
- Gergen, K.E. (1985). *The social construction of the person*. New York: Springer-Verlag.
- Goldman, H. (1982). Mental illness and family burden: a public health perspective. *Hospital and Community Psychiatry, 33*, 557-560.
- Goldman, H.H., & Gatozzi, A.A. (1981). Defining and counting the chronically mentally ill. *Hospital and Community Psychiatry, 32*, 21-27.
- Goldman, H., & Taube, C. (1989). State strategies to restructure psychiatric hospitals: A selective review. *Inquiry, 26*, 146-157.
- Guba, E.G. (1990). *The paradigm dialog*. Newbury Park: Sage.
- Gupta, G.R. (1993). *Sociology of mental illness*. Boston: Allyn and Bacon.
- Harrison, H. (1993). The principles for family-centered neonatal care. *Pediatrics, 92, 5*, 643-649.
- Hatfield, A. B. (1979). The Family as Partner in the Treatment of Mental Illness. *Hospital and Community, 30 (5)*, 338-340.
- Hatfield, A.B. (1987). *Families of the mentally ill: Meeting the challenges*. San Francisco: Jossey-Bass.
- Hatfield, A.B. & Lefley, H. P. (1987). *Families of the mentally ill: Coping and adaptation*. New York: Guilford.
- Hersey, P., & Blanchard, K.H., (1988). *Management of Organizational Behavior (5<sup>th</sup> ed.)*. Englewood Cliffs: Prentice-Hall.
- Hoffman, L. (1993). *Exhanging voices: A collaborative approach to family therapy*. London: Karnac Books.

- Holden, D.F., & Lewine, R.J. (1982). How families evaluate mental health professionals, resources, and effects of illness. *Schizophrenia Bulletin*, 8, 626-633.
- Holloway, I. (1997). *Basics Concepts for Qualitative Research*. Malden: Blackwell Science.
- Horwitz, A.V., & Scheid, T.L. (1999). *A handbook for the study of mental health: Social context, theories, and systems*. New York: Cambridge University Press.
- Johnson, D.L. (1985). Citizens' experiences with the mental health system. *Citizens Alliance for the Mentally Ill Newsletter*, 3(2), 2-3.
- Johnson, B.H. (2000). Family-centered care: Four decades of progress. *Families, Systems & Health*, 18, 2, 137-156.
- Johnson, B.H., Jeppson, E.S., & Redburn, L. (1992). *Caring for children and families: Guidelines for hospitals*. Baltimore: Association for the Care of Children's Health.
- Kessler, R.C., McGonagle, K.A., Zhao, S., Nelson, C.B., Hughes, M., Eshleman, M., Wittchen, H.U., & Kendler, K. (1994). Lifetime and 12-month prevalence of DSM-III-R psychiatric disorder in the United States. *Arch Gen Psychiatry*, 51, 8-19.
- Lamb, R., & Oliphant, E. (1978). Schizophrenia through the eyes of families. *Hospital and Community Psychiatry*, 29, 803-805.
- Lash, M. (1991). Social and emotional supports for children with disabilities and their families. *Focal Point*, 5, (1), 1-12.
- Levine, I.S., & Spaniol, L. (1985). The role of families of the severely mentally ill in the development of community support services. *Psychosocial Rehabilitation Journal*, 8, 83-94.
- Lincoln, Y.S., & Guba, E.G. (1998). *Naturalistic inquiry*. Thousand Oaks: Sage.
- Litman, T.J. (1974). The family as a basic unit in health and medical care: A social-behavioral overview. *Social Science and Medicine*, 8, 495-519.
- Marsh, D.T. (1992). *Families and Mental Illness: New Directions in Professional Practice*. New York: Praeger.
- Mechanic, D., & Aiken, L.H. (1987). Improving the care of patients with chronic mental illness. *The New England Journal of Medicine*.

