

THE IMPLEMENTATION OF A FAMILY EDUCATION PROGRAM  
BY THE BRITISH COLUMBIA SCHIZOPHRENIA SOCIETY

by

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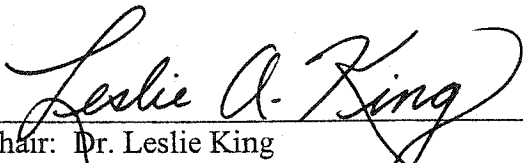
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## Abstract

The thesis describes the formative, improvement-focused evaluation of the implementation of the National Alliance for the Mentally Ill Family-to-Family education program by members of the British Columbia Schizophrenia Society. Using a case study approach, this thesis analyzes the Family-to-Family education program materials and archives, key informant interviews, and content of the records of the British Columbia Schizophrenia Society Regional coordinator in northwest British Columbia. The data collected was used to evaluate the implementation of the Family-to-Family education program. From the analysis, actions were recommended to improve the implementation of the program as follows:

- to clearly state the goals, philosophy, and outcomes of the Family-to-Family education program in the introductory chapter of the program
- to develop more strategies for educators working in remote areas
- to use the profile developed in this thesis for the recruitment of volunteer family educators
- to use the recommended Implementation Fidelity Index developed in this thesis
- to use the recommended Augmentation Index developed in this thesis
- to thoroughly plan the implementation of all new programs
- to use the Checklist for Program Approval for the British Columbia Schizophrenia Society Board of Directors and staff. developed in this thesis
- to ensure that the Family-to-Family education program be funded as a core program by the Northwest Community Services Society
- to develop a “made in Canada” family education program
- to explore the needs of family members of First Nations ancestry
- to create a professional milieu of acceptance of appropriate family involvement in the lives of individuals with a mental illness by incorporating family involvement into the job descriptions of community and hospital based mental health employees.

## TABLE OF CONTENTS

ABSTRACT		ii
TABLE OF CONTENTS		iii
LIST OF TABLES		vi
LIST OF FIGURES		vii
ACKNOWLEDGEMENTS		viii
 Chapter One	Introduction	 1
Chapter Two	Mental Health System In British Columbia	9
	Definitions of Mental Illness	9
	The Mental Health System	11
	Role of BCSS in the Mental Health System	12
	Role of Family in the Mental Health System	17
Chapter Three	Literature Reviews	20
	Voluntary Organizations and Their Role in Health Service Delivery	20
	Family Education	23
	Relapse Prevention as an Outcome of Psychoeducation	41
	Other Outcomes of Family Education	42
	Review of Research on Families of Psychiatric Patients	43
	Families not in Contact with Their Relative with a Mental Illness	44
	Cultural Perspectives in Mental Illness	44
	Factors Affecting Program Implementation in Health Education Programs	46
	Evaluation of Program Implementation	52
	Implementation Issues	52
Chapter Four	Family-To-Family Education Program	70
	Description of the <u>Family-to-Family</u> Education Program	74
	Outcomes of the <u>Family-to-Family</u> Education Program	79
	Program Selection and Early Implementation of the <u>Family-to-Family</u> Education Program	81
	Phase I of the <u>Family-to-Family</u> Education Program	82
	Phase II of the <u>Family-to-Family</u> Education Program	85

	Program Management Mechanisms	88
Chapter Five	Methodology	92
	Analysis Plan	97
Chapter Six	Implementation	98
	Plan for Implementation of the <u>Family-to-Family</u>	
	Education Program in British Columbia	98
	Facilitators of the Program Implementation in	
	Northwest BC	105
	Community Outreach Strategy	105
	Pre-Course Family Visit Strategy	107
	Program Content	108
	Barriers to the Program Implementation in Northwest	
	BC	109
	Systemic Misunderstanding of the Program	109
	Funding Barriers	111
	Volunteer Burnout	112
	Complexity of the Language of the Program	113
	Geographical Isolation and Distances to Travel	114
Chapter Seven	Participants and Non-Participants	115
	Trained Family Educator Participants	115
	The Need for Mentorship	116
	Training more Volunteers	117
	Support Group Facilitator Training	117
	Education Program Participants	118
	Non-Participants	122
Chapter Eight	Analysis	125
	Discussion of Implementation	125
	Augmentation of the <u>Family-to-Family</u> Education	
	Program	126
	Unplanned Effects from the Delivery of the	
	Program	129
	Gaining Acceptance	131
	Task Specification and Resource Estimation	133
	Project Management Mechanism	134
Chapter Nine	Recommendations	136
	General Recommendations	136
	Recommendations to the <u>Family-to-Family</u> Program	
	Developers	137
	Recommendations to the BC Implementors	144
	Recommendations to the Implementors in Northwest	
	BC	144

	Recommendations to the Board of Directors of BCSS	145
	Recommendations to Northwest Community Health Services Society	147
Chapter Ten	Conclusions	149
	Future Research	150
	Conclusions	152
Bibliography		156

## LIST OF TABLES

<b>Table 2.1:</b>	Brochures, Fact Sheets, and Videos Produced by BCSS	15
<b>Table 3.1:</b>	Literature Review of Family Education and Psychosocial Needs	26, 27
<b>Table 3.2:</b>	Ranking of Symptoms Causing Family Burden as Perceived by Family Members of Individuals with Bipolar Disorder and by Professionals	35
<b>Table 3.3:</b>	Ranking of Symptoms Causing Family Burden as Perceived by Family Members of Individuals with Schizophrenia and by Professionals	36
<b>Table 3.4:</b>	Literature Review for Program Implementation	53, 54
<b>Table 4.1:</b>	Education Courses Available for Consumers and/or Family Members	71
<b>Table 4.2:</b>	Elements in the Nuts and Bolt Chapter	84
<b>Table 4.3:</b>	<u>Family-to-Family</u> Education Program Content	86
<b>Table 4.4:</b>	<u>Family-to-Family</u> Program Principles of Support	87
<b>Table 8.1:</b>	BCSS Fact Sheets added to the <u>Family-to-Family</u> Education Program	128



## LIST OF FIGURES

<b>Figure 2.1:</b>	Services Consumed by and Community and Social Interactions of Individuals with Mental Illness	10
<b>Figure 3.1:</b>	A Community Development Health Planning Model	48
<b>Figure 6.1:</b>	Time Line for the Implementation of the <u>Family-to-Family</u> Education Program Phases 1, and 2	102-4
<b>Figure 9.1:</b>	Profile of a Voluntary Family Educator	139
<b>Figure 9.2:</b>	Implementation Fidelity Checklist for the <u>Family-to-Family</u> Education Program	142
<b>Figure 9.3:</b>	Augmentation Index for the <u>Family-to-Family</u> Education Program	143
<b>Figure 9.4:</b>	Checklist for Approval of Programs	146

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## Chapter 1     Introduction

Serious, disabling psychiatric illnesses pose complex and diverse challenges for the health care system, health care providers, voluntary health organizations, the individuals with these illnesses, and their families. One of the more common and most disabling of these afore-mentioned conditions is schizophrenia, a complex disorder involving disturbances of thought and language, emotion and behaviour (American Psychiatric Association, 1994). The lifetime prevalence of schizophrenia is 1% of the population (Youth's Greatest Disabler, 1999). Many of the symptoms of schizophrenia can be controlled with medication, but patients are often left with considerable residual disability, which requires ongoing support from mental health system, family, and society at large.

As with other health conditions, the problems associated with schizophrenia have given rise to voluntary organizations whose mandates encompass various aspects of this disorder, including advocacy and fund raising for the purposes of research and easing the burden of the disorder. As families are both affected by and play a prominent role in providing support for the affected individual, the provision of services for families appropriate to the role of voluntary organization, is an important function for these organizations.

This thesis deals with the implementation by the British Columbia Schizophrenia Society (BCSS) of an education program for families of patients with schizophrenia and other significant psychiatric illnesses. The Family-to-Family education program (formerly

called the Journey of Hope) encompasses the philosophy of family empowerment through self-education by improving knowledge, skills, comprehension, and support (Burland, 1998, undated). The program has three goals. The first goal is to empower families through self-education (Burland, 1998, undated). The second goal is to prevent traumatic impact of mental illness in their family from further undermining family members' stability and compromising their effectiveness as long term caregivers (Burland, 1998, undated). The third goal is to promote personal healing and restoration (Burland, 1998, undated). This thesis follows the introduction and implementation of the Family-to-Family education program in British Columbia over a period stretching from 1993 to June, 1999. The process of advocacy, adoption, and implementation of this program appeared to provide an opportunity to explore some of the important forces that affected the adoption of the program by BCSS.

A specific focus of this thesis is the implementation of the program in northern British Columbia. Implementation of a program in a geographic locale characterized by sparse population, great distances between small communities, cultural diversity, and extreme climatic conditions raises special challenges that may provide insight into ways to improve the program or affect organizational policy. As the author of the thesis was responsible for implementation of the program in northwest BC, the opportunity to undertake a case study of this nature appeared to be providential.

Health care in Canada is provided by a mix of publicly administered and funded, and non-profit community based voluntary organizations. The delivery of specialized

health care programs by non-profit voluntary agencies is often done in partnership with the formal or government funded health care system. Usually the specialized service programs delivered by these voluntary organizations supplement services provided by the formal health care system through provision of extra services. The focus of the non-governmental organizations is directed towards service delivery to groups affected by a specific disease, health condition or cluster of conditions.

Volunteer organizations face considerable challenges when implementing programs in rural and remote areas in Canada. The significance of looking at the experience of BCSS with the Family-to-Family education program is reinforced by the findings of the Report of the Northern and Rural Task Force, a body set up in 1994 by the BC Ministry of Health to “determine the health needs of residents of remote and rural communities and identify creative and feasible ways to address those needs”(1995, p.3). The report outlines the characteristics often found in rural and remote communities in British Columbia that affect the delivery of programs in these areas:

- small population centres distributed over large areas
- a single resource base with marked vulnerability to changes in the economy
- relatively large distances between small communities and larger centres of population
- geography and climate are a strong influence on daily life
- there are large and growing aboriginal populations, often actively engaged in treaty negotiations
- predominantly young populations
- significantly increasing numbers of elderly residents who are no longer able to or interested in retiring in southern urban areas
- difficulty in gaining access to health, education and social services based in urban centres
- lower [than] average levels of schooling
- limited pools of people for leadership positions
- a practice of competing with other rural communities for scarce resources - to the detriment of regional planning (1995, pp. 7-8)

Many voluntary organizations include family members as their primary focus or part of their focus for education. The BCSS is consistent with this trend in providing services to family members of individuals with schizophrenia and other related illnesses (BCSS Minutes of Board Meeting, Jan. 1999). As resources for health care diminish, families become primary caregivers for people suffering from many specific diseases or disorders. Schizophrenia appears to be a particularly clear example of this trend. As primary caregivers, families face the task of providing supervision of medications, monitoring of the patient's recovery, physical and psychosocial care, and financial support. These responsibilities create family needs that have resulted in the development of education programs that teach families to be part of the treatment team.

Within the field of mental health service provision, education and intervention provided to families of individuals with mental illness and the individual consumer are referred to as bio-psycho-social education (van der Leer, 1998). It is the specific nature of mental illness that contributes to the need for family education. The mentally ill family member requires a carefully planned, safe social and physical environment that provides a milieu for the recovery and the management of the individual's social and physical impairment caused by brain disorders. Family members need to be knowledgeable about the illness and how to care for their relative. Due to the social stigma associated with mental illness, families with mentally ill relatives face great challenges as shown in the family education literature review section in chapter 3. Included among these challenges are the following. There is a tendency of society to blame individuals with a mental illness and their families for the illness. This is referred to as the 'Blame and Shame' syndrome

(Youth's Greatest Disabler, 1999). Families and patients have to overcome the societal view that mental illness is "...caused by childhood trauma, bad parenting, or poverty or the result of any action or personal failure by the individual" (Youth's Greatest Disabler, 1999). Thus, families need support in order to deal with the stigma.

The onset of schizophrenia most frequently occurs between the ages of 16 and 25, when parents are often ready to let go of their responsibilities to their children. Thus, parents may feel burdened by the obligation of providing care to a teenager or an adult (Caldwell-Smith, 1990). Mental illness tends to be episodic in nature and these episodes create added stress for the families involved (Torrey, 1995). Relatives with mental illness are either treated on an out-patient basis through a mental health clinic and/or psychiatrist or released from the hospital still suffering from non-acute but still 'florid' symptoms (Burland, 1998). The family member with mental illness may show arrested development based on the age of onset of the disease. Therefore, the individual may not follow the "normal" life path of establishing relationships and entering the work force (Burland, 1998). Often people with mental illness use negative coping strategies to face their illness. This maladaptive behaviour is often directed against their families and members of the general public. This in turn causes a backlash against the individual and their families (Burland, 1998). Diagnosis of mental illness is challenging. Often patients and families live for extended periods of time without an accurate diagnosis and hence without a treatment plan (Torrey, 1995). For all these reasons it is apparent that families of individuals with severe and persistent mental illness need training to contend with the impact of mental illness on their lives and the affected individual's life.

The Family-to-Family education program was developed to fill the need to assist families to become better informed about the illness (Burland, undated). It was targeted to families and friends of individuals with schizophrenia, bipolar disorder, depressive disorder, panic disorder, and obsessive-compulsive disorder (Burland, 1998). The Family-to-Family education program has two phases. The first phase is the training of the volunteer family educators and the delivery of a twelve-session bio-psycho-social education program (Burland, 1998). The second is a family support group facilitator training and support group delivery program. This program uses trained volunteers who are also family members with parallel experience rather than professional health care workers. These family members can provide experiential knowledge that usually is not provided by professionals.

This thesis describes the implementation of the Family-to-Family education program by one member and one staff member of the BCSS. In addition, implementation issues particularly focusing in remote and rural regions are described. The rationale behind exploring the implementation of the Family-to-Family education program is to perform a formative evaluation of the program implementation, and to explore how innovation in a non-governmental health care organization can occur. This evaluation will concentrate on the facilitators of and barriers to implementation process. This topic was chosen because the researcher was the Northwest BC Regional Coordinator for the BCSS charged with the task to implement the Family-to-Family education program. Thus, the researcher is an active participant and bias is an issue which must be addressed.



This case study thesis will first approach the subject by describing the context in which the implementation of the program took place. It encompassed the following:

- an overview of the mental health system in British Columbia
- a literature review of some voluntary organizations that provide family education and support
- a literature review on the family educational and psycho-social needs
- a literature review on program implementation
- a description of the role of the BCSS in the Mental Health System
- a description of the role of the family in the Mental Health System

In the next section the Family-to-Family education program and its implementation is described. This process of describing the implementation proved to be complex because of the various levels of policy and decision making that took place within the structure of a provincial voluntary organization. A significant factor that added to the complexity of studying the program was the interpersonal relationships of volunteers within the organization.

After the describing the program and its implementation, this study will evaluate the implementation of the program in northwest British Columbia by examining:

- the Family-to-Family education program
- the implementation of the program in British Columbia

- the characteristics of the facilitators of and barriers to implementation that were encountered by the Northwest BC Regional BCSS Coordinator
- the solutions found to overcome the barriers to implementation
- the characteristics of the participants
- the characteristics of the non-participants.

Next, this thesis will answer the analysis questions generated from the literature search.

The conclusion will summarize the improvement-focused recommendations targeted to the program developers, program implementors, British Columbia Schizophrenia Society, and the Mental Health System in northwest British Columbia.

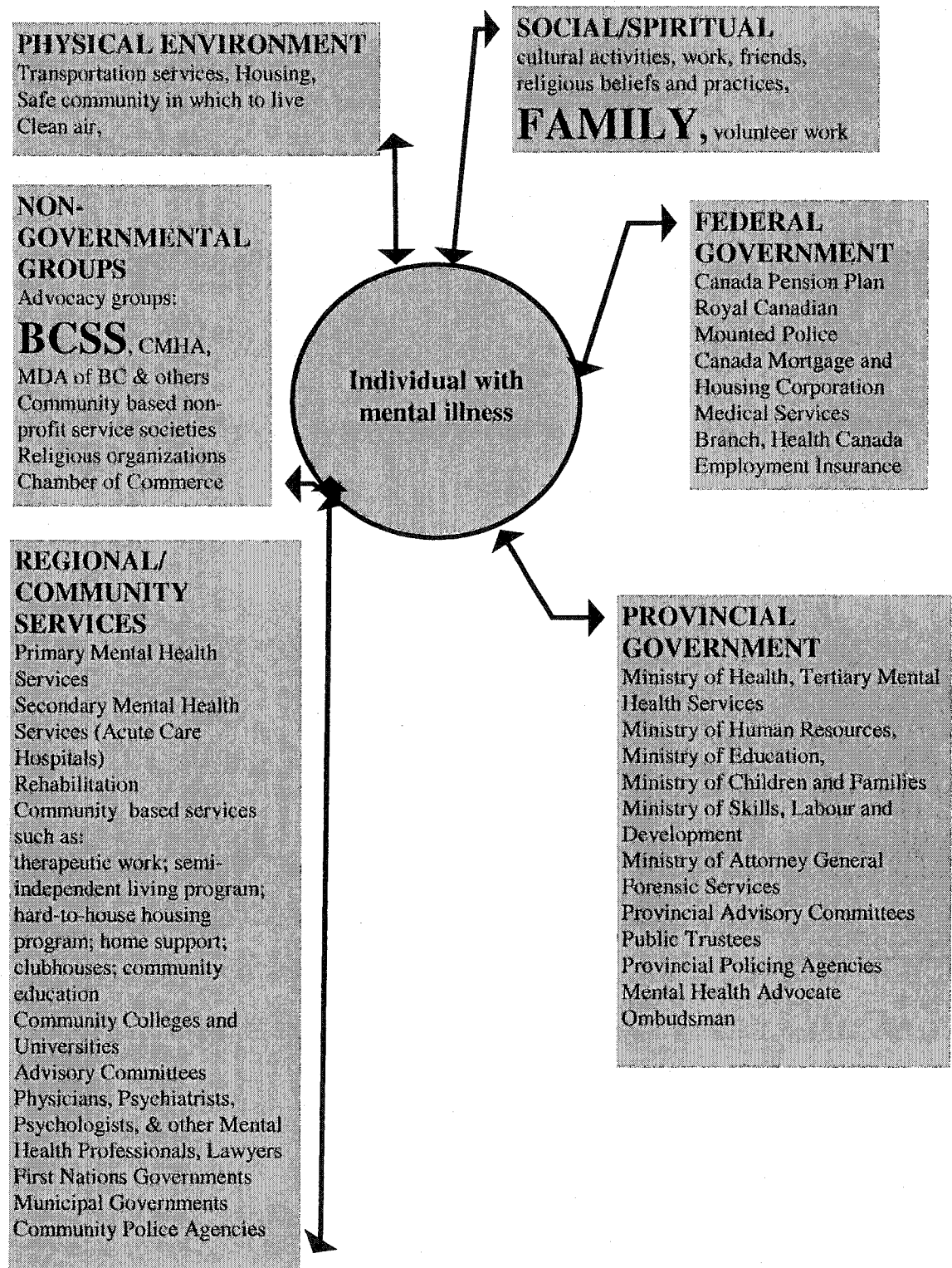
## Chapter 2 Description of the Mental Health System in British Columbia

The Family-to-Family education program was implemented by BCSS within the broader context of province's overall system of mental health service provision. Understanding that context is crucial for interpreting many features of the program and its implementation. Consequently, this chapter describes the provincial mental health system focusing on the characteristics of mental illness, governmental and non-governmental systems that provide services, the roles of BCSS in the mental health system, and the roles of the family in the mental health system. A systems summary is warranted because the Family-to-Family education program is delivered outside the formal health care system but within the informal mental health system.

### Definition of Mental Illness

Various definitions of mental illness can be found in the literature. In 1993 the National Advisory Mental Health Committee in the United States defined severe mental illness "as including disorders such as schizophrenia, schizo-affective disorder, manic-depressive disorder, autism as well as severe forms of other disorders such as major depression, panic disorder and obsessive compulsive disorder" (cited in Torrey, 1997, p. 4). The Riverview Hospital Replacement Project: North Project Planning Stage Functional Program defined severe mental illness as "a clinically significant behavioural or psychological syndrome or pattern that occurs in an individual and that is typically

**Figure 2.1 Services Consumed by, and Community and Social Interactions of  
Individuals with Mental Illness**



associated with either a painful symptom or impairment in one or more important areas” (HPG, 1997, p. A-7). The Mental Illness and Violence Report defined severe mental illness as “including conditions such as schizophrenia, major depressive illnesses, substance abuse disorders and personality disorders” (Arboleda-Florez et al., 1996, p.2). Burland defined mental illness as including disorders such as “schizophrenia, schizoaffective disorder, bipolar disorder, severe depression, panic disorder, and obsessive-compulsive disorder” (1998, p. NB-1). For this thesis, Burland’s definition of mental illness is used in order to match the definition used by the Family-to-Family education program. Schizophrenia, schizoaffective disorder, bipolar disorder, severe depression, panic disorder, and obsessive-compulsive disorder are described in the Diagnostic and Statistical Manual-IV (American Psychiatric Association, 1994).

### The Mental Health System

The Mental Health system is a complex unification of inter-related governmental and non-governmental services with which individuals interact. Figure 2.1 is a graphical representation of the numerous services that affect the health of a person with mental illness. As can be seen in figure 2.1 that the BCSS and the family (the two subsystems that are the focus of this thesis) represent a very small portion of the overall system. Both are emphasized in large bold type. The arrows indicate a possible two-way interaction between the client and the agency or agencies shown in the boxes.

Between the period 1993-1999, the formal Provincial Mental Health System was comprised of two distinct portions: Adult and Child and Youth services. In 1993, both systems were funded and managed through the Ministry of Health. Through a process of health care reform, the funding and delivery system was changed. As of 1999, the Ministry of Health funded the Adult system<sup>1</sup> whereas the Ministry of Children and Families funded and managed the Child and Youth system. Because British Columbia has a significant number of individuals with First Nations ancestry, two other governments may be involved in the delivery of mental health services as shown in figure 2.1. When First Nations individuals have a mental illness and live on reserves, either First Nations Governments or Health Canada delivers their mental health services.

#### Role of BCSS in the Mental Health System

The British Columbia Schizophrenia Society (BCSS) is a community-based, non-profit voluntary agency that provides a provincial network of peer support for the families of people with schizophrenia or other serious mental illness. BCSS is affiliated with the Schizophrenia Society of Canada and other provincial Schizophrenia Societies.

BCSS started in 1980, as a small group of people from Vancouver needing peer support in the struggle to cope with mental illness in their family (Calder, 1988). Initially called the BC Friends of Schizophrenics, this organization became a legal society in 1983 and was renamed BCSS. In 1984, BCSS became a registered non-profit organization.

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<sup>1</sup> Adult Mental Health services are managed and delivered by either Regional Health Boards or Community Health Services Societies.

Over the years it has grown into a formal agency that fills a service niche unmet by the formal mental health care system.

One role of BCSS in the mental health system is to advocate on behalf of families for better services for individuals with schizophrenia or other serious mental illness (BCSS, 1997). An example of advocacy was the provincial initiative to influence the BC government to proclaim Bill 22, the Amendments to the Mental Health Act, which was passed in 1998, and later proclaimed in 1999.

A second role of BCSS is to provide regionally contracted support for and empowerment of families of individuals with schizophrenia or other serious mental illness (BCSS Schedule B Contract, 1995). Support is delivered on a one-to-one basis with the BCSS coordinator or in a support group.

A third role is to provide regionally contracted community education through the Partnership Education Program, Puppet Program and other educational programs (BCSS, 1997). The Partnership Education Program is a novel approach to community education developed by Anne Bowles (Partnership Video, 1988). This education program is geared to community groups and high school students (Partnership Public Education Program brochure, undated). The education presentation consists of a panel of guest speakers: persons with a mental illness; family members; and mental health professionals (Partnership Public Education Program brochure, undated). The guests are presented as a team, and each describes their own personal experience with mental illness (Partnership

Public Education Program brochure, undated). It is based on a personal story telling model (Partnership Public Education Program brochure, undated).

The Puppet Partnership Program is geared to Elementary School students; specifically, grade four/five students (Funding Proposal, 1999). The puppeteers are trained family members and individuals recovering from a mental illness. This script entitled “Brother, Where Are You?” is a play about four children. One of the children has a sibling with symptoms of early psychosis. Using professionally made puppets and a script from NAMI (Rochester, NY), the play deals with the debunking of stereotypic myths and the understanding of key words associated with mental illness. In addition, the play displays how children can deal empathetically with a person who has a family member with mental illness.

A third BCSS education program the “Kids in Control Support Group Program”, is an eight-session support group and education program targeted at “children aged eight to thirteen years who have a parent with a serious mental illness” (Kids in Control Support Group Program, undated). This program was jointly developed by the Ministry for Children and Families and BCSS. Staff of BCSS believe that “these children face unique challenges, and are at risk for social maladjustment and mental illness, they are an appropriate group for this primary prevention program” (Kids in Control Support Group Program, undated).



