

Leadership in the Consumer and Survivor Movement in Western Canada: A Constructivist
Grounded Theory Study

by

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Abstract

Leadership in the psychiatric consumer and survivor movement is a relatively unexplored and unstudied phenomenon. This study examined leadership practices of 19 psychiatric consumers and survivors in western Canada using constructivist grounded theory. Comparing leadership in organizations controlled by consumers and survivors to organizations not controlled by people with mental health problems, such as mental health charities, the study found commonalities in organizational needs, activities, and struggles, except that poverty was a larger barrier for consumer and survivor organizations. The findings refuted the notion that consumer and survivor organizational leadership was more fractious and fragile than their non-consumer counterpart. The study found three attitudes underlying effective movement leadership and the numerous tasks leaders must accomplish to maximize their chances of success. Participants voiced the centrality of the journey to becoming a leader, from victim to survivor to inner warrior. They voiced that self-realization was leadership's basis. The study concluded that the mainstream system – the psychiatric system and the government – are as much part of the solution as part of the problem; that is, the social movement can work with the mainstream system, not necessarily adopting its values, but aiming to reform the system from the inside. The findings corroborated with three out of the four components of authentic leadership theory, with implications for refining social movement leadership practice and furthering theory development.

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Chapter One

Introduction

The idea for the dissertation began as an effort to reconcile what mental health social work has historically entailed with the new directions social work might travel in its critical or radical manifestations. Historically, mental health social work entailed the messy, complicated interpersonal entanglements within bureaucracies, the ethical and moral predicaments around forced committal of patients to locked psychiatric wards, and an unsatisfying, demoralizing role as a gatekeeper of resources and goods within a prevailing logic of scarcity. The dissertation's genesis comes from the perspective of a social movement whose reason d'être is a critique of the mental health system and the dominant social order which gives the system both its power and its dysfunctionality.

Social work is ostensibly a pillar of the modern nation state, one of the lubricants preventing open class warfare from breaking out within the state and as such is firmly ensconced within the routine relations of power and privilege buttressing Canada's neoliberal governmentality (Mullaly, 2007; 2009). Yet the profession is also conversant with perspectives from society's margins, has been a powerful force for social reform, and at times contemplates and unleashes quite radical ideas and practices within the profession's sphere of influence (Chan, 2018; Jennissen & Lundy, 2011; Knight, 2005). Social work may be conceived of functioning along a continuum containing two poles: social control and social justice (Robbins, Chatterjee, & Canda, 2006). Critical social work, including a Canadian approach of socialist social work known as structural social work, is committed to moving the profession inexorably towards the social justice pole even if this endeavor encounters major obstacles within the profession's mainstream (Carniol, 1992; 2000; Fook, 2002; Moreau, 1989; Mullaly, 2007; 2009). An

important aspect of critical social work is the continuing discursive engagement and political alliances with various social movements in their struggle against the Canadian colonial state, against a polity and cultural assemblage otherwise known as a colonialist white supremacist capitalist patriarchy (hooks, 1981). The psychiatric consumer and survivor movement is one of those social movements in this struggle and forms the centerpiece of the dissertation. The kernel of knowledge I wish to examine is leadership practice within this social movement.

Statement of the Research Problematic: Leadership Practice in the Psychiatric Consumer and Survivor Movement

The psychiatric consumer, survivor, and ex-patient movement (“the movement”) in Canada aims to transform a stigmatized, discriminated identity – the mental patient – into a socially valued one. The movement is part of, yet separate from, the broader disability movement. Paul Longmore suggested there is not one single homogenous disabled peoples’ movement but more than a dozen movements that since the 1970s have joined together politically (Pelka, 2012). The consumer and survivor movement is one and yet also only a convenient moniker encapsulating at least four distinct but related groups: psychiatric consumers, psychiatric survivors, anti-psychiatry, and Mad (Diamond, 2013).

The movement in Canada has experienced many ups and downs, with seemingly as many setbacks as gains (Everett, 2000; O’Hagan, 2014; Shimrat, 1997). Movement leadership has been identified as one reason why there has been limited success because the leadership practices have been inconsistent and fragmented (Hutchison, Arai, Pedlar, Lord, & Whyte, 2007).

“Leadership practice” may refer to the processes by which people with mental health problems effectively (or not so effectively) coordinate efforts to achieve a common goal, in a spirit of egalitarianism without rigid hierarchical constraints. It may manifest in shared values, a

common framework of goods, and shared responsibility among teams (Lord & Hutchison, 2007; Packard, 2009). Please think of the above definition as just a starting point on conceptualizing leadership practice because the weight of this dissertation is to craft a conceptual framework of leadership practice from movement participants-actors-leaders themselves.

Peer support is often acknowledged as the movement's anchor (Campbell, 2005; Clay, 2005). Peer support refers to a process of sharing one's lived experiences of disability to another, in a relationship of equality, uncovering strengths, dreams and possibilities (Lord, 2010). In peer support, mental differences and mental health problems are not only accepted but embraced (Lord & Hutchison, 2007). The philosophy of peer support comprises of both care and emancipation (Campbell, 2005). Care is the mutual aid that people in similar social locations can offer one another in a relationship of empathy and respect. Care addresses social isolation, counteracting the dominant society's harshness and indifference. Emancipation comes from civil rights principles, offering advocacy, human rights education, and envisioning what a just world would look like. Consciousness raising and activities to promote disabled people's solidarity are also common techniques. Leadership is the flip side to peer support as I believe effective peer support leads to good leadership. This study will examine this assumption.

Although the relationship between leadership practice and peer support is an intriguing and important one, in the current study I will concentrate on leadership practices and give only secondary consideration to peer support. This is because my personal knowledge, responses from movement actors, and extant theory suggest leadership practice cuts to the heart of the set of problems facing the consumer and survivor movement (personal communications: Jean Beckett, June 6, 2016; Regina Casey, 2007; Carmela Hutchison, July to August 2014) (Morris & Staggenborg, 2004; Riger, 1984; Staggenborg, 2012). The question of peer support has also

been extensively studied (Mental Health Commission of Canada, 2009; O'Hagan, Cyr, McKee, & Priest, 2010), but the notion of leadership in this movement receives much less theoretical attention (Casey, 2009). I argue that leadership practice is a prime determinant in shaping the consumer and survivor movement's long-term success (or lack of success). However, this leadership is typically practiced from received wisdom, personal preferences, organizational pressures, and unexamined ideological commitments. The untheorized nature of leadership practice is problematic because it inhibits a serious examination of possible options and courses of action and does not provide a concrete basis for evaluating and correcting the movement's mistakes. The dissertation aims to gather empirical data on and formulate from the everyday experiences of movement actors a conceptual framework of consumer and survivor leadership practice. Leadership practice is under researched in most social movements (Morris & Staggenborg, 2004). The proposed study would address the dearth of knowledge on consumer and survivor leadership, examining the issue both on its intrinsic merits and taking a comparative perspective of social movements.

The Contribution to Knowledge Development

The current study's main objective is to assist in crafting a conceptual framework of leadership practice from the personal experiences of psychiatric consumers and survivors, an area rarely researched. The overall research question is elucidating the manner that leadership is practiced within the consumer and survivor movement and how this leadership would shape peoples' experiences within the mental health system. The eventual goal – my study will only be one small step in a larger process – is to build communities of movement leaders engaged in critically examining the relationship between circumstance, action, and consequence in their own situation (Kemmis & McTaggart, 1988). Also, I pose the question whether the unofficial,

marginal, even abject knowledge forms expressed by people experiencing distress can make any contribution to theory development (Ingram, 2005; Voronka, 2015). That is, is it possible people with mental problems produce unique knowledge forms and social practices that destabilize and reinvent that which is commonly known as sound mental health and sound leadership?

My Personal Perspective on Consumer and Survivor Leadership

I explain how I became involved with the consumer and survivor movement to provide greater transparency and accountability to the dissertation that follows. I became interested in the movement because I'm a psychiatric consumer, a patient in ongoing psychiatric care and a user of antidepressant medication for sixteen years. I have never been hospitalized. From first working within the disability movement it was pointed out that I too have a disability – anxiety stemming from a history of childhood abuse. Impressed with the disability movement's cohesion, solidarity, and effectiveness in offering peer support and facilitating policy change, I hope there might be a knowledge translation and exchange from other social movements to the psychiatric consumer and survivor movement, as others have also envisaged (Chamberlin, 2012; Everett, 2000; Hockman, 2010; Morrison, 2005; Pelka, 2012).

The Organization of the Dissertation

The present chapter presents the dissertation's background and rationale. The second chapter provides historical perspectives on the psychiatric consumer and survivor movement, including its relationship with government, the idea of recovery, and the notion that the movement is a fragile one. The chapter also gives literature reviews and critical analyses of social change leadership and resource mobilization theory. Chapter Three explains the methodology and procedures used to collect information for the study, constructivist grounded

theory. It lists the research questions and describes the sample selection and the sites where research was conducted.

Chapter Four is the first of three chapters describing the findings. It describes the organizational context for leadership, comparing consumer and survivor-controlled organizations with the non-consumer controlled organizations. Many commonalities are apparent – common organizational functions, leadership tasks, and organizational struggles – when comparing these two types of organizations. The chapter then describes the leadership issues specific to consumer and survivor organizations.

Chapter Five details the attitudes and activities comprising what participants would consider to be successful leadership within the social movement. A wide variety of leadership tasks are described, including the necessary, but very difficult, requirement for movement leaders to enter the polity. Chapter Six describes the relationship between participants' experiences within the mental health system and their leadership practice. Participants spoke of their developmental journey, from victimhood to empowerment, and they described the system, be it mental health or the government, as an entity that is as much part of the solution as part of the problem.

Chapter Seven is a summary and discussion of the findings. Emerging from the various codes and categories comprising the findings, the chapter presents the leadership challenges facing the participants and highlights their unique, innovative leadership responses. The conceptual framework of leadership derived from the findings bears a marked similarity to authentic leadership theory, and this is discussed. Leadership's negative aspects, which may have escaped the appreciative glances of both the participants and me, and thus missing from the study, are discussed.

Chapter Eight is the concluding chapter. It discusses the dissertation's knowledge contributions, assesses the study's rigor and the study's strengths and limitations, poses directions for future research, and presents concluding reflections.

Chapter Two

Literature Review

To understand how psychiatric consumers and survivors coordinate, talk with, talk back to, manage, inspire, criticize, role model, live out the values, lead a social movement – in short, practice leadership – it is necessary to base this understanding in a body of knowledge. In a study aimed at an improved understanding to accurately guide the subsequent action, I will critically review and evaluate one framework and one theory relevant to the practice of consumer and survivor leadership: the framework of social change leadership and resource mobilization theory. In explaining these two bodies of knowledge, I pose the following evaluative questions. What does it contribute to our understanding of consumer and survivor leadership? What does it assume? What does it leave out, or get wrong?

The chapter starts with a discussion of subgroups within the consumer and survivor movement and the historical development of movement leadership. To provide the necessary context, I then describe two major events that have significantly impacted the Canadian consumer and survivor movement: Ontario's mental health policy reform and the Mental Health Commission of Canada. These events set the scene for the current opportunities and constraints facing the movement. Then, I describe recovery, a powerful, unifying idea and practice modality for both movement leaders and mental health system planners. I assess the utility of recovery within current efforts at mental health reform and the relationship between recovery and movement leadership.

Next, I review the social change leadership framework, built from research with activist communities (Ospina et al., 2012). The chapter closes with a discussion of resource mobilization

theory, the most influential theory explaining social movements today (Edwards, 2014; McAdam, McCarthy, & Zald, 1996).

Leadership practices by people with mental health problems are under researched and inadequately theorized in both the leadership and the social movement literature. The current study addresses this gap in the literature.

Subgroups within the Psychiatric Consumer and Survivor Movement

It is good practice to be careful about using labels, and sometimes not use them at all, because they may mislead, even wound. Thus, the following discussion of various groupings within the movement should be taken with a grain of salt. Indeed, movement leaders often circulate between one or another of the groups and may identify with many or all of them simultaneously depending on the audience (Diamond, 2013). Even the most well-known distinction between consumer and survivor is more mirage than truth. However, I provide these descriptions to show that there are major identity differences and philosophical debates within the movement, related to leadership theory and the social movement framing process.

Psychiatric consumers (“consumers”) might describe themselves as service users of psychiatric care who want to humanize and reform the mental health system: decreasing the power differential between the mental health professional and the service user and creating independent organizations controlled by service users modelled upon Ralph Nader’s notion of radical consumerism (Bollier, 1997; Lord, 2010; Mowbray, Moxley, Jasper, & Howell, 1997). Psychiatric survivors (“survivors”) might describe themselves as people opposed to psychiatry outright, seeing themselves as having only *survived* psychiatric treatment instead of deriving any benefit from it. Survivors emphasize iatrogenic harms and adverse events caused by psychiatry, felt to result from the damaging effects of involuntary hospitalization, involuntary community

treatment, psychotropic medication's adverse effects, and electroconvulsive therapy (e.g., memory loss) (LeFrancois, Menzies, & Reaume, 2013). Survivors do not believe psychiatry deserves to be called a science (Our Voice, 2015a). There are commonalities between consumer and survivor approaches but also deep conflicts on values, strategies, organizational forms, and underlying assumptions (Everett, 2000; Morrison, 2005; Voronka, 2015).

In addition, there are five other applicable constituencies. There are also people who identify as having mental health problems but only a marginal connection, with many having none, to the movement. First, there are the chronically homeless people experiencing psychosis, with great difficulty communicating understandably. They may be, as Everett (2000) suggested, impossible to reach, even for those movement leaders who themselves had been homeless. Second, there are consumers of psychiatry who seem entirely satisfied with the mental health system. They have no cause to complain or to suggest reforms or are simply uninterested in such discourses (Everett). Third, there are those straddling between consumerism and satisfied patient-hood, actively drawing attention to the problems of mental illness but concluding that increased accessibility to psychiatric care would be the best solution. They tend to have few, if any, connections with the movement (Carmela Hutchison, personal communication, July to August 2014). Recently, celebrity spokespersons supported by Bell Canada Corporation have taken an approach of attacking stigma while emphasizing psychiatry's effectiveness. It is conceivable some of these spokespersons will join consumer organizations.

Fourth, Indigenous people are not well represented within the movement's leadership (Chan, 2016; Kelm, 1998; Kirmayer, 2007; Shimrat, 1997; Tam, 2013). Both dominant society's conceptions of mental illness and the movement's own views of mental difference seem preoccupied by anthropocentric notions of politics and wellbeing, preoccupied with (to use

Hart's 2007 phrase) Euro-American ontological and epistemological assumptions, possibly discouraging interest from potential Indigenous leaders, with significant exceptions noted (Hockman, 2010; Senier & Barker, 2013; Shimrat, 1997; Sterling-Collins, 2009).

Lastly, some ex-patients may simply have left the mental health field and never wish to speak on it again (Everett, 2000).

Movement Leadership: Historical Perspectives

In this section, I speak about the intertwined history of the disability and the consumer and survivor movements and describe the effect of Ontario's mental health reforms on consumer and survivor leadership. Since the 1990s, there have been rumors, reports, and studies indicating looming troubles within the Canadian disability movement as the new generation of leaders have not been able to replicate the dazzling successes the movement had achieved in the 1980s (Boyce, Krogh, & Boyce, 2006; Enns & Fricke, 2003; Hutchison, Arai, Pedlar, Lord, & Whyte, 2007; Lord, 2010). The leadership situation in the psychiatric consumer and survivor movement is, according to Everett's (2000) study, even more dire. Although nominally a part of the disability movement, the consumer and survivor movement has had a history of separate development (Beresford, 2012; Oaks, 2012). Possibly labelled as illegitimate and incompetent by both their disabled peers and by dominant Canadian society, consumer and survivors historically have been absent from valuable political opportunities and resources (Everett, 2000).

Psychiatric consumers and survivors have had difficulty gaining a foothold in the leadership of the disability movement partly due to the prejudice that perceived consumers and survivors as having fundamentally poor judgement, removing them from serious consideration for leadership responsibilities (for an exception, see Hockman, 2010). Historically, the modern Canadian disability movement has been dominated by white men with mobility impairments

(Lord, 2010). Not being taken seriously in the disability movement, and with a strong desire to form their own safe space, American consumer and survivor leaders of the 1960s crafted a social movement with the mental patients involuntarily confined in huge state mental institutions – with a social identity based on surviving past the harrowing, heartbreaking abuse meted out in those prison-like structures (Chabasinski, n.d./2012; Chamberlin, 1978; Pelka, 2012).

The modern consumer and survivor movement, according to American movement leader Sally Zinman, has gone through three phases: 1970s – militancy and separatism; 1980s – a transitional time, mainstreaming and re-entering the world; 1990s and beyond – a rapprochement with government and the achievement of some of the movement’s goals (Zinman & Bluebird, 2015). Similarly, the current Canadian disability movement has shed its militant tendencies, adopting a social liberal reformist political philosophy, together with a human rights and entitlements-based advocacy plank, both well-suited to operating within Canada’s parliamentary democracy (Prince, 2009). It relies on a government-focused policy agenda, preferring to negotiate, educate, and partner rather than confront. It has a strong track record of policy success (Lord, 2010; McColl & Boyce, 2003; Neufeldt, 2003). Some have suggested the consumer and survivor movement is more than a decade behind the disability movement’s achievements in leading, organizing, ingenuity, and formal acceptance into the polity (Lord, 2010; Pelka, 2012; Pomeroy & Pape, 1988/1999). The dissertation asks whether the consumers and survivor movement would benefit from adopting some of the disability movement’s leadership strategies; or, if this already has occurred, what the results of these strategies have been for the consumer and survivor movement.

Movement Leadership as a Partnership with Government?

The story of what occurred when consumers and survivors entered the polity in Ontario of the 1990s has been told in one version by researcher Barbara Everett (1997; 2000). I highlight three aspects of that story to explain how previous movement experience serves as a precursor to the current study. First, Everett (2000) narrated that the Ontario government promulgated the terms of engagement with psychiatric consumers and survivors as a partnership (Provincial Community Mental Health Committee, 1988). Partnership seems a benign word, carrying notions of warm cooperation and peaceful negotiation, but indeed it had varying, and quite different meanings, for government on the one hand and the consumer and survivor community on the other. The main difficulty that consumers and survivors faced at that time was an expectation that they would hit the ground running, ready to organize and work immediately, but no one seemed to realize that they would require sufficient resources and time to prepare the elementary infrastructure which would made subsequent work possible (Everett).

Many of the early consumer and survivor leaders were not the accustomed beneficiaries of privilege and largesse that government policymakers might have assumed whenever a partnership agreement had been struck. With a few exceptions, these Ontario leaders were not the eager, well-coifed, middle-class university graduates with whom government managers were accustomed to negotiating with in the boardroom. Many leaders were still figuring out how to throw off the heavy cloak of oppression in which they were encased: emerging from abusive relationships; dealing with intense anger at a lifetime of marginalization and discrimination; traversing a confusing, at times unhelpful and derisive, mental health system; living in dangerous, untidy rooming houses; doing their best to manage mood swings; and managing to live, eat, and have fun on very limited budgets. This point is a significant one because of the class analysis present whenever we talk about social movements (Carten, 2006; Everett, 2000;

Morris & Staggenborg, 2004; O'Hagan, 2014). There is a tendency over time for social movement organizations that are more moderately reform-oriented and aimed at middle-class interests to dominate the organizational network of any given social movement as they are given greater access to institutional polity, accompanied by greater access to resources, whereas poor peoples' organizations tend to struggle in maintaining, and often losing, their political influence and mobilization machinery (Clemens & Minkoff, 2004; Edwards & McCarthy, 2004).

Class Issues in Leadership

First, I would like the dissertation to concentrate mainly on consumer and survivor-controlled organizations, which are typically governed and staffed by poor people, and serve poor people (but not always), to follow up Everett's (2000) research findings made some twenty years ago on the problem of partnership between the powerful and the marginalized. As predicted by social movement theory and organizational theory, the consumer and survivor movement field has come to be dominated by philanthropic mental health organizations which are governed by rituals of middle-class benevolence, even as they employ a rhetoric of lived experience focused on individual stories of overcoming disadvantage (Clemens & Minkoff, 2004; Voronka, 2015). I believe this channelling of resources and legitimacy towards middle-class controlled organizations is being accomplished under the discursive aegis of the various provincial governments, within a neoliberal ideology, and their quasi-governmental subsidiaries, the regional health authorities (for example, Mood Disorders Society, 2018; for explanation, Morrow, 2013; Voronka, 2015). In the dissertation, I aim to test my hunch about this supposed resource transfer with the research participants.

Movement Fragility?

Second, Everett (2000) explained that the Ontario government provided significant funds for what were named consumer and survivor initiatives. Suddenly, funding became available for peer support, drop-in facilities, and small businesses, auspices that were to be controlled by consumers and survivors, analogous to the disability movement's Independent Living Centres (Lord, 2010). Many of these organizations became stable features of the Ontario social landscape (Nelson, Ochocka, Janzen, & Trainor, 2006a; 2006b; Ochocka, Nelson, Janzen, & Trainor, 2006). A few of them have experienced spectacular collapses, most prominently the Ontario Psychiatric Survivors Alliance (Everett). This was one reason why I presume she titled her book, *A Fragile Revolution: Consumers and Psychiatric Survivors Confront the Power of the Mental Health System*, based on her conclusion that certain social movement organizations, while persistent, were functionally unsound. Social movement organizations offer lessons of leadership practices. This sets the stage for what I would like to examine in western Canada, which presently has very few consumer and survivor-controlled organizations. Although occurring within a different region, my study examines whether Everett's idea of movement fragility, convivially constituted in leadership practices, is a convincing argument twenty years later, at a time when society is seemingly more accepting of mental health problems.

Pain, Hope, Leadership Practices, and the Future

Third, Everett (2000) thoroughly portrayed the difficult journey embarked by consumer and survivor leaders, from being perceived as abject bodies in the eyes of the dominant culture to a metamorphosis into socially valued activist identities. From a feminist epistemology, she skillfully weaved together the connections between personal practices, family experiences, and an emergence into political life, both in herself (although she seems quite careful what she

reveals about herself) and in her consumer and survivor research participants. She delved into the hotly debated question, within the movement and in society generally, about the fundamental nature of mental illness and whether such a concept can be explained away as the ruling class's messy, disingenuous strategy to corral and control the poor and the un-conforming of society, an initial assumption of the early movement (Chamberlin, 1978). This question has tantalized many yet eluded easy answers. Why is mental illness so painful, psychically, socially, physically, spiritually? In Everett's study and this dissertation, a central problem focuses on the question of pain: the meaning of it, how it is to be managed, and the relationship of pain to oppression.

Siebers (2008) asserted that the most important problem currently in disability studies is to craft a theory of pain from the perspectives of disabled people, a theory explicitly personal, interpersonal, and political, rather than exclusively biomedical, put to practical use for all of us to render our lives more compassionate and human. In the dissertation, I examine the interface between the personal and the political, focusing on the construct of pain, from my perspective as a person who has survived childhood victimization and sought psychiatry as a healing conduit but more importantly in how my research participants, surviving experiences of abjection and Othering, have found their healing, in this case via political activity amongst other strategies. I will not scrutinize the nature of mental illness itself but examine the process by which personal pain forms the raw material that is transmuted into leadership practice. Everett (2000) concluded her study by stating the psychiatric survivor is "a political identity in search of a future" (p. 217); well, the future is now, and one that I will attempt to document and explain.

In summary, three areas would be examined: the notion of movement partnership with institutional polity, the perceived "fragility" of the social movement, the future of the psychiatric survivor political identity (Everett, 1997). Each of these areas is under researched (Everett).

A Political Opportunity Structure: The Mental Health Commission of Canada

The ruling party, opposition parties, parliamentary government, senior bureaucrats, corporate elites supportive of the above, and their respective organizational auspices are called, in social movement language, *the political opportunity structure*, and it is an arena that consumer and survivor leaders must contend and negotiate with if they wish to achieve their goals. The political opportunity structure may both offer and may take away opportunities for movement leaders.

In 2006, for example, the Standing Senate Committee on Social Affairs, Science, and Technology issued its final report, *Out of the Shadows at Last: Transforming Mental Health, Mental Illness, and Addiction Services in Canada*. The report's most significant recommendation was launching the Mental Health Commission of Canada to act as facilitator, enabler, and supporter of a national approach to mental health issues (Standing Senate Committee, 2006). The report further stated that the newly created Commission, to discharge its mission, "*will form collaborative relationships that amount to partnerships with governments, employers, mental health stakeholder organizations...and, in particular, those Canadians living with mental illness and their families [emphasis added]*" (p. 438). Among psychiatric consumers and survivors there was considerable enthusiasm about this Commission's potential to bring a genuine transformation to Canada's mental health system. This enthusiasm was short lived (Voronka, 2015; White & Pike, 2013). In 2011, the Commission invited interested parties to sketch out the process by which a national advisory council solely composed of consumers and survivors would be created (Our Voice, 2015b). This advisory council was short-lived, axed by the Commission after a few months of existence (Our Voice, 2015b).

By 2012, the consumers and survivors who had been following the Commission's work, especially a core group of activists, had formed very definite opinions about it. Of this group, many evinced disappointment, even betrayal at what the Commission had become (White, 2009; White & Pike, 2013). A top-down, Ottawa-driven, bureaucratic process may have become the Commission's standard operating procedure (Nigel Bart, personal communication, May 4, 2016). Psychiatric consumer and survivor participation, this "partnership" with government and the Commission as quoted in *Out of the Shadows at Last*, was whittled down to what seemed to be merely tokenism and placation (referring to the ladder of participation conceptualized by Arnstein, 1969). In the vivid description of one prominent consumer leader, "the Mental Health Commission stepped on our backs, then broke our backs" (Carmela Hutchison, personal communication, July to August 2014). The Standing Senate Committee (2006) had attracted a range of people – doctors, researchers, family members, consumers, and survivors – in hearings across the country to tell their stories and testify on how to carry out the goal of working together on the salient issues. Ostensibly designed to be a joining together of people from disparate social locations, it aimed to work out a relationship between people historically seen as the mental patient – the poor and marginalized – and the government officials and policy makers responsible for their care, whom almost by definition were representatives of the middle-class.

A cross-class collaboration had been attempted previously in the 1990s, when the Ontario mental health system for the first time in its history had invited mental patients into governance positions (Everett, 2000). That attempt at mental health reform produced mixed results. Psychiatric consumers and survivors, with government funding, began to form their own organizations (Shimrat, 1997). Consumers and survivors voiced fierce critiques of the system; however, the election of the conservative Harris government in 1995 resulted in a scale-back of

mental health reform (Nelson, Lord, & Ochocka, 2001). The biomedical establishment, including psychiatry, and the unions representing mental health professionals struck back, reasserting their power and influence over mental health policy. Conservative elements within the polity reasserted their power to frame and rationalize the mental health system once again as a top-down institution, with consumers and survivors relegated back to the margins (Everett).

What could the Mental Health Commission achieve, more than a decade after the Ontario experiment? Certainly from psychiatric consumers and survivors perspectives, the new hope was that a genuine *partnership* could be realized wherein both parties – the less powerful consumers and survivors and the relatively powerful government officials – would create a safe space in which an equality of work relationships could bring about a transformed, humanized mental health care system (O’Hagan, Cyr, McKee, & Priest, 2010; Mental Health Commission, 2009, 2012). In the process both parties would be transformed, humanized, with a broader and more compassionate perspective of the other, while retaining each side’s integrity, uniqueness, and political acumen. However, what had started out with “optimistic good intentions seemed to have deteriorated into the embodiment of the very problems it was supposed to have solved” (Everett, 1997, p. 1). Everett’s quotation was from her analysis of the long-term failure of previous mental health reforms yet sadly seemed to fit the Commission.

