

**Listen to Me:
Experiences of Recovery for Mental Health Service Users**

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ABSTRACT

There is increasing awareness that mental health consumers may have important information for the development of services. In this qualitative study, I interviewed 10 consumers with the purpose of exploring in depth their experiences in interacting with service providers in the greater Vancouver area. Using constant comparative analysis, I found that the data suggested participants' experiences of recovery developed largely out of connecting with other consumers rather than with service providers. Current services were portrayed as primarily reliant on the use of psychiatric medication. Consumers pointed to numerous difficulties in seeking help, including a lack of treatment alternatives, stigma and isolation. They also presented a strong demand for services and policies that promote an individual sense of recovery and support their fundamental human rights. Mental health service providers need to critically reflect on their current practices and policies, and how they may negatively impact their clients' lives by failing to properly listen to their narratives, grievances, experiences and perceptions. This study suggests further inclusion of consumer's views and participation in services to foster collaborative, recovery-oriented practices.

TABLE OF CONTENTS

Abstract.....	ii
Table of Contents.....	iii
Acknowledgements.....	vi
Dedication.....	vii
CHAPTER I	INTRODUCTION.....1
1.1	Recovery, a personal story.....1
1.2	Purpose of study.....1
1.3	Terminology.....2
CHAPTER II	CONCEPTUAL FRAMEWORK.....4
2.1	Mental health policy development in Canada.....4
2.2	Deinstitutionalization.....4
2.3	The historical development of the recovery model.....6
2.4	The theory and concepts behind recovery.....7
2.5	Implementation concerns and criticisms.....8
2.6	Contrasts in policy and research development.....10
2.7	Recovery-oriented treatment approaches.....12
2.8	Recovery-oriented reforms: British Columbian mental health policy in 1998.....14
2.9	Out of the shadows at last – The Kirby senate commission.....16
2.10	Rationale for study.....17
CHAPTER III	METHOD.....19
3.1	Sampling.....19
3.2	Interviewing and analysis.....20
3.3	Trustworthiness.....21

CHAPTER IV	FINDINGS.....	23
4.1	Participants.....	23
4.2	Emergent themes.....	26
	4.2.1 Current service provision and the lack of	
	choice in treatment.....	27
	a. The dominance of the medical model.....	27
	b. Discrepancies in service provision.....	27
	c. Consequences.....	29
	d. Forced treatment.....	30
	e. Contact with services.....	31
	f. The lack of alternatives and experiences	
	of disempowerment.....	32
	4.2.2 The recovery process.....	33
	a. Participants' definitions of recovery.....	33
	b. The importance of connectedness and	
	involvement.....	34
	c. Rapport with professionals.....	35
	d. Striving for goals.....	35
	e. Medication.....	36
	f. The journey.....	37
	4.2.3 Change.....	38
	a. The need for alternatives.....	38
	b. Advanced directives.....	39
	c. Being treated as an equal.....	39
	d. Empathy.....	40
	e. Accountability.....	40
4.3	Limitations of the study.....	41

	4.4	Observation.....	42
CHAPTER V		DISCUSSION.....	43
	5.1	Regionalized mental health reform: individual pathology versus citizenship.....	43
	5.2	Supporting the Kirby senate commission.....	47
	5.3	Finding alternatives.....	48
	5.4	Implications.....	50
CHAPTER VI		CONCLUSION.....	53
		BIBLIOGRAPHY.....	54
		APPENDICES.....	57
APPENDIX A		Informational flyer.....	57
APPENDIX B		Consent form.....	58
APPENDIX C		Interview guide.....	62
APPENDIX D		UBC Behavioural Research Ethics Board certificate of approval.....	63

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DEDICATION

*À mes parents Roland et Marie-Paule, qui m'ont
offert leur amour et appui à travers les dures
épreuves de ma vie.*

*To my parents Roland and Marie-Paule, who
provided their continued love and support
throughout the harder days of my life.*

“Somewhere in the mind, in the darkness of the unconscious, there is a spark that leads us back to life, to success, victory, confidence and happiness. When the difficult problem is our own condition, we are forced to reinvent ourselves.” (Carten, 2006, p.116)

CHAPTER I INTRODUCTION

1.1 Recovery, a personal story

Until October 2005, my family had only known about clinical depression as it was portrayed in mainstream media: the product of stressful times combined with series of unfortunate events with perhaps a biological component in the mix. When my father progressively fell into an inexplicable sense of despair, our perceptions of “mental health” were radically challenged. This once proud medical practitioner was suddenly unable to leave his home. The shame, the doubts, the fear of illness and its consequences overcame him and paralyzed his very being. The man we once knew as our father was seemingly a shadow of himself. His trial continued on for several months but with a concerted effort, a very supportive environment and proper self-care, he managed to turn his life around. This experience, however, had shown us how important a combination of treatments, multiple supports and, more importantly, the presence of hope had been essential for a recovery process to occur. As a young social worker working in a community clinic, I have also witnessed time and again how these factors influenced outcomes for my clients. Many were not as fortunate as my father had been. They often felt the need to discuss their experiences in mental health care settings, only to find few outlets to do so. This brought me to question healthcare providers’ policies and practices. Are we honestly listening to persons living with mental illness? Are we providing them with a sense of hope? How are we including their perspectives within the current system of health care?

1.2 Purpose of study

The aim of this study is to provide a voice to clients in mental health. Interviewing people who have been through the current system of health care provides us with an opportunity to learn

about and reflect on the impact of current policies and practices, as well as to capture the personal meaning of recovery for people currently living with mental illness. Qualitative inquiries of this kind are important because they serve as a sounding board for service providers to gain an in-depth evaluation of services from the people who matter the most in the equation - the consumer/survivors. For consumer/survivors in mental health, this provides an opportunity to have their voices heard within a system of health care that often operates from a “top-down” approach to service provision and that has historically been oppressive (Tomes, 2006). For social workers and mental health practitioners, this is a chance to learn more about their role within mental health services as partners in achieving their clients’ stated goals. It is also an opportunity to listen and reflect on current service provision from the standpoint of the client. By portraying clients as human beings with real issues and as stakeholders in the decisions that affect them, this study gives society in general a chance to dissipate stigma around mental health issues.

This paper will be divided in four chapters. In my first chapter on the conceptual framework of the study, I will explore the foundations and applications of the recovery model in mental health in policy and practice. In the second chapter, I will describe the methodology behind this current study. In the third chapter I will describe the relevant findings from participant interviews. I will then discuss these findings and present some of their implications for mental health service provision in chapter four. I will finally conclude with a commentary on consumer/survivor involvement in mental health.

1.3 Terminology

Prior to exploring the conceptual context of this study, I will discuss some of the terminology that will be used throughout the paper. *Consumer/survivor* will refer to a person who has received psychiatric services (consultation, diagnosis and/or treatment) at one point or another in their lives and who self-identifies as such. I recognize, however, that the term *consumer/survivor* remains limited in scope in that people who identify with this term may actually represent a minor proportion of clients who currently receive treatment/support from

mental health service providers. However, I also recognize and respect the value of the consumer/survivor movement in promoting the place of service users as key stakeholders within the mental health field. *Recovery* in this study will refer to the process of accepting the existence of and life with a mental illness. This process, unique to each individual, involves the attribution of meaning and significance to what professionals have dubbed “social determinants of health” (Kirby & Keon, 2006). In more concrete terms, it may be considered, for example, as an individual’s struggle with the remission of symptoms, even if the illness is still present and symptoms may eventually return. Another example could be found in overcoming the challenges brought on by stigma associated with mental disorder or in dealing with diminished confidence due to lengthy periods of grief over the loss of life ambitions. Yet another example could be found in a person overcoming some of the more iatrogenic effects of mental illness in order to achieve greater independence from health care providers (Davis, 2006). Each of the previous examples can be considered as processes of “recovery” as they hold certain significance for the person living with mental illness. For these reasons, this study will not attempt to generalize individual participants’ own conceptions of recovery but will rather focus on this ever-evolving process of living with mental illness otherwise known as “recovery”. *Recovery-oriented* services will also refer to health care providers who place consumer/survivors, and their conceptions of *recovery* first in developing treatment and support systems. This paper also recognizes that the use of the term *mental health* in current formalized service provision settings refers primarily to the presence of individual psychopathology rather than an appreciation of its multi-factorial determinants.

CHAPTER II CONCEPTUAL FRAMEWORK

2.1 Mental health policy development in Canada

The development of the mental health care system in Canada is one which is embedded within the context of health care policy. In order to understand the foundational principles of recovery, I will first focus on the deinstitutionalization movement from the 1960s to the 1980s and its impact on policy development. Then, I will discuss the gradual emergence of the recovery model from consumer/survivor movements of the 1970's and 1980's. I will then turn to British Columbia's gradual shift towards client-centred care in 1998, which included certain characteristics of the recovery model. Finally I will discuss future directions for the mental health system as suggested by the Kirby Senate Commission, the first major inquiry into the state of mental health care in Canada.

2.2 Deinstitutionalization

Since the mid-19th century, asylums throughout the country provided institutionalized care for people with mental illnesses. While at first portrayed as a humane way for society to handle such populations, asylums became increasingly criticized as segregationist and stigmatizing, verily banishing mental illness to the margins of medicine. The lack of effective treatment methods and reliance on “custodial care” meant that asylums progressively became overcrowded and understaffed by the middle of the 20th century (Davis, 2006). From the 1960s throughout the 1980s, Canada witnessed the rapid downsizing of these psychiatric institutions in favour of community-based approaches that would be “more humane and more therapeutic than hospital care” (Bachrach, 1994, p.24). Deinstitutionalization was theoretically devised with three objectives in mind: the transition of patients from long-term psychiatric institutions to community based service alternatives, followed by a switch of new admissions directly to these local services and the development of community-based programs offering both specialized psychiatric treatment and support (Davis, 2006). To understand the development and subsequent failure of attaining these objectives, I will turn to three important factors which originally

influenced deinstitutionalization. The availability of new psychiatric medications by the 1960's provided medical practitioners with a method to treat individuals presumably voluntarily within community settings. The civil rights movement of this period also pointed to the inhumane nature of segregated psychiatric treatment and how the "chronicity" of mental illness could be conceived as a product of institutionalization rather than illness. As such, these advocates suggested that community-based approaches would inherently be more positive than segregation within psychiatric care settings. Finally, as governments and policy makers faced economic crises in the 1970s there was also the observance of an economic advantage from downsizing long-term psychiatric care facilities. Money could be saved by thus shifting the burden of cost to communities and families (Davis, 2006).

