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# Families Are Part of the Solution

## A Strategic Direction for Family Support & Inclusion



Mental Health and Substance Use Services  
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## Acknowledgements

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## Executive Summary

Families and loved ones are key partners in recovery from mental illness. Families play a critical and crucial role to people with mental illness and their contributions must be supported and encouraged. Recovery is facilitated when families are supported through education and other services that enable them to be effective partners in the care of adults with mental illness.

Recognizing the value of families in recovery from mental illness, Fraser Health's Mental Health and Substance Use Services Leadership Team commissioned the development of a strategic direction to strengthen family support and inclusion in mental health care. A Family Support Task Group was created to oversee the process which included: a review of existing family services and supports for families living in the Fraser Health communities; a literature review on evidence-based best practices; and consultation with Fraser Health families, mental health clinicians and consumers.

The review of existing family support and inclusion revealed that education and support for families is available through some mental health programs and in some communities but is not consistent across Fraser Health Mental Health Services. Similarly, family inclusion practices are routine in some programs but limited in other areas.

There is a strong evidence base that the provision of family intervention services enhances families' ability to support their family member in recovery. The literature also revealed potential barriers that impact the extent to which family support and inclusion has been implemented into mental health services.

Provision of support and education to families; communication between professionals and families; peer support; resources; respite; and advocacy training; were identified as priorities by families.

Based on the review of the literature and findings arising from consultation with key stakeholders, the following recommendations are put forth as specific actions that will increase family support and inclusion in mental health:

**Recommendation 1:** Develop an infrastructure in Mental Health Services to support family-friendly services across Fraser Health. The infrastructure would include a Family Specialist position to oversee implementation of the Strategic Direction for Family Support and Inclusion; three Family Consultant positions; a Strategic Direction Steering Committee; development of guidelines/service standards for family inclusion; and the development and implementation of an evaluation framework.

Recommendation 2: Develop and implement an education/training program in working with families for mental health staff. This includes the development of a Knowledge Translation and Exchange plan over a 3 year period; including family consultants as trainers/mentors in the KTE process.

Recommendation 3: Implement enhanced and new family services so that families have a range of options of support. Enhanced services would ensure that families have access to education and family support groups throughout Fraser Health communities. Existing respite services would be evaluated in order to plan for future expansion. New services would include resources to help families navigate through the mental health system and family counselling services for families requiring more intensive interventions.

## Background

*“There have been times I’ve thought I’ve been losing my mind and times I’ve been drowning in depression and/or exhaustion which has weakened my role. I believe that one-on-one guidance from professionals, early in the process is important. (We need) access to a professional re: feedback after the first crisis even before getting help for our loved one. The feeling of invisibility can affect the healthy one as well as the sick one.”*

*(Family Member, 2010)*

### Introduction

With the advent of psychiatric medications and deinstitutionalization of psychiatric care to the community, families have become an integral part of care for people with mental illness. Many formally institutionalized individuals returned to live with their families and many individuals who are newly diagnosed are either currently living with family or return to live with their family out of desire or need.

Health Canada (Decima Research Inc., 2004) estimates that about 500,000 Canadians (approximately two percent of the population) are caring for an adult (family member, friend, or neighbour) who is diagnosed with a mental illness. Other studies have reported (or estimated) that 40 to 65% of adults with mental illness are being cared by a family member (Hatfield, 1979, 1994; Garety and Rigg, 2001; Lehman & Steinwachs, 1998; Solomon & Drane, 1995; Toronto-Peel Mental Health Implementation Task Force; December, 2002; Torrey and Wolfe, 1986). A significant proportion of family members providing care are aging parents, particularly mothers (Cook, 1988; Lefley, 1982).

*“Although the male caregiver population is growing, over 75% of informal caregivers [Health Canada survey] are women, mostly wives and daughters.”*

*(Canadian Mental Health Association, 2004, p.1)*

Health Canada’s survey revealed that approximately two-thirds (63%) of the caregivers reported caring for someone diagnosed with a mood disorder and one-quarter (27%) provided care to someone with schizophrenia. Fewer reported caring for someone with an anxiety (17%) or personality disorder (6%). One percent of caregivers provided care to a family member with an eating disorder.

Ninety-one (91%) of those providing care to someone diagnosed with a mental illness described the condition as something that was long term. Three percent of the caregivers indicated the condition was less acute (less than three months) and four percent reported the condition was medium term (between three to six months).

Many other families have ongoing contact and provide daily or frequent emotional, social, financial and crisis support to a family member living outside the family home. (Penning, 1998; Winefield & Harvey, 1993).

Lehman, Steinwachs, & Survey Co-Investigators of the PORT Project (1998) reported that 75% of patients had contact with their families.

*Family members caring for those with serious and persistent mental illness tend to find themselves becoming a nurse/ counselor/advocate/crisis worker/home-care and income provider all rolled into one.*

*(Canadian Mental Health Association, 2004, p.1)*

Families often serve a variety of roles in caring for persons living with mental illness in addition to providing emotional support. They provide housing, day-to-day basic care; transportation to appointments; are sometimes the only people that an ill relative has contact with; act as informal case manager arranging for services; are often the first to notice early signs of relapse; assist in finding needed help during crises; support the person to stay with their treatment (e.g., medications); advocate for their family member; and provide information to assist professionals working with their family member (Family Mental Health Alliance, 2006).

Families not only provide much of the care needed by their family member, but are also impacted by the mental illness. When first identified, families may feel confusion, fear, and worry. They may blame themselves – for either causing the illness or for not identifying problems earlier. They often lack quality information about the illness, evidence-based treatments and how they can best support their family member. Families may be isolated as a result of stigma and ignorance by others within their social circle and extended family. They may encounter barriers to communicating with mental health professionals about their family member's and their own needs. They may lack information about illness management and handling crises. Relationships within the family can also be impacted e.g., marriage difficulties or tensions between family members. The mental health of caregivers can also be compromised (Cochrane, Goering, & Rogers 1997; Stuart, 2005).

Studies assessing the needs of families of adults with mental illness have consistently found that families need information about their relative's illness, coping strategies, support, understanding of the illness, and assistance with problem-solving (Drapalski, Marshall, Seybolt et al., 2008).

In the past, families received little guidance and support from the mental health system. Families experienced difficulties navigating a complex, fragmented mental health system on

behalf of their loved ones. Although there is some access to education and support, there is a lack of consistency across communities and families continue to struggle to understand the mental health system. The Kirby Report “Out of the Shadows at Last” (The Standing Senate Committee on Social Affairs, Science and Technology, 2004) clearly indicated that Canadian families were being excluded by the mental health system.

As healthcare moves towards a more balanced system that values person and family focused care, there is growing recognition of the need to acknowledge and include families as partners in care, rehabilitation and recovery.

In recent years, the recognition of families’ contributions to mental health care and their needs has been gaining momentum in Canada. At the national level, the role of families is highlighted in the Canadian mental health strategy. Goal Four in “Toward Recovery and Well-being: A Framework for a Mental Health Strategy in Canada” (Mental Health Commission of Canada, 2009) states:

“The role of families in promoting well-being and providing care is recognized, and their needs are supported.” (p.35)

*Family members told the Committee of their need for a variety of things: better information and education; income support; peer support; respite; access to their family member’s care plan and to be included respectfully by physicians and others in discussions of how and by whom that plan will be implemented.*

*(Standing Senate Committee on Social Affairs, Science and Technology, 2004, p 29)*

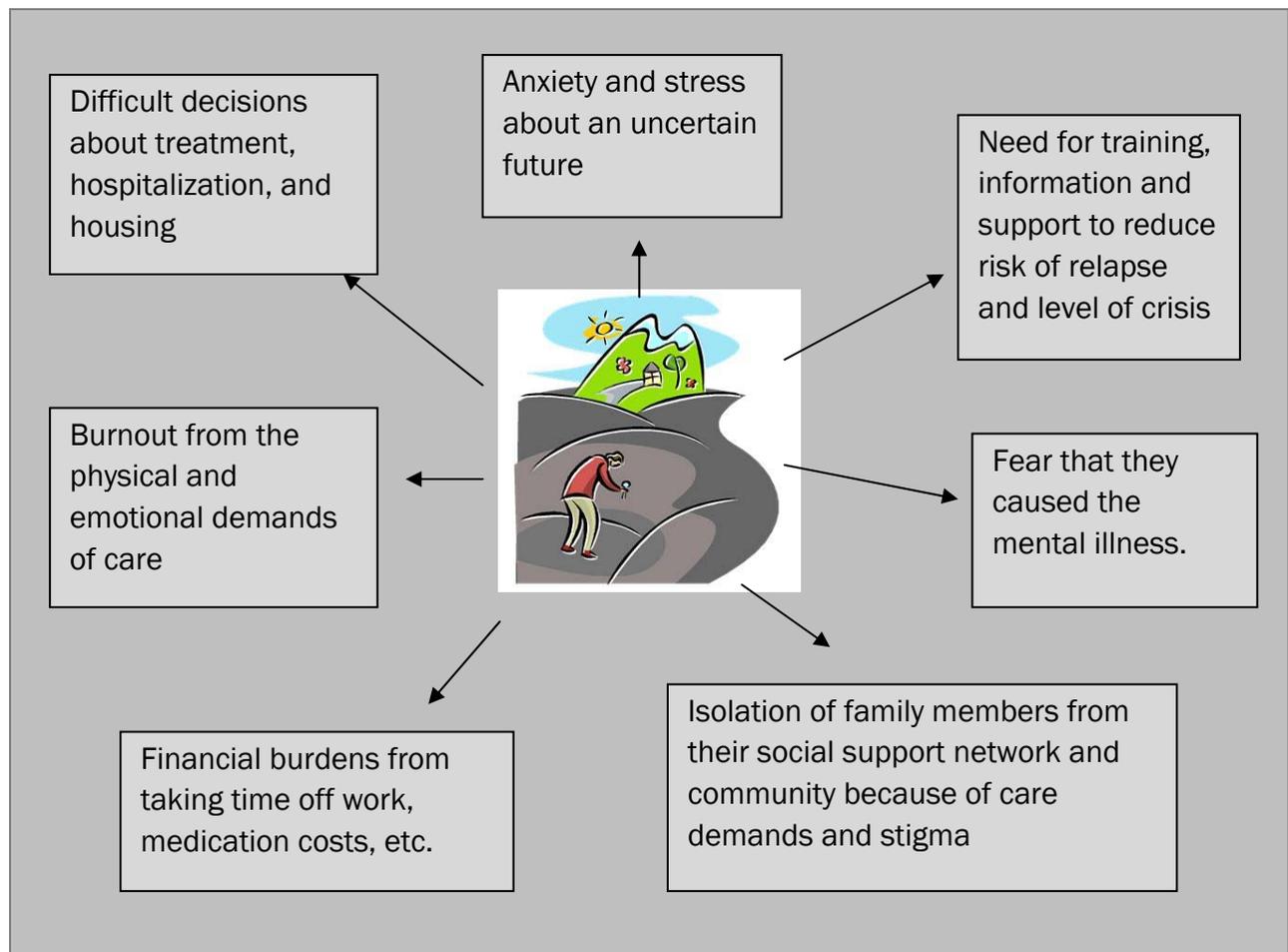
The framework further states:

“The Mental Health Commission firmly believes that families, in all their diversity, must be better supported in the important contribution they can make toward recovery and well-being. Failure to do so will not only pass up the opportunity to improve the well-being of all people living in Canada, but will also increase the costs of care, and produce worse health and social outcomes both for people living with mental health problems and illnesses and for family members themselves. It is therefore in our best interests as a society to recognize the importance of the role of families and provide them with proper support.” (p. 64)

In Fraser Health Mental Health Services, the important role of families in supporting the recovery process of their family member living with mental illness is well recognized. Over many years, Mental Health (MH) has consulted with family members in an attempt to understand and address family members’ service and support needs. Recommendations made by family members on how to enhance family support and involvement in services are now formally recognized in the Mental Health and Addictions Strategic Plan 2007 – 2012

(Fraser Health, 2007a). The two areas of need identified are: 1) well resourced family services, and 2) a system wide culture of family inclusiveness at all levels of service delivery.