**Table 2.1 Brochures, Fact Sheets, and Videos Produced by BCSS**

**Brochures**

	Medication Update
Youth's Greatest Disabler Booklet	Get the Facts: Access to New
Youth's Greatest Disabler Brochure	Medications for Schizophrenia = New
Schizophrenia is a Brain Disease	Hope
Drug, Alcohol, & Schizophrenia A Hazardous	Hospital Discharge Planning & Checklist
Road to Follow	Riverview Lands - The Future
Questions to Ask the Psychiatrist	Schizophrenia How to Manage Common
Schizophrenia in Children	Symptoms: Paranoia, Terror of being
Partnership Public Education Program	Psychotic, Denial of Illness, Stigma, &
Dr. Norma Calder Schizophrenia Foundation	Demoralization

**BC Schizophrenia Society Branch Manual**

**Fact Sheets**

	Benefits of Extended Leave
Getting Satisfactory Results...Some Do's	Extended Leave, Community Treatment
and Dont's	Orders, and Continuing Care
Stages of Hallucinations	Family Charter of Rights
Early Intervention	Recommended Reading Lists
Steps for Working with Delusions	Videos Available for Borrowing

Get the Facts: The Mental Health Act -  
 "The Right to Treatment and Care"  
 Get the Facts: Guardianship Legislation  
 and the BC Mental Health Act

**Videos Produced**

Reaching Out (Physician's Version)  
 Reaching Out (School Version)  
 One in One Hundred

In 1999, BCSS developed a high school curriculum in cooperation with Ministry of Education and Ministry for Children and Families. The “Reaching Out” education program is designed for BC’s grade 11 Career and Personal Planning (CAPP) and is suitable for grade 10, 11, and 12 students. This program “has two fully supported lesson plans and includes the background information [and videos] needed to teach this subject. It was designed to be used by teachers who know little or nothing about schizophrenia or mental illness”(Reaching Out Program ,1999).

BCSS delivers the National Alliance for the Mentally Ill’s (NAMI) Family-to-Family education program. In addition, BCSS delivers the BRIDGES education program to individuals with a mental illness. Both programs are more fully described in Chapter 4.

A fourth role is to disseminate information about schizophrenia or other serious mental illness (BCSS, 1997). BCSS publishes brochures, fact sheets, issues in treatment, Mental Health Act, etc., has videos about schizophrenia for sale at a nominal cost recovery basis (Branch Manual, 1999). A listing of these educational materials provided in Table 2.1.

A fifth role is to support research into schizophrenia or other serious mental illness (BCSS, 1997). BCSS supports research, rehabilitation, and housing initiatives through The Doctor Norma Calder Schizophrenia Foundation that acts autonomously from BCSS though affiliated with it (Dr. Norma Calder Schizophrenia Foundation Brochure, undated). The Calder Foundation complements the work of BCSS and was established in 1993 (Dr.

Norma Calder Schizophrenia Foundation Brochure, undated). The Calder Foundation in cooperation with the Canadian Alliance for Research on Schizophrenia (CAROS) attempts “to attract the most capable researchers to the field of schizophrenia” (Dr. Norma Calder Schizophrenia Foundation Brochure, undated). The Calder Foundation provides significant financial support for the Jack Bell Chair in Schizophrenia Research at the University of British Columbia held by Dr. Peter Liddle (Dr. Norma Calder Schizophrenia Foundation Brochure, undated).

BCSS delivers programs at the provincial, regional, and local levels throughout BC. Programs are developed at the regional and provincial level by regional BCSS coordinators, provincial office staff, and volunteer members of the BCSS Board of Directors. Regional BCSS coordinators, according to their own implementation plans, implement community and/or regionally specific internally generated programs. External programs are dealt with differently by a more-or-less formal process. Proposals that require Board of Director approval are submitted to the Executive Committee. The Executive Committee’s response is forwarded to the full Board of Directors. After discussion, the board of directors determines whether the proposal is supported or rejected.

### Role of the Family in the Mental Health System

Family members of individuals with a mental illness have a role in the mental health system. In British Columbia, there is no estimate of the numbers of families providing a care-giving role of family members with mental illness; however, in the United

States, Lamb and Oliphant (1978, cited in Spaniol, et al., 1987) estimate that as many as 66% of deinstitutionalized patients are returned to their families. Giving statistics from the United States, Goldman said that “of the estimated 375,000 patients with severe mental illness discharges annually, 250,000 persons suffering from mental illness are returned to their families” (1982, cited in Spaniol, et al., 1987, p. 77). If Canadian trends resemble American trends, it can be conservatively estimated that more than 50% of individuals with mental illness live with their families.

Family members provide a myriad of informal care services to their afflicted relatives. Families have a role in the diagnosis of mental illness by providing collateral information. They provide home care, monitor and dispense medications, assist in financial planning, support, rehabilitation, and relapse prevention for the ill relative. Where family members provide the above services, paid mental health professionals do not.

The report, *Sharing the Caring*, concluded that as caregivers, family members want involvement in treatment planning, and recognition as “equals in the provision of care to their relatives with mental illness” (Ministry of Health, 1993, p.9). This report is discussed in greater detail in chapter 3. Family members often provide these support services out of love and compassion for relatives with a mental illness. Because family members provide informal care services, families need support, understanding, training, and education from the mental health system (Ministry of Health, 1993). As well, families often require counseling to assist them in their roles as caregivers (Ministry of Health,

1993). The report, *Sharing the Caring*, also concluded, “emotionally and financially, [families] are often drained by the stresses of having to care and advocate for their loved ones” (Ministry of Health, 1993, p. 8). Too often family members themselves become consumers of the mental health system because they are unable to cope with the realities of having a relative with mental illness.

### Chapter 3 Literature Reviews

#### Voluntary Organizations and Their Role in Health Service Delivery

As of January 1997, there were “19,000 volunteer and community service organizations registered under the [British Columbia] Society Act” (Ministry of Human Resources, 1999, p.5). An unknown number of these organizations provide disease or condition specific information and services. In the National Survey of Giving, Volunteering, and Participating (1998, cited in Ministry of Human Resources, 1999), 32% of BC residents who were more than 15 years old volunteered their time and skills. They gave 169 million hours of work, which is an equivalent to 88,000 full-time-equivalent positions. This volunteer effort in turn is estimated to be equal to 2.7 billion dollars in wages. From these figures, it can be concluded that the work of volunteers significantly reduces expenditures in the formalized health care system because volunteers perform duties that paid service providers do not. Additionally, volunteers often provide services that could be funded; however, there are insufficient funds in the health care system to finance these afore-mentioned services.

A review of voluntary organizations that provide disease or condition specific education and family support was performed because the Family-to-Family education program is delivered by a voluntary non-profit organization. The voluntary organizations chosen for this literature review were the Alzheimer Society of British Columbia, the Canadian Diabetes Association (BC Division), the Canadian Cancer Society (BC Division), the Family Support Institute, and the British Columbia Schizophrenia Society

(BCSS). These organizations were chosen because they focus on family education and support as an integral part of or their entire service delivery pattern and because many of these organizations use trained volunteers to deliver their programs. The literature review focused on common service provision patterns using educational materials, voluntary organization pamphlets, archival information, and administrative reports.

The organizations chosen for this review reflect the differences in organizational structures that occur in voluntary agencies. Even though, the five organizations are registered under the Society Act; they are named a society, institute, or association. Two of the organizations, Canadian Cancer Society and Canadian Diabetic Association, are national organizations with provincial chapters or divisions, whereas, the BC Schizophrenia Society and Alzheimer Society of BC are provincial organizations that are loosely affiliated with national organizations. The Family Support Institute is a provincial organization only. A Board of Directors governs each organization. Additionally, for all of these organizations, signing authority is limited to the Board of Directors and the Executive Director of the provincial organization. In the case of the BCSS, signing authority for branches incorporated under the Society Act is within the branch structure.

These voluntary organizations in the review commonly provide:

1. Disease specific community education and prevention strategies. (Alzheimer Society BC, 1994, BCSS, 1994, Canadian Cancer Society, 1996, Canadian Diabetes Association, undated, Family Support Institute, undated)

2. Advocacy. (Alzheimer Society BC, 1994, BCSS, 1994, Canadian Cancer Society, 1996, Canadian Diabetes Association, undated, Family Support Institute, undated)
3. Training and/or education for the person suffering from the health concern. (Alzheimer Society BC, 1994, BCSS, 1994, Canadian Cancer Society, 1996, Canadian Diabetes Association, undated)
4. Support for the caregivers or family members of the person suffering from the health condition. (Alzheimer Society BC, 1994, BCSS, 1994, Canadian Cancer Society, 1996, Canadian Diabetes Association, undated, Family Support Institute, undated)
5. Advocacy, raise funds for, and assist in establishing priorities for research into the condition. (Alzheimer Society BC, 1994, BCSS, 1994, Canadian Cancer Society, 1996, Canadian Diabetes Association, undated)
6. Encouragement in fund raising activities and strategies. (Alzheimer Society BC, 1994, BCSS, 1994, Canadian Cancer Society, 1996, Canadian Diabetes Association, undated)
7. Encouragement of volunteerism. (Alzheimer Society BC, 1994, BCSS, undated, Canadian Cancer Society, 1996, Canadian Diabetes Association, undated, Family Support Institute, undated)
8. Training of volunteers. (Alzheimer Society BC, 1994, BCSS, undated, Canadian Cancer Society, 1996, Canadian Diabetes Association, undated, Family Support Institute, undated)



As stated in chapter one, most of these organizations include family members as either their primary focus or part of their focus for education. The following examples show where the education of families of individuals suffering from a specific disease or cluster of conditions fits into a society's program delivery. The Alzheimer Society of British Columbia (1994) "... provides information about Alzheimer Disease and related dementias to:.... people who are providing care to individuals with a dementia." "The Canadian Diabetes Association (undated) is Canada's primary source of authoritative information for people with diabetes and their families." The Canadian Cancer Society mentions supporting cancer patients and their families (Canadian Cancer Society, 1996). However, specific education programs aimed at family members are not mentioned as a focus in the literature published by the British Columbia and Yukon Division of Canadian Cancer Society. The Family Support Institute (1995) "...provides information, training, and province-wide networking to assist families [of children with special needs]." The British Columbia Schizophrenia Society (BCSS Constitution, 1994, Minutes of Board of Directors Meetings, Jan. 16, 1999) "... provides support for families of persons suffering with schizophrenia or other serious mental illness ". The above outline shows that each organization seeks to fill a niche not met by the formal health care system.

### Family Education

The need to base service provision on evidence of need and/or effectiveness is no less important for the voluntary than for the public health-care sector. Thus, in the delivery of family education programs there must be supporting evidence demonstrating the

educational requirements of families of individuals with mental illness. In addition, it is important that evidence indicates that family education programs address and meet these requirements.

The strategy for this section of the literature review was to search for literature published after 1990 that explored the psychosocial and cultural needs of family members of individuals with a mental illness. Additionally, this literature review explored some outcomes of family education and some discussion about research on the field of families of individuals with a mental illness.

Table 3.1 is a brief summary of some of literature found in the search for psychosocial needs of family members. In order to be consistent with the definition of mental illness from chapter 2, an analysis of what mental illness is defined as in the aforementioned papers is necessary. Doornbos (1997) and Lundwall (1996) use the undefined term of mental illness with no further explanation. Greenberg et. al. (1997) referred to mental illness as serious mental illness. Ascher-Svanum et. al. (1997) use the term mental illness as patients of the state psychiatric hospitals and/or clients of community mental health centres. Mueser et. al. (1996) referred to mental illness as schizophrenia and bipolar disorder. Marsh et. al. (1996) referred to mental illness as schizophrenia, schizoaffective, bipolar, and major depressive disorder, personality disorder, and others. Solomon and Draine (1995) referred to mental illness as schizophrenia and major affective disorders. Solomon (1996) referred to mental illness as schizophrenia and other heterogeneous diagnosis. Kane (1992) and Wer and Moller (1992) referred to mental illness as

schizophrenia. Pickett et. al. (1997) referred to mental illness as schizophrenia, bipolar disorder, and depression.

Table 3.1 is a summary of the literature examined to determine the psycho-socio-bio-educational needs of families with a relative with mental illness. This analysis shows that family members require education about the etiology of mental illness (Ascher-Svanum, 1997, Doornbos, 1997, Pickett et. al., 1997, Mueser et. al., 1996, Solomon, 1996, Wer, & Moller, 1992). Additionally, they require spiritual and social support (Doornbos, 1997, Pickett et. al., 1997, Lundwall, 1996, Marsh et. al., 1996, Solomon & Draine, 1995, Kane, 1992). Family members want to collaborate with professionals (Greenberg et. al., 1997, Kane, 1992). In addition, they want appropriate mental health services for their ill family members and if necessary for themselves (Greenberg et. al., 1997, Pickett et. al., 1997). Also, family members want additional skills to cope with their situation (Pickett et. al., 1997, Solomon, 1996). Additionally, they want some positive consequences as a result of their encounter with mental illness (Marsh et. al., 1996). Finally, family members want support and connections with other families experiencing mental illness in their family (Doornbos, 1997, Pickett et. al., 1997, Lundwall, 1996, Marsh et. al., 1996, Solomon, 1996, Solomon & Draine, 1995).

Ascher-Svanum et. al. (1997) analyzed the responses of 197 out of 300 family members of individuals with a mental illness in Indiana. These family members were not members of Indiana Alliance for the Mentally Ill (IAMI). Representatives from IAMI and academic and mental health professionals developed the 118-item survey. The survey

**Table 3.1 Literature Review of Family Educational and Psychosocial Needs**

<b>Authors</b>	<b>Variable Studied</b>	<b>Outcome</b>	<b>Methodology</b>
Ascher-Svanum, et. al. (1997)	Educational needs of families	Families want education on: future course of illness; medication benefits and side effects; crisis management	Survey
Doornbos, (1997)	Family coping, fear, and burden	Families required: facilitative attitudes; spiritual support; increasing knowledge about mental illness; support groups	Survey
Greenberg, et. al., (1997)	Family distress	Distress reduced by: appropriate mental health services for ill relative; collaborative relationships with professionals; information; advice from professionals	Interviews
Kane, (1992)	Family coping	Families need: collaboration with professionals; a social support system	Meta-Analysis Study
Lundwall, (1996)	Grief	Connecting with other families for social supports	Psychoeducation and Support
Marsh, et. al., (1996)	Grief and resilience	Families need: social support system; courage; some positive consequences as a result of their encounter with mental illness	Survey
Mueser, et. al., (1996)	Family burden	Families need to understand which symptoms cause the most family burden. The top 8 are: inactivity; delusions; avoiding people; no insight; talking to oneself; up all night; extreme distress; labile mood	Questionnaire
Pickett, et. al., (1997)	Program Evaluation of the Journey of Hope Program	Improvement focus evaluation. Outcomes: participants improved understanding of mental illness, increased knowledge of treatment system, participated in advocacy activities, had improved morale, had more social support, ability to differentiate role of family members. There was little reduction in caregiving burden.	Multiple surveys of participants, teachers, trainers, developers. Statistical analysis of survey outcomes.
Solomon, P. (1996)	Family education	Families need requisite knowledge, skills and resources to provide the primary care for adults with mental illness	Literature Review

**Table 3.1 (continued) Literature Review of Family Educational and Psychosocial Needs**

<b><u>Authors</u></b>	<b><u>Variable Studied</u></b>	<b><u>Outcome</u></b>	<b><u>Methodology</u></b>
Solomon & Draine, (1995)	Family coping	Families need: affective and affirming support; membership in a group that gives family support (National Alliance for the Mentally Ill); a large social network; affirming support from social network; the ability to get the desired outcome from oneself	Interviews, Carver's Coping Scale(1989), Norbeck Social Support Questionnaire (1983), Pai and Kapur's Subjective Burden Interview (1981)
Wer & Moller, (1992)	Program evaluation of an educational program of families and their ill relative	Families were educated about future course of illness; medication benefits and side effects; crisis management. There was no formal assessment of familial needs prior to development of program.	Post-test Likert Scale

most preferred format was either phone consultations or a support group led by a psychiatrist, a psychologist, or a social worker (Ascher-Svanum et. al., 1997). Family members also preferred a one to two hour or a half day Saturday workshop at a community mental health centre or a psychiatric hospital (Ascher-Svanum et. al., 1997). The least preferred workshop types were ten weekly sessions or an all-day weekday workshop (Ascher-Svanum et. al., 1997). The least preferred workshop type merits mentioning because it is the format chosen by Burland to deliver the Family-to-Family education program. The best time for workshops was in the afternoon or evening (Ascher-Svanum et. al., 1997). Participants wanted the service provided free of charge and preferred travel time to course to be less than thirty minutes (Ascher-Svanum et. al., 1997). Additionally, family members felt that their ill relative would benefit from education about and coping strategies with their illnesses (Ascher-Svanum et. al., 1997). This education could be with or without other family members (Ascher-Svanum et. al., 1997).

Doornbos (1997) studied the problems and coping methods of 108 Michigan caregivers of young adults with a mental illness by posing two questions. The first question was, "What are the greatest problems that you encounter as a result of having a mentally ill family member?" (Doornbos, 1997, p. 23). The second question was, "What are the best ways that you found to cope with these problems?" (Ibid.). The five most common problems were "caregiver burden, client's symptoms, negative impact on [the] family unit, grief, ... [and] fear of what will happen to their ill relative when his/her parents die" (Doornbos, 1997, pp. 23-24). Four major coping methods were: assuming facilitative attitudes; relying on faith; increasing knowledge of illness; [and] attending support groups"

(Doornbos, 1997, p. 23). This study focused on nursing implications, however, this researcher believes that these implications are transferable to family educators and program developers. One implication discussed by the author is that nurses (and educators) must gear their information giving or teaching to assist family members in coping (Doornbos, 1997). Additionally, nurses (and educators) can also facilitate in ensuring that the spiritual needs of family members can be met and refer family members to other appropriate agencies where necessary (Doornbos, 1997).

Greenberg et. al. (1997) conducted 778 telephone interviews of family members in Wisconsin to determine how the provision of mental health services to relatives with mental illness affected the level of distress experienced by family caregivers. Greenberg et. al. explored three aspects of mental health services: "the inclusion of family members as collaborators in the treatment process, information and advice given to family members, and direct services to clients" (1996, p. 41). The participants were asked by their relative's case manager to participate in the survey. The family member survey measured two dimensions of objective burden; amount of care and frequency of disruptions (Greenberg et. al., 1996). This survey also measured subjective burden (Greenberg et. al., 1996). The survey found that family members who had a collaborative relationship with professionals experienced lower levels of distress than those without a collaborative relationship (Greenberg et. al., 1996). Additionally, the survey found that information and advice giving by mental health services to family members also reduced their levels of distress when compared to those not receiving the aforementioned services (Greenberg et. al., 1996). Finally, family members experienced low levels of distress when their ill family

member received increased levels of mental health services (Greenberg et. al., 1996). It is noteworthy that individuals with mental illness who lived with other family members received less mental health services than those who lived independently. Also, professionals were more likely to collaborate with, and provide information and advice to family members when their relative with a mental illness was living with them (Greenberg et. al., 1996).

Kane (1992) analyzed 22 papers on programs designed to educate and support the coping skills of family members of individuals with schizophrenia. Kane refers to these programs as psychoeducation (1992). However, since these programs are directed to the needs of family members, they are now referred to as family education programs (Solomon, 1998). Kane was interested in programs that promoted provider-family collaboration (1992). In her review, she stresses the importance of providers understanding that families provide a social support system and act as an important resource for individuals with a mental illness (Kane, 1992). She also explores three models of family intervention. They are single family interventions, multi-family interventions, and short-term, multi-family structured programs (Kane, 1992). She further discusses in detail the planning and implementation of short-term, multi-family structured programs (Kane, 1992). Kane (1992) also discusses where, when, and how often to deliver the aforementioned program. Additionally, Kane (1992) proposed guidelines on how to begin, conduct, conclude, and evaluate a short-term program. She concluded, “with good planning, administrative support, and organization, cost-effective family educational



programs can be offered that enhance the coping capacities and the support system functions of families caring for their relatives with schizophrenia” (Kane, 1992, p. 128).

Marsh et. al. (1996) performed a United States-wide open-ended question survey of 131 family members from the membership roles of the National Alliance for the Mentally Ill (NAMI). This survey explored resilience among family members of people with mental illness. Resilience is defined as “the ability to rebound from adversity and prevail over the circumstances of our lives” (Marsh et. al., 1996, p. 4). When a family member develops a mental illness, often, the entire family experiences adversity. The study respondents were asked to describe the following:

- a) any special personal qualities or strengths they had developed as a result of the mental illness in their family;
- b) any special family qualifications or strengths that developed as a result of the mental illness;
- c) their personal contributions inside or outside the family;
- d) the contributions of their relative with mental illness inside or outside the family; and gratifications [a special feeling of satisfaction].
- e) any gratifications they had experienced in their role as caregiver or concerned family member;
- f) whether they, their family, or their relative with mental illness experienced a process of adaptation or recovery; and
- g) the factors or resources that promoted positive changes in them, their family, or their relative” (Marsh et. al., 1996, p.6).

The study found that the dimensions of family resilience included family bonds and commitments, strengths and resources, growth and development, contributions, and gratifications (Marsh et. al., 1996). Additionally, they determined that the dimensions of personal resilience included personal contributions, improved personal qualities, growth and development, enhanced coping effectiveness, personal gratifications, and better perspectives and priorities (Marsh et. al., 1996). Consumer resilience was found to have

dimensions of positive personal qualities, recovery, contributions to the family, contributions to other consumers, and contributions to the mental health system and to society (Marsh et. al., 1996). Finally, 75% of family members reported positive changes in themselves, their families, and their relative with a mental illness. This reference was included in the review because any educational program targeted towards family members has to acknowledge that family members have personal strengths, which assist them in coping with subjective and objective burdens that mental illness places on them, their families, and their relative with a mental illness.

Lundwall (1996) describes a novel family intervention program that combines an education and a support group format called Psychoeducational Support Group. The goals of the program are either relapse prevention of the mentally ill relative or improved family function depending on the materials used or the desired outcomes. This extensive program lasts 24 months. The first eight classes about the etiology of mental illness are weekly. The second ten classes about handling problems, facilitating the ill relative's rehabilitation, and giving guidance to find appropriate services are monthly. The last six months of the program depend on the needs of family member participants. A multi-disciplinary team of medical, mental health, vocational rehabilitation, and psychosocial rehabilitation professionals delivers the program. The program leadership slowly transfers from the professional to the family members over the 24-month period. This program was designed and proposed by professionals without the consultation of family members. From the description of the program in the paper, it is difficult to determine whether this program has ever been delivered. However, this paper is included in the literature review because

the family member's needs were not assessed, and no planning activities occurred other than a theoretical presentation of a professional's perception of a family targeted program.

Mueser et. al. (1996) developed a questionnaire to assess the perceptions of family members' burden due to twenty common positive, negative, and manic behaviours associated with schizophrenia and bipolar disorder. This questionnaire was given to 48 relatives and 39 mental health professionals (Mueser et. al., 1996). The professionals were included in this study to determine whether professionals had different perceptions of the family burden than the relatives themselves (Mueser et. al., 1996). The relatives and professionals were presented with twenty vignettes of behaviours (Mueser et. al., 1996). The relatives were to rate the frequency of the problem's occurrence using a 5 point Likert scale (1 = not at all, 5 = very often) (Mueser et. al., 1996). Similarly, relatives were asked to rate how much distress this behaviour caused (1 = no distress, 5 = extreme distress) (Mueser et. al., 1996). The professionals rated the vignettes on their belief on how often problem behaviours were exhibited by mentally ill relatives and predicted the levels of distress this behaviour would cause family members (Mueser et. al., 1996). The relatives of individuals with bipolar disorder were most burdened with manic symptoms and had greater total burden than families with a relative with schizophrenia (Mueser et. al., 1996). The lack of insight in their ill relative burdened this group more than any other problem behaviour (Mueser et. al., 1996). The relatives of individuals with schizophrenia were burdened by negative symptoms slightly more than positive symptoms (Mueser et. al., 1996). The inactivity of their relative with schizophrenia burdened this group more than any other problem behaviour (Mueser et. al., 1996). The professionals estimated that

relatives of an individual with bipolar disorder would have more burden from manic symptoms which was a similar finding with family members (Mueser et. al., 1996). However, professionals differed from family members about the behaviour that caused the most distress; professionals thought that overactivity would cause the most burden (Mueser et. al., 1996). The professionals estimated that relatives of individuals with schizophrenia would have burden from positive symptoms, which is a different conclusion than that of family members (Mueser et. al., 1996). Professionals thought that inactivity was the behaviour that caused the most burden. This perception of family burden corresponded with the perception of family members (Mueser et. al., 1996). It was noteworthy that professionals estimated that relatives of individuals with schizophrenia had greater burden than families of an individual with bipolar disorder (Mueser et. al., 1996). This estimate was opposite of the family members' assessment (Mueser et. al., 1996). In conclusion, this paper shows that there are differing perceptions of family burden by family members and professionals (Mueser et. al., 1996). In order to clarify the results from this questionnaire, see tables 3.2 and 3.3. All the symptoms listed are problem behaviours, however, it should be noted that not all problem behaviours caused family burden in the population studied by Mueser et. al. (1996). This is the reason behind inclusion of family members in developing programs targeted towards them. Additionally, this paper supported my experiential knowledge from working with families of individuals with either schizophrenia or bipolar disorder; family members of people with bipolar disorder seemed to experience more burden.