The actual implementation of deinstitutionalization was ultimately only partial and led to a reduction of available beds in asylums combined with changes in the legal protection of people living with mental illnesses. This completed a shift from long-term stays for psychiatric care in institutions to more short-term interventions in hospital ward settings. It became increasingly evident that the final objective of reintegration within the community would never be achieved (Davis, 2006). The new system was described by the Canadian Mental Health Association as "trans-institutionalization", a return to either large psychiatric boarding homes or to families which had little support in coping with the return of severely mentally ill persons (CMHA, 2001, p.5). Fear of and prejudice against those with mental illness remained also prevalent within communities and thus increased barriers to reintegration in social life such as employment, education and housing. Community-based programs struggled in coordinating and providing access to new psychiatric medications. Continuity of care also increasingly became a more pressing concern than the actual treatment of illness (Eaton, 2001). Moreover, it was observed that the persistence of mental illness symptoms could be related to factors intrinsic to mental illness and not simply as a by-product of institutionalization alone. Finally, the economic savings also remained questionable. The shift to community-based care occurred amidst what has been argued as a deliberate neglect and underfunding of alternatives. The move towards community-

based care came with an assumption of cost containment without any clear definition or measure of its effectiveness (Davis, 2006).

Deinstitutionalization policies fragmented the development of mental health care system into often competing stakeholder groups. Clients and their advocates thus discussed issues of choice, empowerment and citizenship rights while some treatment providers and politicians discussed compliance, protection and stricter controls. Families, clients and communities asked for greater support and inclusion in treatment processes while governments stressed cost-efficiency and the implementation of evidenced-based practices. The question remained complex and efforts by provincial governments to devise reforms which consider all these stakeholders have to this day still proven challenging (Davis, 2006).

2.3 The historical development of the recovery model

The notion of “recovery” in mental health has increasingly gained prominence in both practice and policy making. While a number of stakeholder groups influenced deinstitutionalization, the movement towards community approaches to care were mainly spearheaded by professionals rather than ex-patients (Tomes, 2006). Recovery, by contrast, stemmed primarily from the consumer/survivor movement in the 1970’s, wherein a growing number of voices within the community criticized elements of power and influence present within healthcare settings (Tomes, 2006). Early activists based many of their claims on knowledge borrowed from anti-psychiatry, portraying madness not as an illness but as an alternative way of being which challenged the conceptions of “sanity and insanity” (Szasz,1961). The movement initially aimed the development of community-based alternative models of care, rather than transformation of the formal mental health system. Rather than focus on “cures” to mental illness or the reduction of symptoms, the consumer/survivor movement primarily focused on measures designed to return control over the psychiatric patient’s fate and to contribute to all aspects of a consumer-run organization’s operation (Tomes, 2006). Since the consumer/survivor movement’s inception, various subgroups have come to differ in the achievement of self-help and

recovery. Some have preferred focusing on societal change while others have chosen to develop individual/group therapy for example. Other areas of conflict involve consumer/survivors' positions with regards to the development of services and involuntary treatment. Yet for all these apparent conflicts, mental health consumer/survivors and their advocates do hold consensus over guiding principles of a recovery-based system wherein self-determination is at the core of treatment, treatment plans must be catered to the individual client's level of readiness for change and social determinants of health are essential to achieving any sense of a long-term recovery process (Tomes, 2006).

The influence of the consumer/survivor movement has fuelled recent debates in mental health. System reform now includes a focus on issues of empowerment and the inclusion of service users in the development of treatments and policies (B.C. Ministry of Health, 2002). Consumer/survivors' emphasis on guiding principles of choice and collaborative approaches to healthcare have now placed mental health recovery at the core of both Canadian and international efforts within the field of mental health service delivery (Kirby & Keon, 2006).

2.4 The theory and concepts behind recovery

Several issues have been raised both by practitioners and mental health consumers as to what exactly "recovery" might entail. On one hand, practitioners observe it as a form of positive outcome which can be measured or evaluated (Davidson, O'Connell, Tondora, Styron, & Kangas, 2006). On the other hand, for consumers of mental health services "recovery" can take on a very different and more personal meaning (Jensen & Wadkins, 2007). Past studies examining the personal experience of recovery, for example, portrayed the process as an opportunity to develop insight into one's self or as an opportunity to re-connect with one's environment (Ridge & Ziebland, 2006).

To bridge these definitions, a conceptual model calls for several conditions for success both internal to the client and external to the agency delivering services (Jacobson & Greenley, 2001). On one hand internal to the client, we find four major concepts: hope, healing,

empowerment and connectedness. These can be understood as part of an ongoing individual process (Young & Ending, 1999). *Hope* reflects the individual's recognition and acceptance of the problem as well as a commitment to change. It is a personal belief that the process of recovery is possible. *Healing* places the emphasis on active participation of the person in the self-help process. In this case, the client is able to separate the self from the illness and has a level of control over his symptoms. *Empowerment* covers the ability of the person to make decisions and become responsible for the goals and aims he has set for himself. Finally *connectedness* covers the ability of the person to forge links within the community (Jacobson & Greenley 2001).

External conditions related to recovery, on the other hand, cover three main concepts: human rights, a positive culture of healing and recovery-oriented services. *Human rights*, as understood within the recovery model includes the right of service users to live as any other member of society, to have opportunities for employment and have equal access to services. This includes the necessity to confront the stigma and discrimination frequently faced by persons living with mental health issues (Young & Ending, 1999; Jacobson & Greenley, 2001). A *positive culture of healing* refers to a collaborative environment between practitioners and clients in which agencies are willing to cater to the choices of clients. Finally, *recovery oriented services* refer to the integration of all levels of care both in and outside of the institutional setting. With these concepts in mind, the recovery model can be understood as a dynamic process between these two sets of conditions, both the internal and the external influencing one another. (Jacobson & Greenley 2001)

2.5 Implementation concerns and criticisms

It is important to note that while the notion of recovery has been present since the 1970's, its recent pairing with psychiatric rehabilitation programs is relatively new (Davis, 2006). While rehabilitation has traditionally been associated with impairment or disability and thus considered practitioner-driven, the notion of recovery has shifted practice towards more collaborative approaches to treatment with an emphasis on going beyond notions of disability into the more

existential aspects of living with mental illness (Deegan, 2005). This paradigm shift towards collaborative care practices wherein both practitioners and clients create environments in which recovery can be fostered has been met with criticism. Given that such an approach focuses on the broader social aspects of living with mental illness, practitioners have noted that limited resources will need to remain necessarily focused on medical stabilization rather than recovery for individuals suffering from psychotic illnesses (Satel & Zdanowicz, 2003). Yet rehabilitation need not be separate from recovery, nor require the expenditure of further resources. If evidence supports the effectiveness of a given treatment in promoting an individual's capacity to engage in a meaningful process of recovery, then shouldn't resources support practices that are more effective in achieving this overarching aim? Evidence on the effectiveness of recovery-oriented practices has been documented over the past 3 decades even in cases of serious mental illness (Davidson et al., 2006). While the qualm of resource allocation can be raised, one must then ask what is more costly: short term stabilization with no hope of recovery or more long term recovery-oriented treatments? We may argue that the latter may in fact provide communities with more sustainable solutions for mental healthcare service provision for generations to come (Kirby & Keon, 2006).

A second concern expressed by practitioners regards potential risks for a person suffering from psychosis. How can we talk of strength-based interventions when there are pressing needs for basic necessities such as shelter and the stabilization of symptoms? If we prioritize self-determination are we not risking further harm and increased risk to an already vulnerable population? The actual term recovery is rarely used by persons living with mental illness (Davidson et al., 2006). Their concerns often rather revolve around relatively concrete goals such as making friends, holding employment, etc. Their engagement within this process varies throughout phases of treatment in accordance to their stated goals living with mental illness. In acute stages, we may argue that recovery cannot take place until severe symptoms are stabilized. From the individual's perspective the episodes of illness and their associated levels of support and care will thus influence their recovery process. This requires a shift from a professional

perspective of the potential risks involved with illness to the individual person's perspective of illness within their life. In other words, we must ask not how recovery can fit in risk assessment and treatment but rather how our assessments and treatments will play out in the overall process of recovery. Even if a person poses a degree of personal risk, we must allow for individuals to make their own decisions and potentially fail in order to learn from their mistakes (Davidson et al., 2006).

A final qualm raised by professionals concerns the use of certification and forced treatment. Cases of suicidal or homicidal intent where informed consent and permission to treat are suspended temporarily to perform emergency treatments for the usage of life-saving measures may challenge the idea of recovery as an overarching guiding principle. The provision of protective mechanisms such as psychiatric advance directives, where a person designates the form of treatment they desire should they become unable to make informed decisions, would still enable these persons to retain a level of control and self-determination over their lives.

Mental health practitioners have raised important questions concerning the recovery-model. We may recognize however, that its development has significantly impacted recent "best practice" guidelines in mental health care. British Columbia's own health authorities now include concepts found in this model. Consumer/survivor involvement in mental health has increasingly become acknowledged in policy documents of this province under several guises such as choice, inclusion, self-determination, the development of networks of support, the creation hope and a sense of belonging (BC Ministry of Health, 2002).

2.6 Contrasts in policy and research development

While recovery has increasingly gained prominence in policy documents and mental health reforms, I chose to examine further the actual involvement of consumer/survivors in research, policy and treatment development. In examining recent research from industrialized nations' mental health systems, I focused on efforts to describe and understand service users' involvement in mental healthcare settings. One thing which became clear is that often the

discourses of policy makers and professionals were significantly different from that of service users (Edwards & Staniszewska, 2000; Hui & Stickley, 2007). Government documents in the U.K. for example reflected a tokenistic view of clients and a more top-down approach to decision making (Hui & Stickley, 2007). In contrast, service users described recurrent issues of disparity between policy and practice wherein the medical model of care still predominates and is seen as a source of stigma and prejudice (Connor & Wilson, 2006). Clients often discuss the lack of “true listening” from service providers who prefer to impose service frameworks rather than consult with the people primarily affected by these changes (Hui & Stickley, 2007).

These contrasts were in part related to problems in the methods of data gathering with variables such as “users’ satisfaction with services” in quantitative studies through the use of standardized questionnaires. These would frequently show high rates of satisfaction with services. Concerns were raised when qualitative studies exploring the broader experience of users within mental health services demonstrated a different portrait than the quantitative literature (Edwards & Staniszewska, 2000). These findings demonstrated that quantitative research was primarily driven by a provider-led agenda of determining service efficiency. Moreover, researchers did not consider how users’ opinions develop over time. Because it focuses mainly on attitudinal measures the use of follow-up questionnaires as part of a quality-insurance process thus failed to capture the complexity of service users’ perspectives (Edwards & Staniszewska, 2000). As a result, these inquiries provided neither an explanation of the dynamics involved in recovery, nor a description of the social context in which they occur. It became clear that “satisfaction with” did not examine what exactly persons living with mental illness were satisfied about. This approach ultimately did not fulfill the need of clients to have their voices heard in research, practice or policy-making decisions (Edwards & Staniszewska, 2000). While quantitative research may be useful in establishing the efficacy of services, it may be less appropriate in describing and interpreting the actual experience of service users within mental healthcare settings.

