



*The Family Guide to
Mental Health Recovery*

Interactive Documentary Media Project

SUPPORTING FAMILIES FACING MENTAL HEALTH CHALLENGES

The Case for Support

“Family-To-Family Peer Support”

As an evidence-based resource
in Family Mental Health

October 18, 2012

www.familyguidetomentalhealth.com

Created and Produced by



In Association with **F.A.M.E**

Family Association for Mental Health Everywhere



“Families need the opportunity to get support from other families – to learn from the experience of other families who have had to deal with a family member who has faced their own struggles. **There is a huge amount to be learned from other families as well as a huge amount of support that people can get –** from other families, *from that shared experience.*”

[Dr. David Goldbloom, Chair, Mental Health Commission of Canada](#)

“Together Against Stigma”, Press Conference, Ottawa, June 2012

“Start small. Start talking amongst yourselves within your family, and then find another family or an organization in your community where you can take the step to talk to maybe a few more people. I think it’s tremendously important... **if you are really serious about the recovery of your family...then you should take seriously your need to talk about it,** to lift that burden from them and from yourself.”

[Glenn Close, Co-Founder BringChange2Mind,](#)

“Together Against Stigma”, Press Conference, Ottawa, June 2012



Family-to-Family Peer Support – Online

A Case for Support

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1. Environmental Context

To fully consider the need for Family Peer Support in mental health recovery, it is helpful to revisit the environmental context that families have experienced in mental health care.

Throughout the 1970's, 1980's and 1990's, a culture of de-institutionalization and de-hospitalization was followed in Canada and in fact, throughout many western countries, such as the United States, the UK, Australia and New Zealand.

The result was a drastic change of care protocol. Care management transferred from a predominantly professional medical/hospital environment to a community-delivered service scenario¹, where families took on a much more concentrated burden for daily care of their loved one. While other issues emerged such as increased homelessness, poverty, under service and an increase in mental illness in police interactions - our key concern is the effect this has had on families and family members.

A mental health condition arising in a family has wide impact on family members.

There is often initial personal shock, confusion, fear and anxiety that accompany witnessing the disruption of a loved one's life due to a mental health condition. This life experience can be a profound one for all family members and often results in great stress.

A second aspect to coping with a loved one's mental health condition is the need for family members to take on care duties related to finding and managing mental health care support and services for their loved one. Additional tasks such as addressing disruption of employment or financial resources, housing, and other personal issues add to care requirements.

A third aspect that arises for many family members is the substantial pressure, conflict and burn-out that can arise in attempting to juggle their own life responsibilities with care requirements for their loved one. This "multi-tasking" aspect can take a huge toll and does not have an 'end date', as most substantial mental health conditions can take a great deal of time, energy, diligence and attention before they subside or a new balance is found. It can take months, years or decades. Unfortunately, many family members become so focused on their caregiving role, that they fail to monitor or maintain their own health.

There are countless issues that arise for family members. They provide us with a *starting point* for considering the support resources they require to make this journey, successfully.

The Global Context:

Mental Illness is a global health phenomenon that touches all cultures, countries and regions. The World Health Organization estimates 1 in 5 people will experience a mental health condition during their lifetime. This will impact **over 7 million Canadians** and their families.

According to US statistics, approximately **50% of all Americans** will suffer a mental health condition at some point in their lives and it is estimated that 1 in 5 experience a mental health condition each year. This will touch over 70 million Americans and their families, annually.

1 in 5, as a starting point – suggests that *most families* will be affected over time.

¹ "I wanted to learn how to heal my heart" International Journal of Mental Health Nursing V20 2011

For each 1 person affected by a mental health condition, there are often a number of loved ones who are impacted. It may be parents, a spouse, siblings or children. Best friends, neighbours or close colleagues.

Family members need to quickly learn about conditions and find available services. They will be challenged to secure an accurate diagnosis, related care supports, effective & affordable medications (and their side effects), find relevant counseling and therapies - and deal with a host of other personal concerns in the care of their family & family member.

Families will find themselves navigating a mental health care system that can be complicated, often confusing, disconnected and over-subscribed. There are a plethora of mental health conditions, with a wide range of diagnoses, care protocols, available services and projected outcomes.

Traditionally care services follow the Bio-Medical model (a metabolic physical orientation often involving medication) or a Psychological model (involving cognitive, behavioural or attitudinal aspects and talk therapy that is often NOT covered by regional health care systems).