**Table 3.2      Ranking Symptoms Causing Family Burden as Perceived by Family Members of Individuals with Bipolar Disorder and by Professionals** (adapted from Mueser et. al., 1996) (Burden rating 1-20, where Greatest Burden = 1, and Least Burden = 20)

<u>Symptoms</u>	<u>Family Burden perceived by family members (bipolar disorder)</u>	<u>Family Burden perceived by professionals (bipolar disorder)</u>
No Insight	1	6
Inactivity	2	13
Labile Mood	3	2
Delusions	4	8
Overactivity	5	1
Unpredictable Behaviour	6	11
Up all night	7	9
Extreme Distress	8	16
Avoiding People	9	17
Irritability	10	3
Noncompliance	11	5
Blaming Others	12	7
Poor Follow Through	13	12
Talking to Self	14	18
Inability to Handle Money	15	4
Poor Hygiene and Grooming	16	15
Aggressiveness	17	10
Poor Social Skills	18	20
Inability to get a Job	19	14
Strange Appearance or Behaviour	20	19

**Table 3.3      Ranking Symptoms Causing Family Burden as Perceived by Family Members of Individuals with Schizophrenia and by Professionals** (adapted from Mueser et. al., 1996) (Burden rating 1-20, where Greatest Burden = 1, and Least Burden = 20)

<u>Symptoms</u>	<u>Family Burden perceived by family members (schizophrenia)</u>	<u>Family Burden perceived by professionals (schizophrenia)</u>
Inactivity	1	1
Delusions	2	3
Avoiding People	3	9
No Insight	4	6
Talking to Self	5	8
Up all night	6	5
Extreme Distress	7	18
Labile Mood	8	17
Unpredictable Behaviour	9	14
Poor Hygiene and Grooming	10	4
Noncompliance	11	2
Poor Social Skills	12	15
Inability to Handle Money	13	13
Irritability	14	7
Blaming Others	15	19
Poor Follow Through	16	12
Inability to get a Job	17	16
Strange Appearance or Behaviour	18	11
Overactivity	19	20
Aggressiveness	20	10

Solomon and Draine (1995) studied the coping factors of family members of individuals with a mental illness. Two hundred and twenty-five (225) family members acting as caregivers of a relative with mental illness, primarily schizophrenia, were surveyed. Approximately half of the participants never participated in support groups previously (Solomon, & Draine, 1995). The survey collected demographic data on the participants, measured their ill relative's functioning, and measured adaptive coping, social supports, subjective burden, objective burden, and self-efficacy of family members (Solomon, & Draine, 1995). Solomon and Draine (1995) found that social support was the strongest factor in adaptive coping. This social support derived from the ability of family members to confide in members of their own social network rather than from a support group (Solomon, & Draine, 1995). After statistical analysis, they found that there were strong linkages among social support, self-efficacy, and adaptive coping (Solomon, & Draine, 1995). This paper indicates that family members have existing supports outside the mental health system and any programs dealing with family's needs could incorporate strategies to encourage sharing confidences within these social networks.

Wer and Moller (1992) developed a psychoeducation program directed towards individuals with schizophrenia, professionals, and family members. They developed the course during a dynamic process using improvement-focused evaluation from 688 attendees (Wer & Moller, 1992). The program consists of six sessions about the etiology of schizophrenia, living with hallucinations and delusions, understanding medications, and compliance and relapse (Wer & Moller, 1992). This program was the basis of the NurSeminars Recovering from Psychosis: A Wellness Approach program developed by

Moller and Murphy (1997) discussed further in chapter 4. This reference is included in the review because it shows a process of psychoeducation program development based on family needs as well as the needs of individuals with a mental illness.

Solomon (1998) describes four types of family interventions: psychoeducation; supportive family counseling; family education; and family support and advocacy groups. In this thesis, psychoeducation and family education approaches are compared and discussed because the psychiatric profession very actively promotes psychoeducation whereas family-based advocacy organizations, such as BCSS and National Alliance for the Mentally Ill (NAMI), promote family education (Burland, 1998, BCSS, undated).

Solomon (1996, p.1364) stated that,

“the primary goals [of family education] are supportive and didactic rather than therapeutic [and] interventions are focused on improving family members’ quality of life by reducing stress and burden and only secondarily on benefiting the ill relative”.

Most of the current literature about family members of individuals with a mental illness revolves around family burden, coping, resilience, grief, and distress. Education programs geared to family education emphasize familial competencies rather than deficits (Dixon & Lehman, 1995 cited in Solomon, 1996). This means that family education emphasizes that family members are doing the best they know how to do rather than emphasizing that their methods for coping are wrong.

In 1992, the Mental Health Division of the BC Ministry of Health in cooperation with the Provincial Mental Health Family Advisory Committee, set up a family task force



to perform a provincial needs assessment of family members of individuals with severe and persistent mental illness (Ministry of Health, 1993). Family members, service providers, and staff of BCSS, Mood Disorders of BC, Canadian Mental Health Association, BC Division, and Alzheimer's BC were surveyed and/or interviewed about the needs of family members (Ministry of Health, 1993). The responses were collected, analyzed, and reported in the Families Sharing the Caring report (Ministry of Health, 1993). In this report the family task force said, "families want education about mental illness, medications, and survival skills soon after the onset of the illness" (Ministry of Health, 1993, p. 28). Thus, when selecting an educational program in BC, these familial requirements need to be factored into the choice.

More traditional psychoeducation programs include both therapeutic and educational components (Solomon, 1996). The therapeutic components include learning about coping and adaptation strategies, and increasing self-efficacy (Solomon, 1996). The educational components include: relapse prevention strategies; and information about the etiology of mental illnesses; medications; grieving process; rehabilitation; and mental health services available (Solomon, 1996). Psychoeducation programs have limited acceptance by advocacy groups for families of person with mental illness because of the association that has arisen between psychoeducation and the concept of expressed emotion. Solomon operationally defined the concept of expressed emotion as "the family's degree of criticism, hostility or rejection, and over-involvement" (1996, p.1365). Brown et. al. (1966, cited in Davison & Neale, 1994) originated the concept of expressed emotion as a determinant in the relapse of patients diagnosed with schizophrenia. The concept of

expressed emotion has been shown by Linzen, Dingemans, Nugter, et. al. (1997), Barrowclough, Tarrier & Johnston (1996), Wuerker (1996), Lefley (1992), Vaughan and Leff (1976), and others to be significantly and reliably associated with relapse of individuals with a mental illness.

Often advocacy groups that represent family members feel that the concept of expressed emotion implies blaming of families for the ill relative's relapses (Solomon, 1996). The reason behind this misconception is that in the past, families and particularly mothers were blamed for causing schizophrenia. In 1949, Tietze (cited in Torrey, 1995) studied 25 mothers of patients of individuals with schizophrenia with no control group. Since she found the mothers to be hostile and exhibited resentment towards the psychiatrist for blaming them for causing their children to become schizophrenic, she concluded that this evidence was conclusive that mothers caused schizophrenia. The concerns expressed by family members about expressed emotion often deal with the trauma experienced by mothers being blamed for causing mental illness in their relative. For them, it is described as being like a roller coaster ride of believing "here we go again, I didn't cause this illness, but now, I am being blamed for relapse" (Kimmins, 1997, personal communication). This misinterpretation of expressed emotion needs to be addressed by advocacy groups that support family members of individuals with a mental illness.

### Relapse Prevention as an Outcome of Psychoeducation

Psychoeducational programs are geared to the patient's needs rather than the family's. It is beyond the scope of this thesis to study the extensive body of literature looking at family intervention and patient relapse prevention using psychoeducational techniques. Because psychiatrists consider the use of psychoeducation programs as the standard for relapse prevention and family involvement with mentally ill relative, it is important to discuss the gold standard study by McFarlane, Link, Dushay, Marchal & Crilly (1995). McFarlane et. al.'s (1995) four year experimental study on relapse outcomes and the provision of psychoeducation in multiple family groups is one of the most recognized studies in the relapse prevention and family intervention field. McFarlane et. al. (1995) performed a clinical trial to compare the merits of single-family interventions of psychoeducation, multifamily interventions of psychoeducation, and multifamily groups with family dynamic intervention in combination with antipsychotic medication with respect to the rate of relapse of patients with schizophrenia or schizoaffective disorder. The study was conducted in New Jersey using patients and their families randomly assigned to the treatment protocols. The family members were not selected for high expressed emotion unlike previous studies. The family-dynamic multifamily group had a high dropout rate that affected the interpretability of the data. The patient relapse rate was significantly lower when patients and their family participated in the multi-family psychoeducation program in combination with the use of antipsychotic medication by the patient (McFarlane et. al., 1995). This study prompted McFarlane et. al. and others to

study the effect of different patient and family intervention strategies in combination with patient medication on relapse rate of the patients.

### Other Outcomes of Family Education

Solomon, Draine, Mannion, and Meisel (1998a) performed an effectiveness trial using three groups: control (a waiting list), a ten-week group workshop, or individual consultation. Family members were randomly assigned to one of three groups. The trial was designed to determine whether family intervention significantly changed help seeking assistance from community mental health services. There were no significant differences in help seeking behaviour in the two family interventions and the control groups.

Solomon and Draine (1995) studied subjective burden among 225 family members of mentally ill adults in a study using a randomized clinical trial of two modes of psychoeducational intervention. Family members were assigned to group psychoeducation, individual family consultation, or to a waiting list control group. The program designated as psychoeducation would nowadays be defined as a family education program. The family education program consisted of two hours per week for ten weekly sessions. Its objectives were to teach about mental illness and its treatment, promote the idea that family members would understand that they were not alone, and provide guidelines for dealing with their ill family members, other family members, and the mental health system. The individual family consultation model involved using family members to specify the focus of their psychoeducation with their consultant. Families could access the service on an as

needed basis for up to three months for a minimum of six and a maximum of 15 hours. Solomon and Draine (1995) found through the use of pre- and post- test of subjective burden, that, subjective burden was reduced in the psychoeducation and the individual family consultation model groups, but not in the control group.

### Review of Research in the Field of Families of Psychiatric Patients

Rose (1996) reviewed research performed on families of individuals with a mental illness. She found that although, there is a significant body of literature that characterizes the nature of family burden, there was a lack of systematic research into interventions that were efficacious in reducing family burden. Rose found that research on the aforementioned group tended to be qualitative in nature rather than quantitative (1996). Thus, there was richness about the contextual environment in which family members of individuals with a mental illness lived, rather than outcomes of family interventions (1996). Since this review was prior to most of the systematic and randomized effectiveness trials looking at specific outcomes performed by Solomon, it might have provided that impetus for Solomon to perform this research (1998). When performing the literature review, this researcher noted that Solomon was the only researcher found that performed effectiveness trials on family education. Thus, researchers need to determine the efficacy of family education programs delivered in order to determine whether Solomon's analysis and results can be duplicated.

### Families not in Contact with a Relative with a Mental Illness

The needs of families not in contact with their relative with a mental illness are addressed in this literature review because some participants and non-participants of the Family-to-Family education program are not in contact with their relative with a mental illness. Wasow (1994) referred to these families as “a missing group in family research”.

She further hypothesizes that:

1. Parents are not missing, but their offspring are. Parents had no choice in maintaining contact.
2. Parents sever relationships with their ill family member because of ignorance about mental illness in our society.
3. Some families are chaotic and cannot cope. As a result, individual families choose to discontinue contact.
4. Some families are limited by economic hardship, geographic separation, and system failure that can interfere with contact. (Wasow, 1994, p. 720).

### Cultural Perspectives in Mental Illness

Different cultures have different perspectives when dealing with mental illness in the family. Lefley (1998) determined that family members from a Hispanic background viewed mental illness as emotional problems whereas family members from other cultures preferred a medical explanation for mental illness. Additionally, Lefley (1998) found that there were two behaviours exhibited by family members of individuals with a mental illness: sociocentric and autonomous. Family members exhibiting sociocentric behaviours were help-accepting whereas family members exhibiting autonomous behaviour indicated that the acceptance of help infringed on their personal autonomy and perceived that dependence is a weakness. Lefley (1998) also determined that family members of African-

American background had high coping mastery and self-esteem. Therefore, they perceived that they had a lower burden than other cultural groups.

When working with family members from First Nations groups, Johnson and Johnson (1998) perceived that it was important to “know about the tribe and its relationships with other tribes in the area” (p. 89). Cultural differences affect clinical management, presentation of symptoms, lifetime course of the illness, rehabilitation goals and methods, kinship obligations and privileges, and traditional healing treatments (Johnson & Johnson, 1998). Because non-native clinicians were told that certain Indian communities do not have people with diagnosable mental illness, the Native American Family Project was sponsored by the Centre for Mental Health Services of the National Institute for Mental Health in the United States. Unfortunately, the study methodology was not discussed in this paper. Johnson and Johnson worked with native Americans in the states of North and South Dakota, New Mexico, Arizona, Utah, Alaska, and Washington. Because native Americans typically viewed family involvement in the treatment process as natural, Johnson and Johnson state that there is a need for information giving to family members (1998). One finding was that the National Alliance for the Mentally Ill’s (NAMI) written material was helpful to families; however, single information sessions were rarely enough. This project also found that family education in groups was an effective intervention. Furthermore, supported family counseling as developed by Berheim (1982, cited Johnson & Johnson, 1998) appeared to be appropriate for American Indian families. Supported family counseling or family consultation is a flexible and collaborative approach

to supplying expert advice and information to an individual family member or to the whole family unit (Berheim, 1982).

### Factors Affecting Program Implementation in Health Education Programs

Any educational program targeted toward any audience must undergo a process of implementation. Program implementation has characteristics that can be crucial in limiting or enhancing the effectiveness of the education per se. Implementation can be understood as a logical process involving certain components or phases. This section reviews theoretical processes of program planning for the implementation of health education programs. These theoretical processes will be used for analytical purposes to generate questions and to guide the data analysis in this study. Additionally, it will be used for a comparison to the process used by the implementors of the Family-to-Family education program. The strategy used for reviewing the literature on implementation of health education was to search for evaluations of health education programs, which were often implemented as national multi-sectorial programs or exhibited key characteristics of program implementation. Finally some unifying conclusions will drawn at the end of this literature review.

Dignan and Carr define health education programs as “a package of services or information that is intended to produce a.... positive impact on health” (1992, p. 5). Implicit in this definition is the assumption that there is a target group for the health



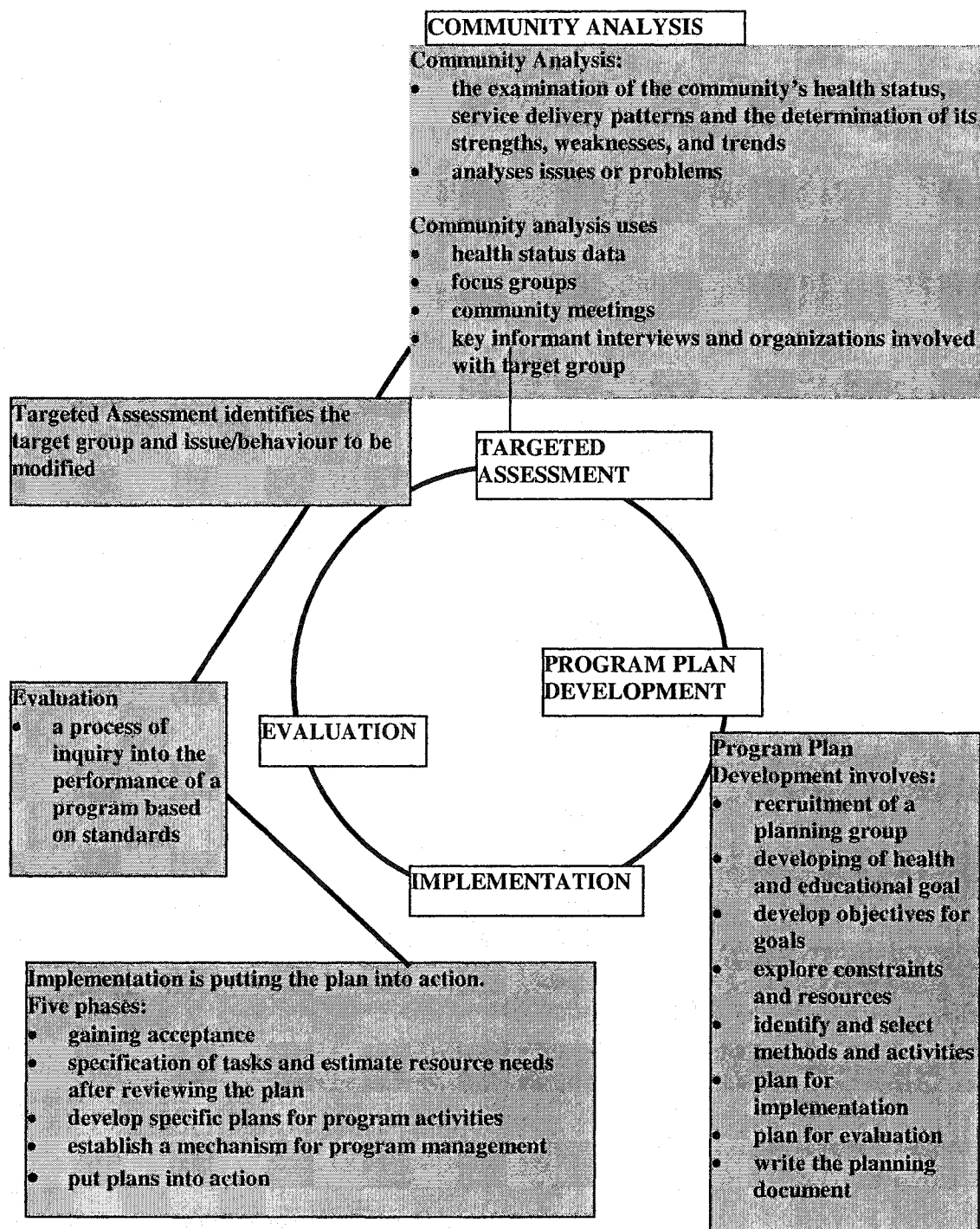
education program. Kiger described five models of health education that often share common elements:

1. the information-giving or medical model
2. the educational model
3. the propaganda or media model
4. the enabling or community development model
5. the political model (1995, p.31)

The information giving or medical model sets up the informant as the expert, who gives talks, promotes clear messages and assumes that the facts will persuade the target group to change (Kiger, 1995). The educational model leads the target group to discover, sets up the group to discuss feelings and challenge facts in order to promote change (Kiger, 1995). The media model employs attractive packaging of the message to manipulate the target group to change (Kiger, 1995). The enabling or community development model encourages the use of individuals' or organizations' strengths to change on their own terms (Kiger, 1995). The political model uses community provocation to mobilize the people in power to effect societal change (Kiger, 1995).

Dignan and Carr (1992) propose a community development model of health education and promotion planning as seen in figure 3.1. This model uses a circle as a graphical representation of the cyclical nature or dynamism of the program planning process. Dignan and Carr (1992) focus on the continued improvements of programs and define the process of program planning as a series of interconnected steps: community analysis; community diagnosis; establishment of program focus; target analysis; program plan implementation; and program evaluation. Burland (undated) states that the Family-to-Family education program uses an empowerment model of self-education which is

Figure 3.1 A Community Development Health Planning Model (Dignan & Carr, 1992)



comparable to Kiger's enabling or community development model and Dignan and Carr's community development model. However, the Family-to-Family education program is actually an information giving and skills building program as will be discussed in chapter 4.

Implementation is putting the plan into action. As shown in figure 3.1, implementation has five phases (Dignan & Carr, 1992):

1. Gain acceptance for the program
2. Specify tasks and estimate resource needs
3. Develop specific plans for program activities
4. Establish a mechanism for program management
5. Put plans into action (p.122)

Because the implementation of a new program involves change, gaining acceptance is challenging. Change can be resisted by individuals in the target group and the provider group (Dignan & Carr, 1992). In the target population, acceptance involves both passive support and active participation in the program. These reactions may be different. A new program can be supported by the target group and still have low numbers of actual participants. Dignan and Carr (1992) contend that the best method to ensure participation is to have sufficient involvement of the target population and the community at large. Resistance to change by provider and funding organizations should be overcome by planning functions performed by the management structure of these organizations. However, local autonomy can play either a positive or a negative role in acceptance of a new program.

In the second phase of program implementation, program tasks are specified from reviewing the plan in detail and the required resources are estimated. Three main tasks are accomplished by reviewing the plan. Determination of the products of the program assists in clarifying the program's goals and steps to achieve these goals is the first task (Dignan & Carr, 1992). The second task is the preparation of a detailed list of program activities (Dignan & Carr, 1992). Determination of the interrelationship between these activities is the third task (Dignan & Carr, 1992). The estimation of resource requirements is an important step in program implementation because without appropriate resources the program cannot be delivered. Estimation of resources includes: staffing requirements; supply and equipment needs; space requirements; media and marketing requirements; education style; and sufficient budget for the resources required (Dignan & Carr, 1992). After estimating resources, a review of the plan may be required if sufficient budget is not available. Alternatively, further firm negotiation for adequate budget to cover the plan may be essential (Dignan & Carr, 1992).

The third phase of implementation is developing plans for program activities. This includes developing a marketing campaign and a direct education portion (Dignan & Carr, 1992). Product, promotion, place, and price are the four components of marketing (Patton, 1980). When implementing a program, one has to decide how to introduce the program. In addition, implementors need examine the status of the program and the sponsor with respect to the target population.

Establishing a system for program management is the fourth task in implementation. Three basic indicators are time, cost, and performance (Dignan & Carr, 1992). Time is easy to control by using a series of estimated times for completion of phases of the program for comparison purposes. When these milestones are reached early or late, changes can be made to the plan. Another indicator is cost (Dignan & Carr, 1992). Budget utilization can be an indicator of adherence to the implementation of the program as planned. Performance indicators for program management are difficult to develop (Dignan & Carr, 1992). Indicators need to be developed that can evaluate outcomes (Dignan & Carr, 1992). For example, the question of whether the program outcomes matches its goals could be answered. Indicators need to be developed that determine whether the target population is the population participating in the program (Dignan & Carr, 1992). Additionally, from whom one collects performance indicators is important (Dignan & Carr, 1992).

The fifth and final phase is putting plans into action. A check should be conducted to ensure that the target population remains unchanged (Dignan & Carr, 1992). Dignan and Carr (1992) suggest that implementors check the target population's readiness to change, any changes in tasks, resource requirements and resources available, review the plans for introduction, and review management plans.

## Evaluation of Program Implementation

Fitzgerald and Illback (1993) stated that “the primary purpose of implementation evaluation is to determine the extent to which the program is operating as planned” (p.41). In their discussion of principles and procedures for the evaluation of program implementation, they included questions about the following:

1. How are nursing care staff engaged in intervention activities and to what extent?
2. In what ways are program participants involved in the intervention program?
3. Are appropriate methods and material being used in the intervention program by nursing staff?
4. What intended and unintended side effects do nurses, patients, and their families, and others perceive?
5. Is there a discrepancy between what was planned and what was actually delivered? (Fitzgerald & Illback, 1993, p. 42)

These principles can be included in the analysis of the implementation of the Family-to-Family education program.

## Implementation Issues

As a result of the reviewing the literature, Table 3.4 summarizes the implementation issues raised in the literature.

Fidelity is defined as “conformity with prescribed elements [of the program] and the absence of non-prescribed elements” (p. 670, McGrew, Bond, Dietzer, & Salyers, 1994). Fidelity is also referred to as adherence to the program (Pentz & Trebow, 1991). This researcher grouped the use of contracts to ensure program fidelity and program

**Table 3.4 Literature Review for Program Implementation**

<b>Authors</b>	<b>Program</b>	<b>Implementation Issue</b>
Kirby, Garfink, Starck, Russo, & Bachman, (1991)	University Hospital Nurse Extender Program, Boston University Medical Centre, Mass.	Internal and external factors that affect acceptance and implementation: leadership, financial, union, training and preparation, licensing, and legal issues
Contento, Kell, Keilley, & Corcoran, (1992)	Changing the Course, American Cancer Society in Elementary Schools in Northeast United States	Training, learning strategies, parent participation, time, support from administrators, integration into core programs. Quantitative measurement of fidelity of implementation & degree of augmentation & qualitative measurement using teachers' perception
Biegel & Song, (1995)	Caregiver Support Program, Midwest United States	Studied program knowledge, referral sources, and facilitators and barriers to participation in Caucasian and African-American communities using variables found in literature review
Jerrel & Ridgeley, (1999)	Dual Diagnosis Program, South Carolina	Quantitative measurement of fidelity of program implementation shows significant differences in program outcomes.
Raizman, Montgomery, Osganian, Ebzery, Evans, Nicklas, Zive, Hann, Snyder & Clesi, (1994)	Child & Adolescent Trial for Cardiovascular Health (CATCH), US National Program	Assessment of exposure using forms for attendance, visits, promotion, participation. Assessment of implementation fidelity using a checklist.
Baker, C. G., (1977)	National Cancer Research Strategy, US.	Discussion of advantages and disadvantages of the use of contracts to ensure fidelity of implementation.
Pentz & Trebow, (1991)	Implementation Issues in Drug Prevention Research, US	Measured acceptance of program and adherence to using program materials. Measured fidelity using self-report and others to determine on-task and off-task behaviour.
Rohland, B. M., (1998)	Medicaid Managed Mental Health Care in Iowa	Emphasizes need for clear, concise, and comprehensive implementation plans. Most problems encountered were due to insufficient plans.
McMillan, Tittle, and Hill, (1993)	"I Can Cope" Educational Program, American Cancer Society	Studied referral patterns and facilitators of referrals. Found that primary physicians were least likely to refer. Facilitators were handouts/brochures, flyers, personal contact, & nurse/social worker referrals.
Jarrett, M. H., (1996)	A Parent-to-Parent Support Program in a Neonatal Intensive Care Unit in Washington, DC	Studied the volunteer training program using pretest/posttest design. Used confidential screening tool with input from volunteer coordinator for selecting peers. Studied referrals using brochures & from charge nurse. Emphasized quick response time.