Qualitative literature, however, provides a more detailed portrait of users' experiences. Several themes are recurrent within qualitative inquiries. Language or how mental illness is socially constructed, for example, is shown to be of concern for service users. This includes issues of stigmatization, misdiagnosis and labelling (Connor & Wilson, 2006). The dominance of the medical model in treatment choices, as a source of prejudice and oppression (Hui & Stickley, 2007) and as an impediment to the empowerment of mental healthcare consumers (Pilgrim & Waldron, 1998) is also mentioned. The relationship with professionals, how interactions are facilitated through a "human touch" has also been found to be of concern (Connor & Wilson, 2006). Finally, the issue of communication between service providers and service users has also been shown to be significant in people's discourses. Users mention often the need for more accurate information about their condition and of potential treatment options (Connor & Wilson, 2006; Hui & Stickley, 2007). These findings have fuelled the need for further research into service user involvement within mental health policy and practice.

2.7 Recovery-oriented treatment approaches

Several community initiatives have been inspired by the recovery model. Some in particular have provided interesting ideas on how to promote the integration of people living with mental health issues. In their study on the experience and meaning of user involvement, Truman and Raine (2002) examined the experiences of service users participating in a community gym who were given the opportunity to gain meaningful work experience first as volunteer staff and later as paid fitness trainers. Using a grounded theory approach to qualitative data (Strauss & Corbin, 1998), the research shows that users gained an intrinsic form of satisfaction with the inclusion as staff members. Another interesting find was that there was a potential for modelling behaviour when new members witnessed former service users in staff positions. This study opens up considerations of the conditions of user involvement and its sustainability over time. It also provides insight into how this can occur in practice.

Another study, by Pilgrim and Waldron (1998), examined patients' concerns over mental health service delivery through structured focus groups. As action researchers, the authors set about facilitating a focus group of service users that would actually have a say in service development. They found that there was still an element of professional paternalism within social services. Although they were affecting some areas of service delivery through their deliberations psychiatric patients involved in the research were unable to generate change in other areas and realized their lack of "social credibility". Again, as echoed in other research findings (Edwards & Staniszewska 2000; Connor & Wilson 2006; Hui & Stickley 2007) users felt that they never had a choice in services, that reforms had been imposed on them even when they were consulted. In the end, their voices had little impact on the development of services that were supposed to be catered to them. Pilgrim and Waldron also reflected upon the principle of reciprocity or lack thereof in current mental health policy and practice. For all intents and purposes, the state restricts the freedom of users to choose treatment alternatives and restricts the ability to create a user-lead change in services while not ensuring the quality and effectiveness of healthcare. Thus, power within decision making bodies remains mostly in the hands of professionals while service users' citizenship rights are essentially negated. There is thus an apparent gap in the literature concerning the impact of top-down decisions on mental health consumers (Morrow, Silke, & Johnson, 2006).

While qualitative literature has contributed, to some extent, to our understanding of the actual themes and processes involved in recovery, some questions remain unanswered. In recent years, mental health policies and practices in developed nations have often touted "recovery-oriented" services, only to present little in terms of the actual inclusion of client's perspectives (Morrow et al. 2006; Hui & Stickley, 2007). Are reforms in mental healthcare across Canada also continuing this trend? If we observe the socio-political context of mental health policy development over the past 40 years, we become painfully aware of the impact of ideology on actual service delivery. Deinstitutionalization efforts, while giving promises of community care and more humane treatment, have done little to improve the lives of individuals suffering

from mental illness. While hospital beds closed and admission criteria became stricter, persons living with mental illness were met with little in terms of alternative networks of support. This translated into a major increase of individuals suffering from mental illness living on the margins of society, often in poverty and relative invisibility, with little or no hope (Aviram, 2002; Davis, 2006).

The past decade gave rise to recovery principles being embraced in system reforms. Yet competing interests and conflicts among stakeholder groups have remained very apparent. Of note are problematic issues for both service users and practitioners with regards to managed care approaches. Iterations of managed care can be found in the selective use of “short term evidence-based practices” promoted in healthcare policy documents wherein cost-efficient and time-limited approaches are favoured as opposed to more committed long term resources (Davis, 2006). Also, the development of “service corridors” wherein clients must pass through several layers of assessments and follow-up by professionals in order to obtain appropriate treatment demonstrates the reach of managed care in the mental health system. As such, cost-containment measures are inevitably shaping the qualitative experience of services (Aviram, 2002; Davis, 2006). If recovery rhetoric then is selectively added in policy documents but not followed through in practice, then what impact will this have for mental health consumers?

2.8 Recovery-oriented reforms: British Columbian mental health policy in 1998

In 1998, the government of British Columbia devised a new mental health plan aimed at enhancing mental health care throughout the province. A key objective of the plan was to work towards the integration of services. The plan also aimed at including mental health consumers in monitoring systemic problems within the mental health care system (Morrow et al., 2006). Government documents of the time reflected this commitment in the assertion of “best practice” research from previous consumer-led initiatives which demand greater independence, increased well-being and stronger social networks and supports. The document stated that:

[...]for consumer involvement to be effective there needs to be meaningful involvement,

not just tokenism, democratic decision-making processes that value and actively include the views and opinions of a variety of consumers, training education and support for consumers, advocacy and outreach to give a voice to those without a voice, and to involve more of them meaningfully. (B.C. Ministry of Health, 2002)

In order to implement such changes, the B.C. government spearheaded the creation of regional health authorities such as Vancouver Coastal Health. These new governing bodies would now oversee the implementation of recovery-oriented policies and practices throughout the healthcare system. According to the Vancouver Coastal Health Authority's own public documents, service delivery would change over the span of a decade into a strength-based, continuum of care with guiding principles of becoming "people-centred, population-based, based on best-practices and sustainability" (Vancouver Coastal Health Authority, 2006). Yet early evaluations of the 1998 mental health plan, which guided the creation of the regional health authorities, revealed that the province had not fulfilled many of its commitments, particularly in providing both adequate community resources and establishing accountability structures, two key elements of any recovery-oriented model of care (Morrow, Frischmuth & Johnson, 2006). Morrow et al., (2006) indicated that policy changes since 2001 have actually eroded many of the community-led initiatives which had provided thus far consumer/survivors with essential supports and advocacy services. Despite promises for a recovery-oriented reform, there was increasing evidence that the provincial government was not, in fact, fulfilling many of the reforms it planned in 1998 (Morrow et al, 2006, p.5). The study further indicated that while the client population was on the increase, the amalgamation of services under the new Vancouver Coastal Health Authority led to a 70% reduction of staff positions within the Adult Mental Health Division of the Ministry of Health. In addition, the new model of mental health delivery shifted to a corporate cost-containment orientation which de-emphasized the participation of consumer/survivors and their families. Cuts in community-based mental health programs, mental health teams and rehabilitation programs also resulted in reports of high case loads for mental health professionals (Morrow et al, 2006, p.6). These are but few of the multiple changes enacted under

the guise of “recovery” and implemented throughout the greater region of Vancouver.

2.9 Out of the shadows at last – The Kirby senate commission

At an international level, Canada remains the only G8 country without a national mental health strategy (Kirby & Keon, 2006). The first and only national report on mental health available in Canada is: *Out of the Shadows at Last*, a report published in 2006 by the Standing Senate Committee on Social Affairs, Science and Technology. Following an inquiry on the future of health care in Canada in 2002, the Committee was authorized to gather evidence on the state of mental health and mental illness in Canada. Among the evidence gathered, the Committee collected more than 2,000 personal stories from persons living with mental illness and their families. The report offered Canadians a unique perspective on the state of mental health in the country and generated an equally impressive list of recommendations. It underlined in particular, how key social determinants of mental health such as access to networks of support and/or employment were being overlooked by current service providers (Kirby & Keon, 2006, p.6). It also discussed the wide prevalence of stigma and discrimination, particularly within the health care professions (Kirby & Keon, 2006, p.4). The report also described several guiding principles for reforms in mental health which would bring together all stakeholders to transform the current system of service provision. I have selected some of these principles as particularly relevant for the current study:

1. *Mental illness and physical illness must be treated with **equal** seriousness and people living with [these] illnesses must be treated with **equal** respect and consideration.*
2. *The central goal of mental health policy is to create the best possible context for encouraging **recovery** [...]*
3. *Promoting mental health and recovery from mental illness requires interventions that address the **social determinants of health** – in particular those related to income, adequate housing and employment, and participation in social networks.*

4. *A focus on recovery will require reorienting the design and delivery of mental health programs [upon] three pillars [...]*
 - a. **Choice** – *Access to a wide range of publicly funded services and support [...]*
 - b. **Community** – *Making these services and supports available in the communities where people live [...]*
 - c. **Integration** – *Integration of all types of services and supports [...]*
5. *Policy decisions [...] must be based on the best evidence available; this includes findings from the medical sciences, data and analyses from the social sciences, **and the testimony of people with direct experience of mental illness.** (emphasis added ,Kirby & Keon, 2006, p.57-58)*

Out of the Shadows at Last presented solid evidence for guiding future policy decisions with regards to mental health service provision in Canada, placing an emphasis on recovery, collaborative care practices and the use of treatment plans which would include consumer/survivors' experiences (Kirby & Keon, 2006).

2.10 Rationale for study

With this evidence in mind, we finally come to the rationale for the current study. The recovery model in mental health has been officially included in the policies and practices of British Columbian service providers since 1998 (BC Ministry of Health, 2002). The uses of the model and its principles however do not seem to have been upheld in practice settings. Morrow, et al. (2006, p.6) write that community mental health teams continue to be underfunded and participation mechanisms for service users have also proven insufficient. Given this socio-political backdrop, I approached 10 consumer/survivors in the community to gain a better understanding of their positions as stakeholders within this system. My research questions explored three potential areas of interest with regards to consumer/survivors' experiences within

mental health services, namely:

- 1. Common themes or experiences of mental health consumers/survivors' recovery process.*
- 2. How their experiences are shaped by local service providers' current delivery systems.*
- 3. How these services may be improved from a mental health consumer/survivor's perspective.*

CHAPTER III METHOD

This qualitative exploratory study was designed with the goals of describing themes emergent from interview data and personal notes using an approach of data analysis inspired from grounded theory (Cresswell, 2007; Strauss & Corbin, 1998). I will now describe the methodology I employed to discover these emergent themes.

3.1 Sampling

Data gathering involved the use of a purposive sampling strategy which reflected the stated aims of this study (Cresswell, 2007). A research proposal was presented to the University of British Columbia's Behavioural Research Ethics Board (BREB) for review prior to recruitment (Appendix D). Upon approval, recruitment began over the course of one month. An informational flyer containing details of the study was distributed within one of Vancouver's consumer-run community mental health organizations and a total of 10 participants were recruited (Appendix A). Each participant identified as a consumer/survivor and had significant experiences of contact with formal mental health services. Considering recovery as a process which ultimately leads to the respect and promotion of service users' voices in the mental health field, I searched for individuals who first and foremost were interested in having their voices heard. I assumed that people who participate in community organizations generally have a more informed stance with regards to the systems, treatments and policies that affect them. Each participant was provided with a 4-page consent form to review and inquire about the study (Appendix B).

Given the nature of this project as a time-limited exploratory study, only 10 participants, 6 women and 4 men, responding to the aforementioned criteria were recruited. The sample was fairly heterogeneous as participants' age range stretched from mid 20's to early 60's and participants had a fairly different range of experiences with both mental health diagnosis and treatment.