While the polity might seem to shape, constrain, and even annihilate social movement leadership practices, leadership practices have power to influence and restructure political opportunities – as McAdam (1996) put it, political opportunity structures are not only an explanatory variable but may be shaped into an outcome variable. This dissertation examines the leadership practice problematic in the consumer and survivor movement. From a social constructionist lens, I intend to build a conceptual framework of consumer and survivor

leadership, aiming to study the developments in consumer and survivor leadership practice since Everett's Ontario study (1997; 2000), although I restrict my analytic field to Vancouver, Calgary, and Winnipeg. Everett's study (2000) was an in-depth examination of the Ontario consumer and survivor movement's emergence and its subsequent leadership struggles. She made compelling, possibly controversial, points about movement dynamics and prognosticated on its future, and I wish to test her prognosis with current data.

Since Everett, there have been other Canadian studies on consumer and survivor movement mobilization, but they have not provided an empirical account of its leadership practices. They touch on related issues: humanizing mental health care (Trainor & Church, 1984/1999; Trainor, Pomeroy, & Pape, 1993/1999), consumer empowerment (Nelson, Lord, & Ochocka, 2001), leadership within the broader disability movement (Hutchison, Arai, Pedlar, Lord, & Whyte, 2007), participatory action research and the consumer voice (Schneider, 2010), reviews of Mad politics and Mad Studies (LeFrancois, Menzies, & Reaume, 2013), a critique of psychiatric survivor activism as being infused with colonialist assumptions (Tam, 2013), the social movement organization as a participatory democracy (Beckman & Davies, 2013), peer support politics and dilemmas (Fabris, 2012, 2013; Voronka, 2015), and various autobiographical memoirs (Carten, 2006; O'Hagan, 2014; Shimrat, 1997). The exceptions are Nelson, Lord, and Ochocka's (2001) study of Ontario's consumer and survivor initiatives, drawing upon empowerment theory and resource mobilization theory to explain leadership practice, and Storey's (2011) narrative study of consumer and survivor leadership, which lacked robust connections to leadership theory.

Recovery

One aspect of consumer and survivor mobilization is reflected in an idea called recovery. Recovery, at an individual level, is a journey of the heart for people experiencing mental health problems (Deegan, 1987/1996). Recovery is experienced as “a transformative process in which the old self is gradually let go of and a new sense of self emerges” (Deegan, 2001, p. 5). Recovery is the work of self-awareness, self-empowerment, and self-determination. Mental health professionals support individual recovery through respecting consumer and survivor knowledge and facilitating a person’s self-determination and recognizing that professionals play a supplementary, rather than a central, role in recovery. The concept is analogous to the idea of consumer control in the disability movement, emphasizing personal self-control, the freedom to take reasonable risks, and the unorthodox knowledge and wisdom inside communities of people with disabilities (Lord, 2010). The mental health professionals’ tendency to ascribe deficiency, decay, and degeneracy to people with mental health problems, often without good evidence, is unacceptable to recovery, which holds that nothing should be decided about us without our informed participation (Charlton, 1998).

Recovery at an organizational level is to ensure that organizational accessibility and equity prevail for people with mental health problems, including suitable accommodations for the variations of needs and abilities, organizational initiatives to refute prejudice and discrimination, and the inclusion of people with mental health problems in organizational governance and program evaluation (Nelson, Lord, & Ochocka, 2001). Organizational level recovery involves groupwork, administrative practices, and organizational leadership, in addition to individual recovery work. Recovery at a societal level addresses the social determinants of mental health as targets for intervention. It focuses on ameliorating the structural root causes of

mental distress such as poverty, racism, homophobia, family violence, misogyny, which in turn are the result of a system of oppression, the colonialist white supremacist capitalist patriarchy, which a comprehensive recovery practice would seek to weaken and dismantle by working to redistribute power to the poor (hooks, 1981; Morrow, 2013). Societal level recovery requires policy analysis and formulation, interventions into public discourses of mental health, and political negotiations and brokerage, including the possibility of radical options such as civil disobedience, plus all the activities involved in the previous two levels.

Recovery is practiced both by people with mental health problems and mental health professionals and administrators. Both a robust consumer and survivor literature (Deegan, 1987/1996, 2001; O'Hagan, 2014) and an expansive mental health professional literature on recovery exist; in the latter, notably in psychosocial rehabilitation (Anthony, 1993), social work (Buckles et al., 2008; Carpenter, 2002), and occupational therapy (Bryant, Fieldhouse, & Bannigan, 2014; Casey, 2009; Townsend, 1998). The concept represents a common goal for both constituencies. In practice, there is considerable controversy between consumers and survivors and the mental health professionals as to recovery's utility and its limits and to the fidelity of its conceptual application to policies, procedures, and practices. Consumers and survivors charge that the mental health system has been disingenuous in its attempts to implement recovery, asserting that the system applies recovery cosmetically without attempting to rectify systemic inequities (Mental Health Recovery Study Working Group, 2009).

The mental health system might reply that a recovery-based system change takes a long time, and that the system is responding to multiple demands and client constituencies, including: reallocating program priorities in response to society's increasing mental health needs, managing budgetary allocations in accordance to government directives, complying with provincial and

federal law, balancing the demands of family members and consumers and survivors, responding to the needs of various community groups and lobbyists, and negotiating satisfactorily with a variety of professional groups – physicians, nurses, administrative staffs, maintenance staffs, social workers – and their respective unions (Casey, 2009; Vancouver Coastal Health, 2015). Within the consumer and survivor movement, different, and at times conflicting, perspectives on recovery mean that recovery is not universally accepted, resulting in sometimes delicate negotiations by movement leaders to bridge ideological divides (Carten, 2006; Everett, 2000). Recovery as a concept and practice enjoys consensus agreement amongst consumer and survivor leaders, with greater skepticism amongst psychiatric survivors (Voronka, 2015). However, inaction regarding recovery-based mental health system reforms and the lack of intervention into the social determinants of mental health elicit significant frustration and anger among everyone involved (Morrow, 2013; O’Hagan, 2014; Townsend, 1998; Voronka).

Sonia Ospina’s Social Change Leadership: A Theoretical Framework

I chose to highlight Ospina et al.’s (2012) social change leadership theoretical framework because of its basis in social movement organizing. Sonia Ospina and her colleagues (2012) selected a sample of 150 leaders or leadership teams from 92 American organizations which were identified as leadership exemplars. All eligible organizations were politically progressive in a broad range of fields, from arts to community development to ecological justice to human rights. These ninety-two organizations emerged from a five-year competition of a program of the Ford Foundation, where Foundation selected 17 to 20 organizations each year out of a field of 1000 to 3000 annual nominations. This highly selective process ensured that these leadership exemplars were of exceptional quality. The theoretical framework derives from the work of 60 organizations with the most comprehensive data. From 2001-2009, the project involved

producing and analyzing a sizeable, almost national data base, albeit one reflecting only the most successful leadership practices in the United States.

Ospina et al. (2012) used three methodologies to conduct their study: narrative inquiry, participatory ethnography, and cooperative inquiry, from which 10 cooperative studies were completed. These studies involved groups of 8 to 10 participants, based on a shared interest around a pressing leadership challenge from the participants' own life, and involved praxis and self-reflection. Ospina et al.'s research approach, enabling community activists to shape the course of the study, bears some similarity to the dissertation, although their project was much more ambitious. Their analytic approach uses analytic induction, in which grounded theory is one variant, another similarity to the dissertation's methodology (refer to Chapter 3).

Emerging from their study, Ospina et al. (2012) crafted a theoretical framework they called a "strategic action to build collective power" (p. 256) (refer to Figure 1). This idea is composed of three components: leadership practices, core activities, and creating collective capacity (intermediate outcomes). They indicate that successful social change leadership's long-term outcomes are: changed structures, changed policies, and changed thinking. The motivators for engaging in leadership practice are: the presence of systemic inequality (images of the present) and visions of human wellbeing and justice (visions of the future) (what social movement theory might refer to as framing processes) (Ospina et al., 2012).

Leadership Practices

Leadership practices that make up the day to day work of the organization cluster around three distinct types (Ospina et al., 2012):

Together they help SCOs [social change organizations] build collective power by helping to *frame and reframe their issues, building meaningful connections with*

others, and *creating the environments* [emphasis added] that allow people to flourish and be prepared to take action. (p. 272)

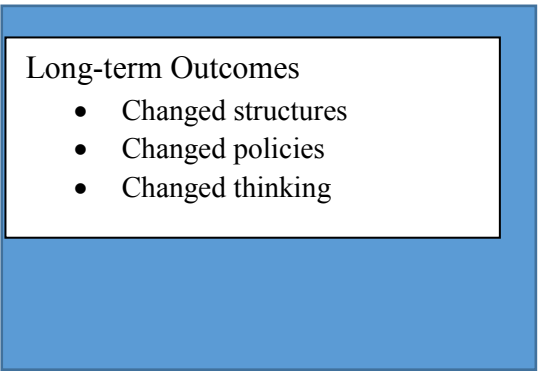
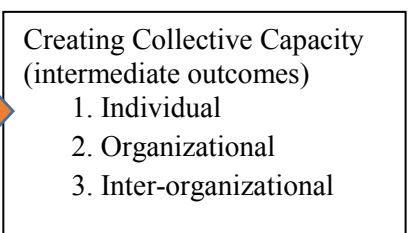
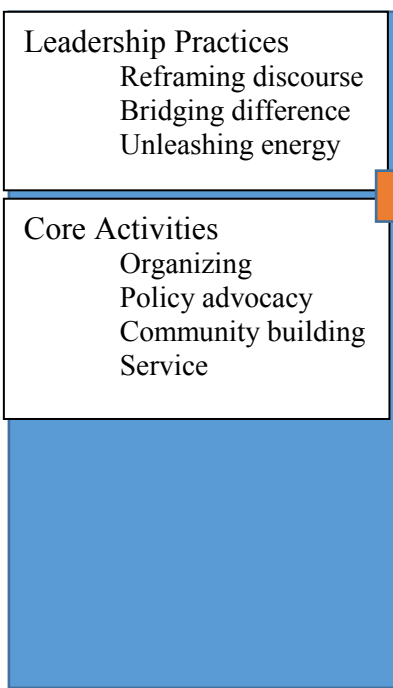
Reframing discourse is very similar to the concept of framing processes in social movement theory (refer to the section below), although Ospina et al.'s terminology reflects a much leaner conceptualization. It is impossible to expect one study, even an extensive

Figure 1 (adapted from Ospina et al., 2012, p. 256)

**LEADERSHIP
DRIVERS**

Systemic inequity
Visions of
wellbeing and
justice

**GROUND
ED
HUMANISM**



investigation, to match the theoretical and empirical richness of several decades of international scholarship on framing within social movement theory.

Bridging difference “entails practices that create the conditions to bring diverse actors together and facilitate their joint work while maintaining and appreciating their differences” (p. 273). As Ospina et al. explain, “weaving relationships among people from different worldviews builds community and ends the isolation and fragmentation” resulting from poverty and marginalization (p. 273). This concept is analogous to social movement theory’s human and moral resources within the concept of mobilizing structures (Edwards & McCarthy, 2004).

Unleashing human energies draws from transformational leadership theory (Burns, 1978). Practices to unleash human energies stem “from the assumption that knowledge is power, and the fundamental source of power comes from within the community, despite its perceived scarcity” (Ospina et al., 2012, p. 274). Yet this instrumental approach is influenced by the expressive commitment to support human development, not only as a means but as an end product, to “create conditions for transformational learning, which allow every member of the group to reclaim their full humanity and, in the process, recognize their inherent power to direct their lives” (p. 274). The underlying belief is that people inherently possess a certain mastery over the problem, emerging from daily life (Ospina et al.).

Core Activities

Core activities are engagements reflecting the group’s overall approach to achieving change and are demonstrated in four specific activities (Ospina et al., 2012). These are: ***organizing*** (recruiting, educating, and mobilizing); ***policy advocacy*** (advocacy in the legislative process); ***community building*** (harnessing social capital, including the use of identity politics); and ***direct service provision*** (meeting the needs of people by providing goods and services).

Core activities bear significant similarity to social movement theory's mobilizing structure, but also encompassing entry into the political opportunity structure (refer to the section below).

Ospina et al. (2012) claimed that these four modes of engagement have been consistently documented in the literature. I would venture that these four modes seem emblematic of most social movement organizations' core activities but do not fully capture the field. Successful social movement organizations typically rely on a selective repertoire of disruptive tactics (Gamson, 1990) and carry on strategic and discursive "framing battles" with government, counter-movements, and competitor movement organizations (McAdam, McCarthy, & Zald, 1996). Ospina et al.'s framework does not include this component.

Creating Collective Capacity (Means and Intermediate Outcomes)

Ospina and her team (2012) describe collective capacity as power in repose, as capability waiting to happen. When it is leveraged toward achieving long term outcomes, power in repose becomes power in use (Gamson, 1990; Ospina et al.). But collective capacity is an important intermediate outcome because achieving individual, organizational, and inter-organizational capacity – even without securing one's goals at the societal and legislative level – "builds confidence, strengthens commitment, and cultivates hope" (Ospina et al., 2012, p. 277).

As they put it, there are three levels of collective capacity: (1) *individual capacity* (when group members recognize their self-worth and realize their disadvantage is related to social oppression; also relates to self-efficacy); (2) *organizational capacity* (when the movement organization can marshal the necessary resources – material, human, symbolic – to enable the work; a sense of trust and cohesion within the group); and (3) *inter-organizational capacity* (strong relationships with both like-minded and unlikely allies in various sectors). To summarize, Ospina et al. (2012) depicted collective capacity as a space full of distributed

leadership, characterized by abundance and possibility within a society of scarcity and indifference. It is a space offering a counterfactual experience – positivity, high expectations, and learning from difference – for people mired in day-to-day inequality and marginalization.

Collective capacity's three levels are analogous to empowerment theory's three levels: individual, organizational, and community (Cattaneo & Chapman, 2010; Hur, 2006; Peterson & Zimmerman, 2004; Rogers, Chamberlin, Ellison, & Crean, 1997; Segal, Silverman, & Temkin, 1995, 2013; Zimmerman, 2000). Ospina et al. dialogue extensively with leadership theory but do not examine empowerment theory. I wonder if Ospina and her team had begun their investigation by first considering empowerment theory, they might have enriched their analysis. Also, nagging theoretical questions at the organizational and inter-organizational or community empowerment levels remain in this framework: namely, a tendency for organizations, even ostensibly empowering ones, as they increase in scale, to centralize leadership instead of sharing it, typically shifting power to a small cadre (Michels, 1915/1962; Segal, Silverman, & Temkin, 2013); and the great distances between individual empowerment, organizational empowerment, and empowerment vis a vis the polity, usually requiring realignments in the political opportunity structure and workable conflict resolution processes within the grassroots to manage the inevitable splits and factionalism (Riger, 1984; Wesley, 2011; Zimmerman, 2000).

As well, collective capacity's three levels bear similarity to Hutchison and her colleagues' (2007) leadership framework in the Canadian disability movement, which posits practice in individual leadership (role modelling), organizational leadership (prudent stewardship), and movement leadership (coalescence of political values and structure). Although Hutchison's research program was also multi-sectoral, multi-year, and national in scope, their

smaller database and lack of participatory methods seemed less robust compared to Ospina et al.'s more extensive investigation (2012).

Critical Analysis of Ospina et al.'s Social Change Leadership Framework

In terms of satisfying Haslam, Reicher, and Platow's (2011) five desirable criteria for a new leadership theory, Ospina and her colleagues' (2012) theoretical framework seems to satisfy the first four criteria: non-individualistic; context sensitive; perspective sensitive; encompasses leadership's transformative potential. On their last criteria, it would be impossible to argue their social change leadership framework has greater empirical support than the theories it hopes to supplant, like trait theory or transformational leadership, each of which bear extensive empirical corroboration over many decades (Northouse, 2010). Given the large research program of Ospina and her colleagues (2012; Ospina & Foldy, 2009; Ospina & Su, 2009), and the wave of recent studies employing relational leadership theory (Crosby & Bryson, 2012; Offermann, 2012;), this problem may not last long.

I understand that Ospina et al.'s framework (2012), based on a large database over a considerable period of time, speaks convincingly for the lived experience of social movement leaders. I believe the psychiatric consumer and survivor movement will find the framework to be useful, especially because it is fashioned from the practices of successful social movement leaders. Their intriguing finding that vertical and horizontal leadership can functionally coexist – that is, formal hierarchy and democratic deliberation – in successful activist organizations is an issue that consumer and survivor leaders may wish to examine in depth, as it is precisely this issue which has stymied many social movement organizations from labor to feminist to Black civil rights (Clemens & Minkoff, 2004). Despite their stated intentions, Ospina and her team (2012) do not explain the social identity basis of leadership practice.

Resource Mobilization Theory

Resource mobilization theory, also called the resource mobilization-political process synthesis, is the most influential theory in social movement studies (McAdam, McCarthy, & Zald, 1996; Staggenborg, 2012). Social movement theory is a middle-range theory – theory in a substantive area backed by empirical research – produced primarily in the disciplines of sociology, political studies, economics, and human geography (Edwards, 2014; Snow, Soule, & Kriesi, 2004). Resource mobilization theory has become prominent enough that adjacent theoretical traditions – political process theory and cultural framing process – have joined together with resource mobilization’s core theoretical concepts, becoming a synthesis theory of social movements (McAdam, McCarthy, & Zald, 1996; Staggenborg, 2012). Many scholars conclude that resource mobilization theory demonstrates both explanatory power and robust empirical support (Davis & Zald, 2005; Jenkins, 1983; Staggenborg, 2012).

There has been sustained American and Western European scholarly work on social movements since the end of the Second World War. Social movement theory seeks to explain the causes, processes, and outcomes of groups of people engaging in contentious politics to change some part of society’s structure, ranging from moderate reform movements espousing modest, incremental goals to revolutionary groups aiming to overthrow a regime by force (Tarrow, 1998). It is noteworthy that research on the psychiatric consumer and survivor movement, few to start with, has tended to steer clear of employing the armamentarium of social movement theory. The major Canadian studies on this movement (Everett, 2000; LaFrancois, Menzies, & Reaume, 2013; Storey, 2011; Voronka, 2015) make only passing reference to social movement theory, with Nelson, Lord, and Ochocka (2001) and Hutchison and her colleagues

(2007) study of leadership being the exceptions in employing resource mobilization and new social movement theories respectively.

Prior to the 1960s, much of social movement theory sought to explain the phenomena of crowds, crazes, mobs, fads, and panics, then thought to be a reversion to animalistic behaviors, a group-think phenomenon where the participants became profoundly irrational (Edwards, 2014; Staggenborg, 2012). The idea of mass irrationality, a plank of collective behavior theory, has been amply criticized for its lack of empirical support (Jenkins, 1983; Staggenborg). Collective behavior theory's earliest versions were quite politically conservative and may have interpreted the actions of the modern consumer and survivor movement as the pathetic dreams of a madman, although we should be careful to not lump together the various elaborations of collective behavior theory into one bin (Edwards, 2014).

Another prevalent social movement theory, prior to resource mobilization's advent, was strain theory, which posited a person, group, or larger community would experience a build up of tension or strain from certain social pressures, such as grievances about the way one is treated by others (Staggenborg, 2012, p. 13). As these grievances build up, contentious, disorderly politics become inevitable as they represent a safety valve to release the accumulated tension and pressure. Strain theory is criticized for its failure to explain why social movements arise in some cases and not in others, given that strains may represent a constant in modern society (Staggenborg). However, strain theory's emphasis on participants' personal beliefs and nascent political thought is to have an enduring influence on subsequent theory (Buechler, 2004).

Then came the Sixties. A new cycle of contention began in the United States, and it seemed that old practices and old ideas, even the American state itself, might fall. These events

spurred fresh thinking on the way social movements worked (Jenkins, 1983). Why did these Sixties-era social movements emerge? What was distinctive about their form and process?

Mobilizing Structures: The Advent of Resource Mobilization Theory

Three key theoretical insights were emerging. Although resource mobilization theory only developed in the 1970s and 1980s, the immediate desire to study the tumult of the Sixties had galvanized scholars to posit three factors within a comprehensive theory of social movements: mobilizing structures, political opportunity structures, and framing processes (McAdam, McCarthy, & Zald, 1996; Staggenborg, 2012). I first describe mobilizing structures.

Contrary to strain theory, it was posited that contentious politics develops not from a surge in the intensity of grievances, assumed to be a constant in modern society (Staggenborg), but from the emergence of a *professional social movement* in the form of movement entrepreneurs and social movement organizations (Edwards, 2014; Neufeldt, 2003; Pelka, 2012). The professional social movement of the sixties and seventies was made possible by American and Canadian societies' increasing prosperity, as a wider swath of society accessed college education, entered the middle class, and chose careers where development of a social consciousness was a part of the training process (Finkel, 1997). As social movements required both leaders and the rank and file, both were swelled from the huge post-war increase in university students and graduates, bringing cultural resources (e.g., critical thinking skills) and material resources (e.g., greater disposable income, increased freedom of movement compared to the previous generations working in factories or farms). The concept explaining this historical phenomenon was called *mobilizing structures*, and the concept was important enough that it became the title for the whole theoretical framework (McAdam, McCarthy, & Zald, 1996).

The quintessential test case in the Sixties was the Black civil rights movement, which social movement theorists have studied in detail (Morris & Staggenborg, 2004). It was felt that a social movement pivots on its mobilizing structures to make the transition from a group of people with ideas to a front capable of drawing people together to petition, protest, march, canvass neighborhoods, and influence government policy (Cone, 1996-98/2012; Jean Beckett, personal communication, June 6, 2016; Staggenborg, 2012). Mobilizing structures include moral resources, cultural resources, socio-organizational resources, material resources, and human resources (Edwards & McCarthy, 2004).

I argue that the most important resource of all is the human resources. In the civil rights movement, the education and experience available to the African-American church leadership, through their college education and the sharing of knowledge amongst pastors and congregational leaders (cultural resources), were indispensable (Cloud, 2013; McAdam, McCarthy, & Zald, 1996). Conscience constituents who contribute to the movement but do not personally benefit from it, like white liberals in the civil rights movement, became a viable human resource, also the result of the rising tide of prosperity in post-war America. The reason I refer to the Black civil rights movement is that a significant portion of the collective action frames, mobilization structures, and leadership practices of the psychiatric consumer and survivor movement (and its closest relative, the disability movement) is derived from it (Chamberlin, 1978; Galloway, 2001/2012; Heumann, 1998-2001/2012; Neufeldt, 2003; Pelka, 2012).

Movement entrepreneurs and social movement organizations. The emphasis on the professionalized social movement highlights two theoretical innovations in the Mayer Zald strain of resource mobilization: the *movement entrepreneur* and the *social movement organization*

(Jenkins, 1983; McCarthy & Zald, 2002). McCarthy and Zald characterized that what differentiates the challenger groups that go out and do things – e.g., stage demonstrations – from debating clubs that discuss ideas but never back up ideas with action is the *movement entrepreneur* who defines the political issues by drawing upon particular streams of public sentiment, those likely to galvanize potential supporters, and demanding for an increase in social change in accordance to movement goals (Staggenborg, 2012). The idea of entrepreneurship is a clean break with the earlier grievance-based conception of movement emergence by delineating the mechanism by which ideas, aspirations, and latent potentials transform into organization, protest, insurgency, or revolution (McAdam, McCarthy, & Zald, 1996).

It posits that challenger groups, and the entrepreneurs promoting them, are more likely to emerge when the absolute level of grievances in a society is lower and the general level of economic and political opportunities are improving (Jenkins, 1983). That is, when life expectations (and its concomitant structural precursors) are improving is the exact time when it is most fortuitous for movements to arise – a tide of rising expectations (this relates to the next idea, the political opportunity structure, below) (Edwards, 2014). In contrast to strain theory, which posits social movements to bubble up in response to increasing structural strain, such as economic hardship and a diminishing quality of life, resource mobilization theory holds that challenges to the polity arise with the mushrooming of opportunities and resources that prosperity, or at least a lack of deprivation, brings (Staggenborg, 2012). The movement entrepreneur becomes synonymous with leadership, or at least one aspect of leadership, although a rational, calculated marketing of the growth of a challenger group, with an eye towards a future payout in fame and monetary support, is a somewhat surprising characterization of activism from

the view of psychiatric consumers and survivors who by and large do not draw any substantial income or fame from movement involvement (Edwards, 2014; Fabris, 2013; Voronka, 2015).

The idea of a mobilizing structure can be traced to Leninist thought (Shandro, 2001; Tarrow, 1998). Because Karl Marx had severely underspecified the resource requirements and political vision required for a revolution, except for an ill-defined idea of a mass proletarian uprising, Lenin shrewdly identified the key mobilizing structure to be decisive leadership from an intellectual vanguard leading the masses (Shandro; Tarrow). The vanguard leadership must be drawn from the intelligentsia and bourgeois progressive elements because a purely spontaneous working-class revolution was impossible under capitalist rule, as the proletariat had been lulled into a political stupor within the hegemonic cultural apparatus (Shandro). The mobilizing structure for Lenin would be the revolutionary party, a politically radical precursor of the *social movement organization*, which needed to be decisive, taking advantage of divisions within the polity and giving a unified and coherent political message, one mirroring the vanguard leadership which controlled it (Johnson, 2001; Shandro).

The social movement organization remains the centerpiece of McCarthy and Zald's (2002) contribution. Movement organizations may take varied forms; however, a viable governance structure, with clear lines of reporting with outside allies and institutional polity, is theorized and demonstrated to provide superior outcomes (Gamson, 1990; Staggenborg, 2012). Organizations are thus understood as resources to be deployed by activists (Clemens, 2005). Without a viable social movement organization, activism would be effervescent and fleeting, with little continuity in pursuing a policy agenda or a media strategy, nor would there be an ability to mobilize diverse communities of constituents. Organizations then can be summarized

as the context for, the actors in, and themselves the objects of contention within social movements (Davis & Zald, 2005).

Novel organizational forms might result from locales which generate significant cultural creativity. Such novel organizational forms often signal the possibility of a social movement becoming a major player in reshaping the cultural frames underpinning the broader society. For example, the creation of the Center for Independent Living in Berkeley helped the larger campaign to redefine disability in America from a narrative of individual tragedy to a framework of rights and freedom from oppression (Edelstein, 2010; Pelka, 2012). In San Francisco's gay and lesbian organizations of the Sixties and Seventies, identity politics had to be produced before a viable solution to the problem of invisibility could be found (Armstrong, 2005). The "Gay + 1" organization, this new organizational form, combined a positive emphasis on identity-building (the "Gay" part) with specific functions – electoral participation, business, arts, religious, sports – it was intended to serve (the "+ 1" part) (Clemens & Minkoff, 2004, p. 166). The psychiatric survivor movement took the hint from both the disability and gay and lesbian movements and established the so-called mental patient-controlled service organization; in Canada, first manifested in 1971 as Vancouver's Mental Patient's Association (Chamberlin, 1978; Beckman & Davies, 2013).

Factors influencing the movement's success or failure. The question of a social movement's success or failure seems to rest on three strategic factors (McAdam, McCarthy, & Zald, 1996). In his classic study of over fifty challenger groups in America, Gamson (1990) found that those who had used disruptive tactics (e.g., civil disobedience) against their adversaries tended to achieve more success than groups that did not. In terms of their objectives, groups that did not pose a mortal threat to their opponents were more successful, as both neutrals

and opponents may decide to opt for opportunities for negotiation instead of a head-on confrontation. Single objective, single issue groups were more often successful than groups addressing many issues (Gamson). For instance, some anti-psychiatry groups espouse the abolition of psychiatry, the removal of their antagonist altogether. Canadian anti-psychiatry groups with this objective have typically failed (Everett, 2000; Shimrat, 1997).