**Table 3.4 Literature Review for Program Implementation** (continued)

<b>Authors</b>	<b>Program</b>	<b>Implementation Issues</b>
Cassady, Orth, Guyer, & Groggin, (1997)	Injury Prevention Programs by State Health Agencies, US	Failures due to ambiguous policy directives, lack of support by agencies/participants, unconvincing program, inadequate monitoring, insufficient organizational capacity, systemic problems. Successes occurred through problem solving strategies.
Bierman, K. L., (1997)	Program for the Prevention of Conduct Problems in Rural Communities in Penn, US.	Discusses the characteristics of rural communities and their impact on implementation. Characteristics include regionalism, geographic dispersion, complicated entry systems, closed social system, difficult to recruit families from outside community,
Shortell, S. M., (1984)	Improving the Study of Health Program Implementation	Quantify implementation wherever possible. Reduce delay in implementation. Necessary to have a clear plan to increase external validity.
Vinokur, Price, & Caplan, (1991)	Employment Program for Unemployed Persons in Michigan, US.	Compared participants and non-participants. Asked the question about who needs the intervention most. Found that non-participants had rate of re-employment & greater confidence in skills despite lower and lower socio-economic & educational levels.



augmentation as elements associated with program fidelity. Augmentation is the addition to or improvement of the existing materials (Pentz & Trebow, 1991). Augmentation is often referred to as re-invention (Pentz & Trebow, 1991).

Acceptance is the degree to which the program is acknowledged by the system in which it is delivered (Biegel & Song, 1995, McMillan, Tittle, & Hill, 1993, Kirby, Garfink, Starck, Russo, & Bachman, 1991). Additionally, program acceptance is multi-factorial and includes referral patterns and methods, exposure of the program, screening of volunteers, participants and non-participants, and community linkages. Biegel and Song (1995) discuss three elements of acceptance: knowledge of the program; accessibility; and intent to utilize services. Knowledge involves the services by the target population, and the potential service providers who refer the target group to the program. Additionally, knowledge involves the purpose of the program. Accessibility involves affordability, availability, and location of the program. There are four factors that affect the intent to utilize services: attractiveness to target group; personal contact; personal attitudes to seeking help; and cultural factors (Biegel & Song, 1995). McMillan, Tittle, and Hill (1993) also include the time of the day as a factor that facilitates accessibility. They found that evening hours were most suitable for delivering programs. However, the timing was based on the needs of the program deliverers rather than the needs of the participants. Exposure is the number of hours in the program and the number of teachers available to deliver the program (Pentz & Trebow, 1999).

Facilitators of and barriers to program implementation are characteristics of the program that assist and impede program success (Biegel & Song, 1995). If a service is to be used, the target group should have knowledge of the program, the service must be affordable, available, and reachable, and the target group should intend to use the service (Biegel & Song, 1995). One of the most important facilitators to implementation is program planning (Posavac & Carey, 1997). Another barrier to or facilitator of program implementation is the characteristics of rural communities, which will be discussed fully later in this chapter (Bierman, 1997, Ministry of Health, 1995).

Contento, Kell, Keilley, and Corcoran (1992) studied the implementation of the Changing the Course education program developed by the American Cancer Society “to provide students with knowledge, motivations, and behavioural skills to adopt health-promoting and cancer risk-reducing eating behaviours” in northeastern United States (p. 411). “The behavioural goals of this program are to eat a wide variety of vegetables and fruits, especially those high in vitamins A and C, to eat more high-fiber foods, and to eat less fat and fewer fatty foods” (Contento et. al., 1992, p. 411). The target populations were lower elementary grade and upper elementary grade school children. The sixteen lesson plans for lower elementary grade children and fifteen lessons plans for upper elementary school grade children were taught by the classroom teachers (Contento et. al., 1992). Quantification of fidelity to the lesson plans was demonstrated through the use of a Fidelity Index developed by Contento et. al. (1992) to determine how closely the teacher adhered to the written material. They started with a score of 16 for lower elementary curriculum and 15 for the upper elementary curriculum. One point was subtracted for each class not

taught, 0.5 point was deducted for each class where an activity or relevant content was omitted, and 0.25 was deducted for each class taught in which the teacher altered instruction or procedure in a manner judged to lessen the value of the curriculum (Contento et. al., 1992).

Additionally, Contento et. al. (1992) developed a quantitative measure for augmentation called an Augmentation Index. "Starting with 0, 1 point was added for each class in which the teacher added relevant content or activity, and 0.5 for each class in which the teacher altered instructions or procedures in a manner deemed to enhance the value of the curricula" (p. 413, Contento et. al., 1992).

As a result of this evaluation, all the educators completed the curriculum between 90-94% of the time according to the fidelity index. The educators augmented the program on average of two activities within the fifteen or sixteen lessons (Contento et. al., 1992). Thus, the program was implemented as planned as shown in the high fidelity scores. Additionally, the material met the needs of the target group as perceived by the educators as shown by the low augmentation scores.

The issues of fidelity to Burland's plan and augmentation of the material relate to the implementation of the Family-to-Family education program as well as the Changing the Course program because both programs are implemented in multiple centres where adhering to a plan cannot be closely controlled. Thus, the use of a fidelity index can assist in reminding educators to adhere to the program philosophy and program goals. Similarly,

the use of augmentation index encourages the supplementation of the program in a manner that encourages reflection upon the suitability of the materials utilized.

Shortell (1984) presented seven suggestions for improving the study of health program implementation. Shortell (1984) identified the first area of interest as the neglect of program implementation process research. He thought that the emphasis on program outcome, as a result of delivering a program, was a detriment to examining how implementation can affect program outcomes. The second area identified was the reasons for failure of programs to achieve their objectives through theory failure and/or implementation failure (Shortell, 1984). Every program has an underlying theory and assumptions behind it. Additionally, the theory is operationalized in a plan that shows how the program should work. The third area is the quantitative study of program implementation (Shortell, 1984). Shortell (1984) advised that quantitative measures such as calculations of delays in the implementation timetable, deviations from projected client numbers, turnover rates, meeting attendance, dropout rates, session attendance, rate of project management forms, and so on should be used as evaluation tools. Quantitative measures can be supplemented with naturalistic observations of implementations, and open-ended questions (Shortell, 1984). The fourth area of interest is triangulation (Shortell, 1984). This “refers to the use of multiple methods - of data collection, measures, research designs, and even theories” (Shortell, 1984, p. 120). The fifth area of interest was the planned variation in program implementation (Shortell, 1984). Programs that are effective at one point in time and in one setting are not necessarily effective at a different time and place, thus external validity was an issue (Shortell, 1984). The sixth area of

interest is the development of closer ties to organization theory and behaviour (Shortell, 1984). The implementation of programs affects the macro or institutional level, intermediate level of work groups and supervisors, and the individual level (Shortell, 1984). The seventh area of interest is the need for longitudinal studies of program implementation (Shortell, 1984). Shortell's (1984) discussion of program implementation evaluation is a reminder about the need for a careful plan and a careful analysis for the generation of the recommendations for the evaluation of the Family-to-Family education program.

Jerrel and Ridgeley (1999) measured the robustness of program implementation of three types of treatment on the outcomes of a dual diagnosis program. The three types of treatment; behavioral skills training, a 12-step recovery model, and intensive case management were delivered to 132 clients who had a diagnosis of severe mental illness with a co-morbid condition of substance abuse (Jerrel & Ridgeley, 1999). The programs were either robustly or loosely implemented (Jerrel & Ridgeley, 1999). Clients who received the robustly implemented behaviour skills, and case management interventions had significantly higher psychosocial functioning at a lower cost when compared to clients who received the less robustly implemented programs (Jerrel & Ridgeley, 1999).

Pentz and Trebow (1991) reviewed the methods evaluating the quality of implementation of drug abuse programs. These methods of evaluating drug abuse programs are generalizable to the evaluation of health education programs such as the Family-to-Family education program. This paper defines program adherence, exposure,

and reinvention (Pentz & Trebow, 1991). They discussed three types of retrospective qualitative measurements to assess the fidelity of program implementation: self-report; other reports; and behavioural observation (Pentz & Trebow, 1991). Additionally, they discussed the parameters of influence being the person, their situation, and environment (Pentz & Trebow, 1991).

Raizman, Montgomery, Osganian, Ebzery, et. al. (1994) performed a process evaluation of the Eat Smart School Nutrition program. The goals of the school lunch program were providing nutritious, reasonably priced lunches, contributing to a better understanding of good nutrition, and fostering good habits (Raizman et. al., 1994).

Raizman et. al. (1994) developed measures for the evaluation of program implementation. Program management forms were developed to assess fidelity to the protocol using Training Attendance Forms, Visit Summary Form, Promotional Activities Form, School Meal Participation Worksheet, Menu/Recipe Collection Forms, and Guideline Checklists Forms (Raizman et. al., 1994). Even though the forms were developed to assess program implementation in a nutrition program, the use of forms as standard methodology for assessing program implementation is generalizable across programs.

Another method to ensure the fidelity of program implementation is the use of contracts. Baker (1977) discusses the advantages of using contracts in the implementation of cancer research programs. In a contract, the goals, objectives, and priorities of the program are set (Baker, 1977). Additionally, a well-written contract will show clearly delineated guidelines for program implementation, monitoring, and evaluation (Baker,

1977). The utilization of contracts can facilitate close and quick control over the program and can allow for program shifts as quickly as new information is integrated into the program (Baker, 1977). Baker (1977) also discusses the disadvantages of using contracts. There can be a shortage of capable program officers (Baker, 1977). Additionally, the regulation established in contracts may be over-elaborate and sometimes not well accepted (Baker, 1977). Furthermore, the use of contracts can create problems in the running of organizations that either generate the contracts or sign them (Baker, 1977). This paper is useful in the evaluation of the Family-to-Family education program because Burland uses contracts with state or provincial coordinators to assist in adhering to the program.

Rohland (1998) comments about the problems that were encountered when introducing a Medicaid funded, contracted-out mental health program in Iowa. The goal of the program was to provide all mental health services, including evaluation, treatment planning, targeted case management, medication management, and substance abuse programs for person with a diagnosis of mental illness, on a fee-for-service basis for a period of two years commencing on March 1, 1995 (Rohland, 1998). Rohland (1998) found that most problems encountered were due to the lack of a comprehensive plan. She determined that standards of quality and performance indicators were not specified and the contractor developed their own which encouraged conflict between the contractors and the contractee (Rohland, 1998). In addition, there was no plan developed during the contractual development process for patients from rural and remote areas (Rohland, 1998). Another problem encountered was that there was no plan for the safe discharge of children into the community (Rohland, 1998). Additionally, patients were denied authorization for

acute health care services when medically required (Rohland, 1998). Within one year, these issues were solved by clearly setting performance standards and expectations and improving the plan. This reference is useful in the evaluation of the Family-to-Family education program because expectations of both the process of program implementation and the outcomes of this program need to be clearly delineated in contracts with program deliverers.

Kirby, Garfink, Stark, Russo, and Bachman studied the University Hospital Nurse Extender Model which was developed “to enhance patient care despite a declining supply of nurses and increasing demand to reduce health care costs” (1991, p. 22). They found that internal and external systemic factors influenced acceptance of the Nurse Extender Model (Kirby et. al., 1991). Union opposition, insufficient training and preparation of nurses, financial constraints, and changes in nursing leadership during the program trial were internal factors that negatively impacted program implementation (Kirby et. al., 1991). Confusion between the label of Patient Care Technician (PCT) given the personnel who delivered the Nurse Extender Model and an already existing Registered Care Technologists (RCT) impeded external acceptance (Kirby et. al., 1991). Additionally, the nurses’ union did not accept the transfer of care giving activities from registered nurses to unlicensed caregivers (Kirby et. al., 1991). Kirby et. al. (1991) found that an ongoing process of implementation, evaluation, reinvention and re-implementation of the program assisted in solving implementation issues. This program evaluation also found that professional acceptance of the program was integral to program implementation, which is relevant to implementation of the Family-to-Family education program.



Yingling and Trocino (1997) discussed five strategies to integrate patients and family education into patient care design of non-insulin-dependent diabetics and their families. These five strategies were integral in establishing acceptance of patient care program (Yingling & Trocino, 1997). The first strategy was building a plan for patient and family education (Yingling & Trocino, 1997). The second strategy was establishing a mission “to improve the health and quality of life” of non-insulin-dependent diabetics and their families (Yingling & Trocino, 1997, p. 248). The third strategy was building involvement of professionals, diabetics, and their families (Yingling & Trocino, 1997). The fourth strategy was to establish collaboration among professionals with differing expertise and the target population to identify educational needs and to provide a learning environment that strengthens self-management and self-efficacy (Yingling & Trocino, 1997). The fifth strategy was to build accountability into the patient and family education process (Yingling & Trocino, 1997). Often, this strategy involves changing the work culture of professionals to value patient and family education (Yingling & Trocino, 1997). Yingling and Trocino (1997) suggested that this could be achieved through changing job descriptions to include patients and family members as team members in patient care strategies. This final strategy is an integral characteristic of acceptance of the Family-to-Family education program into the formalized mental health system.

Cassady, Orth, Guyer, and Groggin (1997) measured the implementation of injury prevention programs in 44 out of 50 states of the United States. No specific programs were evaluated using the mail out questionnaire and telephone interviews. However, “the

responding programs included injury prevention or control, maternal and child health, health promotion and education, emergency medical services, epidemiology units, environmental health, disability prevention, chronic disease, and health departments” (Cassady et. al., 1997, p. 96). They assessed the index of implementation success by exploring five major factors of legislative activities, injury surveillance activities, monitoring and evaluation, community involvement in the development, planning, and delivery, and institutionalization or permanence of the injury prevention and control programs (Cassady et. al., 1997). They found that some reasons for failure or the minimal success of programs were ambiguous policy directives, lack of a constituency of supportive agencies, unconvincing program rationale, inadequate monitoring or oversight practices, and sufficient capacity for implementation of programs (Cassady et. al., 1997). Additionally, they found that program success was dependent upon solving the problems that were identified as reasons for failure of programs (Cassady et. al., 1997). This review of injury prevention programs is generalizable to the Family-to-Family education program because the evaluation of the Family-to-Family education program includes similar challenges as those faced by evaluators of multi-sectorial injury prevention programs. These challenges include policy development, a constituency of support for the program, monitoring practices, organizational capacity for delivering a multi-sectorial program, and the rationale behind the program.

Referral patterns and methods affect the acceptance of programs. Biegel and Song (1995) studied referral patterns to a support group for families of individuals with a mental illness. There were 198 lower social class family caregivers of individuals with severe

mental disability. From the above sample of caregivers, there were 94 Caucasian and 104 African-American caregivers (Biegel & Song, 1995). Using referral patterns, Biegel and Song (1995) assessed support group referral facilitators and barriers. They found that referrals to support groups were most common from human services and mental health agencies and by personal physicians (Biegel & Song, 1995). Thus, professional referrals facilitated support group attendance. The major obstacles were lack of time, transportation difficulties, lack of need, lack of accessibility, and concern for confidentiality (Biegel & Song, 1995). Additionally, this survey determined that 40% of people who did not attend support groups had never heard about support groups (Biegel & Song, 1995). Since not all caregivers were not in contact with mental health professionals, some other approaches need to be taken (Biegel & Song, 1995). These approaches included use of news media, and develop partnerships with clergy (Biegel & Song, 1995). The accessibility issues could be solved by delivering programs in the neighborhood of the participants, and provide transportation to and from the groups (Biegel & Song, 1995). The factors raised by Biegel and Song (1995) are generalizable to the Family-to-Family program because accessibility was an important factor in delivering the afore-mentioned program.

McMillan et. al. evaluated the nationally implemented, and sponsored by the American Cancer Society, I Can Cope education program which provides resources that help people “to cope with the diagnosis of cancer and it attendant problems” (1993, p. 455). The program delivered information about “cancer, coping with daily health problems, expressing feelings, learning to like yourself, living with your limitations, and resources that can help” (McMillan et. al., 1993, p.455). As part of the evaluation of the

implementation strategy, they surveyed referral patterns to a program by healthcare professionals (McMillan et. al., 1993). The referral sources were physicians, nurses, and social workers (McMillan et. al., 1993). It was noteworthy that primary physicians were least likely to refer because they forgot, and they had little knowledge about the program (McMillan et. al., 1993). Additionally, some physicians felt the program did not meet their patient's need, however these unmet needs were not delineated (McMillan et. al., 1993). The examination of referral patterns is generalizable, as an integral part of evaluating program acceptance as part of implementation, thus, this paper is a useful tool to investigate strategies for evaluating the Family-to-Family education program.

Vinokur, Price, and Caplan (1991) studied the implementation, from field experiments, of an intervention program for unemployed persons. The goal of this program was "to promote reemployment in high-quality jobs and to prevent poor mental health and loss of motivation to seek reemployment among those who continued to unemployed" (Vinokur et. al., 1991, p. 548). Participants and non-participants in the above program had different demographics (Vinokur et. al., 1991). Generally, the participant group was more highly educated, older, suffered less economic hardships, had less confidence in skills, and lower proportions of people re-employed whereas the non-participant group was younger, less educated, suffered more economic hardship, had greater confidence in skills, and greater proportions of people were re-employed (Vinokur et. al., 1991). From the data presented, it may be that non-participants self-select to opt out of the program because they really do not need it (Vinokur et. al., 1991). The results from this evaluation of the participants and non-participants are generalizable to the participants

and non-participants of the Family-to-Family education program because the analysis the characteristics of participants and non-participants overlap in both programs.

Jarrett (1996) evaluated the program implementation of the Parent Partners Program, a parent-to-parent support program, in a neonatal intensive care unit in Washington, DC. The goals of this program are:

1. to provide informal support for families experiencing a premature birth, a critically ill newborn, or a newborn loss
2. to give parents the support and confidence they need to feel that they are part of the intensive care or special care nursery team
3. to provide information to families about hospital and community resources for their infant and family
4. to assist families in the transition from the hospital to home (Jarrett, 1996, p. 142).

The support was provided by trained family volunteers who were screened using a confidential screening tool with contributions from a volunteer coordinator (Jarrett, 1996). Volunteers were trained using a four-session program (Jarrett, 1996). The effectiveness of volunteer training was assessed using pretest and posttests to ascertain how well trainees knew factual information from each of four training sessions (Jarrett, 1996). The trainees learned factual information with 89% to 95% accuracy (Jarrett, 1996). Jarrett (1996) found that the success of the program was predicated on the recruitment of volunteers, which mirrors the importance of volunteer educator recruitment for delivering the Family-to-Family education program.

Bierman (1997) evaluated the delivery of the Fast Track Program in rural Pennsylvania. The Fast Track Program was developed

“to evaluate the feasibility and effectiveness of a comprehensive, multicomponent prevention program targeting children at risk for conduct disorder in four demographically diverse sites: rural Pennsylvania; Seattle, WA; Durham, NC; and Nashville, TN” (Bierman, 1997, p. 494).

At each site, children were randomly assigned to the intervention or the control groups (Bierman, 1997). The six year prevention program was followed by comparing the outcomes of the control and intervention group (Bierman, 1997). The intervention group of children were given an adapted version of Promoting Alternative Thinking Strategies (PATH) curriculum (Bierman, 1997). The PATH program “focuses on skills in four domains related to school success:

- a) prosocial behaviour and friendship skills
- b) emotional understanding and self-control
- c) communication and conflict resolution skills and
- d) problem solving skills” (Bierman, 1997, p 495)

Her evaluation focus was the factors of rural communities that played a role in the implementation of and outcomes from the PATH program (Bierman, 1997). She found that geographic dispersion and isolation of rural communities affected implementation of programs because entry into these communities was challenging, due to the time necessary for understanding of and establishing contact with community members and agencies (Bierman, 1997). Additionally, due to the stability and isolation of rural communities, she found entry into the community challenging (Bierman, 1997). Additionally, Bierman (1997) postulated that rural communities tended to emphasize traditional parenting and educational practices, behavior, traditions, and a belief in self-sufficiency. Bierman (1997) thought that rural culture rather than the content of the intervention affected the process of implementing. Thus, establishing positive, collaborative relationships with professionals,

agencies, families and children has to take precedence over the content during the initiation phase of program delivery (Bierman, 1997). However, she also found that once a program is established, “the small, stable, and more insular community structures of rural areas can facilitate a long term commitment to and ownership of a prevention program that may be difficult to attain in the large and fluid school and community structures in the cities” (Bierman, 1997, p. 512). The information from this paper is directly generalizable to the delivery of the Family to-Family education program in northwest BC. Since northwest BC consists of small rural and remote communities, implementors of the Family-to-Family program will probably encounter similar barriers to program introduction.

From the review of factors affecting the implementation of health education and other programs, one can conclude that program implementation is a complex process. This process is based on a multitude of factors including the theories upon which the program is based, community and individual acceptance of programs, a comprehensive and dynamic implementation plan for program fidelity and augmentation, and the allocation of adequate resources to the program.

## Chapter 4      The Family-to-Family Education Program

In 1993, the BCSS embarked on a process of implementing family education as a service to its stakeholders. That process resulted in the implementation of the Family-to-Family education program. This chapter will provide a description of this program, after describing some of the alternatives available. Additionally, this section briefly describes the program goals and philosophy of other family education and family-ill relative psychoeducation programs available for selection during the same time frame that implementors in BC decided to deliver the Family-to-Family education program. The next section describes the goals, philosophy, and history of the development of the Family-to-Family education program. In addition, the results of an outcome evaluation of the program performed by Pickett, Cook and Laris (1997) will be discussed. The program selection and early implementation process is then described. Next, the two phases of the Family-to-Family education program are described more fully. Finally, the program management system is described.

Family education programs targeted towards mental illness available in 1993 are shown in table 4.1. Where possible, the philosophy of each program will be briefly discussed.

Alexander's (1991) Understanding and Coping with Schizophrenia 14 Principles for the Relatives was a guide to coping, caring and surviving for relatives of people with schizophrenia. The guide was based on the experiential knowledge of family members. It



**Table 4.1 Education Courses Available for Consumers and/or Family****Members**

(Cohen, M. H., Lim, O., & Irwin, D. A., 1998,  
 Scadding, S, & Pearson, C., 1998, Alexander, K.,  
 1991, adapted from Torrey, E. F., 1995, p. 351-352)

<b>Author</b>	<b>Program Name</b>	<b>Orientation</b>
Alexander, K., 1991	<u>Understanding and coping with schizophrenia 14 principles for the relatives</u>	Family
Amensen, C.	<u>How to Survive and Thrive with a Mentally Ill Relative</u>	Family
Bisbee, C.	<u>Patient and Family Education</u>	Consumers with family
Burland, J.	<u>Family-to-Family Education Program</u>	Family
Cohen, M. H., Lim, O., & Irwin, D. A., 1998	<u>University of British Columbia Family Education and Support Group</u>	Family
Hatfield, A.	<u>Maryland Family Education Program</u>	Family
LeGacy, S.	<u>Supportive Family Training</u>	Family
Mental Health Association of Southeastern PA	<u>Coping Skills for Families Training and Education Center</u>	Family
Moller, M.	<u>NurSeminars</u>	Consumers with family
Oregon AMI	<u>Bridges: People Helping People</u>	Consumers
Scadding, S, & Pearson, C., 1998	<u>Guelph Wellington Dufferin Family Education Groups</u>	Family
UCLA	<u>UCLA Skills Training Modules</u>	?

was a tool for the empowerment of family members to take control of their lives through self-care and education. A modified version of this program is delivered in partnership with BCSS coordinators and hospital social workers in some health regions BC.