3.2 Interviewing and analysis

Considering the stated aims of this inquiry, data was gathered using semi-structured interviews (Cresswell, 2007). Questions focused on the conception and experience of the recovery process for individual participants and how these were potentially influenced either positively or negatively by policies and service providers' treatment approaches. Interviews also included discussion of participants' thoughts or wishes with regard to their level of perceived participation within mental health services. Special attention was given to allow enough space for participants to express themselves during the interview process and in order to avoid constraining their personal narratives. Although an interview guide was developed for the purposes of this study (Appendix C), it is important to note that the actual interview process with participants followed the natural flow of conversations about three key topics: their life experiences with mental health issues, their process of recovery and their participation in services. Some sample questions included the following:

- 1- Can you please describe your experiences living with mental health issues in Vancouver?*
- 2- What is the meaning of recovery for you?*
- 3- Are there any alternative policies or practices you wish were available to help you?*

Participants were informed of the topics of discussion prior to the interview. Particular attention was given to sensitive issues which were raised during the inquiry, such as dealing with stigma or talking about traumatic experiences. Using a reflexive process of data gathering (Cresswell, 2007), the interviewer made use of memos, notes and thoughts on the conversations with participants which were included in the data analysis phase. Personal notes of the interviewer were primarily used in establishing and clarifying the main themes emergent in the inquiry. Throughout the recruitment and interview process, particular care was also provided in approaching participants to insure free and informed consent. The inquirer took every step necessary throughout recruitment and interviewing to ascertain that participants were free to withdraw their consent and involvement in the study at any given time.

Interviews were audio recorded and transcribed by the interviewer. Transcripts were then given back to each participant for them to verify and provide comments. Out of ten participants, five provided feedback and corrections on the transcript material. The data gathering phase was thus shared with participants. Each participant was also given a final draft of the study for their consideration. Participants were then able to comment or revise any information they deemed as non reflective of their experiences. None of the respondents commented on the final draft report. Coding of transcripts involved several readings and a search for common themes until an appropriate coding scheme was developed with the use of the QSR N*Vivo software program. I used an approach to data analysis inspired by grounded theory as outlined by Strauss and Corbin (1998). Grounded theory consists in three phases of coding (open, axial and selective). It provides a method for developing categories of information (open coding) which may be interconnected to one another (axial coding). These categories or “themes” then lead the researcher to establish a story (selective coding) which connects each of these categories into a cohesive theory (Cresswell, 2007, p.160). I proceeded in only establishing categories of information or “major themes” in an initial open phase of coding. Reports on the major themes found in these data followed a method of constant comparative analysis wherein these open codes were then compared and contrasted repeatedly and then further analyzed as per the techniques of grounded theory, resulting in smaller sub-themes which emerged from the larger overarching themes (Strauss & Corbin, 1998). Preliminary analysis of this data was developed through reflections of interviews and my own notes taken over the course of data gathering process.

3.3 Trustworthiness

The reliability and validity, or trustworthiness of this study was assured through four distinct criteria which have been used in qualitative inquiries to evaluate the soundness of such endeavours. These are better known as credibility, transferability, dependability and confirmability (Cresswell, 2007). Credibility, the extent to which interviews accurately reflected the participant’s views was achieved in a three-step process. Participants were first able to

discuss their views and concerns throughout the interviewing process. They were then provided with transcripts to verify and comment on. Also a final draft report of the study was provided for them to discuss and debate the interpretations of their views. At every stage of this process, participants were invited to point out inaccuracies, misunderstandings and to clarify or expand, if need be, the content of the discussions. Transferability, the extent to which we can generalize our findings to another group was limited in the context of this study (Cresswell, 2007). While the sample size was small, it did confirm other findings from similar inquiries on consumer/survivor involvement such as the Kirby Senate Commission on Mental Health in Canada (Kirby & Keon, 2006). Dependability, the extent to which changes in participants' perspectives might appear over the course of time were not taken into account due to the limited, cross-sectional nature of this study. Although participants discussed changes in mental health provision over the years, no attempt to measure such changes in participants' views was attempted aside from their reviews of the transcripts and interpretations given in the draft report. Confirmability, the extent to which the findings in this study could be confirmed by another researcher is somewhat complex given the exploratory nature of the project (Cresswell, 2007). However, a clear trail of analysis, including my own notes with regards to the interviews and the process through which data were analyzed was shared with a research supervisor who critically questioned my analyses. A data trail was also left behind for others to assess. I have also been clear about my background as a graduate social work student with a professional commitment to the field of mental health. My experiences as a clinical social worker, researcher and family member of an individual who lived through a major depression have all been taken into consideration throughout the creative process behind this study.

CHAPTER IV FINDINGS

Prior to discussing my findings, I would like to briefly describe each participant interviewed in order to provide the reader with some introduction to the lives of mental health consumer/survivors. Data gathered from these 10 individuals through audio-recorded interviews, together with personal notes taken after the interviewing process form the basis of this chapter. Quotes are identified with pseudonyms in order to preserve confidentiality. Formal mental health services refer to any organization governed by the various regional health authorities in the greater Vancouver area.

4.1 Participants

Laura

Laura was the first participant in the interviewing process; she was young, had a fairly high level of education and appeared very knowledgeable about her condition. Facing little support from her family of origin, she lived with the diagnosis and stigma of borderline personality disorder for most of her young life. She noted that multiple supportive services had been provided for in her particular case but that personality disorders remained often misunderstood both in larger society and within the health care system. For Laura this compounded fears of being seen as a label rather than a human being.

Jane

Jane is a middle aged, educated woman with a good sense of humour and sharp wit. She struggled for years with a mood disorder which went undiagnosed by her clinician, despite her stating periodic suicidal ideation. She faced little support from formal health services and was more often than not relegated to the sole usage of psychiatric medication with limited results. She discussed her feelings of isolation with her illness, reporting that it was particularly difficult for her to reach out and obtain support to this day. For Jane, the achievement of some form of meaningful employment and being listened to was revealed as the most helpful aspects of a

recovery process.

Darlene

Darlene is a middle-aged, educated woman with strong views about mental health. She lived through several traumatic experiences dealing with mental health services, including abuse at the hands of hospital staff during her initial stays in psychiatric care. Darlene never obtained closure over the unjust treatments she received decades ago. Left with considerable sequelae from these experiences, she became a staunch critic of psychiatry, promoting community alternatives with other consumer/survivors and collaborative care practices to engage in holistic healing processes that eschew the use of psychiatric medication.

Mark

Mark is a middle-aged, highly educated man involved with community approaches to mental health service delivery. Living with a diagnosis of schizophrenia, Mark initially received limited help from the mental health system, leading him to spend many years in poverty until he finally connected with a psychiatrist who helped him return to a level of functionality. Mark reported that his recovery process, however, started when he managed to both meet with supportive others and engage in meaningful activities and programs which sustained his professional ambitions.

Mary

Mary is an older woman who got involved in the mental health system at a fairly young age. Faced with problems at home, Mary was sent to a psychiatric institution in her teenage years for several months. Once “cured”, Mary wound up living in the community with few supports and medication. With a recurrent mood disorder, Mary eventually developed an addiction to narcotic substances in an attempt to silence her negative feelings. It would take several decades before she was able to address both her addiction and mental health problems. Now involved in the community, Mary related the importance of meeting with others who could share about their

experiences with mental illness in a non-judgemental way.

Kuldip

Kuldip is a young woman who lived through both addiction and mental health issues from a young age. She reported being diagnosed with five different illnesses throughout her contact with formal mental health services and never feeling properly heard. Sensitive with regards to the stigma attached to mental illness, Kuldip professed a strong ambivalence toward psychiatry in light of her own personal experiences. She discussed how her problems were often compounded by prevalent issues of racism and sexism when she attempted to seek help. She also noted the importance of connecting with others and developing one's own sense of spirituality in order to begin a process of recovery.

Paul

Paul is an educated, middle-aged man involved in community mental health service delivery. Struggling at times with severe mental health issues, Paul was often faced with denials of service from providers based on their assessment of his functionality. He discussed ways in which health authorities are dominated by bio-pharmacological interests and only allow for limited consumer/survivor involvement while restricting access to services. Promoting alternatives to healing other than medication, Paul discussed the recovery process as an entry point to gain meaning/spirituality in one's life and challenged western conceptions of mental illness.

Scott

Scott is a young man involved with consumer-run groups. Labelled with a multitude of disorders, Scott stated having little faith in the formal mental health system. Concerned with the use of psychiatric medication, Scott recalled having severe reactions to the drugs he was given. He thus doubted their efficiency and recognized their potentially damaging effects on the body. Faced with limited options in terms of help with his condition and further involvement with

community, Scott has spent his time attempting to find meaningful employment to gain a level of independence.

Jia

Jia is a young man who is both a recipient of formal mental health care and an active person in the mental health community. Faced with difficult mental health issues, Jia managed to connect with a mental health team which catered to his desires for recovery fairly early after being diagnosed with mental illness. Throughout his contact with services, he was able to choose what he felt was appropriate for him and received a consistent level of support. Now involved in a multitude of programs, he has hopes of one day helping others like him as a mental health professional.

Fiona

Fiona is a middle-aged woman involved for many years within both the formal and community mental health systems. Facing physical problems which interacted with her mental health condition, Fiona felt that many of her problems were never looked at simultaneously, leaving her at times with exacerbated states of illness and isolation. She encountered several traumatic experiences while in psychiatric care and attempted to advocate for better treatment for patients, often with limited results. Fiona discussed concerns over the treatment of consumer/survivors within mental health services and the potential risk for abuses of power from professionals.

4.2 Emergent themes

Three main themes were revealed during the data analysis phase: participants' perceptions of the state of current mental health service provision, their conceptions of the recovery process and their suggestions for consumer/survivor oriented changes in the mental health system.

4.2.1 Current service provision and the lack of choice in treatment

a. The dominance of the medical model

The first emergent theme observed in the data concerned the experiences and perceptions of service providers. Nine participants in this study portrayed current mental health services as primarily reliant on a medical model of treatment which emphasizes the use of psychiatric medication.

I've seen several psychiatrists with teams and none of them worked. They all just wanted to drug me up and coerce me into drugs. I've been on 7 different kinds of drugs. (Scott)

They only pay for psychiatrists. I don't know why. (Jane)

Alternative healing? They only focus on the biological model. (Darlene)

[...] in order to qualify for treatment I had to sign a waiver that I would accept the recommendations on medication prescriptions of their physicians. (Paul)

Half of them were faced with few affordable alternatives to cater to a personal sense of recovery.

I think one problem with services is that psychiatry is covered [by medicare] but psychotherapy isn't. That's criminal and wrong. They obviously don't take this seriously. It's like a business monopoly that's not in the person's interest. We don't have access to other treatments or choices to go to. (Kuldip)

b. Discrepancies in service provision

Discrepancies in service mandates were also discussed. Provisions for certain types of illnesses with a perceived level of severity (i.e. schizophrenia) were portrayed as provided with better support and treatment.