Finally, McAdam, McCarthy, and Zald (1996) summarized from the literature that the presence of extremist groups often helps legitimate and strengthen the bargaining hand of more moderate social movement organizations, what they called the radical flank effect. It is possible to consider psychiatric survivor and anti-psychiatry groups a radical flank, analogous to radical feminism in relation to the feminist spectrum. Some have suggested that in the 1980s, consumers and survivors' unalloyed anger and their consistent framing of mental health issues as sequelae of systemic poverty, abuse, and discrimination stimulated the polity's increasing attention to mental health reform (Pomeroy & Pape, 1988/1999; Shimrat, 1997). Consistent with their view of resource mobilization, McAdam, McCarthy, and Zald (1996) assert that while movements are largely born of environmental opportunities, their fate is shaped by their own actions within the organizational auspice: "It is the formal organization who purport to speak for the movement, who increasingly dictate the course, content, and outcomes of the struggle. In terms of our three factors, this means political opportunities and framing processes are more the product of organizational dynamics" than vice versa (p. 15).

Organizational theory is evolving, and an interactive approach now conceives of the social movement organization as a repertoire expressing particular ideologies and identities. Choices of organizational form might simultaneously be vehicles for mobilization, signals of social identity to both opponents and future allies, and etiquettes for collective action

possibilities (Clemens & Minkoff, 2004). Looking at the larger picture, consistent with Davis and Zald (2005), it is within a multi-organizational field that movement entrepreneurs interpret grievances, form evaluations, forge alliances, and tangle with adversaries (Clemens & Minkoff, 2004). Clemens and Minkoff conclude that new organizational forms represent the outcome of tentative truces between movement actors about which frames will predominate in organizing the activities and mobilizations in the field (referring to framing processes, explained below).

Furthermore, applying competition theory to the interrelationships of a cluster of organizations in a movement leads to an interesting result. Once a single organizational brand becomes successful in securing positive publicity and organizational legitimacy, it tends to constrain the prospects of both more conservative and more radical social movement organizations through the mechanisms of inter-organizational competition (Clemens & Minkoff, 2004). Yaziji and Doh (2013) disagreed, finding that while ideological radicalism in social movement organizations increases the ideological homogeneity of their resource base (e.g., funders), this in turn removes or reduces the polity-defined norms of conformity. The greater degree of freedom afforded to these organizations enabled the use of high-profile tactics and the selection of potentially high-impact targets, which may broaden the opportunities for success (Yaziji & Doh, p. 772). In the study, I ask the question of organizational brands – whether it increases or decreases conformity in a cluster of organizations – with movement leaders, those with a sufficiently panoramic view of the organizational network.

Political Opportunities

The second component of the resource mobilization-political process synthesis is called the structure of political opportunities and constraints confronting the movement and it is the central concept of political process theory (McAdam, McCarthy, & Zald, 1996). It focuses on

the relationship between institutional politics and social movements in a society. Social movements would no longer be thought of as irrational crowds isolated from the legitimate polity, driven by emotional outbursts and impulsive actions, but rather as organized entities whose existence is facilitated by formal institutional channels (Edwards, 2014). Research on the political opportunity structure focuses on demonstrating the way that changes in some aspect of a political system creates new possibilities for collective action by a challenger or set of challengers (McAdam, McCarthy, & Zald). Definitions of a political opportunity structure range from being overly broad, at risk of it becoming a catch-all term for all the factors accounting for the circumstances enabling movement activity, sapping the concept's analytical power, to narrow and precise definitions, which risk excluding new and relevant factors (McAdam, 1996a).

Five dimensions of political opportunity. Tarrow (1998) suggested that there are five dimensions of political opportunity for a challenger movement: the *polity's openness or closure*, *shifting political alignments*, *presence or absence of elite allies*, *divisions within the elite*, and a *lack of state repression*. Polity refers to the body politic, the legitimate sovereignty and its supportive apparatus. In Canada, it refers to the parliament, the court system, the ruling political party, opposition parties, the government bureaucracy, and even the chief supporters and benefactors of parties, typically philanthropists, financiers, and industrialists. The elite refers to almost the same, except it refers to the personages, not the institutional apparatus, of government. The rest of the five dimensions then are mainly self-explanatory. What McAdam (1996) wished to emphasize are the enduring sets of elite alliances that “tend to structure political systems over time from the more ephemeral presence or absence of elite allies” (p. 27); for instance, the Canadian labor union leadership as historically allied to the New Democratic Party, and chief executives of Canada's 150 largest corporations as enduring allies to the Liberal

Party of Canada (Business Council of Canada, 2018; The Canadian Press, 2009; Geddes, 2011). Enduring elite alliances make it difficult for challenger groups to enter the polity, as elites have already divided up their spheres of influence to their satisfaction and mutual benefit, unless a challenger group can exploit divisions within the elite or gain sufficient clout to make ignoring it impossible.

For a classic American example, the support of powerful outsiders greatly aided the Sixties civil rights movement, such as white college students, but especially white politicians in northern states interested both in getting the Black vote and making a reality their stated commitment to racial equality (i.e., elite allies). Interestingly, the history of Canadian mental health reform has an international dimension (Enns & Fricke, 2003). Other industrialized nations have made policy statements regarding system transformation from a professional-focused system to a recovery-oriented one, putting an onus on Canada to act similarly (Glover, 2012; O'Hagan, 2014; O'Hagan, Cyr, McKee, & Priest, 2010). Yet Canada's mental health reform seems positioned to broadcast and signal the advanced nature of Canada's liberal capitalist regime – mental health reforms as the regime's medicine for Canada's supposed problem of lagging workplace productivity – framing these reforms as a classical liberal inducement supplementary to an overarching neoliberal relation of ruling (Voronka, 2015). In other words, the reforms argue for equality and rights, yet are clearly subordinate to a neoliberal governmentality that assumes inequality and social stratification must prevail under capitalism (Whyte, 2010).

My impression is that although Canada's political opportunity structure is favorably disposed towards moderate reformist groups in the psychiatric consumer and survivor movement, more radical proposals to tackle the social determinants of mental health/distress –

not only the downstream sequelae of depression or addictions but the probable upstream macrolevel root causes of colonialism, capitalism, and patriarchy – are likely to encounter many barriers and closed doors within institutional polity (Albee, 2005). The polity's openness to Ontario's consumer and survivor groups in the early nineties resulted from shifting political alignments as a Liberal, then a New Democrat, government came to power after many years of Conservative party rule in Ontario (conceptualized in the theory as shifting political alignments). Mental health reform in several American states also added an international impetus to the Ontario reforms (Nelson, Lord, & Ochocka, 2001).

Recently, psychiatric survivor organizations which have directly criticized the probable neoliberal capitalist and colonial roots of mental distress have had their government funding threatened or entirely removed and have had difficulty attracting the attention of private funders (arguably the polity's relative closure; absence of elite allies) (Hladikova, 2015; West Coast Mental Health Network, 2013). Psychiatric consumer organizations, although often moderate groups, have also faced stagnant or diminishing government support, and governments have pressured these organizations to limit their advocacy activities in favor of devoting their resources to providing basic goods and services to consumers (conceptualized as shifting political alignment from a social liberal to a neoliberal, residual form of welfare) (Boyce, Krogh, & Boyce, 2006; Prince, 2009). The dissertation asks whether movement leaders' experiences would support the prognostication that movements appealing to middle-class interests tend to thrive, whereas poor peoples' movements are often unsuccessful (Clemens & Minkoff, 2004).

Framing Processes

The third component of the resource mobilization-political process synthesis refers to framing processes. Although some consider framing processes a separate theory, most scholars

think it is an integral part of the synthesis framework (McAdam, McCarthy, & Zald, 1996; Staggenborg, 2012). Framing process is a relative latecomer to the social movement literature, as calls to bring culture in have come from proponents of the so-called new social movement scholarship in the 1980s, paralleling the social sciences' cultural turn (Agger, 2013; Marshall & Rossman, 2011). Of the three components, framing was the last to develop. Framing theory, although sympathetic to resource mobilization theorists' attempt to supplant collective behavior theory with an improved theory, was based on movement participants' beliefs and ideas, similar to the impetus of collective behavior theory (Staggenborg, 2012).

Framing may be defined broadly or narrowly, each with its own advantages and disadvantages. Considering all the cultural aspects of movement activity to be framing processes may produce a concept so broad as to be theoretically meaningless. Snow referred to framing in a more precise way, as people's conscious, strategic efforts to fashion shared understandings of society and of themselves so that it *legitimizes* and *motivates* collective action (McAdam, McCarthy, & Zald, 1996; Snow, 2004). McAdam, McCarthy, and Zald (1996) explained the pivotal place framing processes occupy in how social movements are conceived:

If the combination of political opportunities and mobilizing structures affords groups a certain structural potential for action, they remain, in the absence of one other factor, insufficient to account for collective action. Mediating between opportunity, organization, and action are the shared meanings and definitions that people bring to their situation. At a minimum people need to feel both aggrieved about some aspect of their lives and optimistic that, acting collectively, they can redress the problem. Lacking either one or both of these perceptions, it is highly unlikely that people will mobilize even when afforded the opportunity to do so. (p. 5)

Framing processes lie at the heart of a movement because they represent its ideas, aspirations, hopes, fears, strategies, and subculture, realized through painstaking personal experience and painstaking collective deliberation. This assiduous process of personal and collective visioning, an intense cycle of self-examination, is rewarded by a sense of personal liberation (Bishop, 2002; Chan, 2016; Johannson, 2001). When accompanied by collective agreement on the values and strategies by which liberation may be achieved, there is often a great outpouring of joy and a spirit of optimism (Heumann, 1998-2001/2012; Pelka, 2012; Shilts, 2008).

There are at least five aspects of framing processes:

(1) the *cultural tool kits* (Swidler, 1986) available to would-be insurgents; (2) the *strategic framing efforts* of movement groups; (3) the *frame contests* between the movement and other collective actors – principally the state, and countermovement groups; (4) the *structure and role of the media* in mediating such contests; and (5) the *cultural impact* of the movement in modifying the available tool kit. (McAdam, McCarthy, & Zald, 1996, p. 19)

McAdam, McCarthy, and Zald (1996) concluded that framing processes remain just as important to the fate of an “ongoing movement as they were in shaping the emergence of collective action” (p. 16). In a mature movement, framing processes are far more likely to be shaped by the conscious, strategic decisions on the part of social movement organizations and be “the subject of intense contestation between collective actors representing the movement, the state,” and any existing counter movements (p. 16). McAdam, McCarthy, and Zald suggested that later framing efforts are significantly constrained by previously adopted ideas and collective identities.

In contrast, Zald (1996) explained that progenitor movements *may* provide master frames, which later movements *may* draw on: “for instance, the civil rights movement provides a language that the later women’s movement and the disability movement can draw upon” (p. 269). I emphasize the word “may” because Zald (1996) posited that no movement, countermovement, or movement organization would *own* any particular cultural frame, but that certain frames, peaking interest from the media and employed by moral entrepreneurs such as politicians, church leaders, journalists, would be used more often than others to “define the issues, invent metaphors, attribute blame,” and define tactics (p. 269). Zald (1996) suggested that frames are less culturally deterministic than others might think, as frames advance and recede in importance without a well-ordered relationship to the actions of movement leaders or organizations (p. 270).

The dissertation does not concentrate on framing processes but considers them alongside mobilization resources and available political opportunities. Much of the consumer and survivor movement’s framing processes are based on a minority social identity (Alcoff, 2006; Diamond, 2013). Its cultural tool kit is largely adopted from the repertoires of the Sixties protest cycle early risers, the Black civil rights movement, feminism, and the disability movement (Chamberlin, 2012). The early movement’s framing efforts had been based on group coalescence and an expression of anger but was not strategic in how these frames may prevent eventual entry into the polity (Zinman & Bluebird, 2015; Morrison, 2003; Pelka, 2012). That is, frames based on anger and condemnations of mainstream systems without carefully thought-out policy proposals are highly unlikely to be taken seriously by legislative authorities, unless they are accompanied by disruptive tactics and civil disobedience (Gamson, 1990).

Mental health awareness is currently a popular trend in Canadian media, bringing with it the possibility that overt discrimination against people with mental health problems is becoming less socially acceptable (Chai & Nicholas, 2017). This suggests the possibility that the movement and its allies have been successful in attracting positive coverage for its agenda from the media and other mainstream cultural institutions, overriding age-old attitudes which would espouse a punitive or shame-based stance on mental health problems. Some have said that corporate discourses have successfully co-opted the psychiatric consumer identity into a commodity, ready to be used in corporate advertising and bereft of emancipatory potential (Linton, 2018). The weakness of movement leadership may be exposed in face of corporate discourse, as the framing contest between the movement and the corporations seems to be decisively won by the latter, withstanding movement leaders' seemingly meagre efforts craft their own cultural tool kits (Linton; Morrow, 2013). These are issues I would examine with movement leaders in the study.

Critical Analysis of Resource Mobilization Theory

I believe resource mobilization theory has a great deal to offer in conceptualizing consumer and survivor leadership practice. Many in the consumer and survivor movement feel they struggle alone, that no one else understands the movement's unique predicament, as no one else has made this journey before (Everett, 2000; Storey, 2011, p. 119). They could not be more wrong, if the resource mobilization literature holds any validity whatsoever. This literature suggests not one, or two, but dozens of other social movements and thousands of movement leaders and followers have faced similarly difficult leadership choices as consumer and survivor organizers, maybe not the same phenomenology of experience but comparable experiences. The consumer and survivor movement leadership would benefit learning from these forerunners.

Resource mobilization theory is a structural-functional sociological theory (Agger, 2013), despite its subject matter of predominantly progressive movements. It focuses on macroscale factors that shape society, with an assumption of homeostasis; that is, the polity always seeks to either pre-empt, absorb, or destroy a challenger group, to restore equilibrium. Conversely, it implies that a challenger group either strives to become the new political order, or to become centrally influential within elite circles, again within a criterion of equilibrium. The theory takes a distinctly objective point of view consonant with its sociological approach, as theorists tending to position themselves as separate knowers, rational and dispassionate, who write out the theory as an object of knowledge and gather data as things to be discovered. The theory's conceptual assumptions follow from this Cartesian dualism (Pascale, 2011) and fits comfortably into the modernist paradigm, the language of independent and dependent variables, precluding theorists from self-examining their epistemological and ontological claims. These things do not necessarily diminish the theory's value, but its insistence on finding objective principles of human behavior, with their implied social facts, makes it unlikely resource mobilization theory could be considered a critical social theory (Agger, 2013; Meekosha & Shuttleworth, 2009).

Summary of the Literature Review

In this Chapter, I first provide a brief history of some key events in the Canadian consumer and survivor movement. Then, I describe recovery, a unifying idea for both the movement and the mental health system. The limitations of current recovery practice are noted, including the current failure to intervene in the root causes of mental distress. Two bodies of knowledge form the conceptual foundation of the current study – the framework of social change leadership and resource mobilization theory – plus a third body, constructivist grounded theory, the study's methodological approach (see Chapter Three). Given the study's applied orientation,

the knowledge contained within the first two theories must be taken with a degree of skepticism in comparison with research participants' the subjective life worlds and lived realities, which would take center stage during the study (Charmaz, 2006; Stringer, 2014). Nonetheless, theoretical insights are significant: the careful elaboration and development of leadership constructs in the social change leadership framework and resource mobilization theory's empirical grounding of social movement processes and predicted outcomes. This discussion of social movement leadership theory provides a signal of the field's seriousness and depth.

The social change leadership framework explains various leadership activities, organizing approaches, and proposed outcomes from cases of high quality leadership. In the dissertation, the academic discussion of leadership practice will be compared to an emerging conceptual framework of leadership derived from the research participants' views, derived from grounded theory analysis (Charmaz, 2014; Stringer, 2014). Resource mobilization theory proposes three major components to any social movement: political opportunities; mobilizing structures (i.e., social movement leaders and organizations); and framing processes. Because resource mobilization theory delineates the factors shaping the trajectory of any social movement, including their antecedents, mediators, and consequences, it will be interesting to compare research participants' experiences with what is proposed by theory.

Chapter Three

Methodology

In the social sciences, research typically lies in three interrelated components (Berg, 2001; Patton, 2015). First, there must be a research question that demands an answer, a driving passion, a puzzle that will not go away (Everett, 1997). Second, there is a theoretical framework which serves both as a navigational aid and a statement of the researcher's a priori assumptions (Marshall & Rossman, 2011). Third, the researcher must settle on some manner of collecting the materials (the data, the information, the knowledge) from which the researcher will craft an answer to the question (Charmaz, 2006; Everett, 1997).

The Leadership Practice Problematic

The broad question driving this study is the leadership practice problematic in the psychiatric consumer and survivor movement. The movement has in some ways come of age, maturing considerably the past twenty years in Ontario (primarily Toronto) through an extensive network of businesses, services, funding arrangements, governance committees, and academic research (Everett, 2000; LeFrancois, Menzies, & Reaume, 2013; Nelson, Ochocka, Lauzon, & Trainor, 2004). The same time, throughout the rest of Canada, the movement has experienced significant setbacks as a number of consumer and survivor organizations, few as they are, have closed down or are in danger of doing so (Gallery Gachet, 2015; Downs, 2011; West Coast Mental Health Network, 2013). Meanwhile, the Mental Health Commission of Canada seems to be thriving, with its funding extended a further ten years by the federal government, while family member, diagnosis-based mental health organizations such as Schizophrenia Society of Canada and the Mood Disorders Society have strengthened their access to the polity and enhanced their public profile through mass media dissemination (Canadian Depression Research and

Intervention Network, 2017; Mood Disorders Society, 2018; Voronka, 2015). How leadership practice influences movement outcomes, within the field of political opportunity factors, how *identity performance* within a *relationship* might constitute leadership practice, and then how a leadership practice frames its relationship with government are questions that strike at the heart of what I want to find out (Haslam, Reicher, & Platow, 2011; McAdam, McCarthy, & Zald, 1996; Morris & Staggenborg, 2004; Uhl-Bien & Ospina, 2012).

The context of the research is threefold. One is Canada's prevailing neoliberal governmentality, which seems to absorb and reuse for the ruling class's own purposes the language and practice of empowerment which hitherto had been considered quite radical (Fabris, 2013; Voronka, 2015). Second is the need for an interjurisdictional comparison of political opportunity structures, movement mobilization processes, and framing battles within mental health (and more broadly disability) activism (Prince, 2009). Third is the researcher's, my, reflexive take on how I construct the data and make interpretations relationally with the significant people involved in the current study.

The Research Questions

Relationship building and earning trust with key people in the movement were my early goals when the study was in the proposal stage. The overarching research issue is elucidating the way leadership is practiced within the consumer and survivor movement, and how this leadership affects peoples' experience within the mental health system. The first research question resulted from an extended dialogue with movement leaders, psychiatric consumers and survivors not holding any official posts, and academics allied to the movement. The first question asks: (1) How is leadership practiced differently (or not) within psychiatric consumer and survivor-controlled organizations compared to within non-consumer controlled organizations? The

second question comes from my own participation in the ups and downs of social movements while also drawing from resource mobilization theory: (2) In what way do dynamics within the movement influence outcomes (successes, failures, compromises)? My third research question attempts to connect personal with political experience, concentrating on the proposition that leadership is made relationally (Foldy & Ospina, 2012): (3) How has leadership practice in the movement affected one's experience within the mental health system? The second and third research questions were mutually crafted with a seasoned psychiatric survivor activist and academic from Toronto.

Overview of the Methodology

The theoretical framework for the study comprises of the social change leadership framework (Ospina et al., 2012) and resource mobilization theory (McAdam, McCarthy, & Zald, 1996). Grounded theory, with an emphasis on its constructivist aspect, is the study's methodology (Charmaz, 2014). Curiously, grounded theory does not recommend an in-depth examination of theory prior to data collection, a proviso I have tended to ignore. I would instead give an extended reading of my participants' perspectives to honor their life worlds but still immerse myself in the research literature (Ramalho, Adams, Huggard, & Hoare, 2015; Strauss & Corbin, 1990). Finally, in data analysis and making interpretations, I would employ constructivist grounded theory with further input by research participants (Charmaz).

I chose constructivist grounded theory because it would produce a leadership conceptual framework grounded in the experiences of my participants. Constructivist grounded theory is considerate of the subjective, constructed nature of social theory yet maintains a belief in the utility of empirical investigation. I believe that striking a balance between subjectivity and empiricism is necessary for good practice, both in research and leadership.

Selection of Methodology: Constructivist Grounded Theory

Psychiatric consumers and survivors have been so-called studied to death, as society has been fascinated by the supposed bundle of pathologies which are perceived to constitute mental illness (Schneider, 2010). The prevailing research mode consists of biomedical and clinical research comparing the life condition of the mentally ill with those deemed normal using professionally predefined, categorical constructs. Historically, the views of the mental patients themselves have been invisible to bureaucrats, politicians, and physicians (Everett, 2000; Reaume, 2000). With the advent of disability studies, experiences of mental health problems which hitherto had been considered purely personal plights would now be re-examined considering its political and cultural context, at times using a feminist power relations analysis (Chamberlin, 1978; Ingram, 2005; Morrison, 2005; O'Hagan, 2014). These politicized narratives have become a significant discourse. Also, psychiatric consumers and survivors have published nearly five decades' worth of newspapers, zines, and memoirs (Ingram, 2005; Morrison, 2005; Oaks, 2012; Pelka, 2012).

Mad Studies has produced a series of deeply philosophical, introspective, Foucauldian deconstructions of what is typically taken for granted in conventional mental health discourse. These works destabilize what might be called bourgeois concepts now in vogue, such as *peer* and *recovery*. These works implicate commonplace knowledges as normative power, so-called truth as an insidious governmentality, and our subjectivity as inescapably governed by neoliberal logics (Fabris, 2012; Voronka, 2015).

From my perspective, I want the current study to employ a methodology with both a practical and theoretical contribution to the consumer and survivor movement while avoiding what I might consider to be *excessive* self-absorption and self-criticism. Seeing a movement

seemingly struggling, I would be happy to contribute to knowledge with pragmatic possibilities – tools to enhance the movement’s influence on the polity, and to strengthen opportunities for movement mobilization without making *irreconcilable* concessions to bourgeois cultural forms. I am, on the one hand, uneasy with some strategies taken by Mad Studies, especially the interpretations of Foucault’s methodology which seem to produce a theology of negation. However, I admire Mad Studies’ tenaciousness in bringing outsider knowledge, dismissed typically as crazy or mad, into academia, in the wake of gender studies and disability studies, arising earlier and becoming successful academic disciplines themselves. Mad Studies’ comprehensive deconstruction of liberal nation states’ ethical assumptions is a serious task, even if it is difficult material to understand (Gillis, 2015).

I did not want to engage in a ruminative deconstruction of leadership, but a pragmatically informed critical analysis of leadership, to identify leadership’s most potent and humanistic aspects. Thus, I chose constructivist grounded theory because of its pragmatist heritage and its marriage of empiricism and constructivism. In pragmatism, “meanings emerge through practical actions to solve problems, and through actions people come to know the world” (Charmaz, 2014, p. 344). Leadership is, for the most part, a practical endeavor. The meanings inherent in leadership manifest through practical actions and immediate emotional reactions, akin to the deployment of emotional labor (Ashkanasy & Humphrey, 2011). A pragmatic methodology seems to be a good fit with the realities of leadership and can create a research product that addresses questions in theory and practice that leaders may have. One goal of the dissertation is to create knowledge useful to the social movement.

Grounded theory is a blend of Glaser’s empiricism, invoking a *reality out there* that scientific methods can discover, and Strauss’s symbolic interactionism (later evolving into a

moderate constructivism) wherein *people construct selves through interaction* (Charmaz, 2014; Glaser & Strauss, 1967). Symbolic interactionism is derived from pragmatism and it focuses on the dynamic between meaning and action, addressing the processes through which people create and mediate meanings in society (Charmaz, p. 345). Again, the focus on meaning creation within a *context of action* seems to be appropriate for the study of leadership, given leadership's emphasis on *doing*.

Blending empiricism and constructivism in methodology appeals to two things: the nature of leadership, and the psychiatric consumer and survivor movement's historical circumstances. First, leadership is a highly subjective experience and phenomenon (Hosking & Shamir, 2012). Using empirical methods to clearly define the phenomenon would serve to decrease the confusion and quiet the cacophony of voices that might shout and yell about leadership issues, as occurs in day-to-day life (Hosking & Shamir). In short, empirical methods such as grounded theory would help bring greater clarity to the discussion.

Second, leadership within the consumer and survivor movement is characterized by the gap between subjective experiences, tending to differ widely on controversial and polarizing issues, and an empirical consideration of those issues, which tend to take a nuanced, moderate view (Everett, 2000; Morrison, 2005). Constructivist grounded theory can simultaneously address both the subjective considerations of participants and place those subjective considerations under examination, to see if the subjective claims can hold validity and coherence when analyzed from others' perspectives, arguments, and contexts. To me, such a method seems a powerful one to critically address leadership questions and construct a viable conceptual framework to inform and improve leadership practice.

Social Location, Reflexivity, and Constructivist Grounded Theory

I will briefly sketch out my social location as regards to the current study.

Self-Location: Insider Outsider

My gender and class privilege, including male authority, money, and an expectation to excel at higher education, fits well with the typically upper middle class, self-actualizing individuation offered by academic psychiatry. In terms of knowledge development, I am writing my positive mental health care experience into research, positioning myself as both an insider and outsider to the psychiatric consumer and survivor movement. An outsider due to my class privilege and my constructive relationship with psychiatry, but an insider to the movement because I intimately understand what it is to live under chronic anxiety and depression.

I am an insider to the movement because I survived a history of childhood abuse like many others with mental health problems. I also no longer consider the body the cause of my consciousness but as a structure of our consciousness (Davis, 2010; Pittman, 2016). And lastly, I am an insider to progressive movements through my subjectivity as a Chinese ethno-racial minority living in a white dominated colonial society. I have devoted my energies as an adult to critically examining the power inequities constituting racism, colonization, capitalism, and oppressions of all sorts. Practically, my interest in cultivating enduring relationships with movement activists has solidified my presence in that activist world.

My social location involves a plethora of elements, an intersectionality of privileges and oppressions considered from the dominant culture's vantage point. For me, the most decisive elements are my class privilege and male privilege, instantaneously intersected by a racialized identity within a white (man)-dominated Canadian society.

Reflexivity and Constructivist Grounded Theory

In constructivist grounded theory, a wide range of reflexivity is accepted (Charmaz, 2014). My reflexivity is rather limited within the dissertation, disclosing my subject positions only in relation to my own mental health history and selected interactions with participants. I have limited writing my reflexivity to spare the reader from becoming bogged down with details from my own life, which may not be all that interesting (!), and to preserve participant anonymity, as detailed reflections on researcher-participant interactions may reveal their identities. Renderings of the decisions I made as the study unfolded, my thoughts and feelings toward the participants, and reflections on various leadership conundrums can be found within the research journal. I also described in my research journal the reason and process for raising initial codes to categories and finally to conceptual categories, including my personal reasons, consistent with constructivist grounded theory (Charmaz).

Sample Selection: Research Sites and Participants

I carried out purposive sampling for this study, wherein I identified and recruited leaders in prior specified movement organizations (Berg, 2001). Snowball sampling was also used as one participant would refer me to other participants – their colleagues and friends. As the study can accommodate only a limited number of participants, the sample is certainly not representative of the entire social movement.