The Bridges: People Helping People education program is an acronym for **Building Recovery of Individual Dreams and Goals through Education and Support (BRIDGES** [Brochure], undated). This program, developed by the Tennessee Alliance for the Mentally Ill, is directed towards individuals recovering from a mental illness. It is based on the belief that individuals with a mental illness can and do recover. Furthermore, these individuals can achieve a new valued sense of self and purpose in accepting and overcoming the challenges of a disability that affects every aspect of their lives: physical, intellectual, emotional, and spiritual. The program consists of two phases: education and peer support. It was fashioned after the Family-to-Family education program as designed by Burland (1993). The education phase is fourteen weeks long and educates consumers about the etiology and treatment of mental illness, learning about feelings and how to manage these feelings (BRIDGES [Brochure], undated). The support phase was developed to provide opportunities to learn and practice coping skills using trained volunteer peers of people with a mental illness (BRIDGES [Brochure], undated). This program is delivered by consumers of the mental health system in some regions of BC.

The NurSeminars Recovering from Psychosis: A Wellness Approach A 3-R's Recovery Phase Course for Clients, Families, and Providers education program was expanded by Moller and Murphy (1997) from a program developed earlier by Wer and

Moller (1992). The philosophy of this program is that “wellness education and empowerment are the keys to understanding and managing psychiatric disorders” (Moller & Murphy, 1997, p. iv). The course was developed to educate individuals with schizophrenia, major depression and bipolar disorder, their family members, and providers using the most current information regarding the etiology and treatment of these diseases. Additionally, the program was designed “to promote personal and family self-awareness” (Moller & Murphy, 1997, p. iv). The program developers felt that mental disorders, particularly psychoses, affect the entire family. Thus, individuals with the disorder and their family are invited to attend together. The developers believed that, “the more knowledge everyone in a family assimilates at the same time, the more solid the family unit will become. Therefore, individuals with mental and psychotic disorders and their families are taught simultaneously” (Moller & Murphy, 1997, p. iv). The developers also believed, “that families and individuals diagnosed with mental and psychotic disorders serve as teachers” (Moller & Murphy, 1997, p. iv). Additionally, the developers felt that they grew and developed both personally and professionally because they learned from program participants.

Family education groups, developed by Scadding and McQuinn in 1995, were initiated by the Guelph Community Mental Health Centre to be delivered in the Guelph-Wellington-Dufferin region of Ontario. A registered nurse and a registered social worker taught this twelve-week family education program. The course content includes: etiology and treatment; Mental Health Act; crisis management; housing; advocacy; and peer support

(The Glorious Aftermath of the Family Education Groups Caregiver Initiatives in Guelph Wellington Dufferin, Ontario-1995-1999, 1999).

The University of British Columbia Family Education and Support Group has been delivered for ten years. This program is an integral part of the Schizophrenia Day Program at the University of British Columbia Hospital. The goal of the day program is “to enable individuals to develop purposeful and meaningful activities, roles and relationships while decreasing their rate of relapse” (UBC Day Program Brochure, 1995). This nine-session program focuses on educating family members about the etiology and treatment of schizophrenia. Additionally, family members are educated about the family and caregiver experience in the context of relapse prevention, realistic goal setting, and the creation of a low stress environment for their relative with a mental illness. This program also educates family members about crisis management and community resources (Helping Overcome Psychosis Early Website, February 13, 2001, [http://liddlelab.psychiatry.ubc.ca/hope/topic/content/srdp\\_description.html](http://liddlelab.psychiatry.ubc.ca/hope/topic/content/srdp_description.html)). From the above information, it can be concluded that this program is a psychoeducational program focusing on the patient.

#### Description of the Family-to Family Education Program

The Family-to Family education program was designed by Joyce Burland (1998, 1993). In its most recent version, it consists of a twelve-week sequence of classes, delivered by trained, volunteer family educators (see Table 4.3). The first edition of the

program did not clearly outline program philosophy and goals. This lack of clarity affected the acceptance and understanding of the program. However, the second edition described the program more thoroughly. In 1993, Burland initially targeted the program to family members of adults with schizophrenia, bipolar disorder, and severe depression. However, in the second edition, the target group was expanded to include family members of adults with panic disorder, and obsessive-compulsive disorder (OCD), as well as schizophrenia, bipolar disorder, and severe depression (Burland, 1998).

The Trauma-and-Recovery Model of family education is the theoretical basis of the Family-to-Family education program (Burland, 1998). Lindemann (1944, cited in Burland, 1998) proposed the trauma-and-recovery model as a secondary intervention framework. Lindemann (ibid.) found that people normally exhibit severe distress to trauma. Additionally, he found that people adjust to crisis in stages. In the trauma-and-recovery model, the keys to planning appropriate interventions are knowing what a person is experiencing and then determining what interventions they require at each stage of crisis adaptation. This approach assists individuals in overcoming adversity. Individuals overcome trauma through psychic healing that involves “establishment of safety, remembrance and mourning, and reconnection with ordinary life’ (Burland, 1998, p.37). The focus of the Family-to-Family education program is to place the trauma of having a family member diagnosed with mental illness into a “fuller life perspective and even achieve the final psychic victory over misfortune” (Burland, 1998, p.37). Thus, Burland (1998) planned the program to assist family members heal from trauma in a safe environment with other family members experiencing and recovering from similar traumas.

Burland (undated) performed a needs assessment by interviewing over a hundred family members of patients with a mental illness about their perceived needs. Families identified two principal areas of need: practical information and skills, and understanding their personal trauma as a result of coping with a relative with a mental illness (Burland, undated). From this analysis, the program philosophy of family empowerment through self-education improving knowledge, skills, comprehension, and support was developed. Thus, Burland (undated) chose an empowerment model of self-education. The principles for helping families come through trauma were outlined as follows:

- the focus is on the family member, not the ill person.
- families are encouraged to regain the primacy of their own lives
- [the crux of self care is in] expressing anger and grief
- teaching empathy is the means of gaining acceptance of loss
- family members can help each other “let go” (Burland, 1998, p. NB-15)

In the second edition of the program, Burland (1998, p. NB-10) stated that the “purpose of this course is to guide family members to emotional understanding”. The first program goal is empowerment and self-help for families of the individuals with mental illness (Burland, undated). Burland fulfilled this empowerment goal through the inclusion of ways to become an effective advocate, through its built-in assumptions that family members can be effective and capable teachers, and by having family members design and implement the family education program. The self-help goal is a recurring theme throughout each class. For example, educators are directed to say, “you can only help yourself or you can only change yourself, you can’t change others”.

The second goal of the program is to prevent the traumatic impact of mental illness in their family from further undermining family members' own stability and compromising their effectiveness as long term caregivers (Burland, undated). When Burland assessed the needs of family members, she asked questions about, "What have you lost in all of this that was most precious to you? and Tell us what you have had to come to terms with that was hardest for you?" (undated, p. 21). Family members' answers included words like "shattering, devastating, horrendous, agony, and desperation"(Burland, 1998a, p. 36). Burland referred to these words as the "language of family pain" (1998a, p. 36). Burland decided to "use a trauma model of recovery as a constant emotional guide and touch-stone" (Burland, undated, p. 21). Burland interpreted this model as a method for normalizing family members' individual reactions to the traumatic event of having a family member diagnosed with a severe mental illness. This method included the reassurance that there was nothing pathological about their normal reactions to the aforementioned events.

The third goal of the program is personal healing and restoration (Burland, undated). The empowerment model of self-education helps validate individuals' experiences, which are believed to assist in personal healing. Family members found that through self-disclosure discussions of their experiences with others encountering similar or parallel situations often validated these experiences. Some individual family members believed that if their peers felt similarly then it was okay to feel this way, thus self-healing occurred. Often family members felt that their personal guilt was reduced after taking the education program, thus the program promoted personal restoration. For example, Burland (undated, p. 22) stated that, "the most characteristic comment on the evaluation is the

family members' sense of liberation of negative feelings of guilt and entrapment and their newly found confidence in themselves and life's possibilities".

Burland (undated) developed two phases of the program. The first phase is a program in which volunteer family educators are trained, through the use of a manual in the delivery of a twelve-class education program. This phase involves advertising and marketing of the program, screening of potential participants, delivery, monitoring, and evaluation of the program. The second phase is a manual-based training program for support group facilitators to deliver monthly support groups. Both phase I and phase II must be implemented.

#### Outcomes of the Family-to-Family Education Program

The expected outcomes of the entire program are not clearly described in the program materials. However, an evaluation of the program performed by Pickett, Cook and Laris (1997) summarized the program outcomes.

In 1996, at a Family-to-Family education training session in Chicago, Illinois, Pickett et. al. (1997) assessed the attendees' participation in the program using face-to-face interviews, and group tests. This group used the modified version of the client satisfaction scale (Attikisson et. al., 1978 cited in Pickett et. al., 1997) to assess satisfaction with the education course. They also used the Journey of Hope evaluations provided by Joyce Burland. The support group program was assessed by a further modification of the client



satisfaction scale (Attikisson et. al., 1978 cited in Pickett et. al., 1997) and the Maton support group assessment scale (Maton, 1988 cited in Pickett et. al., 1997). The Maton questionnaire uses five sub-scales to assess the dimensions of support groups. The sub-scales are: “support received by group members, support provided by group members, friendships, role differentiation, and overall satisfaction with the group” (Maton, 1988 cited in Pickett et. al., 1997, p. 6). This group also used the Thresholds Family Burden Scale (Cook, Lefley, Pickett & Cohler, 1994 cited in Pickett et. al., 1997) to assess the burden of family members of individuals with a mental illness. Pickett et. al. (1997, p.11) used hierarchical regression analysis to “determine whether respondent and relative characteristics, and levels of satisfaction with the Journey of Hope program were predictive of improved respondent outcomes, as well as whether improved outcomes were predictive of outcomes in another [participant]”. Pickett et. al. found that the

“education course students were primarily female, white, parents, several of whom had other family members who had taken the course, and had heard about the course through AMI [the Alliance for the Mentally Ill], a family member or friend, or from reading about the course from newspaper”. (1997, p. 15)

Pickett et. al. also found that the

“characteristics of the relatives with a mental illness were mostly male (62%), had an average age of 35 years old, with an average age of onset of 22 years old, and with an average length of illness of 12 years. Most were unmarried (79%) and 43% lived with the participant in the Journey of Hope education program. Forty percent of the relatives had had a primary diagnosis of schizophrenia; 27% bipolar disorder; 16% major depression; 10% schizo-affective disorder; 4% other diagnosis such as personality disorder or obsessive-compulsive disorder and 3% of the relatives’ diagnosis were unknown to the education course student”. (1997, p. 15)

Using the Thresholds Family Burden Scale, Pickett et. al. (1997) found that caregiving burden was not significantly reduced by participation in the Journey of Hope education program. Furthermore using the other scales mentioned above, Pickett et. al. (1997) found

that participants had an improved understanding of mental illness, an increased understanding of the treatment system and advocacy activities, improved morale, and more friends. Additionally, Pickett et. al. (1997) found that the more the participants participated in differing phases of the program, the greater degree of improved morale.

Overall, in their evaluation of the Family-to-Family education program Pickett et. al. concluded that the outcomes were:

- increased understanding of the etiology, course, and treatment of mental illness
- improved relationships with the ill relative
- increased awareness of sources of assistance and support
- increased morale and self-care
- decreased feelings of stigma, isolation, and guilt
- greater ability to engage in advocacy
- better communication with service providers (1997, p. 5)

#### Program Selection and Early Implementation of the Family-to-Family Education Program in British Columbia

The volunteer implementors of the Family-to-Family education program were Elaine Preston and Margaret deLange. Elaine Preston was the mother of five sons; one was diagnosed with schizophrenia in the 1970's. She dedicated the latter stages of her life (she died in 1998) to a greater understanding of the needs of those with a mental illness and their families. Margaret deLange is the mother of two sons, one has a mental illness that has been diagnosed as schizophrenia. As a former BCSS regional coordinator in the Fraser Valley/North Shore/Sunshine Coast, she has dedicated her life to her family and the education and support of families of individuals with a mental illness and their afflicted

relatives. Preston and deLange selected the program based on hearing a presentation at the 1993 International Association of Psychosocial Rehabilitation Symposium (IAPSRs) (Preston, 1998, personal communication). Preston felt that through her personal experience and knowledge of other BCSS members' experiences, family members needed this program. Her rationalization of this selection was based on the knowledge that Joyce Burland, the originator of the program, was a family member of individuals with mental illness. Burland's personal experiential knowledge validated the program for Preston. Preston was also attracted to the program because family members taught the course to other family members. This empowerment of family members of individuals with mental illness meshed with the role of BCSS in the mental health system in BC.

There was no needs assessment performed by the implementors in BC. Through their personal experiences and their knowledge of other families' experience with having a relative with a mental illness, both deLange and Preston appreciated that families needed information about the mental illness and they had an understanding of the feelings of family members. The primary motivation was to help other families to cope with mental illness in their family. Preston said:

"I'm glad that I didn't listen to the people who were against it. This is the one thing in my life that I really felt that I don't care what they think. I am going ahead with it. WE NEED IT. I knew what it did for me the first time I taught this; the first time actually I took my training. I said I have made so many mistakes but it's okay now I can rectify those mistakes. It's what I need and if I need it, so does everybody else. It's just everything that I thought it would be and more" (1998, personal communication).

The original name of the program, Journey of Hope, meshed with the BCSS message of hope for alleviating the suffering caused by schizophrenia and other related disorders. Preston felt that “hope was the light at the end of a tunnel for family members of individuals with mental illness” (1998, personal communication).

### Phase I of the Family-to-Family Education Program

This section provides general information about phase I of the Family-to-Family education program as it began to be implemented in BC. The first phase of training of volunteer educators involved a three-day intensive training session by the provincial coordinators of the program. The training was done in co-leader pairs for each venue. After learning the philosophical basis of the program, the participants practiced delivering some of the workshops in the curriculum and teaching the material. The provincial program coordinators offered tips and constructive advice on improving the teaching styles of the educators. A comprehensive manual was provided for each family educator. The motto of this program was “it’s all in the [Family-to-Family Education Manual] book” (Preston, 1996, personal communication).

The program trainers also provided samples of funding proposals because the provincial budget for the Family-to-Family education program only covered the training of the volunteer family educators and support group facilitators. The delivery of the local Family-to-Family education programs had to be locally funded through the health authorities responsible for administering Consumer and Family Initiatives Funds. These

health authorities were in turn funded by the BC Ministry of Health. In northwest BC, these funding proposals included: rental of the venue, coffee break supplies, charts, photocopying, miscellaneous supplies, end of class celebration, and travel, accommodation, and meals when the program was delivered in Smithers or Prince Rupert.

The second portion of the first phase was the delivery of the program by the co-leader pairs. The program manual was organized in a sequential, task flow manner. The first chapter, "Nuts and Bolts", described the basic elements of the program (see table 4.2).

The marketing and advertising phase was important for gaining acceptance as an integral part for the successful delivery of the family education program. To attract family members, the program needed to be marketed in the community in which it was delivered. Community outreach or marketing encompassed many of the strategies that the program suggests (Burland, 1993). Any advertising for the program had to encourage the target group to participate. Therefore, community organizations, religious organizations and places of employment were targeted for poster advertising. Also, the community activities section of local newspapers provided free advertising for voluntary organizations.

**Table 4.2      Elements in the Nuts and Bolt Chapter** (Burland, 1998)

- |                                                                               |                                      |
|-------------------------------------------------------------------------------|--------------------------------------|
| -the length of the course                                                     | -participants who qualify            |
| -group size                                                                   | -choosing a site                     |
| -mixing relative groups                                                       | -mixing "old timer" and "new comers" |
| -how to deal with drop-outs                                                   | -how to deal with late-comers        |
| -working out leadership roles                                                 | -role of the support person          |
| -job description of the resource person                                       | -course video                        |
| -the pre-course family visit                                                  | -course description                  |
| -teaching skills                                                              | -principles of family support        |
| -group process skills                                                         |                                      |
| -connecting education classes to support groups                               |                                      |
| -educator attributes that assist in delivering family education               |                                      |
| -principles of helping families come through trauma                           |                                      |
| -how to deal with someone wishing to take the course who has a mental illness |                                      |
| themselves                                                                    |                                      |

Local cable television companies provided free messages on their community calendar channels. The advertising strategy also encouraged professionals to accept the program, and refer family members to the program. Therefore, promotional material geared to professionals was needed to elaborate how the program can facilitate the delivery of their services. For example, emphasizing that family intervention reduces relapse rates in individuals with mental illness assisted in marketing the program to physicians.

The content of the twelve-week program is shown in table 4.3. Burland (1998, undated) developed the content based on the needs assessment and the trauma-and-recovery model..

#### Phase II of the Family-to-Family Education Program

This section provides general information about phase II of the Family-to-Family education program as it began to be implemented in BC. The second program phase involved the training of support program facilitators as co-leader pairs and addressed the delivery of support groups to graduates of the first phase. The training program entailed: an introduction, program overview, role of the facilitator, communication skills, facilitation skills, common group problems, problem solving, support group exercises, support group logistics, how to introduce Family-to-Family support groups to existing support groups, and the facilitator as a person (Mayeux correspondence, July 24, 1996).

**Table 4.3 Family-to-Family Education Program Content**  
(Burland, 1998, p.1.26)\_

<b><u>Class Number</u></b>	<b><u>Class Content</u></b>
1	Introduction to Family Education
2	Symptoms of Schizophrenia, Major Depression, Bipolar Disorder; Getting through critical periods
3	Subtypes of Depression and Bipolar Disorder; Panic Disorder and OCD; Telling our stories
4	Basics about brain biology and the causes of brain disorders
5	Problem solving workshop
6	Medication review
7	Empathy: Inside mental illness
8	Communication skills workshop
9	Self-care
10	Rehabilitation; Making choices for recovery
11	Fighting stigma; Advocacy
12	Evaluation, certification, and celebration



**Table 4.4 Family-to-Family Program Principles of Support**  
(Burland, 1998b, p.10)

<b>Number</b>	<b>Principles</b>
1	We will see the individual first, not the illness.
2	We recognize mental illnesses are brain disorders.
3	We aim for better coping skills.
4	We find strength in sharing experiences.
5	We reject stigma in ourselves and others.
6	We won't judge anyone's pain as less than our own.
7	We forgive ourselves and reject guilt.
8	We embrace humour as healthy.
9	We accept we cannot resolve all problems.
10	We expect a better future in a realistic way.
11	We will never give up hope!

This second phase reinforced the principles delivered in the education program. The Family-to-Family principles of support are shown in Table 4.4. These principles in tandem with standard meeting format guidelines and a family-to-family approach contributed to a successful support group program (Mayeux, undated). Using a structured format to keep the support meeting on track is fundamental to having meaningful group discussions that helped the family member participants. This phase of the program re-emphasized the skills learned in the education phase and the value of experiential knowledge in providing peer support.

#### Program Management Mechanisms

Burland established a program management mechanism. When first introducing the program to a new venue, Burland used contracts to ensure fidelity to the program (Journey of Hope Contract, 1994). Once the contract to follow the program was signed, it was expected that the program deliverers would follow the program management mechanism described in the “course forms” section of the program manual (Burland, 1998, 1993).

The first program management form is the Class Sign-up Sheet for use in classes 1 through 3. All attendees sign the form with their name and contact phone numbers (Burland, 1998). The form also includes the location of the class and the name of the affiliated organization. This form will be sent “to the state or provincial program director after class 3” (Burland, 1998, p. CF-3).

The second program management form is the Class Composition Report. This form includes information about the course location, the course start date, and the names and contact numbers of the teachers. The co-educators include the names of all attendees (even those who have dropped out), the relationship to their ill family member, and their relative's diagnosis (Burland, 1998, p. CF-6). If a person dropped out, the co-educators were instructed to place a "D" beside their name. A copy of the form was made and the original was to be sent to the provincial program director after class 3. In BC, this information was sent to Preston until her death, then it was sent to deLange until 1999. Starting in 1999, the material was sent to the BCSS provincial office.

The third form to be delivered to the program directors is the Final Census Form. This form includes information about the course location, the course finish date, and the names and contact numbers of the teachers. The attendees fill in their name, address, phone number, their willingness to join NAMI or BCSS, continue to be members of NAMI or BCSS, and availability to volunteer.

The family co-educators fill-in the Final Census: Class 12 form for delivery to the program directors (Burland, 1998, p. CF-9). This form elicits information about the course location, and contact teacher. It requests information about the total number of people who started the course, and the total number who finished the course. It wanted to know if the dropouts were visited before the course, and whether the dropouts were drop-ins. The form requests the names of the dropouts and the reasons for dropping out. Also, it includes the

number of evaluations that were not collected. These forms also included reminders for the educators to collect and include the class evaluations, final class list, and both teacher evaluations.

The fifth form to be included is the NAMI Family-to-Family Program Course Evaluation form. This form includes “a family information portion with the date, course location, information about the caregiver, and information about the relative of most direct concern to you who has a mental illness” (Burland, 1998, p. E.1). The second part of the evaluation form is devoted to program evaluation. This section consists of three short answer survey questions and three questions about content and presentation. The first part asks for your “overall impression of the NAMI Family-to-Family education course. How do you feel you have benefited from taking the course?” (Burland, 1998, p. E.2). The second part asks about possible improvements and “how the course has enriched your experience” (Burland, 1998, p. E.2). The third part asks for comments about the teaching-support team leading the class. For the next question, participants were asked to rate the course and presentation on a scale from one to five where one was poor, and five was excellent. The first area assessed was about diagnostic, research, and medical information found in classes 2, 3, 4, and 6. The second area assessed was problem solving and communication techniques found in classes 5, and 8. The third area assessed was learning about feelings, self-care and empathy found in classes 1, 7, and 9. The fourth area assessed was learning about rehabilitation, recovery and advocacy in classes 10 and 11. The sixth and seventh areas assessed were whether the course content and presentation met the participant’s expectations. Expectations were scored on a scale from one to five where one

was equivalent to “did not meet my expectations” and five was equivalent to “exceeded my expectations” (Burland, 1998, p. E.3). The final question in the evaluation is, “as a result of taking the course, do you feel more confident and more comfortable dealing with your family member who has a mental illness?” (Burland, 1998, p. E.3). The participants were instructed to check one of the following: not at all; somewhat; a good deal; or a great deal.

The final program management form is the Teacher Evaluation form. This form elicits information about the course location, teacher’s name and date of evaluation. The family educators were asked four questions in an open-ended question format. The first question is, “give us your overall impression of how the course was received by your class” (Burland, 1998, p. CF-11). The second is, “tell us how the teaching experience affected you” (Burland, 1998, p. CF-11). The third question is, “would you be willing to teach the course again next year?” (Burland, 1998, p. CF-11). The final question is, “tell us of any ideas, suggestions, comments, etc., you might have about the course or the training, now that you have taught the course” (Burland, 1998, p. CF-12).

The use of these forms enabled the program directors to monitor and evaluate the program. The improvement-focused evaluations were used to revise the program based on the comments of participants and educators for the second edition of the education program.

## Chapter 5      Methodology

A case study method was chosen as the method for conducting a formative evaluation of the implementation of the Family-to-Family education program. Creswell (1998) supported the use of this qualitative approach as an appropriate choice for evaluation research. He noted,

“a case study is an exploration of a bounded system...over times through detailed, in-depth data collection involving multiple sources of information rich in context. This bounded system is bounded by time and place and it is the case being studied - a program.... Multiple sources of information include observations, interviews, audio-visual materials, and documents and reports. The context of the case involves situating the case within its setting, which may be a physical setting or the social, historical, and/or economic setting for the case.” (Creswell, 1998, p. 61)

Posavac & Carey (1997) described an improvement-focused model in which the evaluator notes discrepancies between what is planned, projected, or needed, and what was observed, then makes recommendations for improvement. They further stated that there needs to be clear explanation of “what is not occurring as expected” (Posavac & Carey, 1997, p. 27).

In this study the question of interest was how the Family-to-Family education program came to be implemented, rather than program outcomes. If outcomes were to be evaluated, this researcher would have assessed outcomes using pre-test and post-test standardized tests (from the literature) of knowledge about the disease etiology and treatment, burden scales, cross-sectional analysis of ill relative’s relapse rates, and usage of mental health services.

The methods employed in this thesis to build a complete picture of the implementation of the program included:

1. A review of archival reports, brochures, and administrative reports to describe voluntary organizations and BCSS
2. A review of the academic and self-report literature of the educational needs of family members of people with mental illness
3. A review of the literature on program implementation
4. A review of government documents to describe British Columbia and Northwest British Columbia and to provide an overview of the mental health system
5. A analysis of the interviews of key informants on the selection and implementation of the Family-to-Family education program
6. A review of the correspondence about and funding proposals for the Family-to-Family education program
7. A review of both editions of the Family-to-Family education program itself
8. Experiential knowledge arising from the role as regional coordinator of the Family-to-Family education program
9. Observational data and reports from the Family-to-Family education program.

