



# **MAKING THE CASE FOR PEER SUPPORT**

**REPORT TO THE  
MENTAL HEALTH COMMISSION OF CANADA  
MENTAL HEALTH PEER SUPPORT PROJECT COMMITTEE**

**Mary O'Hagan, Céline Cyr, Heather McKee, and Robyn Priest**

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## VOICES FROM ACROSS CANADA

*“Beginning five years ago, I participated in a weekly support group over a two year period. It changed my life knowing other people who had struggled and overcome...Even though I have struggled with illness on and off since the age of fifteen, until that point in time I hadn't realized what was lacking in my life. Eventually, three years ago, I made a career change and became a Peer Support Provider. I never could have done this without the metamorphosis that took place during my two years attending the support group. I love my work and have never attained this level of wellness before.”*

*“I have learned that there are many roads to wellness and the simplest, most insignificant thing can be the catalyst for change in someone. I have learned that I am NOT alone and that there are others who are in my corner encouraging me to go on. I have also learned that by serving, by helping, by listening; that there is healing for me. It is kind of a selfish thing, but when you help others, you in fact are helping yourself.*

*“It took me just over three years to recover. I have no idea where I would have been without my group. From the first time I went, I continued to hear and be encouraged by: Trust me. You will get better. Be patient. It will take time. Learn as much as you can. Set realistic goals and surround yourself with people that make you feel good. Above all, look forward. You cannot change the past but the future is yours for the taking.”*

## EXECUTIVE SUMMARY

People with lived experience of mental illness and mental health problems from across Canada have contributed to the *Making the Case for Peer Support* project by sharing their experiences with peer support in their recovery journeys - francophones from Quebec and New Brunswick; young people overcoming a first episode of psychosis in Halifax; First Nation, Métis, and Inuit peoples from downtown Toronto and northern British Columbia; women with schizophrenia staying in peer-run crisis support services.

Over 600 individuals from across Canada took part in focus groups and interviews. Another 220 people offered their input through written and online surveys.

Together, this wide variety of people with lived experience of mental health problems have worked together to create this report. Together, we want to share with the Mental Health Commission of Canada, and Canadians who look to the Commission for leadership, our experiences with peer support - to describe it, to make the case for it, and to make recommendations on how the Commission can join with us to support its development.

We also reviewed Canadian and international research, government policy statements, evaluation reports and other 'grey' literature. This report describes what we heard and learned from many sources and many people.

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.

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 and quasi-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.

The key to the success of peer support programs - both those that are independently run and those that are located within mainstream mental health organizations - is to hold on to the values of peer support and its unique features, while at the same time providing adequate funding and support to run efficient and effective programs. Research shows that the values and processes of peer support - among them, recovery, empowerment, and hope - help individuals

develop the skills they need to take charge of their lives, and help change mental health services so that they can better contribute to the recovery process.

Mental health professionals and organizations are key partners in the ongoing growth of peer support across Canada. The development of peer support has been boosted by the recovery philosophy, which policy makers and service providers have placed at the centre of mental health policy in many jurisdictions across the world. Whatever shape it takes (i.e., support groups, one to one support, social activities, recovery education, social enterprises, or advocacy services), a variety of stakeholders have an interest in ensuring that more people become aware of, are referred to, and can take part in peer support.

While peer support can take place in self help groups in a local community centre, faith community or mental health service with no more funding than what is needed for refreshments, increasingly small, but important, amounts of government health funding are being invested into these services. From peer support workers helping people who are leaving the hospital to million-dollar consumer-run services and alternative businesses, leadership from government as well as champions from mental health services and other sectors can dramatically increase access to this evidence-based option.

Research knowledge, as well as the knowledge gained from the lived experience of people who take part in peer support, shows the remarkable improvements in people's lives that can occur even with relatively small investments. But there are still many challenges to the sustainability and growth of peer support.

Growth is uneven across the provinces at the levels of legislation, policy, funding, development and provision. Ontario, British Columbia, New Brunswick and Quebec appear to be furthest ahead in the development and support of peer support services, yet they still have a long way to go. While research shows that people from many backgrounds can benefit from the peer support process, we found that it was primarily white, middle-aged and urban mental health consumers who have been the face of the peer support movement. Aboriginal respondents said they have their own equivalents to peer support which have mental health benefits, but these are not recognised or funded by government or mainstream service organizations.

Enhanced investment is needed to offer peer provided, value-based training to people interested in being peer support providers. This will increase the number of people confident in their ability to work in a peer support role, who are paid a living wage, and who work in workplaces that have accommodations and flexible disability income benefit programs.

Most respondents agreed that peer support needs to continue to develop both inside and outside the mainstream mental health system. Independent peer run organizations require policy, administrative and funding support to build and maintain strong infrastructures. Positive working relationships with mainstream service providers need to be cultivated through good communication and working honestly through differences.

The growth in the number of peer support workers and services in mainstream mental health services can help build positive relationships between colleagues working in both independent and mainstream services. Respondents were clear, however, that there are also challenges inherent in this growth that cannot be ignored. Peers working in mainstream mental health

service organizations are often in large bureaucratic settings, where they may be but a small add-on, meaning there is risk of their values getting swamped. Some peers working in mainstream settings describe feeling dominated by professionals who do not understand the value of their work. Ongoing system change and training for professionals to develop the skills to work in and deliver recovery oriented, anti-oppressive services in partnership with peer providers is required.

Peer support providers and organizations also face change as our values and programs become more integrated into the mainstream. We will need to continue to work to create our own groups and services, acknowledge the peers who have been excluded from our movement and reach out to work equitably with them. Negotiation with service systems, with which many of us have had negative and coercive experiences, is also important. Advocacy, research, evaluation, and leadership skills are needed to be able to contribute to this process, as does the ability to maintain hopefulness in a time of increasing pressures on the health care system.

In the words of 'Out of the Shadows at Last', the Senate Committee report that was the catalyst for the formation of the Mental Health Commission of Canada,

“No single treatment model should dominate the policy environment...it is people with mental illness themselves who should be the final arbiters of the services that are made available...People and families living with mental illness are turning more and more to self help and peer support as a substitute or adjunct to hospital, community and professional services...A new and tenuous addition to the mental health and addiction system, the future of self help and peer support programs remains insecure.”

We offer these recommendations below in the hope that this 'new and tenuous addition to the mental health and addiction system' becomes well established and secure. The Mental Health Commission of Canada needs to lead the sustainable development of peer support across Canada with the following actions.

1. Develop guidelines on the **definition** of peer support as a core component of mental health systems, which include:
  - definitions and types of peer support
  - peer support values
  - peer support standards
  - peer support performance and outcome measures
2. Develop guidelines for the **funding** of peer support which include:
  - a target and deadline for the percentage of mental health funding to go to peer support
  - a recommended level of funding for peer support initiative, and for staff, that is equitable with other mental health services
  - recommended funding of a mix of independent and mainstream peer support initiatives
  - templates for contract specifications and accountability requirements
  - recommended funding of development infrastructures for peer support

3. Create guidelines to support the **development** of peer support, which include:
  - templates for peer workforce roles and competencies
  - curricula for peer support workers leading to a formal qualification
  - options for affordable training opportunities
  - education guidelines for peer support and its values for the non-peer workforce
  - consumer/survivor led evaluation of peer support
  - support for consumer/survivor led organizational development, training and education for mainstream mental health services, funders and other key stakeholders on the roles, values, processes and structures of peer support
  
4. Use this report and/or the guidelines developed
  - to highlight the need for peer support to be a core service available to everyone, in the Commission's strategic framework for reformed mental health services across Canada
  - to promote peer support and to educate regional governments, health authorities and service providers about it until the Commission closes in 2017, through conferences, publications and other forms of communication
  - to develop a national resource centre for peer support, where all the information is provided in both French and English and is accessible to disabled people.

## INTRODUCTION

The Mental Health Commission of Canada (MHCC) was set up to be a catalyst for national mental health reform; one of its roles towards this end is to disseminate evidence based information across Canada. It is also developing a national mental health strategy and intends to use the information from this report to promote peer support in the strategy. The MHCC's Service Systems Advisory Committee commissioned this report and established a project group of people with lived experience of mental health problems to lead it.

Peer support initiatives have an emerging evidence base and are highly valued by the people who use them. There are many issues that need to be addressed, however, before they can assume their full place in a reformed Canadian mental health system. The major issues surrounding peer support will be discussed in this report.

This report has three functions:

- To provide a high level description of peer support in Canada and in other countries;
- To make the case for peer support; and
- To recommend to MHCC how it can drive the development of peer support in Canada.

For our investigation, we conducted formal and grey literature searches and web searches, including French-language sources on:

- The international literature on peer support initiatives; and,
- Policy and funding frameworks relating to peer support in Canada and other countries.

We also collected data on peer support initiatives across Canada through an online survey. This database provides contact information, as well as a brief description of the peer support services provided, for those organizations that completed the survey (n=65). This database is available as a separate document.

Most importantly, we received over 220 online and written submissions and conducted interviews and focus groups with over 600 individuals throughout Canada, to elicit:

- The views and experiences of people who both provide and use peer support initiatives;
- The views and experiences of other stakeholders – mental health professionals, researchers and administrators.

We want to signal our awareness of the complex Francophone/Anglophone relationship in Canada. We worked hard to ensure Francophone Canadians were consulted for this report. We are, however, struck by the similarities in the responses between Francophone and Anglophone Canadians, demonstrating that the experience of mental health problems and peer support can transcend linguistic and cultural differences. We also acknowledge that not all Canadians identify as Anglophone or Francophone, including its indigenous peoples, whose healing practices have much in common with recovery and peer support.

Because of the size of Canada and the breadth of our investigation, we have kept this report at a high level; we have analyzed and interpreted all the information gathered, and kept the

provincial level information in summary form. This has been done to reduce the length of the report and to ensure the messages don't get buried in detail.

We begin with the literature review then continue with the remainder of the report which summarises the findings from the consultations and makes the case for peer support. Our recommendations flow logically from our findings and the analysis. We have taken care to ensure they are achievable, reflect consumer/survivor aspirations, and are consistent with progressive mental health reform in Canada.

## LITERATURE REVIEW

### CANADIAN & INTERNATIONAL LITERATURE ON PEER SUPPORT

#### *Definitions, Models and Forms of Peer Support*

To begin, what is peer support? At the most basic level, it may be described as support provided by peers, for peers; or any organized support provided by and for people with mental health problems. We are using a broad definition of peer support so we can discover the full diversity of peer support initiatives within Canada. For the purposes of the *Making the Case for Peer Support* project, a working definition of peer support was proposed by the Project Committee and consultants and is outlined on page 41.

#### **Other Consumers' Definitions and Descriptions of 'Peer Support'**

Defining the nature and meaning of peer support for mental health consumers is a challenging task as one of its defining features is the flexibility to suit people's needs and interests, so that "there are as many different definitions of peer support as there are peer support programs" (National Network for Mental Health, 2005, p.46). A selection of definitions follows:

"Peer support is based on the belief that people who have faced, endured, and overcome adversity can offer useful support, encouragement, hope, and perhaps mentorship to others facing similar situations" (Davidson, Chinman, Sells, & Rowe, 2006, p. 443).

"Is there a spirit of advocacy in the group? To some degree or another is there an expression of the liberation dream? For this is the root of real self-help groups" (Zinman, in Leblanc & St-Amand, 2008, p. 187).

"Peer support is social emotional support, frequently coupled with instrumental support, that is mutually offered or provided by persons having a mental health condition to others sharing a similar mental health condition to bring about a desired social or personal change" (Gartner & Riessman, 1982 in Solomon, 2004, p. 393).

"Traditional therapeutic relationships are different from peer relationships. Peer relationships have more of a mutual, reciprocal nature and include friendship and an equal power base" (quote from unnamed 'consumer/peer' in Forchuk, Jewell, Schofield, Sircelj, & Valledor, 1998, p.202).

Peer support is “the process by which like-minded individuals with similar experiences – who have travelled or are travelling the road – encourage and assist each other to continue the healing” (Muise, 2007, p. 1).

Peer support is “a system of giving and receiving help founded on key principles of respect, shared responsibility, and mutual agreement on what is helpful” (Mead, Hilton, & Curtis, 2001, p. 135).

“Peer support is about normalizing what has been named abnormal because of other people’s discomfort” (Dass & Gorman, in Mead et al., 2001, p.137).

Peer support – “is a process in which consumers/survivors offer support to their peers. Peer supporters experience their own mental health issues and therefore are in a unique position to offer support to others in order to improve the quality of their lives” (British Columbia Ministry of Health Services, 2001, p.11)

“This [self-help] movement specifically incorporates peer lay individuals with experiential knowledge who extend natural (embedded [i.e., family, friends]) social networks and complement professional health services” (Dennis, 2003, p.322).

Some similarities can be discerned across the definitions. For the purposes of this review, we are focusing on peer support that takes place between two or more people, distinct from individuals engaging in self help techniques on their own or self management strategies (for examples of individual self help, see Deegan, 1995; and the individual features of the Wellness Recovery Action Plan approach, Copeland, 1997). Shared experience, often a ‘negative’ experience or one that is a challenge to the individual, is the connecting point. Social support and social networks are key features, as is the notion of change, of movement towards improved conditions, or at least successful coping with the present state. The idea of reciprocity, of beneficial exchange between participants is captured in the less commonly used term ‘mutual aid’.

There are also differences among definitions. Self help and peer support in mental health can differ from many other health and social conditions by a focus on the shared experience of being a patient in the psychiatric system, often viewed as negative and coercive experiences, rather than on the illness experience (Beresford & Hopton, 2000; Burstow & Weitz, 1988; Everett, 2000; Hardiman, Theriot, & Hodges, 2005; LeBlanc & St-Amand, 2008; Shimrat, 1997; Story, Shute, & Thompson, 2008).

What some consumers speak of then is “the experience of ‘consuming’ services” (Story et al., 2008, p.2) rather than, or primarily, the ‘illness’ experience. For Mead & MacNeil this is the result of peer support growing “out of a civil/human rights movement in which people affiliated around the experience of negative mental health treatment” (2004, p. 4). Hardiman and associates, in their summary of the evidence, argue that “a defining characteristic of populations served by consumer-run programs may be their shared negative experience with the traditional mental health system” (2005, p.112). At a minimum, peer support is viewed as arising “in response to barriers or deficiencies encountered in the present health-care system” (Dennis, 2003, p.322). In this conceptualization, peer support often involves consciousness raising about

injustices, comparable to its use in other social movements such as the women's, disability, or queer movements, rather than solely, or at all, dealing with psychiatric symptoms.

But peer support also can be built upon an acceptance of the medical model of mental illness and the need to learn how to cope and live with the experience of illness. This can take place in self help meetings organized by peers alone, as well as within traditional mental health agencies and hospitals. Peer support has a long history of being recognized and valued by mental health, addiction and other health and social service professionals. In this vision, peer support fits comfortably within many traditional and emerging medical models, including health promotion, nursing, up to and including recommending self help groups as part of 'treatment' (Barbic, Krupa, & Armstrong, 2009; Dennis, 2003; Humphreys, Wing, McCarty, Chappel, Gallant, Haberle et al., 2004; Magura, 2008).

### **Frameworks of Peer Support: Structures & Processes**

Self help is a process that takes place within many different structures and can occur through a variety of processes. In order to understand its nature, advocates and researchers alike have sought to create frameworks to explain the forms of organization and relationships in which self help occurs. According to activists in the consumer/survivor movement "a self-help group can take many different forms; its parameters are limited only by the desires, energy, and possibilities of its members" (Zinman in Campbell & Leaver, 2003, p. 13).

The grassroots nature of many forms of peer support poses challenges for categorization, "it is not straightforward to define or even recognize what a service user-run or service user-led service is" (Doughty & Tse, 2005, p.12). Also authors use different terms to refer to similar concepts, and these concepts may overlap in practice (Mowbray, Holter, Stark, Pfeffer, & Bybee, 2005a).

Despite these challenges, peer support has been categorized in both grassroots and academic literatures in several ways (Campbell, 2005b; Davidson et al., 2006; Doughty & Tse, 2005; McLean, 2000; Nelson, Janzen, Trainor, & Ochocka, 2008; Mowbray et al., 2005a; Solomon, 2004; Van Tosh & del Vecchio, 2000).

Some authors classify peer support activities by the ideological stance of the group towards psychiatric treatment and beliefs around mental illness and experiences of emotional distress or difference (Everett, 2000; McLean, 2000). This approach appears to be found in earlier work (before 2000) or reflect earlier phases of the consumer/survivor movement. Chamberlin and Emerick (in Van Tosh & del Vecchio, 2000) classified three types of consumer/survivor groups; exclusively anti-psychiatric, 'moderate' (willing to work with the mental health system but from a critical perspective), and 'partnership' based (working closely with professionals with self help as an adjunct to psychiatric treatment).

Authors may describe these ideological divisions as reducing over time: "consumer run services were originally established an alternative to the formal mental health system but have evolved and are entering a phase of partnership and collaboration with the system" (Forchuk, Martin, Chan & Jensen, 2005, p. 577; see also Nelson et al., 2008; Schell, 2005). While some consumer advocates would suggest that there has always been a range of perspectives within the movement and within groups (Consumer Survivor Business Council & The National Network for

Mental Health, 1994), the importance of the nature of the ideological stance is the impact it may have upon the type of peer support in which they engage.

After a review of consumer-run programs, Mowbray and colleagues conclude that “given the lack of definitional clarity for CRS [consumer-run services], there is considerable heterogeneity among programs identified as consumer-run” (2005a, p.279). As examples of this, they described the differences in a variety of programs on the basis of organizational features such as the number of paid staff positions, annual budgets, and types of services provided. They then outline a two by two matrix model built on two key concepts; who has control of the organizations (consumers or service providers), and what is the aim (mutual support or formal service provision) (Mowbray et al., 1997 in Mowbray et al., 2005a)? Thus this framework is based on process and structural criteria, in which four main options exist,

- consumers running mutual support,
- consumers running formal service provision,
- service providers offering mutual support for consumers, and
- service providers running services.

The proposed model echoes an earlier survivor-created definition based on two questions, “Who holds the real power? Clients or not?” and “Is there a spirit of advocacy in the group? To some degree or another is there an expression of the liberation dream? For this is the root of real self-help groups” (Zinman in Leblanc & St-Amand, 2008, p. 187).

While some consensus exists over the role of ownership, power and control as being essential factors in defining peer support run organizations, defining the meaning of ‘control’ and ‘mutual help vs. service’ remains elusive. As discussed in more detail below, maintaining these values in practice also remains a struggle within the consumer/survivor and mental health communities (Davidson et al., 2006; Mead et al., 2001).

A more common type of framework offered in the literature is based upon the organizational structure that provides or facilitates peer support. As an example, Solomon defines six categories: self-help groups, Internet support groups, peer delivered services, peer run or operated services, peer partnerships, and peer employees (2004, p.393). Davidson et al. proposed three broad categories of peer support activities; mutual support, participation in peer-run programs, and the use of consumers as providers of services and supports (Davidson, Chinman, Kloos, Weingarten, Stayner, et al., 1999, in Davidson et al., 2006, p.444). For their survey of existing groups, Goldstrom and colleagues also delineate three categories, including mental health mutual support group, mental health self help organization, and mental health consumer operated service (Goldstrom, Campbell, Rogers, Lambert, & Blacklow, 2006, p.95).

To describe different types and locations of peer support, this review will follow the common framework of organizing by organizational structure and processes of support. We recognize that this is a rough approximation of the realities of peer support work in communities across Canada and internationally. These structural elements may emerge out of one structure to become another over time, or exist along a continuum. For the purposes of the *Making the Case for Peer Support* literature review, we will focus on four main structures in which peer support takes place,

1. informal grassroots self help groups run by volunteers,

2. independent peer run organizations/initiatives, staffed and governed by consumer/survivors,
3. peer support programs within mainstream agencies, and
4. peer support workers employed or contracted by mainstream services.
- 5.

### *Self Help*

The best known peer support structure is the self help group, exemplified by Alcoholics Anonymous (Health Systems Research Unit, Clarke Institute of Psychiatry, 1997; Salzer, 2002; Solomon, 2004; Trainor, Pomeroy, & Pape, 2005; Van Tosh, Ralph, & Campbell, 2000). Self help groups exist for every imaginable illness, problem, life experience and identity. One review organizes them by the different reasons they are formed; for dealing with transitional stressors such as childbirth and bereavement that occur over the lifespan, situational stressors such as adjusting to long-term or chronic disabilities, and health promotion activities that focuses on information sharing (Dennis, 2003).

Mental health self help groups are active across Canada, organized in many different ways. This may include meeting together on the basis of psychiatric diagnosis (e.g., Organization for Bipolar Affective Disorders, Alberta; Double Trouble/Double Recovery groups for people with addiction and mental health issues, specific groups of consumers (e.g., Women's Program, Manitoba Schizophrenia Society), as well as specific recovery strategies (e.g., Wellness Recovery Action Planning at Consumer Initiative Centre, Nova Scotia) among others.

Self help groups are often sponsored and/or run by mental health, social service and community agencies (Solomon, 2004). They may be facilitated by a peer who has been mentored or formally trained in skills to run groups, or by a clinician (although the focus of this review excludes clinician facilitated groups).

Mental health self help groups are a common form of support. The Canadian Community Health Survey: Mental health and well being report, released by Statistics Canada in 2002, found that five percent of people who were identified with a mental disorder or substance dependencies sought help from a self-help group, with telephone hot line or internet support group each being used by two percent of people (Statistics Canada, 2002, p. 3).

Results from a comparable survey conducted in the United States were reported to be significantly higher, "17.5% of people with serious mental illnesses attended a self-help group (not run by a health professional) for a mental or emotional problem in the 12-months prior to the survey" (Wang, Berglund, & Kessler, 2000 in Goldstrom et al., 2006, p. 93). In another survey from the U.S., the number of groups and programs run by people with mental illness and their family members reportedly outnumbered professionally run mental health services by almost a two to one ratio (Goldstrom et al., 2006).

Despite these significant numbers, self help groups may not be reaching all those who might benefit from them, as research indicates that "few people with SMI [serious mental illness] seek out and join these groups by themselves" (Chinman, Young, Hassell, & Davidson, 2006, p.177).

### *Peer Run Organizations*

At the next level of degree of organization and structure are peer run organizations, many of which developed out of grassroots self help groups into more formalized structures (Goldstrom et al., 2005; Hutchinson, Arai, Pedlar, Lord, & Yuen, 2007; Shimrat, 1997). There are a wider variety of these types of organizations than in other categories of peer run activities and some debates over the defining features of 'peer run', as well as the nature of the helping process that occurs in these organizations.

Within the category of peer run organizations, a distinction can be made between two key activities - advocacy and support (National Empowerment Center, 2007; Nelson et al., 2008). Campbell, in her review of eight consumer run services participating in a national (U.S.) study, calls these the "emancipatory" and "caring" functions of the organizations (Campbell, 2005, p.34). Studies on 20 consumer-run drop-ins in Kansas, United States used the terms "social supportive" and "empowering" for these concepts (Brown, Shepherd, Merkle, Wituk, & Meissen, 2008).

In a review of peer support provided for other health and social conditions (but not specifically mental health), Dennis identifies three "critical attributes" that are somewhat different. These are emotional, informational and appraisal support functions (2003, p.325). Emotional and appraisal (defined as providing motivation and optimism) support can be incorporated into the social support activities, while informational could fit in either support or advocacy functions, depending on the type of information that is being shared.

Dennis' framework explicitly excludes "instrumental support (e.g., the provision of practical help or tangible aid)" (Wills & Shinar, 2000 in Dennis, 2003, p.325) as she claims that it is a rare occurrence in the peer support relationship. However, in the mental health context, practical support, such as that provided through drop-ins and other types of peer run organizations (e.g., access to housing, food, transportation) is very common, perhaps identifying a difference in the way in which peer support has developed among people with mental illnesses.

Peer run organizations may be defined by their choice to focus on one activity or the other, but many do advocacy and support functions (Nelson et al., 2008). Members and advocates may value one activity over the other, or be active in different groups with different aims, or at different periods of time,

A self-help alternative can be anything from a support group, a theatre group, a drop-in centre, a housing project or even a small business. Conventional mental health services provide many of these things too. In self-help it's not so much what you do, but how you do it that makes the difference. The 'how' is really the essence of self-help (O'Hagan, 1994, p. 48)

Advocacy or emancipatory functions have the goal of creating "a society where a psychiatric diagnosis has no impact on a person's citizenship rights and responsibilities" (Campbell, 2005, p.36). Activism against involuntary, compulsory psychiatric treatment, participating in mental health planning tables, or advocating for access to the basic elements of citizenship are some of the 'emancipatory' functions that peer-run groups engage in (Canadian Coalition of Alternative Mental Health Resources, n.d.; Church, Fontan, Ng, & Shragee, 2000; Janzen, Nelson, Trainor, & Ochocka, 2006). While the 'supportive' nature may be obvious in traditional types of self help

activities, there is little literature speaking to the way in which advocacy activities might also function as a form of peer support; by creating new meaning of personal experience, providing social support and comradeship, and working towards common goals.

Quebec has developed some innovative models of peer support advocacy based organizations. Founded in 1990, Association des groupes d'intervention en défense des droits en santé mentale du Québec (AGIDD-SMQ) represents 25 organizations throughout the province. Some of these organizations are self-help groups that have developed advocacy practices. The rest are organizations found in each administration region of the province that defend the rights of people with mental health issues. From its inception, AGIDD-SMQ trained peers so they could become informed advocates. Since then, courses on advocacy are delivered by service users through member organizations. AGIDD-SMQ has updated its peer support advocate training and documentation with its publication, *L'entraide, reprendre sa voie dans la promotion-vigilance: Avec et pour moi ... des pratiques à partager* (2008).

Another noteworthy service-user initiative at AGIDD-SMQ, is the training of service users as representatives on various government committees in health and social services. Based on their book published in 1995, *Guide critique des médicaments de l'âme*, service users have delivered training in partnership with a non-peer trainer on psychiatric medication use from a critical perspective.

#### *Peer Support Programs in Mainstream Agencies*

The process of 'peer support' may be most commonly understood as part of the support or caring function. Examples of supportive/caring functions include running self help groups, drop-ins, and warm lines; and the creation of a community of peers through the day to day activities of the peer group or organization. Within the support function of the peer run organization, Mowbray and colleagues' category (described above) of the aim of the organization, separated into two types, mutual support or formal service provision, can be applied to further examine the nature of the peer support process.