A new aspect of overall Care & Support has emerged in the last two decades.

Another pillar of mental health recovery is PEER SUPPORT and incorporates information and resources to support all aspects of mental health education, experience, care and recovery.

PEER SUPPORT involves peer-to-peer communication that allows those with lived experience to share their learning, experiences and insights with those who are just beginning their journeys.

Peer support is an evidence-based, ubiquitous part of health recovery in many areas of health care and is now a crucial aspect of **mental health recovery for individuals and families**.

The FAMILY GUIDE TO MENTAL HEALTH RECOVERY is a family peer-to-peer interactive documentary media project that will allow families to help other families by sharing their insights and support via digital media. As such, our research summary will focus on the relevant aspects of peer support in this area.

The purpose of this CASE FOR SUPPORT is to consider **the problems and needs of families** and **the impact that Peer Support can provide to all Family members** as they undertake a family journey back to mental health recovery.

2. The Issue: The Need for *Family* Support

Before we consider specific aspects of the project, we must first define the issue, and the need. **What kind of support do family members need when a loved one faces a mental health condition?**

The following are excerpts of recent research examining the impact of mental illness on families:

“The impact on family members of a young person developing a mental illness, such as psychosis, or a mood, personality or eating disorder, is extremely distressing.

This first exposure to symptoms of mental illness is difficult for families to grasp. Families often cope through denial (“It’s just a stage he or she is going through.”), or they experience grief and loss at the adverse changes in their family member.

Families feel unprepared and inept. Research indicates that some strategies may create further distress. Self-sacrifice (“giving up my life to care for my child”) is an example. Family members may give up social contacts and employment, resulting in isolation and financial strain. Most people with mental illness live with family members, who become the primary carers — an unrelenting task if the illness results in disability and social dislocation.

Interviews with family carers found that over two-thirds **(77.7%) suffered psychiatric levels of anxiety and depression themselves**. Yet, in spite of these research findings, not to mention the expressions of distress from families themselves - the needs of family members are still largely ignored.”

SOURCE: Minimizing Collateral Damage: Family Peer Support and other Strategies.
THE MEDICAL JOURNAL OF AUSTRALIA 2007 187

“Due to de-institutionalization, the care of people with mental illness has shifted from large psychiatric institutions to the community (Select Committee on Mental Health 2006).

Family caregivers now provide vital, informal caregiving, without which there is a far greater risk of homelessness and diminished quality of life (Jensen 2004). Despite their pivotal role, family caregivers can be unprepared for caregiving and can experience poorer health outcomes and significant subjective and objective burdens relating to their caregiving.

In a recent study, caregivers had the lowest rates of physical and mental well being of any population group, with **56% having moderate depression** (Cummins et al. 2007).

Caregivers have reported **subjective burden**, including emotional exhaustion (burnout), loneliness and isolation, psychological distress, and emotional problems. **Objective burden** includes coping with the illness and its effects on the person, and financial and occupational demands in performing their caregiving roles.

Most had experienced long-term burdens and stress in caring for their family member. For nearly all, stress was also linked with other parts of their life, such as work demands and juggling the needs of other family members with the person with the mental illness.”

SOURCE: “I Wanted To Learn How To Heal A Hole In My Heart” 2011
Family Experiences Receiving Peer Support - INTERNATIONAL JOURNAL of MENTAL HEALTH NURSING

Most had experienced long-term burdens and stress in caring for their family member. For nearly all, stress was linked with other parts of their life, such as work demands and juggling the needs of other family members with the person with the mental illness.”

‘My stresses, my distresses, my difficulties in dealing with (her) illness...problems with communication with mental health people, problems with just ‘surviving’ it, you know all sorts of issues came up, and that’s why it really got too much for me.

Your whole life is really ruined...it’s been a terrible burden, and I’ve thought at times of actually just disappearing...just disappearing completely.’

“There is clear evidence that carers face ongoing difficulties beyond accessing support and care for their loved one. Carers must come to terms with a range of emotional and coping responses: shock and grief (*how can this have happened?*) and guilt (*could I have prevented it?*). It is the eroding frustration and helplessness to cure or assist that impacts the most. Living with a person with a mental illness impacts tremendously upon the family: it can affect relationships, work and finances, one’s sense of personal freedom, and the mental and physical health of the carer as a whole. (Baronet 1999).