The key informants selected for the interviewing process included the volunteer program implementors, Elaine Preston and Margaret de Lange. They were selected because they had the knowledge of their plans for implementing the Family-to-Family education program. Furthermore, this knowledge was not available in the program

archives. The taped interview with Elaine Preston was conducted over the telephone on April 10, 1998. Both the interviewer and interviewee were in their own homes. The taped interview with Margaret deLange was conducted using a face-to-face interview on June 19, 1998 at a conference in Kelowna, BC. Both interviews were transcribed and analyzed. Other key informants were four members of the Board of Directors of BCSS in 1994. Selected members were asked about the board discussions about the presentation by Elaine Preston and Margaret deLange in 1994.

The key informant interviews involved the use of the following open-ended statements or questions:

1. Tell me about how you decided to choose the program.
2. What was it about the program that made you feel that it was what you wanted?
3. What did you know about the people who developed the material?
4. Did you look at other programs?
5. Tell me about the decision to try the program.
6. What happened when you brought the program to the BCSS board?
7. Did you try to get funding?
8. Tell me about your plan to implement the program.
9. Did you perform a provincial needs assessment?
10. When you started did anybody look through the literature showing that there was a role for family education?
11. How was the pilot received?
12. Tell me about your personal experience with mental illness.



13. Is there anything that you would have done differently as you reflect back?

During the interview process, the interviewer asked other questions when necessary to clarify statements made by the key informants. The interview process provided information about the education phase (phase 1) of the program but no information on the implementation of support group phase (phase 2).

The collection of information was impeded by the death of one of the key informants, Elaine Preston. This resulted in the need to collect correspondence to other regions, other BCSS coordinators, and BCSS members throughout the province in order to complete the picture of the implementation of phase 1. This death also affected the ability of this researcher to collect archival information about the implementation of the Family-to-Family education program in British Columbia. Previous to Preston's death the transfer of archival information to this author was free flowing, whereas after her death, the archival information released was controlled. This control resulted in recall bias that this author could not control. However, it is important that this bias be acknowledged.

The author of this thesis used her own personal experience and records as a source of information and had an insider relationship with the implementors and BCSS. The researcher was responsible for the implementation for the Family-to-Family education program in northwest BC. Therefore, bias in the collection and interpretation of the data could be problematic. The foremost type of bias of which to be aware in this study was recall bias (Hennekens, et. al., 1987). Recall bias occurs when events are self-reported in a non-comparable manner (Hennekens, et. al., 1987). The records of this author were not

comparable because she was the only person responsible for the implementation of the Family-to-Family education program in northwest BC. In some cases, the author was able to confirm information by debriefing volunteer family educators, specifically, Eileen Callanan from Terrace. Another area of bias which needs to be discussed is the objectivity of the researcher when she is an active participant in the implementation and evaluation process. This author tried to be objective when self-evaluating her implementation of the Family-to-Family education program in northwest BC. The process was already started before her employment in 1995, thus she had no control over the early implementation events. It took almost a year to write and implement a more effective plan for implementation, based on community consultation, in northwest BC. In addition, because this case study involved active participation, it was impossible to blind the author in order to maintain an absence of bias in analysis and objectivity. The selection of topics to be evaluate was biased because the selection was based on her experiences as a participant rather than an outside observer. It is feasible that another author may have selected different topics to be analyzed. A second source of selection bias occurred through the selection of the key informants. Other key informants could have been selected. Some potential key informants were not selected because they were new employees, new board members, and/or the researcher felt that the data collected from other key informants was reproduced dependably.

Another type of bias of which to be aware was interviewer bias when collecting information. Since the researcher was aware of the potential for recall and interviewer bias prior to conducting the research, the key informant interviews were designed to solicit

similar information from the volunteer implementors. This author used the same questions for both key informants. When analyzing these interviews, the reliability of most of the data used was strengthened because they were confirmed by both key informants.

### Analysis Plan

The analysis plan included sequentially outlining the implementation events using the key informant interviews, Family-to-Family Education program correspondence, and reports, followed by the examination of the facilitators of and barriers to implementation of the program. Information about the participants was analyzed using the data collected from the program evaluations. Information about the non-participants was collected from the personal experiences of the researcher and one teacher, Eileen Callanan. At the end of this section, specific recommendations targeted to improve the procedures for the implementation of the Family-to-Family education program will be suggested. Also, improvement focused recommendations will be directed to the program developers, program implementors, BCSS, and Mental Health System in northwest British Columbia.

## Chapter 6      Implementation

This chapter expands more fully on the implementation of the Family-to-Family education program in BC and northwest BC, based on the methods outlined in the previous chapter. Additionally, this chapter analyses some of the barriers and facilitators to implementation. This analysis will enable the generation of focus-improvement recommendations.

### Plan for Implementation of the Family-to-Family Education Program in British Columbia

Initially, there was no comprehensive written plan for the implementation of the Family-to-Family education program. However, the implementors of the program had a strategy for the delivery of the program. From the key informant interviews, Preston and deLange (1998) knew that they needed the following:

- financing for the program
- to pilot the program
- family support for the program
- BCSS support for the program at the branch and provincial level
- professional support for the program
- a method for delivering the program throughout BC.

Figure 6.1 presents a temporal analysis of the implementation of the Family-to-Family education program. This time line is a result of the analysis of key informant interviews with Elaine Preston and Marg deLange, and correspondence, and archival information from

the Family-to-Family education program. This time line reflects the accurate name of the program at the time of each step in implementation. Critical points that influenced the direction of the implementation will be discussed in temporal order.

The lack of endorsement by the BCSS board of directors in 1994 greatly influenced the implementation. When asked, some board members told the researcher that they did not understand what the program's expected outcomes were and felt that BCSS did not have sufficient resources to fund the program. Other board members felt that there was no plan and they felt that there was nothing to endorse. Because this program focused on schizophrenia and other mental illnesses, this broadened focus was unacceptable to some board members of BCSS. Unfortunately, this rejection was misinterpreted as a personality conflict by Elaine Preston. The board members who voted to approve the plan had existing trust relationships with the volunteer implementors and this trust relationship positively affected their level of understanding the program.

As a result of the vote to reject the endorsement of the program, the members of the unincorporated Langley Branch of BCSS were motivated by Preston with the support of deLange to use the resources of the afore-mentioned branch. The Langley branch raised the funds to purchase the rights to the program using funds raised through a casino gaming license (Preston, 1998). In August 1994, Preston signed a contract with the Louisiana branch of National Alliance for the Mentally Ill (NAMI) to deliver the program (NAMI Contract, 1994). The Louisiana branch of National Alliance for the Mentally Ill (NAMI) acted as the official agent for Joyce Burland, the originator of the program.

In January, 1995, the pilot delivery of the program in Langley and Maple Ridge was well received by family members (deLange, Preston, 1998). The pilot was considered a success because the participants told the implementors in the evaluations that it met their needs and that the program should be delivered everywhere in BC. The implementors communicated the results of the evaluations to the staff of the Adult Mental Health Division, BC Ministry of Health and other professionals. The evaluation results spread through informal communication channels (ibid.).

In spring 1995, professional support from the Provincial Adult Mental Health Division influenced the Canadian Mental Health Association, BC Division (CMHA) to fund the program from the provincial mental health education fund administered by CMHA and now administered through the provincial office of BCSS (Preston, 1998).

After deLange and Preston were trained to train other volunteer family educators in May, 1995, they proceeded to recruit family educators from branches and the membership of BCSS (Correspondence, 1995). Arrangements were made to deliver training sessions in various health regions with deLange and Preston (Personal communication, 1998). In 1996, Preston and deLange were trained to deliver training of volunteer family support group facilitators (Correspondence, 1996). Thus, support group facilitator training begins in the fall of 1996 (Preston, 1998).

As the success of the program grew, greater numbers of family members and professionals accepted the program. The successful pilot drove the training of educators for the education program and training for the support group facilitators. The program expanded and was delivered in most areas in BC. The family members from these health regions in BC found that the program met their educational requirements as shown by the Family-to-Family program evaluations. Due to the program's success and influence from the grassroots of the organization, the BCSS board of directors unanimously approved Journey of Hope education program as an official BCSS program in June 1997 (Minutes BCSS Board Meeting, June 1997). Additionally, the board of directors appointed Elaine Preston to be the volunteer provincial coordinator (Minutes BCSS Board Meeting, June 1997).

The Journey of Hope education program name changed in the Fall of 1997 to the Family-to-Family education program due to legal issues in the United States (NAMI Correspondence, 1997). The Journey of Hope education program continues as an eight-week program offered through Health Maintenance Organizations instead of NAMI (NAMI Correspondence, 1997, Journey of Hope Correspondence, 1997). Preston and deLange decided to deliver the NAMI Family-to-Family education program due to their own personal commitment to the twelve week program designed by Joyce Burland (deLange 1998, Preston, 1998).

Figure 6.1 Time Line for the Implementation of the Family-to-Family Education

Program Phases 1, and 2

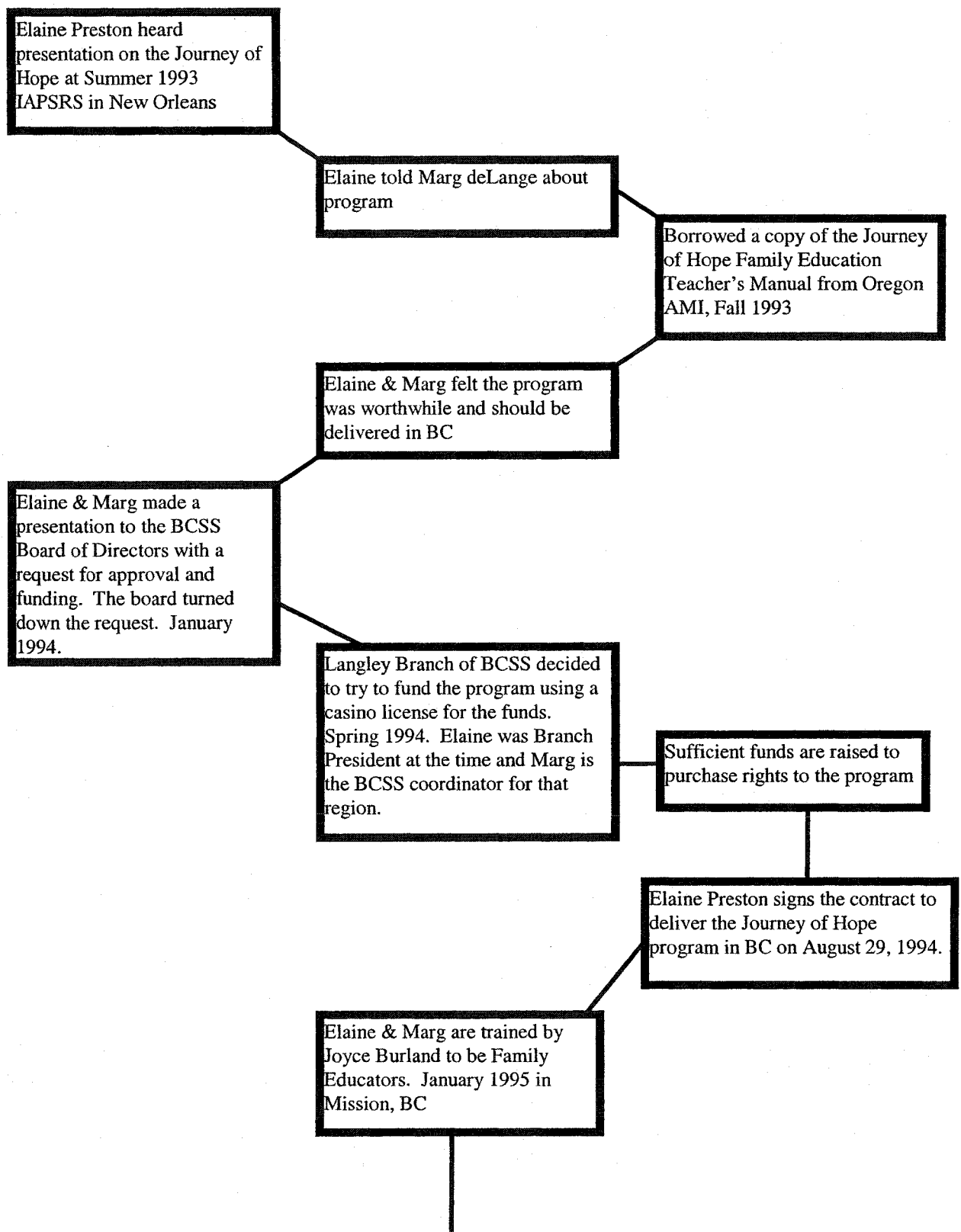




Figure 6.1 Time Line for the Implementation of the Family-to-Family Education

Program Phases 1, and 2 (continued)

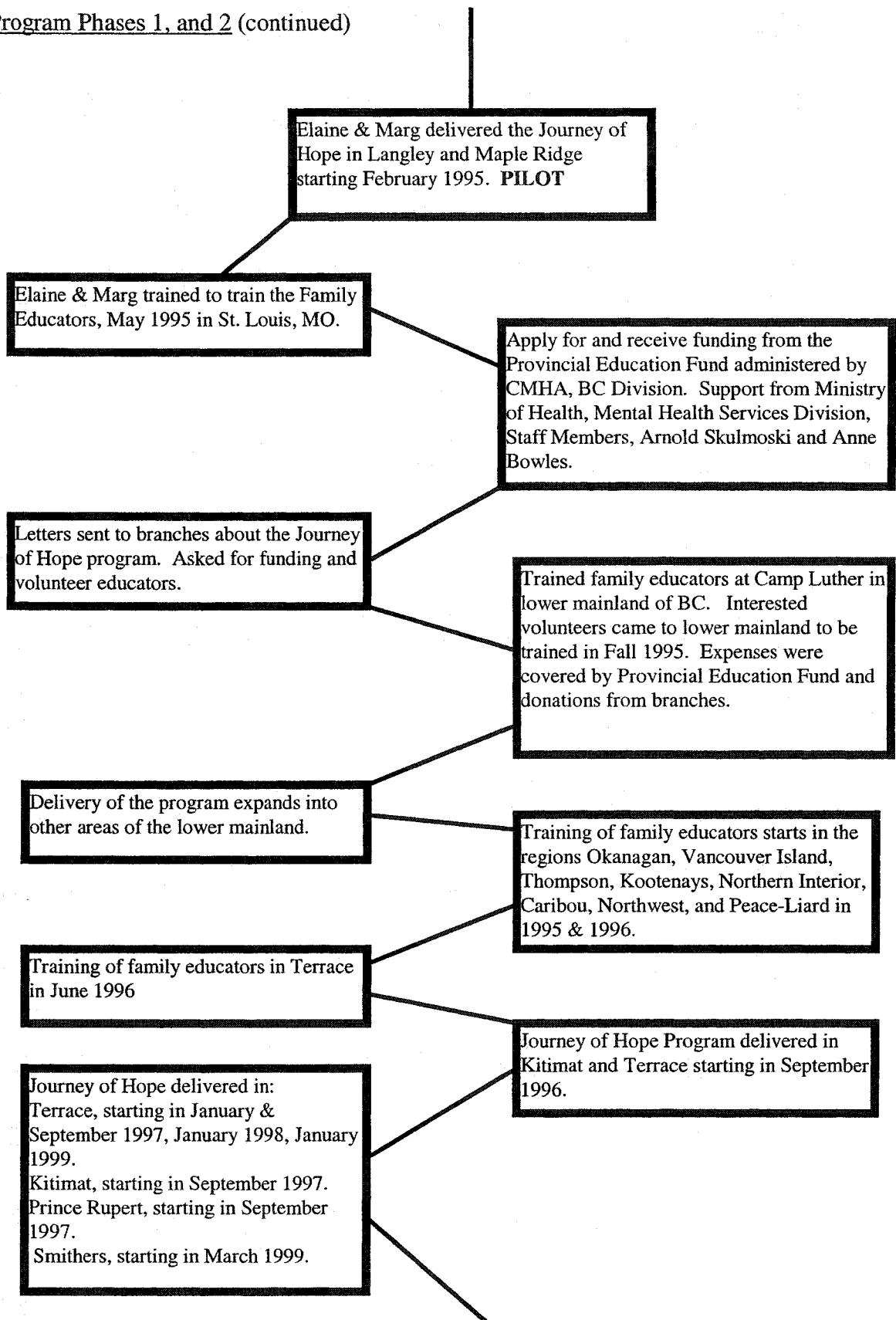
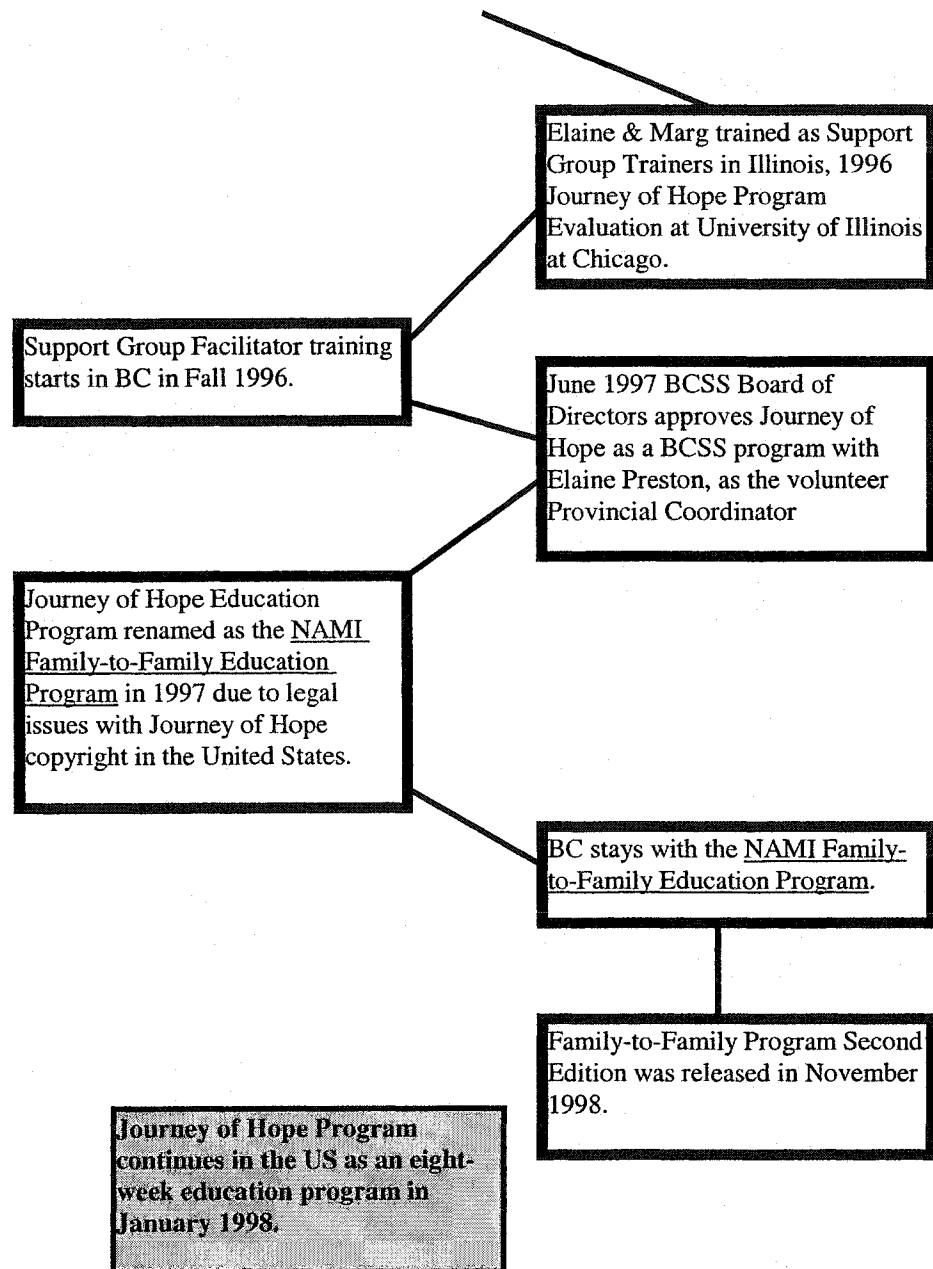


Figure 6.1 Time Line for the Implementation of the Family-to-Family Education

Program Phases 1, and 2 (continued)



As part of the implementation strategy for the Family-to-Family education program, letters and information packages were sent to the branch presidents of BCSS. In Terrace, the branch president received this information and the branch decided to run the training program in 1996. Fourteen volunteer family educators were recruited and trained in June 1996. In Kitimat and Terrace, the family educators delivered the Family-to-Family education program commencing in September 1996. There was no plan for the implementation of the program in northwest BC at that time. However, in 1997, a plan was developed by the northwest regional BCSS coordinator to implement the program. As of May 1999, the program has been delivered five times in Terrace, two times in Kitimat, and one time in Prince Rupert, and Smithers.

#### Facilitators of the Program Implementation in Northwest British Columbia

##### Community Outreach Strategy

The community outreach strategies and the elements in the “Nuts and Bolts” chapter of the manual facilitated the delivery of the Family-to-Family education program (Burland, 1998, 1993). Commencing in 1996, family educators in Terrace, this researcher, and a Northwest Community College Mental Health Worker practicum student charged with the task of assisting the delivery of the program in Kitimat implemented the suggested community outreach strategies. The practicum student was working under the supervision of the BCSS coordinator for a three-month placement.

The community outreach strategy utilized the community development planning model described in chapter 3 (Dignan & Carr, 1992). The BCSS coordinator designed and

carried out a specific community awareness campaign that strategically targeted specific professional groups. This campaign was designed to demonstrate to professionals how the program could make their work easier. For example, when the letter was targeted to the social worker at the hospital whose role it is to inform families about a specific mental illness and plan for discharge from the hospital, the letter explained that the program teaches family members about the etiology, and treatment of mental illness and gives the family members a discharge checklist to assist the social worker. The social worker from Mills Memorial Hospital stated, "it makes my job easier when I work with graduates of this program" (Braid, 1999, personal communication).

The "Nuts and Bolts" chapter, outlined in Table 4.2, empowered the educators with some skills to effectively deliver the classes (Burland, 1998, 1993). Family educators self-reported in evaluations and in debriefing conversations with this researcher. They reported that the tips in handling the differing roles of family members were important for developing empathy for parents, siblings, children, and/or friends (Burland, 1998, 1993). Additionally, the educators reported that the section on mixing "old timers" and "newcomers" proved invaluable when trying to encourage newcomers to be hopeful about recovery against the backdrop of old-timers whose relative with a mental illness had been treated with older and less effective strategies and typical anti-psychotic medication with many side effects. The educators further reported that this section assisted them to accentuate the differences between then and now and encouraged a hopeful attitude. In the second edition of the program, the section on group process skills assisted the educator's understanding of the delivery of the program (Burland, 1998). In 1999, the checklist on the

attributes of a family educator (shown in Figure 9.1), developed by a volunteer family educator and the BCSS regional coordinator was helpful when the Terrace group recruited new trainees. In retrospect, such a checklist would have assisted the BCSS coordinator in the initial family educator recruitment drive.

### Pre-course Family Visit Strategy

Burland (1993, 1998) designed a pre-course visit by the family educators to the potential program participants. For the delivery of the program in northwest BC, the pre-course family visit was the most effective facilitator of the program. The staff of the psychiatric ward at Mills Memorial Hospital in Terrace sent some potential participants to the program without referring these participants to the educators for a pre-course visit. As a result, seven drop-ins occurred. The course drop-ins were friends of a young individual newly diagnosed with schizophrenia, a professional and his/her family, a patient in the unit, and his/her spouse. This serendipitous occurrence gave the family educator and this researcher an opportunity to make comparisons between participants with a pre-course visit and the ones without the visit. The participants with a pre-course visit established a level of safety and comfort with the educators and understood the reasons behind the course, whereas, the drop-ins had no relationship with the educators and appeared to feel threatened. The drop-ins tended to be argumentative in the class. They argued with the educators about the diagnosis of mental illness, treatment strategies, and the use of medications. The BCSS coordinator and one of the family educators intervened and made visits to the drop-ins in order to clarify what the program was designed to deliver. After

these interventions, the drop-ins decided that they would receive their support and education on a one-on-one basis delivered by family volunteers or the BCSS coordinator. Additionally, since the program targets friends and family members of individuals with a mental illness, the family educators considered the participation of the patient, the professional, and his/her family inconsistent with the program's orientation. After this occurrence, the BCSS coordinator met with hospital staff and discussed with them about making appropriate referrals to the Family-to-Family education program. It is noteworthy that the pre-course visit would have made the drop-ins feel more comfortable and would have given them the opportunity to determine whether the program was appropriate for them.

In addition, the family educators in one northwest community did not perform the pre-course visit resulting in a dropout rate of 50% (Final Class Census Forms).

### Program Content

In northwest BC, another facilitator of the program was the content of the education program itself. This content reflected the needs of family members from the pre-dominant culture in the region. This content and the word-of-mouth reports of the content enabled the educators to attract family members to the program.