Eventually I ran into a good psychiatrist who was helpful and found a good medication, a low dosage of an old psychotropic that seemed to work very well for me. (Mark)

By contrast, services for other types of illnesses such as personality disorders and/or dually diagnosed disorders (i.e. co-morbid addiction and mental illness issues) were found lacking in many areas.

Like having schizophrenia is like having the right diagnosis to get help. Because that's biological and that's not your fault. Borderline personality, you're just difficult. Personality is the most fundamental part of who we are. Being referred to as having "personality disorder" makes it seem like who you are is fundamentally flawed. (Laura)

Accordingly, the level of professional understanding of the unique needs of consumer/survivors in such circumstances varied widely across service settings, some stating having received substantial support from their mental health teams.

[The mental health team] helped me out a great deal. They trained me in working within mental health services. I can also take it further if I want to. (Jia)

Others discussed fairly negative experiences such as being summarily refused access to services or being simply labelled and treated solely through medication without any results.

They gave me tests and labelled me retarded like in high school. It never amounted to anything, zero. I went back to the team and they put me on Paxil and Luvox which didn't do much. (Scott)

This was particularly relevant when participants discussed access to more specialized treatments or therapies based on formal diagnosis, suggesting how the mental health system may in fact actively restrict the consumer/survivor's range of choices to cater to his/her sense of recovery by employing arbitrary, symptoms-based gate-keeping mandates of service provision.

Where do you fit if you don't fit the mandate? You know? Like whose mandate is it to help? And what if you have a diagnosis that doesn't fit people's mandate? Where do you go to get help? That can be... hard not to take that personally; that there's something wrong with you, you don't fit the mandate. [...] it makes you feel excluded, like you don't

have the right diagnosis to get help. (Laura)

c. Consequences

The apparent absence/restrictions of treatments and/or poor understanding by certain professionals contributed to several participants facing at times a slow progression towards more exacerbated states of mental illness and isolation.

How could I trust these people, how could I tell them anything? They won't understand.

There's no treatment for people like me that have been abused in such a way. I've never recovered from it. Even now it makes me feel these bad feelings. (Darlene)

In some cases this also led to poverty, poor physical health

I got myself a place in the downtown eastside, where else was I going to go? [...] I would walk around and it would be difficult to walk around the streets because I felt vulnerable, suffering from akathisia or restlessness as it's called. (Mark)

substance abuse,

So they said I was sick and 3 months later that I was all better. Nothing really had changed, I kept drinking and drugging. It was after we were in the hospital that I started heroin and doing other drugs. (Mary)

exacerbated suicidal ideation,

I've gotten into emergency at an outpatient psychiatry service and they didn't take me in. What do you want to see? Do you want to see me with a blade in my veins with blood spurting all over the place? What more do you want than a personal testimony that I need this service? (Paul)

and states of internalized oppression.

So that's it, I don't know how other people do it, you know, that have a mental illness. It's bad enough to have that but you stay home and how do you get self-esteem without the tracings, without all the markers you would use for success? I mean if I don't have that how do I feel successful? There's nothing in this system, this mental health system, to give

you any feeling of success. It's like set up that way, you will always feel less than everyone else. (Jane)

d. Forced treatment

The use of forced treatment in psychiatric settings also brought the issue of traumatisation for participants. Five of the consumer/survivors interviewed compared their experiences of involuntary psychiatric admission to that of incarceration.

[I was] being forced, tied down to a bed, having my clothes stripped, being threatened by a needle if I didn't take my medication, that sort of thing. This happened quite a bit. (Kuldip)

They just drugged me, monitored me to control my behaviour, like they do with thousands of people. They're not there to really help, treat or cure people. They're extensions of the criminal justice system and the police basically. (Scott)

I tend to say I was treated like a criminal but even criminals have more rights. When you're certified as a mental patient, you have no rights. People can do what they want with you. I suspect prisoners had more rights than I did at that moment. (Fiona)

Many explained difficulties regarding the rationalizations provided for the arbitrary suspension of their rights and their subsequent experiences of degradation.

When I was [studying] and wound up at [the hospital] I felt I was badly treated. I had without any warning been picked up by four security guards that forced me down on a mat in a quiet room and given an injection against my will. [...] I filed a complaint about that sometime after that, I wasn't particularly well when I filed the complaint. The response I got was that staff felt it was appropriate to be treated the way I had been at that time. So I didn't follow it up but it was interesting how I felt about it at the time. I made this complaint and I was being sent a letter and you know... how could I appeal, how could I ask people how to address my concerns? I felt that I was abused in that hospital and they weren't really listening to me. They just said: "Staff indicated that...

you needed this and that.” What I really wanted to do was talk to the people involved and say: “Look this is what happened, this is my side of the story. What is your story? Why did you do this?” That never happened, it never came to it, I never got my day in court so to speak. (Mark)

Other participants also pointed to a lack of accountability from services to appropriately respond to their grievances following such involuntary admissions. Consequently, this was revealed as an important factor in negotiating future contact with services. For four respondents, it went so far as to apparently fuel a profound mistrust of providers and psychiatry in general.

I consciously avoided getting into the system. I could see how they were trying to make me a professional patient and I was resisting that. I was criticized for resisting. I’ve seen what people do when they become chronic patients because I worked in mental health myself. (Fiona)

e. Contact with services

For consumer/survivors in this study contact with mental health services occurred often through a crisis. Response by professionals/institutions in these key moments would then shape the relationship users had with services either positively or negatively thereafter.

I have been sexually assaulted by a person who was supposed to treat me. You know? He was supposed to heal me. [...] I was very depressed. I decided I was going to go in the hospital. I signed in myself thinking that I don’t want to kill myself that I just want to heal from this and I’ll be ok but what a shock that was. They lied to me, they said they were sending me for tests and what happened is that they actually sent me for electroshocks. [...] That’s what you get when you get into the psychiatric system. You get systemic abuse. (Darlene)

It’s hard to live your life when you’ve been diagnosed with schizophrenia and you’re treated like a second-class citizen even in the system itself. My experience in the system

brings out a lot of pain, anger and resentment towards a lot of people because it didn't help. [...] (Kuldip)

I wound up having community [mental health] services taking me as a client. They've been looking after me since, for about 5 or 6 years now. They pay a lot of attention to me, they support me in so many different ways, whether it's getting a job or just anything. They have groups that I go to. They influenced me a lot. (Jia)

Initial experiences in particular shaped perceptions of service providers and the consumer/survivor's subsequent search for alternate networks of support. Participants who thus failed to connect with formal mental health provision systems in their initial stages of illness would more often than not wind up seeking consumer/survivor groups in the community to deal with their illness.

What saved me was AA, Alcoholics Anonymous because without that group I wouldn't have stopped using drugs. I think I can see my position now as much better than 4-5 years ago. I'm stable, I have a home, I'm in a steady relationship... (Kuldip)

This was revealed as particularly relevant for older participants who mentioned having faced harsher forms of psychiatric treatment in past institutionalized settings such as forced ECT, forced psychiatric medication and/or long-term seclusion in psychiatric wards.

When I need some people to help me, I know that if I go to them I may get mistreated. [...] I've been able to relate to [consumer/survivors], to share stories. We've been able to share experiences. We've been able to heal together. (Darlene)

f. The lack of alternatives and experiences of disempowerment

Upon reflecting on the individual experiences of mental health consumer/survivors in this study, much of the interview data collected indicated an apparent lack of alternatives or denial of service based on current mandate provisions. Services offered to many of the participants could be construed as reactive rather than proactive in establishing treatment plans. Responding often

primarily to criteria of acute crisis (i.e. suicidal intent or psychosis) to allow access to services, providers had seldom contributed to many participants' recovery process.

I've been refused help as I supposedly don't fit the criteria. [...] You have to prove yourself desperate and I think incompetent at every level of existence. It's not enough to say that you are in pain or assure them that you are at the end of your rope. Your life circumstances clearly demonstrate that you are in need of mental health counseling and talking with friends that they would assure you that this man is suicidal but they wouldn't give services for me. (Paul)

This led three of these consumer/survivors to reach at times a level of vulnerability in which they faced increased levels of disempowerment.

I felt I had been re-traumatized in the system because I ended up on this rollercoaster in and out of hospitals and using drugs. Nobody really helped me with my drug problem. (Kuldip)

Such forms of disempowerment have been identified as a main contention with regards to formalized service provision and could explain the reluctance of certain consumers to subsequently engage with mental health services. Through the lens of mental health recovery, service providers may thus have actually contributed very little by offering many of their treatments through a medium that can be construed primarily as a "crisis response". The establishment of an actual recovery process for participants, further discussed in the next theme, will thus often involve connecting with resources which are represented as outside of the formal mental health system – within consumer-run agencies, support groups or with individual peers.

4.2.2 The recovery process

a. Participants' definitions of recovery

A second emergent theme in this study involved the development and implications of the mental health recovery process for consumer/survivors. Recovery was portrayed by all participants as a unique process for each individual irrespective of diagnosis and requiring a great

deal of flexibility from support networks and treatment services. Here are three examples:

Recovery for me would mean like accomplishing what you wanted and feeling good about it, getting satisfaction. To try different things that work for myself and feel an accomplishment after that. (Scott)

Recovery? It means wanting to get better. It's saying to myself that I'll get up tomorrow, take my medication, see my doctor, see my friends, and do something about it. (Jia)

Recovery, let's see... It means I live out in the community on my own. It means I can work. I have limitations because of my health but I can go out on my own. (Fiona)

b. The importance of connectedness/involvement

For practically every participant the establishment of a recovery process involved meeting with one or more individuals who would listen to their story in a non-judgmental and supportive fashion. This would subsequently trigger an independent and progressive effort towards developing one's own sense of recovery. Through this connectedness the participants developed new skills, narratives and support systems.

I made some friends [like] my neighbour who was very important in my recovery. He was very accepting of me and when I told him about my illness, which was a big step, I deemed or had felt a need to explain to people where I had been and where I was at. He was very accepting and our friendship continued without any consequences. (Mark)

The people that I met on my journey I think. People I ended up networking with. I think that is the only positive thing I can think of right now [...] friends, people I've met. Very compassionate, very interesting, very thoughtful, very caring people, yes. (Paul)

Those who did make use of educational, rehabilitation or work programs and services stressed the presence of well established supportive networks.

I made new friends in the mental health community which was very supportive. [...] There

are social connections you can make within that community and it's good [...] for me it was a way station towards a more full life. (Mark)

Participants often found these sources of support outside of the mental health system (i.e. primarily through connecting with other peers or family). These supports were often discussed as essential in establishing a sense of recovery.

[...] people like myself who have been through it, who have been traumatized by their experiences have been the most helpful to myself. I've been able to relate to them, to share stories. We've been able to share experiences. We've been able to heal together. (Darlene)

c. Rapport with professionals

Consumer/survivors who continued follow-ups with formal treatment and support services also identified several positive characteristics about their rapport with certain professionals. They reported good contact with health providers who listened attentively to their needs, promoted a variety of treatment approaches, were consistent in long-term service provision, displayed openness and flexibility with their treatment options, and promoted accountability for their services.