While some consensus exists in the literature over the role of ownership, power and control as being essential factors of peer run organizations, defining the meaning of 'mutual support vs. service provision' remains contested within the consumer/survivor and mental health communities (Davidson et al., 2006). These differences are illustrated through the separation of 'peer run organizations' and 'peer run services/programs within mainstream mental health services'.

Solomon uses the term "peer run or operated services" for those "services that are planned, operated, administered, and evaluated by people with psychiatric disabilities" (Solomon, 2004, p.393). Further criteria include that the service be a freestanding legal entity, usually employing staff and with volunteers, but with many variances in the types of services provided. Examples include drop-ins, crisis services, and peer matching support programs.

Solomon's categorization distinguishes these from "peer partnerships" - where primary control is with mental health peers but is shared with non-consumers (Solomon & Draine, 2001 in Solomon, 2004, p. 394). These are often located within mainstream (non-consumer specific)

organizations, with the sponsoring organization having fiduciary responsibility for the program. Solomon compares this model to “hybrid self-help groups” where non-peer professionals “have a major role in the group” (Powell in Solomon, 2004, p.394).

The theory and research on consumer-run organizations described in this review has been built out of the experiences of English-speaking developed countries. Throughout the rest of the world, people with mental illness and experiences of psychiatric treatment, along with their family members, struggle to fight for improvements in their lives and care without access to even the limited amount of resources available to Canadian consumers. In these contexts, our categories of support and advocacy functions may or may not be useful for understanding or, may look different by degree.

### *Quebec*

In Quebec, peer support is often comprised within the alternative approach in mental health. Although the distinctiveness of self-help is recognized, it shares common values with alternative treatment, alternative community housing, alternative crisis centres, and alternative community-based case management. This also speaks about the different organization of the mental health system in Quebec, New Brunswick and France, which has influenced the genesis of approaches, agencies and innovations.

The province of Quebec stands out amongst Francophone jurisdictions with its extensive network of community organizations. More specifically in the field of community mental health agencies, the “Alliance des forces communautaires et alternatives en santé mentale” which is made up of provincial coalitions and regional tables, represents a total of 420 organizations in Quebec. Out of this network, we highlight the work of three coalitions: Regroupement des ressources alternatives en santé mentale du Québec (RRASMQ), Alliance des groupes d'intervention pour le rétablissement en santé mentale au Québec (AGIR), and Association des groupes d'intervention en défense des droits en santé mentale du Québec (AGIDD-SMQ). These three agencies were chosen as they currently the main players in the alternative and advocacy movement in mental health in Quebec. Between the three of them, they reach out to approximately half the community mental health organizations in Quebec. The RRASMQ and AGIR will be dealt with together as they have the same mission of supporting and representing alternative treatment organizations while AGIDD-SMQ has the specific mandate of advocacy.

### *RRASMQ and AGIR*

RRASMQ was founded in 1983 and now counts 120 member organizations throughout the province of Quebec. Self-help groups, crisis centres, community case management, housing, treatment centres and work integration are examples of member agencies. AGIR, founded in 1985 in the Quebec City region, represents 36 member organizations and has a similar mission as RRASMQ. About half of the member organizations of both coalitions are self-help groups. Few self-help groups are run solely by service users. However, there is a strong tradition of service user involvement ranging from having a majority sitting on the board of administrators to running the activities of the centre.

### *Mutual aid as a general value*

Mutual aid is cited as one of the values of alternative member organizations of the RRASMQ and as such is not restricted only to self-help groups. The RRASMQ's manifeste mentions that:

*L'alternative doit avoir comme orientation de créer des lieux, des temps et des espaces pour permettre l'émergence et la survie de l'entraide. Les ressources alternatives reconnaissent que cette notion est non seulement une valeur en soi mais aussi un processus, une démarche, une dynamique en constante évolution. Les ressources accordent une grande importance à la diversité, la valorisation et la richesse des expériences de chacune des ressources au sein du RRASMQ (2009, p.8)*

The alternative must have guidance as to create places, times and spaces to enable the emergence and survival of mutual aid. The alternative resources recognize that this concept is not only a value in itself but a process in constant evolution. Member organizations place a high emphasis on diversity, development and wealth of experience of each agency in the RRASMQ (translation, Cyr, 2010).

This essential value is about solidarity between the individuals of the organizations, but also between RRASMQ organizations as well (2009, p.9).

If one wishes to know more about the experience of Quebec peer support, one also needs to look up the peer-reviewed literature on this alternative approach to mental health. Some Quebec writers on this topic are: Ellen Corin, Martine Dupérré, Jean Gagné, Lorraine Guay Francine Lavoie, Hélène Provencher and Lourdes Rodriguez. Unfortunately, few of these writings are available in English. Much research focuses on defining what an alternative approach to mental health is, and the experience of and potential benefits for service users. For example, in the book, *Les ressources alternatives de traitement*, Isabelle Lasvergnas and Jean Gagné devote a chapter to evaluating the RRASMQ's specific contribution over the last twenty years (2000, p.31), while Lourdes Rodriguez, Ellen Corin and Lorraine Guay, report the results of their study where they asked service users what it was like to attend an alternative agency and what was helpful (2000, p.49). If we look to AGIR, they recently held a day of reflection on the theme of defining what an alternative practice is and what its future will be (AGIR, 2009). The role of AGIR as a coalition of alternative agencies has been studied by Martine Dupérré in a recent publication (2009). Alternative organizations have the added pressure of defining what they do in comparison to mainstream service organizations and this includes peer support as well.

If one wishes to explore the wealth of peer support experiences and one speaks French, one would need to look up the grey literature: reports, newsletters, the journals "L'Entonnoir" of the RRASMQ (recently replaced by "L'autre Espace") and L'Aliéné of AGIR.

One could make the parallel that the Québécois are used to reflecting on self-identity and that it comes naturally to them to try to define alternative practices, within a society where the dominant model for treating overwhelming emotional distress is medical.

#### *Other European Experiences*

France has undergone a major transformation of its mental health system over the last years. As stated by Le Cardinal, Ethuin and Thibault, « la différence entre le système culturel français et le système anglo-saxon [est] qu'il y a chez nous beaucoup plus d'aide médicosociale organisée par

des structures étatiques » (2007, p.813). In other words, services are organized and delivered almost solely by the government. The development of a network of community organizations in mental health is recent. Let us go back to year 2000, to understand this fundamental shift in French mental health history.

#### *La Loi No 2005-102 du 12 février 2005*

Three community-based organizations advocated for the implementation of a new law in France. La Fédération nationale des associations de patients et ex-patients en psychiatrie (FNAP-PSY) is the national coalition of users. The second organisation called UNAFAM (l'Union nationale des amis et familles de malades mentaux) represents the national coalition of friends and family. Lastly, La Fédération d'aide à la santé mentale Croix Marine (Croix Marine for short), describe themselves as a national movement in favour of people who suffer from mental health issues. It is made up of public and private medical establishments, as well as some user associations and therapeutic clubs. These three coalitions with diverse agendas joined their forces and banded together to advance the cause of users. « La loi No 2005-102, du 12 février 2005 pour l'égalité des droits et des chances et la citoyenneté des personnes handicapées » introduced for the first time the notion of "handicap psychique" or psychiatric disability. The law also included support for the established of self help groups, groupe d'entraide mutuelle (GEMs), of which over 300 have since been created throughout France.

The three founding organizations, the FNAP-PSY, UNAFAM and Croix Marine are sponsoring different GEMs across France, with the goal that, in time, user's associations will be in charge in all GEMs. With respect to funding, 20 million Euros per year will be allocated, and will come from the "Caisse nationale de la solidarité pour l'autonomie" (CNSA). This separate fund is described as follows:

*« qui a l'avantage non seulement d'être indépendante mais de piloter elle-même l'élaboration des étapes de son évolution et de ses limites dans un dialogue permanent avec le terrain » (Baillon, 2009. p.33)*

"which has the advantage not only of being independent but will be in charge each step of the way as it is evolving and will also define its own limits in a continuous dialogue with the field" (translation, Cyr, 2010).

This independent source of recurrent funding gives a greater stability to these agencies, but also flexibility as the CNSA will be in a permanent dialogue with the groups. The average grant is 75,000 Euros per agency (ANEGEM, 2009) with which most GEMs have been able to hire two 'animators'. In addition, funding has also been obtained by many GEMs from regional government sources.

Speaking at a conference in 2008 sponsored by the WHO – European region on strengthening user and carer (family) involvement in mental health services and systems - a Croatian user described his experience. Reflecting on presentations from peers from France, Scotland, Belgium, as well as from other countries and European-level associations, where a common theme was the need for enhanced financial resources from governments and the challenges of relying on volunteers, the user from Croatia is recorded in the notes as saying:

Strange to hear money spoke about so often. 350 Euro monthly in the country he is from; users have no social security, unemployment very high, and uneducated people many (Daumerie, Caria, Roelandt, & Laferriere, 2008, p. 26, as in the original)

This conference was part of a recent WHO European initiative that has the aim of increasing user involvement (see World Health Organization Regional Office for Europe, 2009). While the primary emphasis of the user and carer groups involved is advocacy functions – specifically, strengthening their voices and associations in order to participate and shape policy making - peer support is not excluded. In a summary of recommendations, these groups noted the importance of working with groups internationally in order to “share experiences, to learn about good examples and practices and to overcome the burden of isolation” – a form of peer support at the organizational level (Daumerie et al., 2008, p. 32).

The impact of international networking upon the different forms and activities that the European user groups participated in was demonstrated by a group presenting at the conference that organized the first “Mad Pride” festival in Belgium, which both inspired controversy and involvement (Daumerie et al., 2008, p. 25). In addition to increased access to peer support, and service user led and run resource centres, the European groups recommended “create new jobs as peer [sic] workers to reduce the gap between needs of patients defined by health professionals and needs perceived by users” (Daumerie et al., 2008, p. 32).

Under the current WHO- European action plan and declaration for mental health reform, non-governmental peer groups are encouraged in their role of “organizing users who are engaged in developing their own activities, including the setting up and running of self help groups and training in recovery competencies” (World Health Organization Europe, 2005, p. 5).

### *Peer Support Workers*

Much of the academic literature included in this review does not describe programs run by consumers within mainstream organizations where the degree of control by consumers may be contested, despite the fact that this issue is a major area of debate within the consumer/survivor movement (CMHA Ontario, CAMH, Ontario Federation of Community Mental Health and Addiction Programs, & Ontario Peer Development Initiative, 2005; Morris, 2004; O’Hagan, McKee, & Priest, 2009). This debate has not been settled, even as peer support continues to have a growing impact on mainstream services through the increasing number of people openly self identified as peers who work in mental health systems to provide support and service to others in their process of recovery.

A variety of terms are used to describe and define these roles including ‘peer support workers’, ‘prosumers’, ‘certified peer specialists’, ‘peer providers’ and ‘consumer-providers’ (Gates & Akbas, 2007; Mancini & Lawson, 2009; Salzer, 1997; Solomon, 2004). These are positions that are focused on providing peer support, where being willing to openly self identify as a peer is considered an essential function of the job. This is different from positions open to any candidate, even though “increasingly mental health services are employing people who have their own experience of mental illness – in a range of roles and responsibilities” (Warriner, 2007, p.3).

While the numbers of people in peer support roles is growing, the academic literature is only now beginning to catch up. Solomon's review of the research including the role of peer providers noted that only 'anecdotal-level evidence' existed to define their roles (2004).

The lack of formal role descriptions for the people who are paid and who volunteer for specific tasks may be seen as both a strength and a weakness of peer support groups. For those who place a strong value on egalitarian relationships, creating divisions among peers on the basis of different roles within an organization may be problematic. Some of the earlier consumer/survivor groups avoided government funding in order to run on a collective, consensus-based model, rather than have paid managers, staff and volunteer boards (Shimrat, 1997).

In a qualitative review of the perspectives of key stakeholders (consumers, administration, providers) positive roles for peer workers were thought to be support, role modelling and providing hope for recovery, helping connect people with their communities, and acting as a "bridge" between consumers and mental health services (Chinman et al., 2006, p.184).

The Georgia, United States peer support certification process has become a well-known model, although there are a range of programs around the world now offering comparable training. The Georgia model claims to have led to the creation of over 200 new employment opportunities for consumer/survivors in that state and increasingly across the U.S. as other states adopt this innovation (Center for Mental Health Services, 2005). These certified peer specialists work in both mainstream mental health and other services and independent consumer/survivor run organizations.

Some advocates feel strongly that the development of formalized training and certification of peer support workers is essential as "mental health system providers often resist transformation initiatives that focus on consumer-directed services and may not want to hire consumers as professionals" (Center for Mental Health Services, 2005, p. 15). Georgia peer specialists argue that training and certification has been key to supporting that transformation.

Supporters of certification approaches also argue that they can be the foundation for the type of research required to define peer support as an evidence based practice. Training can be conducted using standardized manuals (for a review of some see Woodhouse & Vincent, 2006), which allows for the replication of practices, a traditional component of evidence based research (Addis & Krasnow in Campbell & Leaver, 2003).

Critics of the standardized approach to peer support question the impact of "professionalizing recovery" by adopting the language and styles of traditional mental health services (The Herrington Group, 2005, p.6). For example, some question the use of the term "peer specialist" instead of peer support worker (McIntyre, 2008). In addition, some forms of consumer-run organizations such as alternative businesses may not as easily fit the image of 'peer support' as presented in some forms of peer support training programs.

Understanding the impact of training and certification of 'peers' upon the nature of the active ingredient or the change mechanism of peer support is taking place on the ground by peers and through research. In a qualitative, grounded theory study of peer providers, the "emotional labour" of their role resulted in role strain and blurred boundaries when they were viewed by

consumers who were their 'clients' "less as fellow survivors and more as mental health professionals" while "at the same time they may also feel that they are undervalued by their non-peer co-workers who they feel treat them more like patients than professionals" (Mancini & Lawson, 2009, p.12).

Quebec has become a laboratory for this new experience, which is being studied by H el ene Provencher of Universit e Laval. "Pair aidant r eseau" is the first Francophone peer specialist training, which also has plans to expand to France in the near future. This initiative has taken roots in the political context of Quebec's 2005-2010 Mental Health Action Plan from the Ministry of Health and Social Services. Specifically, this reform called for the hiring of peer support workers in 30% of assertive community treatment and case management teams across the province.

A Quebec organization, l'Association Qu ebecoise pour la R eadaptation Psychosociale (AQRP), dedicated an issue of their journal '*Le Partenaire*' to consumer/survivor initiatives such as the National Network of Mental Health (G elinas, Forest, 2006, p. 4-8) plus a summary of the literature on the integration of peer support workers in the Anglophone international mental health movement (G elinas, 2006, p.9-41). The information in this last article was not previously available in French-language material in Quebec.

#### *The 'Active Ingredients' in Peer Support*

The nature of the control of the organization or structure within which peer support occurs is important to understand in that research suggests that structure shapes the processes and nature of peer support; or what authors call the "active ingredients" (Davidson et al., 2006; Weaver, Randall & Salem cited in Rogers, Teague, Lichenstein, Campbell, Lyass et al., 2007), "helping technology" (Hardiman, Theriot, & Hodges, 2005), or "helpful processes" (Nelson et al., 2006, p.250) of peer support.

Davidson and colleagues argue that the potential uniqueness of peer support is "just beginning to be explored and developed" in research (2004, p.448). To provide direction for this exploration, they propose a theoretical continuum of helping relationships, from the "one-directional" relationship at one end of the spectrum (exemplified by office-based clinical psychotherapy) to the "reciprocal" naturally occurring relationships found among friends (p.444-445). Dennis also developed a continuum model, distinguishing as well two types of social networks, those that are "embedded" (i.e., naturally occurring without deliberate organization such as family and friends), and those social networks that are created – the many different types of peer support of this review (2003, p. 322).

Within this spectrum exists the range of roles and relationships played by people with personal experience of mental illness in the mental health system; as peers in self help groups, as peer workers in consumer-run agencies, peer providers working as adjuncts to traditional services, and as providers in mainstream agencies –openly self-identified and even those who are not.

The points on this continuum are defined by a number of criteria, one of which is the degree of reciprocity within the relationship. Davidson et al., focus on peer staff working in mainstream organizations but providing 'peer' based rather than conventional clinical services. In these situations, the mutuality of the peer relationship becomes an "asymmetrical – if not one-

directional- relationship, with at least one designated service/support provider and one designated service/support recipient” (2006, p.444).

Is this peer support? For many advocates, the answer is a categorical ‘yes’ or ‘no’, but many more struggle to understand these complex roles, as they represent relationships that are “neither fish nor fowl” (Davidson et al., 2006, p.446).

For those who would say ‘no’, the rationale includes that these relationships lack “the reciprocity that is core to mutual support” (Davidson et al., 2006, p.446). Many advocates explicitly warn against the creation of unequal roles in peer run structures, “maintaining [the] non-professional vantage point is crucial in helping people rebuild their sense of community” (Mead & MacNeil, 2004, p.4). The formally structured and funded consumer/survivor initiatives in Ontario were originally designed not to provide services, but to create new kinds of opportunities” that moved beyond the “limitations of the service system” that do “not give people the chance to use their own skills and capacities; instead, they become clients again” (Consumer Survivor Development Initiative, 1992, p.2-3).

However, the degree to which mutuality can be said to exist where one ‘peer’ is paid to provide ‘service’ to another is debatable (Mancini & Lawson, 2009). Developing a list of ‘critical ingredients’ of consumer run services by expert panel review, the criteria that led to the most discussion was the role of staff, including the role of hierarchies between staff and members (Holter, Mowbray, Bellamy, MacFarlane, Dubarski, 2004). One author advocated the provision of training to support peer workers, but to keep training minimal so that the “peerness” of the relationship is not lost (Giblin, 1989 in Dennis, 2003).

At what point along a continuum of helping relationship does the peer worker transition into a paraprofessional role? At what point do “their talents and accountability to the target population” shift “to the health-care system” (Eng & Smith, 1995 in Dennis, 2003)?

Rather than debate whether or not this is ‘real’ peer support, Davidson and colleagues seek to understand the nature of this role and relationships, recognizing that research in this area is in its infancy. Such future research may shed light on the nature of many types of peer support,

Our challenge is to identify those specific interventions people in recovery can offer that are based at least in part on their own personal history of disability and recovery such that other people who do not share this history would be unable to provide them, or at least be at a distinct disadvantage in their efforts to do so (Davidson et al., 2006, p.447)

## *Effectiveness and Outcomes of Peer Support*

### *Types and Challenges of Research on Peer Support*

A growing body of literature has increasingly been able to demonstrate positive outcomes for peer support in the context of self help groups, consumer-run organizations and services, as well as peer support workers in mainstream services. Several projects conducted over the past

decade have been earning peer support-based organizations recognition as evidence based practices (Centre for Research and Education in Human Services, 2004). Until recently, researchers and advocates would only be able to say that “little systematic research or empirical evidence is available about the effects of such programs or their intended outcomes” (Rogers et al., 2007, p.786).

Newer collaborative and multi-method approaches to mental health services and community-based research, in which methods are selected which are appropriate to the research question rather than according to a priori ideology and also include active involvement of all stakeholders, hold much promise to confirm the early findings on effectiveness while retaining the richness of participant perspective and context.

Research has been conducted using both quantitative and qualitative methodologies, using ‘values-based’ practices as a complement to evidence developed by traditional empirical methods, and using participatory research designs more consistent with peer support values. This is important, as “attempting to force [consumer run organizations] into a true experimental design would change the conditions of these initiatives, thereby defeating the purpose of examining [them] as they naturally occur” (Humphreys & Rappaport, 1994 in Nelson et al., 2006, p.255).

Although tension exists within the movement over the role and value of research on peer support, some advocates argue that peer-run organizations and activities will not continue to grow and expand without greater engagement with mainstream research methods and evaluation processes in order to demonstrate their continued relevance in an ‘evidence-based’ system (Campbell & Leaver, 2003; Davidson et al., 2006; Hardiman et al., 2005). For these advocates, one of the goals of increased evaluation and research of peer-run programs is to ensure that consumer providers are treated as equals with non-identified providers in mainstream mental health systems.

Regardless of practical, methodological or philosophical challenges, a diverse and growing field of research has developed to measure the effectiveness of self-help strategies and groups, peer-run organizations and services, and increasingly, peer support workers in mainstream mental health services.

### *Effectiveness and Outcomes of Self Help Groups*

Self help as a strategy to help people cope with a variety of health and social conditions has a well established body of research showing its usefulness for reducing symptoms and the use of formal health care use, and increasing a sense of self-efficacy, social support, ability to cope with stress, and quality of life (Campbell & Leaver, 2003; Humphreys et al., 2004; Solomon, 2004).

### *Effectiveness and Outcomes of Peer Run Organizations*

The methodological quality of research conducted with and on peer-run organizations, offering a range of support/caring and advocacy/emancipatory functions, has significantly improved over the last decade (Campbell & Leaver, 2003; Centre for Research and Education in Human

Services, 2004; Doughty & Tse, 2005; Forchuk et al., 2005; Rogers et al., 2007). The result is increased confidence in the effectiveness of this type of peer support.

Previous research had demonstrated promising results, but the studies were mostly descriptive, exploratory or qualitative with small samples and considered to have limited generalizability (Campbell, 2005; Rogers et al., 2007). However, these studies did suggest that participants in peer support organizations were satisfied with their involvement, had a decrease in use of hospital services, and experienced improvements in their psychiatric symptoms, social networks, quality of life, self esteem and social functioning. See Campbell, 2005 pp. 46-57 for a review of the evidence base from 20 studies published from 1995 to 2002 and Doughty & Tse, 2005 for a systematic review focusing on international, primarily quantitative studies.

#### *Consumer Operated Services Program, United States*

Since that time, results from a large scale controlled trial and experimental and quasi-experimental Canadian studies have been reported. One of the largest experimental studies conducted on peer run services was the Consumer Operated Services Program, known as the COSP study, which took place in the United States between 1998 and 2002 (Clay, 2005). Eight peer-run organizations participated in the study, offering three main types of peer support services; drop-ins, mutual support, and education/advocacy. In addition, the research team included people with lived experience and was led by self-identified survivor academic (Jean Campbell).

The COSP study's "overall purpose [...] was to rigorously examine the effectiveness of COSP's [consumer operated service programs] on various psychological, social, and objective and subjective functioning domains among individuals who receive traditional mental health services" (Rogers et al., 2007, p.787). Participants were randomized to either a traditional mental health service or a traditional service plus consumer operated program (Campbell, 2005a).

Among all three types of consumer-run programs, there was more improvement in a composite well-being scale incorporating a range of measures (quality of life, empowerment, hope, social justice, recovery, social acceptance) among the participants also involved in peer support groups, but the results were not significant (Campbell, 2005a). However, the drop-in groups on their own demonstrated significantly higher improvements on the measures used in the study.

Particular features and values of the peer support organizations that had the highest association with improvements were "inclusion" and "self expression" variables. Inclusion referred to a sense of community, no hierarchy among members and staff, and no coercion. Self expressive variables were artistic expression, opportunities for sharing life experiences and telling one's story, and formal peer support activities (Campbell, 2005a).

#### *Connections Peer Support Program and Transitional Discharge Model, Ontario*

Two significant research studies in Ontario used experimental and quasi-experimental methods to evaluate the effectiveness of several types of peer support activities. One, a study conducted in south-western Ontario, looked at the impact of a transitional discharge model and peer support program on outcomes for people being discharged from hospital after a long-term stay.

Trained peer support volunteers met with patients before they were discharged and after in the community to support their return to community life. A control group consisted of people whose transition to the community did not include dedicated peer support (Forchuk et al., 2005).

While there were no significant differences in quality of life, levels of functioning or use of hospital services for the group receiving peer support, they were discharged much earlier from the hospital, on average 116 days sooner. This early discharge resulted in considerable hospital cost savings (Forchuk et al., 2005, p.556).

Peer support in this study represented an interesting hybrid of different models. The individual peer volunteers were trained, supervised and received ongoing support by part time volunteer coordinators from more than 11 consumer-run organizations, who received time limited project funding from a non-governmental source (Forchuk et al., 2005). The role of the peer volunteers was strictly non-clinical and was based on a “friendship” model of peer support (Forchuk et al., in Forchuk et al., 2005, p.557). Peers met with their match to go for coffee, attend free community events or just talk. The consumer-run groups provided the infrastructure that allowed for the training and management of over 300 volunteers.

#### *Longitudinal Study of Consumer/Survivor Initiatives, Ontario*

The Longitudinal Study of Consumer/Survivor Initiatives in Community Mental Health was a participatory action research study conducted by four consumer-run groups in south-western Ontario, the provincial network organization of these groups and a community-based research group (Centre for Research and Education in Human Services, 2004). Using both qualitative and quantitative methods, this study examined the types of activities and the impact they had with new members. The study also looked at any impacts made by the consumer-run groups at the ‘systems’ level, representing the ‘advocacy’ function of the groups.

Over the 18 months that members of these groups were followed, improvements occurred in satisfaction with their quality of life and social support, and reductions in hospital admission rates and use of hospital emergency services (Community Mental Health Evaluation Initiative, 2004, p.23). Consumer-run groups were also active at the systems level, taking part in political advocacy, creating connections with hospitals in order to increase people’s access to peer support, as well as taking part in the research study itself.

#### *Effectiveness of Peer Support Workers*

Much of the research that was first conducted on peer workers in mainstream mental health organizations focused on whether there was any risk to clients in doing so. While often this research focused on people with lived experience working in traditional service roles (e.g., case managers), the evidence base developed to show that no detrimental effect was shown and that outcomes were equivalent for people receiving services from peer or non-peer workers (Chinman et al., 2006; Davidson et al., 2006; Simpson & House, 2002).

One of the most recent studies has gone further to conclude that, based on a pilot program in five mainstream mental health services, the expansion of “peer support workers across mental

health services in Scotland, and beyond, would be beneficial for service users, peer support workers and mental health teams” (McLean, Biggs, Whitehead, Pratt, & Maxwell, 2009, p.1).