...Carers and families experience significant and comprehensive impacts...leading to a traumatized family system. Physical and emotional exhaustion, chronic stress, depression and grief are commonly experienced by family members. Social isolation and low self esteem, economic losses, decreased life opportunities, and difficulties accessing effective treatment and support services all add to the pressures that carers and families experience.”

SOURCE: ARAFEMI AUSTRALIA - FAMILY CAREGIVER INVOLVEMENT: 2008

“Identifying Carer needs, peer support models. REPORT PHASE 1: “Gathering Lived Experience”

Given these scenarios – the needs of families and family members are substantial.

As we are focused on helping to alleviate the pressures, isolation, suffering and functional needs of all family members, we suggest the following as SUPPORT NEEDS for the entire family, *in addition* to the specific care required for a loved one’s mental health condition:

- Access to information: regarding mental health conditions, support services and other resources for their specific situation & care scenario
- Access to information: regarding the journeys of other caregivers and families who have made the journey
- Awareness of peer experience – is my situation and experience common or normal?
- Ways to reduce personal and family isolation – due to fear, shame and stigma
- Role models - who share their experiences
- Tools and activities to help them plan, manage and monitor their own self-care and the health of other family members
- Social contact and peer support – accessing a community that understands what they are going through and can offer relevant guidance
- Ethnically & Community relevant understanding and resources.

While the needs of families are substantial, in many cases there are barriers to accessing it:

- **Lack of available local care resources** designed to serve family members
- **Resistance, fear and stigma** that keep families from reaching out for care or support
- **Distance** to available regional resources
- **Language and cultural barriers** to accessing or using support services or resources
- **Economic cost** to access support services
- **Lack of awareness or information:** what resources exist to support family members?

For Example:

LACK OF LOCAL SERVICES:

There are a number of population groups in Canada who have high need for mental health support. Many of these groups have difficulty in *accessing* it:

“700,000 people in Alberta are living with mental illness. Our organization which is the only provincial mental health consumer organization has a budget of less than \$100,000.”

“In our town, there is NO support for young people...”

“You need to match peer support with the culture of the person you are treating. Our support does not offer specialized cultural support.”

SOURCE: MENTAL HEALTH COMMISSION OF CANADA (MHCC) REPORT:
“Making The Case For Peer Support” SEPTEMBER 2010

RESISTANCE TO SERVICES: (various sources)

- 50% of those with mental illness in their families or suffer from mental illness **would not tell anyone about it**, even today; (Source: MHCC 2012)
- 40% of parents say they would not tell anyone if they thought their child had a mental illness (Source: MHCC 2012)
- Of those who are diagnosed, only 1 in 6 children will get treatment. (Source: MHCC 2012)
Only 1 in 3 adults who suspect suffering from having a mental health condition will seek treatment. (Source: Ontario MOHLTC 2007)
- Mental health problems are highly prevalent among young adults, with **up to 25% experiencing a mental health problem in a given year**. Despite this high prevalence, young adults are particularly unlikely to seek help due to stigma and negative beliefs about mental health care providers.

As our research illustrates, the burden and impact on Canadian families can be enormous. Families suffer yet they must continue to provide care for their family members, with limited or no dedicated family care or support resources. This is a hidden impact of the phenomenon of mental illness in our community.

To those who have experienced it and to those who work in the mental health care sector – the burden on families is no surprise, nor should it continue without being seriously addressed.

3. A Recovery Resource: **Family Peer Support, Online**

Ultimately, mental illness is a complex phenomenon and the needs of millions of individuals from families across regions, provinces or countries, of different ages, cultures and relationships cannot be sculpted down to one or two solutions that fit all. But there are a few basic resources that family members could use to help face common problems and challenges:

- Families need access to a wide range of information on mental health, care and resources
- Families need information and perspective on the challenges of being a family member within a family facing a mental health condition
- Families need external connection to keep from isolating themselves or succumbing to stigma
- Families need support, encouragement and hope - personally and collectively
- Families can benefit from meeting other families who have made the journey, who can act as relevant peers and positive role models

Regardless of the specific tactic, the solution requires **Support for Families**.

The established health care systems in most regions predominantly have instituted care for those with mental illness focused on the bio-medical, and psychological models.

In terms of accessing & creating resources for families and family members, our solution focuses on Family **Peer Support**.