The MHA Strategic Plan identified the following issues that families face when dealing with mental illness:



## Development of a Strategic Direction for Family Support and Inclusion

In recognition of the need for consistent support and inclusion of families across Mental Health Services, the Mental Health and Substance Use Services Leadership Team commissioned the development of a strategic direction for family support and inclusion. The Rehabilitation and Recovery program area was the logical choice for taking on the planning. Building upon historical advocacy for family support and involvement in their 2008/2009 Service Plan, Rehabilitation and Recovery Services had tasked itself with the following:

**Goal:** Enhance capacity of families to be able to participate effectively in the treatment and recovery process with their family member.

**Plan:** Develop a strategic direction for family support and inclusion for Fraser Mental Health services.

The process included:

- (1) The establishment of the Family Support Task Group, who helped facilitate the development of the strategic direction. The group was comprised of family members, Fraser Health mental health staff, and community agency staff (BC Schizophrenia Society).
- (2) Examination of family support and inclusion practices currently operating with Fraser Health Mental Health Services.
- (3) Review of evidence-based and best practices for family support and inclusion and research on additional services identified by families as important to their mental and physical well-being e.g., respite, support groups.
- (4) Consultation with families, mental health staff, community agency providers of family support services/programs and consumers (Fraser Health adults receiving mental health services) as to the support and inclusion needs of families.
- (5) Development of recommendations regarding family support services and inclusion in mental health care.

## Current Family Support and Inclusion in Fraser Health Mental Health Services

A review of existing family support services and inclusion in MH services to people with mental illness was undertaken as part of the planning process. Table 1 provides a summary of services offered through community mental health agencies.

Fraser Health Mental Health Services contracts with the BC Schizophrenia Society to provide a number of family support services for Mental Health. Mental Health recently consolidated several of the family support services that were only available in some communities and expanded their availability so that families throughout Fraser Health communities could access them. The BCSS Family Support and Respite Service, is made up of three components:

- 1) Family Support Coordinators: Support to family members is provided through three regionally based family support coordinators. Coordinators assist family members during their recovery process through education, self care, skill development and goal setting. They also help families who face difficulties gaining access to the treatment planning for their ill family member.
- 2) Respite Care: Temporary, short-term respite care designed to give relief to a primary unpaid caregiver. Funding up to a maximum fixed amount is provided to cover the costs of care. Family caregivers are assisted in developing practical ideas to arrange for much-needed breaks from caregiving.
- 3) Family Education Program: A 10 week psycho-educational course for family members, “Strengthening Families Together”, which has a strong interactive support component and is delivered by trained family facilitators. It covers a variety of topics including symptoms, treatment, recovery, coping skills and navigating the mental health system. At the completion of the program, families are referred to local support groups operated by community agencies such as local branches of the BCSS and MDA.

In addition to family services offered through BCSS, family support groups in the South are available through the Mood Disorders Association (MDA), Canadian Mental Health Association (CMHA) and the Early Psychosis Intervention (EPI) program. MDA also has a family support group in the Fraser East. Resources for families are also available from MDA, CMHA and the EPI Program.

**Table 1. Community Agency Family Services**

Family Services	BCSS	MDA	CMHA	EPI
Family Support Coordinators	North, South East			
Respite	North, South East			
Family Support Groups	North: 3, South: 3 East: 2	South: 1 East: 1	South: 1	South: 1 North: 1
Family Education Groups	North: 2, South: 2 East: 2			North, South, East
Resources	North, South East	North, South East	North South	North: 1, South: 1, East: 1

The inclusion of families in treatment planning has been incorporated to some extent into mental health services. For example, Burnaby Mental Health Services includes families in assessment and treatment planning. In the Inpatient Psychiatric Unit, the family is invited to be part of the initial admission meeting where collateral information is collected. They are encouraged to call the unit on a daily basis for an update from nursing staff on their family member's progress, and be involved in patient care and treatment planning. Family meetings are booked ahead of time to allow ample time for families and staff to attend. At Burnaby Central Mental Health Centre, questions about families are included in the assessment. Clients are routinely invited to have their family members come to sessions as needed. Families provide collateral information to the treatment team. Families are referred to a family education program and community support group.

A program area that consistently includes families is Child, Youth and Young Adult Mental Health and Substance Use Services. Professionals work as much as possible with families and see them as having an integral role in assessment and treatment. Increasing family partnership is one of the strategic priorities for Youth and Young Adult Mental Health 2007-2012 (Fraser Health Mental Health and Addictions, 2008).

The Early Psychosis Intervention (EPI) Program has made the inclusion of family members foundational to the program and part of their culture. Each of the three EPI Programs in

Fraser Health has a group and family therapist. In addition, clinicians involve families in the assessment and during the course of treatment. Family members are also involved in training new clinicians and participate as presenters and audience in the Annual EPI Conference. Clinical services available specifically for families in the EPI Program include:

- Multi-family psycho-education groups
- Multi-family support groups (often led or co-led by a family member)
- Multicultural family education groups (in Punjabi/Hindi, in Cantonese/Mandarin)
- Family therapy services

### **Service Reviews**

In 2008, the Group Therapy Services Review found that families are under-served by MH groups and recommended that family groups be provided in every community. Although there are community based family support groups, most Mental Health Centres do not currently offer in-house family education or support groups.

In March 2010, a Resident Needs Assessment was completed, and seventy-two clients living in Community Residential facilities were assessed. The majority of families were included in the assessment and a large proportion of the families were supportive of their family member in care. Of those families, 51% had never had any contact with the clinician. Forty-two percent of the clients had been in some type of residential placement for over 10 years.

The assessment of current mental health services revealed that there are some programs of family support/education and inclusion of families in treatment and care planning within Fraser Health Mental Health Services but there is a lack of consistency across communities, programs and services.

## Building the Foundation

### **Person and Family-Centered Care**

Within healthcare, there has been a shift to person and family-centered care that incorporates the person (also referred to as client or patient) and family perspectives in the design, delivery and evaluation of health care services. Healthcare services are moving from a system where professionals did things for or to patients to one where professionals work in partnership with patients and families.

Person and family-centered care is based on collaboration and partnerships between health care providers, clients and their families. Dignity and respect, education, participation and collaboration are core values underlying this approach to health care (Conway, Johnson, Edgman-Levitan, Schlucter, Ford, Sodomka, & Simmons, 2006).

*“Family-centered care is an evidence-based best practice. Research demonstrates that involving families hastens client recovery from mental illness and addiction, lowers the risk of mortality, reduces reliance on health care services, reduces the rate of rehospitalization and relapse, enhances medication compliance and bolsters client interpersonal functioning and family relationships. Family-centered care improves health care quality and cost effectiveness and both health care professionals and clients have found that this collaborative approach results in greater satisfaction with health care.”*

*(Community Research, Planning and Evaluation Team 2004, p.2)*

### **Recovery-based Mental Health Services**

The recovery model is increasingly being adopted as the guiding principle of mental health care. The Fraser Health Mental Health Framework (Fraser Health, 2007b) notes that the concept of recovery-oriented practice has been articulated in a number of key Mental Health and Addictions (MH&A) planning documents: Mental Health & Addictions Strategic Plan (December, 2003), the MH&A Services Strategic Direction (2006), Goals and Objectives; and draft Mental Health & Addictions Strategic Plan 2007 – 2010.

*“A recovery vision of service is grounded in the idea that people can recover from mental illness, and that the service delivery system must be constructed based on this knowledge.”*

*(Anthony, 2000, p.159)*

The term “recovery” has been defined in many ways but generally refers to living a full and satisfying life (i.e., work, learn and participate in one’s community) despite having a mental illness. Recovery is viewed in terms of gaining control over one’s life, including the illness and its symptoms (Trainor, Pomeroy, & Pape, 2004). Elements that support recovery include meaningful daily activity; positive family or peer relationships; medications; and recovery-oriented mental health services

Relationships are central in the concept of recovery. Families and friends form the informal support network of persons with mental illness. Evidence shows that there is an increased likelihood of recovery when a person receives informed and integrated support from family and close friends. Pernice-Duca (2010) found that support and reciprocity with family members were important dimensions of a personal support network that related to the recovery process.

*“The relationships, personal support and encouragement provided to a person experiencing mental illness can play an extremely important role in promoting their recovery”.*

*(Government of South Australia, 2007, p.13)*

Families often best know the person, what his or her interests and aspirations were and are, and can help in guiding recovery that would fit best with the interests of the person. Through their day-to-day contact, families can contribute to helping the person to make the most of their life.

The principles of recovery also apply to families of people with mental health problems, who are on their own recovery journey. When mental illness strikes, families may have to re-evaluate their own lives and make accommodations and adjustments (e.g., O’Grady & Skinner, 2007).

## Literature Review

### Family Interventions

Family intervention can be loosely defined as a set of clinical practices for working with families that have a specific supportive, educational or treatment function and include problem solving/crisis management work. Falloon (2003) reviewed evidence on family interventions and concluded there was sufficient scientific evidence to conclude that strategies that enhance the caregiving capacity of family members have a clinically significant impact on the course of mental illness. The evidence was strongest for schizophrenia and bipolar affective disorder. Comprehensive methods that integrated caregivers into the therapeutic team through education and training in stress management strategies, and had continued professional support and supervision over a period of at least two years produced the best results. Inclusion of family members as part of the treatment team has been found to enhance the effectiveness of other evidence-based practices and reduces family burden (McFarlane et al, 2000; Mueser et al, 2002).