More emphasis is now being placed on what unique value peer workers bring to their work, particularly where they are facilitating or providing mutual support activities, and the structures and cultures in mainstream organizations that will increase positive outcomes from the use of peer workers. Research is looking at the potential barriers that peer providers face integrating into the mainstream mental health labour force. Authors have suggested that these include; peers’ past negative experiences with services affecting their current role as providers, feeling stigmatized or not treated as equals by non-peer colleagues, negotiating blurred boundaries and dual roles as providers and patients, and lack of consensus and policies on confidentiality and self-disclosure (Davidson et al., 2006; Gates & Akbas, 2007; Hodges & Hardiman, 2006; Mancini & Lawson, 2009).

Results from one qualitative, exploratory study, proposed some responses to these and other challenges primarily in terms of human resources and workgroup management (Gates & Akbas, 2007). However, the findings of this study, as with most on this theme, remain to be evaluated in practice.

## *Values*

Peer run organizations have been described as “value-based services”, that is, mental health services valued by consumers but lacking sufficient quantitative research on their effectiveness to declare them “evidence-based” (Tracy in Hardiman et al., 2005, p.112). Understanding shared values, and any challenges between values, for peer support is necessary “because values suggest both the processes and goals towards which policy and practice should be directed” (Hardiman et al., 2005 & Tracy in Nelson et al., 2008, p.194).

The research and grey literatures on peer support values are primarily descriptive and theoretical. Particularly within the context of peer support and peer-run organizations, it is often difficult to categorically separate out ‘values’ from ‘definitions’, ‘processes’, and ‘outcomes’. Thus the term ‘empowerment’ is used to describe a value, a process that takes place within an organization, and an outcome of that activity (Rogers et al., 2008). A few studies empirically define and measure concepts such as ‘empowerment’, primarily as outcomes (Segal, Silverman, & Temkin, 1995; Rogers et al., 2008).

In a review of American consumer/survivor self help programs, values are described as “the driving forces behind its [self help] development and success” (Van Tosh & del Vecchio, 2000, p.11). The authors distinguish between common values shared with other self help movements and ones unique to mental health consumer/survivor groups. Shared self help values, according to these authors, include: “peer-based support and assistance; non-reliance on professionals; voluntary membership; egalitarian, non-bureaucratic, and informal structure; affordability; confidentiality; and non-judgmental support” (Tosh & del Vecchio, 2000, p.11).

Values that are claimed to be unique include empowerment, independence, responsibility, choice, respect and dignity, and social action. Other features of self help, such as peer support,

hope, and recovery can be considered as values (Tosh & del Vecchio, 2000, p.11-12). Another description comes from Ontario's Consumer/Survivor Initiatives, who are "guided by a set of values that include member empowerment and participation, social justice, sense of community and peer support, and mutual learning" (Centre for Research and Education in Human Services, 2004, p.1).

"Common ingredients" described in the Consumer Operated Services Program (COSP) study in the United States included three main categories; structure, values, and process (Campbell, 2005, p.8). Values that were found to be common across the eight peer-led programs were the peer principle, the helper's principle, and empowerment.

In another review, the foundational values of peer support were found to be social support, valuing and sharing experiential knowledge, respect for the experiences of others who have gone through similar situations, and a sense of community identity related to shared lived experiences (Solomon, 2004). Values commonly found in the literature in relation to peer support are described below under five thematic headings.

### *Empowerment & Participation*

"The concept of empowerment is central to the belief system of consumer/survivor self help" (Tosh & del Vecchio, 2000, p.11). Some describe "enhancing personal empowerment [as] the primary objective of self-help agencies" (Segal & Silverman, 2002, p. 304). Campbell, in her framework of the 'caring' and 'emancipatory' functions of peer run organizations, defines empowerment as one of the caring functions (in Rogers et al., 2007).

While empowerment is said to be a key value, defining it is challenging as "no consensus on its meaning appears to exist" (Rogers et al., 2007, p.787). In part, it is defined by its opposite - "feelings of disenfranchisement and powerlessness among mental health consumers as a result of a perceived lack of choice and control over their mental health services and treatment" (Rogers et al., 2007, p.787). Others extend the importance of a sense of control to all aspects of peoples' lives where they often feel disenfranchised, including housing, jobs, and involvement in shaping mental health systems. Independence, another related value, speaks to the need not to have to depend on others for basic aspects of living (Van Tosh & del Vecchio, 2000). Beyond a response to disenfranchisement, empowerment includes reciprocity between people in the helping process, gaining control over one's life and a person's ability to influence one's environment (Campbell & Leaver 2003).

Values, like structures and activities, can and do change and evolve over time. The Mental Patients Association in Vancouver, started in 1971 by ex-mental patients provided housing and drop-in space, run "on the principles of self-help and self-government (participatory democracy)". They described their membership-driven governance model as 'power reversal', "essential to improving decision-making abilities and people's sense of self worth" (Frank, 1979, p.116).

Moving south along the coast, to the San Francisco Bay area, California, United States, Segal and associates conducted an investigation in the early and mid-1990s of four 'self-help agencies'. There groups were said to reflect the "original principles" of the "early leaders of the self-help movement that founded them" (Segal & Silverman, 2002, p. 304). The first of these principles,

that “the people who use the services also run them and make all decisions” is defined by the researchers as “organizational mediated empowerment” (p. 305). This self help value is in contrast to what people experience even in supportive professionally led services; “it seems that the crucial element lacking is the opportunity for empowered decision making” (p.309).

This early vision of models of alternative support, based on “a suspicion of leaders and of organizations” (Shimrat, 1997, p. 53) has largely been eclipsed (at least in visibility to outsiders) by more mainstream and traditional consumer organizations.

#### *Choice, Voluntariness, & Self-Determination*

Having a choice in what services and supports to use is a key value for consumers, driven both by a sense of the loss and potential loss of these values by mental illness and the mental health system, and by a focus on self-determination, a common theme in groups of people with disabilities and other groups. Voluntary use of peer support was the top rated value of peer support organizations in one survey of key informants (Holter, Mowbray, Bellamy, MacFarlane, & Dukarski, 2004).

The importance of self-determination is often exhibited by fears within the consumer/survivor movement of “cooptation”, a process of traditional systems using the language and structures of peer support without change in the underlying power imbalances between ‘psychiatrized’ and other people. For advocates, not only is “consumer control [...] an essential organizational characteristic”, it have also been shown to be “the best predictor of personal empowerment and social functioning” (Segal and Silverman, in Brown, Shepherd, Wituk, & Meissen, 2007, p. 75).

#### *Peer Support, Reciprocity, & the ‘Peer Principle’*

In Ontario, members of the Ontario Peer Development Initiative, a network of consumer-run organizations, held a province-wide meeting to affirm peer support “as the fundamental value of consumer/survivor organizations” (The Herrington Group, 2005, p. 2). Peer support can thus be described as a value, as well as the process of peer-run activities.

The ‘peer principle’ refers to “relationships based on shared experiences and values and are characterized by reciprocity and mutuality” (Clay, 2005, p.11). Surveying key informants to develop a theory of the critical ingredients of consumer run services, one study organized these values into ‘process’ measures, grouped into overarching categories of ‘opportunity role structure’ and ‘social support’ (Holter et al., 2004, p.53)

#### *Recovery & Hope*

Recovery has emerged around the world as a driving force for reform of mental health services and as a value shared through the peer support process (Clay, 2005; Mental Health Advocacy Coalition, 2008; Mental Health Commission of Canada, 2009; National Empowerment Center, 2007; New Freedom Commission on Mental Health, 2003; OPDI, n.d.; Orwin, 2008; Sainsbury Centre for Mental Health, 2005). As with other concepts, recovery has many definitions and meanings. For some, this fluidity is a virtue:

Recovery is defined in the Blueprint [New Zealand mental health implementation plan] as the ability to live well in the presence or absence of one's mental illness (or whatever people choose to name their experience). Each person with mental illness needs to define for themselves what living well means to them. The definition is purposefully a broad one, because the experience of recovery is different for everyone and a range of service models could potentially support recovery (Mental Health Commission [New Zealand], 1998, p.1)

The consumer/survivor movement is often viewed as one of the main sources of the recovery concept, as "peer support is the only mental health role to emerge that is grounded intrinsically in recovery" (Orwin, 2008, p. 3). As mental health systems increasingly adopt the language and value of 'recovery', peer support advocates both celebrate this value shift but also question non-peers' versions (Mental Health "Recovery" Study Working Group, 2009; National Network for Mental Health, 2005) and stress the need to "ensure that what is being promoted is *real* recovery and empowerment – that is, the opportunity for people to make their own decisions and control their own lives" (National Empowerment Center, 2007, p. 50). The values underlying a recovery-oriented mental health system, according to the Consumer Issues subcommittee of the United States' New Freedom Commission are; self-determination, empowering relationships, meaningful roles in society, and eliminating stigma and discrimination (in Campbell & Leaver, 2003, p.7).

Francophone mental health movements have developed their own identity over the years. The "recovery paradigm" is making inroads both in Quebec and in France. At a fundamental level, French Canadians and the French envision the field of mental health differently. While the perspectives are different, there are intersections with the recovery vision. In Quebec, the alternative movement, with its slogan "ailleurs et autrement" (« elsewhere and differently ») meant that, with deinstitutionalization, resources would be developed outside psychiatric institutions where new practices would emerge (RRASMQ, 2009, p.5). The advocacy wing of the movement with its emphasis on rights and empowerment are also important in shaping the Quebec landscape.

In France, the "psychiatrie citoyenne" movement has been exemplified by Jean-Luc Roelandt and Patrice Desmons in their book, *Manuel de psychiatrie citoyenne*. Another text, *L'avenir d'une désillusion*, focuses on the need to eliminate the exclusion lived by the 'psychologically hurt' and on how they can become fully fledged citizens. Another influence is the concept of psychological resilience of Boris Cyrulnik and other exponents. This is about a person's ability to grow in the face of violence, trauma or severe neglect. Resilience emphasizes the role of society in order to develop resilient citizens – psychological resilience goes hand in hand with a resilient society.

As with the Anglophone movements, there is international sharing of experiences, which can lead to similarities in values and processes. Over the years, Quebec community mental health activists have been training people in France, Belgium and Switzerland on mutual aid and the role of peer support specialists. Francophone Europeans are also attending and presenting at Quebec conferences. Most recently, Roy Muise, a consumer advocate from Nova Scotia and one of the first 'certified' peer support workers in Canada, trained people in France on peer support.

Hope is described as a facet of the larger goal of recovery (Mead & Copeland, 2000), and as a value in its own right (Van Tosh & del Vecchio, 2000). Recovery is driven by “a vision of hope that includes *no limits*” (Mead & Copeland, 2000, p.317, emphasis in the original). Hope is related to the peer support process in that it is said to be fostered by reciprocal relationships; “as we feel valued for the help we can offer as well as receive, our self-definitions are expanded” (Mead & Copeland, 2000, p.318). Again, this value is contrasted to the unidirectional nature of the professional and client relationship, which advocates say result in “conventional service providers [being] haunted by *guarded hope*” (Storey, Shute, & Thompson, 2008, p.2, emphasis in the original).

### *Valuing Experiential Knowledge, Mutual Learning, & the Process of “Re-Naming”*

Peer support advocates often promote critical learning and the “renaming of experiences” based on peer learning and experiential knowledge (MacNeil & Mead, 2005). For people in recovery “critical learning doesn’t assume a medical definition of the problem and opens us to exploring other ways of thinking about the experience” (Mead & MacNeil, 2004, p.10). Central to this is the process that occurs among peers “by sharing our own process with this shift we aren’t telling the other person what to do but offering our own critical learning experience” (Mead & MacNeil, 2004, p.10).

This value is often seen as part of the caring function of peer support, yet it can also be viewed as being ‘emancipatory’ in its challenge to dominant paradigms. Expressed through participation in self help groups oriented to “working together to redefine the meaning of symptoms” (Mead & Copeland, 2000, p.323), critical learning can provide new tools for individual recovery. But peer or social learning that takes place in peer run organizations can also achieve broader goals in that it can also change society’s meanings of madness or mental illness.

Alternative businesses, also known as social enterprises, have developed a particular version of this mutual learning, “where people acquire new knowledge to transform their definition of self” (Church et al., 2000, p.23). Skill development in this context is not just about “improvement in the skills, behaviours and general functioning of employees; rather it is empowerment” (Church in Church, Fontan, Ng, & Shragge, 2000, p.20).

As mentioned in the Anglophone portion of this literature review, confusion about the principles, values and benefits of peer support is also an issue in Francophone writings, and merits further study. However, despite this apparent shortcoming, the values described help to understand self-help better.

The “Cadre de référence des groupes d’entraide membres du RRASMQ” (1996, p. 3-4) is representative of the values cherished by the peer support movement in Quebec and elsewhere. Valuing experiential knowledge, focusing on strengths as opposed to weaknesses, respecting the rhythm of every one, collaboration as opposed to competition, the right to make mistakes, recognizing and valuing differences are listed and described. One word about the value of “difference” which can be paradoxical as brought up by Boutet and Veilleux from Centre d’entraide Émotions of Quebec City in their chapter on their agency’s approach (2007, p.13). Service users suffer from the effects of stigma and wish to be treated no different than the rest. However, the plurality of experiences translates as differences among peers and as such is valued positively.

Moreover, several self-help groups are successful in applying these values despite the normal ups and downs of group life and their limited means. Direct experience of a group as a participant or observer is often necessary to believe and understand how such groups of disfranchised, stigmatized, and hurt users have succeeded in carving out a new identity and helping each other. We also could have added the values of reciprocity, equality, freedom, gratuitous, which are mentioned as characteristics in the RRASMQ framework. Empowerment as a value is also pertinent as it includes the constellation of values mentioned above and is mentioned by several authors as an inherent value in peer support, alternative or recovery-based approaches.

The question of the autonomy of self-help groups, of “par et pour” (“for and by” users) as the expression goes in Quebec, is still present. What qualifies as a peer support group? How can we encourage self-help groups that are entirely run by service users? Serge Goulet in his reflections as an “entraïdant” in one of the few articles in French on mutual aid in self-help groups in mental health, discusses his worries about the future of groups that are “autogéré” or managed totally by service users (1995, p110). In the Montreal region, the demise of the self-help group “Solidarité-Psychiatrie” which later changed its name to “Solidarité en santé mentale” was a blow to the alternative mental health community. “Sol” as it was known, was the loss of an organization, but also of a symbol. “Sol” had been around for so many years and had succeeded in doing the so-called impossible at the time – survive and thrive without any service providers. “Les Frères et Soeurs d’Émile Nelligan” which was a coalition of self-help groups run by service users, is still around, but they too struggle. How can we best support these initiatives?

We will give Goulet the last words on the situation of self-help groups in Quebec:

*L’histoire des groupes d’entraide dans le “Mouvement alternatif” au Québec est marquée par une forte diversité dans la façon de concevoir et de réaliser l’entraide. Les groupes d’entraide ne sont pas tous nés de la même façon, ne fonctionnent pas non plus selon les mêmes principes. Cela constitue une richesse mais cela provoque à la fois débats, confrontation, inquiétudes par rapport à ce que devrait être l’entraide (1995, p.104)*

The history of self-help groups in the "alternative movement" in Quebec is marked by high diversity in how to design and implement mutual aid. Self-help groups are not all born the same way, do not operate under the same principles. This is a treasure, but it causes debate, confrontation, and concern over what should be mutual aid (translation, Cyr).

## *Involvement of Marginalized and Minority Consumer/Survivors in Peer Support*

Among people who experience mental health challenges and the mental health system is a wide range of experiences and identities, which are in turn reflected in the diversity of the consumer movement.

Some define consumer/survivor activism as equivalent to other social movements, such as anti-racism, women's, and gay, lesbian, bisexual, and transgender movements (Consumer Survivor Business Council & National Network for Mental Health, 1994). Anti-oppression is one concept that has been used to bring together an understanding of the way in which different identities and experiences relate. This is a process of putting "structures of oppression and discrimination at the centre of analysis, attending to the diversity of oppressions and their interlocking nature, in an attempt to eradicate oppression, in all its forms" (Supportive Housing and Diversity Group, 2008, p. 4).

For some survivor activists, the experience of madness or mental illness or even involvement in the mental health system is only a small part of the shared experience. For them, the issues of poverty, social marginalization, trauma, and discrimination on the basis of race, gender, sexual orientation, gender identity and other identities, are their defining experiences (Brown, 2002; Shimrat, 1997). Peer support is consciousness-raising "through developing an understanding of oppression as a common theme among all of us with psychiatric labels" (Mead, Hilton, & Curtis, 2001, p.134).

People with labels and experiences of mental illness may be active in peer support activities that are organized around another part of their personal identity, such as sexual orientation, race or immigration experience. In one review of the involvement of 'black and minority ethnic' users in mainstream mental health services, while racialized users expressed dissatisfaction with involvement and racism from other users, they still found that "the most productive and satisfying involvement for service users has been through peer groups where supporting each other and finding a common purpose were the main aims" (Kalathil, 2008, p. 23).

Communities in other parts of the world have developed different explanations, such as the Maori concept of *tino rangatiratanga* or "self determination". However, the degree to which people's different identities and diversities of experience are recognized as existing within the consumer community, and the way in which people negotiate differences and create meanings of shared experiences through peer support has not yet received much research attention.

The discussion is not simply academic. The meaning of identity is key to many notions of peer support. If the foundation upon which the 'consumer' experience changes, for example, through the shift to a 'post-institutional' mental health system located within the communities it serves, than how does the identity of 'consumer' change? As one service provider describes it, "is being 'a consumer' about a shared label or a shared experience" (Warriner, 2009, p. 8)?

The experiences of racialized consumers in peer support groups, both general ones and those created specifically by racialized survivors, has received some research attention. British 'Black' and minority ethnic' users have, for example, created a number of user-run organizations and developed a relatively significant amount of literature on their experiences. Based on the experiences of these users, one review concludes that black and minority ethnic users do want to participate in shaping the services that affect their lives but face increasing barriers to doing so (Begum, 2006).

It is clear that consumers from a range of racial and cultural backgrounds participate in and benefit from peer support. For example, 'Vet-to-Vet', a peer education and support group for American military veterans with 'chronic psychiatric disorders' developed by a peer advocate,

has been successfully implemented in the Veterans Affairs healthcare system. In one study of over 1800 vets taking part in the program vets from Black, Hispanic, and 'other' backgrounds represented over 50% of participants (Barber, Rosenheck, Armstrong, & Resnick, 2008, p.437).

Women living in seven different communities across Ontario, who were considered by clinicians to be at 'high risk' for postnatal depression and who took part in one-to-one telephone supportive conversations with a peer, reported high rates of satisfaction and halved their risk of developing depression, a significant finding (Dennis, Hodnett, Kenton, Weston, Zupancic, Stewart, & Kiss, 2009). The peer volunteers included women from a variety of backgrounds, with over half self identifying their ethnicity as "non-Canadian", half were not born in Canada, and 20% were 'newcomers' having moved to Canada within the past five years (p. 3 of 9). Having peers from diverse backgrounds may be important to ensuring the success of such support, as being a newcomer and undergoing "acculturation" to a new society was linked in this study to increased risk for experiencing depression in the post-natal period.

Members of a self-help group in Hong Kong reported positive experiences with their group that included the importance of the knowledge they learned from their peers, the warm and caring atmosphere that developed, and the growth of their social networks; all of which led to subjective improvements in their mental health (Leung & Arthur, 2004). The authors suggest that part of the success of the tightly knit group that developed was the need to develop support within communities where stigma against mental illness remained high.

Users from black and minority ethnic communities experience both the strengths and challenges of the interconnection of identities. As such, they may often have their unique experiences devalued or unrecognized by both mental health peers from dominant racial and cultural groups, and by non-psychiatrized members of their racial and ethnic communities. Begum notes that while funders and policy makers may connect with community leaders, they often fail to directly connect with minority users. Equally, "the mainstream service user movement cannot represent black and minority ethnic service users until race equality and anti-discriminatory practice becomes integral to everyone's work" (2006, p. viii).

Support for this comes from other countries as well. In one of the few studies specifically on differences among members of consumer-run organizations, significant differences were found in the sense of community and social support depending on the racial composition of the membership (Woodward, Mowbray, Holter, & Bybee, 2007). Based on clubhouses (a non-peer model) and consumer groups located in Michigan, United States, the study found that as the number of African-American consumers participating in these agencies increased, so too did their individual sense of community. However, at the same time, white consumers perceived a decrease in community with growing racial diversity. The authors note that there is no reason to assume that the racism against African-Americans and other communities by whites that exists in the broader mental illness system and society will not also exist in consumer run organizations. However, such findings speak to the ways in which the identity of 'consumer' and the experience of madness are not necessarily enough to overcome other oppressive social structures.

Consumer/survivor groups have acknowledged the need to move beyond a singular focus on the shared experience of madness and develop cultural competency understandings and practices (National Empowerment Center, 2007; Van Tosh & del Vecchio, 2000). It remains a struggle to

do so, as Black and minority ethnic users described their experiences in the British user's movement,

In user groups, raising issues related to one's race and identity sometimes generated accusations of creating divisions within the group. The focus was on user/survivor identities; the tendency was to brush over other markers of identity, like that of race (Kalathil, 2008, p.15)

The impact and interrelationship among diverse identities is particularly evident in the growing number of people with mental health problems who are coming into contact with the criminal justice system. One American consumer run organizations says of the experiences of criminalized consumers, "it's just a different door – race, ethnicity and class, not criminality, often dictates whether a person enters the mental health system and treatment or the criminal justice system" (Mayes, 2008, slide 2). Despite this reality, again, a divide may exist between members of the consumer community, this time through the experience of incarceration or even contact with police and diversion. According to the Howie the Harp Advocacy Center, an American peer run organization, most consumers who have been in jail haven't been connected with the consumer movement and most peer groups have not made much effort to connect with this group (Mayes, 2008, slide 4). The Center has been active in addressing this divide by developing peer support training for people with forensic histories, who in turn connect with peers.

Consumer/survivors who are gay, lesbian, bisexual, transgender and other sexual and gender minorities have been active both within the broader mainstream consumer/survivor movement and, in some places, have created their own spaces. For some consumers, their experience of madness and queer identity are strongly interconnected. Some make the connection between their experiences of homophobia within the mental health system to their roles as activists in the consumer community (Suhanic, 2001).

While traditional mental health services are increasingly recognizing the need to provide culturally competent services that include the experiences of lesbian, gay, bisexual and transgender (LGBT) consumer/survivors, the need for consumer-run support has led to the creation of a few groups and organizations (e.g., the Rainbow Heights Club in New York, US, 'Pink and Blue' peer support groups, Davis, 2006).

One diversity that has historically been highly debated within the mental health system has been the needs and experiences of people with so-called serious or severe mental illness, including those who the system often considers 'hard to serve'. Some researchers have concluded that consumer services organizations are particularly accessible to individuals who would not otherwise use traditional mental health services, either through choice, ineligibility, or denial of service (Beresford & Branfield 2006; Campbell & Leaver, 2003; Hardiman et al., 2005; Mowbray et al., 2005).

In Ontario, Consumer/Survivor Initiatives have been criticized as not being useful for people with the most severe experiences of mental illness. To address this, the Longitudinal study on these groups, specifically asked 'who uses self-help organizations'? They found that, while different from people receiving assertive community treatment team services, members of these peer-run organizations experienced both severe illness, along with some degree of

'functioning' but also significant instability in their lives (Goering, Durbin, Sheldon, Ochocka, Nelson, & Krupa, 2006).

## *Future Research*

As peer support remains a valued resource for recovery for many people who experience mental illness or distress, researchers and advocates alike support ongoing research and evaluation (Centre for Research and Education in Human Services, 2004; Hardiman et al., 2005) in order to increase our understanding of its nature and its impact.

Davidson and associates, focusing on the "active ingredients" of peer support, write, "we consider the state of the field to be similar to where research on psychotherapy stood prior to the introduction of manualization and other rigorous design features (e.g., fidelity scales)" (2006, p. 449). While not all advocates would share this focus on standard rules and approaches, the challenge of developing processes that achieve similar evaluation aims using approaches built on survivor experiential knowledge and values is welcomed (MacNeil & Mead, 2005).

Results from the experimental COSP study of peer run organizations supported earlier findings that, even among peer run organizations running similar programs, the specifics of each and the types of participants, were quite different. Results could not, therefore, be analyzed by the original program categories, a finding which the research team suggests warrants further research (Rogers et al., 2007). Mowbray et al., argue that while this heterogeneity makes it particularly challenging to evaluate consumer operated programs as an evidence-based practice (because they lack the formal set of standards found in other programs, like assertive community treatment teams), it also makes it all the more necessary for programs to develop fidelity standards, to ensure adherence to key values within a wide range of models (2005).

The research team for the Ontario study of Consumer/Survivor Initiatives (Longitudinal study) supported further research built on a 'participatory action research approach' consistent with consumer values and providing opportunities for development of research and evaluation skills. Specific future topics included more research with other groups (beyond the few who took part in the study), especially those in northern and rural regions, and research on new models of peer run services, such as peer-led supported education, employment programs or housing (Centre for Research and Education in Human Services, 2004).

As peer support activities continue to specialize to work with different groups of consumers and the mental health system increasingly acknowledges the importance of becoming culturally competent, research will be needed for better understanding of the intersections of different identities.

Another important area may be to ask what the future of peer support will be as mainstream mental health services increasingly adopt the language and the practice of recovery and focus on wellness. If peer support has traditionally been defined by "what makes it different from the services they [people with mental health problems] have been receiving" (Pocklington, 2006, p.3), then what would peer support look like if mainstream service genuinely reform themselves to better meet the needs and values of the people they serve? How will peer support respond to

the very system change that the consumer/survivor movement has struggled for, that of promoting recovery and inclusion?

A service provider in a leadership position in New Zealand, a man without a personal history of mental illness, proposes open discussion on whether, in a 'post-institutional' mental health system, some fundamental changes will need to take place within the consumer movement,

The more effectively mental health services are integrated into community, where social determinants of health might assume greater importance, the less important will become the need to define, determine and isolate the notion of 'mental health consumer' (Warriner, 2009, p.8)

Peer support work within mainstream mental health services can be expected to continue to grow, so ongoing work to provide the best possible use of these positions and the structures needed to support this work have been identified as a need (Mancini & Lawson, 2009).