I asked research participants from consumer and survivor-controlled organizations in Vancouver, Calgary, and Winnipeg to take part in both designing the research and participating in interviews and document research. I chose these three cities because they offered opportunities for comparison across a region with shared histories but distinct political cultures (Wesley, 2011). Winnipeg was my home base, where I lived, with a significant history of

disability movement leadership (Enns & Fricke, 2003; Neufeldt, 2003). I chose Calgary because one of my key contacts in the consumer and survivor movement resided there and could introduce me to local movement leaders. I chose Vancouver because of that city's historic contributions to movement mobilization (Chamberlin, 1978), its unique geopolitical position, exemplifying what might be considered a textbook case of neoliberalism (Mitchell, 2004), and my personal connections to the city as a former resident. Response was robust, with more participants volunteering than I could accommodate. Few, however, were interested in a hands-on participatory approach and helping me to design the research project.

By *consumer and survivor controlled*, I refer to a situation where both the board of directors (or an equivalent governance structure) and their staffs each form a numerical majority of persons self-identifying as experiencing mental health problems (Clay, 2005). I sought self-avowed psychiatric consumers and survivors interested in sharing their leadership experience. Vancouver currently has three consumer and survivor-controlled organizations, Calgary has one, and Winnipeg has zero. Non-consumer controlled organizations included mental health organizations that did not meet the above criteria.

Having three western Canadian cities allows comparison of leadership practices in quite different geopolitical environments (Wesley, 2011). As my first research question requires a comparison of leadership differences between consumer-survivor and non-consumer controlled organizations, I would like consumer and survivor leaders in the latter organizations to participate, forming a comparison group.

Participants: Accessibility and Profile

I spoke with potential participants through my membership and presence in several consumer and survivor organizations. Consistently identifying myself as a survivor of childhood

abuse and a psychiatric consumer, I aimed to cultivate healthy working relationships with consumers and survivors. I received acknowledgement that they appreciated my perspective, even if I did not always agree with all aspects of an organization's politics or practices (A. Fitch, personal communication, July 2013; J. Beckett; R. Carten; C. Hutchison; L. Paul; personal communications, July to August 2014). The study's research questions resulted from these dialogues and from consultations with three consumer and survivor academics.

Profile of the Participants

Nineteen consumer and survivor leaders participated. Eight participants were from Winnipeg, eight from Vancouver, and three from Calgary. Strictly speaking, one of the Winnipeg participants lived in a rural community close to Winnipeg, one of the Vancouver participants lived on an outlying peninsula near Vancouver, and a second Vancouver participant lived in a small city close to the Rocky Mountains but maintained ties with both Vancouver-based organizations and national organizations. Only one Calgary participant lived in Calgary, whereas two others worked for a rural organization near Calgary.

Participants ranged from senior movement leaders with a national profile, regularly featured on the television news, to participants who would never be recognized in public and might not even be well-known within their own organizations, due to having a narrower focus in their work. Seventeen participants had formal responsibilities in organizational governance and organizational development. Nine participants identified as women and nine as men. Most participants seemed to identify as White Canadians, although I did not ask participants to describe their ethnic origin, so a range of ethnicities was possible. One participant identified as an ethno-racial minority. The lack of ethnic diversity in both the participant sample and the

leadership cadre of the movement is remarked upon in Chapter Four and discussed in Chapter Seven.

The Unit of Analysis

The unit of analysis is the person interviewed and their perspective. I focused on the research participants' life worlds, their shared social constructions and geopolitical context, to describe and explain the life experiences, dilemmas, worldviews, assumptions, and structural constraints underlying leadership practice. Participants are identified by their interview number; for example, the interview with the first study participant is indicated as "P1."

Data Collection: Interviews and Document Review

Data collection consisted of one-to-one *interviews* and *document review* (Charmaz, 2014). An additional data source rested in my research journal, documenting the researcher's hunches, reactions, interpersonal harmonies and struggles, strategies for the formulation of data patterns, early interpretations, and what has been learned. In the end, the research journal was only supplemental to the voluminous and rich data generated by the interviews. The journal information were mainly interim steps – initial codes and the reasons for raising initial codes to higher levels of abstraction – that were to find full expression in the writing of the dissertation and the resulting conceptual framework that emerged.

Although classic grounded theorists recommend it is best *not* to look for research literature prior to data gathering (Glaser & Strauss, 1967), saving the perusal of the research canon only after considering community members' localized knowledges and informal theories, I found it nearly impossible to attempt a doctoral dissertation without a substantial literature search (Charmaz, 2014). Thus, interview questions although worded in general terms would

draw upon ideas of social change leadership and resource mobilization, discussed in the previous chapter, as sensitizing concepts, using Herbert Blumer's term (Charmaz, 2006).

Interviews

One-to-one interviews provide opportunities for participants to describe the phenomenon in their own terms. The interviews were a mix of informal conversation, as I wished to first establish a gentle and comfortable tone to the proceedings, and subsequent probing questions on leadership specifics. At first, I asked very general questions to enable understanding the way participants experienced their life. At least eleven participants provided a tour of their lifeworld: the activist lifeworld; what their home, office, or community habitat means to them; how the personal intersects with the public aspects of leadership (Spradley, 1979). All interviews were recorded electronically. I wrote down on the interview question form (Appendix A) and the interview context form (Appendix B) my impressions of the interviewees' body language, voice tone, and attitude.

I conducted nineteen interviews. The interviews generated 305 pages of single spaced, 12-point font transcript. Interview eight was not transcribed because the participant did not answer the questions on the interview guide. He focused on his personal experiences in the mental health system but ignored my leadership questions. Data for this interview came from my journal reflections on the participant's perspectives. Interview fourteen did not record properly on the recorder. The participant instead wrote out brief answers to my interview questions, one page in length.

Based on experience, I had planned to pilot an interview guide first, discerning if fine tuning or major revisions were necessary. My first interview was for this purpose. After the interview, I surmised that no major revisions to the interview guide were necessary. In May

2017, during my Vancouver trip to conduct interviews four, five, and six, I found that my question about communication strategies typically yielded only concrete and technical answers (refer to Appendix A). I found this to be unsatisfactory. I amended my question to instead reflect a conceptualization based on resource mobilization theory, to draw out theory-rich and experience-rich answers: “How do you present your ideas to win support, gain members, and gather resources?”. Because this involved an amendment to the research instrument, I submitted an amendment request to the University of Manitoba research ethics board and the request was approved on August 8, 2017.

I subsequently incorporated the new question into my interview guide and used this second iteration of the guide for interviews nine to nineteen (refer to Appendix C). For interview seven, I retrospectively asked the participant the new question after the interview because amended interview guide had not yet been approved at the time of the interview. For interview eight, the participant did not answer most of my planned questions, as he talked mainly about his own mental health struggles.

Interview data is hereby referred to using “P” for participant, followed by a number denoting the interview number; for example, P1 refers to the participant in interview one.

Document review

I had planned to review leadership vision and implementation and organizational governance documents from the consumer and survivor-controlled organizations affiliated with the participants. Unfortunately, participants were not able to provide me with these documents, except one participant from a Calgary-based organization provided rather dated documents on public consultations and organizational vision and mission. Overall, the influence of internal organizational documents on the study findings is minimal.

The remainder of the document review was the work of reviewing publicly available documents of both consumer and survivor and non-consumer controlled organizations, mainly accessed through their websites. Three types of documents were of interest. Only for large, quasi-governmental organizations – the regional health authorities – would all three types be publicly available, and for some small, non-governmental organizations, none of these documents were accessible to the public. First, documents describing an organization's history, vision and mission, and structure (hierarchy) are helpful. Such documents identify how leadership derives from values, world views, and assumptions, and the way such ideas are materialized in practice (i.e., *framing processes*).

Second, those documents relating to organizational governance and change, such as internal committees, changes in management, re-structuring efforts, and task forces, provide archival evidence of leadership practices, especially on how decisions are made in mobilizing cadres and resources (*mobilization structures*). These documents are rarely accessible to the public, although snippets of such documents are often available through media reports, which I found to be true for regional health authorities and the larger nongovernmental organizations. Third, I reviewed documents on an organization's transaction with outside actors: other consumer and survivor organizations, government; funders, mass media, other social movements, recruitment efforts, and neighbors. This information relates to *political opportunity structures* and suggests the degree to which leadership efforts are sustainable (i.e., *mobilization resources*). Publicly available documents of this type are only available for regional health authorities and government agencies, and I reviewed several such documents (for e.g., *Downtown Eastside Second Generation Health System Strategy*; Vancouver Coastal Health, 2015).

It is important to emphasize documents are not objective data although they often represent what their authors assume to be objective facts (Charmaz, 2006). From a social constructionist perspective, I asked the following questions about documents to bring forth the purposes and contradictions of this ready-made source of information (Charmaz, 2006):

What are the parameters of the information?

On what and whose facts does this information rest?

What does the information mean to various participants or actors in the scene?

What does the information leave out?

...

Who is the intended audience for the information?

Who benefits from shaping and/or interpreting this information in a particular way?

How, if at all, does the information affect actions? (p. 37-38)

Overall, the document review was strictly supplementary to the richer interview data.

Analysis Procedures

I would first review the research questions when starting data analysis (Berg, 2001; Casey, 2009). Following an interview, I transcribed the contents from audio to written form. Following my perusal of a document, I interrogated its content and structure employing the social constructionist questions listed above. The bulk of the analysis consisted of analyzing the nineteen interviews.

Following interview transcription, I began initial coding, line by line, guided by constructivist grounded theory (Charmaz, 2014). I did focused coding, raising the codes to categories, then lastly raising categories to conceptual categories, the basis for the conceptual framework of leadership practice. A document analysis is performed using constructivist

grounded theory questions as well, but without the line by line precision demanded by an interview analysis. Instead, for each document significant to the emerging conceptual framework, I wrote an analytical memo (Charmaz, 2014). I privileged the interview as the study's main source of data because of interviewing's relational, context-specific, and co-constructed nature. The nineteen interviews provided a greater depth and breadth of information than any other source. Document analysis served a supplementary role, as internal organizational documents were not available (Berg, 2001; Casey, 2009; Morrison, 2005).

I member checked with all nineteen interview participants: presenting the transcript to them post-interview, asking for their feedback regarding the interview, providing feedback to them about their answers, presenting the focused coding to interested participants (although not all showed interest in this), and asking all but four interviewees additional questions to further understand the topic. I also checked with participants on my impressions of a document, although this occurred only a few times because of the scarcity of documents. All these procedures strengthened the study's trustworthiness (Charmaz, 2014). The resulting conceptual framework of leadership was also member checked.

I attempted to analyze the interview data using pen and paper methods, writing on index cards and then sorting them. After analyzing two interviews using this method, I realized that the amount of data overwhelmed the sorting capacity of pen and paper methods. I acquired the software program NVivo and used it to analyze the data. I started initial coding line by line, not missing any vocalized data. The number of codes generated became overwhelming, at nearly five hundred codes. At the study's midway point, starting with Interview Thirteen, I began only to code for leadership attributes, functions, and barriers. I stopped coding for material pertaining to interviewer-interviewee dynamics and other ideas not relevant to leadership.

The final step in focused coding consisted of sorting the categories into the three research questions, attempting to answer the questions that drove the study. Within each research question, I grouped clusters of categories into conceptual categories, the basis of the resulting conceptual framework of leadership practice.

Quality Criteria for Constructivist Grounded Theory

Qualitative researchers often debate about the appropriate criteria for rigor. Some adopt the criterion of *trustworthiness* from the interpretivist paradigm (Lincoln & Guba, 1985). Checks for trustworthiness assess the following attributes of a study: credibility, transferability, dependability, and confirmability (Marshall & Rossman, 2011).

Considering my insider-outsider position and my adoption of a moderate social constructionism, trustworthiness would be an appropriate criterion. Trustworthiness tests whether the researcher has established the veracity, the truth value, of the information and analysis emerging from the research. It checks that the research findings do not merely reflect the researcher's biases and perspectives and that findings are not based on simplistic or superficial analyses of the problem being investigated (Stringer, 2014). Also, trustworthiness acknowledges that knowledge is co-constructed, a relational process carried out (ideally) in a community of self-critical learners (Kemmis & McTaggart, 1988).

Here, I employ two elements of trustworthiness to assess research quality – *credibility* and *transferability* – because these two elements by themselves seem to capture the concept's main points. The elements that I am not employing, dependability and confirmability, seem to turn upon the concept of the audit trail, a technique, I believe, of limited usefulness in qualitative research. The audit trail provides the documentary footsteps in which future researchers hypothetically might follow upon to verify that I have indeed done the work in the manner I have

stated. Exact replications of qualitative studies are very rare, and literal exactness is impossible due to the passage of time and changing contextual conditions.

Credibility refers to a study's plausibility and integrity. It allows readers to assess that the inquiry has been conducted in such a manner as to ensure the subject is appropriately identified and described (Marshall & Rossman, 2011). Credibility is the closest thing that qualitative research has for the so-called truth value, identified within the positivist paradigm as the internal validity. Lincoln and Guba (1985) recommended two tasks to demonstrate credibility. First, the researcher should carry out the study in such a way that the probability the findings would be found to be credible is enhanced. In grounded theory, there are several ways of demonstrating credibility (Charmaz, 2006):

1. Has the research achieved an intimate familiarity with the setting and topic?
2. Are the data sufficient to merit researcher's claims?
3. One might consider the range, number, and depth of observations contained in the data.
Are systematic comparisons made between observations and between categories?
4. Are there strong logical links made between the data and the researcher's argument and analysis?

Second, the researcher demonstrates the findings' credibility by having them approved by the constructors of the realities being studied – the participants themselves (Lincoln and Guba, 1985). Stringer (2007) further explains:

the credibility of research processes is a fundamental issue. Unless participants are able to trust the integrity of the processes, they are unlikely to make the personal commitments that are essential to a well-founded inquiry. (p. 95)

I employed the following methods to assess credibility: triangulation (corresponding to Lincoln and Guba's first task), member checking (Lincoln and Guba's second task), and participant debriefing (second task) (Marshall & Rossman, 2011; Stringer, 2014). Triangulation is the act of bringing more than one source of data to bear on a single point (Marshall & Rossman). Information from different sources – multiple methods (interviews and documents), multiple organizations, multiple geographic locations, multiple informants – are used to construct, corroborate, and elaborate the resulting categories and the final conceptual framework. In member checking, participants reviewed the analyses derived from the research procedures. This enabled them to verify that the research adequately represented their perspectives and knowledge and provided opportunities for them to clarify and extend the analysis (Charmaz, 2014; Stringer, 2014). Participant debriefing was conducted together with member checking, although these communications involved multiple emails and phone calls for a few participants. Member checking and debriefing occurred through email, but I had made phone calls with two participants for these purposes. I also communicated with one participant through surface mail, at his request.

Transferability refers to the possibility of applying the study's outcomes to other contexts. For a small grounded theory study, as this is, the findings typically only apply to the people and places that were a part of the original study (Stringer, 2014). However, a detailed description of the study's context, events, and activities makes it possible for readers to judge whether the study's context and subject matter is sufficiently similar to an external context for transferability to be viable (Everett, 1997; Stringer, 2014).

Lastly, I assessed the study's usefulness (Charmaz, 2014). Charmaz (2014) asked: Does the study offer interpretations that people can use in their everyday worlds? She posed the following questions to assess a study's usefulness:

- Do your analytic categories suggest any generic processes?
- If so, have you examined these generic processes for tacit implications?
- Can the analysis spark further research in other substantive areas?
- How does your work contribute to knowledge? How does it contribute to making a better world? (p. 338)

Ultimately, "an entire community of people will become the arbiters of the legitimacy of the knowledge produced by the present work" (Everett, 1997, p. 159).

The assessment for quality in this study is presented in Chapter Eight.

Ethical Issues

I applied for Research Ethics Board approval, within the University of Manitoba, and received approval on February 16, 2017. On August 8, 2017, the Research Ethics Board approved an amendment to the interview guide (please refer to above for details). On February 8, 2018, the ethics approval was renewed, with expiry on February 16, 2019. I did not anticipate any major ethical problems, and none surfaced over the study's duration. Almost all participants were experienced in formal leadership roles, with some having local or national media exposure. Their responses to the research questions (I imagine) were not significantly different from the questions they face in their regular work within the movement and their organizations. Neither I nor my advisor were in a position of power vis-a-vis the participants. The study would not expose participants to emotional stress beyond what they might experience in their day-to-day

movement work. Their consent to participant was voluntary, and they possessed significant expertise on the research topic.

It is possible information about participants may be obtained from sources other than the participants themselves. For example, another interviewee may make a comment about a participant. Documents may illustrate a participant's role and capacity within an organization or within the movement. Given the study's constructivist orientation, I privileged first hand information, from the participant or from my own observations and journaling, as primary. Compared to the participant's own words, external sources about a participant's leadership were mainly fleeting and superficial.

I was concerned that interviews might yield potentially explosive material, but the concern was unfounded. During the interview proper, most participants were diplomatic and considered in their responses. The exceptions were two participants who voiced pointed criticism at individuals in the health care system, naming them in front of me. One of these participants wished to tell me that his psychiatrist and various psychiatric nurses, people whom he no longer saw, had acted, in his perception, in a disrespectful, abusive way. This participant ignored my interview questions and spoke only about his sense of victimization. I decided not to transcribe his responses because he had failed to address the research topic. A second participant criticized a social worker, using her name, as an example of social work's indifference to people with disabilities. This passage was never used as a reference for any category, so the initial disclosure of the name will not be an issue.

The data has been stored in a cabinet at my home office and on USB. Stored data will be destroyed five years after completion of the study.

I anticipated ethical issues with anonymity and confidentiality, but no concerns surfaced during the study. I deliberately refrained from elaborating on the biographical details of each participant to preserve anonymity. Nonetheless, a movement insider may be able to discern participant identity if they carefully read each quotation by a participant and made inferences from their typical speech mannerisms, but this would only amount to a guess. In all other instances, anonymity would be preserved.

It is possible that dissemination of the findings may compromise confidentiality, given the small, tightknit network which comprises the consumer and survivor movement. As described above, only movement insiders would have any ability to discern identity from quotations, and this would only amount to a guess. For participants who do not have a public profile or who play secondary roles within an organization, confidentiality should be rather straightforward to maintain.

Summary

This chapter describes the research design used in the study and the methods used in gathering the data. I start by discussing the movement leadership problematic, the three research questions, and the reasons for selecting constructivist grounded theory as the methodology. I then touch upon my social location as a researcher and provide a brief profile of the participants. I describe the two methods used, interviews and document reviews, and discuss the study's analytic approach. I elucidate the quality criteria for constructivist grounded theory and end the chapter with a discussion of ethical issues pertaining to the study. The following three chapters, Chapters Four to Six, describe the study findings, with each chapter corresponding to one of the three research questions.

Chapter Four

A Comparison of Leadership in Consumer and Survivor Organizations and Non-Consumer Controlled Organizations

In this chapter, I provide participants' responses to my first research question: How is leadership practiced differently (or not) within psychiatric consumer and survivor-controlled organizations compared to within non-consumer controlled organizations? I interviewed consumers and survivors working in the consumer and survivor-controlled organizations and in non-consumer controlled organizations. Seven leaders worked in consumer survivor-controlled organizations. Eleven leaders worked in non-consumer controlled organizations. One person worked equally in both types of organizations. The final numbers for each of these two organizational categories ended up quite close to what I had anticipated in the research proposal. Only one consumer-controlled organization provided documents as additional data to supplement the interviews.

Overall, I found a great deal in common in leadership process across both consumer controlled and non-consumer controlled organizations. Both sets of organizations required flexibility and accessibility in how leadership tasks would be performed. Both engaged in leadership activities including mentorship, maintaining peer support as the central activity, and attempting to influence public discourse through recovery stories.

Consumer controlled organizations and non-consumer controlled organizations faced common struggles. For both, fundraising was an essential but very difficult task. Fundraising, participants suggested, often put organizations into ethical quandaries. The other major struggle was that various mental health organizations historically have been perceived as disempowering. Addressing disempowerment's historical impact and making amends was a task that several

leaders from both sets of organizations were engaged in. Finally, several participants noted that both types of organizations struggled to accept cultural diversity.

Several issues came up that were specific to consumer and survivor organizations. Participants related that a purely middle-class leadership orientation seemed to fall short of what the social movement has historically promised. There was some evidence that consumer and survivor organizations, as well as select non-consumer organizations heavily driven by consumer input, demonstrated an inclusivity for leadership done by poor people. Nonetheless, interviewees felt that poverty remained a massive barrier to leadership, which I will discuss in detail. Dissension and factionalism seemed to be a problem for some consumer and survivor organizations, but with the caveat that two out of the four such organizations contacted for this study expressed no such problems. Lastly, I will discuss the question of social identity vis a vis the consumer and survivor organization and close the chapter with a discussion on whether the word “fragile” is an apt descriptor for consumer and survivor organizations. On both topics, participants demonstrated significant variations in opinion.

I begin this chapter with a discussion of the commonalities between consumer and survivor-controlled organizations and their non-consumer controlled counterparts: their common organizational needs, common leadership tasks, and common struggles. I follow by describing issues specific to consumer and survivor organizations, including the seemingly insurmountable barrier that poverty presented, and the controversial issue of dissension and factionalism. I conclude the chapter with what might be considered the most noteworthy aspects of the responses concerning the study’s first research question.

Common Organizational Needs: Accessibility and Flexibility

Both consumer and survivor-controlled organizations and non-consumer controlled organizations required that leadership promote accessibility and flexibility in organizational procedures. Five participants spoke on this topic. Consumers and survivors would desire organizational procedures to be flexible, based on a basis for empathy, and for procedures to discourage unnecessarily judging others based on social difference. In this way, an organization would become accepting of body, behavioral, and emotional variation. One participant plainly stated, “we run support groups, we have non-judgmental people” (P15, p. 6). Another participant observed that in one consumer and survivor organization, “people are very...accepting of all kinds” of ways to express oneself (P9, p. 15). For example, work roles may have to be adapted, and attendance may need to be waived if a colleague became unwell. A backup plan may have to be put into place if a period of absence became prolonged:

when you have individuals, who have severe mental health issues running organizations, you have to take that into account...and the organization itself has to take into account and plan for the fact that at some point, one or more of those individuals are going to become incapacitated potentially (P9, p. 13)

Common Leadership Tasks and Activities

Participants indicated the leadership tasks to be performed within both consumer and survivor-controlled organizations and non-consumer controlled organizations included mentorship, peer support, and changing public discourse through recovery stories.

Mentorship

Six participants understood mentoring to be a large part of what it meant to be a leader. This topic cut across both non-consumer controlled and consumer and survivor organizations. They indicated that mentoring helped to educate future generations of leaders. It allowed older

leaders to remain relevant and still connected to the movement, while imparting wisdom and giving younger leaders the opportunity to compare different leadership perspectives. Participants also noted that mentoring encouraged mutual aid across organizational boundaries:

for example, some of our smaller committees, we have allies like [a national organization], [a second national organization], some of the top people in those whom we can call on at any time. And who have a depth of experience and years of experience. For me they are kind of like your peer supporters or your mentors. (P2, p. 23)

Mentorship involved a sustained working relationship between a mentor and mentee (P1, 2, 9, 10, 12, 16). A related concept was the role-model, which involved a brief meeting, wherein the role model was someone looked upon by others as an example to be imitated. One interviewee spoke of his dual role as a founder of an organization and as a teacher. Within both, there were rich opportunities to become a role model for the public and a mentor for his students:

my leadership role is helping the organization run, but also speaking for the organization at events that help to reduce stigma, and a lot of that has to do with me speaking frankly about my experiences. Sharing my experiences, and I think people are very appreciative of that when I do that. And I do the same thing in my classes...And many of the classes that I teach have content that is related to psychiatric illness. I usually weave in my own story into any discussion, for example, depression, bipolar disorder, because I was diagnosed with depression when I was an undergraduate, in my second year, and I was diagnosed with bipolar disorder in my first year of my PhD. I had my first manic episode. So, I usually tell that story. It is important, I have had students come back to me, sometimes years later, sometimes right after the class, telling me how much they

appreciate me speaking openly about it because they had been suffering from such and such for so long. (P9, p. 17)

Peer Support: A Family, A Community

Eight participants expressed the great value of peer support to their life. At least five people said that they focused their leadership toward peer support: initiating it, providing it, and educating about it. From virtually all nineteen participants, they told me that peer support was the central occupation of both consumer controlled and in non-consumer controlled organizations. In a way, as suggested by the quotation above, peer support seems very similar to mentorship. However, as I understood it, participants tended to refer to peer support as an organized group activity – a peer support group – whereas they usually referred to mentorship as a one-on-one dynamic. I used the word family to describe peer support because of the social intimacy that some participants attributed to peer support (P2, P10, P18, P19). For them, peer support extended well beyond a clearly demarcated and time limited activity amongst acquaintances in an office setting but approached a level of social and emotional intimacy more characteristic of family life. One participant spoke of several peers, former movement colleagues, in the following manner:

[they] were also very dedicated right to this organization and they still are. They are the most, I love them just as much as I love [my current colleague], they have met, they are still very much in our hearts, and I visit them and we have dinner at their assisted living facility that they live at (P18, p. 15)

One leader, who worked as a paid employee providing peer support, stated that consumers “constantly refer to...coming back [to us] to spend a day with family” (P10, p. 17). She commented that her organization’s peer support offered a vital platform for healing, “for

people to grow from because we don't heal on our own. We heal within community" (p. 18).

Another participant described a group of his peers who took turns speaking at public forums, sharing their recovery stories. They were not only speaking on an individual basis, but as a group, and they seemed to challenge each other, on the various assumptions that they might hold:

that is a group of us sharing serendipitously... We are about seven people, and we share our stories at events, churches, schools, fundraising banquets believe it or not, things like that. There we are, all of us have a different kind of story, and we tell our story in about eight to ten minutes. We get such positive feedback from that. But the other thing is that group has become like a kind of a group counseling session for us. Because we kind of push and challenge each other on some of our things, that we say. (P2, p. 6-7)

As this person described, the group seemed to have grown very close, allowing themselves to become vulnerable to one another, serving as each other's support through various anxieties and even crises. Through becoming vulnerable with one's peers, being a reliable support through both good days and bad days, this participant related, they built up mutual trust. I felt that his comment about dropping everything and rushing out to help his peer should they run into real trouble was telling:

P: we work together, we speak together in these sessions, and that's been good... Like I say, even though it's not an official support group, it has become a support group. I have learned a lot through them... when they tell their story. I don't know how to explain that but, it changes the level of the interactions. Like if one person would call me and say, I really need help, I'd drop everything and get in my car and drive there.

I: Oh really!

P: [laughing] Yeah. Oh, we've grown very tight, and we've done that kind of thing. (P2, p. 7)

Changing Public Discourse Through Stories of Recovery

A major leadership task, according to six interviewees, would be honoring one's story and telling those recovery stories to the public. This task seemed to be as important for the non-consumer controlled organizations as it would be for the consumer and survivor organizations. Many leaders felt that the first task of leadership should be *listening* to the stories of consumers and survivors (P2, 3, 10, 11, 12). One man explained that if one were to listen to people's stories, one would hear people not just recovering from mental health problems but "recovering from unresolved trauma...recovering from a non-recovery oriented mental health system" (P3, p. 3). When consumers and survivors *listened closely* to people's stories, they would in effect be role-modelling a therapeutic behavior that mental health professionals should consistently be engaging in, but often did not (P3).