The 2010 updated Cochrane review on family intervention for schizophrenia (Pharoah, Mari, Rathbone, & Wong, 2010).concluded that family-based interventions (when compared to standard care) resulted in:

- Reduced relapse rates
- Reduced re-hospitalization rates at one year
- Adherence to medications (which is predictive of better outcome and may thus contribute to decreased relapse)
- Family outcomes such as reduced expressed emotions, families' understanding of patient needs, lessened burden
- Economic analysis: Net savings in direct or indirect costs – a consistent and important finding

Other benefits that have been identified for persons with schizophrenia and their families include:

- Decreased psychiatric symptoms (Dyck, Short, Hendryx et al., 2000; McFarlane, Hornby, Dixon, & McNary, 2002).
- Improved social functioning (McFarlane, Dixon, Lukens, & Lucksted, 2003)
- Improved quality of life (Pitschel-Walz, Leucht, Bauml, Kissling, & Engel, 2001).
- Improvement of knowledge about schizophrenia (Pitschel-Walz et al., 2001.)
- Improved family well-being (McFarlane, Dixon, Lukens, & Lucksted, 2003)

- Reduction in family burden (Magliano, Fiorillo, Malangone, De Rosa, & Maj 2006; Pilling, Bebbington, Kuipers, Garety, Geddes, Orbach, et al., 2002; Pitschel-Walz et al., 2001).
- Relative increased perception of professional support (Magliano, et al., 2006).
- Increased social contacts for relatives (Magliano et al., 2006).

Professionally-led family psycho-education programs have been the most extensively researched and data supporting the efficacy of family psycho-education is very strong (Dixon, Adams & Lucksted, 2000). A large body of controlled studies indicates that patient relapse rates are generally cut in half during the active phase of family psycho-education interventions. Programs have also been shown to impact other important clinical outcomes, such as levels of positive and negative symptoms, as well as psychosocial outcomes, such as employment rates and social functioning (Murray-Swank & Dixon, 2004).

Given the vast amount of significant evidence regarding the effectiveness of family psycho-education models, family psycho-education is considered an evidence-based practice (Drapalski, Marshall, Seybolt, Medoff, Peer, Leith, & Dixon, 2008). In 2009, the Schizophrenia Patient Outcomes Research Team published updated Treatment Recommendations and continues to include family education and support as evidenced-based best practices (Kreyenbuhl, Buchanan, Dickerson, & Dixon, 2009).

Components associated with positive treatment outcomes for both clients and their family members included:

- Provide information about mental illness (Glynn, Cohen, Dixon, & Niv, 2006; McFarlane, Dixon, Lukens, & Lucksted, 2003).
- Provide emotional support (Glynn, et al., 2006; McFarlane, et al., 2003).
- Crisis intervention (McFarlane, et al., 2003).
- Strengthen family communication (Glynn, et al., 2006).

Cuijpers (1999)'s meta-analysis concluded that family interventions of less than 10 sessions have no significant effects on family burden. Another meta-analysis (Pitschel-Walz, Leucht, Bauml, Kissling, & Engel 2001) reported that more intensive, long-term interventions (at least 9 months) are more successful than short-term interventions. Shorter programs may influence knowledge, attitudes and quality of relationships, but do not affect relapse rates (e.g., Vaughan, Doyle, McConaghy, Blaszczyński, Fox, & Tarrier, 1992).

The evidence is mixed regarding whether single versus multi-family psycho-educational approaches are more effective, although multiple family groups are more cost effective (McFarlane et al., 2003). Multi-family groups have been found to address social isolation, stigmatization, and financial and psychological burden directly through increasing the social support network, and hence mutual aid (Jewell, Downing, & McFarlane, 2009).

Research suggests that family psycho-education is more effective than individual therapy across nearly all major cultural populations, including: British-American and Australian,

African-American, Spanish, Scandinavian Northern European, Chinese, and Japanese (SAMHA, 2003).

Family involvement and support has also been shown to be effective for the treatment of other disorders e.g., bipolar disorder, depression, substance abuse disorder, and borderline personality disorder (Miklowitz, Justo, Soares & Calil, 2007; Miklowitz, Simoneau, George et al., 2000; Simiazu, Shimodera, Mino, Nishida, Kamimura, Sawada, Fugita, Furukawa & Inoue, 2011; O'Farrell, Fals-Stewart, 2003; Gunderson, Berkowitz & Ruiz-Sancho, 1997).

Research on peer-led family education (taught by trained family members) is not as extensive as research on professional-led family psycho-education (Dixon, Adams, & Lucksted, 2000). Peer-led family psycho-education programs provide information on various mental illnesses, typically schizophrenia, depression, bipolar disorder, and obsessive-compulsive disorder. Other areas covered include: problem-solving skills; coping strategies; normative reactions to mental illness; self-care; community treatment programs; and recovery (e.g., Pickett-Schenk, Lippincott, Bennett, & Steigman, 2008). Since their review, Dixon, Luksted, Stewart et al., (2004) found that participation in family peer led education, compared to a wait-list control group, resulted in increases in knowledge, empowerment, and self-care, as well as reductions in subjective burden. These benefits were sustained at a 6-month follow-up. Pickett-Schenk, Cook, Steigman et al., (2006) found that, when compared to a wait-list control group, participants in the family peer-led program experienced reduced depressive symptoms, greater emotional role functioning, and less negative views of their relations with their ill family member. Murray-Swank & Dixon (2004) noted that peer-led family psycho-education is not limited to families of individuals who are in treatment whereas professional-led psycho-education is often only available to families of clients who are receiving services.

### **Elements of Effective Family Intervention**

In the late 1990's, encouraged by the World Schizophrenia Fellowship, consensus on the elements of effective family intervention was reached that are currently supported in the US by the Substance Abuse and Mental Health Services Administration (SAMHSA) and the National Alliance on Mental Illness (NAMI) (Murray-Swank and Dixon, 2004). The elements are:

- Coordinate all elements of treatment and rehabilitation to ensure that everyone is working toward the same goals in a collaborative, supportive relationship.
- Pay attention to both the social and the clinical needs of the consumer.
- Provide optimum medication management.
- Listen to families' concerns and involve them as equal partners in the planning and delivery of treatment.
- Explore family members' expectations of the treatment program and expectations for the consumer.

- Assess the strengths and limitations of the family's ability to support the consumer.
- Help resolve family conflict by responding sensitively to emotional distress.
- Address feelings of loss.
- Provide relevant information for the consumer and his or her family at appropriate times.
- Provide an explicit crisis plan and professional response.
- Help improve communication among family members.
- Provide training for the family in structured problem-solving techniques.
- Encourage family members to expand their social supports networks.
- Be flexible in meeting the needs of the family.
- Provide the family with easy access to another professional in the event that the current work with the family ceases.

### **Family Support Groups**

Support groups for family caregivers of a person with mental illness are an avenue for families to get information about mental illness, treatment and community resources; learn how to advocate for their family member; and provide an opportunity to share feelings and experiences in a safe environment.

Studies reviewed by Chien & Norman (2009) reported the following benefits of group participation: increased knowledge about the illness, reduced burden and distress, and enhanced coping ability and social support. A review by Pickett, Heller, & Cook (1998) indicated that support group participation resulted in reduced feelings of burden, improved relationships with the ill family member, better coping ability and increased knowledge about mental illness and services.

### **Respite Care**

Respite, the temporary provision of care has been identified as a need by family caregivers to maintain their health and wellbeing, both in the literature and the consultation process. Providing respite is based on the assumption that the temporary relief will lead to a reduction in stress experienced by caregivers, leading to increased wellbeing of the caregiver and enabling the person being cared for to remain living in their community.

A review by Jeon, Brodaty, & Chesterson (2005) revealed there were few empirical studies on the effectiveness of respite care services for family caregivers of person with mental illness. The research literature on respite care predominantly focuses on frail elders, people with dementia, intellectual disability, and children. Their review revealed contradictory findings on outcomes of respite care services and a lack of controlled empirical studies and evaluative research on effectiveness.

No evaluative research on respite care for people with serious mental illness was found. A few studies examined caregivers' satisfaction with services. Jeon, Brodaty, O'Neill & Chesterson (2006), found that family caregivers who were able to access respite care and

have quality time off whilst the patient was in respite care reported positive experiences. They felt it helped them and their ill relative to cope better. Other caregivers reported negative experiences due to their family member refusing to go, poor quality of the service, or an insufficient respite period. It was recommended that respite care services should be targeted, flexible and accessible for both caregivers and their family members.

### **Best Practices**

Dixon, Adams, and Lucksted (2000) reviewed 15 studies on family interventions and schizophrenia and based on their review, the researchers recommend three “provider actions” for optimal effectiveness from family interventions:

1. Educate family members about schizophrenia and other mental illnesses, illness management, navigating the mental health system, and community resources.
2. Assist family members in learning communication and problem solving skills.
3. Support family members to develop a good relationship with mental health providers and enhanced ability for family members to support each other.

A review of best practices in mental health reform by the Public Health Agency of Canada (Clarke Institute of Psychiatry, 1997) revealed that research on family self-help was limited in quality and quantity. However, generally participation in support groups was associated with:

- Increased levels of information among participants
- Improved coping skills
- Reduced caregiver burden
- Improved identity as caregiver
- Improved relationship with and ability to support ill relative
- Improved emotional support

Recommendations from best practices BC Mental Health Reform for Family Support and Involvement (British Columbia Ministry of Health, 2002) included:

- Provision of professional counselling for family members in need
- Partnerships among families, consumers and professionals in the treatment plan
- Training opportunities and resources to support self-help
- Diversified respite care
- Inclusion of families in the planning and evaluation of services
- Training for mental health professionals to include skills and competencies that would increase their understanding and improve their ability to meet the needs of families
- Increasing public awareness of mental health issues through education and a variety of approaches
- A coordinated approach to providing family members with support, information, resources, education and training

The Centre for Addiction and Mental Health (2004) recommended the following strategies to involve families in their family member's mental health care:

- Listening to families' concerns, needs and questions, and understanding the unique issues facing family members as a function of their relationship to the care recipient (e.g., spouse, parent)
- Soliciting their input and feedback particularly because they have intimate knowledge of the client and can shed light on the strengths, interests and competencies of the client as well as the rate and severity of decompensation and substance use;
- Acknowledging strengths, expertise and contributions of family members
- Exploring families' expectations of the intervention and the client
- Assessing the capacity of the family to support the client
- Facilitating the resolution of family conflict by responding thoughtfully to emotional distress
- Acknowledging and dealing with feelings of loss
- Working with families to develop a crisis plan
- Helping improve communication between family members
- Providing education and training for the family, including structured problem-solving techniques, at suitable times
- Encouraging family members to expand their support networks
- Being flexible in meeting the needs of the family
- Providing resources to facilitate involvement (e.g., childcare)
- Providing the family with easy access to another professional in case current work with the family ceases and
- Developing strategies for resolving problems related to confidentiality. (p.5)

### **Barriers to Involving Families in the Mental Health System**

Despite the significant advances in evidence-based research and understanding of the family's importance in care and recovery from mental health challenges, family involvement is not always easily incorporated into the routine of mental health services (Dixon, McFarlane et al., 2001; Fadden, 1997).