The move towards an evidence-based mental health care system creates many challenges and opportunities for the peer support movement. Hardiman and associates suggest steps for consumer-run programs to consider taking, beginning with a "dialogical process first within their own organizations, and then extend outward", asking key questions about the meanings for them of knowledge, evidence and how the evidence-based practice approach will impact peer support services (Hardiman et al., 2005, p.116).

Key to this process will need to be support for the growth of survivor led research. Survivor academics and advocates are also developing alternative visions to "forge a philosophy for research that will value users' experiences" (Rose, n.d., slide 26) and strategies to critically incorporate consumers' experiences directly into research and evaluation processes and outcomes (Beresford & Branfield, 2006; Centre for Research and Education in Human Services, 2004; MacNeil & Mead, 2005; Mead et al., 2001; Tew, 2008; Turner & Beresford, 2005).

Creating methods and approaches to better understand peer support in ways that are consistent with the values of the consumer/survivor movement is a key area for future research. As MacNeil and Mead conclude in their description of developing trauma-informed peer support standards, "there is much work yet to be done" (2005, p.241).

## **THE REPORT: Finding from the cross-Canada consultations in context**

### PEER SUPPORT DEFINITIONS, ORIGINS AND VALUES

#### *Definitions*

The key terms we are using in this report are defined below.

#### **Consumers/survivors and peers**

Consumers/survivors and peers are two expressions we use for people with lived experience of mental health problems. We tend to use 'consumers/survivors' as a general term and 'peers' in the context of peer run services.

#### **Mental health problems, diagnosis of mental illness and madness**

We use these terms to describe the psychological conditions that affect consumer/survivors and peers. None of these terms is universally used in the peer community, so we use them interchangeably. 'Madness' is a somewhat controversial term; it is a reclaimed word, similar to the term 'queer' as it has been used by the lesbian and gay movement.

#### **Peer support**

We have used a broad definition of peer support for this project and define it as any organised support provided by and for people with mental health problems. The families of people with mental health problems also provide peer support to each other. However, this report does not include peer support for families.

We define peer support initiatives as the programs, networks, agencies or services that provide peer support. They can be:

- Funded or unfunded;
- Use volunteers, paid staff or both;
- Operate out of psychiatric consumer/survivor run organizations or other [non specifically peer run] agencies;
- Delivered by a group of peers or by an individual peer in a team of professionals;
- A primary activity of the initiative or a secondary benefit, e.g., consumer run businesses;
- Part of an indigenous healing ritual.

(Mental Health Commission Canada, 2009)

Peer support is sometimes known as self-help, mutual aid, co-counselling or mutual support. These terms are all used for processes that bring people with shared experiences together in a wide variety of structures; in groups, in organizations, online, and one-to-one.

## Independent and mainstream

We refer to independent peer run initiatives as those which are run by consumers/survivors, and to mainstream peer initiatives as those which are not run by consumers/survivors. The mainstream agencies referred to in this report are usually community or hospital based services funded through health departments or ministries.

## Clients and members or participants

We define clients as people who use peer support services within mainstream agencies and members or participants as people who use independent peer run initiatives.

## Definitional uncertainties

In our consultations we came across uncertainties surrounding some definitions in peer support which will need to be clarified as the area develops. For instance:

- Should peers name themselves in a way that defines them in relation to the mental health system, with terms such as consumer or survivor?
- Does peer support become something else when it's run from a mainstream organization?
- What is the difference in role between friendship and the peer support relationship?
- What are the differences in roles between paid staff and/or volunteers and members in an independent peer run initiative?
- If services are defined by the traditional professional-client inequality, then should we even define independent peer run initiatives as services?

## *Origins of peer support*

The origins of peer support lie in the social nature of human communities and more specifically in the consumer/survivor movement (or the alternative movement as it is known in Quebec) as well as in the recovery philosophy in mental health.

## Consumer movement

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; it has arisen from the development of membership to multiple communities in modern society. These multiple communities have taken on a new dimension in the last decade with the development of online communities.

The earliest known peer support group in mental health was the Lunatic Friends' Society established in England around 1845. Some peer run groups also formed in Germany in the late nineteenth century, which protested on involuntary confinement laws. In addition to this a number of individuals in the eighteenth and nineteenth centuries publicised their protests about their treatment in autobiographies and petitions (Peterson, 1982).

The most well developed peer support network was established in 1937. Alcoholics Anonymous has spread to every country and its twelve step method has been adapted for other addictions and for mental health problems. Also in 1937, an American psychiatrist called Abraham Low established Recovery Inc (now Recovery International) which uses cognitive behavioural techniques in a peer group setting. It currently supports 600 groups across North America.

GROW, a 12 step program was started by a priest in Australia in 1957, has also spread to many countries. These forms of peer support are all apolitical.

A new brand of peer support and advocacy in mental health emerged out of the international consumer/survivor movement which began in the early 1970s, around the same time as the civil rights movement, gay rights, the women's movement and indigenous movements. All these movements have in common the experience of oppression and the quest for self-determination. The new brand of peer support was initiated by peers themselves and was based on a critical perspective of psychiatry and society, rather than just the need to 'reform' oneself (Chamberlin, 1978).

The consumer/survivor movement exists mainly in democratic countries. It has changed in the past 40 years from a small, unfunded, radical movement to a larger, more diverse and diffuse collection of people. The movement originally worked independently of the mental health system on two main fronts – peer support and political action. In peer support people aim to change themselves and recover from their experiences. In political action people aim to change the people and systems that affect their well-being. The first Canadian peer support service, the Mental Patients Association was established in 1971 in Vancouver. Since then Ontario has developed more independent funded peer support services than other provinces (Chamberlin 1978; Everett, 2000).

In the last decade or two many consumers/survivors have also taken up new opportunities to work within the mental health and addiction service system. It could be argued that we are in a third wave of development in peer support – the use of peer support within mainstream mental health services, where peers are contracted or employed, usually to provide one-to-one support for people using the service. This development gives new opportunities for the growth and funding of peer support, but some respondents expressed concern that mainstream services may be adapting peer support to their own values rather than the values of the consumer/survivor movement.

## Recovery philosophy

The recovery philosophy underpins mental health policy in all English speaking jurisdictions across Canada and in Quebec. In French, 'recovery' is usually translated as 'rétablissement'. Francophones and Anglophones we consulted had similar views on recovery.

We asked people what recovery means to them. These kinds of responses were typical:

*"Finding something which was once lost – me."*

*"Living a life worthwhile."*

*"Not being a victim of my symptoms."*

*"Madness is about gifts not symptoms."*

*"Allowing yourself to fail and have setbacks."*

Recovery evolved out of the consumer/survivor movement and progressive thinking in psychosocial rehabilitation in the late 1980s (O'Hagan, 1994). It is a philosophy where:

- hope for and self-determination of people with a diagnosis of mental illness is paramount;
- madness is seen as a valid and challenging state of being rather than just an illness;
- there is recognition of the multiple determinants and consequences of mental health problems;
- there is recognition of the broad range of responses needed; and,
- people with a diagnosis are the major contributors to their own recovery.

(California Institute for Mental Health, 2006; The Future Vision Coalition 2008; Mental Health Advocacy Coalition, 2008; New Freedom Commission, 2006; Sainsbury Centre for Mental Health, 2005)

This philosophy takes us in the direction of the leadership of service users in services, including as part of the workforce. It strongly implies that we need a much broader range of services than is available now, including peer-run services. It puts service users at the heart of their own recovery and the recovery of their peers.

A good way to understand the recovery philosophy is to compare it and its application to traditional mental health services, as this table shows (Mental Health Advocacy Coalition, 2008). This table needs to be viewed as a continuum; most contemporary services sit somewhere between the two extremes.

<p style="text-align: center;"><b>TRADITIONAL SERVICES</b> <b>RECOVERY-BASED SERVICES</b></p> <p style="text-align: center;">-----Continuum-----</p>			
<b>B E L I E F S</b>	<b>Views of madness</b>	Pathology No meaning in madness	Crisis of being Full human experience
	<b>Philosophy</b>	Maintenance Paternalism	Recovery Self-determination
	<b>Language</b>	Focus is on languages that is: <ul style="list-style-type: none"> <li>• Medical</li> <li>• Objective</li> <li>• 'They'</li> </ul>	More focus on language that is: <ul style="list-style-type: none"> <li>• Personal</li> <li>• Subjective</li> <li>• 'We'</li> </ul>
<b>P E O P L E</b>	<b>Service users</b>	Passive recipients	Active agents & participants
	<b>Families</b>	Unsupported and grieving	Supported and supporting
	<b>Workforce</b>	<ul style="list-style-type: none"> <li>• Mainly medical</li> <li>• Expert authorities</li> </ul>	<ul style="list-style-type: none"> <li>• Diverse workforce incl. peers</li> <li>• Collaborators</li> </ul>
	<b>Communities</b>	Fearful & discriminatory	Accepting & inclusive

S E R V I C E S	<b>Main service types</b>	Drugs and hospitals	Broad range of therapies, peer support, recovery education, housing, education & employment support and advocacy
	<b>Service cultures</b>	<ul style="list-style-type: none"> <li>• Authoritarian</li> <li>• Segregation from society</li> </ul>	<ul style="list-style-type: none"> <li>• Participatory</li> <li>• Inclusion in society</li> </ul>
	<b>Service settings</b>	Hospitals & clinics	Community, home based and online services
O U T C O M E S	<b>Social networks</b>	Service community	Natural community
	<b>Housing</b>	Hospitals, group homes and other residential services	Own home
	<b>Work</b>	Pre-vocational services Sheltered workshops Unemployment	Real work for real pay A valued contribution to society

In summary, there have been three waves of peer support over the last century – the twelve step approaches starting in the 1930s, the more politicized independent consumer/survivor peer groups starting in the 1970s, and the introduction of a peer support workforce into mainstream services in the 2000s. These developments have been reinforced by the emergence of the recovery philosophy in mental health services, starting in the late 1980s.

### *Values of peer support*

*“In three words peer support is: humanize, depathologize and socialize.”*

*“Peer support is about providing all the tools besides medication - the tools for the other 80% of your life.”*

We asked all respondents about the values of peer support. Most believed peer support initiatives apply values that differ from those applied in mainstream services. These values revolve around three themes – self-determination and equality, mutuality and empathy, and recovery and hope.

#### **Self-determination and equality**

*“We don’t have to fake it at a peer service”*

*“We can say what we need after years of being told what’s good for us”*

Respondents described the power relationships in the peer support context as egalitarian, empowering, transparent and respecting of autonomy and self-determination. Participation is entirely voluntary and it is up to each person to decide what is best for them, and for the peer support service to enable choice in how people use them.

In contrast, respondents often described the power relationships operating in mental health services as controlling, directing, hierarchical, patronising or authoritarian. It was much less common for them to experience mainstream services as empowering or egalitarian.

Self-determination was seen to be reflected in the following kinds of practices:

- When peer members participate in the running of independent peer run organizations or peers are free to shape the services they provide within mainstream services;
- When members or clients are encouraged to choose their goals and supports in both independent and mainstream settings; and,
- When there is a commitment to social justice, especially in independent peer support initiatives.

## Mutuality and empathy

*“In peer support we can see what professionals can’t see.”*

*“They don’t deal with deep and personal issues in mental health system but we do here.”*

*“I want to be listened to and validated in my pain; I want to express my distress and NOT shut up and locked up.”*

*“Been there, done that, going back to help.”*

Respondents often described the importance of shared experience in peer support. They used expressions such as camaraderie, empathy, reciprocal, mutual, acceptance, community and belongingness when asked about peer support values. Many also valued confidentiality. Even paid peer support workers talked about mutuality in their relationships with clients or members. Respondents felt peers could be more honest with each other than people in the traditional client professional relationships. On the one hand people didn’t have to fake it in peer support settings and could deal with deep personal issues. On the other hand, others who understand could challenge people if they were stuck. Positive role modelling is also an important feature of mutuality.

Mental health services were described by some as focusing just on a person’s illness, as trying to fix people rather than work with them, and as valuing book learning over lived experience. Respondents believed that peer support environments are more accepting and less threatening or intimidating than some mental health services. They spoke of non-judgmentalism, dignity, safety, respect, diversity, compassion and unconditional positive regard.

People told us mutuality is reflected in the following types of practices:

- When peer support involves reciprocal roles of helping, learning and responsibility; and,
- When there is less role distinction between peer staff and members or clients than there is in the traditional relationship between professionals and clients.

## Recovery and hope

*“Peer support is not about how ill we are but how well we are”*

*“Professionals forget we know how to live with mental illness as we do it each day”*

*“Recovery and hope is reflected in the Aboriginal world view; holistic health being the balance with the spiritual, mental, emotional and the physical.”*

Respondents described peer support initiatives as holistic and encompassing the psychological, social and spiritual domains of life and as offering hope and tools for recovery and personal growth. Peer support helps people gain a sense of purpose and self-responsibility. It encourages people to reframe their personal stories to move beyond an illness or victim identity. It needs to enable them to be ‘the architects of their own wellbeing’.

The dominance of the deficits approach and medical model in mental health services was criticised, as either limited or harmful by respondents who talked about peer support helping them to regain a healthy identity as well as roles and relationships disrupted by their mental health problems and use of services.

Recovery and hope is reflected in the following types of attitudes and behaviour:

- When people believe in each other;
- When they feel better about themselves;
- When they feel optimistic about their future; and,
- When they are making positive changes in their lives.

## A 'MAP' OF PEER SUPPORT IN CANADA

Canada is geographically the second largest country in the world with a population of 33 million people. It is a wealthy, developed country, rich in resources, with a nationalized health service and welfare provision. Canada has a diverse population, including an Aboriginal population consisting of approximately four percent of the population (Kirmayar & Valaskakis, 2008).

### *Types of peer support*

One way of understanding the variety within the peer support landscape in Canada is view it in various dimensions, including the different types of provision, interest groups, organizational structures, methodologies, technology and funding.

#### Types of provision

We found a huge variety of peer support resources, responses and services across Canada. The most common are self-help support groups where peers meet regularly to provide mutual support, without the involvement of professionals; and one to one peer support such as co-counseling, mentoring or befriending.

There are also many types of peer support services that are more specialized. Many of these types of services or resources are also delivered by mainstream providers. There are examples of most of these types of services across Canada but most are not commonly available. These other peer support services include:

- Support in housing, education and employment;
- Support in crisis (e.g., emergency rooms, acute wards and crisis houses);
- Traditional healing, especially with indigenous people;
- System navigation (e.g., case management);
- Material support (e.g., food, clothing, storage, internet, transportation);
- Artistic and cultural activities;
- Mentoring and counseling;
- Recovery education for peers;
- Social and recreational activities;
- Small businesses staffed by peers.
- Systemic and individual advocacy;
- Paper and online information development and distribution;
- Community education and anti-discrimination work.

#### Interest groups

We also found that some peer support initiatives for people with a diagnosis of mental illness specialize in the populations they serve, for example there are initiatives that are specifically for:

- Life stage (e.g., young people, new mothers);
- Gender ( e.g., women);
- Sexual orientation;
- Ethnic groups (e.g., Chinese);
- Language groups (e.g., French, Cree);

- Diagnostic groups (e.g., depression, bipolar, schizophrenia, 'dual diagnosis');
- Occupational groups (e.g., armed forces and veterans); and,
- Faith based groups (e.g., Christian).

### Organizational structures and arrangements

There are a range of organizational structures that peer support initiatives can sit within:

- Informal grass roots networks run by volunteers;
- Funded independent peer run initiatives staffed and governed by consumer/survivors;
- Mainstream agencies with peer support programs within them; and,
- Mainstream agencies that employ or contract individuals to provide peer support.

The distinction between these three types is not always clear cut. There are occasional examples of peers who are employed by independent consumer/survivor agencies but work in mainstream settings, or of mainstream boards with a majority of consumer/survivors on them.

There is also a very recent trend for employers to create peer support initiatives. Veterans Affairs Canada and the Department of National Defense have set up a peer network for the armed forces, veterans and their families who have Operational Stress Injury. We also heard that car manufacturing firm has set up a peer support network for employees with mental illness but we have been unable to verify this.

### Methodologies

Some of the oldest methodologies that equate to peer support come from Canada's Aboriginal peoples in the form of sharing circles and sweat lodges. Some Western practice methodologies or technologies in peer support are emerging. Perhaps the best known ones are the Wellness Recovery Action Plan, known as WRAP (Copeland, 1997) and "Intentional Peer Support" (Mead 2005).

WRAP is a self-administered template that provides a structure for people to monitor their distress and wellness, and to plan ways of reducing or eliminating distress. Many peer support initiatives and some mainstream mental health services train people to do their own WRAP, in Canada and elsewhere.

Intentional peer support is a philosophy and a methodology that encourages participants to: step outside their illness and victim story through genuine connection, and mutual understanding of how they know what they know; redefine help as a co-learning and a growing process; and help each other move towards what they want. Training in intentional peer support is available in a number of countries, including Canada.

Other practice methodologies have been developed, such as:

- PACE (Personal Assistance in Community Existence) Recovery Program – workshops designed to shift the culture of services from maintenance to recovery and hope;
- Recovery education curricula developed in Vermont, British Columbia and Ontario;
- Self-stigma workshops for consumers/survivors in development in New Zealand; and,
- User-led research projects in England.

Some existing generic self-help and clinical methodologies can be incorporated into peer support, such as Cognitive Behavioral Therapy, mindfulness and meditation.

## Technology

Peer support in itself is a low technology activity but information technology is opening up new ways of delivering it, such as 'skype' (online telephone audio and video calls) video conferencing, instant messaging, interactive websites and mobile technology. This is already starting to enable online peer support. However, there is some evidence that a majority of people with major mental health problems do not have access to the internet, and those who do seldom use it for health related purposes (Borzekowski, Leith, Medoff, Potts, Dixon et al., 2009; Nicholson, & Rotondi, 2010). Despite this there is little doubt that online peer support will become much bigger in the future, especially in rural areas and for people who prefer remote interactions. The challenge will be to make it available to the most disadvantaged consumers/survivors.

## Funding arrangements

Because of the variety of types of peer support and the variety of organizational structures they sit in, the sources of their funding also varies. Grass roots support networks sometimes exist with just donations from the members or with small philanthropic grants. Once independent peer support initiatives start to employ people they are much more likely to enter into a contractual arrangement, usually with the local health funder. Peer support services or workers inside the mainstream services receive their funds through the service, just like any other team or employee.

It is difficult to get an accurate estimate of the proportion of mental health funding that goes into peer support and peer run initiatives but we know that the percentage is tiny, even in the jurisdictions where peer support is most developed, such as Ontario at 2%, and British Columbia which is probably even lower.

## *A summary of peer support in the provinces and territories*

We may have left out some details in these summaries that are important to the local people, but our priority has been to give fair coverage to all the provinces and territories by providing a high level description of peer support activities. Virtually all the initiatives we describe in this section are funded.

### Alberta

Alberta has one provincial health structure – Alberta Health Services which replaced the eight regional health authorities in mid 2008.

A few years ago the provincial government allocated some time limited funding for a peer program in Edmonton. When provincial funding ceased the host agency paid for the peer support initiative out of its operational budget. Currently there is no provincial government funding directly allocated for peer support.

There are a few peer initiatives within Alberta. They include a consumer run program, Opportunity Works, in Calgary which provides peer support and business development for

people with lived experience who want to be self-employed, and a number of self help groups linked with the Organization for Bipolar Affective Disorder (OBAD). In addition, the only peer support initiative in Canada for gay, lesbian, bisexual and transgendered youth, Miscellaneous Youth Network, is based in Calgary. A few peer run services in the major centres are provided out of other agencies such as the Peer Options Program through a Canadian Mental Health Association agency, and peer support initiatives through the Schizophrenia Society.

The government funded mental health provider in Edmonton has reallocated some funding from its mental health services budget to continue programmes originally funded by the province, such as a recovery education program. It is also re-orientating some initiatives. For instance they are reallocating funds to pay for four peer workers employed by Schizophrenia Society to work with the addictions and mental health teams, and on wellness education modules delivered by clinicians and peers.

### **British Columbia**

The Provincial Health Services Authority (PHSA) has a province-wide mandate for specialized health services. PHSA services are provided either directly through PHSA agencies or through funding and collaboration with the six regional health authorities.

The Vancouver Mental Patients Association was established in 1971 and was the first 'second wave' mental health peer run service in Canada. Independent self-help networks include the West Coast Mental Health Network, the Mental Health Resource Centre, the Richmond Mental Health Consumer and Friends Society, and the Eureka Clubhouse (not the 'clubhouse model') which is on Vancouver Island. They are funded from a variety of sources.

Since the early 1990s the health authorities have all funded various forms of peer support. Depending on the health authority, these include self help groups, education programs, drop in centres, social recreation and so on. Peer support started to receive annualized health funding in parts of British Columbia in 2004.

Currently, some of the health authorities fund peer support services within community mental health teams. Some peers contract directly with the health authorities while others are contracted through community organisations. The peer workers are on disability income benefits and work for two to three hours per week. A few years ago the welfare rules were changed so that people on disability income benefits who work as part-time peer support workers in community mental health teams were entitled to earn without any benefit abatement.

There is a peer advocacy/support training program run out of one of the independent agencies and training for the peer support workers in mainstream agencies.

### **Manitoba**

Manitoba has a mental health self-help policy. Manitoba Health is the umbrella agency for the eleven regional health authorities. Each Regional Health Authority is responsible for funding services within their area. A few mainstream services employ peer support workers. All self-help initiatives are funded through Manitoba Health. They include the Mood Disorders Association, which is also starting discussions with some of the First Nation groups in Northern Manitoba to work in collaboration. Manitoba Health also funds peer support initiatives within the

Schizophrenia Society and Canadian Mental Health Association. Its funding provides for regional offices for self-help groups. Many of the peer workers are volunteers. Selkirk Hospital in Winnipeg has a unique peer initiative where current inpatients sign up to support other peers in hospital. They are trained to do the work but receive very limited pay.

Manitoba Health closed one of its two psychiatric hospitals (the Brandon Mental Health Centre) in 1998 and allocated all the funding to community services. The local services all follow an integrated service delivery model where services cooperate to decide what is required and negotiate funding. Peer support services are incorporated into this collaborative environment. Various agencies and programs employ peers in paid and voluntary positions.

## New Brunswick

In 1988 the Canadian Mental Health Association in New Brunswick made policy recommendations to the New Brunswick government on the transition from institutional based to community based mental health services, including self help programs. As a result of this document the province formed the New Brunswick Mental Health Commission in 1991 which operated for seven years and established sixteen activity centers and some provincial initiatives. Although the Commission had advice from consumers across the province, they allocated just 0.5% of the mental health budget to peer support. In 2005, 1.8% of the budget went to peer support (LeBlanc, & St-Amand, 2008).

The *Mental Health Services Act of New Brunswick, 1997*, paves the way for peer support when it states in its preamble that ‘the purpose of mental health services is to promote self reliance and less dependence on formal systems of care...The contribution of families, persons with mental disorders and community agencies are valued important components of mental health care’.

In late 2008 New Brunswick moved from eight health authorities to two, based roughly around the English and the French language groups in the province. Since the 1980s peer support has been predominantly delivered through government funded activity centres. There are fifteen French activity centres funded, eleven English activity centres, and three provincial initiatives:

- New Brunswick Consumer Network/Réseau des Bénéficiaires en Santé Mentale du Nouveau-Brunswick;
- New Brunswick Mental Health Activity Centre Association/Le regroupement des centres d’activités en santé mentale du Nouveau-Brunswick; and,
- Our Voice /Notre Voix – a newsletter.

## Newfoundland and Labrador

Newfoundland and Labrador have four regional health authorities. Currently peer support is funded in two of the four health authorities – Eastern and Central – through the mental health and addictions services.

The Eastern Regional Health Authority provides funds for a peer worker in the assertive community treatment (ACT) team and for the only mental health peer support service in the province, Consumers’ Health Awareness Network Newfoundland and Labrador (CHANNAL). The province also provides some money for CHANNAL to provide provincial services. CHANNAL provides web based resources, facilitates groups in different parts of the province to support self help, education and advocacy, and works with government to ensure the voices of consumers are heard. It was under the Newfoundland and Labrador Canadian Mental Health

Association when it formed in 1990 but it became independent in 2006. There is also a cross-disability peer support initiative (the Independent Living Resource Centre) which has an active membership of people with mental health problems.

The Central Regional Health Authority has recently hired a peer worker for their assertive community treatment team. The Western and Labrador Grenfall Regional Health Authorities do not appear to fund any peer support initiatives, although an ACT team in the Western region has a vacant position for one peer support worker.

### Northwest Territories

There are eight health authorities in the North West Territories. As far as the consultants can find there is little specific peer support funding in the province for the Aboriginal populations or the general population, though the current Mental Health and Addictions Strategy Framework (2002) does promote self help.

### Nunavut

Nunavut has one health region – Nunavut Health Region. Nunavut is the least populated territory in Canada and the largest geographically, with a high proportion of Inuit. As far as the consultants can find, there is no specific peer support funding in the province for the Aboriginal populations or the general population. However, the Embrace Life Council, an interagency collaboration to contribute to the ‘emotional and physical health and community wellness of Nunavut residents’ has a generic peer support component.

### Nova Scotia

Nova Scotia has nine district health authorities and the IWK Health Centre for Children and Youth. Most of the nine health authorities do not fund peer support.

IWK Health Centre for children and youth has peer support staff. There are a few peer workers within adult hospital settings while other Self-help groups, rights advisors, drop-in centres, are funded by district health authorities and other funding groups as well. Most self-help groups receive no funding at all but are flourishing anyway.

Empowerment Connections has a contract with the provincial government to provide rights advisors, who are mostly peers, to people under the *Involuntary Psychiatric Treatment Act*. The Healthy Minds Cooperative is an organization made up of consumers, family, friends and mental health professionals and does offer peer support to its consumer membership. It is funded by the Capital District Health Authority. The Self-Help Connection is a provincial self help resource centre. The Consumer Initiative Centre falls under the umbrella of the Self-Help Connection. It offers several programs to people living with a mental illness and offers Peer Support. It has a Certified Peer Specialist. Besides offering peer support to participants, they have spent the last 6 years promoting peer support across the province of Nova Scotia, nationally and internationally. They are working on developing a peer support training program for NS and beyond and are partnering with the Nova Scotia Community College to instruct the program in 2012.