- Merriam, S.B. (1998). *Qualitative research and case study applications in education* (2<sup>nd</sup> ed.). San Francisco: Jossey Bass.
- Minkler, M. (1999). *Community Organizing and Community Building for Health*. New Brunswick: Rutgers University Press.
- Morris, W. (1981). *The American heritage dictionary of the English language*. Atlanta: Houghton Mifflin.
- Murphy, J.W., & Callaghan, K.A. (1988). Systems theory and the family: a critique. *Early Childhood Development and Care*, 39,163-176. Princeton: Carnegie Foundation.
- National Alliance for the Mentally Ill. (2002). [www.nami.org](http://www.nami.org).
- National Institute of Mental Health, Impact of Mental Illness on Society. NIH Publication No. 01-4586, [www.nimh.gov](http://www.nimh.gov).
- Office of the U.S. surgeon general. *Mental Health: A Report of the Surgeon General-Executive Summary*. [www.surgeongeneral.gov](http://www.surgeongeneral.gov).
- Patterson, J. (1991). Family resilience to the challenge of a child's disability. *Pediatric Annals*, 20(9), 491-500.
- Patton, M.Q. (1990). *Qualitative evaluation and research methods*. Thousand Oaks: Sage.
- Prelock, P., Beatson, J., Contompasis, S.H., & Bishop, K.K. (1999). A model for family-centered interdisciplinary practice in the community. *Topics in language disorders*, 19,3, 36-51.
- Rappaport, J. (1981). In praise of paradox: A social policy of empowerment over prevention. *American Journal of Community Psychology*, 9, 1-25.
- Read Together Booklet Series. (2001). *Respect: Dare to care, share, and be fair*. [Brochure]. St. Meinrad: Abbey Press.
- Robins, L.N., & Regier, D.A (1991). *Psychiatric disorders in America: The Epidemiologic Catchment Area Study*. New York: The Free Press.
- Sandelowski, M., & Barrolso, J. (2002), Third Quarter). Finding the findings in qualitative studies. *Journal of Nursing Scholarship*, 34, 213-219.
- Sawa, R.J. (1992). *Family Health Care*. London: Sage.

- Sawa, R.J., Henderson, E.A., Pablo, R.Y., & Falk, W.A. (1985). Family practice impact of a teaching curriculum in family dynamics. *Family Systems Medicine*, 3, 50-59.
- Singer, G.H.S. & Powers, L. E. (1993). *Families, Disability, and Empowerment: Active coping skills and strategies for family intervention*. Baltimore: Paul H. Brookes.
- Singer, G.H.S., Powers, L.E., & Olson, A.L. (1996). *Redefining family support: Innovation in Public-private partnerships*. Baltimore: Paul H. Brookes.
- Spaniol, L., Zipple, A., & FitzGerald, S. (1984). How Families Can Share Power with Families: Practical Approaches to Working with Families of the Mentally Ill. *Psychosocial Rehabilitation Journal*, 8(2), 77-83.
- Sprenkle, D.H., & Moon, S.M. (Eds) (1996). *Research Methods in Family Therapy*. New York: Guilford Press.
- Stewart, R.P. (1984). Building an alliance between the family and the institution. *Social Work*, 29, 386-390.
- Tausig, M., Michello, J., & Subedi, S. (1999). *Sociology of Mental Illness*. Upper Saddle River: Prentice Hall.
- Torrey, E.F. (1986). Continuous treatment in the care of the chronically mentally ill. *Hospital and Community Psychiatry*, 37, 1243-1247.
- Turnbull, A.P., & Turnbull, H.R. (1986). *Families, professionals, and exceptionality: A special partnership*. Ohio: Charles E. Merrill.
- U.S. Department of Health and Human Services (1999). *Mental Health: A Report of the Surgeon General-Executive Summary*. Rockville, MD: U.S. Department of Health and Human Services, Substance Abuse and Mental Health Services Administration, Center for Mental Health Services, National Institutes of Mental Health.
- Waggoner, R.W., & Carek, D.J. (1964). *Communication in clinical practice*. Boston: Little, Brown and Company.
- Walker, B., & Singer, G.H.S. (1993). Improving collaborative communication between professionals and parents, In *Families, Disability, and Empowerment*, Singer, G.H.S., & Powers, L.E. (Eds.). Baltimore: Paul H. Brookes
- Wang, P.S., Demler, O., & Kessler, R.C. (2002). Adequacy of treatment for serious mental illness in the United States. *American Journal of Public Health*, 92(1), 92-98.

Wasow, M., & Wikler, L. (1983). Reflections on professionals' attitudes toward the severely mentally retarded and the chronically mentally ill: Implications for parents. *Family Therapy*, 10 (3), 299-307.

Weick, A., & Saleebey, D. (1995). Supporting family strengths: Orienting policy and practice toward the 21<sup>st</sup> century. *Families in Society: The Journal of Contemporary Human Services*, 76, 141-149.

## APPENDIX A

### **PARTICIPATION AGREEMENT/CONSENT FORM**

I agree to participate in a research study conducted by Suellen Evavold through the Graduate School of Virginia Tech, Blacksburg, Virginia, College of Architecture and Urban Studies. The purpose of this study is to understand the experiences of family members who have a mentally ill relative, have had with mental health professionals. This study will report the stories told by family members of mentally ill loved ones who are currently receiving mental health services. This study will involve seven other family members.

The procedures to be used in this research are in-depth interviews. The time and conditions required to participate in this project will be scheduled at a time and place convenient for me and the researcher. I understand that any possible risks or discomfort to me as a participant will be minimal. If needed, the researcher will provide a telephone number of a local mental health agency that may be able to assist with counseling services.