Research on barriers includes barriers identified by family caregivers and those identified by mental health professionals (Kaas, Lee & Peitzman, 2003; Rethink, 2003; Rose, Mallinson, & Walton-Moss, 2004; Winefield, Burnett, & Peter, 1996; Wright, 1997, Zipple, Spaniol & Rogers, 1990). Table 2 provides examples of barriers reported in the literature. The list is illustrative and not exhaustive.

Table 2. Barriers to Family Involvement in Mental Health Care Identified in the Literature

Barriers Identified by Family Caregivers	Barriers Identified by Professionals
Confidentiality issues; refusal to share information with families	The mental health care system does not support working with families – lack of resources, lack of recognition to family care, few opportunities for skill development; issues of confidentiality; lack of physical space to meet with families
Professionals don't understand or acknowledge family caregiver experiences	Time constraints and high caseloads limit/prevent professionals from working with families
Services lack continuity and integration across settings making it difficult for families to develop trusting relationships with professionals e.g., high turnover of therapists; lack of coverage for emergencies; inadequate funding for community services	Families “resist” involvement; refuse invitations to be part of the planning/treatment process
	Lack of knowledge by mental health professionals regarding the impact of mental illness on families and of the burdens faced by families
Overemphasis on medical conditions in hospitals e.g., shorter length of stay for inpatient care; premature discharges	The loss of hope and giving up by the family
	Families’ feelings of guilt and shame,
	The client not wanting the family to be involved,
	The family’s difficulty in communicating with the client
	Professionals experience feelings of conflict about treating the client versus treating the family
	Professionals hold belief that family involvement may be harmful to the client
	A lack of visible or measurable results of the benefits of including families in the care and treatment of the client

	Lack of clinical supervision for working with families
	Feared loss of power
	Parents perceived as responsible for the illness
	Lack of skills to meet needs of families

Mohr, Lafuze and Mohr (2000) noted that mental health clinical training programs continue to use textbooks, terms, and concepts that focus on family pathology rather than family coping, adaptation, and competence.

### **Confidentiality and Sharing Information with Family Caregivers**

There are several examples of best practices regarding confidentiality and information sharing with family caregivers from the UK and Australia. For example, Slade, Pinfold, Rapaport, Bellringer, Banerjee, Kuipers, Huxley (2007) outline a best practice framework for guiding information sharing when service users do consent to sharing information with others. Harvey, Ning, Callander, Leggatt, Stephen, Gooding, & Woodhouse (2009) outline ways to promote best practice. Marshall and Solomon (2004) presented a model intervention clarifying confidentiality policies regarding releasing information to families or significant other. The Office of the Chief Psychiatrist (Australia) has a general framework to guide good practice regarding issues of privacy, confidentiality and the sharing of information (Office of the Chief Psychiatrist 2007). Pinfold, Farmer, Rapaport, Bellringer, Huxley, Murray, Banerjee, Slade, Kuipers, Bhugra, & Waitere (2004) have also described effective ways to involve caregivers in information sharing.

### **Policies and Standards**

The essential role of family, friends, and partners in the lives of the vast majority of consumers is being recognized and supported worldwide by innovative policy and legislation.

In 2003 the Australian Capital Territory developed a Caring for Carers Policy that embodies the following principles:

1. Carers have the right to decide whether to take on or continue the role of care and are supported in their choices.
2. The health and well being of carers is supported through services and programs that are flexible and responsive to individual needs and circumstances.
3. Resources are available to provide timely and adequate assistance to carers.
4. Affordable services of a high standard are available to people who need care, complementing the role of the carer.

5. The critical contribution of carers is recognized, valued and promoted in the community.
6. The carer and the person receiving care are regarded as a partnership, in which each person has rights and responsibilities.
7. Organizations welcome and support carer participation at all levels of decision-making, with respect for the rights and choices of people receiving care.

In the UK, the National Service Framework for Mental Health (1999), Standard 6: Caring for Carers has the aim:

“To ensure health and social services assess the needs of carers who provide regular and substantial care for those with severe mental illness, and provide care to meet their needs.”

In this standard, it is recognized that carers themselves should have an assessment for their caring, physical and mental health needs and their own written care plan implemented in discussion with them. Information, support and care are seen as three key elements, representing a policy package for carers.

In Western Australia, South Australia and the Northern Territories, the rights of families are enshrined in ‘Carers Recognition’ Legislation (The Carers Recognition Act, 2010). The Act requires that the role of carers is recognized, including them in the assessment, planning, and delivery, as well as a review of services that impact on them.

In Townsville, Queensland, practice standards were introduced as a way to involve carers in adult mental health services (Commonwealth of Australia, 2002). An evaluation of the impact of standards on practice based on audits of hospital and community files pre and post introduction of standards found improvement in the quality of participation of families/carers, but the gains were modest (Lakeman, 2008). The standards were well received by staff and not difficult to apply, but inconsistently attended to.

In Canada, Manitoba Health implemented the 2005 policy: Family Member and Natural Support Participation in Mental Health Service Planning, Implementation and Evaluation (Manitoba Health, 2005). The purpose of the policy is to provide direction to health authorities in development of plans for meaningful family member/natural supports participation. Although in British Columbia, the 10 Year Mental Health and Substance Use Plan refers to the importance of families throughout the plan and explicitly makes a recommendation for parental mental health and substance use, it does not explicitly note family support and inclusion in adult services (British Columbia Ministry of Health, 2010).

## Consultation with Fraser Health Families, Service Providers and Consumers

*“There are other families that are going through the same thing, and you can be there to support them. This is an illness and information should be shared so we can all move forward to have this illness understood.”*

*(Family Member, 2010)*

Stakeholder involvement in the development of family support services consisted of a consultation process that included families, service providers and consumers from across Fraser Health. The Task Group drew upon the recommendations identified in the MHA Strategic Plan 2007 – 2012 (Fraser Health, 2007a) and the recommendations in the Best Practice Report: Family Support and Involvement (British Columbia Ministry of Health, 2002) to guide the process.

The Task Group consulted with:

1. Family members, and/or significant individuals in the life of the consumer
2. Fraser Health mental health clinicians<sup>1</sup>
3. BC Schizophrenia Society
4. Consumers

### Method

During the period of January to May 2010, families were consulted through focus groups held in various communities throughout Fraser Health and an online survey. Two sets of focus groups were held: (1) Focus groups on strengthening family services; and (2) Focus groups on including families in treatment. Families were recruited through press releases to all local community newspapers informing about the upcoming focus groups and through local Consumer and Family Advisory Committees. Posters were put up in the local Mental Health Centres and also given to clients to take home to their family and support people. The posters were sent to all non-profit agencies that held mental health contracts and also posted in the Psychiatric Units of Fraser Health hospitals, Community Clubhouses, and at some libraries. BCSS, MDA, Anxiety BC and BC Partners for Mental Health and Addictions Information also assisted in distributing the poster through their networks. The focus groups were held in community facilities in Abbotsford/Mission; Burnaby; Chilliwack; Delta; New

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<sup>1</sup> An attempt was made to seek answers to online questions from psychiatric staff on inpatient units and ER but there was almost no response and insufficient time to follow through with reminders.

Westminster; Hope/Agassiz; Langley; and South Surrey/White Rock. (See Appendix B for questions asked in the focus group and online survey.)

### **Family Focus Groups**

A total of 138 families participated in the focus groups. One hundred and seventeen participated completed the registration form. Of those, 83 were women and 33 were men. The majority of participants (both women and men) were: over 45 years of age; listed their cultural group as white; and indicated that English was their first language. The majority of participants were either a parent or a spouse of a person with mental illness, although there was some representation from adult children, siblings, extended family and friends. The following communities were represented: Abbotsford, Burnaby, Chilliwack, Delta, Hope/Agassiz/ Harrison, Langley, Maple Ridge/Pitt Meadows, Mission New Westminster, South Surrey/White Rock, Surrey, Tri-Cities (Port Moody/Port Coquitlam/Coquitlam).

### **Family Online Survey**

A total of 114 people participated in the online survey. Ninety were female and 24 were male. Ages ranged from 19 to +65, with the majority being between the ages of 45 and 64. The majority of participants listed Caucasian as their cultural group and that English was their first language (82%). Similar to the demographics from the focus groups, the majority of participants were either a parent or a spouse of a person with mental illness, although there was some representation from adult children, siblings, extended family and friends. Participants indicated they lived in one of the following communities: Abbotsford, Burnaby, Chilliwack, Delta, Hope/Agassiz/Harrison, Langley, Maple Ridge, Mission, New Westminster, South Surrey/White Rock, Surrey, Tri-Cities. Thirty participants listed “Other” as their community.

### **Mental Health Service Providers**

Mental health clinicians from the majority of mental health centres participated either in face-to-face consultations or through an electronic survey. Some Mental Health Centre Coordinators also participated in the consultation. A total of one hundred and eight MHC staff participated in the consultation (91 MH clinicians and 8 clinicians from the EPI and Adolescent Day Treatment program (ADTP)). (See Appendix C for clinician questions, including questions specifically for EPI staff.)

The BC Schizophrenia Society was consulted through a questionnaire. (Please see Appendix A for BCSS questions and answers.)

### **Consumers**

Consumers were given opportunity to participate through a series of questions that were part of a larger questionnaire. Consumers completed the questionnaire by themselves or

with the assistance of their case manager. A total of 47 consumers participated in the consultation process<sup>2</sup>. (Please see Appendix F for consumers' questions and answers.)

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<sup>2</sup> Demographic information was not available for this group.

## Findings

*“We tried to be in discussion with doctors, nurses, etc. We would get a phone call telling us that she had left the psychiatric ward. We felt very frustrated and left out even though we were the main caregivers.”*

*(Family Member, 2010)*

### Families and Mental Health Clinicians

The data collected from families and mental health clinicians is summarized below into two themed areas: family inclusion and family support, and further illustrated by diagrams. However, there is overlap between both areas, and consequently some items will be mentioned in both areas. (See Appendices D and E for a fuller summary of the information collected from families and mental health staff.)

### Aspects of Family Support

Families identified a number support services they would like to see made available to them. There was overlap between the services identified by families and mental health staff as well as additional services identified by either the families or the mental health staff. The themes are presented in Table 3.