The Consumer Initiative Centre is also part of a working group that has submitted a proposal to the Capital District Health Authority for 5 FTE peer support positions. Lang House also has a peer support program.

## Ontario

Peer run initiatives have been around in Ontario for many years, but they did not receive substantial funding until 1991 when the Consumer/Survivor Development Initiative (CSDI) was established by the then Ministry of Health. Funding was made available to support the expansion of the provincial organization, the Ontario Psychiatric Survivors Alliance (OPSA), as well as local peer run initiatives providing a broad range of peer support, advocacy and alternative businesses.

The Consumer/Survivor Initiatives as well as other peer support initiatives deliver a range of peer supports and services in Ontario, such as:

- Peer support workers on ACT teams, crisis services, hospitals, and in community mental health services, including many Canadian Mental Health Association (CMHA) agencies;
- Consumer advisors to the CEO of a regional health service;
- Self-help resource centres;
- Self-help groups;
- Independent peers working with corporate companies and government departments to include peer support in the workplace; and
- Unfunded groups such as the Mad Student Society (for university students) and the Secret Handshake (for and by people with a diagnosis of schizophrenia).

In 2008 Ontario moved to Local Health Integration Networks (LHINs). There are fourteen of these. Each LHIN is responsible for funding services within their area. All the LHINs fund peer support initiatives.

There have been changes in the provincial level organizations. In 2001 CDSI became incorporated and changed its name to the Ontario Peer Development Initiative (OPDI). After a review in 2005 by their funder, the Ontario Ministry of Health and Long Term Care, OPDI lost half of its funding and the mandate to provide developmental support to its member groups. There is now no comprehensive provincial development support for consumer-run groups in Ontario. In 2008 however, OPDI received a substantial foundation grant to develop a toolkit for peer support training with the aim of training 200 consumers/survivors across the province.

Ontario's mental health policy has signalled the need for the development of peer run initiatives since 1993 (Ontario Ministry of Health, 1993). Despite the policy, which came after the funding envelope for peer run initiatives in 1991, progress has been slow on the growth and development of peer run initiatives; many peer run initiatives have been absorbed into mainstream agencies and they have not increased their share of the mental health budget. Their share is tiny – estimated to be 0.2% of the total mental health budget (Centre for Addiction and Mental Health, Canadian Mental Health Association, Ontario, Ontario Mental Health Foundation, & Government of Ontario, 2004).

## Prince Edward Island

Prince Edward Island has two departments responsible for the full range of health services – the Department of Health and the Department of Social Services and Seniors. All health and social service policy, programs and services are managed through those departments. Recently, the Department of Health announced that they are establishing an arms-length authority called Health PEI, which will manage the health programs and services for the Island.

There is currently no dedicated peer support funding. There are some unfunded self help groups on the island such as Emotions Anonymous, and other groups for depression, bipolar and anxiety who receive limited support from the provincial CMHA. The facilitators of these groups do not receive formal training for their role, but they receive limited support of other types.

## Quebec

Quebec is a unique province; it is linguistically different from the rest of Canada but aspects of its culture are very different from French speaking Europe. The Quebec health system differs from both Europe and the rest of Canada.

Quebec has 18 health authorities that in all provide over 90% of mental health services. The remaining services are provided by community organisations, some of which define themselves as ‘alternative’ mental health providers. These agencies are run by both peers and non-peers. The alternative providers consist of three main umbrella agencies : l’Alliance des Groupes d’Intervention pour le Rétablissement en Santé Mentale/Québec (AGIR); l’ Association des Groupes D’intervention en Défense des Droits en Santé Mentale du Québec (AGIDD-SMQ); et, le Regroupement des Ressources Alternatives en Santé Mentale du Québec (RRASMQ).

These agencies have values that are reasonably consistent with peer support and mention peer support or mutual aid in one of their manifestos. Many peer support groups and networks are led or assisted by professionals. The identity and practice of peer support is largely centred in these alternative provider/user networks, though there are some stand-alone peer-run providers of peer support. For example, there are: a stand-alone empowerment project; a book and training program produced by the Collectif pour un Pouvoir Fou (Mad Power Collective); and the Gaining Autonomy with Medication (GAM) project, which supports people to look at medication and its impact on their quality of life.

In addition, efforts are underway by Association des Personnes Utilisatrices des Services de Santé Mentale de la Région de Québec (APUR), a peer initiative based in Quebec City, to create a service user federation for the province. It is hoped that the voice of service users will also be carried further with the following two peer initiatives that are organizing and training service users on different projects of representation: the projet de représentation from the coalition of rights groups in mental health in the province of Quebec, Association des Groupes en Intervention et en Défense des Droits en Santé Mentale du Québec (AGIDD-SMQ); and in the Montreal region, the Projet Montréalais de Représentation des Personnes Utilisatrices.

The 1989 mental health policy of the government of Quebec prompted the funding of several self-help groups in Quebec. However, the government was not explicit in its definition of self help. The latest mental health policy document, the Mental Health Action Plan 2005-2010, does not mention self help but introduces peer support specialists who are now working in about thirty Quebec hospitals, community agencies and assertive community treatment teams. This

reflects a political will for the development of peer support. Peer support specialists get training based on the Georgia peer support specialist model adapted by Pairs Aidants Réseau of the l'Association Québécoise pour la Réadaptation Psychosociale (AQRP). This initiative represents the first Francophone training of its kind in Canada and Europe.

## Saskatchewan

Saskatchewan has thirteen regional health authorities and one independent peer support initiative funded through Saskatchewan Health. The Crocus Co-op in Saskatoon provides a drop in, casual labour, and self help groups, as well as lunch and supper programs.

As far as the consultants can find, there is no other specific peer support activity or funding in the province for the Aboriginal populations or the general population. However, generic community peer support exists in all Aboriginal communities where people gather for social, cultural or recreational activities. These activities are not funded.

## Yukon

Yukon has only one Health Region, the Yukon Territory Health Region. Currently it funds the Second Opinion Society, based in Whitehorse, which provides peer support, advocacy, a resource library, recreational and social activities, and workshops.

These provincial and territorial summaries show there is significant variation in the development of peer support. It seems that the provinces that are doing the most peer support (i.e., Ontario, New Brunswick, Quebec and British Columbia) are developing peer support on various fronts; in policy, funding allocations, and workforce development.

## *Minorities and other population groups*

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, for various reasons. Many of the people who use peer supports are middle-aged, urban Caucasians.

### First Nations, Métis and Inuit

*“Our First Nations and Metis healing strategies are not recognised.”*

*“Peer support is not a business but an ancient protocol that involves individual community members, family, community and Nation that understand the balance of mental, spiritual, emotional and physical quadrants.”*

*“Due to oppression our ceremonies were outlawed and have just recently (1960s) been allowed to practice again. They are rapidly coming back into First Nation communities and [are] effective in overcoming mental health issues.”*

Aboriginal Canadians are a small but fast growing population with high rates of mental health problems stemming from colonization and deculturation. One dedicated group for First Nations and Métis group was consulted for this project. The respondents stressed the need to develop

their own networks and services, by their own people, for their own people. Aboriginal peoples do not practice peer support in specific mental health groupings, but in their natural communities – in sweat lodges as well as sharing circles led by elders. These ceremonies have many similarities to western peer support; they provide safety and holistic healing for people – talking, dancing and drumming. Respondents said that while these activities have mental health benefits they are not recognised in western evidence or funded. Elders with high levels of expertise are also unrecognised because they do not hold western qualifications.

## Ethnic minorities

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

The philosophy of the consumer/survivor movement in North America tends to be individual rather than family focused, which doesn't always resonate with consumers/survivors from ethnic minorities. Respondents acknowledged that Aboriginal peoples and ethnic minorities were not accessing peer support as much as people of Caucasian origin. They said that the concept of peer support in a mental health peer context is not familiar to many ethnic minorities, who are more likely to use the support networks in their own families and ethnic communities. However, ethnic minorities are not always immune from discrimination against people who have a mental illness diagnosis, and peer support initiatives and workers may also hold racist beliefs or lack understanding of how to relate to people in other ethnic groups. Identity can become complex for people who belong to two or more marginalized groups. For instance consumers/survivors in ethno-cultural minorities can be devalued by their consumer/survivor peers as well as by their own ethnic community.

## Francophone people

Although Quebec and New Brunswick are relatively well supplied with peer support initiatives in comparison to other provinces, Francophone people living in English speaking areas of Canada do not have reliable access to peer support in their own language.

## Rural people

*“I have to take two buses to get here [to the peer support service]. Sometimes that takes hours.”*

Canada covers a large area; most of its population lives within one hundred miles of the US border, while some rural populations live hundreds of kilometres away from their nearest mental health service. Peer run initiatives in rural areas struggle with few resources to reach out to a far flung population. The costs of transportation can be prohibitive and public transportation may simply not exist. Some rural peer support groups are starting to use information technology for distance communication.

## Young people

*“In our town, there is NO support for young people who face housing needs, food and clothing needs, and if you try to involve politicians, they just want to wash their hands and bury their heads in the sand, so they won't see the problem.”*

It was commonly acknowledged that peer run initiatives often do not attract young people. Sometimes they are not funded to provide for young people, and the staff and members are usually older. However, peer support initiatives in mainstream agencies sometimes do focus on young people, for example, some first psychosis episode programs in Ontario have peer support workers on-staff. Laing House in Nova Scotia is an example of a mental health agency with a dedicated focus on young people and a holistic approach to recovery from mental health challenges. Peer support workers and other positions held by people with lived experience are key elements of the service.

## Seniors

The researchers found no mental health peer support initiatives specifically for older people, though some older people use adult peer support services. Peer support for older people is likely to be a growing concern given the changing age structure of the population.

## Canadian forces and veterans

A peer support program is jointly funded by the Department of National Defence and Veterans Affairs Canada. There are now over 28 peer support workers across Canada who work with individuals and their families. The peer support workers are hired as public servants with supervision and performance reviews. The paid peer workers have all experienced 'Operational Stress Injury' themselves and need to have a psychiatric clearance in order to take on their position. The peer support workers are trained by mental health professionals who are assisted by peers. They are trained to work with clinicians as well as community supports and resources.

## People with learning, sensory, physical and developmental disabilities

*“Peer support organizations are often not funded to provide accessibility and need funding to conform to the Charter of Rights and Freedoms... Linguistic, plain language, ASL [American Sign Language] and disability accommodations of every stripe MUST be provided for and also must be seen as an important part of the operational budget.”*

People with disabilities, especially deaf people, have high rates of mental health problems. Yet not all peer run initiatives are accessible for people with other kinds of disabilities. Venues may be physically inaccessible or information produced in inaccessible formats. Mental health peers may not always understand other disability issues.

## Gay, lesbian, bisexual and transgendered people

*“Most of the peer support workers I have seen are white and straight, leading to not much diversity, not much chance to meet someone who comes from your background.”*

Gay, lesbian, bisexual and transgendered people also have high rates of mental health problems. We came across only one unfunded peer support service in Canada specifically for them.

### People involved in the criminal justice and forensic systems

Consumers/survivors involved with the criminal justice system or forensic mental health services do not have much access to peer support. Peer run initiatives could have a greater role in providing services or supports to people involved in the criminal justice system at different stages, from prevention services through to diversion and after release. A peer support service and a consumer operated service in Ontario are funded to provide these services as part of the larger provincial cross-ministerial response to the growing numbers of this group of consumers/survivors.

## CHALLENGES FOR PEER SUPPORT

Respondents raised a variety of issues which are proving to be a challenge for the development of peer support. These include access, funding, organizational structures, development issues, and stakeholder relationships as well as internal issues from governance to the involvement of members.

### *Access to peer support*

*“Most people who could benefit have never heard of peer support.”*

*“I don’t think many people know it exists – it seems like people stumble on to 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.”*

*“Yikes – we have only two options for independent peer support, and a few mainstream peer support positions for 1.5 million people in our locality – so tiny percentage [have access to peer support].”*

Most respondents said that a ‘very low’ percentage of people in Canada with mental health problems use peer support. There are however, very few statistics on the use of peer support. Vancouver Coastal Health in British Columbia, which has one of the most developed peer support services inside community mental health teams in Canada, noted that less than 5% of their community mental health clients have access to a peer support worker. In a Canadian health survey, up to 9% of people with mental health and/or substance abuse problems used self-help groups, telephone hotlines, or internet support groups (Statistics Canada, 2002). In addition to this, mental health services can be slow to refer people to peer support initiatives, even when they are available. Respondents told us that some professionals didn’t know what peer support is, or discouraged people from associating with other people with mental health problems.

In an ideal world everyone should have the same access to peer support services as they do to clinical services and medications. Respondents told us that many people who could benefit don’t know about peer support and may not live near a peer support initiative, especially if they live in a rural area. If people did know about peer support there would be far too few peer support initiatives to meet demand. Respondents also told us repeatedly, that they wanted peer support to be available ‘everywhere’. People were particularly keen to see peer support workers in emergency rooms.

## *Funding and planning*

*"I find it odd that while everyone thinks peer support is a great thing, they don't want to pay for it!"*

*"There is an inconsistency with funders saying we value you, but please volunteer as there is no money. Do we ever ask social workers, OTs, nurses and psychiatrists to volunteer as there is no money for them?"*

*"We get about 1 million in funding for 25 to 26 activity centres, consumer networks, support groups and 'Our Voice'. The activity centres work out to be about \$1.96 per head per day, versus a bed in the unit at approx \$740 per day"*

*"Listen to what people have to say about what actually works rather than continuing to fund what doesn't"*

*"There has been much success in New Brunswick and Ontario because of the support the governments there give."*

*"They have given it a very low priority in their immediate plans. I was part of a committee that was asked by the managers in this province to write a paper on peer support so that standards could be created. That paper sits gathering dust because right now peer support is not on the radar. Until the political will is there, nothing will be done."*

There will always be a place for unfunded self help networks run by volunteers but many of the networks we consulted were frustrated at their over work, lack of recognition and lack of funding for development and provision. First Nations and Métis people particularly felt that their own healing strategies were not recognized by funders. There are simply not nearly enough peer support services of any kind to meet demand. Virtually everyone agreed that funding for independent peer support initiatives is close to unsustainable. Many people working in independent and mainstream peer support initiatives are on government disability pensions which the agency topped up with the allowable amount, before abatement started.

Once funded, people often stated that funders tried to reshape peer support services and gave them the same reporting requirements as mainstream services. This was seen as a sign that funders did not understand what they were 'buying'. Some peer run initiatives reported that they felt over scrutinized by funders, who seem concerned about 'crazy people screwing up'.

People said peer initiatives in mainstream settings are generally in a more viable situation. Peer support initiatives and peer support workers employed or contracted by mainstream agencies have more access to generic workforce development, but they may lack access to training and development specific to peer support. Employees tend to be low paid, though there are some exceptions to this. In one service they said they are paid less than the cleaners, and in some areas people were contracted on the minimum wage as a disability income benefit top up for only two or three hours a week.

Many respondents wanted to see peer support funded in both independent and mainstream settings, though some felt strongly that peer support could easily be exploited and colonized in mainstream settings.

The people we consulted suggested various reasons why peer support initiatives as a whole get such a tiny slice of the pie, and also, why individual peer support initiatives are poorly funded in comparison to other community mental health providers:

- There is still no comprehensive transparent funding formula in many of the provinces. The overall funding for services does not appear to be based on, for example, the number of full time equivalent staff needed, or the number of consumers/survivors that need a particular intervention or service. There is still a tendency for funding decisions to be ad hoc, based on what providers are available rather than a consensus on what and how much is needed. This may have led to favouring the types of services that are already well established.
- Funders and mental health leaders in the provinces are sometimes ambivalent about peer support initiatives because they do not understand them or because peer support initiatives lack definition and standards. In addition to this they may have seen some peer run initiatives that have had significant difficulties, are not innovative, or have not kept up with the times.
- Peer run initiatives have a limited evidence base compared to some other funded responses, which may discourage funders from investing in them. As one person put it, 'you have no evidence, you get no funding: you have no funding, so you can't produce the evidence' (Curtis et al., in MacNeil & Mead, 2005, p 243).
- Peer support initiatives are easily viewed as a cheap option and add-on to 'real' services rather than as core services or supports in their own right.
- Peer support initiatives in the provinces are not coordinated, and some lack the political contacts and know-how to get their voice heard by planners and funders, who themselves sometimes neglect to involve them in planning and funding discussions.
- Respondents said poor funding results in recruitment and retention problems, sub-standard locations, high stress, and reduced ability to meet all contract requirements.

Some provinces have had an injection of funding into peer support services. This was seen as helpful but not nearly enough to meet demand. There was a general consensus that clinical services get the lion's share of the funding when they cater for only a small portion of people's needs.

### *Organizational structures*

*"Peer support should only happen outside the system."*

*"Independent [organizations] promote the growth of new ideas and initiatives."*

*“Peer support works in spite of not being run by peer organisations.”*

*“Never have one peer working alone in an agency.”*

*“There is a financial advantage to having health professionals involved in peer support because they have more access to money and there is more help to put things into action.”*

*“We won’t be taken seriously unless integrated into the system.”*

It needs to be remembered that there is a plethora of small unfunded grassroots self-help groups around the world run entirely by volunteers. However the big growth in peer support in the last generation has been the development of staffed and funded initiatives. Initially these peer support services were just provided by independent peer run organizations but mainstream organizations have also got in on the act through employing peer support workers or establishing peer initiatives within the mainstream service. This has been controversial in all countries, as the quotes above show, although it looks like peer support in both kinds of settings will continue.

Respondents were clear about what types of organizational structures work well for peer support initiatives. Many believed peer support workers should be employed by peer run agencies and either work within them or be seconded to mainstream agencies. They told us the best types of agencies to ‘house’ peer support services are small, non-profit, community or peer driven with a flat hierarchy and consensus inclusive decision making. However, these organizations need to be structured, with plans and procedures, training and supervision, and with clear boundaries such as confidentiality.

Some respondents believed peer support workers who work inside mainstream agencies should never work alone in a team of professionals, due to the differences in philosophy and power and the sense of alienation this can set up for the peer support worker. People were also emphatic that supervision and performance appraisals of peer workers inside mainstream agencies should be done by other peers and not professionals.

### *Service and workforce development in peer support*

*“This is a calling, not merely a job”*

*“There’s so few training opportunities tailored to peer support”*

There are some peer support development initiatives in Ontario, British Columbia and Quebec which we described in the provinces section.

Respondents agreed across the country that there is not nearly enough development work going into the peer support workforce and peer support initiatives. Virtually everyone saw the need for some standardization and formalized training and ‘professional development’ in peer support if peer support initiatives are going to grow and become an integral part of the mental

health system. But people also expressed concerns about these developments. 'Professionalizing' peer workers could erode the reciprocal relationships in peer support initiatives, and standard workforce training could steer peer workers into taking on the language and culture of mainstream mental health services (The Herrington Group, 2005, p 6). Many aspects of peer support training are not covered in mainstream curricula, so new curricula need to be developed. This has happened in Georgia, Arizona, New Zealand, and elsewhere.

People stressed that training needs to be tailored to the different roles in peer support initiatives. These include not just the paid staff but volunteers and the board. Because reciprocity is a key element of peer support resources need to also focus on the personal development of clients (in mainstream services) or members (in independent peer support initiatives), either through the training of peer support workers or directly through providing learning opportunities for members and clients.

Some training topics that may be unique to peer support initiatives, or to be interpreted differently for them are:

- History and culture of mental health services;
- Mainstream and critical perspectives on mental health issues;
- History and principles of the consumer/survivor movement;
- Values and culture of peer support;
- What helps and hinders recovery;
- Peer boundaries, ethics, and shared risk taking;
- Peer practices (e.g., WRAP, intentional peer support, alternative businesses);
- Delivering recovery education;
- Group facilitation and meeting skills;
- Goal setting and recovery planning;
- Assisting people self-manage medication, self harm, voices, and other unwanted 'symptoms';
- Working with or within mainstream services;
- Empowerment (e.g., as offered by the Collectif pour un pouvoir fou); and
- Psychiatric medications (e.g., Gaining Autonomy with Medication).

Barriers to education and training include lack of funding and/or failure to create a budget for staff development. Some peer workers have felt uncomfortable and excluded when they have attended mainstream training. There is also little or no training specifically for peers whose first language is not English, including Francophone people outside of Quebec.

### *Relationships with non-peers*

*"One doctor said – we would have consumers on staff if they had something to say."*

*"Our peer support worker is completely appreciated and sought out by the healthcare team, which includes professionals and para-professionals."*

Some people we talked to believed government officials, planners and funders may have lower expectations of peer support initiatives than professionally led services. If this is the case, the

impact of this attitude cannot be overstated. Lower expectations, at whatever level of consciousness, can lead to an oscillation between neglect of peer support initiatives and too much interference when things go wrong.

Others said that people in the mainstream mental health system do not understand consumer/survivor history and values. This means they are likely to regard peer support initiatives as either second-rate or just like mainstream services that happen to be run by consumers/survivors. They asserted that consumer/survivor initiatives need to be regarded as 'equal but different'.

Perhaps the biggest barrier to the development of peer run initiatives around the world has been the longstanding inequality and marginalization of people who have received a mental illness diagnosis and its impact on consumers/survivors as well as the people who work in and run the mental health system.

Many of the people involved with peer run initiatives have not felt helped by the mental health system, and some have felt deeply harmed by it. They are now taking an active role alongside or within the same system. Because of their experiences, they are sensitive to acts and/or attitudes of exclusion and control. They often feel some degree of ambivalence about engaging with the system that they see as tainted or even unsafe for them. In addition to this they may not understand the rules of power and influence that the people who run the system are familiar with, or have the networks to tap into the most powerful people.

The people who have always been relatively privileged in the mental health system may still harbour stigmatizing beliefs about consumers/survivors. If they have not had analogous life experience of being marginalized, then they may be unable to understand the situation and experiences of their consumer/survivor colleagues. Because of this, they may respond defensively to consumer/survivor scrutiny. Some may feel a discomforting guilt about the harm the mental health system has done in the past, as well as today.

## Independent peer support initiatives

*"Successful peer services know the politics and know how to dance."*

*"Consumer organisations have to see themselves as not just what the mainstream tell us we are."*

*"[We have] excellent relationships with other services and organizations."*

*"I have not seen much success... Stigma is alive and well in this field."*

Peer run initiatives around the world, especially the ones established in the earlier days of the consumer/survivor movement, were often somewhat separatist and didn't want much to do with mainstream services (Nelson et al., 2008; Shimrat, 1997; Van Tosh & del Vecchio, 2000). Over the decades this has changed and respondents generally agreed that building relationships with the mental health system and other stakeholders was vital to the success of independent peer support initiatives. Some peers however, carry ambivalence about their relationships

within the mainstream mental health system which they experience as daunting, frustrating or unequal.

People mentioned that there is stigma and discrimination against consumers/survivors in the system, which can subvert good relationships. People complained that they were not always included or taken seriously. It may also be true, that people who perceive they have some power within the mental health system are more successful handling their relationships within it.

## Peer support initiatives in mainstream services

*“We [peer workers] used to be treated not so well [by mainstream colleagues], but after being here for a while we now have more acceptance and respect”*

*“Please regard individuals dedicating themselves to peer support as co-professionals”*

*“I work at an organization that is not run by consumer/survivors, but we do have a number of consumer/survivors working here and we are all viewed as competent at our work as non consumer/survivors”.*

One rationale for placing peer support workers in traditional mental health services is so they will help bring about culture change. This is perhaps a tall order for people who are usually at the bottom of the hierarchy. About half of the respondents said their presence had helped to create culture change, through role modeling, informal dialogue, education and creating the conditions where some professionals have felt safe to ‘come out’ as consumers/survivors. People said it was much harder to change staff if they had other priorities and rigid beliefs. Some professional staff are unwelcoming of peer support workers. We heard stories that peer support workers were not allowed to use the staff toilets or weren’t invited to the staff Christmas party.

It can be particularly difficult for peer support workers working in the same service they use or have used. We heard examples of supervisory professional staff failing to make the distinction between clinical and employment issues when they were dealing with the peer support workers. We also heard of peer support workers in ACT teams who were expected to engage in clinical activities such as medication drops, which have the potential to be coercive.

It was generally considered good practice for staff in mainstream agencies to get training on peer support and related issues before peer support workers join their teams. The presence of peer support in mainstream agencies has some potential to change the culture of those agencies but there is a risk that those agencies will change the culture of peer support if the professionals harbor prejudices and don’t understand the values and benefits of peer support.

## Governance

*“There are huge inconsistencies between organisations and the way they implement peer support”*

Governance issues differ markedly between independent and mainstream services so they will be dealt with separately.

### Independent peer support initiatives

*“The governance skills within our movement surpass those of any other voluntary sector that I’ve been involved with.”*

*“We get scrutinized around budgets and governance more than most organisations – it’s like we are the crazy people and will screw it up”*

*“Big problem area. There needs to be more training opportunities for volunteers to learn about governance.”*

Many respondents believed that the boards of peer run initiatives performed reasonably well, but it is hard to find the right mix of financial, legal and peer, community skills and experience from the local consumer/survivor community. Some boards have a minority of people who are not consumer/survivors while others don’t observe the strict separation of governance and operations that exists in the corporate and large non-profits contexts. Some boards of peer run initiatives have members, volunteers and staff on them. Others are just governed by the members, while others bring in users and survivors from the wider community. At the very least, the board of an independent peer run initiative should have a majority of consumer survivors on it.

### Peer initiatives in mainstream settings

*“[The influence peers have in non-consumer organizations] completely depends on the value given to truly equal partnerships and how this is practised in the organization. In equal and respectful partnerships they will have a great deal of influence. Unfortunately, this is not usually the case.”*

Peer initiatives in mainstream settings are governed by boards that do not necessarily have any consumer/survivor members on them.

Respondents reported mixed experiences with mainstream boards. They felt they had little or no influence over their boards or had to rely on the management, who do not always understand the issues, to make direct representations to boards. They felt they only had influence if the board requested it, not when the peer workers requested it. Some felt they had a lot of influence on their boards. It helped if the organization was small and there was good consumer/survivor representation on the board. Conventional governance arrangements are set up so the workers and board have minimal contact and some respondents may not have

understood this. However, these comments may reflect a preference from peer workers to work in a less defined operational/governance split.

## *Management*

Management issues also differ markedly between independent and mainstream services so they will be dealt with separately.