The Science Behind Peer Support

Much evidence supports that peer support is a critical and effective strategy for ongoing health care:

“Overall, studies have found that social support, a broader definition of peer support, decreases morbidity and mortality rates, reduces health care service use, increases life expectancy, self-efficacy, knowledge of a disease or conditions and self-reported health status and better self-care skills. Additionally, providers of social support report less depression, heightened self-esteem and self-efficacy, and improved quality of life.

In particular, peer support can link people who share knowledge and experience that others, *including many health workers*, do not have.”

SOURCE: PEERS FOR PROGRESS - A Program Of The AMERICAN ACADEMY OF FAMILY PHYSICIANS
University Of North Carolina At Chapel Hill Supported By THE ELI LILLY FOUNDATION.

“After years of listening to consumers speak about how self-help groups have helped them, professionals have *also* recognized the effectiveness of self-help groups. In a landmark report on mental health issued by **the US Surgeon General**, the evidence for peer support was summarized this way:

*‘As the number and variety of self-help groups has grown, so too has social science research on their benefit. In general, participation has been found to **lessen feelings of isolation, increase practical knowledge, and sustained coping efforts.**’*

The 2006 report of the Canadian Standing Senate Committee “Out of the Shadows at Last: Transforming Mental Health, Mental Illness and Addiction Services”, identifies the importance of shifting the orientation of the system from one centered around service providers - to one centered around patients and families.

Key to this is the adoption of a recovery value to mental health supports and services. The report identifies the value of peer support organizations in bringing hope and recovery to people living with a mental illness *and their families*.

The report acknowledges that this is a new area of research and findings are still emerging. There appears to be an increasing appreciation for the value of peer support on the national horizon. Support for this comes from national policies in the UK, the US and Australia.”

Source: CMHA BC DIVISION – 2007 “Environmental Scan on Youth & Family Peer Support”

The practice, review and dissemination of PEER SUPPORT as an evidence-based practice has now been active for decades.

“People have always engaged in mutual support to deal with life’s difficulties within their families and local communities. But the idea that people from disparate families and communities who share a life experience can support each other is a more recent phenomenon. These multiple communities have taken on a new dimension with the development of online communities.

Values of peer support:

- *“In three words peer support is: humanize, de-pathologize and socialize.”*
- *“Peer support is about providing all the tools besides medication: tools for the other 80% of your life.”*
- *“Peer support initiatives apply values that differ from those applied in mainstream services. These values revolve around three themes; self-determination & equality, mutuality & empathy, and recovery & hope.”*

Source: “Making the Case for Peer Support” MENTAL HEALTH COMMISSION OF CANADA Sept 2010

A new movement in many progressive regions is **FAMILY PEER SUPPORT** as a tool to build a foundation for the support and recovery of the family as a whole, and the needs of each member. This is becoming a more common resource in the US, Australia, New Zealand & the UK and specialized services are being delivered to great effect.

The following is research related to FAMILY PEER SUPPORT programs now in operation:

“Family-to-Family (F2F) peer-delivered support for families with mental health challenges is a rapidly growing component of the service array in the US (Hoagwood et al., 2010).

The growing awareness of the benefits of F2F peer-delivered support has evolved from a confluence of several factors: advocacy by families drawing on their own experience in accessing and managing the care of their children; studies documenting high levels of burden and strain in families and the key role of this strain in driving service use. F2F support has existed as a resource for families for over 25 years, but has evolved rapidly in recent years.

The core goals of F2F support have been categorized as follows:

- **Decrease isolation** - help family members identify and access their own formal and informal support network and community resources (i.e., support organizations, and support networks, including those available online).
- **Decrease internalized blame** - assist in decreasing the feelings of stigma and blame that families may experience regarding their mental health problems
- **Increase realization of importance of self-care** - help families increase their awareness of the need for self care.
- **Take action** - help increase a family's ability to learn how to take action through gaining knowledge and actively engaging in services.
- **Increase feelings of self-efficacy** - help caregivers and other family members feel stronger and more positive about their skills and abilities in caring
- **Increase acceptance and appreciation** of challenges and increase ability to work with both formal and informal supports.

Source: FAMILY-TO-FAMILY PEER SUPPORT: Models And Evaluation - October 2011
OUTCOMES ROUNDTABLE, Family Involvement Center, Phoenix, AZ USA

"Parents wanted *their own support* in order to enhance their emotional well-being in order to cope better with their child's problems. Peer support enables parents to give voice to these kinds of concerns without fear of judgment and without alienating the clinical staff, upon whom they and their child depend. Families also spoke of their other siblings who were experiencing worry and anxiety about their brother or sister's condition. Some parents suspected these children secretly worried that they might also become unwell.