Table 3. Services Identified by Families and Mental Health Staff

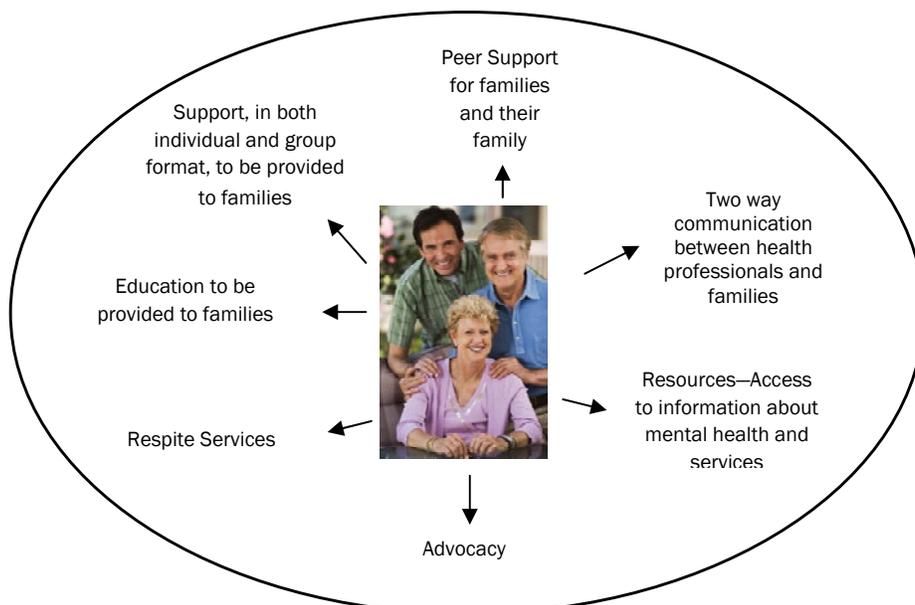
Families	Mental Health Staff
Education with regard to: mental illness, medication, relevant legislation, advanced directives, navigating the mental health system, advocacy, coping skills, communication skills and estate planning	Education
Ongoing support groups	Support
Coordinated peer support in a group or individual family basis	
Help with advocacy for themselves and their loved ones	Advocacy training
Crisis support, for example from the emergency department staff and the police	

Telephone support 24/7	
Family therapist to provide coaching, problem solving, and communication skills to employ with their loved one; as well as help managing their own grief and stress	Counselling
An annual family conference	
They want Fraser Health to do more promoting of; and providing support to, community agencies.	
	Respite

Most of the Mental Health staff recognized that family members need support and also recognize that for a variety of reasons they are not currently providing adequate support. Confidentiality issues were identified as the most prominent reasons for not being able to provide support to families. The staff wanted clarification around confidentiality and sharing of information in order to be able to support families better.

Some of the Mental Health staff recognize that contracted agencies currently provide some of these services and that clinicians need to be making more referrals to these contracted agencies. Although the clinicians did recognize that they should be providing support to the families of their clients, they feel they would need to have smaller case loads if they were to provide this support themselves. Alternately, many of them asked that a family therapist/consultant be hired and to be available to each Mental Health Centre.

### Aspects of Family Support



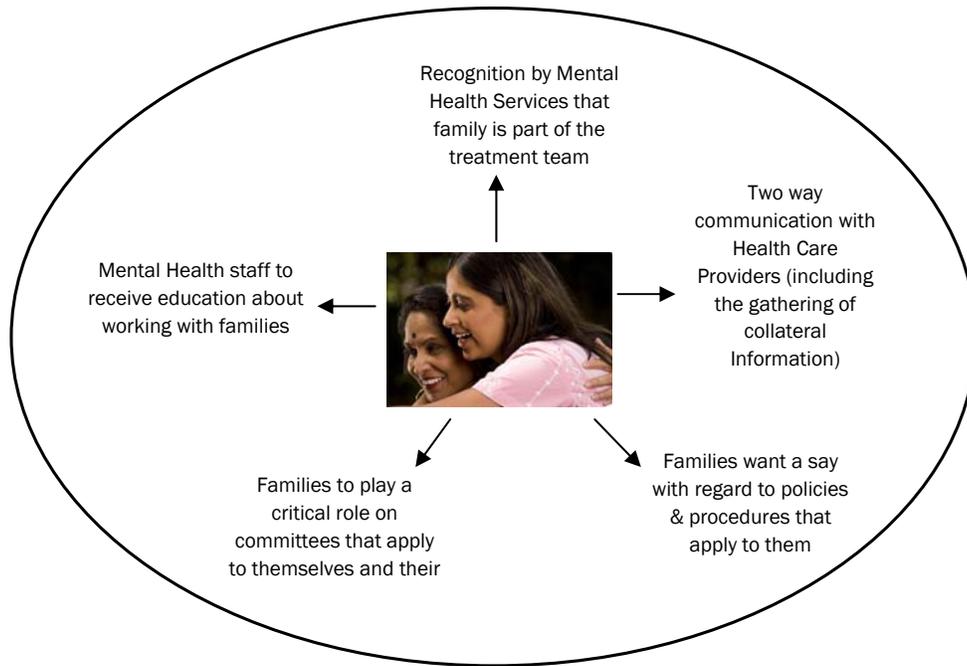
### ***Aspects of Family Inclusion***

Families want more inclusion in treatment and more support for themselves in their role of assisting their loved one with mental illness. Mental health clinicians voiced similar aspects of family inclusion but also added a number of additional themes. The main themes are presented in Table 2.

Table 2. Family Inclusion Themes

<b><i>Families</i></b>	<b><i>Mental Health Staff</i></b>
Be officially recognized as part of the treatment team by Mental Health	To engage families more than they currently are
Be invited to share collateral information with the treatment team	To ask for collateral information from family members
To have collateral information respected and incorporated in treatment planning	To address confidentiality issues in order to facilitate family inclusion
Have easy access to Mental Health professionals for two way communication	To include family members in treatment planning
Have staff become educated about what is required to effectively work with families	To become better educated with regard to how to include and support families
Be invited to sit on Fraser Health Mental Health committees that are relevant to them	For families to “have a voice” by sitting on Advisory Boards
Be invited to participate in Policy and Procedure Reviews that affect them	To have two way communications with family members
Have easy access to Mental Health professionals for two way communication	For families to have assistance in navigating the mental health system
	For families to have access to literature about mental illness, coping strategies and resources
	For families to have access to Review Panels

## Aspects of Family Inclusion



### Family Priorities

After reviewing suggestions in the focus group process, family members identified the following priorities:

#	Priorities
1	Providing Support to Families
2	Communication between Professionals & Families
3	Education to Families
4	Respite
5	Peer support for their loved ones and themselves
6	Resources
7	Advocacy Training

## Consultation with Consumers

Consumers were asked three questions with respect to family support/involvement. (See Appendix F for complete data). The majority responded that talk/emotional support and encouragement were the main ways their families were involved. Other ways families were involved included: participating in the program, visits/outings, financial support, transportation, and as a partner also in recovery.

The majority of consumers who responded felt that their families did provide the support they wanted.

The consumers indicated that they would like their families to be involved by being supportive and giving encouragement; have a better understanding of addiction issues; spending time with them; helping with financial issues; and being a part of their recovery.

## Discussion

*“Change the culture that the medical system seems to have too frequently of ‘we know best’, there is nothing you can do, go home and let us take care of it. But they don’t.”*

*(Family Member, 2010)*

The MHA Strategic Plan clearly acknowledges the need for enhanced family support and involvement. In the table below, the seven recommendations from the Fraser Health MH & A strategic plan are placed alongside the corresponding recommendations for best practices from Best Practices: Family Support and Involvement (British Columbia Ministry of Health, 2002).

MH&A Recommendations	Best Practices – Family Support and Involvement
<b>1:</b> Enhance consumer and family involvement in service planning	<b>6:</b> Including families in planning and evaluating of services
<b>2:</b> Educate service providers on the meaningful roles of consumers and families in the planning, implementation and evaluation of Mental Health and Addiction Services.	<b>6:</b> Including families in planning and evaluating of services
	<b>7:</b> Training professionals to understand the needs of families.
<b>3:</b> Improve consumer and family access to information about services available within Mental Health and Addictions, and the continuum of support through the community.	<b>8:</b> Public awareness and education.
	<b>9:</b> Regional co-ordination of family support and involvement
<b>4:</b> Provide more counselling and support for family members	<b>2:</b> Access to professional counselling for family members.
	<b>7:</b> Training professionals to understand the needs of families.
<b>5:</b> Improve family member involvement in treatment planning	<b>3:</b> Family/Consumer/Professional partnerships in the treatment plan.

<b>6:</b> Increase availability of Respite Care	<b>5:</b> Diversified Respite Care
<b>7:</b> Increase support for self-help training	<b>4:</b> Training for self-help

### ***Services for Families<sup>3</sup>***

The findings from the literature review and consultation with families, service providers and consumers indicate that, in order to best serve families of people with mental illness, a range of options needs to be available to families. The families who participated in the consultation prioritized the need for: support and education to families; peer support; navigation and access to information about mental health resources; respite; and advocacy. The consumers appreciated the support they received from their families and recognized the need for family education about mental health, substance use problems, and recovery.

#### Family Education and Support

Families and clinicians are asking for family education and support groups accessible to families in each community. As indicated in the literature review, family education and support are considered evidenced-based best practices (Kreyebuhl, Buchanan, Dickerson, & Dixon, 2009).

Family education is essential to supporting families. Mental health literacy for families is a key to helping families in their understanding of mental illness and in providing informed support to recovering family members. Education can be provided through a variety of ways: written material, including translations (fact sheets and access to websites); family education groups (which can be separate from or combined with support groups, and could be in multi-languages); and information directly from clinicians and physicians. There are several models for providing family education and support groups. Family education can be offered on an individual basis or in a group format. Education sessions may be taught by a professional or a trained family member.

Support group models include group facilitation by: 1) professionals, 2) family members (also called peer-led groups), and 3) family member and professional co-jointly. There are advantages and disadvantages to each model. Professionally led groups have the advantage of providing expert knowledge to family and supporters. Peer led family support groups offer a safe environment where families can come together to share their experiences without fear of reprisal from the professionals who are treating their family

<sup>3</sup> A comprehensive family services plan would include addressing parental mental health and substance use. However, this is beyond the scope of this plan and was not raised in focus groups or questionnaires, although staff from the Child, Youth and Young Adult MHSU services referred to the impact of parental mental illness or addiction on their children. Parental Mental Health and Substance Use is being addressed in Fraser Health and at the provincial level, and is included in the BC 10 Year Plan on Mental Health and Substance Use.

member and to offer emotional and practical support to one another. Peer-led groups are often more cost effective than professional led groups as they utilize volunteers for facilitators. Co-joint professional and family led groups enable families to benefit from the expertises of both professionals and families.