### Independent peer support initiatives

*“Peer agencies generally have good financial management as they have less money and do more for what they have.”*

*“Consumer survivor organizations have historically been underfunded and have at times not been able to recruit trained and experienced staff because of low wages and poor benefits. Sometimes this has also resulted in insufficient board training to fully understand their role and the role of senior staff.”*

*“There tends to often be a lack of belief and trust in the ability of initiatives to be responsible and credible in carrying out important management functions. Often the initiatives are only ‘paid lip service’ as to their capabilities.”*

Many people believed that independent peer run initiatives are well managed especially under the difficult circumstances of poor funding and workers with fluctuating health. Successful managers lead through empowering the staff and members and upholding the values of peer support.

But managers are vulnerable to a cascade of problems, starting with poor funding. People said peer support initiatives are often unable to afford or train managers with the required skills, particularly in the area of finance and fundraising. Burnout is a major problem. Occasionally, people recruited into management roles are not the best people for the job; they could be inconsistent, have blurred boundaries or be self-serving and treat others badly.

### Peer initiatives in mainstream settings

*“We feel that our ‘superiors’ are following their agenda and we have to fit in to their scheme.”*

There are also peer support workers in mainstream services in many places in Canada. A number of mainstream organizations have begun to add peer support to their service delivery. This has taken a number of forms including: implementing WRAP, hiring staff with lived experience into peer support positions, developing partnerships and referral arrangements with consumer/survivor-run organizations to expand access to employment or drop in centre options, as well as hiring people with lived experience to do training on peer support and other topics.

People were very clear that the mainstream management of peer support initiatives could only work if this was done in a spirit of partnership with the peer workers in organizations that 'get' peer support values. Unfortunately, it's more common that peer workers in these settings feel over-controlled and under-respected by their professional and management colleagues. These organizations often have other priorities so the peer support part of the service may be neglected. Some said consumer/survivor interests did not come first in these organizations and professionals tended to see peer support workers as cheap labour who lessened their own workloads, rather than a separate form of service delivery.

Peer support workers based in clinical teams sometimes have little or no autonomy. In one area the peer support workers were told by their manager what they had to do with clients and the case manager had to approve the recovery plan worked on between the client and the peer support worker. Sometimes this meant dampening down or interfering with the persons goals, which is contrary to the values of peer support.

## *Staff*

*"I fear that if we use paid staff it destroys the altruistic nature of peer support."*

*"I'm in two minds because if we're paid it may change the power imbalance [with clients] but the system needs to value peer support and it's not deemed legitimate if it's not paid"*

*"Everyone should get paid - we shouldn't have to rely on volunteers"*

*"It is unconscionable that funding for mental health consumers in paid positions is far below a living wage and often without benefits. Creation of properly paid positions within our movement needs to be built in."*

*"I don't believe they view peer support as the effective and efficient tool that it is. I would like to see at least 50% of the jobs in the mental health field going towards consumers. If consumers don't get jobs in the field, then there's no way they'll be represented."*

If the peer support workforce is to develop, peer support services need to be adequately funded as a core service like clinical services that consumers/survivors should have access to. People were overwhelmingly in favour of fully paying peer support workers. Paying people a fair wage is a sign that their work is valued by the system that pays for the service. It also provides employment and financial independence for people who might otherwise be still on a disability income benefit.

Peer support workers may be paid or unpaid in both mainstream and independent settings. Some may have their disability income benefits topped up to the maximum rate before they start to be abated. Respondents said that paid workers had more status than volunteers. They were often more skilled, with clearer accountability than volunteers.

Staff with mental health problems often need different kinds of supports and workplace accommodations than other workers, due to the fact they are in pioneering roles that currently

lack traditions and standards, as well as the sometimes lingering presence and impact of their mental health problems. People felt strongly that peer support staff needed supervision from experienced peers, rather than non-peer professionals. They also thought employers should be open to being flexible about work hours, work conditions and sick leave for those who continue to experience mental health problems.

The downside of fully paying peer support staff was the possible power and status imbalance created with volunteers, members or clients. This could make it harder to apply the values of equality and empowerment that are so central to peer support. Lived experience of mental health problems is not the only requirement for peer workers; they also need work related skills and attributes.

There was widespread agreement that peer support work needs to become an occupational group in mental health, though people are afraid that peer support values will be destroyed if peer support becomes too professionalized. On the other hand people recognized that peer support needs to grow and become more standardized, with nationally recognized training and standards that can be adapted at the provincial level. At the moment there is no career pathway in peer support and peer support workers tend to get stuck on low wages which discourages good people from staying in it.

Peer run initiatives have difficulty recruiting and retaining skilled workers because their pay is not competitive with peer workers in mainstream agencies, and some consumers/survivors are afraid of the stigma of openly identifying as such.

## *Volunteers*

*“It shouldn’t cost you to be a volunteer”*

*“One thing that makes it easy to volunteer is that it looks good on a resume.”*

*“There is an important role for volunteers.”*

*“In our organization the board of directors has a firm philosophy that volunteer participation is a key component of self worth and recovery. There is a spiritual need amongst our consumers to feel that they are “giving back.” Any task they are qualified for from answering the phone to providing direct support to a mental health consumer in crisis to testifying before parliament.”*

*“The main challenge with volunteers is that they can leave at anytime for any reason. This causes huge challenges to create a good team.”*

People tended to define volunteers in a variety of ways – as people who aren’t paid anything, not even expenses, people who are paid expenses and people who are paid well below the minimum wage as a top up to their disability income benefits.

Peer run initiatives often rely heavily on volunteers. There were mixed responses to the existence of volunteers in peer run initiatives. A few said everyone should be paid. A lot of people could see the benefits of volunteering for people who were in transition from a 'consumer' role to a full working role; volunteering enables them to build up confidence, skills and working hours. However, there is a danger that people may get stuck in the volunteer role and not move onto paid work because funding doesn't allow it or their free services are taken for granted. Also, volunteer supports and accountabilities can be unclear.

There are two Chinese peer support initiatives in Vancouver and Toronto. Both said that Chinese people found it much easier to identify as volunteers than as members because a volunteer was a more socially valued role, in a cultural setting where it is social death to openly acknowledge mental health problems. They considered it an honor to be a volunteer. On the other hand, we heard a story of a man who missed out on his food at a food bank so he could attend a meeting as a consumer representative in a voluntary capacity with well paid professionals. These kinds of situations are unacceptably inequitable.

### *Work conditions*

Peer run initiatives and mainstream employers try particularly hard to create a supportive work environment. They need to negotiate workplace accommodations for staff, such as flexible work hours and sick leave entitlements, quiet work areas, acceptance of unusual behaviour, the need to take time off for appointments and so on. Some respondents suggested that not all peer run initiatives do well at supporting their staff, due to lack of funding for supervision and training, as well as lack of management skills at times. For instance one person told us that accommodations for one staff member had overburdened other staff members with extra work.

It can be more difficult to create a supportive work environment for peers working in mainstream services, as these services may operate in ways that peers are uncomfortable with, and they may have a less supportive workplace culture. Peers may be isolated from each other, and mainstream colleagues may harbour prejudices, or are not used to working with consumers/survivors. Some people believed that these situations could be avoided if these peer workers were employed by peer run initiatives that contracted them out to work in mainstream services. At the very least peer support workers in mainstream organisations needed mutual support opportunities.

Positions are often part-time due to lack of funding, and to allow people to keep receiving a welfare benefit. Peer run initiatives often cannot afford to pay additional health benefits, such as payment for medication and doctor's visits, which are usually available to mainstream workers and to beneficiaries. Thus, some part time peer support initiative staff can get stuck in the perverse incentives created by the benefit system. There is also a high turnover in peer run initiatives, as people often leave due to burnout and overwork or to work in a higher paid job.

## *Clients and members/participants*

*“The people we serve come first”*

*“When I go to the peer run initiative I’m not a patient anymore. I’m a human being with strengths and abilities.”*

*“Many clients do not trust themselves enough, or believe in themselves enough in order to participate. That may change over time as they attend more peer support groups. Or, it may not change but the benefits of peer support can still be gotten by using close supporters instead of a group situation. Opportunities are that they can feel validated and heard which can improve belief in themselves and grow their knowledge from there.”*

Mutuality is a core value of peer support; this requires that clients, members and participants have every opportunity to be actively involved in choosing their own supports and in the general development and direction of the service. Generally there are many opportunities for members or participants to become involved in independent peer run initiatives – on the board, hiring staff, program development and review, evaluation and volunteering in the delivery of programs.

Independent peer run initiatives refer to people as members or participants rather than clients because these role titles create more potential for members to become actively involved in the peer support initiative. Members and participants are more than just recipients; they also need to be considered as human resource, with training and development needs.

However, some people said it is difficult to get members or participants actively involved because they lacked hope and self-belief or were captured by the medical model which encourages passivity. Others said the lack of opportunities for members and participants to gain new skills were also a disincentive for their active involvement. Clients in mainstream services are less likely to have opportunities to be involved in these services, though it is common for them to sit on interview panels for staff.

## BENEFITS AND SUCCESSES OF PEER SUPPORT

### *Benefits*

*“Knowing you are not alone. Seeing that you are able to live with a mental health diagnosis and still go to school, get degrees, have a job, have a relationship/family. Feeling you are more 'normal' or 'okay'.”*

*“If it were not for peer support, I wouldn't be alive.”*

*“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 of being committed.”*

*“It was my passage way to getting better, pretty much the only one.”*

*“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!”*

Respondents were virtually unanimous on the benefits of peer support. Many of 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.

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'. This atmosphere allowed people to recover self esteem, hope, meaning and purpose, empowerment, self-responsibility and to experience personal growth through both the helper and the one who is helped.

These changes led to more concrete outcomes for people, including:

- Better coping skills;
- Better understanding of mental health issues services;
- Increased community engagement and less isolation;
- Reaching life goals and experiencing a sense of accomplishment;
- Increased quality of life; and
- Reduced crises and hospitalization.

We asked people if they had had negative experiences with peer support. The majority said no. Those with negative experiences talked about being 'triggered' by other people's distress or negativity. They also said some peers had poor skills that led to over-involvement in others' problems, breaches in confidentiality and frequent power conflicts. Some mentioned that some peer workers had been co-opted by the system to carry out clinical or coercive roles. One or two mentioned that they had not felt welcome. Many of these negative experiences could be avoided if peer support was better defined with a more consistent ethical base and its own standards on roles and boundaries.

### *Some examples of good practice*

There are many thriving peer support initiatives in Canada and elsewhere. Below are just a few of them, selected to show the diversity of good peer run initiatives.

Some examples of independent consumer/survivor good practice include:

#### **Our Voice/Notre Voix, New Brunswick**

Our Voice/Notre Voix is a mental health magazine from New Brunswick whose purpose is to promote the viewpoints of psychiatric users or survivors. This initiative is a means for them to enhance empowerment and reinforce solidarity within their community.

[www.ourvoice-notrevoix.com](http://www.ourvoice-notrevoix.com)

#### **Opportunity Works, Calgary**

Opportunity Works is a peer delivered service that provides self-employment and mental health support to any individual in the Calgary community who identifies as a mental health consumer. It offers:

- A holistic and integrated approach to business development.
- Employability and mental health self-management.
- One-to-one coaching supplemented by group learning.
- Flexible, self-paced, self-directed and participant driven timelines.
- A graduated approach to achievement of long-term goals.

[www.opportunityworks.ca](http://www.opportunityworks.ca)

#### **Mood Disorders Association, Manitoba**

The Mood Disorders Association operates throughout the province of Manitoba supporting those affected by mood disorders and to their friends, families and caregivers. It provides:

- Peer support.
- Public education and media.
- Advocacy.
- Education for people with mood disorders.

<http://www.depression.mb.ca/>

## GAM – Gaining Autonomy with Medication/Gestion autonome des médicaments de l'âme, Quebec

A unique expertise initiated by service users in Quebec from the two coalitions, RRASMQ and AGIDD-SMQ, is GAM - Gaining Autonomy with Medication. The ongoing GAM project has been 15 years in the making and is now being developed in Ontario, Spain and Brazil. At the core of this approach is the examination of one's quality of life in relation to medication. Although GAM consists of a working alliance between service users and service providers from rights groups and alternative community agencies, peers are leading GAM group sessions, training other service users and offering support according to the GAM philosophy. Its evolution and implementation are led by the RRASMQ and being studied by the research team, Équipe de recherche et d'action en santé mentale et culture (ERASME). Another influential complement to GAM is "The Other Side of the Pill", training on psychiatric medications from a critical perspective from l'AGIDD-SMQ, taught by service users to other users and/or providers. GAM and "The Other Side of the Pill" are a winning duo for the empowerment of people regarding psychiatric medications.

## A-WAY Courier, Toronto

A-WAY is a social purpose enterprise courier service which was established over 20 years ago. It employs 70 full and part-time people, all survivors. The Board is made up of a majority of consumer/survivors. They cover the whole metropolitan area of Toronto, doing same day delivery of packages for their over 1000 customers. The service is like any other courier company providing a same day service guarantee. Couriers use public transportation rather than vehicles or bicycles and are paid on a commission basis per delivery. For this, each courier receives a monthly bus pass that they can use any time. They have a strong business ethic.

At the same time, A-WAY is a model of mental health accommodations in the workplace. Employees work flexible hours and varied hours, depending on their choice. Peer support is a big part of keeping this organization running. New hires are trained by peers and much time is taken to support each individual consumer/survivor, not only in maintaining their employment but in assisting with issues such as housing, community supports, pensions and all kinds of other advocacy issues. Social events and informal get-together are a big part of making this organization the tight team that it is. Donations of food and clothing are always available through their many partnerships.

[www.awaycourier.ca](http://www.awaycourier.ca)

## Sound Times, Toronto

Ten years ago Sound Times, a consumer operated service, had a budget of around \$200,000; it now has funding of over one million dollars. Sound Times has been supported by government via capital funding to buy the building they are located in. They provide:

- The opportunity to learn from peers to give and get support;
- Support to find food, clothing, and other essentials;
- Advocacy;
- Service co-ordination and referral;
- Education for members;
- Social and recreational opportunities;
- Support for consumers and survivors in contact with criminal justice;
- Harm reduction for drugs and alcohol;

- Community support; and
- Gaining Autonomy with Medication (GAM) approach.

Sound Times has been heavily involved in providing a consumer/survivor voice in the current health system changes. Staff are expected to work from consumer/survivor informed practice. [www.soundtimes.com](http://www.soundtimes.com)

### The Krasman Centres, Richmond Hill and Alliston

The Krasman Centres in Ontario are peer support-based drop-in centres for people with mental health concerns or labels, as well as people who experience homelessness. Recovery-supporting services and programs are governed and delivered from a lived experience perspective. A peer-run and delivered 'Warm Line', a telephone service, is available toll-free seven nights per week. [www.krasmancentre.com](http://www.krasmancentre.com)

### The Culture of Recovery project, Ontario

This project advances a recovery perspective to consumers/survivors and professionals using participatory and experiential education. It provides:

- A recovery clearing house.
- A leadership network of consumers/survivors.
- Self-help recovery education.
- Recovery education for mainstream allies.
- Like Minds: Peer support education.
- Showings and discussions on 'Extra Ordinary People' – an anti-discrimination documentary.

[www.cultureofrecovery.org](http://www.cultureofrecovery.org)

### CHANNAL, Newfoundland & Labrador

CHANNAL aims to strengthen self-help initiatives among individuals, combat isolation and educate the public on issues relevant to consumers. A provincial organization, CHANNAL exists to build and strengthen a self-help network among individuals who live with mental health issues. They are seen as an innovative service due to the fact that they have limited funding and yet retain a strong membership base.

[www.channal.ca](http://www.channal.ca)

### Peer Support and Wellness Center, Georgia, USA

This service has been operating for one year and provides alternative wellness supports. They aim to keep people from going to the hospital and have three beds where people can stay up to seven nights. The program also allows people to come during the day and access varied programs. People can self-refer. Evaluation results already show the program has decreased hospitalization significantly (Darnell, 2008). Programs include:

- Talking the taboo;
- Aromatherapy;
- Computer training;
- WRAP (Wellness Recovery Action Planning);
- Negotiating peer relationships;
- Food;
- Double trouble in recovery (for people with 'dual diagnosis');
- Trauma informed peer support;

- Sport and recreation;
- Music and wellness;
- Sacred space;
- Creative writing;
- Arts; and,
- A 'give back' group.

[www.gmhcn.org/wellnesscenter](http://www.gmhcn.org/wellnesscenter)

### CAN Mental Health, New South Wales, Australia

CAN Mental Health was awarded money from the Commonwealth government to deliver an innovative new service, a 'hospital-to-home' transition team. The team receives referrals from the hospital and works with people on whatever is needed for the first 28 days after their discharge. A peer led external evaluation tool has been developed by Victorian Mental Illness Awareness Council, a state wide consumer network, to evaluate the service. Run by paid staff who are required to complete a peer support training program (developed by Australian and American consumers), they undergo regular supervision. The service also runs a recovery centre and a national 'warm line' telephone service.

[www.canmentalhealth.org.au](http://www.canmentalhealth.org.au)

### Mind and Body Ltd., Auckland, New Zealand

Mind and Body is a limited company. It provides:

- One-to-one peer support work;
- Anti-discrimination work;
- Consumer advisors to mainstream statutory services;
- Certified training for peer support workers; and,
- Consumer led research.

Mind and Body has a strong philosophy that underpins everything it does. It invests in a lot of training and supervision for staff.

[www.mindandbody.co.nz](http://www.mindandbody.co.nz)

A wide range of examples of successful peer support programs within mainstream organisations exist, including:

### Leeds Survivor-Led Crisis Service, England

This service is part of mental health network in Leeds but maintains its own identity. The service operates:

- A help line in the evenings; and
- A house that is open in the evenings at the weekends, which can arrange transport for people who come, and includes a family room where people can come with their children.

The service is staffed by paid employees and volunteers who have regular supervision and a monthly reflective practice group. Staff are trained in a variety of issues, including working with self harm, suicide, hearing voices, loss and bereavement. There is also a small emotional support budget for staff which includes counselling, gym membership and so on.

[www.lslcs.org.uk](http://www.lslcs.org.uk)

## Recovery Innovations, Arizona

Recovery Innovations is a mainstream agency that has established services in four other American states as well as their home state of Arizona. The service creates opportunities and environments that empower people to recover, to succeed in accomplishing their goals, and to reconnect to themselves, others, and meaning and purpose in life. Some of its major programs are:

- Crisis support.
- Peer support & self help.
- Recovery education.
- Peer training & employment.
- Community living.

[www.recoveryinnovations.org](http://www.recoveryinnovations.org)

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## Laing House, Halifax

Laing House is a youth-driven, community-based organization for youth with mental illness between the ages of 16 and 30 years with diagnoses of mood disorders, psychosis, and/or anxiety disorders. Many staff employed by the agency self identify as consumers, including some working as peer support workers. Laing House programs, including employment, healthy living, education, outreach, and peer and family support, are designed to help youth recognize and develop their own strengths, talents, and resources. Laing House describes itself as the first and only organization of its kind in Canada.

## Pairs Aidants Réseau (PAR), Quebec City

Pairs Aidants Réseau (PAR), a project managed by the non-profit organisation, l'Association Québécoise pour la Réadaptation Psychosociale (AQRP), was the first Québec initiative to offer training and support to certified peer specialists and hiring organizations. Through PAR, 60 peer specialists and 30 hiring organizations across Québec have received training. This program, recognised by l'Université Laval, awards academic credits to consumers. Furthermore, the Gaining Autonomy with Medication (GAM) approach is integrated into the curriculum. GAM highlights the expertise of people with lived experience regarding managing psychiatric medications. PAR is sharing its expertise with European Francophone countries.

[www.agrp-sm.org/projets/pairs-aidants](http://www.agrp-sm.org/projets/pairs-aidants)

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## Certified Peer Support Specialists, Georgia

Certified Peer Specialists are responsible for the implementation of peer support services, which are Medicaid reimbursable under Georgia's Rehab Option. They serve on Assertive Community Treatment Teams (ACT), as Community Support Individuals (CSI) and in a variety of other services designed to assist the peers they are partnered with in reaching the goals they wish to accomplish. The training and certification process prepares Certified Peer Specialists to promote hope, personal responsibility, empowerment, education, and self-determination in the communities in which they serve. Certified Peer Specialists are part of the shift that is taking place in the Georgia Mental Health System from one that focuses on the individual's illness to one that focuses on the individual's strength.

[www.gacps.org](http://www.gacps.org)

### Learning and Recovery Centre, Maine

This sits under the umbrella of a mainstream mental health service. The recovery centre respite service allows people to stay between three and seven days. As well, the service provides peer support in emergency rooms, weekly peer meetings and ongoing education to mainstream staff. The service has worked through many issues in its partnership with the mainstream service that it is a program of, including a successful challenge of human resources policies that excluded people with a criminal history working for the Centre. There has also been mistrust and lack of referrals between the Centre and mainstream services which is now largely resolved. The Centre has been engaged in narrative evaluation of the service since it opened.

[www.sweetser.worldpath.net/peers.aspx](http://www.sweetser.worldpath.net/peers.aspx)

### Craigmillar Peer Support Service, Scotland

This is a recovery orientated service staffed by peer specialists who build a relationship with people to assist them in finding a way forward in life, as well as involving them in social activities. The staff have worked hard at gaining the trust of professionals, but this is still a challenge. An evaluation of the pilot showed that people who use the service were very satisfied with it and had been able to exceed their own expectations of recovery.

[www.penumbra.org.uk/craigmillarpeersupport.htm](http://www.penumbra.org.uk/craigmillarpeersupport.htm)

### Self-Help Connection, Dartmouth, Nova Scotia

In 1999, the Self-Help Connection received national recognition as a “Mental Health Best Practice Program” from the “Federal, Provincial and Territorial Advisory Network on Mental Health” for self-help and consumer initiatives. In 2002, the Self-Help Connection set up the Consumer Initiative Centre to help people living with mental health problems and illnesses. The centre provides capacity building programs in the areas of Peer Support, Personal Development, Entrepreneurship and Employability Enhancement and Informatics Education.

[www.selfhelpconnection.ca](http://www.selfhelpconnection.ca)

### *Success factors*

*“Even when peer support is not done quite right, it still works better than the system.”*

We searched the literature, asked the people we consulted, and asked people involved with the innovative initiatives above – what makes a successful peer run initiative? There was a lot of congruence in the literature and in people’s responses.

Some success factors had a lot to do with holding to the values of peer support.

#### Passion and commitment

A very clear theme throughout the consultation was that people do not see peer support as just a job but as a calling with a passion for making a difference to people’s lives. People talked about the need for compassion, love and open-mindedness as key ingredients in success.

#### Translation of peer run initiative values into action

The values are what sets peer run initiatives apart from traditional mental health services. Conscious and ongoing translation of these values into practice is crucial. Peer workers and initiatives in mainstream services have the biggest challenges in translating their values but

independent peer run initiatives also need to check they have not drifted from their values base and defaulted to being like traditional services.

### **Organisational support for values**

Independence from mainstream services helps peer run initiatives stick to their values. If complete organizational independence is not possible and they are absorbed into mainstream agencies, then there needs to be a clear agreement on their respective powers and responsibilities and a willingness to allow a high degree of autonomy for the peer worker or initiative.

Other success factors emphasised the effectiveness of peer support:

### **Information, development, and advocacy for peer support initiatives**

Many people said that peer run initiatives need a structure that looks after their interests as a collective – to advocate for peer run initiatives to funders, policy agencies and government, to establish opportunities and resources for organizational and workforce development, to provide information and advice, and to connect peer run initiatives to each other. A provincial structure has achieved some success in Ontario, but there are no other provincial entities dedicated to the development of peer support.

### **An efficient, viable business**

Successful peer run initiatives are adequately funded for their purpose. With funding comes the requirement to be accountable and efficient. Peer run initiatives have sometimes been slow to adopt sound business practice, which for some have created tensions with their values (O'Hagan, 1994). Most recognize that successful peer run initiatives have to develop the discipline and controls to be efficient and viable, as well as stay true to their egalitarian and empowerment values. In mainstream settings the challenge is more likely to be the other way around – how to express peer support values in a highly regulated setting

### **Supportive and accountable human resources practices**

Successful peer run initiatives combine their values and sound HR practice with their staff in both independent and mainstream settings. Managers mentioned clear job description, formalized recruitment and competitive pay. They talked about the importance of ongoing training, specific to the role of the peer worker. Peer workers had routine supervision, where they had an opportunity to reflect on their practice. Peer workers need support and workplace accommodations but they also need to be accountable. In mainstream settings non-peer staff needed anti-discrimination training and education about peer support to know how to accommodate peer colleagues.

### **A peer understanding of ethics and boundaries**

There is wide recognition among peer support initiatives and workers that peer ethics and boundaries differ from professional ethics and boundaries. Peers work with more self-disclosure and share more common ground with members or clients than professionals are taught to. Though formal definitions of these ethics and boundaries have yet to be developed successful peer initiatives in both mainstream and independent initiatives have the awareness and freedom to explore and reflect on their ethics and boundaries.

## Peer led evaluation

As a relatively new type of response, resources need to go into the evaluation of peer run initiatives to assist them to keep improving, to refine our understanding of what peer-run initiatives are or need to become, and to build up the evidence base on their effectiveness. These evaluations must be designed and undertaken by consumers/survivors using deliverables and measures that matter to them. The process of evaluation needs to be seen as integral to the ongoing development of peer support.

Finally, the rest of the success factors emphasised equalising, empowering relationships:

## Empowering leadership and management

Successful peer run initiatives have leaders, who are trusted, know how to translate their values into actions that permeate the essence and operation of the organization and have the business skills to run an organization. They are transparent and include staff and members in decision making. In mainstream organisations the higher level leaders are often not peers. Successful leaders in this context recognise peer support as different from mainstream service delivery and make the adjustments needed for the initiative or the worker to be empowered to express the values of peer support.

## Empowerment of members and clients

Empowerment of members is a core value of peer run initiatives and this can be achieved in many ways, such as easy access or self-referral to the initiative, the freedom to choose the supports they want, the ability to give as well as receive support, involvement in decisions about the initiative, an atmosphere that offers validation and hope and programs that offer genuine opportunities for recovery, personal development and social inclusion. In mainstream settings it means that the client chooses the supports they want in collaboration with the peer worker and that the peer workers are never involved in any coercive practices such as compulsory goal setting or medication drops to clients under forced treatment.