## Barriers to Program Implementation in Northwest British Columbia

### Systemic Misunderstanding of the Program

In northwest BC, the greatest barrier to the implementation was the lack of understanding of the program's philosophy, goals, and expected outcomes. It became apparent that this lack of understanding was systemic and included family members, the BCSS coordinator, professionals, and consumers. Initially, there were no referrals from professionals, and it was very difficult to recruit program participants. The initial recruitment was mostly due to the personal relationships with volunteer family educators and the BCSS coordinator. Additionally, because the program materials did not clearly explain the program, the coordinator found it difficult to put together a funding proposal and an information package. The promotion of this new, American program in northwest BC would have been easier if there had been supporting documentation from the program developers. A single page describing the program's philosophy, goals, and expected outcomes would have been more effective in assisting the volunteer educators to gain acceptance of and local funding for the program. This documentation would be targeted at professionals who would refer family members to the program. This researcher found that psychiatrists, doctors, psychiatric nurses, social workers, and other professionals needed to be persuaded to make referrals. The use of published reports and self-report literature would be a solution to this identified barrier. Additionally, an explanation of the expected outcomes would increase accountability by setting a standard by which health authorities could measure performance.

Another potential facilitator for the understanding of the program in northwest BC would be a written report of the success of the pilot programs in Langley and Maple Ridge. The BCSS coordinator could have taken the written results of the pilot to mental health service providers. Unfortunately, this author received no information about piloting the program until she started the process to research this thesis topic.

Some consumers felt very angry about an education program targeted towards family members when there is no comprehensive education program targeted towards consumers of the mental health system in northwest BC. This anger was directed towards the individual family members, the BCSS coordinator, and some family educators. The anger directed towards family members by their relative with a mental illness caused family members to refrain from participating in the program. To alleviate, some of these bad feelings, the BCSS coordinator organized a conference in November 1998. One of the speakers was the volunteer BC coordinator of the BRIDGES program who discussed this program and Schizophrenia Anonymous (Conference [Brochure], 1998).

### Funding Barriers

Another barrier to the delivery of the Family-to-Family education program was the discrepancies in the Mental Health Division, BC Ministry of Health's implementation of the Consumer and Family Involvement Fund in different communities in the northwest region. In Terrace and Kitimat, the fund was implemented as a Consumer and Family



Involvement Fund (CFIF) whereas in Prince Rupert and Smithers it was implemented as a Consumer Involvement Fund (CIF). In 1997, the BCSS coordinator applied for funds from the Prince Rupert Consumer and Family Involvement Fund for the delivery of the Family-to-Family education program in that community. The request was denied by way of a phone call because there was no Consumer and Family Involvement fund, only a Consumer Involvement fund. At this point, the BCSS coordinator was confused. Staff from the Mental Services Division clarified the situation as described in the next paragraph. Funds were obtained from an alternate source and the program was delivered in Prince Rupert. The BCSS coordinator informed the acting director of Mental Health Services for the Northwest Community Health Services Society (NWCHSS) about this discrepancy and the contract for Prince Rupert was amended to reflect family involvement commencing in the 1998-1999 fiscal year. In 1999, the BCSS coordinator faced similar problems when applying for funds to deliver the Family-to-Family education program in Smithers. Again, the BCSS coordinator had to inform the acting director Mental Health Services for NWCHSS that the approval process was delayed due to the lack of clarity about family involvement funding. The Consumer and Family Involvement Funds contract was amended to reflect family involvement commencing in the 1999-2000 fiscal year.

The Consumer and Family Involvement Funds were included in 1992 BC Ministry of Health Mental Health Plan (Skulmoski, 1998, personal communication). The language of the consumer and family involvement in the 1992 plan is nebulous about the Consumer and Family Involvement Fund. The 1992 plan clearly states that “\$3.4 million is allotted to new Consumer [and] Family Initiatives” (Ministry of Health, Mental Health Services

Division Orientation Program Package, 1992, p. 2). However, it also states that “Mental Health Services will increase the number of Mental Health programs and services managed directly by consumers (to 10% of all Mental Health program)” (Ministry of Health, 1992, p. 2). This ambiguity resulted in differing interpretations for the implementation of the same fund. In some communities and regions in BC, the fund was set up as a Consumer and Family Initiatives fund (in Terrace, Kitimat, South Fraser, Prince George, Okanagan, Thompson, Kootenays, and others) and in others the fund was set up as a Consumer Initiatives fund (in Prince Rupert and Smithers). This incongruency demonstrated the need for standards in the provision and funding of Mental Health Services.

### Volunteer Burnout

Another barrier to implementation was volunteer burnout. Three volunteer educators of fourteen quit teaching the program because they felt that they could no longer volunteer. One discontinued teaching because her/his relatives with a mental illness had a relapse. Another volunteer ceased teaching because s/he found it difficult to teach the course in balance with her/his family responsibilities. The third volunteer to burnout found that the pre-course visits and advertising campaign were too difficult to manage and maintain her/his business interests. The BCSS coordinator developed some strategies to reduce volunteer burnout. One strategy to reduce burnout was to ensure that workload of volunteer tasks was shared. It became apparent that the BCSS coordinator needed to meet with the volunteer family educators and ensure that the tasks were shared in an acceptable manner. As the program in the northwest evolved, the BCSS coordinator had to cover

more and more of the administrative tasks including the preparation of funding proposals and administration of funds. To assist with the administrative workload, the BCSS coordinator used Mental Health Worker Program students from Northwest Community College until the program was canceled in 1996<sup>2</sup>. Students from Kitimat and Hazelton did their practicum placements with the regional BCSS coordinator. Using community development techniques, some of their duties involved locating and engaging family members of people with a mental illness. Additionally, with supervision, one of the students did the budget preparation, community advertising, and pre-course interviews for the initial delivery of Family-to-Family education program. Thus, these students drastically reduced the workload and volunteer burnout of family educators by recruiting participants, doing home visits, and doing administrative work (Northwest BCSS Coordinator Files, 1996-1997).

### Complexity of the Language of the Program

An additional barrier to implementation of the Family-to-Family education program was the complexity of its language. Family members have voiced differing opinions about the language complexity. One said, "I need to know and understand the way that doctors talk"(Program evaluation, 1996). Others voiced the opinion that the language was intimidating, both in the course and when spoken by doctors. The first edition of the program had no explanation of the terminology used in the program. A family educator

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<sup>2</sup> In 1996, Northwest Community College announced plans to discontinue the Mental Health Worker Program. Thus, the last cohort to start the program commenced in September, 1996. This class graduated in June, 1998 (Cheryl Brown, Personal Communication, 2001). Thus, the last practicum placement with the BCSS coordinator was in the fall of 1997.

from Terrace developed a glossary of terms during the delivery of the Family-to-Family education program for the first time. This glossary facilitated the learning of participants by giving them a tool to understand the material in the program. The glossary was forwarded to the provincial coordinators of the Family-to-Family education program in January 1997. The evaluation of the program by Pickett et al (1997) recommended that a glossary of terms with the appropriate pronunciations would enable the learning by the participants. Burland (1998) developed a glossary for the second edition of the Family-to-Family education program (Burland, 1998). In northwest BC, the family educators now use both the program's glossary and the locally developed glossary because the locally developed glossary defined words not found in the Family-to-Family education glossary.

### Geographical Isolation and Distances to Travel

Another barrier to implementation was the “relatively large distances between the small communities” in the northwest region (Report of the Northern and Rural Health Task Force, 1995, p. 7). The BCSS coordinator was charged with implementing the Family-to-Family education program in a region where the complexity of each community was difficult to understand from outside the individual communities. Because the BCSS regional coordinator lives in Terrace, she had a better insight into the dynamics of the community of Terrace than other communities. The relatively large distances between these communities tend to isolate them making it difficult for an outsider from Terrace to develop trust relationships with the consumers, family members, and professionals.

## Chapter 7      Participants and Non-Participants

This chapter deals with the characteristics of participants of the Family-to-Family education program. This analysis relates to the question of whether the program reaches the target population and whether the program meets the needs of the multi-cultural cross-section of the target group. In addition, this chapter examines some of reasons given to a family educator, and the researcher for not participating in the program.

### Trained Family Educator Participants

In June 1996, fourteen volunteer family educators were trained in Terrace. These educators came from Terrace, Kitimat, Hazelton, Prince Rupert, New Aiyansh, and Greenville. Seven of the trainees had First Nations ancestry, six are from the predominant culture, and one person originated from outside of Canada. Of these fourteen-trained educators, only six female trainees from the predominant culture delivered the program. These trainees taught the course from one to seven times each. It was noteworthy that no trained family educators from a First Nations background chose to deliver the program due to different needs.

Recruitment of trainees and participants was a challenge in northwest BC. There was a "limited pool of people for leadership positions" (Report of the Northern and Rural Health Task Force, 1995, p. 8). This affected the recruitment of volunteer family educators for the program due to limited number of people willing to take a leadership role.

Additionally, because less than half of the trainees delivered the program, recruitment was problematic and needed to be examined. Some issues were raised by the trained volunteer family educators which prevented them from delivering of the program. The high literacy level of the course materials influenced trainees with lower literacy skills to discontinue their participation in the delivery of the program. Recruitment was also initiated before the BCSS coordinator had any in depth knowledge of the program because no materials about the program had been forwarded to the coordinator by the program implementors (see chapter 6). The initial recruitment strategy involved a quick process with assistance from mental health staff in Terrace and Kitimat, and psychologists from Hazelton and New Aiyansh. No referrals for training were given by Mental Health staff in Smithers and Prince Rupert. The lack of information about the program philosophy, goals, and expected outcomes limited the ability of the coordinator to recruit appropriate potential trainees. A sample profile of a family educator could be used as a guide for volunteers and staff charged with the task of recruiting volunteer family educators. There still are trained volunteer family educators with First Nations ancestry in this region who could be delivering the program.

### The Need for Mentorship

In the First Nations community, the trained volunteers chose not to deliver the program. This occurred because the volunteers wanted more support by having the BCSS coordinator provide a mentorship role. Unfortunately, due to high travel costs estimated to be \$1680.00 per community for three communities, the BCSS coordinator could not

comply with this request. With adequate resources, this request for true mentorship could have met the needs of one group of First Nations family educators in their community. This vignette demonstrates the need for an alternative training and delivery strategy to accommodate differing cultural needs.

### Training More Volunteers

In January 1999, the need to train more volunteer family educators in Terrace was identified. In the northwest with its remote and rural characteristics the number of new volunteer family educators, who require training at any one time is small, usually one or two people. This does not justify the cost of flying a trainer in from the lower mainland. To access the out of town training sessions is problematic as it interferes with work schedules and usually involves trainees taking off work without pay. This is unacceptable for volunteers. Thus, there has been no additional family education training in northwest BC as of June, 1999.

### Support Group Facilitator Training

Another issue is that this researcher as the BCSS coordinator had received no written information from the provincial Family-to-Family education program coordinators about phase II of the program during the time period studied in this thesis. Therefore, the coordinator has no information to entice family members to take the training. Another gap is in the information about the support group program in the education phase. A strong

linkage between the support group phase and the education program is vital for participation of family members, but there has been no clear concise information of the support program philosophy, goals, and expected outcomes. This lack of information contributed to the reticence of the BCSS coordinator in initiating the training and implementing this phase of the program. Another factor considered by this researcher is that most of the graduates of the Family-to-Family education program do not use the current infrastructure of monthly family support groups. Therefore, the question arises whether or not family members will participate in the Family-to-Family support program. Of the 59 participants who have received the program thus far, only one person expressed the need for continued support.

#### Education Program Participants

In order to evaluate the implementation of the Family-to-Family education program, it is necessary to determine who participated in the program. These data were reconstructed by the BCSS coordinator with assistance from family educators because she was unable to collect data from the Provincial Coordinator due to her death. As of the end of spring, 1999, there had been 59 participants in the northwest region, 12 from Kitimat, 4 from Prince Rupert, 3 from Smithers, and 40 from Terrace. All the attendees live in the major population centres with less than 20,000 inhabitants (Statistics Canada, 1991 cited in Regional Health and Management Plan for the Northwest Regional Health Board, 1996). Of the participants, 64.4% (38 out of 59) were female. The participants' ages ranged from 11 to 75 years. Most participants (84.7%, 50 out of 59) were between thirty and sixty years



old. When examining the cultural background of the participants, the following data were generated:

Predominant culture	72.9%	43 out of 59
Portuguese	8.5%	5 out of 59
Italian	5.1%	3 out of 59
Chinese	3.4%	2 out of 59
East Indian	3.4%	2 out of 59
First Nation	1.7%	1 out of 59
French Canadian	1.7%	1 out of 59
German	1.7%	1 out of 59
Unknown	1.7%	1 out of 59

Most participants have high school equivalency or better education levels (93.2%, 55 out of 59). These data are not usually collected by the Family-to-Family program course evaluation; however, it was felt by the educators in the northwest region that these data were noteworthy and should be collected because according to Statistics Canada (1991), 42.1% of the population had less than grade nine education. Most participants were married (84.7%, 50 out of 59). Of the 59 participants, 26 (44.1%) lived with their relative with a mental illness, 26 (44.1%) were in contact with their relative with a mental illness, 5 (8.5%) were not in contact with their relative with a mental illness, and 2 (3.4%) of the relatives with a mental illness committed suicide. In summary, the participants were predominantly married females of predominant culture with more than high school education and they lived with or had contact with their relative with a mental illness. The

Journey of Hope Evaluation Report (Pickett et al., 1997) had the typical participant profile as being female (79%), white (92%), married (75%), ranging from age 20-94 years with an average income between \$40,001 and \$50,000, and 98% with high school or more education. In northwest BC, the participant profile was similar. However, there was no collection of income data. From my personal observation, most participants had middle class socio-economic status.

Most of the participants in the education program (44 out of 59, 74.6%) knew the family educators before they took the course. In Terrace, 36 out of 40 (90%) of the participants knew the family educators before the course, 1 out of 40 (2.5%) was referred by mental health, and 3 out of 40 (7.5%) knew about the course from community advertisements. It is noteworthy that four of the participants from Terrace who fit into the “knew the educators” category, also, were referred to BCSS by the one of the two psychiatrists residing and practicing in the northwest region. In Kitimat, 6 out of 12 (50%) knew the family educators, 5 out of 12 (41.7%) were referred by mental health, and 1 out of 12 (8.3%) knew about the course from community advertisements. In Smithers, 2 out of 3 (66.7%) knew the family educators, and 1 out of 3 (33.3%) heard about the course through a friend. In Prince Rupert, 4 out of 4 (100%) were referred by mental health. As of June 1999, there are six clients waiting for the program in Prince Rupert and one client waiting for the program in Kitimat.

In northwestern BC, these 59 participants had 56 relatives with a mental illness or undergoing the diagnosis of a mental illness and 3 had friends with a mental illness. Most

(32 out of 56, 57.1%) of the relatives with a mental illness or undergoing the diagnosis of a mental illness were male. Of these relatives, the following data were collected about their diagnosis:

Schizophrenia	46.4%	26 out of 56
Bipolar Disorder	30.4%	17 out of 56
Depression	16.1%	9 out of 56
Unknown diagnosis	7.14%	4 out of 56
Schizoaffective Disorder	1.8%	1 out of 56

These relatives with mental illness are analyzed according to the relationship to the participant:

Males			Females		
Son	31.7%	9/60	Daughter	8.3%	5/60
Brother	13.3%	8/60	Sister	8.3%	5/60
Husband	11.7%	7/60	Wife	10.0%	6/60
Father	1.7%	1/60	Mother	6.7%	4/60
Friend	1.7%	1/60	Friend	3.3%	2/60
Other relative	0%	0/60	Other relative	3.3%	2/60

In interpreting the data, it is noteworthy that the number of relatives with mental illness is different than the numbers analyzed according to relationship because often one or more family members with different familial relationships are represented in the data. For example, in one family a sister and a father of an individual with a mental illness attended the program, therefore, the relationships are represented as a son and a brother for one person. In summary, the profile of the relative with a mental illness is male with either

schizophrenia or bipolar disorder. Because no data about the ages of the relative a mental illness, length of illness, number of hospital stays, and exact living arrangements was collected, no comparisons can be made to the Journey of Hope Evaluation Report (Pickett et al., 1997).

### Non-Participants

In northwest BC, people from First Nations backgrounds rarely participated in the program. People with a First Nations ancestry comprise about 20% of the total population in this region. However, only one person of First Nation ancestry participated in the program. When one compares the population data for and the participation of people from First Nations background, it becomes apparent that this program did not satisfy their needs. Evidently, the issue warrants further exploration. A needs assessment of family members with First Nations ancestry should be performed to determine this portion of the community's educational needs. Additionally, the non-participation in the program by individuals with First Nations' ancestry shows a lack of acceptance for unexplored reasons.

Another group of non-participants were family members with less than high school graduation level of education. According to Statistics Canada (1991 cited in Regional Health and Management Plan for the Northwest Regional Health Board, 1996), 42.1% of the population in northwest BC, had less than grade nine education, and family members are represented in this group. Five clients, who fit into this category, refrained from taking

the course for various reasons collected by the family educators and the BCSS coordinator.

Their reasons were:

- takes too much time
- too long
- I want you to come to my house for one-on-one visits
- I can't read

It is noteworthy that one program participant was functionally illiterate and still was comfortable in participating in the program due to the reassurance and acceptance given by the family educators and the other participants in the program.

The following data were collected by the BCSS coordinator and the family educators about the non-participants. Two non-participants had conflicts with work schedules. This group was encouraged to come when they could and make up missed classes in subsequent sessions. Four non-participants and dropouts did not like the program's emphasis of dealing with family members' feelings of grief. This group wanted information and nothing else. One non-participant was philosophically opposed to experiential or peer support activities. This individual communicated that professionals were the experts and that peer support providers contributed inaccurate information. Also, this person felt that other family members did not have the skills to deliver a program and that other family members were "whiny". One non-participant did not accept the philosophy of self-care. A final group of non-participants self-reported to the BCSS coordinator that they had personality conflicts with a particular trained family educator. This conflict affected the delivery of the program in one northwest community.

Another issue that merits further exploration is that it is possible that some family members feel accepting that their family member has a mental illness. It is possible that these family members are not traumatized, they have the information that they need to cope, and their needs are being met in another manner. As found by Vinokur, Price, and Caplan (1991), it is possible that non-participants self-select to defer from participating in the program because they really do not need it

This chapter discusses the analysis of elements of program implementation not discussed in previous chapters.

### Discussion of Implementation

Only phase 1 of the Family-to-Family education program has been implemented and delivered in northwest BC. The delivery of this phase is based on recruitment of family members of individuals with a mental illness. From the experience of this researcher, recruitment is dependent on self-referral by individual family members. Phase 2 of the program, the support group phase, should be implemented in northwest BC, however due to the barriers discussed in the previous chapter it cannot be implemented.

Additionally one should ask if there is no formal plan then can a program be implemented? The Family-to-Family education program is delivered and thus is implemented because a set of tasks was put into action that brought forth the program. However, planning can improve effective implementation and delivery of programs. As shown in figure 3.1, planning is integral in the implementation of programs by identifying the target group, assessing the needs of the target group, by developing goals and objectives, exploring constraints and resources, identifying and selecting methods and activities, planning the implementation, and planning the evaluation. Because the program was purchased from the NAMI, the tasks of target group selection, assessment of needs,

identifying methods and activities, implementation plan (in the United States), and a post-test evaluation plan were already completed (Burland, 1998, 1993, undated). However, the purchase of a program does not preclude the need for exploring the constraints and resources that affect the delivery of the program in BC. Because of differences in health care delivery, geography, climate, and other factors, there was a need to develop an implementation plan for BC. The absence of plan caused a reactive rather than a pro-active approach when attempting to solve barriers to the implementation. Using a pro-active approach includes exploration of the potential barriers of and facilitators to program implementation. Furthermore, a pro-active approach can make use of brainstorming strategies to determine potential barriers and to create possible solutions before the barriers become a problem. Additionally, the process of writing the planning document enables the planners and implementors to review and reflect upon the implementation of the program.

#### Augmentation of the Family-to-Family Education Program

Because the Family-to-Family education program was developed in the United States, some of the data given in the program were not appropriate. When American data about housing, prevalence rates, health management organizations, etc. were presented in the program, the educators in northwest BC replaced the American information with relevant Canadian data provided by BCSS. This deviates from the program developed by Burland. Preston was given permission from Burland to supplement material if the supplements were supplied on a different coloured paper (Preston, 1998). The regional



BCSS coordinator and a family educator from Terrace also provided supplemental information such as BCSS Facts sheets as shown in table 8.1.

The BCSS coordinator also added the Individual Rehabilitation Service Plan and the Rehabilitation Services Planning Tool from the Mental Health Division, Guidelines for Rehabilitation Services (1996). Preston and deLange (Personal Communication, 1998) included information about the Canadian Mental Health Association, BC division, the Mood Disorders Association of BC and how laws are enacted in BC. One of the family educators from Terrace added information about Changeways, a rehabilitation program for people recovering from depression and other mood disorders (Paterson, 1997, Paterson, McLean, Alden & Koch, 1996) and the McCorkell Court decision (BCSS Friends, 1993)<sup>3</sup>. Additionally, the same family educator added a sample of a stigma fighting letter and a sample of an advocacy letter directed towards a member of parliament. The BCSS coordinator added examples of monitoring advocacy, which she performed on the implementation of the provincial mental health plan in northwest BC.

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<sup>3</sup> The Community Legal Assistance Society (CLAS) put forward the case of Mr. McCorkell who suffered from bipolar disorder to test the constitutional validity of involuntary committal and detention under the provisions of the BC Mental Health Act. CLAS challenged the act on the basis of the criteria being too vague and the scheme for involuntary detention was not in accordance with fundamental justice. CLAS lost the challenge on both accounts. The decision found that dangerousness and/or protection are valid criteria for detention under the Mental Health Act. In addition, the decision found that the standards for committal strike a reasonable balance between the rights of an individual to be free from restraint by the state and society's obligation to help and protect the mentally ill. This decision named the McCorkell decision was seen by members of the BCSS to provide the legal support for the right for treatment and to be sane over the rights of the individual to refuse treatment. In the 1998 Mental Health Act (Ministry of Health, 1999) which was declared as of November 15, 1999, the committal criteria were changed partially as a result of the McCorkell decision.

**Table 8.1 BCSS Fact Sheets added to the Family-to-Family Education Program**

Schizophrenia	Neuroleptic Malignant Syndrome
Stages of Hallucinations	Steps for Working with Delusions
How to Manage Common Symptoms	Benefits of Extended Leave
Getting Satisfactory Results....Some Do's and Don'ts	The Mental Health - The Right to Treatment and Care
Books available from BCSS	Videos available from BCSS
Zyprexa Fact Sheet	Hospital Discharge Planning and Checklist
14 Principles for Family Members	Release Form for a Doctor to sign that a relative with mental illness no longer requires treatment under the Mental Health Act
Crisis Fact Sheet	Family Support Program in Northwest BC

Augmentation of the Family-to-Family program has been performed in other regions of BC. In order to track augmentation and ensure that all program participants in BC receive the same degree of program modification, an augmentation tool could be developed as Contento et al did (1992). The augmentation tool does not necessarily need to be quantitative (Contento et al, 1992); however, it should be qualitative showing the materials used to augment the program.

### Unplanned Effects from the Delivery of the Program

There were some unplanned effects as a result of the delivery of the Family-to-Family education program. The northwest regional BCSS coordinator used the results of brainstorming of issues from class eleven<sup>4</sup> as a tool to inform Community Health Council members, directors of the Northwest Community Health Services Society, and service providers about issues with which family members of individuals with a mental illness were concerned. Commonly, these issues involved improvement of services directed towards the relative with a mental illness rather than the family member. The regional coordinator used the issues generated by fifty-nine family members from nine classes delivered in the northwest region as the results from de facto focus groups. There were many common themes about improving housing, educational opportunities, and suitable work opportunities for people with a mental illness, liaison with Royal Canadian

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<sup>4</sup> Class 11 is the advocacy class. In this class, participants learn about the types of advocacy and how to effectively advocate on their own behalf or on behalf of their family members with a mental illness. Participants brainstorm their problems, then turn the problems into systemic needs. After the need is identified, participants propose implementation steps for each solution (Burland, 1998).

Mounted Police (RCMP), using continuing treatment orders, insufficient services for youth when they first start to manifest symptoms, and appropriate rehabilitation assessments and services for the person with a mental illness. The only services that families wanted were respect and understanding from professionals, input into diagnosis and treatment planning, respite, and increased community awareness about mental illness.

When the Family-to-Family education program was introduced to BC, the program had a broader focus than that of BCSS. BCSS focused on its mission of “alleviating the suffering caused by schizophrenia”(BCSS Constitution, 1994). Family-to-Family focused on family education of family members of individuals with schizophrenia, bipolar disorder, severe depression, obsessive-compulsive disorder, and/or anxiety disorder (Burland, 1998). This discrepancy caused considerable philosophical disturbance within BCSS. It influenced the BCSS board of directors to direct a board committee with staff support to survey the branches to determine whether the grassroots of BCSS wanted to change the focus of BCSS (Focus Survey Responses, 1998). Out of the 38 branches, 29 branches responded to the survey (Focus Survey Responses, 1998). The results were that thirteen branches wanted to expand the focus of BCSS, twelve branches wanted to maintain the status quo, and four branches were undecided (Focus Survey Responses, 1998). As a result of this survey and discussion, the board of directors passed a motion to expand the purpose of BCSS by adding the words “or other serious mental illness” (Minutes of Board of Directors Meeting, Jan. 16, 1999) to its mission.