The stories of people experiencing hallucinations, highly stigmatized topics in the dominant culture, needed to be listened to and honored to facilitate effective, humanistic techniques of managing these often-frightening experiences. Three leaders explained that hallucinations can be creatively worked with and viewed as valuable, if at times very disturbing, aspects of one's self (P4, P12). These three participants were involved in the Hearing Voices Network, an international support organization for people experiencing hallucinations, which advocated for people to find some meaning in their hallucinations. This peer support organization focused on techniques for voice hearers to contain and manage these experiences so that they would not overwhelm one's life, but understood that only relying on neuroleptic medications, while effective for some, would be ineffective for others at controlling

hallucinations, leaving these folks “feeling very disempowered” (P4, p. 6). If neuroleptics could not contain the hallucinations, yet still produced distressing side effects, that clearly would be very frustrating, and a bad choice in terms of the tradeoff between medication benefits versus adverse effects. One participant explained:

I’m also running a group called Voices...it’s for people who experience hallucinations and medications don’t really help...or if they’re still fighting with those hallucinations. So, we’re looking at, instead of medicating them when it’s not helping and going to hurt their liver or cause diabetes and all this other stuff, looking at how we can help them be able to work with those voices in order to still live a productive life. How do you silence them? Can you put them in a jar and make them quiet? Can you tell them, I’ll talk to you during this time, but right now you’re going to leave me alone because I’m going to school, and it’s actually working, right? Some people also have good voices and bad voices. I mean there’s good voices that come after bad voices, so we’re working with that sort of stuff as well here. (P12, p. 5)

Participants indicated that to be a leader first involved listening to and honoring the unique stories of consumers and survivors. Leaders then must go out and educate the public about mental health problems and recovery, something that basically every participant agreed with, although one or two interviewees had reservations about personally engaging in publicity. To break down stigma, one man explained that sharing his story was much more effective than quoting statistics and theory:

When you tell a story, people have to listen. When you give statistics, they could care less...It goes in one ear and out the next. It is useful. I go and tell my personal recovery story. I do a presentation and I feel well. I tell it, not only to be a good actor, it is

supposed to be from the heart, right? I took part. It is not so easy perhaps. Some people may not feel comfortable speaking in front of a crowd. Tell your story. Your own story, you see that the stigma attached, you overcome it every time. (P11, p. 9)

Stress arose, understandably, when faced with speaking in front of a crowd and revealing one's story in newspapers and on television. That stress, for one or two participants, had contributed to the return of their psychological symptoms (P1, P11). However, about half of the participants maintained a significant and consistent media presence, giving interviews on television, for newspapers, and on the internet. While none of them could be considered household names, they were known within the consumer and survivor and disability communities. For example, one person had received a respected mental health award, and had given numerous interviews to newspapers and on television.

One participant pointed out that despite the Mental Health Commission of Canada's shortcomings, it has successfully stimulated public dialogue about mental health issues nationwide (P7). He noted that nationally recognized sportscaster Michael Landsberg has worked with the Mental Health Commission to help the Canadian public begin speaking about mental health in a respectful, non-stigmatizing way. A Vancouver participant had been very pleased that the President of the University of British Columbia, Santa Ono, recently disclosed on social media, without embarrassment or shame, that he experienced what was commonly referred to as "bipolar disorder" (P9, p. 17). Although most Canadians have never personally met any of these public figures, they nevertheless may serve as role models for disclosing one's mental health problems. As one interviewee emphatically stated, "it's happening. People are talking about it...It's coming out, it's coming out" (P7, p. 26). A prominent consumer and survivor leader, whose leadership routinely worked with not only national organizations but international ones as

well, had been quite critical on the use of celebrities, especially wealthy, White media stars, to promote mental health awareness (P16). The criticism centered on the inability of such campaigns to change public perceptions of the poor with mental health problems, the homeless, and those who were not very articulate or photogenic. At least six other participants voiced similar concerns, although not as clearly stated as this leader. These criticisms aside, she acknowledged that these campaigns still had something valuable to offer:

But I do recognize that those campaigns start conversations, and maybe conversations that wouldn't have happened. I know parents in this community who because of the [broadly publicized] campaign realized that their children, their teenager was struggling, and that started a conversation which I think is beneficial. (P16, p. 14)

Common Struggles

Participants identified several common struggles and problems facing both the consumer and survivor controlled organizations and non-consumer controlled organizations: the struggle for funding, some organizations having been historically disempowering toward consumers and survivors, and failing to accept cultural diversity. The last issue discussed in this section, the notion that a middle-class leadership would fall short, was directed at non-consumer controlled organizations, but also a vigorous topic of debate within consumer and survivor controlled organizations.

The Struggle for Funding

What I heard loud and clear from participants in both non-consumer controlled and in consumer and survivor organizations was that funding was essential. At least twelve out of the nineteen leaders spoke on this issue, some at length. It seemed such an obvious issue for any organization, but this did not make it any less important, as in the same breath, many participants

explained their arduous struggle to get and then maintain a viable funding stream. Even though the federal government has increased their mental health funding opportunities, the various provincial governments have done the opposite. This led to local mental health organizations competing for a small pot of dollars, “clamoring for that” (P1, p. 10). Several other interviewees corroborated the opinion that local organizations competed with one another for government money, often resulting in distrust between organizations (P16).

A participant in a non-consumer controlled organization explained that she had just graduated a class of students from her peer support training, but her organization currently did not offer any paid positions for these graduates (P12). This person matter-of-factly stated that the province determined her organization’s budget, and that was the end of it. Many interviewees concurred with this opinion, adding that their organizations were chronically understaffed in relation to the work demands because they cannot afford to hire more people (P5, P16, P17, P18). For example, one organization acted as an intervenor in human rights court cases, according to one participant, but subsisted with a barebones staffing complement of two staffs, with one staff part time (P16). The organization intervened in cases at the provincial courts, federal courts, and international courts, a very significant workload and responsibility. What would they do, this person asked, should the government not renew their funding in the middle of a court case? The lack of staffing was a risk factor that must be considered in organizational strategic planning:

we require funding and financial resources to do the consultations, to pursue the court and litigation cases that we do, to go internationally to speak to the different committees...and other legislation that address human rights...

At the end of our funds, what are we going to do? And what if we're in the middle of a court case, and our funding from the government ends, and then we can't continue pursuing it? Like I think we have four court cases on the go right now, that are taking human rights violations and the disability community to another level, and one of them is regarding the [inaudible] Mental Health Act. (P16, p. 9)

Another participant explained that the funding arrangement with the provincial government underscored the rather disrespectful working relationship between the province and the mental health organization:

It is an unequal relationship. The relationship that we have with the Manitoba government is, they are the senior partner, and they also give only minimal funding, very minimal funding for the size of the organization, so it's not a partnership except that they do rely on us to do some very important peer support work for a very, very, very low price so in that sense, they depend on us a bit...It's not a very respectful relationship because they don't respond to our requests (P17, p. 4)

In the case of an organization with a private funding stream from philanthropists and private citizens, the government typically preferred this arrangement. But even fundraising success might pose a threat to the organization, because the government might then decide their funding would be superfluous:

I think you're right, seeing that if you can be self-sufficient, there's no point in them funding it. So, if you have successes, success is great but sometimes from a funding standpoint, if you're successful, you're not going to get more funding from a government. It's a Catch-22 situation, so you have to be very savvy in how you're dealing. (P15, p. 9)

This leader felt that the government would put the organization in a bind; that is, they would only offer the organization what it would no longer require. In the future, should the organization express a real need for support, the government would not provide – a definition of the Catch-22. The financial precariousness of a nonprofit organization was an issue that was “always in play” (P15, p. 9). Because his organization’s funding would have to be renewed year to year, it was always on “the edge of being shut down” (p. 9).

The reality was that various mental health organizations, some non-consumer controlled and some consumer and survivor controlled, lost their funding and a few completely closed down. The past five years, these funding cuts have been especially severe for Vancouver-based mental health organizations. Through the channeling mechanism of the health authority, Vancouver Coastal Health, the British Columbia government completely halted funding for Action, Research, and Advocacy, a Downtown Eastside advocacy organization focused on people with mental health problems, and West Coast Mental Health Network, a peer support oriented, consumer and survivor-controlled organization. Action, Research, and Advocacy closed its doors. The West Coast Mental Health Network appeared inoperative currently. Neither of these two organizations participated in the current study, but various interviewees made observations about the debacle that these two organizations ran into.

Access Community through English, an in-house program of Vancouver Coastal Health, provided an opportunity for new immigrants to learn English while supporting their mental health. One interviewee noted that this had been a very innovative program, but it too was cancelled (P4). At least four other mental health organizations in Vancouver have suffered funding cuts from the government during the same period but have managed to survive (P4). One interviewee suggested that Action, Research, and Advocacy and the West Coast Mental

Health Network were especially valuable resources, because they provided a place where people alienated by the mental health system could access help and information (P4). The other four organizations were recovery oriented and provided a platform for people to speak out about social marginalization as well as build interpersonal connections (Hladikova, 2015).

At least eight participants were concerned about the danger that movement organizations have become defanged and corporatized because of corporate financial support. The push for corporate funding seemed to have displaced the focus on serving consumers and survivors, most of whom were poor folks. One leader articulated this shift in focus at her organization:

I just wanted to say, what about support groups?! What about support groups?!

[Laughs.] The problem with support groups is that they don't bring in money. (P5, p. 7)

It was noted that mental health professionals have taken up office space at her organization, which had historically been a peer support initiative. However, these professionals paid rent, whereas peer support groups did not generate any income. These professionals charged fees for their services. The peer support groups were free of charge.

This participant noted that she had been involved in governance activities within her organization, but had felt intimidated, because the other leaders were male business professionals focused on fundraising. She was the lone person with lived experience, and she would have felt more comfortable and more assertive had there had been others with lived experience present:

I am in a very different class. I felt quite intimidated to speak up. Possibly, if there had been two, three other consumers there, I probably would have felt the courage because I am speaking for several of us. But I felt very isolated there...and I just didn't have the courage to speak up. It just felt like their whole purpose was on money. (P5, p. 6)

Some of the largest corporations in Canada, including Bell, TD Bank, and Great West Life, have begun funding initiatives purporting to combat stigma and promote mental health literacy (Linton, 2018). However, current and former employees of some of these corporations have come forward, charging that their employer in fact created fear and distress in their employees. Bell and TD Bank apparently forced upon them an unreasonable workload and an aggressive, possibly emotionally abusive, management style, directly contradicting the principles of their mental health campaigns (Johnson, 2017a, 2017b, 2017c). Historically, pharmaceutical companies have been consistent corporate supporters of mental health organizations. One leader stated, “when I started I was a little bit more naïve...we were funded by pharmaceuticals” (P7, p. 11). The influence of pharmaceutical industry funding, another explained, has been to garner support for a biomedical reductionist explanation for mental illness, and a tendency to devalue recovery and self-determination, and this was still a problematic tendency within some mental health organizations (P3). Because organizations were struggling for funding, the chance of getting corporate money was very enticing, because they could use the money to address unmet needs, although the dollar source seemed “very problematic” the same time (P16, p. 12).

Some Mental Health Organizations Have Been Historically Disempowering

The organizations that I refer to below are nongovernmental organizations, not including regional health authorities and the formal mental health system, entities that would be discussed at some length in Chapter Six. Seven participants felt that non-consumer controlled mental health organizations have historically acted in a paternalistic, disempowering manner towards consumers and survivors (P1, 3, 4, 10, 16, 18, 19). Disempowering organizations historically operated according to a top-down, patronizing charity model, including public discourse designed to evoke fear, pity, and guilt (P4) (Longmore, 2009). Such organizations, always non-

consumer controlled, were the reason for the creation of consumer and survivor-controlled organizations, to provide safe spaces and a sense of community. One leader who worked simultaneously with more than a dozen organizations provided the following perspective on organizations that disempower:

[I'm] trying to balance between the consumer driven organizations and the service driven organizations and charities. Historically, there were some true wrongs that occurred in some of the service providers and some of the charity groups. There are people who are in their 50's and 60's and 70's today who were damaged by these organizations historically and don't trust them at all...

I think the charity model is hugely problematic, and I think that service organizations that do not engage with the disability community that they serve are problematic as well.

(P16, p. 9)

Some organizations with a dubious past record have made genuine attempts to right historical wrongs (P16). These organizations may work on recruiting consumers and survivors to their governance bodies:

However, I've seen in the last year and a half an attempt by some of those organizations to meet at the table with the consumer driven organizations and try to address those historical wrongs, try to work better together, try to discuss how to be better, engaging and ensure that it's not tokenism when they have somebody who's disabled on their Board or in their office. I'm not saying it's perfect, and there are certainly some organizations that are doing a poor job. (P16, p. 9)

Currently, the reason why some continued with disempowering approaches was because these groups were dismissive of recovery. Seven participants felt that a few non-consumer

controlled organizations struggled with recovery, but other non-consumer groups have been recovery trailblazers (P1, 3, 4, 7, 9, 10, 11). One leader reported that the non-consumer controlled organization that she volunteered in was “definitely recovery oriented,” but in other provinces, there existed mental health organizations opposed to recovery (P1, p. 8). Therefore, even grassroots mental health organizations have resisted recovery – such organizations have tended to be oriented to the interests of the families of mental patients and subscribed to a chronic illness model of mental illness (P1, 3, 4, 8). These organizations stuck to a narrow, pathological view of mental health:

P: [the important thing] is that we are recovery oriented because out in [another province] you might find, or you will find, that they don’t believe in recovery for people with schizophrenia...

I: So, what would they believe in then? [laughs]

P: well, [laughing] they think that if you know that you have schizophrenia, then you don’t have schizophrenia. (P1, p. 8)

The group she referred to, dismissive of recovery, and other organizations with a similar philosophy, in her experience seemed to engage in a no-win, double-bind way of thinking. If one understood that one had a mental illness, then one must in fact not have a mental illness. Consequently, from the frame of reference of these groups, anyone who recovered from mental health problems, or even acknowledged that they had a problem, should not be deemed mentally ill. Three participants felt that these groups understood their primary role would be to persuade people that they were mentally ill and to persuade them to take medications:

Number one, convincing people that they have schizophrenia. Number two, convincing people that they have to take their medication. (P3, p. 3)

Many participants expressed a great deal of frustration trying to work with groups that did not believe in recovery (P1, 3, 4, 10, 16, 19).

Struggling to Include Cultural Diversity

At least five participants felt that both non-consumer controlled organizations and consumer and survivor organizations struggled, and mostly failed, to include cultural and ethnic diversity into their leadership structures. Indigenous leadership has not been represented. One interviewee opined that in both sets of organizations, and in the social movement generally, the “First Nations voice” was not present (P10, p. 25). Given the western provinces’ colonial history, she thought this omission untenable. She concluded that the “white middle-class agenda” driving the movement and most mental health organizations was “very marketable. That’s lovely and it gets money but it’s not, it’s still not addressing the problems” (p. 25). Another interviewee followed up on this critique, explaining that the corporate agenda that was driving mental health funding, and the corporate marketing campaigns on mental health, did not help the public become more comfortable with cultural diversity (P16). They portrayed mental health problems in the context of mainly white, wealthy, attractive celebrities, which did not help society to become comfortable with people who were struggling or who did not control their symptoms well.

One leader, who identified as coming from an ethnic immigrant background, poignantly suggested that he did not belong anywhere. He felt that mental health organizations have struggled to understand his ethnicity and queerness, while his own ethnic community distanced themselves from him because of stigma:

I: does the movement or the work that you do respond to different ethnic communities?

P: [animated tone] No [laughs]!!! You know what, for someone who identifies as GLBT, having a mental health issue and also from an ethnic immigrant background. [Feel] weird when I go up to a stage, [saying] hi! My name is [name]...It boggles my mind...I hate getting up and telling my story because [inaudible] where's my own people, where's my own kind. Like I am wondering whether I serve to do justice to them. The people in this same city, I'll just say that...I don't know them. I'll never know them. Because the stigma is so strong, the cultural barrier is so strong. (P11, p. 12)

His perspective was striking. I heeded his words, about his ethnic community, "I don't know them. I will never know them" (P11, p. 12).

A Purely Middle-Class Perspective Undercuts the Movement's Promise

Seven participants spoke about what they perceived to be the middle-class bias in mental health organizations. They focused their comments on non-consumer controlled organizations, which they felt to have a demonstrable bias toward the wealthy segment of society, ignoring or misunderstanding the structural barriers facing poor people. The consumer and survivor movement historically has been a liberation movement: liberation from medical oppression, from ableist norms, and from class oppression (Morrison, 2005). One participant narrated that he became furious when he conducted a demonstration exercise with nursing students. He pointed to their class privilege:

it's a game, a simulation of the mental health system. I have to explain one thing that is very hard for me...I was in a nursing class...But they found it too hard to deal with [going to jail for the simulation]. I yelled at them. You can't stand it for fifteen minutes! ...Because they say this is too pointless, this is too difficult, I have never been angry in facilitation [of a group], or speaking in front of others. Only that day, I got very angry,

very angry, because as I said...the system, this is just a game, welcome to my fifteen years of life! Many people have much more of this hell than I do. (P11, p. 3-4)

He explained that he became furious because these students, most of whom, I am assuming, did not identify with mental health problems themselves, could not tolerate feeling uncomfortable or feeling poor and disempowered. He suggested forcefully that being poor and disempowered has been his reality for fifteen years.

I had a lively discussion with several interviewees about the recent phenomenon of celebrity mental health spokespersons. One participant perceived that the celebrities who spoke publicly on their mental health problems were not in fact risking their livelihood, nor risking anything for that matter. In contrast, rank and file consumer and survivors, if they came out, might risk their livelihoods:

when you look at class and who is the speaker that's put out front, it's always somebody who presents really well in these campaigns...It's not making everybody more comfortable with individuals who maybe don't present well. It's people with privilege who can talk about having depression or anxiety, and there's no real impact on their lives. Whereas, I am not in a solid employment situation, and this is why I don't out myself as living with a mental health diagnosis very often...It'll close doors for me. People will make assumptions. They'll make assumptions about what I can handle or can't handle, or how often I might get sick, and how that would look like in their workplace. (P16, p. 12-13)

She seemed to suggest that the wealthy typically gained social capital from outing themselves. The poor, in precarious employment or unemployed, stood to lose social capital should they speak about their mental health problem. If the solution to end stigma was simply

for everyone to out themselves, she explained, the wealthy stood to gain recognition and affirmation while the poor risked further marginalization (P16).

Several participants acknowledged that they have never been poor and would have difficulty understanding what such an experience would be like. One person mentioned that his colleague was “still on welfare. And come out of that background. It’s really interesting because when they see certain things, when we talk about certain issues, they often come at it with different eyes than what we see” (P2, p. 20).

A younger leader reported that she has not provided peer support with people who were very marginalized. She explained, “I typically do [the work] ...with younger people who were still living with their parents, and people who were fairly well off...Their parents were quite supportive, and they lived in decent housing” (P6, p. 12).

One leader critiqued that the “white middle-class agenda” was very marketable and embraced by most non-consumer controlled organizations (P10, p. 25). One consequence of this middle-class agenda has been a major push toward private fundraising. Given that policy of the provinces was to maintain a precarious funding arrangement with nongovernmental organizations, it was not surprising that these organizations must seek funding from private sources. Fundraising was a political activity, more specifically a class interest, that seemed to unite the middle-class leadership of mental health organizations, in turn coupling the business interests of community organizations with government’s neoliberal assumptions, wherein commercial business would take an increasingly larger role in supporting public health initiatives (P1, 5, 10, 17). Yet there were groups and leaders that opposed the middle-class agenda within the non-consumer controlled organizations. One leader reported that she would like rank and file

consumers and survivors to be included within fundraising activities, instead of being led by wealthy philanthropists and middle-class professionals:

They push our fundraisers towards. Upper middle class, upper class...our golf tournament and Gala...We are starting to lose the fundraisers that don't do as well, that are more consumer oriented, because we [are] focusing only on the big money fundraisers...which is something I have been fighting on the board (P1, p. 13-14)

I had stated earlier that one participant felt immediately intimidated and out of place – “I am in a very different class” – amongst the businessmen who comprised her governance committee (P5, p. 6). She acknowledged that perhaps this problem was her own issue, as she might have mustered up the courage to speak and assert her perspective given adequate preparation and training. Nonetheless, she surely would have welcomed the presence of consumer and survivor compatriots on that committee (P5). She acknowledged that while financial support was “critical” for her organization to keep running, investment in support groups was equally crucial because those groups brought people into the organization (P5, p. 8). Another participant was concerned that an organization, ostensibly geared toward peer support, would be replicating the same power dynamic as the mental health system, with professionals occupying the mantle of responsibility and income generation, while consumers and survivors returned to the needy recipient role: “now that there are psychologists, and doctors, using [our offices], I think are paying rent, but the support groups are not bringing in the income” (P5, p. 7).

Leadership Issues Specific to Consumer and Survivor Organizations

Participants discussed five issues specific to consumer and survivor organizations: the seemingly insurmountable barrier that poverty presented, a flat organizational structure, the

controversial issue of dissension and factionalism, contested social identities, and the idea of organizational fragility (previously noted by Everett, 2000).

Poverty Has Been an Almost Insurmountable Barrier

At least six participants surmised that it has been very difficult for poor people to establish a leadership role. It was difficult for an economically and socially marginalized consumer and survivor to occupy a leadership role, effectively giving those roles for the middle-class consumer to fill (P18). One reason, at the individual level of analysis, may be that poverty produced distress psychologically and biologically. This distress stymied leadership potential. Poverty may breed a lack of confidence: “I think poverty or somebody who has grown up in poverty may affect their mental health in some ways and not make them very confident in themselves” (P5, p. 11). One participant provided an analytical view of the effects of poverty interacting with symptomology, conceptualizing poverty as a major stressor:

poverty obviously places a stress on individuals who have mental health issues and potentially is going aggravate their symptoms as well. I mean it’s basically an added level of complexity that you have to take into account when you are dealing with people who have both mental health issues, and who are also financially unstable. It’s a very difficult situation to be in. (P9, p. 9)

The upshot was that poverty interacted with the mind to produce or exacerbate distress. Personal distress, among other factors, seemed to contraindicate the possibility of taking on a leadership role.

Another reason offered was that living in poverty did not leave much energy for activism. Or perhaps that poverty closed off opportunities for education and socialization (which seemed to me to be the definition of poverty itself):

You're spending all your time going to try to get food and money and resources, just trying to function. It doesn't leave a lot of time for activism. I think it's very problematic, and it doesn't allow a lot of time to become educated on anything outside of your own exact moment and experience, right? And you can't have a movement from one person's exact experience. There needs to be that engagement and discussion and dialogue and even arguing, right? (P16, p. 11)

Not being able to engage in a world of ideas outside of one's immediate experience, but only surviving on a day-to-day basis, seemed for this participant to be the meaning of poverty. Another participant suggested that leadership involved self-actualization, but living in dire conditions made it very difficult to work on self-actualization:

if you are living in poverty, you are struggling with things like putting food on the table. There is no way you can. Like Maslow's hierarchy of needs, you can't get to self-actualizing until you deal with your own issues...like to me, living in poverty you are constantly struggling to put money on the table, or to put food on the table (P7, p. 22)

Another participant stated, "I am afraid that the leader would...not be someone with too many issues around poverty... It is hard. I'm on welfare. I'm on disability" (P1, p. 13). One more participant noted, "I can understand that someone whom, you don't even have a place to live or much food to get by day to day, it would be a lot harder to get involved in leadership" (P6, p. 12).

Six interviewees stated that access to technology was necessary in leadership roles, but the poor enjoyed only limited access. Interviewees stated that many consumers and survivors did not own a computer. Similarly, many consumers and survivors were not computer literate, currently a leadership necessity:

I think that technology is making it extremely difficult. In the old days, anybody who had a running start at basic literacy could become a leader. But now, it's getting harder and harder. You can't check into a hotel without a credit card. Without basic computer literacy, you can't really function on most boards nowadays. (P18, p. 20)

At the community and societal level of analysis, poverty seemed related to public policy and the social determinants of health. Six participants indicated that as a demographic group consumers and survivors stood at risk of becoming homeless (P1, 3, 6, 9, 16, 18). Homelessness seemed an obvious and major impediment to becoming a leader. The risk of homelessness became greater as the cost of renting or purchasing a home rose beyond what the majority could afford. In Vancouver, there has been little optimism about the prospects for affordable housing; indeed, the problem was growing worse (Connolly, 2018). One participant corroborated this reality, even as he was optimistic overall about other aspects of the movement:

I am not very optimistic about that, despite the efforts of municipal and provincial governments to skim the cost of housing in Vancouver, it seems to have stalled things, but certainly there has been no decrease in the valuation of homes or the cost of rental. In fact, the rent has gone up during the time when housing prices have stalled. I am not optimistic for this city in terms of cost of housing, and I am not optimistic about, at least not yet, about people living on the streets. I think that is going to be an increasing phenomenon. You just drive around and you can look, it is not only people sleeping on the streets, but people sleeping in cars, sleeping in campers, it is becoming a regular phenomenon in Vancouver. But people sleep in vans because they cannot afford anything else. (P9, p. 21)

Some consumers and survivors lived in a state of semi-homelessness, couch surfing and staying at rundown rooming houses and single room occupancy hotels. These accommodations were described as inadequate, stressful, unsafe:

I met many people, at my work at [a consumer and survivor organization] in the downtown eastside...who both had mental health issues and were living in SROs.

Essentially very stressful environments, according to them, and I believe it (P9, p. 9).

I do not know if any of the study's participants had ever lived in terrible conditions, but major newspapers have reported about Vancouver's horribly depilated rooming houses, infested by mold, with washrooms covered by human wastes, where assaults and homicides took place, that catered to housing consumers and survivors in the deepest depths of poverty (Ryan, 2017; Stueck & Hager, 2018). Globe and Mail and Vancouver Sun reporters interviewed people living in Vancouver's Regent Hotel, notorious for its poor conditions (Ryan; Stueck & Hager). People living in such terrible conditions, seemed to exist on the edge between survival and death, and even those living in better but still precarious conditions, as the above participant illustrated, would be focused on just getting through their day, with little energy for anything else.

Nonetheless, a counter argument can be made. There were consumer and survivor leaders now, actively carrying out organizational duties, who lived in precarious accommodations, one participant pointed out (P9). People in poverty, a fraction of the total population, might be "very hungry to be a part of social change," another leader, who had firsthand experience of poverty, remarked (P10, p. 22). Indeed, many of the current study's participants themselves lived with poverty or subsisted very modestly.

Consumer and Survivor Organizations with a Flat Structure

An innovation amongst consumer and survivor controlled organizations was an organization without hierarchy, but one with a flat structure. Participants from two of these organizations functioning on “a flat structure” (P9, p. 6) described their mode of operations. One leader in such an organization explained, “We have a collective that makes all the decisions, the important decisions” (P13, p. 4). Their collective was constituted from all the members of the organization. Members generally were people with mental health problems who sustained an interest in the organization’s work, including its community development initiatives. Once they had demonstrated regular attendance at the organization, they could apply for membership. Members worked on their individual projects and career portfolios, and were eligible to take part in the collective’s monthly meetings:

everything is done, the important decisions are done, each month we have a meeting, and we discuss policies and stuff...and we decide if we have a [decision] to make. We decide through votes, people vote, so it’s sort of an [anarchist?] model... We have staff, 3, 4 staff members that do a lot of work, but they’re basically not the ones that make the decisions, other than the hands-on stuff (P13, p. 5-6)

He emphasized the organization’s democratic procedures. Organizational staff were not held to be higher in authority or more important than the members, he said (P13). Once the membership collective had voted on an issue at a monthly meeting, then the paid staff would implement that decision operationally. The staff would be afforded a capacity to work on strictly technical matters without first consulting the collective. He described their operations:

We have committees. We have 6 or 7, 5 or 6 committees, some of which are in-house, some of them are more exclusive, and that’s how we make decisions, committees, but to

bring back the important decisions to the monthly meetings and just [for all the members] to decide on it democratically. (P13, p. 10)

Procedural details – the criteria on which topics would fall to the collective to decide upon versus those handled by the staff, the use of consensus versus parliamentary decision making, the record of previous decisions made – were not available because for this organization, as I did not receive any documents apart from publicly available material.