## Equitable partnerships with mainstream services and community organizations

Successful peer run initiatives create equitable partnerships with mainstream services and agencies. They do not exist in silos. They have political understanding and know the rules of engagement and how to promote peer run initiatives to the system. If they meet resistance, then they deal with it assertively rather than with ongoing anger or withdrawal. Likewise the peer workers and initiatives inside mainstream services know the best ways to work cooperatively and advance their agenda inside the system. Successful peer support initiatives in both mainstream and independent settings, network within their communities and agencies around them. This opens up contact between the local communities and their members or clients.

## THE INTERNATIONAL PICTURE

How does Canada compare to other countries and jurisdictions in at the levels of legislation policy and funding? We sought information on the international scene through literature searches and connecting with the member groups of the European Network of Users and Survivors of Psychiatry and the International Initiative for Mental Health Leadership.

### *Legislation, Policy and Funding*

We could find no legislation anywhere that had a direct impact on peer run initiatives, except in France. Relatively few countries and jurisdictions have developed explicit policy on peer support. The following countries and states show that the existence of policy is important for the development of peer run initiatives. But policy is never enough, particularly in decentralized health systems. Policy needs to be championed by individuals and agencies that are close to the decision makers at the levels of planning and funding, and in the large provider organizations.

Many peer run initiatives receive government funding, though initially in the movement there was resistance to this due to mistrust, and to fears of loss of independence (Van Tosh, & del Vecchio, 2000).

All countries and jurisdictions have unique mental health funding structures in terms of central control, devolvement, taxpayer funding or private funding, and the diversity of funding agencies or sources. These all have a unique influence on the way peer run initiatives develop in each jurisdiction. Despite this, there are many common themes between jurisdictions on the funding of peer initiatives, suggesting that more basic forces than specific structural ones are at work; these could include stigma and discrimination within the system, the relative lack of influence of peer support providers compared to clinical providers, and a continuing over-reliance on expensive clinical services 'at the bottom of the cliff'.

Very few countries or jurisdictions have a definition or description of the types of responses provided by peer-run initiatives, so contracts are often ill-defined or inappropriately modelled on traditional mental health services.

In addition, funders generally do not have guidelines on the quantity of peer run initiatives needed and peer run initiatives are always very poorly funded as a percentage of overall mental health funding. For instance, in New Zealand peer run initiatives make up 0.5% to 1.0% of the total mental health budget (Mental Health Commission [New Zealand], 2005). They are also poorly funded individually and therefore rely heavily on volunteers (Brown et al., 2007, Scottish Executive, 2007).

In some countries and jurisdictions there have been calls for peer run initiatives to be allocated a percentage of the total mental health budget, usually in the region of five to ten percent. (Campbell & Leaver, 2003; Centre for Research and Education in Human Services, 2004).

## France

France has undergone major transformation in its mental health system over a number of years, with the recent development of a network of community mental health agencies. In the early 2000s three national organisations including a consumer/survivor and family organisation lobbied the French government to ensure equal opportunities and citizenship rights for people with mental health problems. This resulted in the passing of *Law No 2005-102* in February 2005, which enabled the formation of over 300 self-help groups in France within the following three years. The French government funds these self-help groups at a total of €20,000,000 per year with an average of €75,000 going to each agency.

## New Zealand

New Zealand's current mental health strategy (Ministry of Health, 2005) mentions peer support services as part of a broader range of services. New Zealand also has a service user workforce development strategy (Mental Health Commission [New Zealand], 2005). There is not much evidence that the peer related actions in these two strategies are being implemented. The growth of peer run initiatives in New Zealand is being driven by district level funders rather than policy.

New Zealand's Blueprint for Mental Health Services is the only government document that has quantified the services needed to implement the mental health strategy, including peer support and advisory services (Mental Health Commission [New Zealand], 1998). The Blueprint states that consumer advisory services and consumer run initiatives are to be funded at four full time equivalent positions per 100,000 population. Peer run initiatives have recently been added as an optional service to New Zealand's National Service Specifications, which are the Ministry of Health's list of services that are eligible for funding.

## Queensland, Australia

The overarching mental health policy documents in Australia do not mention peer run initiatives. There are very few peer run initiatives there. Queensland is the only state in Australia that mentions peer run initiatives in its state wide mental health plan. Queensland has recently set a funding benchmark for peer run initiatives at three places for consumers per 100,000 population (Queensland Government, 2008).

## Scotland

Scotland's latest mental health policy document states that a pilot training program and employment for peer support workers would be in place by 2008 (Scottish Executive, 2006). Six boards have implemented the pilot; most employed peer support workers directly and one contracted them through a peer run organization. A recent report of the pilot published by the Scottish government has evaluated the pilot as a success and recommended the roll out of peer support services across Scotland (McLean, Biggs, Whitehead, Pratt, & Maxwell, 2009). The Scottish Recovery Network has been instrumental in promoting peer run initiatives, as well as the value of recovery.

## United States, National level

In the U.S. the President's New Freedom Commission on Mental Health stated in its second goal that 'consumers will play a significant role in shifting the current system to a recovery-oriented one by participating in planning, evaluation, research, training, and service delivery' (New

Freedom Commission, 2003). Peer run initiatives were already established in many states before the Commission, and they have continued to grow since then.

In 2007, the US Centres 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 (Eiken & Campbell, 2008). National level agencies, including the National Association of State Mental Health Program Directors and the Office of Technical Assistance (formally National Technical Assistance Center) have been active in promoting peer run initiatives. This support is also available at the state level through the states' Offices of Consumer Affairs.

### United States, Georgia

In the state of Georgia peer support services have been Medicaid reimbursable under Georgia's Rehabilitation Option since around 2001. Medicaid has documented the definition and description of the service, the staffing requirements, referral sources and the target population. The impetus for including peer support as a reimbursable service came from the Surgeon General's report in 1999, consumer/survivor lobbying and high level support for the development of peer support services. The reliable funding stream enables people to both train and get work as peer support specialists. These positions are paid a living wage but some of the people who lobbied for the introduction of peer support specialists in Georgia now regret that they did not push for a higher rate of pay when the program began.

### United States, New Hampshire

The New Hampshire Department of Health and Human Services has two 'rules' relating to peer support (available online from [www.dhhs.state.nh.us](http://www.dhhs.state.nh.us)). One rule covers the major features of peer support services such as purpose, supports and services, responsibilities, fiscal management, board issues, staff development, and quality improvement. The other rule covers the rights of people receiving peer support services, such as notice of rights, fundamental rights, personal rights, suspension of membership, member and participant rules, and grievance procedures.

In summary, funded peer support integral to the mental health system is in its infancy not just in Canada but worldwide. In most countries progress is fragile but this stage is also full of opportunities to shape the future of peer support initiatives.

## MAKING THE CASE

We finish with a picture of mental health problems in Canada as well with a summary of the evidence and consumer/survivor views on the responses available to them to help in recovery.

### *Mental health problems in Canada*

Over ten percent of Canadians experience mood conditions (4.9%), anxiety conditions (4.7%), or substance dependence (3.0%), in a 12 months period according to a 2002 survey (Statistics Canada, 2002). The prevalence of these conditions decreased over the lifespan:

- 15-24 18%
- 25-44 12%
- 45-64 8%
- 65+ 3%

According to the survey, 37% percent of these people sought professional help for their condition or dependency from (in order of frequency); a family doctor, psychiatrist, social worker, psychologist, or a religious or spiritual leader.

A much smaller percentage used other forms of help:

- 5% used self-help groups
- 2% used internet support groups
- 2% used telephone hotlines

Although young people were more affected, they were the least likely age group to seek help.

In this survey about 21% of people with mood conditions, anxiety conditions and substance dependence believed their needs were unmet. The percentage with unmet needs reduced slightly over the lifespan.

Of all the Canadians surveyed:

- 4.6% responded that they were dissatisfied or very dissatisfied with life; and,
- 6.9% rated themselves as having fair or poor mental health.

In another survey 2.2 percent of Canadians reported having a psychological disability which limited the amount of kinds of activities they could do, due to a psychological, emotional, psychiatric condition or substance dependence. Psychological disability affected females more (2.5%) than males (2%) (Statistics Canada, 2001).

The findings from other similar countries are consistent with Canada (Te Rau Hinengaro 2006; U.S. Department of Health and Human Services, 1999). All these studies show similar prevalence for 'mental disorders' as defined by the Diagnostic and Statistical Manual:

- Around half of the population will experience a mental disorder at some time in their lives;

- About 20% of the population experiences mental disorder in any 12 month period;
- About 10% of people experience significant functional impairment in any 12 month period;
- Around 2 to 3% have what is described as "severe and persistent mental illness"; and,
- Prevalence is higher in young people and people from low socio-economic groups.

According to the World Health Organization, five of the ten leading causes of disability worldwide are related to mental disorders. It predicts that depression will become the second leading cause of disability by 2020 (Statistics Canada, 2002).

### *Social determinants and consequences of mental health problems*

Current evidence has identified the following risk groups and factors in the social determinants mental health problems:

- Youth – adolescents and young adults;
- Trauma – abuse and neglect in early life, war, physical or sexual assault;
- Inequality – particularly relative poverty, lack of hierarchical status and racism;
- Deculturation – particularly for indigenous people; and,
- Fragmented communities, extreme individualism and the loss of shared values.

(Durie, 2004 & 2006; Marmot, 2005; New Economics Foundation, 2004; Wilkinson, 2005)

The social and economic consequences of mental health problems include:

- poorer relationships;
- poorer productivity;
- poorer physical health; and,
- a shorter lifespan, by up to 25 years.

(Keyes, 2007; Government Office for Science, 2008; Marmot, 2005; Wilkinson, 2005; World Health Organization 2008)

These consequences are particularly severe for people with the most serious mental health problems, who are disproportionately isolated, single, unemployed and physically unwell. They are also more likely to be traumatized or re-traumatized by experiences inside the mental health system such as inadequate responses to personal distress as well as compulsory treatment, detention in locked facilities, seclusion and restraint as well as.

These consequences come at a high cost to the whole of society. For instance:

- According to Health Canada mental disorders were the third highest healthcare cost in Canada in 1998;
- The World Health Organization has estimated that mental health problems account for up to 23% of lost years of healthy life in developed countries (Royal College of Psychiatrists, 2008);
- It is estimated that mental health problems cost every household in Europe more than €2,200 (CAD 3,000) per annum (McDaid, Zechmeister, Kilian, Medeiros, Knapp et al., 2008); and,
- The costs of 'schizophrenia' across all government budgets, was estimated to be €10.4b (CAD 14.6b) in England in 2005. (McDaid et al., 2008, p. 1).

In summary, mental health problems are common. Young people, people with trauma histories and people from disadvantaged backgrounds tend to be more vulnerable. Only a minority seek help from professionals or peers. Mental health problems are usually personally distressing, reduce people's life chances and have very high social and economic costs.

### *Responses to mental health problems*

The range and quality of society's responses to mental health problems has historically been hampered by stigma and discrimination, human rights breaches, social exclusion and powerful interest groups. Some people have remained trapped in mental health services while many in need have not sought or received help from them. However, international policy trends (Compagni, Adams, & Daniels, 2006) are signalling a new direction – for recovery focused mental health services that are:

- part of a whole of government approach;
- integrated with other sectors and with mental health promotion efforts;
- set up so service users can determine the services, supports and resources they use; and,
- based on sound evidence.

This policy and current thinking all suggests that a much broader range of services is needed for people with mental health problems. (California Institute for Mental Health, 2006; The Future Vision Coalition, 2008; Mental Health Advocacy Coalition, 2008; Sainsbury Centre for Mental Health, 2005). Peer support is commonly described as one of the broader range of services that need to be accessible to all (Ministry of Health, 2005; New Freedom Commission, 2006).

The dominant response, however, to people with a diagnosis of mental illness in primary health and mainstream mental health service is still bio-medical. While people can be almost guaranteed access to medication, other therapeutic and support services are much harder to come by. For instance, an extremely small percentage of people have access to peer support in any country. It is often difficult for people to access talking therapies and support for housing, employment and education. This often translates into negative experiences of services. In fact, 41% of people responded that their experience of services was negative according to a survey of the Standing Committee on Social Affairs, Science and Technology when preparing its report 'Out of the Shadows at Last' (2006).

What do the people who use services think contributes to their recovery? An analysis of several British surveys (Read, 2009) concluded that psychiatric drugs, while seen as helpful or very helpful by up to two thirds of people, usually rated lower than support from family and friends, talking therapies and occupational therapies.

A New Zealand study on 40 people's experiences of recovery, (Lapsley, Nikora, & Black, 2002) showed the most successful strategies for recovery were learning about mental health, experiencing support from others, undergoing a process of emotional growth, adopting healthy attitudes and personal practices, and undertaking different types of therapy (including psychiatric drugs for some).

In an Australian study on recovery from schizophrenia of 60 people with this diagnosis (Tooth, Kalyanansundaram, & Glover, 1997) the most important theme in their recovery was themselves – their optimism, determination, self-management and self-acceptance.

In the report, *Mental Health Recovery: What Helps and What Hinders*, the authors state that “under the dominant medical model there is an over-dependence on medication as the primary approach or single tool” (Onken, Dumont, Ridgway, Dornan, & Ralph, 2002). Of all the major domains of recovery, which included basic material resources, personhood and hope, self-determination and choices, community connections and formal services, formal services were viewed as a much more hindering than any other.

These studies are typical. They show that:

- Deficits approaches, so common in formal services, are often a hindrance to recovery;
- The dominance of bio-medical responses persists despite their limitations; and,
- The most powerful themes in recovery are people’s own personal resourcefulness and relationships or roles that reinforce their belief in themselves.

The development of personal resourcefulness and self-belief are the foundation of peer support.

### *Evidence base for peer support*

Given survivor/consumer news about recovery, it’s not surprising that there is an emerging evidence base for the effectiveness of peer run initiatives, particularly peer support, which includes:

- Reduction in hospitalization;
- Reduction in ‘symptom’ distress;
- Improvements in social support; and,
- Improvements in quality of life.

(Canadian Mental Health Association, Ontario Division et al., 2005)

### *Summary*

In summary, there is widespread acknowledgement that today’s bio-medically dominated, deficits based mental health services are at best only part of the solution, and at worst may be damaging to recovery. We now know what helps people to recover. While many acknowledge there is a role for mainstream services and medical treatments, people are virtually unanimous about the paramount importance of personal resourcefulness, personal support and self-belief in their recovery. Peer support initiatives are probably the best evidence based approach to foster these.

## CONCLUSIONS

This report has provided a high level description of peer support in Canada and in other countries. This has shown that peer support is in its infancy in every country, full of promise but woefully under-recognised 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.

We have also made the case for peer support through assembling the evidence on the increasing prevalence of mental health problems, its high personal, social and economic costs, the limitations of the dominant biomedical responses, and people's views on what assists their recovery. All this evidence points to a mental health system that often doesn't help people recover and is coming under more strain as people stay in it longer than they should and population demand for services increases. The solution has to be a broader range of cost-effective responses that get to the nub of recovery – increased personal resourcefulness, self-belief, and hope. Peer support directly assists people to develop these attributes.

In someone else's words,

No single treatment model should dominate the policy environment...it is people with mental illness themselves who should be the final arbiters of the services that are made available...People and families living with mental illness are turning more and more to self help and peer support as a substitute or adjunct to hospital, community and professional services...A new and tenuous addition to the mental health and addiction system, the future of self help and peer support programs remains insecure.

These words come straight from 'Out of the Shadows at Last', the Senate Committee report that was the catalyst for the formation of the Mental Health Commission of Canada.

Our recommendations will ensure that the 'new and tenuous addition to the mental health and addiction system' becomes well established and secure. The Mental Health Commission of Canada needs to lead the sustainable development of peer support across Canada. It is difficult to think of any other single course of action it could take to optimize the chances of recovery for the mental health sector's most important stakeholders.

## RECOMMENDATIONS

“If you want to know what’s best for me, ask. I know what’s best for me.”

“Health Ministers need to be proactive about mental health rather than reactive about mental illness”

“We feel the mental Health Commission of Canada is [focusing on] mental illness and NOT on mental health”

“If peer support is seen as best practice by the Mental Health Commission of Canada then fund it as such”

“Do not use us as window dressing”

“Please don’t put the report on the shelf”

Respondents were very clear about the contribution they wanted from the Mental Health Commission to the development of peer support. The Mental Health Commission of Canada, with the leadership of consumers and survivors, including their national and provincial organizations, needs to create the building blocks for the incremental development of peer support initiatives. These need to be specific but flexible enough to be adapted to all provinces and territories in Canada, and to its diverse communities including Aboriginal, Francophone and disabled people.

We offer these recommendations below in the hope that this ‘new and tenuous addition to the mental health and addiction system’ becomes well established and secure. The Mental Health Commission of Canada needs to lead the sustainable development of peer support across Canada with the following actions.

1. Develop guidelines on the **definition** of peer support as a core component of mental health systems, which include:
  - definitions and types of peer support
  - peer support values
  - peer support standards
  - peer support performance and outcome measures
2. Develop guidelines for the **funding** of peer support which include:
  - a target and deadline for the percentage of mental health funding to go to peer support
  - a recommended level of funding for peer support initiative, and for staff, that is equitable with other mental health services
  - recommended funding of a mix of independent and mainstream peer support initiatives
  - templates for contract specifications and accountability requirements
  - recommended funding of development infrastructures for peer support

3. Create guidelines to support the **development** of peer support, which include:
  - templates for peer workforce roles and competencies
  - curricula for peer support workers leading to a formal qualification
  - options for affordable training opportunities
  - education guidelines for peer support and its values for the non-peer workforce
  - consumer/survivor led evaluation of peer support
  - support for consumer/survivor led organizational development, training and education for mainstream mental health services, funders and other key stakeholders on the roles, values, processes and structures of peer support
  
4. Use this report and/or the guidelines developed
  - to highlight the need for peer support to be a core service available to everyone, in the Commission's strategic framework for reformed mental health services across Canada
  - to promote peer support and to educate regional governments, health authorities and service providers about it until the Commission closes in 2017, through conferences, publications and other forms of communication
  - to develop a national resource centre for peer support, where all the information is provided in both French and English and is accessible to disabled people.

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## APPENDICES

### Appendix 1: Overview of the Mental Health Commission of Canada and the “*Making the Case for Peer Support*” project

The Mental Health Commission of Canada (MHCC) was established by the federal government in 2007 to focus national attention on mental health issues and to improve the health and social outcomes of people living with mental illness.

In 2009, the Commission launched the *Making the Case for Peer Support* project in order to better understand in order to share the value of mental health peer support with a wide range of stakeholders, as well as provide guidance on how to strengthen peer support in communities throughout Canada.

The findings of the *Making the Case for Peer Support* project will be available to inform the Commission’s national mental health strategy and other initiatives. A database of peer support initiatives across Canada is in development and may become part of the MHCC Knowledge Exchange Centre. This literature review supports the findings from interviews and focus groups with consumers, advocates, policy makers, mental health service providers, government funders and other stakeholders.

Together, these sources of information will be available in a final project report. Including descriptions of peer support activities across Canada and internationally, the project report includes recommendations on successful strategies to fully include peer support into provincial/territorial systems and a national mental health framework.

*Making the Case for Peer Support* is led by a project committee, who reports to the Service Systems Advisory Committee of the MHCC. The project committee consists of people living with mental health problems, illnesses and/or experiences of the mental health system, from across Canada, service providers, and researchers. Over the life of the projects, members have included:

Loïse Forest (Co-Lead)

Laurie Hall (Co-Lead)

Andy Cox

Joan Edwards Karmazyn

Tanya Shute

Susan Lynn Hardie, MHCC Associate Research Officer, with this project until October 2009

Gail MacKean, MHCC Senior Research Officer, with this project as of November 2009

Steve Lurie, MHCC Service System Advisory Committee Chair

Carol Adair, Research Consultant, MHCC

Janice Popp, MHCC Senior Policy and Research Officer

Mary Bartram, MHCC Senior Advisor, Government Relations

Working in close collaboration with the project committee and the MHCC, the project was conducted by an international and bilingual consultancy team of advocates with direct experience of mental illness, madness and the mental health system.

APPENDIX 2:



Questionnaire

**MENTAL HEALTH COMMISSION OF CANADA**

**MAKING THE CASE FOR PEER  
SUPPORT**

**PROJECT INFORMATION  
&  
CONSULTATION QUESTIONNAIRE  
FOR ELECTRONIC WRITTEN SUBMISSIONS**

**2009**

# PLEASE READ THIS FIRST

## Consultation questionnaire

We are inviting all people in Canada who use mental health peer support, deliver peer support, or have some relationship with a peer support initiative to fill in this questionnaire.

The information you provide will be summarized in the report to MHCC and comments will not be attributed to any individual or group.

Your answers can be as short or as long as you like. There's no limit to the space for typing under each question

You do not have to answer as a representative of any organization or initiative; personal views are just as welcome.

This is a long questionnaire. You may not want to answer all the questions. This is OK. Just move onto the next question.

The consultants and staff at the Mental Health Commission of Canada (MHCC) who read your comments are bound by confidentiality. We will do our best to ensure any comments of yours that we use in the report will not be traceable to you or your organization. After the report is completed the questionnaires and any recordings of focus groups or interviews will be placed in a locked environment at the MHCC offices in Calgary. The data (without any identifying information) may be made available to other researchers if they comply with security and confidentiality requirements.

**Please email written responses to Mary O'Hagan [mary@maryohagan.com](mailto:mary@maryohagan.com)  
no later than 13 November 2009.**

## Database questionnaire

For those of you who run peer support initiatives we also have a database questionnaire asking you for details about your initiative so we can develop a comprehensive peer support database.

Download it from

<http://www.mentalhealthcommission.ca/English/Pages/servicesystemsinformation.aspx>

## Pass it on

Pass this file or the website link on to others you know who might be interested in taking part in the project.

## More information on project

For more information about the project, and the consultation questionnaire, please read on.

# ABOUT THE PROJECT

The Mental Health Commission of Canada (MHCC) is funding this project to inform provincial policy makers, funders and other stakeholders of the value of mental health peer support, and to give them guidance on how to strengthen peer support in their respective provinces. A group of international consultants with lived experience are gathering the information needed. The report will describe peer support activities across Canada and make recommendations on the integration of peer support into provincial and territorial mental health systems. The findings will also inform the MHCC Mental Health Strategy for Canada and other MHCC initiatives. A database of peer support initiatives across Canada will also be developed which may become part of the MHCC Knowledge Exchange Centre.

The investigation will consider the factors that influence the situation of peer support across Canada. Factors internal to peer support initiatives include values, benefits, governance, management, delivery and membership. External factors include legislation, policy, funding as well as mental health cultures and attitudes. The consultants are seeking contact with peer support initiatives throughout Canada.

## What is peer support?

*We are using a broad definition of peer support so we can discover the full diversity of peer support initiatives within Canada.*

*We define **peer support** as any organised support provided by and for people with mental health problems. Peer support is sometimes known as self-help, mutual aid, co-counselling or mutual support.*

***Consumers/survivors** are people with lived experience of mental health problems*

*We **define peer support initiatives** as the programs, networks, agencies or services that provide peer support. They can be:*

- *Funded OR unfunded.*
- *Use volunteers OR paid staff OR both.*
- *Operate out of psychiatric consumer/survivor run organisations OR other agencies.*
- *Delivered by a group of peers OR by an individual peer in a team of professionals.*
- *A primary activity of the initiative OR a secondary benefit eg in a consumer/survivor business.*

***Please get in touch if you think your initiative fits this definition.  
We want to hear your views!***

## How we're finding the information

The information for this project will be gathered through:

- Focus groups, interviews and written submissions from across Canada.
- International and Canadian literature searches.
- Data collection on the characteristics of peer support initiatives in Canada.

### About the MHCC

The Mental Health Commission of Canada was established by the federal government in 2007 to focus national attention on mental health issues and to improve the health and social outcomes of people living with mental illness. It is based in Calgary, Alberta.

The MHCC has acknowledged the importance and effectiveness of peer support in a reformed mental health sector in its draft framework of a mental health strategy for Canada.

### About the project committee

The Mental Health Peer Support Project Committee is supported in its work by the MHCC Service System Advisory Committee. The Project Committee (PC) developed the vision for this project, and is working collaboratively with the consulting group on the project. The PC is made up of people living with mental health problems or illnesses from across Canada, and their allies. The members include: Loise Forest (Co-Lead), Laurie Hall (Co-Lead), Carol Adair, Mary Bartram, Andy Cox, Joan Edwards-Karmazyn, Susan Lynn Hardie (MHCC Associate Research Officer), Joe Leger, Steve Lurie, Tanya Shute.

## About the consultants

**Mary O'Hagan** initiated the survivor movement in New Zealand in the late 1980s, was a full time New Zealand Mental Health Commissioner from 2000-2007, and is now an international consultant.

**Robyn Priest**, an Australian living in New Zealand who has been involved in the user/survivor movement in both countries and has held management roles in mental health agencies.

**Celine Cyr**, a service provider with lived experience from Quebec who is involved in the user movement there and has trained users and professionals for the last 15 years.

**Heather McKee** is a survivor from Ontario, active in the movement there and across Canada, who works in knowledge transfer, research, policy and evaluation activities.

### Timeline

**Focus groups and interviews.**

Late June/early July & all of September 2009

**Deadline for written responses.**

13 November 2009

**Completion of draft report.**

21 December 2009

**Consultation on draft report.**

### For more information

**Visit the website**

<http://www.mentalhealthcommission.ca/English/Pages/servicesystemsinformation.aspx>

for:

- The consultation questionnaire
- The database questionnaire
- The schedule of the consultation visits
- Updates on the project
- Email inquiries and feedback form

11 January to 5 February 2010

**Final report MHCC.**  
28 February 2010

**Or contact Robyn Priest**  
416 564 3964  
robpriest13@gmail.com

## DEMOGRAPHIC INFORMATION FORM

We need this information to check that we are consulting with a wide enough cross-section of people in Canada. We will detach this sheet from your answers so we cannot identify you. Please do not put your name on this sheet.