Parents (and families) need to receive support from someone who *understands* what mental health means for a family...Parents expressed gratitude for having someone who had been through a similar experience.

It was surprising that providing some form of peer support had not been more widely used. We believe that the findings suggest that clinical staff are not always fully aware of the vulnerabilities and needs of family members."

Source: "Sharing the Load: Parents & Carers" Australia,
INTERNATIONAL JOURNAL OF MENTAL HEALTH NURSING (2011) 20, 253–262

While the instances where FAMILY PEER SUPPORT is introduced and delivered to family members have shown to be effective, there is still only a small segment of the affected community that accesses this support, IF it is available in their local communities.

At the same time that PEER SUPPORT has been evolving during the last two decades, a parallel revolution in communications has led to new behaviours and preferences in accessing health care information and participating in care communities: **ONLINE HEALTH CARE ACTIVITY**.

- The Internet has become a key space for health information sharing with **78% of American young adults looking for health information online**. In fact, people are more likely to use the Internet to find health information than to go to a physician.²

² "What Are Young Adults Saying About Mental Health?" 2011 Mobilizing Minds Research
Dept. of Psychology, **YORK UNIVERSITY**, Toronto ON Canada

“Peer support in itself is a low-technology activity but information technology is opening up new ways of delivering it, such as interactive websites and mobile technology. This is already starting to enable online peer support. There is little doubt that **online peer support** will become much bigger in the future, (particularly)...for people who prefer remote interactions.”

Source: “Making the Case for Peer Support” MENTAL HEALTH COMMISSION of CANADA Sept 2010

The future is digital healthcare.

Dr. John Powell, MB, PhD, MRCPsych, says that earlier studies have identified three factors in online peer support:

1. **Universality of experience.** People find it helpful to know that they are not alone.
2. **Installation of hope.** Knowing that others have been through a similar experience, and knowing that they coped or survived, brings hope.
3. **Quality of empathy & interaction.** People feel that only those in the same situation can understand. Peer patients understand because they have been there; they do not give ‘textbook’ answers that might be given by a healthcare professional who does not have the experience of being a patient.

The Internet allows people to connect with others who are geographically dispersed but have the same condition. It is not just about communication with others, but communication with others with the *same problems*. That is not to say that the clinic’s patients did not seek advice from their healthcare professionals; it simply points out that they found **peer support** to be **the most useful**.

Not only is the Internet user community ready and willing to receive healthcare support online but there is evidence that the Internet... creates immediate opportunities to engage patients on matters relating to their health and to build and interact with communities through a platform that many patients are already familiar and comfortable with.”

Source: “Warwick University Identifies The Unique Strength Of Social Media For Patients”
2011 A study by the WARWICK MEDICAL SCHOOL, COVENTRY, ENGLAND UK.

Family peer support is a growing movement in family mental health care, and providing health support online is a platform that is growing exponentially, and may be able to reach many who might be resistant to accessing or engaging in ‘in-person’ support services.

We believe this can be a powerful union – one that can *activate* family mental health support.

4. The Family Guide Project (summary only)

THE FAMILY GUIDE TO MENTAL HEALTH RECOVERY

While there are established resources available for those with mental health conditions - there are shockingly limited resources to help family members manage own their stress and suffering.

We can ease this burden quickly and provide a powerful foundation for recovery if we can provide support that can be reached easily and can overcome resistance to formal care programs.

“The Family Guide to Mental Health Recovery” Project is an interactive documentary media project that has been designed as a FAMILY PEER SUPPORT program to provide insight, information and guidance to families as they begin the process of understanding and overcoming a mental health condition in their family.

It is a platform that allows *FAMILIES TO HELP FAMILIES*; by connecting the wisdom, insight and experience of *Families who have made the journey* with those that may just be beginning their experience or have just decided to finally reach out for support.

The key is – easy access to a wealth of material that many family members can powerfully relate to across a range of ages, cultures, care conditions and locations. It is a *first step* in support.

Content will be presented in a simple documentary format, providing family member interviews who share their experiences and learning on video, universally accessible on our project website: www.familyguidetomentalhealth.com, and on DVD for individual or group screening.