A second nonhierarchical organization was governed in a similar manner, although its membership's socioeconomic status and the context in which it operated seemed vastly different from the first. This organization offered peer support groups. All group facilitators were eligible to be members of the board governing the organization. Anyone who attended their support groups – anyone self-identifying with mental health problems – were eligible to become facilitators, once they had completed the group facilitator training. One participant reported, “The board meetings are where we talk about how [the organization] is going, things that we need to change, or things that we would like to change” (P6, p. 9).

Another leader within that organization summarized their operations, noting that when they had founded this organization, they felt strongly that it ought to be a nonhierarchical one:

We are all board members essentially, so it's a nonprofit organization where there is no president, vice-president, or anything like that. We are all just board members. Anyone who wants to be a board member can be a board member. If you don't want to be a board member, you are still considered a part of [the organization] but they are not listed as a board member or a director of the organization...it's a flat organizational structure. We felt that was very important (P9, p. 6)

I probed further as to whether a flat organization might have some problems. The participant answered, laughing, that “I don’t know why [it] works as well as it does organizationally” (P9, p. 14). I laughed in unison. He mentioned that there have always been people stepping up to fill a need in the organization, so that tasks would not remain uncompleted:

You might think that with a flat organizational structure, it might...reach an implosion point. But it hasn’t. I think to a large degree we have been very lucky with having people taking spearheading roles. [One leader] for example is really the spear-header [for us] right now...other people have served as the primaries at previous times. There has always been. Even though they haven’t been called the President or whatever, there has always been someone who has been motivated and help motivate movement within the organization. (P9, p. 14)

The participant reported that his organization has been “very lucky” (see above, p. 14). He related that he has stepped back somewhat from the day to day tasks of the organization. Again, I did not receive any documents, apart from those publicly available, for this organization. Thus, I was not able to compare what was said to what was documented.

Facing Dissension and Polarization within the Social Movement

At least seven interviewees described significant problems with dissension and polarization within the psychiatric consumer and survivor movement. Resulting from the early years battling against the horrid conditions within state mental institutions, against forced psychosurgeries such as lobotomies, the movement developed a combativeness that may no longer be useful for its current context, several participants explained (P6, P14). Antagonism, one participant narrated, seeped deep into the movement, in how it managed debate, disagreement, and politics, forming into an “us [versus] them mentality” (P14, p. 1):

we've [created] a movement together...The problem is that people start to criticize something that they don't agree with, and then they freak out, "oh, I don't agree with that. And you are so stupid! I can't believe you're on medication! You're just falling into the capitalist system!" They go on a tangent, and the other person shuts down...What is going on in our movement that we can't just be supportive? (P16, p. 5-6)

This interviewee explained an especially controversial issue, the movement's position toward psychotropic medications, as a wedge that has polarized the movement. One faction of the movement attracted people who were pro-medication, while another faction attracted those vehemently against the use of psychotropics (P16). There has been "much tension" because these two factions cannot talk to one another (P16, p. 5).

Another leader, having worked for decades within the movement, reported that due to factionalism, "we cannot even convene ourselves in a wide-ranging national conference where we can bring all the voices together and come to some [agreements] about that" (P18, p. 19). Several interviewees related to instances where they were subjected to personal attacks from other movement actors because of disagreement over their policy positions (P3, P4, P16, P18). One person argued that factionalism may have resulted from long term poverty, years of feeling vulnerable and marginalized, and from a society that encouraged narrow-minded individualism:

Why is it ever so fractured and we jump to conclusions and really don't support each other? I think it's because of years and years of scarcity. I think it's from years of [not?] being heard. I think that often as a society, we're not trained to think outside of our own unique experience, so the idea of understanding that something didn't work for you, but it might work for somebody else is impossible. (P16, p. 6)

As a result, working relationships and dialogue at times may become strained and fractured both within the consumer and survivor-controlled organizations and between the various consumer and survivor organizations (P9, 16, 18). Also, the non-consumer organizations and the government have found it difficult to understand how to communicate with consumers and survivors given their assortment of factions and schisms. As one participant noted (P3, p. 11), speaking from the perspective of a Crown corporation, “it was a challenge because who are the consumers, and where are they? What groups do we connect with...and what groups do we not connect with?”

It was possible that non-consumer controlled organizations faced an equal level of antagonism and dissension within their ranks. Three participants indeed spoke about non-consumer organizations facing infighting and even organizational collapse from poor leadership choices (P11, P17, P19).

Identity: Contested, Controversial, Fluid

Social identity was a less prominent issue within non-consumer controlled organizations but appeared as the central basis for consumer and survivor organizations. It was an identity based on: an experience of psychic pain; dissatisfaction toward governmental and medical systems, with some even feeling abused by these institutions; and an inclination to come together, sharing experiences and providing support to one another. These factors formed the basis of organization for consumer and survivor groups – all 19 participants essentially spoke of these factors. Yet significant disagreements on identity terms emerged, as I had expected, and as indicated by the literature (Everett, 2000; LeFrancois, Menzies, & Reaume, 2013; Morrison, 2005). My use of the dual term consumer and survivor was an attempt to link together two wings of the social movement, even as these two wings often engaged in mutual disagreements.

Use of the dual term has been based on researchers and movement practitioners who emphasize commonalities, rather than differences, within the movement (Everett, 2000; LeFrancois, Menzies, & Reaume, 2013; Morrison, 2005).

Two participants strongly identified with the term survivor (P8, P13). One person told me unequivocally that psychiatry for him was only an ordeal of survival, as psychiatric technologies have mainly harmed him (P8). Identifying exclusively with the term survivor, however, was the minority opinion within the current study.

At least five participants identified with *both* words, consumer and survivor (P1, 4, 7, 9, 11). A two-way exchange between these two social movement identities, where one's identity was not fixed but relative to the circumstances, seemed describe this dynamic. These participants produced their own definition of the terms, according to each of their experiences. These five acknowledged that they had benefited from psychiatric treatment, but they pointed to the system's problems – the harmful presence of prejudice and discrimination.

In a more radical sense, these leaders considered themselves to have survived the harm done to them through psychiatry: for treatments that did not work but caused severe side effects; for demoralizing, dispiriting, and disparaging attitudes directed towards them within the mental health system (P4, 9). This came *on top* of the sense that they had survived the harm caused by a mental health problem. One participant, who by no means would reject psychiatry outright, nevertheless pointed to the stigma that he felt when hospitalized psychiatrically. He was not allowed to communicate with people outside the hospital, harming his work life. When he was released from the facility, he “had to explain to people where I was, for a month and a half...I faced a lot of social stigmas as a result” (P9, p. 3). He continued his story:

I found in the hospital that the way I was treated by some of the nursing staff. Some of the nursing staff were excellent, but some of the nursing staff, I felt, treated me in a punitive or weary sort of fashion because of my diagnosis...

So, I felt stigmatized in that environment which I [felt to be] quite odd in retrospect because you should [inaudible] in the least stigmatizing environment (P9, p. 3)

He perceived that his psychosis might have been alleviated by medications within the regimented hospital environs, but he found that when he left the hospital, he would “feel completely lost” (P9, p. 3). He described his experience evocatively: “I feel completely lost...it is like a part of me has been taken away from me. I don’t really know how to describe it” (p. 3). In that sense, he had survived. I believed that was what he meant.

In addition to the meanings ascribed above to the term survivor, three more interviewees used the word to denote a survival of childhood trauma. Of these three, two participants spoke of surviving severe childhood abuse (P16, 18). They, in that sense, identified as survivors. One more person, rounding out the three, understood himself to have survived the death of a close family member when he was a child (P11). His symptoms of mental distress were a consequence of this childhood trauma, he explained.

The five participants, identifying with both consumer and survivor, held a rather fluid view of psychiatric consumerism and the surviving of psychiatry, which, at first thought, might seem strange given that actively choosing to consume psychiatric care would seem the opposite of surviving that medical regimen (P1, 4, 7, 9, 11). One man explained that he was an “unofficial” psychiatric survivor, as he understood a survivor’s reality, living at life’s nadir:

I am very frustrated with the system, how it operates, and how it often marginalizes people. Does not help the poor, excludes people, and that’s where I am very aware of the

flaws of the overall system. That's why I say I am unofficially a [psychiatric survivor]. I mean I live with schizophrenia, and I have been at the bottom of the heap, you know? Where I was on social assistance, and I was battling getting my meds. Assisted with getting financial support for my meds, with being on social assistance and really marginalized, I've been there. (P7, p. 3)

The leader above collaborated closely with many sectors of society, including the psychiatric profession. Although his organization did not meet the fifty percent rule on its governing board, he still felt his organization was lived experience driven. He has been using psychotropic medications for most of his life, and the medications have remained a part of his life and coping repertoire. When I asked him why he would consider himself only an "unofficial" actor within the consumer and survivor movement, he sighed, and said, "Well, I am a psychiatric survivor" (P7, p. 2). He continued, "We have government funding, some might say that disqualifies you from being a true survivor if you have government funding. Or if you have psychiatric support, and if you are not actively being antipsychiatry" (p. 3).

One person conveyed both acceptance and uneasiness with the word consumer. She had difficulty as well with the meaning of survivor, as she understood herself to have stepped beyond mere survival, with the limitations inherent in a survivor ethic:

the whole term consumer, I think when people started using that term a lot more, I think ...but there's something very market oriented, to me, around that term, and so it makes me a little uncomfortable, I guess you would say...Mainly because of my own experience with mental illness and being in the system that I really fought my way out, and it put me on a very different path. So, I didn't want to be part of that. I really worked away from being a consumer [with inflection in tone] in the field, but at the same time...there are

many services out there that I accessed and were a part of my recovery. In terms of the word survivor, I have a lot of issues around. I guess you would call it woundology language [both interviewer and participant laughing]. (P10, p. 5)

Three other participants also felt uneasy with the word consumer because of its negative connotations, as “someone who wastes, spends, or destroys” (P18, pp. 18-19), in a “parasitical” (P13, p. 4) manner of behavior. The participant (P10) quoted in the paragraph above alluded to the word’s connection to a capitalist ideology. In my understanding, the term consumer originated from the ideas of a broader consumerism movement, popularized and led by Ralph Nader (Bollier, 1997). The disability movement in the United States, particularly the Independent Living Movement, started in the 1970s to use the term consumer to denote a person with a disability invested with the decision-making power to choose in what form supports and treatments are provided, from a marketplace of services (Derksen, 1980; Neufeldt, 2003). The psychiatric consumer and survivor movement subsequently adopted the term consumer (Morrison, 2005).

Three participants expressed a discomfort, even rejection, with the term survivor. One stated, “I would never use that term” (P15, p. 3). Another participant did not feel comfortable with the dual term, consumer and survivor, because in her opinion, “any research I have done with the consumer slash psychiatric survivor movement, it has tended to be sort of antipsychiatry” (P6, p. 2). She simply did not identify with antipsychiatry. One leader, as she expressed her reservations about being called a survivor, evoked a mutual laughter between the two of us (P10). She explained that she could relate to the word, having survived serious trauma, and she had lived as a survivor – “I did this” – but the term for her suggested becoming stuck in a place of woundedness (P10, p. 14). She felt that she had moved beyond the woundedness

stage. She explained that staying permanently in a wounded state would be counterproductive and unhealthy. She continued, “when you are in a victim-oriented place, you make a lot of things into monsters. You make people into monsters. You make systems into, and you forget that they’re made up of people” (P10, p. 15).

Consumer and Survivor Controlled Organizations: Fragile, Struggling?

Six participants remarked that the overall movement, but especially its consumer and survivor-controlled organizations, have been struggling. I asked whether the word “fragile” was an appropriate descriptor, based on Everett’s (2000) characterization of the Ontario consumer and survivor movement in the years following the release of the Graham Report (Provincial Community Mental Health Committee, 1988). Although only a minority of the leaders interviewed felt that the word “fragile” was an appropriate one, no less than fifteen interviewees described a tendency for both non-consumer controlled and consumer-controlled organizations to struggle and become mired in leadership and financial crises. Overall, consumer and survivor-controlled organizations found themselves in difficult situations, although the exact reasons remained unclear. A movement veteran remarked, consumer-controlled organizations were: “Uneven...because I’ve seen the movement over twenty years, and every time I think this is going to be really great...it crumbles...it’s so insecure and so everything can go poof, and it all blows away” (P18, p. 11). Another leader stated, “From my little corner, it’s doing fairly well. I know when I hear the broader situation, it doesn’t seem that way” (P2, p. 9).

Another leader commented, “I don’t think the consumer survivor movement is strong. I think the medical model establishment is stronger” (P4, p. 14). She reported that in Vancouver, several very well received consumer and survivor-controlled organizations have dissolved or were in danger of dissolution (P4).

Six participants said the word fragile was an appropriate descriptor for the functional state of consumer and survivor organizations (P3, 7, 9, 14, 17, 18). One veteran leader opined, “Yeah, in Canada, it has been a fragile one” (P3, p. 11). Another participant felt that people with mental health problems periodically would become unwell and might contribute to an organization’s instability. Organizational fragility seemed a fact of life:

it always has been and I think it will remain in a sense...I think people...with mental illness...oftentimes, whether they are treated or not [they] can become...unwell. If you are dealing with an organization that is completely, one hundred percent run by the consumers, and if there is...an imbalance, some people getting unwell, even one person becoming unwell on a board can cause chaos. I have seen that happen, on my own board...one person becomes unwell, you bring in one person who hasn't done their homework, they can cause chaos...so, do I think it is fragile? Absolutely, and I think it will remain that way. (P7, p. 13-14)

He added that individual mental health problems were not the only cause of organizational fragility but combined with the cultural perception that people with mental illness should not be given any trust or responsibilities, these two factors combined to undermine efforts. He was skeptical as to whether having an organization one hundred percent run by consumers and survivors would be a viable or realistic practice. At least three other participants perceived, however, that such a view may be unfounded and overly cautious, the assumption that consumers and survivors as a group cannot practice good leadership.

Two interviewees reported that decision makers in the mental health system and their federal government patrons feared that angry, aggressive people, identifying as psychiatric survivors, would misguide, even destroy, the social movement (P3, P7). One leader narrated:

“Some people in the mental health field, at the top, like at the high end...believe that consumers are going to destroy the social movement. That we are going to...destroy our chances of freedom, our chances of [being] a social movement are going to end” (P7, p. 11-12). He explained that the top decision makers in the system preferred working with the compliant, collaborative consumers, because they felt that “if you leave it up to the activists and the people who are aggressive and confrontational... [they are] going to run it into the ground” (p. 12). A second interviewee replied that the antipsychiatry wing of the movement, including the efforts of psychiatric survivors, has been ineffective and often counterproductive. They have “not helped the movement. Unfortunately, not garnered any respect or credibility” (P14, p. 1).

Another participant observed that rigid, almost fundamentalist, leadership practices were detrimental to both the health of organizations and the movement overall. He perceived that an unhealthy rigidity may occur in both non-consumer and consumer and survivor organizations. He described one experience within a consumer controlled organization as a “horrible” time, because the people who got into leadership acted obsessively rigid: “There wasn’t good leadership and so the people...in leadership wanted everything to go their way, etc., it ended up being baggage to the organization... [these people felt] there’s only one way to really approach this. Everything has to be organized to the hilt” (P2, p. 14). However, he disagreed with the word fragile on principle, because he perceived that the social movement, including both the non-consumer and consumer and survivor-controlled organizations, was a more flexible and resilient creature than many give it credit for:

I don’t like the word fragile. I would describe it more that the movement is subject to shifts and changes. Some people come in and would like to see it to go in only such and such a direction. But other people come in, I would say much more I like to see, as an

amorphous group of people that can absorb different shocks, different changes. (P2, p. 10)

He explained that leaders would be wise to keep an open mind regarding change:

Some people get up, don't like change. You know. It was this way, and it worked so well. Well. [laughs] You add, you add thirty thousand Syrian refugees, and [laughs] you might say the movement doesn't work at all. Or we might say the movement is adapting really well to something that is quite unfamiliar to us. (P2, p. 12)

Summary

The participants spoke a great deal about the common themes spanning both the consumer and survivor-controlled and the non-consumer controlled organizations. Peer support seemed essential. I was struck by one participant's idea, that the power of peer support was channeled through the principle that we heal within a community (P10). Funding was a common need for both sets of organizations. On the one hand, there was optimism that financial support for peer support would increase over time. On the other hand, participants expressed their struggle to keep their organizations financially solvent. Managing one's relationship with government, a primary funder for most of these organizations, was a delicate proposition due to the government's dominant position and at times fickle judgement. Corporate funding was enticing but came with serious ethical dilemmas.

An issue that cut across both sets of organizations was the historical wrongs that have been committed by mental health organizations operating from a top-down, charity model. It was the history of such organizations that spurred the formation of consumer and survivor-controlled organizations as an alternative organizational model. Some efforts have been made to correct these historical wrongs. Unfortunately, several non-consumer controlled organizations

continue to actively oppose recovery and disparage the human potential of people with mental health problems.

The primary modality for both consumer and survivor organizations and their non-consumer controlled counterparts to unravel prejudice and discrimination was to tell stories of recovery publicly. For some participants, the stressful nature of public speaking, and especially being in front of the camera, discouraged them from this activity. There was disagreement about the extent to which the movement should support or critique the current public discourse led by corporate-sponsored, celebrity spokespersons.

Both types of organizations seemed to struggle with an acceptance of cultural diversity. I was struck by the comments of one participant, a self-described second-generation immigrant. He felt anguish in that he belonged neither within his own ethnic community, because of their stigma, nor within the social movement, because of its perceived Euro-American ethnocentrism; furthermore, as a non-heterosexual individual, he felt triply excluded.

Also, there was a sense that a purely middle-class perspective on leadership within mental health organizations would undercut the historical mission of the consumer and survivor movement, which was to achieve liberation from oppression, including class oppression. A white middle-class agenda was marketable and convenient, and suitable to the expectations of the polity, but the consensus among the participants was that a bolder, more innovative poor peoples' leadership was where the movement should be headed.

Both participants and the literature indicated that poverty discouraged most consumers and survivors from attempting to become leaders (Morris & Staggenborg, 2004). Poverty was a life bereft of or with severely limited social, educational, and economic opportunities; without those opportunities, taking leadership was not something people even thought about. The

extremely high cost of housing in many Canadian cities, especially Vancouver, was a significant stress for many consumers and survivors. Some people slid into homelessness. Taking leadership was extremely difficult if one was homeless.

Rather innovative organizational structures were in place at two consumer and survivor organizations involved in the current study, in that they exhibited a nonhierarchical structure. Details of how nonhierarchical decision making would be operationalized were lacking, as I did not receive any documents on governance from these two organizations. Dissension and polarization within consumer and survivor-controlled auspices were spoken about, and I hoped for the current study to follow up on Everett's (2000) pinpoint analysis of this matter almost twenty years ago. It was not entirely clear whether dissension was such a unique phenomenon, tied to the very mental makeup of the movement leaders, as Everett had suggested, or that conflict and infighting were just as common within organizations run by people without mental health problems.

Social identity, the basis of the consumer and survivor-controlled organizations, continued to attract controversy. What I found noteworthy was that among some participants, the terms that they used to describe themselves were situation specific. While it may seem to be common sense that presenting one aspect of the self is a rational, calculated response to social circumstance, the literature has suggested that the psychiatric consumer and the psychiatric survivor were diametric binaries (Burstow, 2013; Fabris, 2011; Shimrat, 1997). What I found among five participants was a willingness to be fluid, to try different aspects of identity. They suggested that one could be both a consumer and a survivor without irreconcilable contradictions in their chosen identity.

There was no consensus among the leaders interviewed about whether consumer and survivor-controlled organizations demonstrated any sort heightened tendency to fracture and crumble. Indeed, fifteen participants alluded that mental health organizations of all sorts, including the non-consumer controlled, have struggled organizationally and exhibited leadership breakdowns.

Chapter Five

Attitudes and Activities of Leadership

In this chapter, I provide participants' responses to my second research question: In what way do dynamics within the movement influence outcomes (successes, failures, compromises)? Most participants, however, did not focus on whether the movement had in fact achieved its goals, but did speak amply on what it would take to embark on the journey to get to those goals. Much of this material is placed in the next chapter, because it focuses on the relationship between one's experiences as a patient within the mental health system and one's leadership practice. This chapter instead focuses on movement-centered leadership practices.

Participants spoke at great length about leadership tasks, noting that task performance influenced movement outcomes. These tasks were numerous, complex, and multidimensional, and required careful discernment to carry out properly. I would not attempt to describe all the leadership tasks that interviewees engaged in, but only the ones most extensively discussed. The first three tasks, adaptability, listening, and positivity and optimism, were attitudes as much they were tasks. Overall, the leadership tasks included:

- adaptability;
- listening;
- an attitude of positivity and optimism;
- cultivating allies;
- entering institutional politics;
- knowledge drives leadership, esp. social movement knowledge and formal education;
- building up both local organizations and a national presence;
- steering organizational development

- helping across different organizations
- training thought leaders, building up a network of thought leaders
- supporting one another

I begin the chapter with a discussion of three attitudes underlying effective movement leadership, according to the participants: adaptability, listening, and positivity and optimism. I then describe various tasks of leadership, outlined above, that were seen to be necessary if the movement were to achieve its goals. I end the chapter with a summary of what I would consider to be the most noteworthy responses for the study's second research question.

Attitudes Underlying Leadership: Adaptability

The word "balance" was only used by three participants to describe a way of leading (P2, p. 14; P4, p. 24; P16, p. 8). Others used different words to convey what I considered to be similar meanings, such as: "adaptable" (P2, p. 14), to "bend" (P2, p. 13); "checks and balances" (P2, p. 14); "almost a dance" (P16, p. 15). In total, seven interviewees spoke on this idea, with some not choosing to convey the idea in one word but through a leadership lesson (P2, 3, 4, 6, 12, 13, 16). On a concrete level, one participant stated that her job was balancing between groups with different, sometimes conflicting, agendas: "trying to balance between consumer driven organizations and service driven organizations" (P16, p. 8). This person also needed to navigate and balance between the government side, the "people who hold the money and...the ability to address legislation," and the consumer and survivor organizations (P16, p. 15).

One leader replied that he disagreed with the word "fragile" to describe the social movement's leadership. Everett (2000) previously used this word to describe Ontario's consumer and survivor movement. My participant understood that the movement possessed a potential that was much more resilient than others would give it credit for (P2).

Several other participants emphasized the need to be adaptable and being willing to change with the times. One man felt that his organization now was functioning adequately, but things could change anytime. They would then need to shift their approach (P13).

Another pointed out that in his mind, the movement should not be boxed in, that there should be a bit of “ambiguity” and “nuance” in leadership (P2, p. 11). To be clear, in his other statements, this leader had emphasized that he preferred clearly thought out procedures and policies. But for the movement to adapt to changing circumstances, he suggested a measure of nuance and thinking outside of “a neat little box” (p. 12). He recognized that culture and religion, among other factors, differed between people, which would lead to differing conceptualizations of mental health. That was why, he explained, “there needs to be almost a certain ambiguity. In a good sense, so that we can absorb and interact and be supportive of all kinds of people” (p. 11). He pointed out that there would be new Canadians coming into the country, such as recent arrivals from Syria. He explained that to support new arrivals, “some mental health supports and work...is going to be different than the way it is today...that’s going to mean there’s going to have to be changes...the way we deliver and work with mental illness” (p. 12). This participant cautioned against the tendency to slide into orthodoxy and resist change: “some people get ups, don’t like change. You know. It was this way and it worked so well. Well [laughs]” (p. 12). He preferred adaptability in leadership as opposed to rigidity.

Attitudes Underlying Leadership: Listening

Eight participants emphasized the importance of listening when leading. Listening and maintaining an attitude of humbleness were important all the time when in a leading role, these people suggested. Early in her development as a leader, one woman described her experience joining a somewhat intimidating committee:

I: in the [Committee], how did you feel? Like did you feel out of place here, or did you have to kind of break into it, or how did you manage that?

P: I had to break into it. I was still really young and not quite well, but well enough, but it almost felt like tokenism at that time, but I did a lot of checking, and a lot of learning, and a lot of talking to people and gaining knowledge, and so I grew into the role. But I probably wasn't the best fit for the role when I was first put in there. Does that answer the question? (P12, p. 10)

At that young age, she stated, she did not bristle at the perceived tokenism in the committee, but she later identified it as a potential problem. She understood that her main task at that committee was to learn as much as she could, and to grow into that role.

An experienced leader observed that she mentored young women who were more comfortable working behind the scenes, but not comfortable in the spotlight. She stated that doing background work was just as valuable as leadership in the spotlight:

I'm mentoring some young women that I have identified as having leadership skills, but I'm also mentoring people who are more behind the scenes, and I don't think that either are any less as leaders. Some people lead from behind the scenes, and some people lead from the front, and if we understand that when we build a community around that, then I think we have a much stronger community. I mean not everybody needs to be in front of the camera all the time, or being the person quoted on interviews, we need the people who make sure that there's coffee at an event and make sure that the posters are printed, get those phone calls at the last minute to make sure enough people show up for something, create the big posters that we hold up when we protest – all those pieces I

think are leadership. I just think that somehow in our convoluted society, we value the person who's in front of the TV. (P16, p. 11)

This person stated that a diversity of leadership styles was beneficial, emphasizing that the quiet, behind the scenes person was just as valuable as the louder, out front person. A young man identified himself as just that, a behind the scenes worker: "I have spoken one year with the United Way speaker's bureau with potential donors and campaigns...and I don't want to be frontpage. I want to be the support so that other people can be the frontpage. I am more behind the scenes, and I am more good at that" (P11, p. 3). He identified himself as supporting the ones who go in front of the camera. Another participant, who was his organization's board chairperson, nevertheless did not think of himself as a leader. He attributed leadership to the overall actions of the collective that he was a part of, but that he had stepped into his role because certain organizational requirements needed to be filled. The conclusion was that "necessity makes the leader" (P13, p. 9).

It was crucial to listen to the needs of the movement rank and file. One leader, alluding to the Black Civil Rights Movement and the leadership group that included Rev. Martin Luther King Jr., opined, "to me that is a good leader...you are astute to the times, meaning that you listen to the people" (P3, p. 21). He added that their success can be attributed to a leadership group, not to just one individual: "it was [not only] Martin Luther King doing it...there were many leaders. There were many allies" (p. 17).

Another participant observed that her program manager, ostensibly not a person with lived experience, listened and respected the knowledge of her team of peer supporters. This act of listening and respecting made a huge difference for her and for the people in crisis coming to the program because "you're in an environment that...it's not just paying lip service to things

like. For instance, one thing that you hear from our guests is how much they appreciate being treated as adults because of the freedom and respect that's given in that space" (P10, p. 17). She said that as much as she and her team "counsel, provide feedback, and guide people, more so than anything, we're there to walk with people, to really see their potential and nurture that so that they're standing on their own two feet...we want to make sure that people are owning every step of their journey" (p. 17). Walking with, and by extension, listening to, people was her message for being an effective leader. At least one other leader mentioned the same concept, that walking with was what he would offer to consumers and survivors (P2).

For me, there seemed something quite humble in the words above. One leader similarly remained humble, when asked about the nature of leadership: "I don't know if I am the best person to define this, or make a definitive answer" (P17, p. 6). Another participant cautioned prospective leaders from playing the expert role, especially not to become bossy, because from her perspective, this tended to backfire. She preferred sharing her own journey and asking the person to reflect upon whether what was offered would be of any use: "The only thing I can say, it's worked for me, that's where I come from. I can't say whether it is going to work for you. So, whatever I am telling you, you take what you need, leave the rest behind" (P5, p. 14). The other person can listen and determine what their own wishes and priorities would be.

An Attitude of Positivity and Optimism

Eleven participants suggested that a positive and optimistic attitude was integral to effective leadership. One participant related that from his perspective, his work has been successful: "We have been fairly successful but my experience has been with [a nation-wide mental health organization] and some of those, the upper echelon of leadership has some form of lived experience [with mental health problems] ...there is a pretty tight connection" (P2, p. 8).