These models of family education and support groups are already in existence in Fraser Health Mental Health Services.

- The BCSS Family Support & Respite Service offers individual and group family education and support. A family support coordinator is available to assist families on an individual basis. The “Strengthening Families Together” program offers education to families and the Care and Share support groups provide emotional and practical support to families.
- The EPI Program has implemented: 1) regularly scheduled family education groups that are professionally led; 2) peer-led family support group in Fraser North called Triceps, and in collaboration with BCSS in the Delta area of Fraser South; and 3) family member and professional co-facilitation in the White Rock/Surrey area of Fraser South.

Depending on budgets, availability of family members, interest of staff, and presence of BCSS branches, there could be a variety of family education and support groups across Fraser Health communities.

### System Navigation

Many families find navigating the system confusing, especially those new to the mental health system. Who to call, what to expect, what services are available, how the system works, what and how to ask, can be bewildering for families, especially when they are distraught and in crisis. Families need assistance in system navigation. Written guides or brochures have been produced to support families navigate what can be a complex mental health system. Some examples that currently exist that could be built upon for each community include:

- A brochure outlining the geriatric system in Chilliwack (Appendix G)
- Family resource guide produced by the Langley Community Advisory Committee
- A comprehensive mapping of services produced by Vancouver Coastal Health Authority, that includes a hospital guide for family members, addressing issues related to emergency rooms and psychiatric units, and states the families’ right to be included.
- The FORCE Society for Kids’ Mental Health produced an Orientation Guide to Child & Youth Mental Health Services for Vancouver families and an Orientation Guide to

Child & Youth Mental Health and Addictions Services for families living within the Greater Victoria area.

In addition to brochures, there are websites that families can turn to for support. The Here to Help website ([heretohelp.bc.ca](http://heretohelp.bc.ca)), developed by the BC Partners for Mental Health and Addictions Information, contains helpful information about mental health and addictions services in BC. The website also includes a variety of fact sheets and toolkits that can help families in understanding various mental illnesses, and in supporting themselves (self-care) and their ill family member.

System navigation can also be provided through family peer support. The following are two examples from the child and youth mental health sector to consider as potentials for the adult mental health system.

- The Kelty Mental Health Resource Centre, BC's information source for children, youth and families, is a provincial resource located at BC Women's and Children's Hospital. Kelty provides a variety of information to families of young people ages 0-24, through literature, a website, and professional phone support for system navigation. In addition, Kelty has partnered with the F.O.R.C.E. Society for Kids Mental Health, who provides a parent peer support worker for phone and in person consultation.
- Fraser Health's Child, Youth and Young Adult, Mental Health and Substance Use Services will be embarking upon a partnership with the FORCE, the Ministry of Children and Family Development, and Provincial Health Services Authority to take the parent peer support worker to the next level and develop Parent-in-Residence positions. There will be Parent-in-Residence position for each sub-region of Fraser Health, providing parents with another parent to connect with for information, resources, navigation, advocacy, and mentoring. The Parent-in-Residence will provide on-site support to parents who have youth admitted to the Adolescent Psychiatric Unit, the Early Psychosis Intervention Programs, and the Adolescent Day Treatment Programs. They will also provide remote support and information by phone to families.

### Respite Services

Family members who are primary caregivers face exhaustion and burnout. Respite is an important resource for families. The BCSS Family Support and Respite Service provides funded temporary, short-term care designed to give relief to primary unpaid caregivers. The Respite Services Coordinator helps family caregivers develop practical ideas to arrange for much-needed breaks from care giving. As families become more aware of available resources, there will be more demand for respite services which will then require an expansion of services.

## Counselling Services for Families

Through the consultation process, families and clinicians suggested that counselling services would be helpful to some families. Families may be struggling with issues that can impede the recovery process and would benefit from more intensive interventions in addition to the education and support available to all families. For example, conflict in family relationships or trauma resulting from crises can impact on the family's ability to provide the care and support necessary for the client's wellbeing. Helping families work through their issues enables them to move forward and focus their energy on providing the care and support needed by their ill family member.

### ***Clinician Practice***

Both families and service providers saw the need for training of service providers in how to work with families. One of the main issues that needs to be addressed is confidentiality and sharing of information with families. Some of the mental health staff also felt that changes would need to be made with respect to their workload in order for them to be able to support families. The Burnaby Central Mental Health, Inpatient Psychiatric Unit, and the Early Psychosis Intervention (EPI) Program offer models of family inclusion.

## Education/Training for Clinicians

In order to bring about an enduring change in clinician practice and the culture of the mental health system, clinicians need to be educated about: 1) the merits of family inclusion and support; and 2) how to work with families. Family members are asking that clinicians receive education about family functioning, as well as how to include families and provide support to families. Clinicians are also asking for this education. Clinicians have also mentioned the need to have psychiatrists join them in developing an attitude of family inclusion and support. Typically, psychiatrists have limited training in family inclusion; however, there is a movement within the Advancement of Psychiatry to teach Residents family skills (Heru & Drury, 2006). Education and training for clinicians and psychiatrists should be offered across the mental health system, from the mental health centres to inpatient psychiatry.

The discomfort in inviting families into the assessment and treatment process often comes from limited knowledge, training and experience in working with families. The "how to" of family inclusion is key to practice change. Clinicians are not expected to provide family therapy which is best delivered by qualified family therapists. Most families want information about mental illness, medication, coping skills, and crisis management, which clinicians can provide. Clinicians and physicians are being requested to involve families and provide them with support and education so that families can better understand mental illness and how to support their family member, as well as take care of themselves. An education program similar to the regular education and mentoring provided by the EPI Program for EPI staff on family work could be considered. An essential component of education would be the

inclusion of family members so that clinicians can learn from the experience of family members themselves.

### Practice Guidelines and Service Standards

Implementation of family and inclusion can be facilitated by developing clinical practice guidelines for mental health clinicians, hospital staff and psychiatrists. Potential areas for guidelines include: confidentiality and sharing of information with families, providing education and support to families; referring families to community supports; collection of family collateral information, and involvement families in treatment and discharge planning. The development of practice guidelines will need input from management, coordinators and front line staff, in consultation with the BCSS and other community organizations.

Service standards can help to ensure consistency across Mental Health Services (acute and community) and assist in the development of performance indicators and evaluation of services to families.

Ensuring implementation at the daily practice level will be key (i.e., clear direction, performance expectations), as found in the Queensland study that introduction of standards does not necessarily translate into routine practice change.

### **Implications for Organizational Infrastructure Development**

As indicated in the literature, an effective way to implement family support services within a mental health system is to establish a funded position (Mueser & Fox, 2000). As with many change management strategies, a leadership position is often required to lead change. Funding a lead position also gives the strong message that family inclusion is a priority for Mental Health Services. A family leader position would be fundamental to beginning the development of an infrastructure for a mental health system that engages and partners with families.

It has been suggested that to support the implementation of the recommendations put forth in this strategic direction, a Strategic Direction Steering Committee would need to be established. In Vancouver Coastal Health, their Family Advisory Committee, endorsed by senior management, oversees the implementation of their family plan. The Vancouver Coastal Health Family Advisory Committee recently completed a survey about barriers to family involvement in the mental health teams. They have found that the primary factor is the attitude of the leadership toward family involvement (verbal communication with Shirley Rogers, Coordinator of Family Support and Involvement, 2010). Thus it is important to involve Coordinators/ Supervisors on the Steering Committee, as well as family members, clinicians, and representatives of community agencies.

Finally, as with any new or enhanced service development, an evaluation framework to assess effectiveness is essential (see Mottaghipour, Woodland, Bickerton, & Sara, 2006 for

Australian family inclusion service development model). Program evaluation of family involvement and service experience, and staff knowledge and skill development, would be some examples to be included in the framework.

## Recommendations

It is recognized that implementing change within mental health is a process that will take time and building family-friendly services into practice will require leadership commitment, careful management and involvement of all key stakeholders in the design and implementation.

### **Recommendation 1: Develop an infrastructure in Mental Health to support family-friendly services across Fraser Health.**

- a. Develop and hire a Family Specialist position. This position will lead the implementation of the Strategic Direction for Family Support and Inclusion, including developing a work plan, and chair the Strategic Direction Steering Committee. The Family Specialist will also have Knowledge Translation and Exchange responsibilities and support the education and training of mental health clinicians in family work. Initially, the specialist will provide consultation as needed. Over time, this position may need to be converted to a Family Consultant position (see below).
- b. Develop and hire 3 Family Consultant positions, one for each sub-region of Fraser Health (i.e., South, North and East). These positions will be filled by qualified Master's level family therapists, AAMFT certified where possible. The Family Consultants would report to the Rehabilitation and Recovery program area and also have support from family therapists in the Child, Youth and Young Adult Mental Health and Substance Use program area. The Family Consultants will be responsible for providing consultation to mental health clinicians; ongoing education/mentoring of clinicians; and assessment and short-term family counseling where it is needed to enhance recovery for the client.
- c. Establish a Strategic Direction Steering Committee, chaired by the Family Specialist and comprised of key stakeholders such as family members, mental health staff, community agency representatives and consumers. It is recommended that the committee report to the Quality Performance Committee. The steering committee will advise on and oversee the implementation of the Family Support and Inclusion Strategic Direction.
- d. Develop and implement clinical practice guidelines/service standards for family support and inclusion.
- e. Develop and implement an evaluation framework.

**Recommendation 2: Develop and implement an education/training program in working with families for mental health staff.**

- a. Develop a Knowledge Translation and Exchange plan over a 3 year period, coordinated by the Family Specialist, to educate and train clinicians and physicians in working with families. Education and training will include:
  - Outcome evidence for family intervention
  - Introduction to family systems
  - Dealing with confidentiality
  - Review of best practices and FH MH practice guidelines
  - Basic skill development in working with families

The KTE plan could include smaller training workshops and larger conferences. The plan would be reviewed on a regular basis and reconsidered post-3 years to reach new staff.

- b. The Family Consultants will be included as trainers/mentors in the KTE process.

**Recommendation 3: Implement enhanced and new family services so that families have a range of options of support.**

- a. Ensure family education is available for all families in the form of clinician and physician provision of information, written documents (i.e., fact sheets, access to websites), and family education groups (the latter could be combined with the family support groups).
- b. Expand existing family support group program so that each community has a support group. Determine the model for each community.
- c. Ensure families have adequate resources for system navigation and information on services available. Support for navigating the system could be available in the form of written documents (i.e., program brochures or booklets including what to expect from a service, confidentiality policies and information sharing) and family peer support.
- d. Evaluate benefits of the respite program for families and determine future needs of families.
- e. Develop and implement family counselling services (see Recommendation 1b). Family assessment and counseling will be offered to families where family issues are impacting the recovery of the client. These services will be delivered by the Family Consultants.