Our goal is to provide an overview of the family journey from first onset, through treatment, stabilization and recovery. Specific relevance to conditions, regional care resources, family role, age, culture and many other personalized circumstances will provide the depth, complexity and personal connection that can powerfully touch a family member and make the resource highly effective and hopefully, empowering.

Our project addresses a number of issues in reaching and serving FAMILIES in need of support:

- Web content is free and can be accessed from any location, on PC, tablet or mobile phone
- Our content can be viewed privately, at any time & place that is convenient to the viewer
- Family members can view content by subject or may view individual family interviews most relevant to them. We will offer a wide range of ages and cultures to maximize relevance
- Family members can choose to watch for a few minutes and return at any time, or they can watch for hours at their convenience. They receive the depth of information they value
- They can access in-depth text resources or links to sites that can provide specialized support

We will reach families predominantly online but will also access networks of families by reaching out to health and mental health care practitioner institutions, community and family support organizations, educators and employee assistance programs.

There are millions of family members affected regionally in Ontario and nationally across Canada. The vast majority does not know where to access relevant support and information. Based on our research there is a great shortage of professionally produced material for families in this format, and our project supporters believe there will be great demand for its use by families and by many healthcare, education, employee and community programs.

To date, we have shot over 30 family interviews; resulting in more than 25 hours of material.

We will present content in many forms; as a traditional documentary, as mini-documentaries that focus on relationship & subject, and as a gallery of individual interviews for viewers to choose from. This will provide a series of options to maximize our ability to connect with viewers.

Video content will be augmented by text resources that offer specific information for families based on primary relationship, the mental health challenge their family member is facing & regional resources. We are hoping to partner with expert organizations to present specialized content on our site or to link to their online resources. Our DVD and online video content will be supported with text-based user guides for educators and health care practitioner use.

Our project has been designed by an exceptional advisory group of leading mental health practitioners representing care & educational institutions in a range of practice areas, including:

- Family Association for Mental Health Everywhere (FAME)
- Schizophrenia Society of Canada
- Mood Disorders Association of Canada
- CAMH
- Family Outreach and Response Program (FOR)
- University of Toronto School of Medicine, Family Practice
- The Toronto District Catholic School Board

We have made a wide range of connections to best-practice organizations in Canada and around the world and hope to unite our resources to present a unique best practice family mental health support resource, unlike any other currently presented in the world.

We are currently completing production on the Pilot Version of the project. Upon release, our first focus will be to reach families in Ontario and then expand reach into other Canadian regions.

In summary - given the need to support millions of family members with limited in-person resources and potential resistance or intimidation that keeps families from accessing services, we believe that presenting Family Peer-to-Peer video content online will be a powerful tool to successfully engage families in taking **a first step toward support**.

Exposure to Peers shows family members they are not alone; there is support for their loved one and for their family - at a time when there is often great distress.

Our mission is to offer family members a new option to access family peer content to find relief, support, encouragement and most of all, HOPE!

5. Research Evidence – Impact & Examples

While Family Peer Support programs are now growing in many countries including Canada, and are being incorporated into national Mental Health Strategies and Policies, many sector-funding bodies still ask the question: **Does it work?**

Research compiled in Canada, USA, UK, Australia and New Zealand all provide resounding evidence that the answer is yes!

The following research highlights provide an international cross-section of reported outcomes.

From: “Making the Case for Peer Support” MENTAL HEALTH COMMISSION OF CANADA Sept 2010:

“Over 800 Respondents were virtually unanimous on the benefits of peer support: Peer support works. Peer support is effective. People with lived experience of mental health challenges can offer huge benefits to each other.

We found that the development of personal resourcefulness and self-belief, which is the foundation of peer support, can not only improve people’s lives but can also reduce the use of formal mental health, medical and social services. By doing so, peer support can save money.

Their comments centered on the values of peer support in contrast to their experiences of the mental health system. People’s responses clustered around two concepts – process and outcomes:

“My life was turned around.” “Peer support got me through when I got nothing from the formal system.”

“I can tell peers stuff without fear.” “Peer support contributed to 80% of my recovery.”

“Every visit I walked away better and better.” “Beautiful, wonderful, lovely – words can’t actually describe it.” “Peer support saves lives PERIOD!”