### Age group (please mark with an X)

19 or under	20-30	30-40	40-50	50-60	60-70	71 or over
-------------	-------	-------	-------	-------	-------	------------

### Gender (please mark with an X)

Male	Female	Transgendered
------	--------	---------------

### Ethnicity (please with an X – you can mark more than one)

Aboriginal	Caucasian	Asian	Middle Eastern	African	Latin American	Other (please state)
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### Province or territory (please mark the province you live in now with an X)

AB	BC	MB	NB	NL	NT	NS	NU	ON	PE	QC	SK	YT
----	----	----	----	----	----	----	----	----	----	----	----	----

### Role/s (please mark box with an X – you can mark more than one)

Peer support member/ 'client'		Provincial/territorial official	
Peer support paid staff		Planner/funder	
Peer support volunteer		Mental health service provider	
Peer support management		Academic/ researcher	

Peer support board		Consumer/survivor/user	
Other (please state)			

## THE QUESTIONS

### Definitions

1. In your own words, how do you define peer support?

2. What are the different types of peer support initiatives that you know of? (please mark box/es with an X)

Run by consumer/survivor run organisations	
Run by non consumer/survivor run organisations	
Provided by one or two peer workers in a mental health team	
Provided by a team of peers	
Provided by volunteers	
Provided by paid staff	
Unfunded	
Funded	
Other (please state):	

3. In your own words, what is your understanding of recovery in mental health?

### Values

4. What are the values that underlie peer support?

5. How are peer support values similar to or different from mental health system values?

6. What makes it easy or difficult to peer support values into action in consumer/survivor run services?

7. What makes it easy or difficult to put peer support values into action in organizations that are NOT consumer/survivor run? (for instance mental health services or family organizations)?

## Delivery

8. What range of supports, services and resources do you know of, that are delivered in the name of peer support, mutual support, self-help, co-counselling or mutual aid? Please mark box/es with an X

Self-help groups	
One-to-one support eg co-counselling, harm reduction	
Support in housing	
Support in education	
Support in employment	
Support in crisis eg crisis house, emergency room	
Social and recreation	
Material support eg food, clothing, internet	
Traditional healing	
Artistic and cultural activities	
System navigation	
Case management	
Small business	

Systemic and individual advocacy	
Education and training for consumers/survivors	
Paper and online information development and distribution	
Research and evaluation	
Others (please state)	

**9. What other supports, services and opportunities could be offered by peer support initiatives; within consumer run orgs and in mainstream orgs with peer support initiatives?**

**10. Are you able to estimate the proportion of consumer/survivors in your area, province or territory that have access to peer support? Why do you think access is as low or high as it is?**

## Benefits

**11. What have been the benefits of being involved in peer support for you, or others you know?**

**12. Have you, or other people you know, had negative experiences as a result of being involved in peer support?**

**13. How important has peer support been in your recovery, or the recovery of others you know, compared to the importance of formal or mainstream mental health services?**

## Members/ 'Clients'

**14. What are the opportunities and barriers for members or 'clients' to participate in delivery and decision making in the different types of peer support initiatives you know of?**

## Volunteers

15. Assuming that peer run initiatives can afford to hire paid staff, in what circumstances is it better to use volunteers instead of paid staff?

16. What are the opportunities and barriers to using volunteers for peer support? *(for instance, recruitment, retention, reimbursement for expenses, workplace accommodations, performance problems, workplace conflict, training)*

## Staff

17. Assuming that peer run initiatives can afford to hire paid staff, in what circumstances is it better to use paid staff than to use volunteers?

18. What are the opportunities and barriers to using paid staff in peer run initiatives? *(for instance, recruitment, retention, pay, benefit abatement, workplace accommodations, performance problems, workplace conflict, training)*

## Management

19. What successes or challenges do peer support initiatives run by consumer/survivor organizations have in their management? *(for instance planning, budget control, management of staff relationship with membership improving the service, relationships with funder/s)*

20. What successes or challenges do support initiatives in organizations that are NOT run by consumers/survivors have in getting support from management?

## Governance

21. How do peer support initiatives run by consumer/survivor organizations perform in their governance roles? *(for instance strategic planning, financial control, risk management, employment of the CEO)*

22. How much influence do peer support initiatives have over the boards in organisations that are NOT run by consumers/survivors?

## Organizational structure and culture

23. What types of organizational structures work well for peer support and why?

24. What types of organizational structures do NOT work well for peer support and why?

25. Have the peer support initiatives that you know of, that are NOT run by consumer/survivor organisations, been able to change the attitudes of the people in the organizations they work for?

## Marginalised and Minority Consumer/Survivors

26. What are the barriers and opportunities faced by the following groups when it comes to participating in and benefiting from peer support in your area, province or territory? *(for instance First Nations, Inuit, Metis, Francophone, ethnic minorities, gay, lesbian, bi and transgender, consumers/survivors in criminal justice system, young people, rural people)*

## Stakeholders

27. How successful are the relationships peer run initiatives run by consumer/survivor organizations have with other people and organizations? *(for instance provincial and territorial governments, policy agencies, planning & funding agencies, mental health service providers Consumer /survivor movement , family organizations, MHCC.)*

28. How successful are the relationships peer support initiatives that are NOT run by consumer/survivor organizations have with other people and organizations? *(for instance provincial and territorial governments, policy agencies, planning & funding agencies, mental health service providers Consumer /survivor movement , family organizations, MHCC.)*

## Planning and funding

29. How have the organisations that decide who gets the funding for mental health service delivery helped or hindered the development of peer support in your region or province? *(for instance the Regional Health Authorities in a lot of provinces or the Local Health Integration Networks in Ontario)*

30. Is the current level of funding for peer support initiatives in your region, province or territory sustainable or not, and why?

## Legislation and policy

31. How has the legislation in your territory or province helped or hindered the development of peer support? *(for instance health and mental health legislation)*

32. How have mental health policies, standards or guidelines in your province or territory helped or hindered the development of peer support?

## Success

33. What are the most successful peer support initiatives you know of?

34. What enables them to do such a good job?

**35. How could the opportunities for creative and innovative peer support developments be maximised?**

## Evaluation

**36. What are the opportunities and barriers to consumer/survivor led evaluation of peer run initiatives in your area, province or territory?**

## Your recommendations

**37. What would a strong and equitable peer support presence in the mental health system look like to you?**

**38. If you have not already said so, how would you recommend the following stakeholders show commitment to the development of peer support?**

- Provincial or territorial government
- Policy agencies
- Planning & funding agencies
- Mental health service providers
- Other service providers eg family doctors, social services
- Consumer /survivor movement
- Families
- Mental Health Commission of Canada

**39. If you have not already said so, how would you recommend the following features of peer support initiatives be better defined, changed or developed:**

- Sticking to the values
- Governance performance
- Staff work conditions
- Organisation structures
- Management performance
- Volunteers work conditions

- Evaluation & promotion of benefits
- Delivery – more options to more people
- Membership diversity & participation

40. Do you have any other recommendations?

## Key points

41. To summarise, what are the THREE key points you have made that you would most like to see reflected in the report?

## Information

42. Do you have or know of any paper or electronic information on peer support that we may not know about. If so, can you provide details of the information and where we can get it from?

# TO FINISH...

## Database questionnaire

A reminder for those of you who run peer support initiatives: We also have a database questionnaire asking you for details about your initiative. Download it from <http://www.mentalhealthcommission.ca/English/Pages/ServiceSystem.aspx>

## Copies of the report

Please mark boxes with an X

Do you want a confidential copy of the draft report to comment on?	<input type="checkbox"/>
Do you want a copy of the final report?	<input type="checkbox"/>
If so, please provide us with your email address:	

## Email this questionnaire

**Please email this questionnaire to Mary O'Hagan [mary@maryohagan.com](mailto:mary@maryohagan.com)  
no later than 13 November 2009.**

**Thank you for your participation.  
We really appreciate it.**

## APPENDIX 3: Informed Consent Form

### MENTAL HEALTH COMMISSION OF CANADA MAKING THE CASE FOR PEER SUPPORT INFORMED CONSENT FORM

I give my consent for my comments to be written and recorded at this focus group or interview.

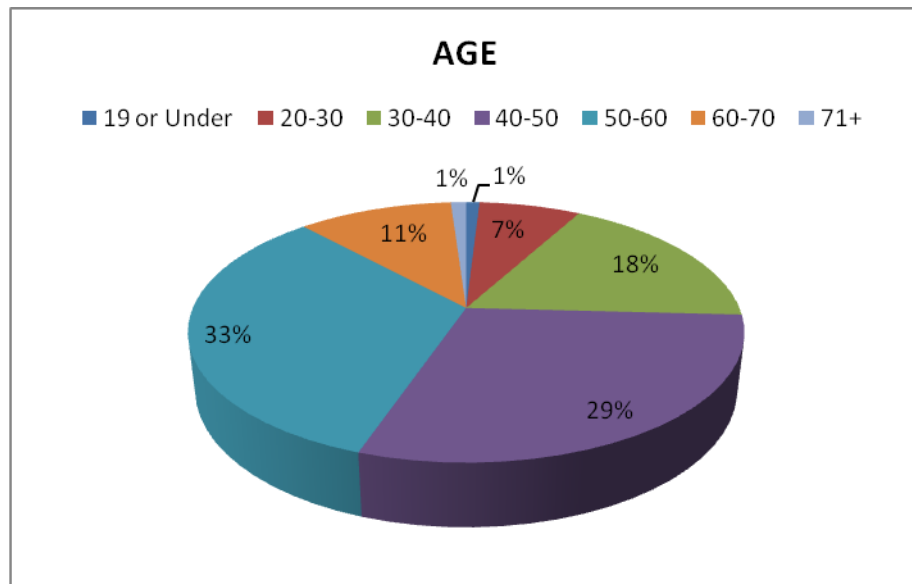
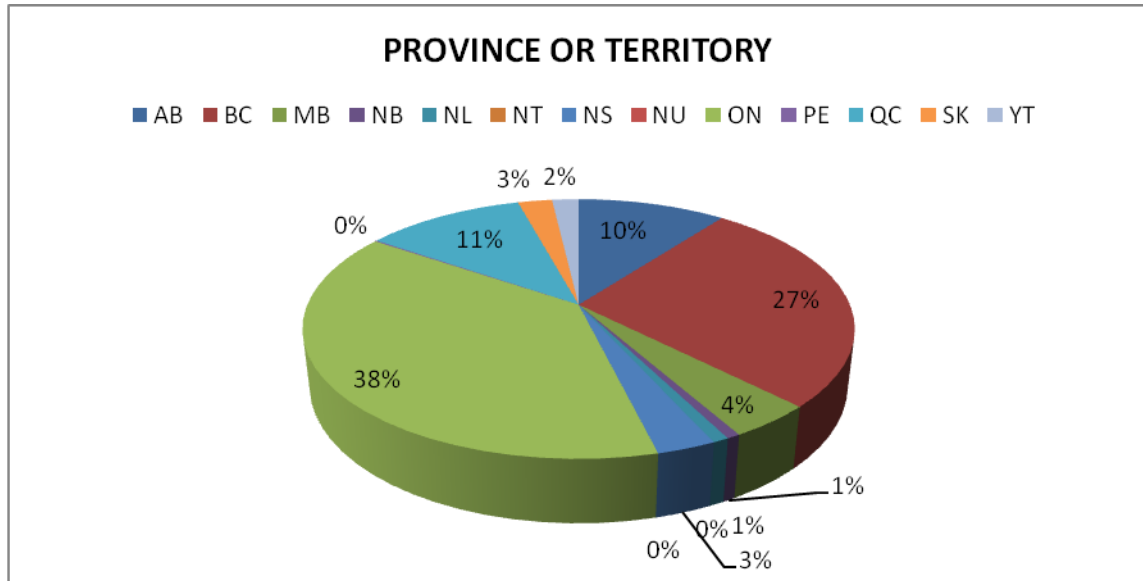
I understand:

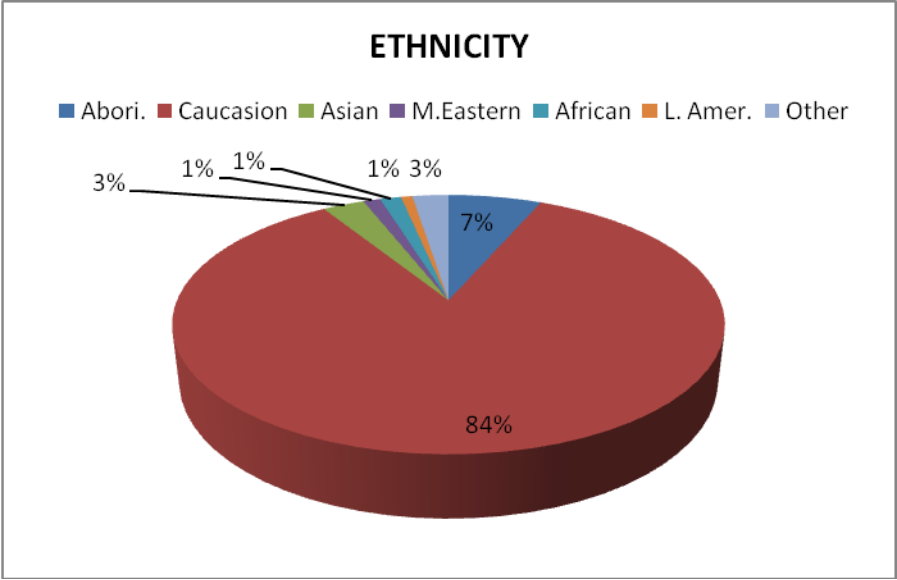
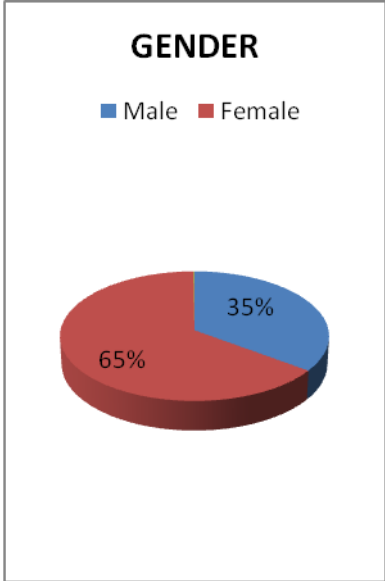
- The consultants and staff at the Mental Health Commission of Canada (MHCC) who see or hear my comments are bound by confidentiality.
- My comments may be used in the upcoming report on peer support in Canada for the MHCC, and the writers will do their best to ensure that all comments are conveyed accurately and are not traceable to me or my organization.
- The notes and recordings taken from this meeting will only be viewed or heard by the consultants on the project in their analysis and writing of the report.
- After the report is completed the notes and recordings will be placed in a locked environment at the MHCC offices in Calgary. The data (without any identifying information) may be made available to other researchers if they comply with security and confidentiality requirements.

<b>My name</b>	
<b>My signature</b>	
<b>Date</b>	
<b>Consultant signature</b>	

## APPENDIX 4: Respondents

### *Our respondents: Some demographic information*





## APPENDIX 5: Schedule of Consultations

### ENGLISH CONSULTATIONS

DAY & DATE	PLACE	TIME
Sunday 28 <sup>th</sup> June	Newfoundland & Labrador	6:30 pm – 9:30 pm (teleconference)
Monday 29 <sup>th</sup> June	Newfoundland & Labrador	TBA
Tuesday 30 <sup>th</sup> June	New Brunswick (both French & English groups)	1:30 to 4:30
Thursday 2 <sup>nd</sup> July	Prince Edward Island	TBA
Friday 3 <sup>rd</sup> July	Nova Scotia	10.00am – 1.00pm 1:30 to 4:30 pm
Monday 31 <sup>st</sup> August	Ottawa ON	10.00am – 1.00pm OR 1.30pm – 4.30pm
Tuesday 1 <sup>st</sup> September	Smiths Falls ON	9.30am – 12.30pm
Tuesday 1 <sup>st</sup> September	Lindsay ON	4.30pm – 7.30pm
Wednesday 2 <sup>nd</sup> September	Burlington ON	9.30am – 12.30pm
Wednesday 2 <sup>nd</sup> September	London ON	3.00pm – 6.00pm OR 6.00pm – 9.00pm
Thursday 3 <sup>rd</sup> September	Central Toronto ON	10.00am – 1.00pm
Thursday 3 <sup>rd</sup> September	Richmond Hill ON <b>Cancelled</b>	3.00pm – 5.30pm
Thursday 3 <sup>rd</sup> September	Toronto ON – business services	7.00pm – 10.00pm
Friday 4 <sup>th</sup> September	North Bay ON	10.00am – 1.00pm OR 1.30pm – 4.30pm 4.30pm – 6.30pm Aboriginal group
Tuesday 8 <sup>th</sup> September	Collingwood ON	10.00am – 1.00pm
Wednesday 9 <sup>th</sup> September	Toronto ON	2.30pm – 5.00pm
Friday 11 <sup>th</sup> September	Brantford ON	9.30am – 12.30pm
Friday 11 <sup>th</sup> September	Milton	2pm – 5pm
Tuesday 15 <sup>th</sup> September	Winnipeg MB	9.00am – 12 noon 12.30pm – 3.30pm
Wednesday 16 <sup>th</sup> September	Regina MB - First Nation and Metis	TBA
Thursday 17 <sup>th</sup> September	Edmonton AB	9.00am – 12.00 OR 1.00pm – 4.00pm
Monday 21 <sup>st</sup> September	Calgary AB	10.00am – 1.00pm OR 5.15pm – 8.15pm

DAY & DATE	PLACE	TIME
Thursday 24 <sup>th</sup> September	Kelowna BC	9.30am – 12.30pm
Thursday 24 <sup>th</sup> September	Penticton BC	2.00pm – 5.00pm
Friday 25 <sup>th</sup> September	Surrey BC	2.00pm – 5.00pm
Monday 28 <sup>th</sup> September	Courtenay BC	10.00am – 1.00pm
Monday 28 <sup>th</sup> September	Victoria BC	4.00pm – 7.00pm
Tuesday 29 <sup>th</sup> September	Richmond BC	9.30am – 12.30pm
Tuesday 29 <sup>th</sup> September	East Vancouver BC	6.30pm – 9.30pm
Wednesday 30 <sup>th</sup> September	Vancouver BC	9.30am – 12.30pm
Thursday 1 <sup>st</sup> October	Whitehorse BC	1.00pm – 4.00pm

**Thank you to the following people who helped organize the focus groups:**

Newfoundland and Labrador	Karan Ann Parsons – CHANNAL
New Brunswick	Eugene LeBlanc
Prince Edward Island	Roma Arsenauet – CMHA PEI
Nova Scotia	Andy Cox – IWK Health Centre
Ottawa	Denise Linnay - PSO
Smiths Falls	Halina Shannon – Mental Health Support Project
Lindsay	Paul Orchard - SPAN
Burlington	Debbie Jones – TEACH
London	Michelle Solomon - CONNECT
Central Toronto	Laurie Hall – AWAY Couriers
Toronto – cancelled session	Tanya Shute – Krasman Centre
Toronto Business Services	Laurie Hall – AWAY Couriers
North Bay	Sandra Barberi, Garry Fay - NEMHC
Collingwood	Kelly Potvin – Mental Health Consumer Project
Toronto	Greg Kim – CMHA Toronto
Brantford	Martha Rybiak - Brantford Vocational Training Association
Milton	Debbie Jones - TEACH
Winnipeg	Tara Brousseau - MDO
Regina	Dorothy Lloyd, Harry Desmonie – Eagle Moon
Edmonton	Komala Pepin – Alberta Health Service
Calgary	Eva Pettinato/Beth Henry - Opportunity Works, Debbie Wiebe - Peer Options CMHA Calgary
Kelowna	Charly Sinclair – CMHA Kelowna
Penticton	Sharon Evans Schizophrenia Society, Lisa Eccelstone - South Okanagan Adult Mental Health Services
Surrey	Peter Andres – Communitas, Debbie Sesula Fraser Health
Courtenay	Christopher Bates – Eureka Clubhouse
Victoria	Wendy Mishkin – BC Schizophrenia Society
Richmond	Barbara Bawlf – Richmond Mental Health Consumers & Friends Society
Vancouver	Ron Careton – West Coast mental Health Network
Whitehorse	Leslie Robert - Second Opinion Society

Ontario Patients Council telephone

Theresa Claxton – Ontario Patients Council  
focus group

## APPENDIX 6: Description of Literature Review

This is a review of academic, grey literature, policy reports and other material on peer support by people with lived experience of mental illness and the mental health system. The review includes materials developed by peer support groups and individual consumers such as newsletters, policy and project reports, personal accounts, annual reports, and other sources.

English-language literature has been collected from Canadian national and provincial, territorial, and regional mental health systems. The work of consumer/survivors from as American, British, Scottish, European Union, Australian, New Zealand, and the mental health systems of other countries for theoretical contributions to peer support as well as for comparison. The focus is on material dated from 2000 onwards, with the inclusion of some earlier articles which have been referenced as key documents. French language material from Canadian, French and other Francophone peer support networks has been reviewed, with some translations, by Céline Cyr.

Academic articles were acquired using several social science and medical databases including MedLine, PsycInfo, CINAL, PubMed, Google Scholar, and Health Business Full Text Elite. Search terms included variations on 'peer support', 'self help', 'consumer/user run services', 'alternative businesses', 'involvement', 'participation', 'mutual aid'. Various terms for people with mental illness and mental illness were used including 'mental patient', 'consumer', 'peer', 'peer specialist', 'consumer-provider', 'peer-provider', 'patient', 'user', 'mental disorder', 'mental health'.

Some materials come from the personal collections of the consulting and project team, based on their personal and professional involvement in the consumer/survivor/user movements in Canada, New Zealand, Australia, and internationally over the past decades.

The literature that was collected was reviewed for contribution to key conceptual themes developed by the MHCC Project Committee at the beginning of the process, with additional themes emerging from the literature. These include,

- Definitions, types and frameworks for peer support processes and models
- Values and philosophies of peer support and the consumer/survivor movement
- Evidence of effectiveness and outcomes
- Involvement of consumers from marginalized and minority communities
- Organizational development, including governance, management, employee, volunteer and member human resources
- Relationships with traditional mental health services and other stakeholders
- Areas for further research

The current literature review builds upon a previous one conducted for the Consumer/Survivor Initiatives Builder Project in 2008-2009. Funded by the Ontario Ministry of Health and Long Term Care, administered by the Ontario Federation of Community Mental Health and Addiction Programs, and led by a steering committee of consumer and peer support advocates, the goal of the Builder project was to review current issues of consumer-run agencies in groups and propose recommendations to ensure their continued relevancy in a reformed mental health

system. With some unique features, these consumer-run organizations had been funded through provincial government health funding since the early 1990s, and were run on the basis of the principles and processes of peer support (O'Hagan, McKee, & Priest, 2009).

In contrast to the Ontario project, the current review focuses on peer support and where it takes place in different organizational structures and locations. While the Ontario review was limited to a few models of consumer-run organizations, these are models which provide a broad range of services, including, but not limited to peer support.

#### *Limitations of the review*

While the aim of this review is to include much of the significant literature related to peer support for mental health issues, many gaps may exist. Articles were not selected using consensus processes, nor were they evaluated for quality or organized according to levels of evidence as might be done for a focused 'clinical' question. Instead recent materials from the search, supplemented from material collected by the consultants during their years in the movement, were used to produce a narrative summary of the topic, as was feasible for the broader subject matter to be covered in this report.

Despite these limitations, this review attempts to provide a comprehensive overview of many of essential themes found in the literature on the nature and meaning of peer support. As such, it is hoped that this will contribute to the overall goal of the project to increase understanding of the values, philosophy, models, outcomes and future opportunities of peer support and the important role peers play in the process of recovery. It provides a context and foundation for a focused systematic review or reviews on any peer-support-related specific question.

#### *A note about the terms used in the review*

We use a variety of terms to refer to individuals who experience mental illness, experiences of 'madness', and/or the mental health system. These terms include 'consumer', 'consumer/survivor', 'user', 'person with lived experience', 'people with mental illness or mental health problems'. We recognize and respect that different terms may have different meaning for readers. The use of specific terms is not meant to indicate a preference for some values or approaches over others, but to demonstrate respect for people's right to define and name their own experiences. Also, some terms are more commonly used in certain countries and regions (e.g., 'consumer/survivor' in Ontario, 'user' in England).

## APPENDIX 7: The Consultants

### **Céline Cyr**

Céline Cyr, both a “lived-experience” expert and knowledge expert, has been involved in the service user movement in Quebec for over 15 years. She is well connected to the agencies in her province, and has taught and trained service users and service providers from Abitibi to Outaouais and from Gaspésie to Montréal – her home base. Her “calling” to transfer knowledge has led Céline from Quebec to the rest of Canada. Peer support continues to enrich her life. She is presently completing her master’s thesis in social work.

### **Heather McKee**

Heather has been involved in the consumer/survivor movement at local, provincial and national levels for the past 15 years as a member of self-help groups, a board member and as a staff member of several Consumer/Survivor Initiatives. She managed several projects at the national office of the Canadian Mental Health Association and has worked in knowledge transfer, research, policy and evaluation activities. She has a M.A. in political science.

### **Mary O’Hagan**

Mary O’Hagan was a key initiator of the mental health service user movement in New Zealand in the late 1980s, and was the first chairperson of the World Network of Users and Survivors of Psychiatry between 1991 and 1995. She was one of three full-time Mental Health Commissioners in New Zealand, between 2000 and 2007. Mary is now an international consultant. She has written and spoken extensively on user and survivor perspectives in many countries, including on participatory action research. Mary has been an international leader in the development of the recovery approach, including peer run services; she has developed and managed peer run services. Mary has also written a book on peer run initiatives, based on her international Winston Churchill Fellowship. She wrote New Zealand’s first service user workforce development strategy in 2005.

### **Robyn Priest**

Robyn’s Post Graduate Diploma involved majoring in Social Research Methods and Public Policy and Health. She has been involved in the consumer movement within New Zealand and Australia. She also has many connections overseas within the movement. She has worked in peer/consumer dedicated positions for both Government organisations and not for profit organisations, as well as holding senior management positions in both types of organisations. She has recently been the Project Manager for a world first community based acute service alternative encompassing cultural, peer and clinical approaches working together in an equitable way. Robyn has a passion for sustainability and quality management within the sector and is committed to providing high quality reporting with realistic recommendations.