## Concluding Remarks

“The unique role of families - whether they are made up of relatives or drawn from a person’s broader circle of support – in promoting well-being, providing care, and fostering recovery across the lifespan is recognized, as are the needs of families themselves. ... Wherever possible, families become partners in the care and treatment of their loved ones and are integrated into decision-making in a way that respects consent and privacy.”

(Mental Health Commission of Canada, 2009, p .58)

Families, however we define them, are vital to our sense of belonging, connection and support. With the vulnerability inherent in illness, particularly serious mental illness and addiction, families are a critical element in recovery from mental illness. The focus on treating individuals neglects important dimensions of the person’s life that are essential to recovery. The evidence is clear: proactively reaching out to families and working with them as partners at whatever level is appropriate, results in better outcomes for consumers and their families.

Families are often bewildered not only by changes they see in their family member but also by the challenges of navigating what appears to be a labyrinth system of care. Families also have needs of their own, particularly around increasing their understanding of mental illness and their own self-care.

Clinicians are also sometime bewildered by how they can assist families. Their training and work experience has not necessarily prepared them for incorporating a family perspective into their work.

Fraser Health Mental Health Services already has elements of good practice where families are welcomed as partners in care, and provided with support and information. The Strategic Direction for Family Support and Inclusion will strengthen these existing services and build family involvement in client’s treatment and recovery. It is feasible and is doable over time but requires leadership and a commitment of funding. Mental Health has an opportunity to accelerate reform of its services to embrace and support families at all points of the continuum of care.

Now is the time to act.

## Appendix A

### Questions for Community Agencies for Family Support Service Plan

#### Response from the BC Schizophrenia Society

1. What recommendations would you make to promote a system-wide culture of inclusiveness for family members and/or supporters at all levels of service delivery in Fraser Health?
  - Involvement of families in treatment planning
  - Access to and coordination of family services and supports
  - Access to information and assistance with bridging and linkages to services
  - Access to respite services for family caregivers
  - Training for mental health professionals on the importance of family involvement
  - Training opportunities and resources for families to run self-help programs
  - Access to counselling for families
  - Increase public awareness about mental illness through public education and other approaches
  - Inclusion of family members in planning and evaluation of services
  - Improved discharge planning and communication between hospital and community services, including families.
  
2. What support services would you recommend Fraser Health provide to family members and/or supporters of people living with a mental illness and how can existing services be enhanced?
  - a. Existing BCSS family caregiver services currently funded by Fraser Health
    1. Individual Family Support  
Regional Coordinators provide crisis support and ongoing support in person, by phone and through correspondence. Individual support may include encouragement and guidance through the recovery process, advocacy, facilitation and education. This program would benefit more families if more case managers, doctors, social workers, and other mental health staff referred family members to this resource on a regular basis.
  
    2. Respite  
The Respite Program provides temporary, short-term care designed to give relief or support to a primary unpaid caregiver. The Respite Services Coordinator helps family caregivers develop practical ideas to arrange for much-needed breaks from caregiving. More families could be served by this program if it were expanded.
  
    3. "Care and Share" family support groups

A forum for close friends and family members of people living with a mental illness to share their experiences with others who understand and learn from others about community resources plus caregiving and coping strategies. These groups offer caregivers with much-needed emotional support, and provide hope that recovery is possible.

Over the past few years the BCSS has been introducing their local "Care and Share" groups to the NAMI model of facilitation which is an evidence-based model that gives family caregivers the encouragement and support they need for coping and recovery. Fraser Health should consider the "Care and Share" model as a template if they wish to develop more family support groups in the Fraser Health region. Not only do they give family members the support they need, they are efficient in terms of cost and human resources. Additional funds would be useful to help train more facilitators for each community so that we have greater capacity to run "Care and Share" groups.

4. "Strengthening Families Together" Psycho-Educational groups for family caregivers

BCSS's *Strengthening Families Together* education course is a free 10-session educational program for family members and friends of people with serious and persistent mental illness. A recent quantitative and qualitative evaluation of the program suggests *Strengthening Families Together* is effective at reducing the caregiver burden.

The program would benefit more families if more case managers, doctors, social workers, and other mental health staff referred family members to this resource on a regular basis. Additional funds would be useful to help train more facilitators for each community so that we have greater capacity to run *Strengthening Families Together* courses.

b. Other BCSS family caregiver services

1. "Kids in Control"/"Kids in Control for Teens"

The BC Schizophrenia Society's *Kids in Control Program* provides information, education and support to children 8 to 13 years of age who have a parent with a serious mental illness. Recently, the BCSS has developed a similar program for teenagers between the ages of 13 to 19. Feedback on this program from the children who completed it and their families has been overwhelmingly positive. Kids in control would be an excellent program to be made available in Fraser Health.

## 2. Online Support

The BC Schizophrenia Society facilitates a series of online support groups for family members and friends of people with mental illness. Online groups are anonymous, private and available 24 hours a day, seven days a week. There are also special groups for siblings, adult children, or same sex partners of a person with a mental illness. This program is available and funded through the BCSS Provincial Office. It would be helpful if more case managers, doctors, social workers, and other mental health staff referred family members to this resource on a regular basis.

## 3. Ulysses Agreement Support

A Ulysses Agreement is a voluntary process that is used by a person that has a mental illness. The plan outlines to others what they should and should not do to support in case of a relapse. Our organization works with families and professionals to develop effective and workable agreements. Fraser Health should consider consulting our trained Ulysses Agreement Facilitator so that we can work with clients, family members and case managers as needed.

## Appendix B

### Consultation Questions for Family Members

1. What roles do family members/supporters play in their loved ones Lives?
2. Family Members /supporters who were included in treatment planning and those who weren't.
3. How were needs met to be included?
4. What additional needs could have been met?
5. Work Sheet Three - What Additional Family Support Services are Needed?
6. Respite Services
  1. Have you used? Yes No
  2. If yes was it helpful?
  3. If yes what additional needs could have been met by respite services?
  4. If you never used them what prevented you from using them?
7. Recommendations
8. After reviewing the suggestions you've been given to all these questions, which do you believe should be given top priority to be addressed by FH?
9. One thing you have learnt in this experience you would pass on?

## Appendix C

### Consultation Questions for Mental Health Centre Staff

In your careers as Mental Health professionals no matter where you've worked:

1. What is your experience of involving family members or supports in the treatment planning of clients?
  - a) Positive experiences:
    - i) How did this help you in your work with the clients?
  - b) Not so positive experiences:
2. If you have not had the experience of involving families and supporters in the treatment planning of clients, or, your attempts to do so didn't materialize, what obstacles prevented this from happening?
3. What ways can family members and/or supporters help you help your client?
4. What ways could Fraser Health make it easier to include family members and supporters in treatment planning through Mental Health? (The following are some examples to reflect upon: A Specialist with a background working with families on every team; family therapist works across regions like Concurrent Disorders Therapist and informs case-managers; all Clinicians get minimal training on working with families; training needs such as understanding the application of confidentiality for both family members and staff; assess strengths and limitations of the family's ability to support their loved one.)

**With the next couple of questions we want to capture a snapshot of: the type of family services being given to families; the level of comfort working with families; and recommendations.**

1. Are there any services to families happening at or being delivered through your own centre? Yes  No  If yes, what are they?
2. How many families are you actively involved in? Weekly: \_\_\_\_\_ Monthly: \_\_\_\_\_  
Please describe (generally) the type of involvement you have with them.
3. How would you rate your level of comfort with involving family members in the treatment planning of their loved one? \_\_ % (0 = not at all, 100% = very comfortable)  
Please explain:
4. How skilled do you feel in working with families?  
\_\_\_\_\_ % (0 = no skill at all, 100 = very skilled) Please explain:

5. If counselling services to families were offered through your Centre, what approach would you suggest be given consideration:
6. Recommendations: Based on what we've covered today, what do you believe should be given top priority to be addressed by Fraser Health? (Please list them in order of highest to lowest.)

***Consultation questions for EPI clinicians***

1. How do you involve families?
2. What barriers do you experience in involving families?
3. What recommendations do you have for Adult Mental Health in involving families?

## Appendix D

### Summary of Information Collected from Families

#### Family Support

##### Providing Education to Families:

- Coping skills
- Strengthen BCSS's "Strengthening Families Program"
- Advanced directive training – e.g. WRAP, Ulysses Agreement, Representative Agreement
- Providing resources
- Navigating the Mental Health system (beginning, middle, end)
- Self-advocacy
- Topics – diagnosis, meds, relevant legislation, coping skills, recovery, resources available
- Communicating with professionals
- Estate planning (wills, trust funds) with families
- Consumer peer support workers connecting with families

##### Family Support:

- Supports groups – ongoing, for children as well
- Self-care support
- Counselling, coaching, problem solving, guidance
- Respite
- Telephone support (24/7)
- Crisis support, e.g. emergency department staff at hospital, police
- Advocate for families
- Family peer support
- Financial relief

##### Peer Support for loved ones and themselves:

- More support and promotion for community groups; BCSS, MDA (don't lose their funding, make sure they are maintained)
- Monthly meetings
- Coordinated peer support network (information re: workshops, support groups, literature, meds, connection with new members)

##### Communications between Health Professionals and families:

- Ongoing in-service sessions between family members and Mental Health professionals communicating their concerns, successes, ideas for improvement

- Mutual exchange of information and resources (a two way street)
- Annual family conference: stakeholders, family members and consumers
- Recognition by professionals of families' need for support ,resulting in better solutions for their loved ones - listen to them, "do not tell them to go home"
- Search family members out on the real story re: their loved ones

#### Advocacy:

- Family members sit on Advisory Boards
- To help navigate the system
- Understand confidentiality
- For acceptance of collateral information
- Promote families' rights
- Assistance with appeal procedures re: loved ones (e.g. Income Assistance, denial of disability benefits, etc.)
- Treatment and discharge planning
- Access to review panels

#### Family Inclusion

##### Families Recognized as part of Treatment Team:

- Must be official management expectations and collaborative culture where families are given the opportunity to be included.
- It needs to be consistent, ongoing involvement.
- Creating a welcome environment including the physical space.
- Explain to families the decisions made by professional treatment team including: transfers, medication side effects, changes to medications, alternatives to medications.
- Clear definition of roles and expectations of all those involved in treatment planning.
- As a matter of course, attempts should be made to get release of information from consumers so that families can be included.

##### Gathering Collateral Information:

- Sharing the early warning signs of problems: e.g., deterioration of behavior, poor hygiene, general functioning, communication problems, and non-compliance with medication, irregular sleeping patterns, and safety concerns.
- "We live with them; we know them."
- Families' safety needs to be considered.
- Professionals need to hear the full picture; a complete picture of life lived.
- Information provided by families needs to be valued and reflected in the treatment plan.
- There needs to be ongoing feedback re: how treatment is or isn't working.