The benefits of being in a peer support context were very important to people. A key benefit was the trusting, safe and accepting environment of peer support where people could ‘talk openly’, ‘feel validated’ and ‘share stories’, exchange information and learn from each other.

People valued the sense of community and belonging, based on shared experiences – ‘a rich understanding from those who have been there’. These changes led to more concrete outcomes for people, including:

- Better coping skills;
- Better understanding of mental health services issues;
- Increased community engagement and less isolation;
- Reaching life goals and experiencing a sense of accomplishment;
- Increased quality of life; and Reduced crises and hospitalization.
- *“Even when peer support is not done quite right, it still works better than the system.”*

This support resulted in changed attitudes towards managing their family member's mental illness and managing everyday life. For most participants, this included a stronger sense of well-being, as well as a greater understanding of, and ability to manage, the effects of mental illness.

Peer support is in its infancy in (most) every country, full of promise but still under-recognized and under-resourced. Yet, the evidence base for peer support grows every year and our consultations confirmed what the research evidence states; peer support is beneficial to people, it can save lives, it can help people get back the lives they have lost."

PEER SUPPORT is now being formally established in leading health care jurisdictions:

France

Peer Support resources are now well established in France. The passing of *Law No 2005-102* in February 2005, enabled the formation of over 300 self-help groups in France within the following three years. The government funds these self-help groups at a total of €20,000,000 per year.

United States - National level

In 2007, the US Centers for Medicare and Medicaid Services declared peer support **an 'evidence-based' model of mental health service delivery**, and specified requirements for Medicaid funded peer support services. National level agencies have been active in promoting peer run initiatives for those with lived experience and their families.

Canada

There is substantial growth in interest in peer support in the mental health field in Canada. Ontario, British Columbia, New Brunswick and Quebec appear to be furthest ahead in the development and support of peer support services. The British Columbia Ministry of Children and Family Development stands out in Canada for its support of **parental peer support**.

Family voices from around the world tell a similar story:

"Being able to speak with people who had been through this before made an amazing difference. They understood my anxiety and they listened. They gave me hope, passed on their knowledge of the system and didn't judge. This gave me strength at a time when I felt like I had none."

"The success of our Family Peer Support program is based on one simple idea – that the people who have personally experienced a situation are those best able to provide support to others in the same situation. I have been really heartened by the genuine goodwill in validating and supporting mental health carers. There is/has been such inequity in recognition and support on so many different levels, and the degree of trauma experienced can really be immense. Thank goodness for people who understand and care."

Source: ORYGEN Youth Health Family Peer Support Program – Australia

A robust and growing research evidence base shows peer support is associated with:

- Reductions in hospitalizations for mental health problems,
- Reductions in 'symptom' distress,
- Improvements in social support and Improvements in people's quality of life.

Canadian research has contributed significantly to our knowledge base. Several experimental studies have demonstrated not only the benefits to individuals involved, but also to mental health system and communities as a whole, by saving millions of tax-payers dollars through reducing the use of the most expensive types of services.

A key issue that was highlighted repeatedly across research into peer support was, need for measurement:

“We knew Parent Advocates were doing good things but nobody really knew except for the families.”

Formal studies that measured satisfaction with Family To Family Peer Support (F2F) services found that parent caregivers consider F2F programs as helpful and valuable (Davidson & Fristad, 2004; Hoagwood et al., 2010; Green, & Ferron et al 2010). For example **98% of parents provided the highest rating**.

Of 193 caregivers followed from baseline to follow-up, 25% reported doing better on items related to support groups and respite, 20% reported doing better for caregiver optimism, and 12% reported doing better for caregiver involvement (Craig, 2010).

Source: FAMILY-TO-FAMILY PEER SUPPORT: MODELS AND EVALUATION - October 2011
OUTCOMES ROUNDTABLE, **Family Involvement Center**, Phoenix, AZ USA

In summary, Family-to-Family Peer Support is an emerging field that is increasingly demonstrating improved outcomes for families in need of mental health support services and with improved measurement, it is now recognized internationally as an evidence-based practice.

Connecting to health care information and communities online is a huge new area of activity but there are few family mental health *peer support* sites to provide data for our review. We know it is crucial we reach young people where they are and the statistical research in this area is very clear – they are on line & on mobile and this is where they are becoming most comfortable seeking health information and community connection.

Launching a Family Peer-to-Peer Support online has qualities that, based on our research, will provide an effective and wide-reaching first entry point for families in need of support.