My participation in this research project will be to provide information regarding the experiences with mental health professionals. I understand that there will be no stipend offered for this interview.

The information I provide will have my name removed and only a subject number or pseudonym will identify me during analyses and any written reports of the research. A professional transcriber will transcribe audiotapes used in the data collection for this study. Only Suellen Evavold, and a committee member who is a qualitative methods expert will only review the transcribed interviews. All tapes, transcripts, and written memos and field notes after the completion of Suellen Evavold's dissertation will be kept in a locked safe for a period not to exceed two years. After a period of two years all tapes, transcripts and written memos and field notes will be destroyed.

I understand that I am participating in this study voluntarily, and I am free to withdraw from this study at any time without penalty.

This research project has been approved, as required, by the Institutional Review Board for projects involving human subjects at Virginia Polytechnic Institute and State University and by the College of Architecture and Urban Studies Doctoral Program in Environmental Design and Planning.

I grant permission for any data collected to be used in the process of completing a Ph.D. degree, including a dissertation and any other future publications.

I agree to meet at the following location on the following date \_\_\_\_\_ for an interview of two hours, and participate, if needed for purposes of clarification or gather more information, in a follow-up one-hour telephone interview. I also understand that it is my responsibility to call and reschedule an interview if I need to have it postponed.

I have read and understand the informed consent and conditions of this project. I have had all my questions answered. I hereby acknowledge the above and give my voluntary consent for participation in this project.

Should a reason arise which would prohibit my participation in this project, I understand that it is my responsibility to inform the researcher as soon as possible. I agree to abide by the rules of this project.

Participant's Signature \_\_\_\_\_ Date \_\_\_\_\_

Participant's Signature \_\_\_\_\_ Date \_\_\_\_\_

Should I have any questions about this research I will contact:

Dr. Carol Bailey  
Committee Member

(540) 231-2247

Dr. James Bohland  
Committee Chair

(540) 231-5517

Dr. JoAnn Carmin  
Committee Chair

(540) 231-5426



## APPENDIX B

### INTERVIEW GUIDE

- How long have you been working with a mental health professional?
- Thinking back to when your son, daughter etc. initially entered into the mental health system, what did that process look like for you?
- Were you able to get your (son/daughter) in for an assessment in a timely fashion? Were you asked to be part of the initial assessment?
- Once you were at the appointment were you as a family member allowed in the initial assessment?
- Was the invitation to sit in on the appointment initiated by you or by a staff member?
- Were you asked about your thoughts and observations during the assessment?
- Were you given information about (name of mentally ill person) illness?
- What has been the most effective way to find out about \_\_\_\_ illness, treatment etc.?
- Did the mental health professional help you to understand what was going on?
- Were you given advice on how to cope with \_\_\_\_ illness?
- Have you attended any workshops/groups on how to help you cope at home with \_\_\_\_ illness?
- Were you given information about \_\_\_\_ treatment program?
- Have you been kept apprised of on-going treatment procedures?
- What are your feelings regarding the information you have received?
- What information do you need more/less of? (such as, diagnoses, medication information, side effects of medication, social events, vocational events)

- How involved are you **today** in the care and treatment of \_\_\_\_\_?  
*If not involved:* What attempts have you made to be part of that care and treatment?
- What opportunities have you been **offered** for involvement in \_\_\_\_\_ treatment?
- What opportunities have you taken part in?
- Of the opportunities that you have taken part in, what do you think has been the most helpful in dealing with \_\_\_\_\_ illness?
- How involved in the care and treatment of your son/daughter do you want to be?
- Are you invited to treatment planning meetings?
- If you are unable to attend a meeting, how is the information passed on to you? Is it given to you directly from a mental health professional, or from your loved one?
- What arrangements are made for maintaining communication and contact between you and the mental health provider?
- Are workers and doctors accessible for you? (After hour availability, returning calls)
- How often do you have contact with a mental health professional?
- Is it enough contact?
- How have mental health professionals supported you and your needs in caring for your loved one? (Such as: provided you information on social outlets for yourself, support groups, provided respite and crisis services, provided information on possible financial assistance.)
- What would be adequate support for you as a family member?
- Are there times when you need more support than others? When would those times be?
- What, if anything, would have been more helpful had you known about it earlier?

- How would you like the mental health professionals to include you?
- What is your opinion about services provided?
- Are they easy to access?
- Can you access them without a mental health professional?
- Are you able to find your way around the “system” easily?

## APPENDIX C

### **Definition of Terms**

**Caretaker:** A caretaker is defined as a person employed to look after or to take charge of goods, property, or a person: custodian. (Morris, 1981).

**Family Member:** A family member is defined as a parent, grandparent, spouse, sibling, child, aunt, uncle, niece, nephew, or cousin who provides the primary care and support to the mentally ill person.