- Respectful, inclusive collaboration.

#### Communication between Health Professionals and Families:

- Families have found that professionals are not interested in listening to families.
- Families cannot get an appointment, not invited, phone calls not returned.
- “Feel I’m not being heard in my attempts to communicate.”
- Families give information but don’t receive what they think is an appropriate response.
- Families idea of emergency does not = an emergency in the eyes of a professional i.e., families feel their concerns are minimized.
- Families and professionals do not speak the same language; therefore, do not understand each other.
- Open door is needed with ongoing dialogue.
- Should be an administrative expectation that families and supporters be included.
- Families excluded or not contacted in a timely manner re: discharge.
- Families are unlikely to have input in discharge planning.

#### Staff Education about Working with Families:

- Understanding family systems/how families operate. This includes who consumers consider their family and other supports.
- This means support people need to be included in the same way as biological families.
- Need education about functional and dysfunctional family dynamics and how to manage this.
- Cultural diversity and spiritual diversity and how they relate to an understanding of mental illness.
- Knowledge of community resources to be shared with families.
- Knowledge of continuum of services within and outside Fraser Health.
- Helping families in crisis (facilitation skills).
- Mental Health Act Training and other related legislation.

#### Family Members on Mental Health and Addictions Committees:

- Family members should play a critical and ongoing role on these committees and continue to stay represented on existing committees such as Rehab & Recovery, Consumer and Family Involvement, local Mental Health Community Advisory Committees.
- Adhoc committees to be struck so that ongoing input is provided from the family perspective.
- Family members to be educated to have realistic expectations of the system.
- Acknowledgement of skills family members bring.
- Mutual respect of each other’s roles.

### Policy and Procedure Review

- Feedback from families gathered and considered when there are cutbacks and changes in services.
- Create a family committee to review Mental Health and Addictions policies and procedures that apply to them.
- Develop a complaint process specific to Fraser Health Mental Health and Addictions.
- Mental health clinician data with regard to family inclusion
- Gathering collateral information from families.
- Provides a more comprehensive understanding of information about the client, such as history/meds/early warning signs/family dynamics/past crises.
- Provides a more comprehensive treatment plan that increases safety and well-being of the client.
- Easier to identify concurrent disorders.
- Family engagement increases mutual supports.

## Appendix E

### Summary of Information Collected From Mental Health Staff

#### Family Support

##### Providing education to families

- Families need education about mental health services, medications, and self-care
- If education is provided through contracted resources then professionals need to refer and follow up after the referrals
- Crisis management
- How to be an advocate for their loved one
- Holistic model of recovery
- Education about roles and responsibilities of family/loved one in recovery
- Translation services sometimes required
- Multicultural sensitivity in education programs

##### Providing support to families

- Staff need to refer families to contracted agencies
- In order to support families clinicians indicate more staffing is required
- Staff believe more time is required at the beginning of contact in order to engage families
- Intake procedure should include families
- Need to take an inventory of strengths, challenges and requirements for families to support their loved one
- Family orientation sessions perhaps once a month
- Need Family Specialist/Consultant for each Mental Health Centre
- 24/7 phone line
- Quarterly public open houses in Mental Health
- Clinicians need time to connect with families and share information and plans

##### Peer support for families

- Available family members at the Mental Health Centres to meet with each other

##### Communication between health professionals and families

- There needs to be open communication between professionals and families
- Deal with confidentiality issues
- Identify limitations on both sides
- Recognize that when family members are excluded from information they become either withdrawn or a “squeaky wheel”
- Invite families to meetings

- Involve families in planning for their loved one
- Delegate roles and responsibilities with minute, action plan, time frame follow up and agenda for next meeting
- Have a website to exchange common questions and answers

#### Respite

- A majority of professionals surveyed were not aware of respite services
- Those who were aware have sometimes referred family members to respite

#### Advocacy

- Recognition of the Mental Health Community Advisory Committees as agents of advocacy
- Wish for regular orientation sessions for families
- Believe families should be kept up to date on changes in policies and procedures in Mental Health
- Work needs to be done with regard to the application of confidentiality re: Mental Health Act/FOIPA

#### Resources

- Families need access to information on mental health and addictions
- Important that it be easy to find phone numbers, user-friendly websites
- Important that case managers be willing to talk to family members at orientation sessions, and responsive during questions and answers

#### Family Inclusion

##### Gathering Collateral Information from Families:

- Provides a more comprehensive understanding of information about the client, such as history/meds/early warning signs/family dynamics/past crises.
- Provides a more comprehensive treatment plan that increases safety and well-being of the client.
- Easier to identify concurrent disorders.
- Family engagement increases mutual supports.

##### Barriers:

- Families who will not share information.
- Families who don't want to cooperate.
- Families who give irrelevant information which is not efficient for professionals.
- Families who have unrealistic expectations of Mental Health Professionals resulting in loss of client's voice.
- Mistrust by families results in breakdown of communications.

#### Communication between Mental Health Professionals and Families:

- Helps prevent burn-out in families and strengthen relationships.
- Decreases feelings of guilt and responsibility for families.
- Assists in development of care plan to enhance and sustain client's Rehabilitation & Recovery.

#### Barriers:

- Current approach is adhoc, i.e. No formalized approach currently in Fraser Health leads to inconsistency in involving families in Treatment Planning.
- Mandate in Mental Health Centres is only for client with mental illness.
- Such a grey line and each provider seems to have a different take on what can/cannot be shared because of "confidentiality" in legislation.
- Unrealistic expectations and cultural sensitivities/languages.
- Lack of buy-in of team members.
- Philosophy of independence versus interdependence.
- Dysfunctional behaviours in families: overriding care plan/refusal of meds/client won't allow family involvement/threatening behaviour/ultimatums by some family members towards mental health professionals.

#### Staff Education about Working with Families:

- Want a family therapist on staff.
- To gain a better understanding of client.
- Training of Mental Staff re: interpretation of FIPPA and Mental Health Act.
- Education of care in acute care/emergency/ and community partner.
- Training in family systems/dynamics.
- Education re: Representation Agreement (Ulysses) with involvement of families.
- Understanding cultural backgrounds.
- Literature readily available to staff about these topics.
- Ongoing training and discussion about families, e.g. case review of complex family cases.

## Appendix F

### Questions for Consumers and Summary of Consumers Responses (n=47)

A couple of questions about having support in your life

Fraser Health would like your input on a consultation project – to develop a Family Support Service Plan. The Plan will look at ways in which family members and/or supporters can be a better support to someone living with a mental illness. We welcome your feedback on these two questions. We want to note that your answers are confidential.

#### Questions on Family Involvement and Support

1. If you have a family member and/or supporter involved in your treatment, how are they involved?

Participating in Program	Talk / Emotional Support	Financial	Visits/ outings	Transportation	Encouragement	Partner also in Recovery
5	25	3	3	1	13	1
How many people answered this question						42 out of 47

2. Does your family member and/or supporter, give you the support that you want?

Yes	No	Somewhat	Total number answered
34	4	8	46
How many people answered this question			46 out of 47

3. If they are not involved, would you like them to be involved?

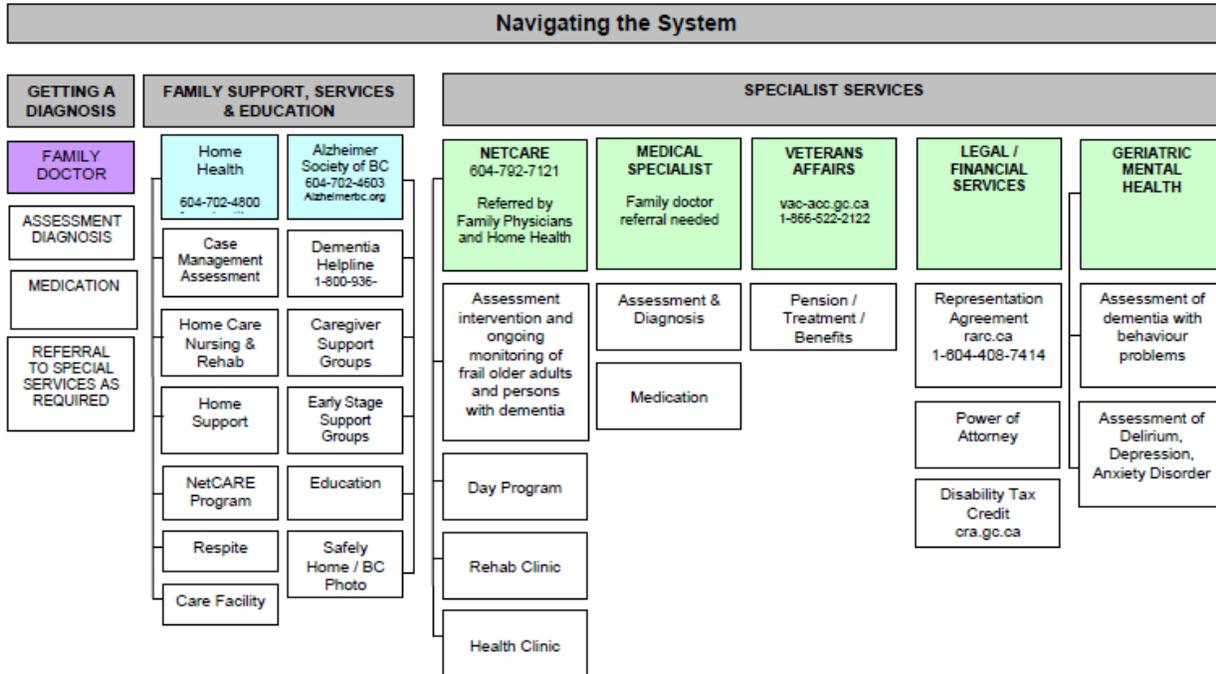
__ Yes		___No		N/A
<b>If yes, how would you like them to be involved?</b>		<b>Do you care to comment?</b>		7
Email	1	No comment	10	
Just be more supportive/give more encouragement	2	I have lost most support over continual relapse	1	
Keep tabs on bank account	1	If supporters could better understand addiction and the whole cycle of addiction	2	
More one on one, better understanding of addiction (Education & Understanding)	2	My family lives in Kenya and I currently do not have a girlfriend	1	
Be part of Recovery Plan	1			
Spend time with me while in recovery	2			
Financial support	1			
Their support is a cornerstone of my recovery	1			
<b>How many people answered this question</b>			<b>37 out of 47</b>	

## Appendix G

An example of how information might be presented to consumers and their families to show pathways through the Mental Health and Addictions system.



Chilliwack Dementia Services



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