Despite the struggles and setbacks in other parts of the movement, he concluded that, “I don’t write off the movement. I think that the movement has really grown a fair bit” (p. 12).

One interviewee previously had been excited by mental health reform: “when the mental health system was shifting toward being more recovery oriented, I was really excited by that. I felt like the system was moving slowly but in a good direction” (P4, p. 12). She subsequently lost her enthusiasm when she perceived that her region’s mental health system backtracked on its promises.

Another participant, a very experienced movement leader, confidently stated that he has been well prepared to work in the movement because of his life experiences and formal education. First, his religious belief informed his values in “a compassion for people, a sense of social justice” (P3, p. 1). He continued:

In light of all my family experiences with mental health problems, my own mental health issues, courses I took in university as well as [earning graduate degrees]. I was one of the few [students] to study...a strong emphasis on leadership. All of those, that training, the experiences, the grooming...for the first forty-two years of my life have all come to serve me very well in my position working in the mental health movement. (pp. 1-2)

He described a successful record of steering and reforming mental health organizations. He narrated, “so [these mental health organizations] have been very slow to adopt the recovery philosophy. [My organization] was the first to adopt fully the recovery philosophy...so that in five years, I moved the organization to be recovery-oriented, and person-centered” (p. 3). He continued, “it only took five years to transform [the organization]. We were the first [organization of its type] to have consumers on our board. The first, and only one of [a few organizations], to have a consumer as president. We fully adopted the recovery model” (p. 13).

One participant spoke about the benefits of their peer support. He based his opinion from the stories of the organization's members: "many of them claim, it's been a great help to them. They felt much better about themselves, and where they see themselves in the world after having attended those sessions" (P9, p. 4). He was optimistic about the financial position of the organization as well because of its efficiency and its effective working relationship with a benefactor:

I am in the process of considering approaching [our benefactor] to secure some funding, and I am going to be meeting with someone in the coming weeks about that. And presenting, well [our organization] has been running seven years, it serves a lot [of people], and [many people] say great things about their experiences in it. (p. 17)

Another leader was optimistic about the general future of peer support and about her organization's future. She hoped to expand her organization to other regions because of the demand for peer support. She predicted increased future funding for peer support. This leader stated that there currently was "a huge demand for peer support training [offered by our organization]. There is like a hundred people on our waitlist right now" (P6, p. 19). She concluded that the mental health system would soon put more money "to hire peer support workers. I think that is on the horizon. At least I hope it is. So, I think, it looks really good" (p. 19).

A leader who performed many public speaking engagements about the effects of childhood abuse believed that his message was being heard, despite age differences between the audience and he: "as I keep asking, why do you want a seventy-year old man speaking to young people, and the reason is pretty simple. It's been proven to be very effective. I get a lot of people and young people coming and talking to me" (P2, p. 8).

Another participant discovered a vexing problem within her peer support program (P10). Her colleagues did not understand, or were even dismissive of, addictions and the people affected by addiction. She struggled with these dismissive views and questioned whether she would even want to continue working there. This person advocated to her program manager to bring in an appropriate training package for the staff:

I talked to my manager and I said, this needs to be addressed. Your staff are, from my perspective...we've got a challenge here because we're not able to support our guests appropriately, and it's creating problems. And the staff are asking, they're coming to me...asking...can you do something to help us out here. I wasn't seeing any action being taken in that direction at the time. (P10, p. 26)

The organization did not take any action, but she kept providing one-on-one education and dialogue with her coworkers. She kept following up. After searching for various training options about addictions, she mailed these to her program manager who then decided to move forward on this: “[addictions community trainers] were going to come and speak to us, the entire workshop tailored around the questions our staff had, which, I was like, bravo! That’s part of how I work, if that answers your question” (p. 26). She suggested that a sustained advocacy campaign would bring positive results for her organization.

Some participants felt optimistic about the positive changes taking place in public discourse on mental health. They observed both positive and negative changes in Canadians’ attitudes about mental health, but participants preferred to focus on the former, the hopeful aspects. One man spoke on the future of public discourse:

I like to think that stigma is going to get rarer. Social stigma at least, self-stigma is hard to battle. I am very encouraged by recent articles in the newspapers that talk out against

negative depictions of mental illness in the news...I hope and I see it happening is there is going to be a reduction in stigma as people talk more and more openly about these things. (P9, pp. 19-20)

He felt that the movement seemed to be going in the right direction. He was concerned about Vancouver's problem with poverty and homelessness, as he believed that only the mental health goals of the movement, not the structural goals, would likely be achieved:

I think things are going in the right direction right now, it is gathering momentum, and you just get a sense of momentum picking up at least in this [organization] and to a lesser degree in Vancouver as a whole. But my hope is that, the [members] that walk away [from our organization], in this environment, where there is more and more acceptance of mental health issues, are going to carry that way of thinking with them into positions where they can make a difference to the broader society. (P9, p. 22)

However, he suggested that there was little evidence that movement's structural goals, its anti-capitalist goals, were likely to be achieved anytime soon, at least in Vancouver.

In a minority opinion, two participants felt that public discourse and mental health policy remained stigmatizing and discriminatory (P4, 8).

Varied and Complex Leadership Tasks

Moving forward from the three attitudes above, participants described various leadership tasks, which demanded considerable discernment to properly carry out. I would not attempt to discuss all the tasks that the participants itemized, only those most extensively referenced. They included: cultivating allies; entering institutional politics; knowledge driven leadership; building up both local organizations and a national movement; steering organizational development; helping across different organizations; and training new thought leaders.

Cultivating Allies

At least thirteen interviewees spoke about the central importance of cultivating allies. Allies were people and institutions outside the consumer and survivor movement that demonstrated an interest in helping the movement. One man stated, “absolutely, we do need that. The movement will only be as strong as the weakest ally because of the relationship...you are always dependent [on allies] ...they can be allies because they have resources. Not only money, it can be other things too. Their connections, their network, so allies are so important” (P11, p. 10). He suggested that the movement would always require well-connected individuals and powerful organizations which would publicize mental health issues to the masses, connect the movement with politicians, and provide a powerful machinery for fundraising. Another leader pointed to the example of the Black Civil Rights Movement, where powerful allies, such as middle-class white liberals, had made a decisive difference: “there were many leaders. There were many allies that...joined forces with and collaborated with Martin Luther King’s dream...and then there were white people, freedom riders...who joined forces in the marches” (P3, p. 17). He suggested that the history of how supporters were recruited by the Civil Rights Movement offered some valuable lessons for the psychiatric consumer and survivor movement.

One movement leader identified that he frequently networked with elected officials. He had ready access to his local member of the provincial legislature: “Our MLA in the region...he is a former [psychological] counselor. He’s been very receptive and open to ideas because that’s been his first love, and he’s been very good for any projects relating to mental health...we have pretty close relationships with many of our elected officials” (P2, p. 17). He added, “I can go to my local MLA and knock on his door in the middle of the night [laughs]” (p. 17). He also cultivated an acquaintance with the family of Canada’s prime minister.

Another participant narrated that there have been a growing number of allies in universities. He reported that at one university, “literally 68 percent of undergraduate students are reporting significant depression or anxiety in the previous year. There has been a major push by this university as well as other universities in Canada, and in the U.S., to try to deal with this issue” (P9, p. 18). He felt that a university can be a very valuable resource: “I think there are allies to be found all over the place now if you look carefully enough. I know some of the big players at [one university] that are involved in mental health awareness...to help solve some of the mental health problems of students” (p. 18). He seemed to suggest that consumers and survivors might consider partnering with universities to start program initiatives.

Collaborating with mental health professionals was a key task for many participants, but this group of allies will be discussed in the next chapter.

Likewise, five additional participants understood that many allies were to be found if one looked for them (P2, P5, P7, P12, P16). These included: homeless shelters; churches; other religious organizations; everyday people who were willing to provide a donation; professional people with an interest in mental health such as architects, accountants, lawyers. One interviewee narrated the process by which he began his organization. Identifying their allies and supporters led to the pooling together of resources:

I had a dream of starting at that point. It was like an idea, or dream of starting a...recovery center. I started a database. I started collecting names of people who would be interested...we started pitching our idea around to different people, and we didn't have a place yet. We didn't have anything. We didn't have any money yet. We found this place which was just a warehouse, really undeveloped...we got some startup funding

from [a religious organization] and they gave us enough money to rent this place. And we started developing it, it was volunteer resources. (P7, pp. 1-2)

To conclude this section, I would mention that four participants emphasized that one needed to speak a language that allies can understand. This often involved putting down your project in concrete terms, showing them that it would save the government time and money. One leader emphasized that creating work for consumers and survivors, part of his organization's mission, would save money for the government: "well, hopefully, I'd rather be optimistic than pessimistic [chuckles]. I think that it's going to grow, and when more people see that things work, they can continue to do the work...like the more work there is, then the less [need] there is for money to be spent by government" (P13, pp. 12-13). Another participant wished to build upon the structures already put into place by the mental health system, first designed to reach out to the families of patients – these can be reformulated to serve consumer and survivor interests. Mental health managers and policy makers communicated through such structures and procedures, and she could use them as a conduit for the proposal of reforms: "we just started a Peer Committee, so, that is a step to developing a working relationship with senior management. We already have a well-established and respected Family Advisory Committee so, they are a role model of what can be done in partnership with the system" (P14, p. 1).

Approaching allies required a positive attitude and an appreciation for the limitations that allies operated from, one participant explained (P10). It was necessary to make people uncomfortable at times, as assumptions may need to be challenged. One can always suggest ways that would make life easier, in practical terms, to allies. Presenting this attitude – diplomatic, shrewd, respectful – was crucial. She explained ally recruitment in detail:

your good attitude is so crucial. If I have a shitty attitude about my management or my organization, this isn't going to go right. I've seen the limitations, and I respect the limitations that they're operating from. I can think of what can I do as this one person respectfully, and sometimes we need to dress over people and then sometimes you're going to make people uncomfortable and that's necessary, but more of the time, there are ways of going about it that you're actually doing a service for them. You're saving them money. You're saving them time, energy, but I think in terms of like advocacy really working, what I found is I need to know how to speak other people's language. What I mean by that is, I've got to be able to do it in a way that, it's not from my own lens, I've got to be able to communicate it to people in a way that, like the communication really lands for them and meets them and speaks to them personally. (P10, p. 27)

Entering Institutional Politics

To cross the border into institutional politics, the politics of the state government and the opposition parties, is the objective of every social movement that hoped to achieve a social progress that endures. Or at least that was what the literature would suggest (McAdam, McCarthy, & Zald, 1996). That was what the above participant (P10) was suggesting in "speaking other people's language," the language and protocol of the polity, but for her specific example only at the scale of her local organization's management. On a larger scale, a coalition of disability advocacy groups was currently negotiating with the Canadian government for what will be included within the long-awaited federal disability legislation (McQuigge, 2017).

Three participants with three different organizations felt that governments respected the work that they did (P16, 17, 18). Even if their respect wavered, government at least expressed a certain dependence for their help in keeping the mental health system afloat (P17). One

participant reported, “there’s definitely a partnership [between] the federal government staff, at the Office of Disability Issues” and her organization (P16, p. 10). Her organization’s primary role was engaging the polity, both the federal bureaucracy and the federal partisan electoral machinery. She also maintained close contact with grassroots groups (P16). Another leader reported that a provincial funding officer had declared that “[she was] respected [by the province], [please] use us as a resource” (P18, p. 24). Governments seemed to depend on these mental health organizations for service provision and to provide a line of communication between bureaucrats and the rank and file consumers and survivors.

Crossing over into institutional politics was often perilous, eight participants reported. Surviving this journey required savvy and astuteness, they suggested. A government’s whims and unilateral decision making may wreck a social movement organization (P16). One leader explained that her tenuous relationship with government, concretely expressed in financial support, was dynamically conceived as mix of interpersonal and political relationships:

we have a cabinet shuffle that happened at the federal level. None of the national disability organizations know what’s going happen about money, and already I see people freaking out and being disinclined to work together because of fear of money. I think there’s lots of factors, and I spend many nights thinking about how can I work to address these factors? How can I?

...what’s problematic is previously the last government shut down our funding and didn’t consult with the community, so I think that tenuous relationship, depending who’s in power, is really a problem. In a better world, I would like to see that the funding that’s allocated to consumer organizations [be] at arms’ length from the whim of the government. (P16, p. 10)

Another interviewee espoused a similar view on the government-organization relationship. This organization provided an extensive array of services at what was perceived to be a very low cost to the government. The organization was growing, and several members of the organization were insiders within certain political parties. Still, the organization operated at the pleasure of the government in power: “it is an unequal relationship. The relationship that we have, that [the organization] has with the Manitoba government is that they are the senior partner and they also give only minimum funding, very minimum funding” (P17, p. 4).

Six participants described the way that they might cultivate a realistic working relationship with a politician. One person described her organization’s interaction with politicians: “we are always lobbying them, trying to raise awareness. And having a good relationship with the MP who is [Minister of Health], and there are some politicians who do come to our events” (P1, p. 11).

Another participant reported that he maintained a close working relationship with the local member of the provincial legislature. He narrated that his riding’s MLA has been very receptive and open to ideas; in addition, he and his MLA were neighbors (P2). He also cultivated helpful working relationships with various other legislative representatives (P2).

One leader, working extensively with all levels of government, from municipal to provincial to federal, described her experience navigating through the corridors of power: most of the work that I do is navigating people who hold the money and hold the ability to address legislation, policies, etc., and consumer groups, so kind of making both happy. I think that I kind of, it’s almost a dance. (P16, p. 15)

At the same time, she was accountable to consumer and survivor organizations and mental health organizations. And even more so, she was accountable to herself as a person, to

tell her truth, and to stay true to her values. Although she might adapt the way she presented herself depending on the audience, it would always be “very grounded in the values that I have” (P16, p. 15). Navigating through these three aspects became, as she said, like a dance. Having a supportive government in power helped, but she realized that such governments may come and go. As well, ruling governments may change their priorities and allegiances without necessarily giving much prior notice to their social movement allies. Nonetheless, the current federal government has been at least willing to talk to her and her organization. They have backed up their talk with consistent funding:

I think currently with a government that seems to be, at least publicly, more supportive of inclusion, I found in my stint as Chairperson [of our organization], the Office of Disability Issues, the Status of Women Canada, the Minister for Disability have all been quite engaging. They do fund a large portion of our money. They have been consulting with us since the Liberals were elected. (P16, p. 10)

Another seasoned leader pointed to the lack of control that partnering with government entailed (P10). However, despite these risks, establishing a viable working relationship with a senior bureaucrat or a cabinet minister helped a great deal. Sometimes, she said, it is about having “the right people” working with you (P10, p. 22).

One participant even mentioned that he has spoken with the Prime Minister’s mother, who has been known to advocate on mental health issues (P2, p. 17).

Savvy and risks within institutional politics. Describing the institutional political process, interviewees returned to the issue of funding as emblematic of the risky bargain that mental health organizations struck with government. To survive these interactions required savvy and wisdom, interviewees emphasized. One participant alluded to the concept of the

Catch-22 as a metaphor for his organization's funding negotiations with the provincial government. A Catch-22 is a problem for which the only solution is denied by a circumstance inherent in the problem (Merriam-Webster, 2018). I started off this topic by speaking on a government's tendency to maintain status quo funding for organizations, effectively decreasing funding over time because other costs increased. The organization was expected to fund itself, the interviewee said, but this created a curious dilemma:

I think you're right, seeing that if you can be self-sufficient, there's no point in them funding it. So, if you have successes, success is great, but sometimes from a funding standpoint, if you're successful, you're not going get more funding from a government. So, it's a Catch-22 situation, so you just have to sort of be very savvy in how you're dealing with. (P15, p. 9)

The organization in such a situation, if it was to endure, was forced to resort to fundraising to continue its programs, yet still serve at the pleasure of the government (P15). If either of these two sources of funds did not materialize, and both sources were unreliable, for different reasons, then the organization would enter a crisis, possibly ending its existence (personal communication with participant, May 25, 2018). The participant referred to savvy, but he did not explain what the characteristics of such savvy might be. Another leader explained that he was certainly not a token figure when serving on government committees, and that his opinion, and critique of the status quo, was respected. However, he found that maintaining a balance between critique and compliance was necessary: "critique is healthy, I think, and bringing in an opposite opinion to something. But if I openly denounce the government of the day, I am shooting myself in the foot, you know" (P7, p. 17). He admitted that this situation was less than ideal and grated on his nerves:

because we are fragile, and we depend on government support for help. I have to watch what I say. I can't be outspoken about my political beliefs and, that part of the job is hard. I don't...if I didn't rely on government funding, I think it would be easier to lobby for things. But when you are, when you are trying to get funding from all sources, you have to play the nice guy with everyone (P7, p. 17)

This person concluded that critiquing government policy was not the only thing that he wanted to do. He needed to devote his energy to his own organization, and make it a success, and not become bogged down in government affairs:

I am working in certain government organizations where I have the ability to criticize things...I am not just a token player. How much energy I want to invest in a certain government policy or mandate is up to me. It can be a little draining if I get totally caught up in that world. (P7, p. 17)

Another danger was becoming bogged down in internal movement power struggles, hampering one's ability to function effectively in the polity. A participant expressed caution about working with the movement elements perceived to be negative or rigidly oppositional (P3). Another leader voiced a similar opinion, to take care in who one approached for advice: "if you are going to assemble a team, you want people who are trying to make it happen, not people who are going to tear it down" (P7, p. 18). If one assembled a team of people who caused conflict and chaos wherever they went, this person suggested, institutional political actors would close their doors, and the movement would stall.

One movement leader, who worked inside the mental health system, remarked that a successful movement would recruit an eclectic mix of compatriots and allies (P4). She strategized that an effective movement used a multipronged approach. One prong would be

groups that took a radical, hardline stance. The other prong might consist of moderate, mainstream groups. Reform groups within the mental health system were necessary, as well as groups outside the mental health system, who had greater freedom to critique the system. All of them would work together on shared goals. She explained:

I think for a movement to be effective you need to have all these prongs of approach.

You need groups that take a very strong, hardline stance that may be external to the mainstream organization, and they need to be able to take that hardline, external stance.

You also need to have groups that are more in the middle taking a more moderate, middle stance toward the same thing. Because they are going to appeal to a group of people that the more extreme people will not appeal to. And you need to have people who are inside the organizations of power to influence those organizations from within, in ways that the external groups can't. So, you need to have multiple groups with multiple approaches.

(P4, pp. 20-21)

She concluded that a common goal that united these different groups. Different groups approached this common goal on different paths. She pointed out that the danger lay with having the group inside the system criticized simply for existing inside that system, as that kind of discourse in her opinion was merely infighting (P4). She suggested that the group inside the system was in a unique and valuable position. Although they were required to take a moderate approach, they were positioned closer to the ears of the policy makers, whereas outside groups were less likely to be invited for their opinions:

one thing that does not work is to sit there and say your approach is the right one, and you are going to criticize this other group because you think it's using a different approach...

All of that, that is just infighting, and it takes away from the goal of your movement.

You need to recognize that you need multiple approaches, and they all have value and they all have a role (P4, p. 21)

Knowledge Driven Leadership

Ten participants spoke on what they considered to be the foundation for any leadership endeavor, knowledge. Five interviewees spoke about taking formal education as a preparation for leadership. Eight interviewees suggested that leadership relied upon research and evidence. Eight interviewees formulated leadership strategy by drawing upon the history of social movements. One interviewee summarized this topic well, when he remarked, “in terms of being a true leader who has influence, you have to become a thought leader” (P3, p. 15).

Formal education was necessary preparation. Five participants spoke on this. One person had completed numerous practicums as a post-secondary student, of great benefit to her learning. She gained familiarity with the nuts and bolts of organizational functioning through her practicum. She practiced how to listen and how to intervene with people, in a respectful way:

I started out doing one of my practicums there. I started doing everything...whether it was cleaning toilets, helping in the kitchen, just spending time in the drop-in center but a big part of that practicum, they gave me permission to shadow everybody, so working with the Pastoral Care team, that kind of thing, and doing emergency food...After I did that practicum, I wanted to continue to be involved with them, and so when I came back, they actually asked me if I wanted to be on the Pastoral Care team, and also to sit on the Justice Committee. So that was a really important time because I was there, it was 3 summers in a row, for the full summer, that's where I spent my time. (P10, p. 2)

She suggested that her practicum experiences were her initiation into community development and learning how to intervene at the individual, small group, and the neighborhood

level. She seemed to appreciate that her practicum allowed her to work with folks struggling with poverty, homelessness, and addictions. Also, the practicums, especially her continued involvement in the religious organization referred to above, seemed to provide for her a needed sense of community and belonging.

One participant earned multiple graduate degrees. He noted that his academic training has been very useful, especially his ethics and leadership training (P3). Another leader's university education had been interrupted by his mental health problems. He struggled but with some assistance re-enrolled in university, giving him back some structure: "there is this dip there where I was diagnosed...I think I had a year basically where I was taking medication but...doing a lot of art...exercising a lot. Trying to be continually healthy and doing things that were good for me. I bounced back quickly, and that's when I went to [university]" (P7, p. 5).

Partly because of his university education, he was inspired to create his own organization to assist other consumers and survivors with their recovery. Another participant was an academic, teaching and researching in a university. He stated that his academic work was relevant to the topic of mental health, which contributed to his own knowledge base as a consumer and survivor leader (P9).

Leadership that relied on evidence and research. Eight participants either referred to specific research findings or were personally involved in research themselves, explaining that these things have significantly influenced their leadership approach. Participants cited studies that they thought would provide a foundation for building consumer and survivor leadership, including: the adverse childhood experiences study (Felitti et al., 1998), *Chez Soi* (Goering et al., 2014), *Imagining Inclusion* (2018), and *Soteria* (Calton, Ferriter, Huband, & Spandler, 2008). The adverse childhood experiences (ACE) study used the health information of over 13 000

people in the San Diego area to determine if there was a relationship between childhood trauma and adult mental and physical health problems (Felitti et al., 1998). One participant explained that the ACE study provided the knowledge claims for changing the mental health system from a chronic illness model to a trauma informed model: “it is still very relevant. Slowly, we are seeing today, that some individuals within various professions within mental health...returning to study the ACE study...so mental health services [becoming] trauma informed” (P3, p. 3). This leader’s personal history of childhood abuse was buttressed by evidence that most consumers and survivors had traveled the road from childhood trauma to adult mental illness. He suggested that a combination of research evidence and personal experience provided considerable legitimacy when conducting systemic advocacy.

One person identified leadership goals by drawing upon the Chez Soi study (Goering et al., 2014). She briefly explained the difficulties that consumers and survivors faced when attempting to obtain adequate housing (P1).

An interviewee spoke about her involvement in *Imagining Inclusion* (2018), which offered a photovoice study on the experience of mental distress in Vancouver, and a follow up study examining the possibilities of positive change in the mental health system. This person used her research experience to learn effective ways to dismantle stigma and discrimination, which she would apply in the field as she expanded her organization to new sites, some with engrained histories of discrimination and ableism. One participant trained her peer support group facilitators to role model support based upon psychotherapy research: unconditional positive regard, active listening, genuineness, warmth, and demonstrating empathy (P6).

One participant was a lead researcher in a large study on depression, one that offered valuable background information on a condition that many consumers and survivors faced (P9).

Another interviewee felt that he effectively advocated at an advisory committee, made up entirely of psychiatrists, to be cautious and careful with prescribing certain psychotropic medications to patients under the age of eighteen. The committee would form its conclusion based on research evidence. However, he reported, “I questioned them on some things, and they listened so that’s good” (P2, p. 3). Another participant had been involved in research across Canada, as well as in international research. These studies afforded an international, multicultural perspective on mental health issues that she otherwise would not have known about (P18, p. 9). The participant who discussed Soteria – a minimal medication intervention for people with psychosis – addressed topics which I would return to in the next chapter.

One participant narrated that her experience conducting research, guided by more experienced academic colleagues, was a powerful formative experience opening her mind to new possibilities. She previously had dismissed the idea of working with the government due to its history of top-down control:

in doing my research I was working alongside with the people who supported me like Manitoba Research Alliance...I look at the work they’re doing...working with them really helped me to adjust my attitude a bit around government. I used to [feel about] government, yuck, you know, and that’s shifted a bit...I realized that, instead of shutting down options immediately, let’s look at well, can we do it differently? (P10, p. 22)

She suggested that both the experience of being researcher and the evidence that was brought forward in the study enabled her to become a more thoughtful, knowledgeable community organizer. She did not narrow her repertoire to simply opposition to government but helped her to see more than one option in pursuing her work.

Drawing upon social movement knowledge and history. Eight participants spoke

about formulating strategies based upon the knowledge that social movements themselves generated, both knowledge internal to our movement and knowledge from other social movements. Bridging with other movements was a good way to learn about one's own, a few leaders stated. One woman explained that consumers and survivors "needed the support of other groups in struggle" to advance their own, citing a historical example:

I remember in terms of the women's movement...it just always stuck with me where, they said, for years and years the problem was that they continued to, they would set their priorities aside in order to support other struggles, whether it was Black Rights or different [movements], and that began to compromise their own position, and eventually they got to a point where they had to stand alone 100 percent, focus on their own rights, but I think that in doing what they had done, in support, being a part of these other struggles, they came to know their own better. They also came to know how to move forward better because of the groups that they worked with. (P10, p. 30)

She stated that consumers and survivors did not understand their own movement, suggesting that the mistakes the movement has made resulted from living in a fragmented perspective, then becoming "stuck" in it (P10, p. 15). Various groups, she explained, each with a limited knowledge base but not communicating well with one another, led to "much fragmentation and internal conflict" (p. 30). Learning from other movements would help remedy this problem, because others can offer fresh insight and approaches.

Another leader offered a similar explanation on the budding leader's need to step outside of their own immediate experience, to maintain a cognitive curiosity (P16). Learning from other social movements, or just from people with a different perspective, can be valuable training: "I think that often as a society, we are not trained to think outside of our own unique experience, so

the idea of understanding that something didn't work for you, but it might work for somebody else is impossible [to accept]" (P16, p. 6).

One movement leader studied the Black Civil Rights Movement. He surmised, "the fight for equality and equity did not just begin with Martin Luther King Junior. You see this slow movement developing to the point where it was able to address government structures and systemic discrimination, and get legislation changed" (P3, p. 20). This man learned about the Civil Rights Movement's successful organizing methods, as well as the rough words and leadership struggles inside that movement. He tried to apply these lessons to our consumer and survivor movement. The participant compared the two movements:

racism is a form of prejudice, as is mentalism. They are both stigma. People of color are stigmatized. People with mental illness are stigmatized. Stigma is a caricature based on a fear or misunderstanding. Call it prejudice, then. Prejudicial attitudes always lead to prejudicial action. That action is what we call discrimination. So, stigma is an attitude. Discrimination is an action. Our goal is to end the discriminatory action. (P3, pp. 19-20)

One of the Civil Rights Movement's goals was the passage of legislation to make systemic racism illegal. The interviewee suggested that the consumer and survivor movement should work toward a similar goal, that of passing legislation to make discrimination illegal against people with mental health problems. To an extent, this has occurred in Manitoba and Ontario with the passage of accessibility law. He suggested furthermore that a key piece was structural inequality, the class oppression that kept poor blacks in a downtrodden state, which similarly kept people with mental health problems in a downtrodden state. Structural inequality, this leader noted, has not been adequately addressed in either Canada or the United States.

Building Both Local Organizations and A National Movement

Almost all participants expressed that they focused on building local mental health organizations. However, ten participants worked at the national level in leading the consumer and survivor movement. Some did not speak much on their national roles, but, given that they participated in national endeavors, such as the Mental Health Commission of Canada, I considered them as having a national role. Except for perhaps one or two participants, none would be considered household names.