[My GP] is very honest and open with me. She's open to different kinds of healing modalities. She's open to different kinds of therapies, more naturopathic. She will refer me to other people if she cannot do it herself. (Darlene)

d. Striving for goals

Moreover in developing their recovery process participants also gained some sense of purpose, meaningfulness and/or goals to strive for. Well remunerated and meaningful work, in particular, was consistently identified as a key step in their recovery and was linked to a greater sense of control over one's life. Nine out of ten participants have achieved this goal by actively becoming involved in the community with other consumer/survivors.

I run two support groups a month and I started working as a peer support worker at another mental health team. I hope [these jobs] will lead me to a bigger job [in mental health]. (Jia)

[...] I think landing the jobs in consumer groups was good. Feeling that I was impressing people with my ability to get the job done and to communicate with them on an equal footing was very good for my confidence. (Mark)

e. Medication

The place of medication within the participants' recovery narratives varied greatly. While some recognized its use as a contributor in enabling them to function on a daily basis, others stated it was detrimental to their lives.

I was on [medications] and I decided I didn't really need that. Every now and again I feel like I don't need my meds but I forget that this is what works rather than the other way around. (Mary)

I was on an anti-depressant that was really making me sick. I was going to my family doctor and telling him that this medication was making me really sick. It was at the point where I couldn't do anything because I was too sick. (Fiona)

All were concerned with its adverse effects on the body and potential for long-term harm, leading certain of the participants to often make difficult decisions with regards to the potential trade-offs involved in psychiatric drug use.

I had a real hard time [with the drugs]. I didn't want the main one, lithium. It's just, it's like just a zombie, you know? And I just resisted it for ages. I remember she put on this new one and I got an allergic reaction and ended up in [a hospital's emergency ward] (Jane)

f. The journey

The recovery process from the perspective of mental health consumer/survivors in this study was also portrayed as a starting point for a journey that involves a multiplicity of positive and negative experiences which are intricately linked within the person's life narratives. Participants were specific in explaining what these experiences meant for them and how they could incorporate healing over the course their lives.

It's like I've matured with my illness over the years and to me I think that's the key to get better. You need to understand yourself and understand what makes you sick and what happens to you. (Jia)

This participant in particular described healing eloquently as somewhat of a maturational process wherein progress is mediated by the environment in which the person is living in. In other words, for recovery to take place there appears to be a strong need for a perceived level of support, care and understanding. The role of supportive networks in the participants' stated recovery process thus could not be underestimated. Participants who held narratives of seemingly exponential change recognized being first well connected with others who respected them as human beings. Whether these networks were composed of other peers or professionals they all reflected a certain level of understanding, compassion and positive regard.

I have a group at [a hospital] I have been going to for 7 years, it's a [specialized support/treatment] group. That's been a major positive support. [...] that's probably the thing that helps the most when things are really in crisis or out of control... They know how to deal with it in a way that helps. And there's one of the leaders that I have a good connection with, she makes the most difference. (Laura)

Thus the positive impact of mental health service provision was portrayed accordingly as more profound for consumers who were treated not as psychiatric labels but as persons with the right to choose what is best for them.

4.2.3 Change

A final theme which emerged from the data concerned participants' own perspectives on changes required within mental health services to contribute to their recovery process.

a. The need for alternatives

The majority of respondents stated a need for a greater variety of supports and treatment alternatives. Several modalities such as peer-consultancy, psychotherapy (both individual and group), psycho-education, art therapy, acupuncture and orthomolecular medicine were identified as desired alternatives to traditional psycho-pharmaceutical approaches.

Some people learn in a different way. Some people learn things about themselves in a different way and talk therapy is good to a point. I think there are some things that private therapists can be more helpful in that they do music therapy, art therapy.... I wish there was some more of that provided. (Mary)

[...] sexual abuse counsellors. Psychotherapists, music therapists, art therapists, counsellors that will take you on not just for 7 weeks. I mean a long-term relationship with somebody and that sort of thing. (Kuldip)

I'd like to advocate for more alternative therapies to be covered [by medicare] and to have at least a safe house for people to have access to these alternatives. I would also like more therapy that focuses on self-care like holistic treatments – vitamins, exercising, yoga, meditation, tai-chi. I'd like therapies that are good for the mind and the body as well. (Scott)

One participant in particular debated the terminology used in health care around “alternative and complementary” healing practices. He preferred the use of “integrative healing” as a more appropriate term defining what was needed as “*a person-centred approach that puts the health of the client before ideological and economic boundaries*” (Paul).

Nine out of the ten participants also demanded that a greater role be played by consumer-run resources in providing treatment, linkages with other peers, advocacy and support services.

I think advocacy and peer support is really important. Even if it's one person at a time, if we got enough people to do it we'd be able to help our own community. (Mary)

I think the best thing is probably groups like they run [in the community], to get everyone connected, helping each other. The whole peer-support thing, it's on the rise where I am. (Jia)

b. Advanced directives

Along with increased treatment alternatives, many also requested the ability to issue advanced directives in order to preserve control over the decisions that would affect them in moments of acute illness and involuntary psychiatric treatment.

I wish there was some way I could work out a plan so that if I am in crisis or not coping I could just contact someone and they would understand what it means. At the time when you most need to have those advocacy skills, you don't have them. We would need some way to contract with someone about these issues. (Fiona)

c. Being treated as an equal

Every participant thus expressed in some shape or form the desire to have services that respects their rights as consumers and that treat them as equals.

I just like being treated as a person who is intelligent and can make my own decisions. (Laura)

Nobody wants to be treated like a sick person. Even if they are sick they want to be treated like a human being with dignity and respect. (Darlene)

We should be treated with the same respect and dignity as somebody with a physical illness. (Kuldip)

According to some consumer/survivors in this study, such a shift would entail turning away from forced treatment and soliciting voluntary contact with services.

[...] choice is what it's all about, the right to choice in treatment. It is human rights, you can't force treatment. There is one human rights lawyer who compared forced treatment to torture. It falls under the category of torture as defined in certain conventions about torture, international covenants on torture. Now, I admit that some mental health patients, schizophrenics or bipolar at times can be very hard to handle. The question is do we take a principled stand or do we just do things that are efficacious? You can be pragmatic and say "look we've got to stop these people from harming themselves or others". I personally think we need to take a leap of faith into a system that is voluntary. (Mark)

d. Empathy

The majority of participants also discussed a need to be treated with a level of compassion and empathy from treatment providers.

There's a lot of "damned if you do and damned if you don't". If you try and stand up for yourself, you're confrontational and non-cooperative but if you don't, you're seen as passive. People need to have a better range of terms to let people be people. (Fiona)

e. Accountability

Five participants also discussed a need for greater accountability amongst service providers, for consumers to be able to be included in decision-making processes further and have their concerns publicly debated.

Expenditures and monetary allocations are brokered by gate-keepers who are largely educated in an old conservative western exploitive model. They are educating people who make decisions about this. They have to be educated towards a more person-centred approach. (Paul)

The notion of various interest groups manipulating the development of mental healthcare was also of concern for four individuals in the study. The role of private interests in pushing psychiatric medication and the need to be vigilant about this issue, for example, was brought up on several occasions.

[...] for long-term preventative medicine you have to basically look outside of the standard box of medications and surgery that's been promulgated or pushed by western manufacturers. (Paul)

They don't mention about the studies that say [psychiatric drugs] don't work. They just say that they work better than some other drug and that they cause less side-effects or something. (Darlene)

I think it's come out of the press recently that pharmaceutical companies suppress adverse drug trial results. They suppress results that do not promote the sale of their medications. If you have any experience in life it should come as no surprise that they do that. They want money they want to sell the product so why should they ruin years of research with bad results from a few trials. (Mark)

Through this dialogue with study participants three main themes emerged, namely the mixed state of current service provision and its potential impact on the lives of mental health consumer/survivors, the importance of understanding the unique features of an individual's recovery process and the necessity of change in the field of mental healthcare towards a more rights-based form of service provision which promote equality and fairness. Each theme brings support to recent inquiries into alternative models of service provision based on the concept of recovery which will be further discussed in the next section.

4.3 Limitations of the study

The use of an exploratory, qualitative approach to outline consumer/survivor experiences within mental health services limits the extent to which their views can be generalized to the

larger community. Given the relatively small scope of this pilot project it was thus not possible to pursue a full grounded theory approach which involves theoretical sampling to saturation (Cresswell, 2007). This, in turn, limited our search for themes and common threads in users' experiences. However, as we have outlined, there was significant overlap found among the experiences of mental health consumers/survivors in this study to build on other larger reports concerning the state of mental health service provision (Kirby & Keon, 2006). The few themes which emerged from our data offer support for larger inquiries of this kind to further examine the context of current mental health service delivery systems from consumer/survivor perspective.

4.4 Observation

Upon completing the search for themes, I became aware of an interesting find which warrants some particular note. While the sample size for this study was relatively small and heterogeneous, I still noticed that younger participants held more positive narratives of formalized service provision than older participants. This said, I had insufficient data from this sample to make any form of claim. However, the hypothesis of service provision having changed over the years and how this may now have provided for increased positive outcomes in younger mental health consumer/survivor populations warrants further investigation from future research.

CHAPTER V - DISCUSSION

Throughout the course of this study, mental health consumer/survivors offered unique perspectives on the recovery process. They also demonstrated their own understanding of the role they play as stakeholders in the health care system and outlined potential gaps in current service provision. Finally, they offered potential insight into the impact of recovery-oriented practices. In this last section, I will discuss the significance of these findings in light of other recent developments in mental health reforms of British Columbia and the rest of Canada.

5.1 Regionalized mental health reform: individual pathology versus citizenship

The development of the current formalized mental health systems across Canada can be understood as a product of competing discourses among several stakeholders namely: professionals, administrators and communities (Morrow, 2004). If we consider the history of mental health policy development in British Columbia as an example, we can safely say that it has not been a linear process. Rather, it has remained dependent primarily on how these various stakeholders have portrayed people who live with mental illness (Morrow, 2004).

Definitions of “mental health”, “mental illness” and “psychosocial disability” have all driven both legislative and infrastructure changes which affect the lives of thousands of British Columbians who require such services (Morrow, 2004). Thus we come to a key paradox in policy discussions wherein we must ask the following question: What is the driving force behind our current mental health policy? Rioux and Valentine (2006) have discussed how formulations of disability have a profound impact on human rights legislation and access to resources. According to Rioux and Valentine, current policy developments in mental health are driven by an unstated divergence between the community and government in perceptions of “inclusion” and “citizenship”. While the former may ask for entitlements such as proper access to more treatment or support programs, the latter is focused on cost-containment and “discretionary benefits”, effectively limiting the access and development of specialized programs. Tensions between these stakeholders remain around which approach to pathology drives policy decisions. An

individual-focused formulation of mental illness, wherein disadvantage is individualized through biomedical, DSM-related (Diagnostic and Statistical Manual of Mental Disorders) criteria allows discretionary control over interventions in mental health care. Citizenship in this approach becomes secondary to the relief/cure of objectively measurable symptoms. As a case in point, consider a young person suffering from depression. The focus for psychiatric services in this case is the assessment of symptoms by degree of perceived severity, the assignment of a working diagnosis and subsequent stabilization of this mood disorder either through psychotherapy, pharmacotherapy or a combination of such treatments. While DSM-IV criteria cover multi-axial assessments of mental illness (APA, 1994), any person working in the field of mental health may also notice that treatments primarily emphasize the stabilization and management of symptoms through medication.