In addition to content design and presentation, it will also require our focused effort to track and **measure outcomes** so we can provide clear data to show that peer support efforts perform – and thus, provide research findings for future investment consideration in this practice area.

6. Conclusion - An Opportunity to Make A Difference

In the face of a global mental health reality that affects millions of people, there is growing hope – in part from increased communication and resources now available to individuals, families and caregivers.

Creating a Family Peer-to-Peer resource using the views, experiences and insights of family members to help other families across Canada and the world is an exciting development.

It's part of a movement in Peer Support and recovery orientation that is growing globally as part of a balanced mental health wellness protocol, joining with traditional bio-medical and psychological models of care.

And best of all – the patients and families that access peer support find it to be invaluable in facilitating their recovery.

For us to successfully complete and launch the project, there are still challenges that must be faced but after decades of working with families, **we firmly believe that Family Peer Support delivered online now has the chance to open a door to families, and deliver information and support that can enhance or supplement traditional services.**

We believe Families will open a door for other Families like themselves; who have made the journey; who know what they are going through and can lend their insights and encouragement.

While it is just a first step - sometimes that is all that is needed to start and one day complete a journey to recovery.

We are making this journey for the countless families who need our assistance today.

We hope you choose to make the journey with us.



The NEW Face of
Family Mental Health



www.familyguidetomentalhealth.com

Appendices: Selected Research Sources

Explore these links for further information about family peer support:

- www.arafmi.org (Australia)
- www.arafemi.org (Australia)
- www.mhselfhelp.org (USA)
- www.peersupport.org (USA)
- www.together-uk.org (UK)
- www.tepou.co.nz (New Zealand)
- www.mentalhealthcommission.ca (Canada) – see Report “Making the Case for Peer Support”

Selected Research Resources:

Davidson, K. H., & Fristad, M. A. (2004). The hand-to-hand family educational program: A means of reducing parental stress and increasing support *Child and Adolescent Psychopharmacology News*, 9(2), 7–9.

Hoagwood, K. E., Cavaleri, M. A., Olin, S. S., Burns, B. J., Slaton, E., Gruttadaro, D., & Hughes, R. (2010). Family support in children’s mental health: A review and synthesis. *Clinical Child and Family Psychology Review*, 13,

Hoagwood, K., Rodriguez, J., Burton, G., Penn, M., Olin, S., Shorter, P., & Craig, N. (2009, March). *Parents as change agents: The Parent Empowerment Program for parent advisors in New York State*. Presented at the 22nd Annual Research Conference: A System of Care for Children’s Mental Health: Expanding the Research Base, Tampa, FL.

Tennakoon L, Fannon D, Doku V, et al. **Experience of caregiving**: relatives of people experiencing a first episode of psychosis. *Br J Psychiatry* 2000; 177: 529-533.

Addington J, Coldham EL, Jones B, et al. The first episode of psychosis: **the experience of relatives**. *Acta Psychiatrica Scand* 2003; 108: 285-289.

McNab C, Haslam N, Burnett P. Expressed emotion, attributions, utility beliefs, and **distress in parents** of young people with first episode psychosis. *Psychiatry Res* 2007; 151: 97-106.

Scottish Schizophrenia Research Group. The Scottish First Episode Schizophrenia Study IV. Psychiatric and social impact on relatives. *Br J Psychiatry* 1987; 150: 340-344.

Chambers, M., Ryan, A. A. & Connor, S. L. (2001). Exploring **the emotional support needs and coping strategies of family carers**. *Journal of Psychiatric and Mental Health Nursing*, 8, 99–106.

Glanville, D. N. & Dixon, L. (2005). **Caregiver burden**, family treatment approaches and service use in families of patients with schizophrenia. *Israel Journal of Psychiatry*, 42 (1), 15–22.

Davidson, L., Stayner, D. A., Rakfeldt, J., & Tebes, J. K. (1995, May). **Supporting peer supporters: Strategies for the training, supervision, and accommodation of mental health consumers**. A symposium conducted at the 6th biennial conference of the Society for Community Research and Action, Chicago.

Reidy, D. (1994). Recovering from treatment: The mental health system as an agent of stigma. *Resources*, 6, 3-10.

Canadian Mental Health Association, Ontario, Centre for Addiction and Mental Health, Ontario Federation of Community Mental Health and Addiction Programs, & Ontario **Peer Development Initiative**. (2005).