## Gaining Acceptance

Gaining acceptance for Family-to-Family was challenging. Burland included samples of letters and posters in the program (1998, 1993). The BCSS coordinator modified these examples for northwest BC. The initial advertisement for introducing the Family-to-Family education program in northwest BC was for “family members of people with severe mental illness to learn the skills to cope” (Advertising poster designed by Baxter, 1996). This advertising campaign using humour has been used consistently throughout northwest BC with positive comments from participants. Another advertising strategy is the use of word of mouth about the program by the family educators. This has been the most effective strategy for attracting participants because family educators, as previously discussed in section 7, recruited most participants. Another strategy for introducing the program to mental health workers was by compiling and writing clear and concise information about the program as discussed in section 6.

Another strategy is to market the program as a tool to reduce the workload of professionals. With no referrals from general practitioners, clergy, and community based organizations in northwest BC, there is no apparent need to target these groups with letters. In the past letters were sent to the above target groups with no result, thus, alternative approaches need to be developed. Another approach to introduce the program is to deliver oral presentations to the local and regional meetings of physicians, clergy, and community organizations.

Most participants accepted the program. If the provincial dropout rate is examined, only 109 out of 707 (15.4%) registrants failed to complete the program (Fast Facts, Preston, 1998). In northwest BC, only 15 out of 74 (20%) registrants dropped out. The low dropout rate demonstrates acceptance of the program by participants. The dropout rates for northwest were skewed because one group of family educators did not perform the pre-course family visit which resulted in a high dropout rate of 50%. This caused the dropout rate for the region to increase to 20% (15 out of 74) from 15.6% (10 out of 64). This 15.6% dropout rate is equivalent to the provincial dropout rate of 15.4%.

The acceptance of the Family-to-Family education program by general practitioners was minimal in northwest BC. The evidence for the previous statement is the lack of referrals by general practitioners to the program<sup>5</sup>. Physicians should be surveyed to determine the reasons behind the lack of referrals.

Most mental health service providers in northwest BC accepted the program as shown through numerous referrals to the BCSS coordinator for the Family-to-Family education program. In one northwest community, there were no referrals by either the child/youth or adult mental health teams despite face-to-face meetings between these professionals and the BCSS coordinator. From the lack of referrals, this researcher concluded that the mental health professionals in this community exhibited a lack of

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<sup>5</sup> In the fall of 1999, a family volunteer went to talk to all the nurses who work with general practitioners in Terrace. Even though, the nurses were fascinated by the program, there was no change in the referral patterns.

acceptance of the program. One of the two psychiatrists in the region accepts, refers to, and endorses the program.

Acceptance by psychiatrists was evident in 1998 the Canadian Psychiatric Association (CPA) when Elaine Preston was awarded the CPA Special Recognition Award for Leadership and Dedicated Contribution to the Promotion of Mental Illness Awareness (Friends, 1999, p.3).

As stated previously in section 6, staff from the Mental Health Division, Ministry of Health supported the program after seeing the evaluation results from the pilot programs in Maple Ridge and Langley. Thus, government accepted the program. As the program spread throughout the province, BCSS members and participants influenced the BCSS board to accept it as an official BCSS program. Once this occurred, it became apparent that the provincial office of BCSS needed a staff member to coordinate the program provincially. Additionally, BCSS needed to sign a contract with Joyce Burland regarding the delivery of Family-to-Family education program in BC<sup>6</sup>.

#### Task Specification and Resource Estimation

Burland (1998,1993) designed specifications of tasks and estimation of resources. All tasks are clearly set out. The physical and personnel resource needs were completely

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<sup>6</sup> After a long period of negotiation, the contract was signed in 2000. In June 2000, Burland trained 16 trainers to train the volunteer educators.

estimated. However, the monetary resources were not delineated. There were reasons for this. When establishing a continent wide program, the funds required to deliver the program in each locale vary widely. Thus, it has to be the responsibility of the local and regional program deliverers to estimate costs according to the parameters within which the program is delivered. However, the inclusion of sample budgets and funding requests by the BC implementors was important for estimation of resource needs. Additionally, the lack of regionalized funding for family education and initiatives consumed a lot of the time and energy of the northwest regional BCSS coordinator.

Burland (1993, 1998) designed the development of the program activities as outlined in section 4. The implementation activities for the program in BC were designed by Preston and deLange as described in section 6. Because these activities in BC were not initially formalized in a written form, it was difficult to determine what the specific plans were.

#### Program Management Mechanism

Burland established a program management mechanism. She used contracts to assist in ensuring fidelity to the philosophy and delivery of the programs similarly to Rohland (1998) and Baker (1977). This researcher found the manual to be confusing about the program's philosophy and goals. Additionally, Burland used class sign-up sheets, class composition reports after week 3, final class lists, final census forms, participant evaluations, and educators' evaluations to the provincial or state program directors. Preston



(1998) stated that she had permission from Burland to augment the program if the supplements were copied onto blue paper to distinguish them from the designed Family-to-Family program. However, no mechanism to track this augmentation was implemented.

## Chapter 9      Recommendations

This section pulls together the implementation issues raised by the analysis performed in the previous sections on implementation, participants and non-participants, and analysis. A set of recommendations based on improving the implementation and delivery of the Family-to-Family education program is proposed. These recommendations are directed to the program developers, implementors, Board of Directors of BCSS, and the staff and board members of the Northwest Community Health Services Society.

### General Recommendations

Programming alternatives that are culturally sensitive to ethnic groups can be developed. These alternatives that affect family members in BC should be developed here in consultation with the appropriate cultural groups. For example, when developing program alternatives that provide additional supports for families of First Nations ancestry, they should be involved. According to Johnson and Johnson (1998), native Americans value family involvement in treatment process as natural. Thus, when individuals from a First Nations ancestry develops a mental illness, it is reasonable to expect that their family members would become involved. Johnson and Johnson (1998) also concluded that family members of First Nation's ancestry required information about the mental illness with which their ill relative was diagnosed. The question about the lack of participation by individuals from a First Nations ancestry in the Family-to-Family education program could be explored through a needs assessment specifically targeted towards this group of family

members. Because families from a First Nations ancestry participated at a low rate of 1/59 (1.7%) as compared to the estimated First Nations population of 20% (Northwest Regional Health Board, 1996), alternative strategies for marketing and delivering programs could be explored.

Another aspect that should be explored is the status of BCSS in the First Nations community. Perhaps, the low participation rate in the Family-to-Family education program is due to insufficient exposure of BCSS in First Nations communities.

#### Recommendations for the Family-to-Family Program Developers

To promote and facilitate further and clearer understanding of the Family-to-Family program, the first recommendation is to include clear statements of the philosophy, goals, and expected outcomes (or objectives) in the teaching manual. This researcher in her role as the BCSS coordinator in northwest BC and the volunteer educators found the application process for funds from the Consumer and Family Involvement Fund of Northwest Community Health Services Society (NWCHSS) or other funding sources to be impeded by the aforementioned barrier. This researcher found the information in other publications. Afterwards, she used clear statements of goals and outcomes of the Family-to-Family education program in all subsequent funding applications. Clear statements of the philosophy, goals, and objectives could assist funding agencies in determining whether the program meets their funding criteria. In addition, clear statements of the philosophy,

goals and objectives of the program could assist the educators in promoting the program to professionals.

The second recommendation is the development of alternative strategies for educators working in remote areas. The current strategies for training educators and facilitators in groups of fifteen volunteers were incompatible with the characteristic of remote and rural communities having a limited pool of people for leadership (Ministry of Health, 1995). Thus, an alternative approach needs to be developed. Mentorship may work in some cases, but not in others. Flexibility with distinct guidelines is important to maintain quality service delivery. For example, one suggestion is that a family educator trained to train more volunteer educators could visit remote communities and train a very small pool of educators in a shortened version of the complete training program. Although, there are drawbacks to this method; such as, the lack of forming a cohesive group of family educators for mutual aid and support, there is still merit to this suggestion. It merits consideration because of the nature of small, remote communities in northwestern BC. With a small pool of volunteers, potential family educators could be left untrained because they are unable to travel to larger regional centres training in larger groups.

The third recommendation is the establishment of more distinct and stronger linkages between the education phase and the support group phase in the education phase. For example, whenever the program discusses self-care, the linkages with peer support groups could be further explained and clarified. Kurtz (1997) shows that support groups have five helping mechanisms: giving support, imparting information, conveying a sense

Figure 9.1      Profile of A Voluntary Family Educator

1. Family member of someone with a serious or persistent brain disorder such as schizophrenia, major depression, bipolar depression, anxiety and panic disorder, and obsessive-compulsive disorder.
2. Do not need a teaching background.
3. Do need a good command of the language in which the program is given.
4. Comfortable with both oral and written word.
5. Be willing to participate in the training program.
6. Be willing to return to your community and deliver two 12-week sessions. All sessions are done with two volunteer educators.
7. Need to have time to organize and prepare classes.
8. Be willing to learn new skills and then share this knowledge with other family members.

of belonging, communicating experiential knowledge, and teaching coping methods.

These helping mechanisms could be communicated in class 10, the rehabilitation section of the program. For example, a section in the program about the purpose and value of support groups could be beneficial in motivating interest the support group component of the Family-to-Family education program.

A fourth recommendation is to generate a profile of the ideal family educator with respect to abilities such as fluency in the language in which the course is given, time to dedicate to the program, and other characteristics as shown in figure 9.1. A family educator from Terrace and the researcher generated this profile.

Initially, when this researcher recruited volunteers as family educators, she was not sure about the role family educators played in the Family-to-Family education program. Other than knowing that the educators had to have a relative with a mental illness, she was uncertain who would be a suitable candidate to recruit as a family educator. If a tool similar to the one depicted in figure 9.1 was included in the initial information package, it could be used as a checklist to assist in determining the suitability of the volunteer to become a family educator. Another program that used a volunteer screening tool was the Parent Partners Program, a parent-to-parent support program in a neonatal intensive care unit (Jarrett, 1996).

A fifth recommendation is to develop a quantitative fidelity checklist for implementation of the program as seen in figure 9.2. This quantification of the fidelity of

the implementation of Family-to-Family is similar to the Fidelity Index developed by Contento et al (1992). Because volunteer educators with minimal direction implemented the Family-to-Family education program in various communities, this researcher found that there was variation in the fidelity to the implementation plan as directed by Burland (1998, 1993). Fidelity to the plan could be tracked using program management mechanisms. Thus, this researcher recommends the use of a fidelity index. This fidelity index could be a simple checklist, however, this researcher prefers to quantify the fidelity index for the purposes of enhancing the recognition of the need for the pre-course visit. This pre-course visit is important in establishing acceptance of the program by its participants. Additionally, this visit helps establish a level of comfort between the family educator and the participant before the first class. Also, this researcher chose to include the project management and evaluation forms as part of the fidelity index.

A sixth recommendation is to use an augmentation index that was developed to determine the extent to which the program was improved. This index, shown in figure 9.3, was developed similar to the Augmentation Index developed by Contento et al (1992). Because the Family-to-Family education program was developed in the United States, a family educator from Terrace and this researcher supplemented the program as discussed in chapter 8. Most of the information added to the program was material about Canadian and/or BC data and programs. From conversations with Preston and deLange (1998), many other family educators augmented the program materials. This researcher feels that the augmentation of the Family-to-Family education program should be systematic. The use of the proposed augmentation index in figure 9.3 with the inclusion of a quantitative

Figure 9.2 Implementation Fidelity Checklist for the Family-to-Family Education Program

ITEM	POINTS
<p>1 Advertising(score 1 point for ads distributed to each agency to a maximum of 12):</p> <p>1.1 Ads for</p> <p>1.1.1 TV, Radio, and Newspaper</p> <p>1.2 Ads for clinicians, doctors</p> <p>1.3 Word of mouth (score 1 point per referral)</p>	
<p>2 Pre-course visit or equivalent(score 12 points for visits for all participants and deduct 1 point for each participant with no contact before the classes commence)</p>	
<p>3 Classes (score 1 point for each class given according to manual to a maximum of 12)</p>	
<p>4 Program Management (score 1 point per report)</p> <p>4.1 Class sign-up list (class one)</p> <p>4.2 Class list (class three)</p> <p>4.3 Final Class List (class 12)</p> <p>4.4 Final Census Forms (class 12)</p> <p>4.5 Participant Evaluation (class 12, 1 point per completed evaluation)</p> <p>4.6 Co-teacher evaluations (1 point per completed teacher evaluation)</p>	

Total Points



Figure 9.3 Augmentation Index for the Family-to-Family Education Program

Add 1 point for added information that makes a perceived improvement to the program.

Add 0.5 point for added information that makes a slight improvement to the program.

Deduct 1 point for added information that makes no improvement to the program.

Do not use this information the next time that the course is offered.

Add the name of the material added to the program in space provided. Use as many sheets as necessary.

No.	Material Added	Points
1		
2		
3		
4		
5		
6		
7		
8		
9		
10		
11		
12		
13		
14		
15		
16		
17		
18		
19		
20		
	Total Points	

reflection about the quality of the information supplemented could be useful. This strategy of quantifying augmentation could assist in making educators reflect upon the necessity of including the supplemental information as in Contento et al (1992).

### Recommendations to the BC Implementors

The major recommendation is to use a written plan for the implementation of any program. This plan should include the philosophy, goals and expected outcomes, target group, needs assessment, budgets, the implementation timetable, and evaluation plan. Also, any future proposals presented to the BCSS Board of Directors should meet the criteria and the checklist developed in figure 9.4.

### Recommendations to the Implementors from Northwest BC

The first recommendation is to assess the need for implementation of the support group phase of the Family-to-Family education program in northwest BC. As stated previously, information about the support group training is the key element for further implementation in the northwest region.

The second recommendation is to negotiate with the staff of Adult Mental Health, Northwest Community Health Services Society to transfer funding of the Family-to-Family education program to the BCSS regional contract from the present Consumer and Family Initiatives contract. This would enable the BCSS coordinator to efficiently fund the

program and decrease the burnout of family volunteers. Additionally, this transfer of funding for the Family-to-Family education program would free up time spent generating funding proposals for other contracted activities.

### Recommendations to the Board of Directors of BCSS

The first recommendation for the Board of Directors was to name a provincial Family-to-Family education program coordinator. After the death of Elaine Preston, the coordination of the program has not had the attention that it needs. Because the delivery of Family-to-Family has become a major thrust of BCSS service delivery patterns, this appointment was a priority that was met in late 1998 by the appointment of Dr. Nicole Chovil. However, it took a further two years to finalize a contract between BCSS and Joyce Burland. Prior to the appointment of Dr. Chovil, it was a challenge to obtain statistical information about the Family-to-Family program.

A second recommendation is to use the checklist shown in figure 9.4. This checklist was designed to enable the board of directors to make quality decisions about the approval of future programs. The checklist should assist staff and others in making proposals to the BCSS Board of Directors. The decision making process is facilitated by collecting all available information. For example, in January 1994, when the Board of Directors of BCSS decided to withhold support of the Family-to-Family education program, it was primarily due the lack of information about the program. The Board needed to know where the program fit into the mental health system, what the expected

Figure 9.4 Checklist for Approval of Programs

1	Does the proposal match the mission statement of BCSS? "Alleviate the suffering caused by schizophrenia or other related disorders"	Yes	No
2	Does the proposal match the philosophy of BCSS?	Yes	No
3	Does the proposal outline the program objectives?	Yes	No
4	Do the objectives fit with the objectives of BCSS?	Yes	No
5	Is the target group identified? _____	Yes	No
6	Was there a needs assessment performed?	Yes	No
7	How was the need assessed? _____		
8	Is there an implementation plan?		Yes
	No		
9	Does the plan include a time table?	Yes	No
10	Does the plan include implementation tasks?	Yes	No
11	Is there an evaluation plan?	Yes	No
12	Is the evaluation plan designed to offer the program again if it is successful?	Yes	No
13	Is the evaluation plan designed to alter the program to make it more useful to participants?		Yes
	No		
14	Is the evaluation plan designed to drop the program if it fails to meet the needs?	Yes	No
15	Is there a proposed budget?	Yes	No
16	Is the budget sufficient to cover projected costs?	Yes	No
17	What group, agency, government, etceteras will fund the program? _____		
18	What literature supports this program? (attach list) _____		
19	Has there been a literature review on this topic?	Yes	No
20	Is there professional support for this proposal? (attach letters)	Yes	No

outcomes were, and whether the grassroots members of BCSS would accept the program. At that time, in 1994, this information was unavailable to them. In June 1997, when the Board voted to approve the Family-to-Family education program as an official BCSS program, this information was available as discussed in chapter 6.

The third recommendation is to decide whether the Board of Directors of BCSS wants to direct staff to secure funding for the development of culturally appropriate programs directed at individuals of First Nation's ancestry.

The fourth recommendation is to develop a Canadian program with the Schizophrenia Society of Canada and all of its affiliates. Currently, there is a proposal by BCSS to initiate this recommendation. This national program could integrate the Canadian programs delivered in Guelph, UBC, and other centres.

#### Recommendations to the Northwest Community Health Services Society

The first recommendation is establish standards for mental health program delivery in northwest BC. The mental health staff from this society have recently set standards for the Consumer and Family Involvement Fund and has established that family self-help programs are to be financed through the fund in each community. This recommendation of setting the standards became a basic practice due to the responsiveness of the acting mental health directors to the needs of family members. However, it must be

stressed that the recommended method for funding the Family-to-Family education program, as a core program for family members in northwest BC, is to incorporate the program funding into the regional BCSS contract.

The second recommendation is to promote a service delivery system that promotes a milieu of professional acceptance of appropriate family involvement in the lives of individuals with a mental illness and the need for family self-help education. This milieu should include community and hospital based mental health programs delivered in northwest BC. The acceptance of family involvement in patient care strategies could be incorporated into all job descriptions of service providers employed or contracted by NWCHSS. Yingling and Trocino (1997) suggested this strategy as a method of ensuring the value of patient and family education in delivering programs to non-insulin-dependent patients with diabetes. Additionally, referrals of family members to the Family-to-Family education program (where available) by mental health professionals could be written into their job descriptions.

## Chapter 10    Conclusions

One major consequence that this researcher knows now that she did not know at the beginning of this research process was the influence that the lack of a clear understanding of the Family-to-Family education program philosophy, goals, and expected outcomes played in the non-endorsement by the Board of Directors of BCSS in 1994. Imprecise and nebulous statements about the program made it difficult to make incisive decisions about accepting the Family-to-Family education program as an official BCSS program. Furthermore, this lack of clarity contributed to the problems of implementing the program in northwest BC.

The lack of a comprehensive plan for the implementation of the Family-to-Family education program in BC limited the evaluation of the program. With no plan, it was difficult to determine whether the program was implemented. In BC, there was no implementation timetable, and no needs assessment to analyze.

Linking the evaluation of the implementation of the Family-to-Family education program to the Report of the Northern and Rural Task Force (1995), this researcher found that the characteristics of rural communities affected its implementation. The isolation of small communities affected the ability of the BCSS coordinator to implement the Family-to-Family education program in communities outside her home community. It takes a long period of time and a great deal of effort to develop relationships in communities outside her own. Additionally, the geography and climate added to the isolation of the small

communities in northwest BC. Furthermore, the low numbers of community volunteers in the pool seriously affected the ability of the BCSS coordinator to recruit volunteers as family educators.

The effect of the innovation created by Elaine Preston and Margaret deLange on BCSS was noteworthy. As a result of the implementation of Family-to-Family, BCSS had to face the challenge of examining the expanding of its focus. Because Family-to-Family was targeted to family members of individuals with schizophrenia, schizoaffective disorder, bipolar disorder, severe depression, panic disorder, or obsessive-compulsive disorder, its focus was broader than the schizophrenia focus of BCSS. A report was generated and the board decided to widen its purpose to include “or other related disorders” in January 1999. Furthermore, this innovation initiated further empowerment of family members through its self-help activities in BC. The expansion of the purpose of BCSS and the acceptance of the Family-to-Family education program by the members and Board of Directors of BCSS demonstrates how individuals through perseverance and their commitment to a cause can effectively initiate and make changes in organizations. Additionally, BCSS was able to accept changes in program delivery strategies when the grassroots of the organization wanted changes made.

### Future Research

In order to link the Family-to-Family education program to psycho-education programs delivered by the psychiatric profession, either a prospective or retrospective



intervention study on the relapse rates of the relative with a mental illness after the participation of their family member in the Family-to-Family education program should be performed. It is proposed that the relapse rates in the above cohort be compared to the relapse rates of the relative with a mental illness where the family members have not participated in any family education or psycho-educational programs. It is of additional interest that Solomon (1995) looked at a prospective experimental effectiveness trial of family intervention using family burden as measurement tool. Another measurement of family education program effectiveness could be the systematic use of mental health services by family members.

A systematic analysis of other methods of program delivery to rural populations could be examined. One question that should be explored is - whether the use of technology such as teleconferencing would be effective or is the face-to-face lecture style absolutely necessary.

A study about non-participants and their reasons for not participating in the program would be of interest. As discussed in chapter 7, one group not participating in the program is family members of First Nations ancestry and their needs should be explored further.

Another area of interest that should be studied is the lack of referrals by some professionals and most physicians. The reasons should be determined and strategies to overcome this barrier should be developed.

## Conclusions

This thesis evaluated the process of the implementation of the National Alliance for the Mentally Ill's Family-to-Family education program in British Columbia by members and staff of the BC Schizophrenia Society. The study used a case study approach examining archival material, such as correspondence, minutes of meetings, contracts, debriefing notes of the author, etc., and analyzing key informant interviews and the program materials. From this analysis, the process of implementation was determined. The researcher chose to study three facilitators that she discovered through her experiences with implementing the program in northwest BC. They were community outreach strategy, pre-course family visit strategy, and the program content. In addition, this researcher discovered a number of barriers to implementation of the program in northwest BC. Five barriers were chosen for study: systemic misunderstanding of the program, funding, volunteer burnout, complexity of the language of the program, and geographical isolation and distance to travel.

As a result of studying the implementation of the Family-to-Family education program, six topics related to program implementation theory were discussed. This researcher analyzed the data collected about the participants and non-participants to determine whether the program reached the target population. Generally, the program reached the target population with two exceptions: family members from a First Nations background; and family members with less than high school education. Next, the absolute requirement for program planning with a written plan was discussed. Because this

program was United States based, augmentation of the program was necessary to add Canadian information. Because different educators added different information, it was determined that it was necessary to track and standardize this augmentation. Next, this author looked at the unplanned effects of the program. This author used the issues raised in the Class 11 for presentations of family member generated issues to the health authorities for the purpose of assisting in the improvement of the mental health system. Additionally, the author discussed how the acceptance progressed both provincially and in northwest BC. Most mental health professionals accepted the program. Physicians from the northwest region and mental health professionals in one community demonstrated a lack of acceptance by making no referrals to the program. Then this thesis examined the mechanisms of program management. The mechanisms proposed by Burland were reasonable. However, this author recommended two other program management tools: a fidelity index; and an augmentation index.

In the final chapters of the thesis, this researcher made a general recommendation about studying the needs of family members from a First Nations ancestry and how this segment of society perceives BCSS. This researcher recommended that the program developers include clear statements of the program philosophy, goals, and expected outcomes in the first chapter of the teaching manual. In addition, more outreach strategies for remote areas need to be developed. This researcher also recommended using the volunteer educator profile, the fidelity index, and the augmentation index developed as result of the evaluation research process. Furthermore, it was recommended that the support group phase be linked to the education phase throughout in each class.

To the implementors of the program in BC and in northwest BC, this author recommended that written plans be generated for program delivery. In northwest BC, the author recommended that the need for support group training be assessed. In addition, recommendations were made to transfer the funding for the Family-to-Family education program to the regional BCSS contract.

To the Board of Directors of BCSS, this author recommended to appoint a provincial coordinator of the program and to use the checklist for the approval of programs. This checklist was developed as a result of the analysis of the initial presentation to the Board and subsequent lack of support for the proposal. In addition, a recommendation was made to the BCSS Board of Directors to decide whether they want to pursue funding to develop programs directed towards family members of First Nations ancestry. The final recommendation was to develop a Canadian program in partnership with the Schizophrenia Society of Canada and its provincial affiliates.

The final recommendations were directed to the Northwest Community Health Services Society that delivers adult mental health services in northwest BC. The first recommendation is to develop mental health program delivery standards. The second recommendation is to promote a service delivery milieu that encourages professionals' acceptance of the role that families have in the lives of individuals with a mental illness by incorporating this acceptance in all job descriptions.

Finally, this thesis made some generic conclusions and suggestions for future research. The author concluded that program delivery should be planned. In addition, the barriers between small communities were difficult to overcome. Finally, this author concluded that strong and committed individuals could overcome many barriers in the formal and informal mental health care delivery system. For future research, this author recommends that research should link family education to reducing relapse rates, further study of the non-participants, and study of the referrals to the program by general practitioners.

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