By contrast social formulations of mental illness such as approaches based on psychosocial disability assume that mental illness is not inherent to the individual but rather is a consequence of the environmental structure where social determinants of illness can be identified and addressed. Again, let us consider this young person suffering from depression. What is preventing this individual from participating in society, from enjoying a sense of full citizenship and being able to make the decisions that matter to him? Priority here is shifted from the relief of symptoms to emphasizing preventative/holistic care in enabling a sense of equal citizenship (Rioux & Valentine, 2006). Mental health is thus turned on its head. It no longer remains in the discretionary hands of the service provider or administrator but verily becomes a fundamental right of the consumer/survivor. A social pathology approach to mental illness may drive our knowledge base and understanding of mental illness as a psychosocial disability wherein current environments have failed to accommodate to people's differences rather than placing the onus of responsibility solely on the individual's perceived "illness" (Rioux & Valentine, 2006).

Recent reforms in mental health under the 1998 plan of the B.C. government intimated a willingness to shift our understanding of mental illness from a purely professional perspective

of individual pathology towards a more social perspective where consumer/survivors would be given a say in how they wish to approach treatment (BC Ministry of Health, 2002). Yet, if we observe the actual implementation of these reform plans through the establishment of regional health authorities in 2001, we may uncover that the basic assumptions for service access have remained largely circumscribed to individual pathology (Morrow, 2004). As evidence, one may observe Vancouver Coastal Health's "building on strengths" policy document (2006) where there appears to be a real focus on enhancing the place of community rather than individual treatment approaches to pathology. This document outlining the future of services aims for "people with mental health and addiction problems [to become] fully integrated into community life" (Vancouver Coastal Health Authority, 2006). This same regional health authority yet outlines the establishment a "continuum of care" which stipulates clear restrictions on access to treatments/supportive resources based solely on a physician's appraisal of the individual's mental health.

*Mental illness can strike anyone at anytime. It comes in many forms and our specialized care teams provide help for such conditions as schizophrenia, bipolar disorder, depression, behavioural problems, and dementia. **Only your doctor can determine if you need a referral to such services** (Vancouver Coastal Health Authority, 2008).*

Through this hierarchical tiered-care model, access to expensive hospital based and/or specialized treatments are thus effectively stymied by medical practitioners who are themselves trained to primarily operate under an individual pathology lens. While the regional health authorities speak of a "strengths-based" and "community focused" model of care, access, control, development and outcomes of such services remain largely determined by service providers instead of consumer/survivors' or communities themselves (Morrow et al., 2006).

Consumer participation, while portrayed as central in the 1998 mental health plan, remains to this day largely outside of current reforms due to an absence of mechanisms of participation and input for consumer/survivors and their families (Morrow et al., 2006). As such, not unlike current developments in other countries, we find that policy makers and service

providers in British Columbia effectively use the wordings of mental health recovery on paper but retain little of the core values in their practices (i.e. entertaining a sense of purpose and self-determination in the client) (Hui & Strickley, 2007). This is not to decry every aspect of current services but to acknowledge that we are still very far from a “recovery-oriented” mental healthcare system. Operating still from a traditionally “top-down” perspective of service provision wherein the quality of care is never fully assessed or inquired upon, we find that consumer/survivor involvement within this system remains minimal (Morrow, 2004).

The avoidance of consumer/survivor involvement in the healthcare system for the goal of cost-containment is not new. Such measures have appeared throughout the deinstitutionalization movement with the idea that pharmacotherapy and community organizations alone would see psychiatric patients being supported back in the communities (Davis, 2006). Using parameters of individual pathology service providers can remain discretionary about who to serve and how to serve them best (Rioux & Valentine, 2006). Consequently, professionals and administrators remain the main stakeholders in our current mental health system and have largely left consumer/survivor and community input out of this discourse (Morrow et al., 2006). “Evidence-based” approaches have even been chosen to rationalize and limit current expenditures in mental health, relegating once again the majority of resources towards narrow biomedical approaches of symptom reduction (Davis, 2006). As a case in point, I would again mirror what participants spoke of in this current inquiry, namely the paucity of treatment options for individuals suffering from disorders such as Borderline Personality Disorder which traditionally respond poorly to medication or short-term psychotherapy. Given the fact that persons living with such personality disorders, for example, not only respond poorly to short-term psychotherapy/medication but also suffer from a fair bit of stigma, few resources have been allocated for the proper assessment and treatment of clients living with this condition in the formalized mental health system (Aviram, Brodsky & Stanley, 2006). Rather, these client populations have increasingly become at great risk of being labelled by services as “frequent flyers” and thus get restricted access to longer-term treatments which might prove beneficial to them. This leaves multitudes of people suffering from

such disorders from obtaining any form of tangible help (Aviram et al., 2006).

To sum up, I would like here to return to what the participants in this study discussed regarding their recovery. All mentioned that the beginning of their recovery process involved being treated as an equal. Each of these persons faced trying circumstances throughout their journey in understanding, living with and sharing their mental illness. Yet practically every single one of these participants related stories of being or becoming fully involved in society and of having met people or services which facilitated this goal. Mental health for them is much more than the treatment of individual psychopathology. It verily affects both the person's conception of self and consequently her ability to participate in society. Accordingly, an individual pathology approach alone may never provide the necessary perspective to treat mental health as an essential right of every person. A primary focus on social determinants of mental health thus becomes essential for future reform.

5.2 Supporting the Kirby senate commission

When observing the current state of services, much of the findings discussed in the previous section support a recent major governmental inquiry, the Kirby Senate Commission, which examined the provision mental healthcare in Canada (Kirby & Keon, 2006). As described in the commission's final report for Parliament, the experiences of poor service provision for mental health consumers vastly outweigh the positive. Several complaints made about the state of mental health service provision in our study reflect those found in the Commission. Lack of understanding and compassion from professionals, restricted or non-existent access to services as well as frustration in attempting to ask for help in dealing with mental health problems were all factors of contention identified by the report (Kirby & Keon, 2006). Moreover, many of the suggested recommendations in this study, such as the right of issuing advanced directives, the need for more collaborative treatment approaches and consumer/survivors' reservations with regards to forced treatment also mirrored recommendations from the commission (2006).

The significance of this report for the direction of mental health care in Canada cannot be understated. Among some of the directions suggested is the admonition that “mental health promotion can be achieved through *effective public health and social interventions*” (emphasis added, Kirby & Kleon, 2006, p.413). These objectives, the report continues, are achieved through collaboration among the various stakeholders. As such, the majority of mental health outcomes (i.e. symptom stabilization) may be secondary to other social and economic outcomes. Finally, the sustainability of mental health promotion programmes, which is crucial to their effectiveness, requires “the involvement of all stakeholders, ownership by the community, and continued availability of resources [to] facilitate [this] sustainability” (Kirby & Keon, 2006, p.413). While further research and evaluation of programmes is encouraged by the commission to increase our knowledge of effective interventions, there is also a stated need to determine if this evidence base can be applied across different cultures and settings. As such, these four guidelines for a national mental health strategy again support the idea of mental health promotion as requiring a recovery-oriented system of care which involves consumer/survivors and communities.

5.3 Finding alternatives

Interestingly, the data gathered in this study offered some insight into how the lack of recovery-oriented service provision may in fact push consumer/survivors to find sources of meaningful support and treatment outside of the formal mental health system. Also of particular note was an apparent contrast between those who had experienced what could be construed as collaborative care practices wherein the social determinants of health and significance of a recovery process were actually explored and those who did not. The former group of consumer/survivors seemed to hold more favorable perceptions of mental health services while the latter, quite understandingly, did not.

With regards to the process of recovery we return to Jacobson and Greenley’s (2001) conceptualization of this model wherein both internal and external conditions were outlined. If we focus solely on the internal conditions described by Jacobson and Greenley (2001) we

find that consumer/survivors interviewed in this study have identified contributing factors similar to those discussed in that particular conceptual model. Hope, healing, empowerment and connectedness were all covered and included at some level within participants' narratives of recovery. However, we may argue that connectedness apparently weighed more in establishing an initial sense of recovery. Upon reflecting on our findings, it was apparent that a discrepancy in narratives could even be seen with regards to the presence or relative absence of multiple sources of support. Whether through family members, peers or professionals, connectedness offered the opportunity for these consumer/survivors to subsequently enact significant change in many other areas of their lives and thus feel a sense of empowerment with their decisions. This small scale study thus echoes an already overwhelming amount of evidence for the essential role of support in recent mental health literature (Corrigan, Calabrese, Diwan, Keogh, Keck, & Mussey, 2006; Corring, 2002; Deegan, 2005; Mancini, Hardiman & Lawson, 2005).

Discussions of the development of an individual sense of recovery in this study also provided evidence to potentially describe some of the more influential mechanisms by which social networks impact psychological well-being. Connectedness, as previously discussed appeared to correlate strongly with the subsequent maintenance and promotion of mental health. A model put forward by Cohen and Wills (1985) may offer an explanation as to how social relationships have beneficial effects on mental health (Cohen & Wills, 1985) In the *main effects model* of Cohen and Wills, social influence from peers provides individuals with normative guidelines to develop health-relevant behaviours. Connectedness within these networks may also directly contribute to positive states of well-being, such as purposefulness and self-worth. Furthermore, the location of a supported individual within broader networks may then enhance the likelihood of participation in other health-promoting programs and services (Cohen & Willis, 1985). As discussed by some of the participants in this study, the presence of supports greatly influenced later linkage with other programs. Thus, we find that the recovery process may often involve a certain degree of connectedness with others in order to produce positive outcomes.