**Mental Health Professionals:** These are the individuals who are involved in the treatment of people with a mental illness and include social workers, psychiatrists, counselors, psychologists, human services assistants, and day treatment providers.

**Mental Illness:** Mental illness is any disorder of the brain that disrupts a person's thinking, feeling, moods, and ability to relate to others.

**National Alliance for the Mentally Ill (NAMI)** is a nonprofit, grassroots, self-help, support and advocacy organization of consumers, families, and friends of people with severe mental illnesses, such as schizophrenia, major depression, bipolar disorder, obsessive-compulsive disorder, and anxiety disorders (National Alliance for the Mentally Ill, 2002, Introduction ¶ 1).

## **Suellen A. Evavold**

511 Houston Street · Blacksburg, Virginia 24060  
(540) 449-9294 · Suelar1011@AOL.com

### **EDUCATION/LICENSURE**

Ph.D., Virginia Tech, Health Policy, 2003  
M.S., Virginia Tech, Health Promotion, 2000  
BSW, University of Wisconsin-Eau Claire, 1988  
Licensure: Licensed Social Worker (Wisconsin)  
Certification: Human Subjects in Research  
Continued Professional Development: Grant Writing, Ethics & Boundaries

### **PROFESSIONAL STRENGTHS**

- Exceptional interpersonal skills: communicate and interact effectively with individuals and groups representing diverse ages, capabilities, cultures and socioeconomic backgrounds.
- Versatile experience in health/human services, interagency and multidisciplinary team collaboration, program and process evaluation, case management, assessment, plan development, documentation.
- Experienced in collaborating and implementing new positions.
- Solid foundation in SPSS, Internet research, MS Word, Power Point, Excel.
- Recommendation/Evaluations cite: “impeccable organizational skills,” “excellent communication skills,” “great deal of enthusiasm,” “team player and creative problem-solver,” “remains positive in stressful environment,” “well respected in Mental health, Social Services, and Medical community.”

### **PUBLICATIONS/PRESENTATIONS**

*Tell-A-Friend: Final Evaluation Report.* Baffi, C., Evavold, S., & Perry, T., (July 2001). American Cancer Society: Mid-Atlantic Division.  
*Reach-to-Recovery: Final Report.* Baffi, C., Evavold, S., Peek, A. (July 2000). American Cancer Society: Mid-Atlantic Division.  
Poster Presentation, Collaborative Evaluation Fellow Project (CEFP), American Cancer Society, National Conference, Atlanta, GA, 2001  
Presenter, Program Evaluation Results: (Reach-to-Recovery Program, 2000, Tell-A-Friend, 2001) CEFP, American Cancer Society Advisory Board, Roanoke, VA

## EXPERIENCE

**Evaluation Fellow:** American Cancer Society (ACS), Roanoke, VA, 2000/2001

**Process Evaluation:** Tell-A-Friend program, Southwest Virginia, Washington DC, and Maryland

**Program Evaluation:** Reach to Recovery program, Southwest Virginia  
Excellent hands-on experience in program and process evaluation utilizing accepted methods of research and data collection (surveys, focus groups, telephone interviews), data analysis and reporting of research findings (including narrative reports, tables, graphs).

**Licensed Social Worker:** Department of Human Services, Eau Claire, WI, 1990-1999

### **Welfare-to-Work Unit (W-2)**

First clinician hired by the County in the first state to implement W-2 program. As program's only LSW, held full responsibility for case assessment, treatment plan development/implementation, client/family education, employment assistance, and ongoing counseling and support services, 1997-99.

### **Health Communities 2000 Initiative**

Participated in state-funded program to evaluate quality of health for various demographic groups; focused on Quality of Parenting Issues, analyzed local data and national programs; developed comprehensive Action Plan to address issues/solutions, 1997.

### **Intensive Case Management Unit**

Held full case management responsibilities for heavy caseload; provided one-on-one support services to mentally ill adult clients (including DD, LD, AODA). Spearheaded 'School-to-Work' Program for at-risk high school students. Served on Placement Review Committee. Co-initiated and co-facilitated support groups for mentally ill sexual abuse survivors. Member of department's Audit Team of internal audit of case files. Co-supervised Social Worker intern, 1994-97.

### **Family Services Unit**

Provided one-on-one support and counseling in cases of juvenile delinquency, child neglect/abuse, and other parent/child conflicts, 1993-94.

### **Community Support Unit**

Assessed mentally ill clients' needs as a member of an interdisciplinary team. Developed and implemented intensive treatment plans, including medication compliance, community services resources, and intensive one-on-one counseling/support. Provided on-site, in-home, and workplace support. Developed/implemented after-work basketball program for clients, 1992-93.