5.4 Implications

As previously discussed, the concept of recovery has been part of British Columbian service providers agendas since 1998 (Morrow et al., 2006). However, if we take as evidence the consumer/survivor-based information in this report as well as those found in Kirby Senate Commission report (2006), we find that current state of mental health service provision is portrayed as limited in scope and does not, in many ways, reflect the principles of a recovery-oriented model (Kirby & Keon, 2006). This supports other findings by Hui and Strickley (2007) which showed a tendency of service providers to hold a “recovery rhetoric” in their policy documents while failing to integrate these principles in practice settings (Hui & Strickley, 2007). To understand the impact of such limitations in policy we may turn to recent figures of service utilization. A report by Vasiliadis, Lesage, Adair and Boyer (2005) observed that over the course of a one year period, use of resources for mental health reasons in British Columbia were rated as one of the highest in the country at 11.3% of all healthcare service demands in the province. The study further indicated that mental health service usage occurred primarily through general medical services. Individuals who requested help with mental health issues were thus likely to come in contact their family physicians first, rather than go towards specific mental health resources (Vasiliadis et al., 2005). Given the push for “continuums of care” by regional health authorities this first line of professionals have become the assigned gate-keepers for access to further treatment services (Vancouver Coastal Health Authority, 2006). Access to proper care consequently remains subject to the dominant discourse of psychiatry. From what information we can gather from this current inquiry, the standard approach with problems of this nature by both general practitioners and psychiatrists according to a medical model of individual pathology will likely be pharmacotherapy with little, if any, input from the individual, until symptoms either recede or worsen. In the latter case, access to more specialized treatments may be offered. The consumer/survivor, in this scenario, is again relegated to the role of passive recipient of services and must enter a state of extreme need or crisis in order to become “worthy” of intervention. This approach to mental health is not new. In fact, it remains relatively unchanged from the days

of deinstitutionalization (Nelson, Potasznik & Bennet, 1983). If we are to promote more social interventions, as suggested by the Kirby Senate Commission (2006), then we must consider opening up access and referral systems to mental health care from not only professionals in fields other than psychiatry, such as psychologists, social workers and nurses, but also from consumer/survivors themselves. From a mental health practitioner's standpoint, this would entail more collaborative work between the mental health clinician and the actual person living with mental health issues as well as her supportive networks, including family and consumer/survivor advocacy groups. In contrast to traditional models of treatment planning which emphasize medication compliance (Jensen & Wadkins, 2007), practitioners here are encouraged to provide a range of options (i.e. group psychotherapy, art/music therapy, individual counselling) which take into consideration the person's own personal narratives of mental illness.

In light of such information, we could thus argue that there is a need to better understand and map out service utilization with a recovery model in mind in order to pinpoint the various sources of contention throughout the healthcare system. By observing the quality of initial contacts with mental health services as well as the subsequent linkages (or failure to link up) with supportive networks, we may thus better appreciate an individual's difficulties living with mental illness within our current formalized mental health system. Future research, thus, must now begin to focus further on the social determinants of mental health and where potential needs and/or gaps in service may be addressed for various client populations. If we treat mental health care as a fundamental right, then the aforementioned discretionary nature of services based on individual pathology may eventually be replaced by a universalized system which treats each consumer/survivor with the dignity and respect they deserve.

Again, based on information gathered from inquiries such as the Kirby Senate Commission (2006), we may further understand the importance of including the views of consumer/survivors in all aspects of mental health provision, particularly service evaluation. As demonstrated by this current study, mental health consumer/survivors hold a wealth of

knowledge from their own experiences in dealing with mental health care. The inclusion of their perspectives in the development and subsequent determination of outcomes for future mental health programmes is thus essential in establishing a system of care which can truly be deemed “recovery-oriented”.

Given these aims, one may find that social workers are in a unique position to implement such change due to their training in holistic and collaborative approaches to mental healthcare. The guiding principles of the recovery model, namely self-determination, choice, connectedness and the right to equal treatment are all very similar to the guiding principles of the social work practice (Kirby & Keon, 2006; IFSW, 2005). Whether through connecting consumer/survivors with service providers or advocating for better program evaluations, social workers offer an essential role towards a progressive shift to recovery-oriented services. Building on the strengths of consumer/survivors from every social background, social workers may, in fact, serve as bridges between each group and promote sustainable solutions for communities with different needs.

Future research into consumer/survivor involvement with formal mental health service provision may focus further on the themes found in this current study. While saturation was never achieved because of small sample size (10 individuals), it would be interesting to interview more consumer/survivors regarding the three major themes found in this inquiry, perhaps even by approaching different age groupings of this population. Finally, using some of the knowledge gained from including service users in mental health discourses, research could potentially turn towards the development of a continuous qualitative evaluation system which may bring potentially greater transparency and accountability to mental healthcare service provision.

CHAPTER VI CONCLUSION

This qualitative study, while small and limited in terms of scope, provided an in-depth portrait of the knowledge held by the main stakeholders in mental health care, namely the consumer/survivors. The subjective experiences of the 10 individual participants of this inquiry offered a critical outlook for current mental health services, one which appears all too often on the margins of research and policy. Yet these individuals' hope, desire for change and continued participation within this system on some level or another, despite continued struggles with psychosocial difficulties, provide a living testament of their commitment towards a recovery-oriented system of health care. By listening to consumer/survivors, we may learn more about social determinants of mental health and their accompanying outcomes. This may even allow for a better focus on spaces of contention in service provision. Using this knowledge, mental health practitioners and social workers, in particular, may promote more collaborative forms of treatment planning which could contribute towards the establishment of an overall process of recovery. This ultimately may provide a significantly more meaningful vision of mental health for consumer/survivors in Canadian society.

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APPENDICES APPENDIX A

Invitation to Participate in a Study of: Recovery and Experiences of Mental Health Consumers/Survivors

Purpose of the study

- Provide a voice for mental health consumers/survivors to discuss their experiences living in Vancouver.
- Increase our understanding of consumers/survivors' experiences in relation to mental health services;
- Identify supportive and problematic aspects of mental health services;
- Uncover the impact of recovery-oriented practices on mental health consumers/survivors.

What's involved?

- up to 3 hours, including an interview of approximately one hour in a location of your choosing at a time convenient for you. Participation may also entail an additional 1 or 2 hours reviewing and editing a transcript of the interview and commenting on a draft of the study report.
- A tape recording of the interview for the purposes of this study.
- Findings from this study will be used in a student's graduating essay as a requirement for graduation from the MSW program.

Who's Invited?

We are aiming to recruit persons over 19 years of age who:

- Have received psychiatric care;
- Have used community-based mental health resources.

If you are interested in getting more information or participating, contact Philippe Roy, masters of social work student at:

[phone] or [email]

APPENDIX B
Consent Form

Listen to Me:

A Look at Experiences of Mental Health Consumers/Survivors

Principal Investigator: Brian O’Neill, Associate Professor

[email address]

Co-Investigator: Philippe Roy, Social Work Graduate Student

University of British Columbia

[email address]

Purpose of the study

Recent evidence by the Canadian Centre for Policy Alternatives revealed that there are limitations in the inclusion of consumers’ views within the mental health services of Vancouver. Notably, there have seemingly been few efforts towards addressing the particular needs of consumers in their process towards a personal sense of recovery. In order to increase the understanding of how services may be improved this study will attempt to provide a portrait of the life of these individuals and how their experiences are being shaped by the apparent lack of collaborative practices within the mental health field.

Study Objectives

In this study, we aim to provide a voice for mental health consumers/survivors to discuss their experiences living in Vancouver. We are aiming to recruit persons over 19 years of age who have experiences dealing with psychiatric care and have currently or in the past used community-based mental health resources. If you have been treated for any mental health condition through medication and/or individual or group therapy of any kind, we want to hear from you.

Through this inquiry we aim to increase our understanding of consumers’ experiences in mental health services and identify potential supportive and problematic aspects of the service delivery process. Finally, we hope to examine the current state of recovery-oriented practices within the community. You are invited to participate in this study because you have used community mental health resources.

This study is being conducted as a requirement for a research course for a graduate student involved in the Masters of Social Work Program at the University of British Columbia. It will also be incorporated in a graduating essay as a requirement for graduation from the program.

Study Procedures

This study will require a total of up to 3 hours of participation and will include:

- A private interview of approximately one hour in a private place of your choice.
- You're being asked to comment on:
 - living with mental health issues in Vancouver;
 - your views and experiences on the process of recovery;
 - current mental health policies and practices;
 - the level of participation you have in mental health services;
 - potential changes needed in mental health services.
- Tape recording of interviews and transcription by the interviewer
- An additional 1 or 2 hours reviewing and editing a transcript of the interview and commenting on a draft of the study report.

Confidentiality

- Your identity will be kept strictly confidential
- Both the co-investigator and the principal investigator will have access to the tape of the interview for the purpose of transcribing, and will substitute a code for your name if it occurs during the interview; your name will not be in the transcript
- Documents will be identified only by a code and kept in a locked filing cabinet; computer data will be password protected
- You will not be identified by name or any other personal information in reports of the study.

Contact for information about the study:

If you have any questions or desire further information with respect to this study, you may contact Philippe Roy by phone or by email.

Contact for information about the rights of research subjects:

If you have any concerns about your treatment or rights as a research subject, you may contact the Research Subject Information Line in the UBC Office of Research Services at 604-822-8598.

Consent:

Your participation in this study is entirely voluntary and you may refuse to participate or withdraw from the study at any time.

Your signature below indicates that you have received a copy of this consent form for your own records.

Your signature indicates that you consent to participate in this study.

Subject Signature Date

Printed Name of Subject Date

APPENDIX C

Interview Questions – Mental Health Consumers

Life in Vancouver

1. Can you please describe your experiences living with mental health issues in Vancouver?
2. Have you met any specific challenges or advantages living here?
3. Who or what has facilitated your life in dealing with these mental health issues?

Recovery

4. What is the meaning of recovery for you?

Participation

6. In what ways would you like to participate in the decisions that affect you?
7. Are there any alternative policies or practices you wish were available to help you?

End

8. Do you have any comments you would like to add before we end this interview?

APPENDIX D

**University of British Columbia's Behavioural Research Ethics Board
Certificate of Approval**

*The University of British Columbia
Office of Research Services
Behavioural Research Ethics Board
Suite 102, 6190 Agronomy Road,
Vancouver, B.C. V6T 1Z3*

CERTIFICATE OF APPROVAL - FULL BOARD

PRINCIPAL INVESTIGATOR: Brian O'Neill	INSTITUTION / DEPARTMENT: UBC/Arts/Social Work & Family Studies	UBC BREB NUMBER: H07-02742
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INSTITUTION(S) WHERE RESEARCH WILL BE CARRIED OUT:

I will recruit subjects at community organizations dealing with mental health consumers. Interviews will be conducted either in the subject's home or in a public location which is accessible to the subject. Steps will be taken to insure the privacy of each interview in negotiating with the subject where he/she prefers to be interviewed. The recruitment process will unfold gradually - I may not need to recruit in all the organizations I have identified, depending on the response to recruitment flyers. Letters from agencies agreeing to recruitment will be submitted once we receive them.

CO-INVESTIGATOR(S):
Philippe Roy

SPONSORING AGENCIES:
N/A

PROJECT TITLE:
Listen to Me: Experiences of Recovery for Mental Health Service Users

REB MEETING DATE: December 13, 2007	CERTIFICATE EXPIRY DATE: December 13, 2008
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DOCUMENTS INCLUDED IN THIS APPROVAL:	DATE APPROVED: February 7, 2008
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<u>Consent Forms:</u>		
Consent MH	v2	January 15, 2008
<u>Advertisements:</u>		
MH Flyer	v2	January 15, 2008
<u>Questionnaire, Questionnaire Cover Letter, Tests:</u>		
Questionnaire MH	v1	November 26, 2007

The application for ethical review and the document(s) listed above have been reviewed and the procedures were found to be acceptable on ethical grounds for research involving human subjects.

**Approval is issued on behalf of the Behavioural Research Ethics Board
and signed electronically by one of the following:**

[names of board members]