At least eight interviewees (P2, P3, P4, P7, P12, P14, P15, P18) had won awards for their movement work, with a few winning numerous awards. Interviewees did not speak about their awards, and if they did, only briefly. I only knew about some of these accolades through reading newspaper articles. One participant seemed modest and matter of fact when describing her journey in becoming a recognized leader in her region:

natural progression, right? I started on [the committee], then to a regional rep, to the provincial rep, and started facilitating some groups in the clubhouse, like going to services through [a mental health organization], learning about things, bringing that information back and collaborating with staff to make things happen. It just naturally progressed into me coming to this role, so I was a peer support worker before I actually did the training as a peer support worker, then did the training in Vancouver. (P12, p. 9)

Almost all participants seemed driven to consistently build up their local mental health organizations. In addition, a few participants took part in municipal and provincial politics. Involvement in local organizations can be quite wide-ranging. For example, one leader was simultaneously involved with local chapters of the Canadian Association for Suicide Prevention, the Schizophrenia Society, and the Canadian Mental Health Association. This person was also involved in the local regional health authority, a local agency for supportive housing, a local

speakers' group for mental health, a provincial historical society, and several church organizations.

One participant was especially focused on her local organization because she received the most satisfaction seeing the results firsthand. She saw her role as a group trainer and facilitator: "the only thing I am doing, well, I am doing two things right now. I have developed this workshop. I am in the process of interviewing and training other people to deliver the workshop...and I am also working with somebody to get a support group focused on self-compassion and self-care" (P5, p. 12). She concluded, "this is my passion, right, so it has a narrower focus in that way" (p. 6). She noted that she had developed a strong working relationship with several colleagues at her local organization, and she devoted her energy into nurturing that relationship.

At the national level, one participant was the director of an influential mental health organization, often quoted on television and in newspaper articles. Another participant was the chairperson of an influential advocacy organization, with a close working relationship with the federal government, to cabinet ministers and senior civil servants (P16). The organization also worked closely with dozens of local organizations, helping to coordinate advocacy activities across the country. A third participant was the current chair of a national feminist organization, and past chair of a national consumer and survivor organization (P18). Given the rather limited visibility of the consumer and survivor movement, even these prominent leaders were hardly household names. One leader narrated her journey to becoming a leader at the national level:

We were coming here just to be in our accessible home and just go more for the quality of life and be completely out of the movement whatsoever. The phone rang, and somebody asked us if we would please join [a local consumer and survivor organization].

We asked a few questions, and things seemed to be somewhat more stable, somewhat more organized, so we did, and we were very glad we did. We took part, and our first job was on the bylaw committee. I became President of [a national consumer and survivor organization] in September. I became President of [our local consumer and survivor group] in 2004. (P18, p. 2)

This person, when they became the official head of a rather influential national consumer and survivor organization, obviously began to influence policies and practices at the national level. However, due to funding cutbacks, most of these practices were no longer operating.

Steering Organizational Development

Although almost all participants had responsibilities in organizational development, eight participants spoke about these responsibilities in detail. One participant spoke about the practical need for clear administrative procedures and policies. It was implied that procedures and policies would need to be clearly written, communicated effectively throughout the organization, and complied to provincial law. These procedures were the cornerstone upon which organizations developed, because unclear procedures and policies may invite disaster:

It's like an instruction, right? There are certain practical things that need to be done for a group of people to achieve certain goals, so those practical things can only be done when there are proper instructions, there's proper communication, there's proper procedures. (P17, p. 6)

Another leader described the steps through which her organization, a consumer-controlled entity, had won its independence from a host agency, a non-consumer controlled organization. To separate from their host, a respected organization familiar to the public, was a challenging endeavor. She was part of the team leading this effort and expressed strong

emotions about it: “we value our independence, we sacrificed for our autonomy and we value it, we starved for it, our board gave and supported, and did everything for its independence as a...consumer organization” (P18, p. 13). As part of organizational development, she reported that she would need to review with the board of directors their current mission, because fundraising has not been prioritized. The organization was falling behind in fundraising. This would need to be reviewed strategically: “that is really difficult for us. And makes us be like far back and trying to do everything [from] our grants, our projects. Strategically, we are going to have to look at that. That is like the next step, right?” (P18, p. 18).

She voiced that there was pull from two opposite directions on her time and energy. The need to expand a network of activists was pulling in one direction, one external to the organization. Her mandate was to sit on thirty committees and boards of directors across Canada. The pull from inside the organization was to spend time keeping the house in order and developing local initiatives. She explained:

Because of all the obstacles and the barriers, even my deliverable of 30 boards, committees, and working groups also being a barrier, because everything has been outward and that whole outward voice and “ever widening sphere of influence,” right, limits what you can put in. When networks push out, we don't inward focus (P18, p.18)

This leader would like to develop and refine her organization's demonstrated competencies, to become known for its own knowledge base. One leader, instrumental in developing several well-known mental health organizations, narrated his strategic planning vis a vis these organizations' stubborn resistance to change. Hitting up against attitude of paternalistic, top-down notions of service provision, whereas he would rather advocate for recovery, he appreciated that organizational development was a slow, patient process:

It only took five years to transform [our organization]. We were the first [of our affiliated groups] to have consumers on our board, the first...to have a consumer as president. We fully adopted the recovery model. I'm trying to do that with [my other organization]. I've been at it for ten years. If we take the analogy of turning a large ship around, the ship is halfway around. It hopefully won't take another ten years, it'll maybe just take five years, that we're not ashamed of it. (P3, p. 13)

This man seemed to demonstrate a great deal of confidence in his strategic thinking and determination to persevere.

One leader spoke enthusiastically about the collective leadership capacity of her consumer and survivor organization. Due to the organization's flat structure, this leader claimed that service provision, administrative, and governance duties were managed collectively, as opposed to the conventional separation of tasks based on hierarchy. All peer support group facilitators were considered members, although facilitators must self-identify as people with a history of mental health problems. Members may sit on the governance board, although a few select members, due to their demonstrated interests and availability, performed most of the tasks. The organization was currently expanding, and significant organizational development was taking place, but this did not necessitate a re-examination of organizational values, this leader claimed:

P: we just need more funding to expand. I am the coordinator of it right now. And having the help for other facilitators and board members has been paramount.

I: There is a board that oversees [the organization]?

P: pretty much all our facilitators are also board members. I know that typically boards on nonprofit societies are not employed. And they are just volunteers, so ours is a bit

different in that way. In that people are dual members, but it seems to work really well. The board meetings are where we talk about how [the organization] is going, things that we need to change, or things that we would like to change. We have facilitator trainings every three or four months as well for bringing in new facilitators. (P6, p. 9)

As I was not provided any organizational documents, I could not verify her claims from other sources.

This participant was currently completing her university studies and envisioned that her role might expand after graduation. She described that the organization was part of a regional mental health network having access to very significant resources, such as research capacity, networking with international partners, linkages to other social movements, and interest from young, well-educated volunteers. She narrated that this network was currently restructuring due to a few leadership barriers and inconsistencies, but that its potential was bright:

P: I want to take it a step further in the future when I am done with my studies. Maybe get some help from some other facilitators or board members. Right now, well we are part of the [regional] mental health network. But since the MHN is kind of on a hiatus. Not really a hiatus, but I was also the vicechair of the mental health network this past year.

I: And what is that?

P: It was created in 2010 by. It was two [of our] facilitators who were involved with mental health awareness. They realized there were mental health supports [in the region], but all working in silos. It was a way that we can come together to become more connected to each other. (P6, pp. 13-14)

She explained some of leadership challenges that this network has faced, as well as its strategic direction:

we come together about once a month to talk about the kind of things we were doing, and over time, some of [other organizations joined]. Some strategic goals were developed for 2013 to 2016, and I was hoping to work on those. Assessing them and seeing where to move forward, but I didn't have good leadership from the chair this year. So next year, instead of me stepping into chair, we are going to hire a couple of chairs as we restructure the network. I am going to be working on policy this next year, looking at the strategic goals, how far we've come and to collaborate with more [professionals and citizens] to do this. This will be in addition to [our organization] so while we are a member of MHN, we are not super active because the network is figuring out its direction. (P6, p. 14)

Because the organization would be expanding to other neighborhoods and regions, this person saw a continuing role for herself in steering development. She expressed optimism about the future:

I think it looks good. There will be more opportunities for peer workers. I mean I hope [we] will expand to other [regions] as well because other [regions] want something like [our organization], but just don't have the capacity or whatever to do it. That is what I want to do in my future. (P6, pp. 18-19)

One leader, working with the same organization described above, noted that their organization had started modestly from the efforts of several young adults. The initiative bore fruit with careful planning: "I was one of the founding members... That was eight or nine years ago... two [other founding members] ... basically approached me and asked me if I was interested in helping them start up this new service" (P9, p. 1).

As well, one man told me about his role as the founder of a recovery organization. He proposed his idea to community leaders and potential funders. His family worked closely with him in the planning, providing him with their business contacts. The organization began with, in his words, a “real startup board” of local professionals; however, it was not a consumer-controlled organization (P7, p. 2). The organization grew, with four locations currently.

Helping Each Other Across Organizations

As most participants worked or volunteered in more than one organization, they built up networks and linkages between organizations. During their leadership training, participants may go from one organization to the next, building up knowledge in one area, then either sought out or were referred to another organization to learn another skill or talent. There was also a sentiment that sharing knowledge and helping each other – other consumers and survivors – across different organizations and areas of practice yielded major benefits: “Some of our [events] are done in concert with different organizations... That’s important that we keep our ties to these groups as strong as we can” (P13, p. 12).

Leaders worked closely with myriad organizations, giving them business so to speak: referring a person to them to access their services, helping with local events and festivities to vitalize a neighborhood and community. One organization, faced with funding cutbacks, made plans to share space with another neighborhood organization, sharing resources and saving on rent. Obviously, much planning and negotiation must have taken place to make a partnership possible and doable, negotiations I was not privy to.

Being a good neighbor in a vitalized community seemed to be the goal of almost all the organizations I encountered. There seemed a sense of intimacy between organizations, not understating that formal protocols for cross-organizational work likely existed and were

followed, but a peer support ethic between organizations seemed to prevail. Some of the work felt to me like being within a family of choice rather than a strictly professional endeavor:

In our little corner of the province, we have developed in the last five years a fairly tight group of people that may be involved in a variety of other organizations but work together...and work with consumers. (P2, p. 9)

Such friendly, collegial, and respectful relationships did not always prevail. One person felt that the larger, well marketed non-consumer controlled organizations monopolized the field and went about “cherry picking” the best ideas that the consumer and survivor groups had strategized (P18, p. 16). These large mental health organizations made promises to the community, then broke their promises, this participant claimed, leaving consumers and survivors in the lurch. One man, skeptical of most mental health organizations, was suspicious of, in his perception, their overly medicalized agendas (P8).

There was a sense of giving back to organizations, because almost all the leaders I interviewed started their recovery journey through the help of local mental health organizations. They wished to give back to future generations the help that they had received.

Thought Leaders: Becoming, Training, Networking

Leadership, for nine participants, meant becoming a thought leader. The exact wording for this category came from the ideas of one participant (P3). A thought leader would make positive change not by brute force but by having better ideas and actualizing those ideas in the community. One person stated that leadership meant “somebody who has an idea and has the courage to step up and take it a step further, to communicate it to others who have an interest” (P5, p. 14). Another participant explained that her organization’s original concept was promoting

what was called the “ever-widening sphere of influence” ...to have the voice of mental health consumers represented in as many arenas as possible. The idea was to teach consumers how to be effective representatives and effective citizens. (P18, p. 1)

The key was not only to become a thought leader but to build a network that would train future thought leaders. One participant enjoyed being part of a friendship network in her community, offering knowledge where she felt that would be appropriate:

People in the community and my friends, they know me, go to [name], she'll know, ask her. She'll be able to know who to do...When I was at university...I could go to the Advocacy Conference, and I think things like that are huge. It's really giving people an opportunity to connect and network...

When you say resources [that I need to do my work], I'm stuck. What comes to me is I need a bigger network. (P10, p. 19)

Although in the above passage, the participant spoke about being a knowledge hub in her friendship network, she also performed similar functions in her paid employment. Colleagues would go to her to find information or to receive feedback on complex issues (P10).

One participant, a seasoned peer facilitator, provided peer support training. She shared her knowledge and structured the learning process for current and potential future facilitators: “it takes a lot of training. I did the job for two years...It took me sometimes ten hours a week. Answering emails, setting up the newsletter, setting up training” (P5, p. 10). She provided opportunities for her colleagues to take in information, process, and then receive some feedback (P5). She provided literature on peer support and set up events for social support.

Another person (P6) was familiar with the peer support training referred to above. She felt that their training had been excellent. Her organization offered training in peer support,

except for a different target population. She reported that their two trainings contained many similarities. A goal of her training was differentiating between unhelpful and helpful responses:

[we often offer unhelpful advice] like, you need to study more, or you need to just do these things. Those aren't particularly helpful. Being a role model [for peer support], we don't offer unsolicited advice. I think a lot of people are not aware of how to be supportive. It is not something that we are taught in school. Unless you have parents, who are, or people in your life who are good listeners, those are skills that we don't really have. For me, when I learned about active listening, I was like, oh my god, I had no idea how to listen before! (P6, p. 15)

The broad goal was to disseminate these teachings to the larger society. She continued, "becoming a leader in that capacity. Because our facilitators are people who have come to [our organization], who then want to become leaders [with us]. So, at [the organization], we offer opportunities for leadership" (P6, p. 16). Her colleague concluded that the hope was that these budding leaders, mostly young people, would carry their training into influential positions where they can make a significant difference (P9).

This person also talked about a separate organization engaging in the training of thought leaders, but this time through an artistic modality (P9). That organization accepted members coming from extremely marginalized backgrounds. They showed up at the organization, they did artwork, and they began to receive feedback and guidance from more experienced artists, according to this participant (P9). There would be an exchange of knowledge, bringing with it, hopefully, a sense of belonging. The organization, he said, seemed very nonjudgmental and "accepting of all...kinds of art forms" (P9, p. 15). I had visited this arts organization several times, and I had noticed an emphasis on connecting experiential knowledge to academic

knowledge. I also perused various documents from the organization, in addition to receiving their newsletter. The content of the art varied from the gravely serious to the whimsical. On the serious side, it dealt with themes of trauma, physical and sexual abuse, colonization and structural violence, mental distress, healing, and Indigenous knowledge.

Two participants, older in age than the others, suggested learning from the older generation of movement leaders. Those who, in one man's words, "have a depth of experience and years of experience...for me, they are kind of your peer supporters or your mentors" (P2, p. 23). He spoke about dealing with a vexing problem by consulting these mentors: "well, you know the leader who is now in his late eighties, he is the one who did a lot of good stuff on this. He is still alive. Give him a call [laughs]. I mean, why not? Why not?" (p. 23)

One man, a seasoned movement leader, described his knowledge network. This knowledge network spanned at least two countries:

I am familiar with key leaders like Pat [a prominent antipoverty activist] in Toronto, Ontario, who is about my age. We are in our sixties. I have learned a lot from Pat. I read materials, I have taught with individuals like Dan [a prominent American social movement leader], a psychiatrist who at one point did live with schizophrenia. I have been influenced by Pat [another prominent movement leader], a psychologist, who lives in recovery with schizophrenia. I read emails from...Mad in America (P3, p. 2)

Mad in America was a mental health activist network, with a tendency to favor antipsychiatry perspectives (Mad in America, 2018). The man referred to some seminal documents on mental health reform that he felt to be still very relevant today, including a field-defining paper, the Framework for Support (Trainor & Church, 1984/1999): "It's a great document developed by Bonnie Pape who worked for the Canadian Mental Health Association"

(P3, p. 10). In 1984, it explained, contrary to the prevailing opinion of the time, that experiential (i.e., peer centered) and traditional (e.g., Indigenous systems of knowledge) information were important, in conjunction with the authoritative knowledge of medical science and social science. It suggested that our most basic ways of thinking about mental illness would need to be re-examined (Trainor & Church). Also, it proposed that the way communities provided services and supports in mental health needed to be reformed and restructured (Trainor & Church). It set forth the possibility that consumers and survivors would lead and govern their own services. This participant concluded that he networked “with thought leaders across Canada” (P3, p. 13).

Another leader, who previously worked as a health care professional, admired the teaching ethic of university hospitals: “peers educate peers, everybody educates everybody else, and I love working there because...everybody was always learning from everybody else. We are all learners, we are all teachers” (P18, p. 8). She hoped to replicate aspects of this teaching ethic at her consumer and survivor organization. Not the least of which, she hoped to bring in physicians, nurses, rehabilitation practitioners, and students, for an exchange of ideas, and to impress upon them the practice of peer support and advocacy.

Supporting One Another

The last category that I discuss in this chapter is peer support among leaders. At least seven participants spoke on this. Leadership, they related, if it was to be sustained, required that leaders supported one another. One person spoke a bit humbly about his first job in the mental health field. At that time, he was struggling, and one person at his workplace guided him through that difficult time, allowing him to progress to future leadership roles:

Initially, a work placement, and after the placement, I moved on and found a job. It was so good to me in the beginning. This lady, I am not going to use her name, anyways, she

sat beside me, made sure I learned the system, even typing in the system with one stroke at a time. I just got [inaudible] by volunteering for that, volunteer slash uncompensated...and I stick with [inaudible] for the next three and a half years. I was there until they closed. (P11, p. 5)

At that time, he was not yet a leader, but support on that first job helped him gain skills and experience to be a future leader. Another person valued her peers that she could access for feedback: “if I’m going through something that I need to talk about, I know that I can call one of my other peer support coordinators and just say, hey, this is the situation, right, and just bounce it off them” (P12, p. 11). On a more conceptually rigorous level, she valued her community of practice, which provided a structure for debriefing and an ethics code. She thought that this community of practice was crucial when supervising students on practicums: “especially when I’m training...peer support workers, I need to have that really clear structure” (P12, p. 7).

Another leader, with weighty responsibilities on national and international working groups, said that she practiced wellness activities to keep her balance. She reported, “painting is one of the ways that I keep balanced. People notice if I haven’t painted for a while because I start to not be able to focus and stay on task and engage in a relationship” (P16, pp. 18-19). She related that she was very private, but her friends would not allow her to become overly isolated:

I have a few friends that I can talk with...I’ve also cultivated a lot of friendships with people, who they know when I’m touching base, that there’s a reason, and they don’t necessarily ask me details. My friend just has a knack for understanding when to shoot me like some support or give me a phone call...He would check in without asking for details. I have a couple of very good friends who do the same thing. They know that I’m very private when I’m struggling, but they don’t leave me alone with myself. And we set

up cues with one another, so that we see some sort of behaviors, we touch base with each other. (P16, p. 19)

She understood that compassion fatigue could occur: “I’m careful that I don’t want to burden people. I think a lot of people with mental health challenges feel that it gets exhausting for other people when you’re not well. I mean people are good when you’re sick for a week or two. They’re not good when you’re not well for months” (P16, p. 19).

Lastly, she enjoyed the companionship of a support dog: “I do have a support dog...who makes me laugh and gets me outside even on days when I would rather stay in the house and cry” (p. 19).

One person spoke about lacking support while sitting on a board of directors. She related that as the sole person disclosing to a mental health problem on the board, she did not feel supported by the others. She recognized that feeling out of place is perhaps her own issue, not necessarily the board’s responsibility, but suggested the presence of other consumers and survivors would be helpful (P5). She did not wish to replicate this lack of support when working as a peer support facilitator, instead advocating vigorously for peer support groups and setting up opportunities for emotional support amongst colleagues:

I had to facilitate a liaison role, and I worked to get the communication happening between [the organization] and the facilitators. I think they did feel a lot more supported, emotionally and in their role. I kept sending them stuff. Information, articles, we kept having meetings. We had public issues meetings. Could talk about anything that facilitators were doing because I wanted to balance that out and say there’s got to be energy put into the support groups...into the facilitators in particular, so they translate that message to their groups because they feel supported, right? (P5, p. 7)

Another participant similarly emphasized that peer support principles must be understood and practiced. She especially enjoyed providing training to new facilitators, as each trainee brought unique perspectives: “We are really peer led in that capacity, using our own experiences to inform our practice as facilitators” (P6, p. 15). She said that it was vital that colleagues supported one another. In her organization, there was a protocol for the two facilitators to debrief after a peer support group was over. Most groups tended to bring up rather strong emotions. Her organization’s protocol considered that the group might discuss sensitive topics that could possibly trigger the facilitators, putting them in a vulnerable place. There should be a supportive way of managing that situation:

we get a lot of support from each other as facilitators. We will usually spend a few minutes after group debriefing and maybe talking to each other. Because as facilitators, we don’t necessarily go into our own personal lived experience on things that are very charged. Things that we would need support from the group for, because it puts us in a vulnerable position, and that could be detrimental if the group isn’t there for us in the way that we need them to be. The things that we don’t share in group, we might share with the other facilitator afterwards. (P6, p. 16)

At least four participants spoke about the crucial role family support has played in their leadership careers and their overall wellbeing. One spoke evocatively about his spouse’s role in balancing his life:

P: my wife sometimes tells me, when I have been speaking a number of times. Come home. She would say, the next day, grab a book, read, or do something else, but you cannot think about mental health in any way [we both laugh]. Just do something different. Or she’ll say, just rest.

I: sounds like your wife is a very important resource...

P: She is the one who sniffs out the balance or the lack of balance in my life. (P2, p. 16)

Another leader narrated that his organization was founded with the help of his family (P7). He and his family members worked closely together in its day to day operations. This support was especially important in the organization's early years as "[my family] helped me in writing a proposal and with their connections" (P7, p. 1). He offered a poignant description of the way his family had assisted him during a nadir in his life:

I had this crisis, I called my [mom], and they picked me up, and then that's how I got help...I didn't have the resources, in myself to, except to ask for help. That was the only way. I mean that's been hugely influential in how I have done everything, in moving forward. I just realized that I, alone, I can't do anything. (P7, p. 7)

He realized that he required help, and that aid allowed him to move forward and become a community leader. He was very candid to me about just how difficult his life became, to which he responded by not being afraid to ask for help. Others expressed similarly candid views. One man related that his symptoms had recently returned and was thankful to his spouse for helping to stabilize him, enabling him to remain out of the hospital: "thankfully my spouse stepped in and talked my psychiatrist into not hospitalizing me, and she took a week off from her work to basically monitor me and watch over me. Instead of me being in the hospital" (P9, p. 3). The support of his spouse was a cornerstone: "family support is very important...if it was not for the support of my partner, in my endeavors, and her willingness to put up with my sometimes ridiculously long hours, I don't think I could do it" (p. 19).

Summary

Participants spoke about maintaining a balanced approach to leadership. Many felt that

leaders needed to learn to bend, to be flexible, and to improvise when circumstances did not go as one would expect them. Many participants declared that they were against rigid leadership styles, although a few admitted that they had been too rigid in their thinking themselves (e.g., P2). In contrast, a few suggested that there was only one right way of doing things, and that they would invariably go that way.

Participants spoke about listening to the voices of rank and file consumers and survivors. The first task of anybody stepping up to a leadership role, many suggested, should be to listen. Not all leaders needed to be in front of the camera. The leaders working in the background, supporting the visible leaders, were just as important. Several leaders expressed a great deal of humbleness, as they wanted to learn from more experienced folks. And for them, there were always people whom they can learn from.

Both securing the support of allies and maintaining an optimistic attitude seemed to be based on speaking a language that was hopeful, realistic, and understandable by all parties. Participants felt that the support of allies was a decisive factor if the movement was to be successful. Optimism, an expectation that success would come, seemed to be a belief system that most participants cultivated. The optimism was not a baseless feeling, as participants called up evidence for what progress has already been made. One participant described her process of steering organizational change, noteworthy for its analysis of the thinking involved, her use of lived experience to open a dialogue, and her tenacity on an issue she felt passionate about (P10).

Knowledge drove leadership. Some participants spoke about the usefulness of postsecondary education to the budding leader. A larger number spoke about basing their leadership strategy on research evidence. A few expressed that their self-efficacy was enhanced by conducting research themselves. Also, the research product benefited consumers and

survivors through improving the robustness of the mental health knowledge base. The centerpiece of the knowledge base came from social movements themselves, as their planning, actions, and outcomes generated valuable knowledge to be transmitted amongst movement actors. One leader asserted that our movement deep down truly did not understand itself and would benefit from learning from and working with other progressive movements (P10).

Participants worked in an array of mental health organizations. Almost all participants devoted their energy to local organizations. For some, their reach was very wide, as they consulted in dozens of organizations locally, provincially, and federally. Participants for the most part seemed humble, rarely bringing up mention of awards that they have received.

As much as some participants wanted to, or as I had assumed that a social movement would want to, entry into the polity seemed to be difficult, maybe impossible, at the current time for this movement. When participants spoke about political activities, it was almost always within the context of petitioning for funding. Beyond that, participants mostly worked with governments and political parties at an arm's length consultative manner. They were careful in what they said, and they did not want to offend the political power brokers.

Participants directed criticism toward involvement with elite allies. They suggested that the polity favored non-consumer controlled organizations with a middle-class agenda, but withdrew support from consumer and survivor organizations led by poor people. Not all participants agreed with these criticisms.

The leaders interviewed worked hard at steering and developing their organization. Participants were mostly optimistic about the fate of their organizations. Some felt overworked and fatigued by their organizational duties. Becoming a thought leader and training other thought leaders were important leadership processes. Although individual leaders might possess

great talent, the emphasis was on developing a network for knowledge exchange. This knowledge exchange can be considered part of the interpersonal and community building tasks of a social movement.

Lastly, supporting one another was paramount. Leaders, *walking the talk* of peer support, must support one another, emotionally, intellectually, physically. Participants reported that their families and their home life were strong supports, a foundation for leadership longevity. Several participants acknowledged that they could not do it alone. Their life was a life with family and with a community of support.

Chapter Six

Facing the Mental Health System

In this chapter, I discuss the way participants, as well as the documentary research, addressed the study's third research question: How has leadership practice in the movement affected one's experience within the mental health system? Participants related that they were at life's nadir – some at near self-annihilation – when they entered the mental health system. They journeyed from a position of relative disempowerment and anomie, traveling through various steps to learn to become a leader, then stepping into positions of responsibility and influence.

The categories emerging from the data focused on performing advocacy in a careful, prudent manner based on the experience of many years on the receiving end of the mental health system. Participants generally avoided radical and confrontational methods, but there were a few exceptions. As one participant observed, “the movement seems to have shifted from a totally adversarial advocacy approach to a more collaborative, partnering approach” (P14, p. 1). At the same time, participants mentioned consistently that either they or their colleagues had endured profoundly negative experiences in the system. One man reported that, although aspects of his care had been excellent, “some of the nursing staff I felt had treated me in a sort of punitive or weary fashion because of my diagnosis” (P9, p. 3). The system in their view included not only the mental health system, but also health care, education, and public assistance.

At the same time, the clear majority felt that the system was as much a part of the solution as part of the problem (P2, 3, 4, 5, 6, 7, 9, 10, 14, 16, 17, 18, 19). Their emphasis was on careful collaboration with the historical antagonist of the movement, the mental health professional, instead of viewing any one group of people or any institution as implacable enemies to be defeated: “I think having a collaborative, partnering approach is more effective

because it's about working with, not against. For so long the movement has worked against, not with” (P14, p. 1). Such collaboration was mentioned frequently, possibly as participants felt that consumers and survivors ultimately derived great benefit from a caring and dignified therapeutic relationship: “We genuinely want to work together to establish the best services for [people with mental health problems]” (P14, p. 1). Leading through melding and influencing rather than fighting was what most emphasized, with notable exceptions (P8, 13). One man opined: “Dialogue, not standoff. Because I don’t think standoff...helps” (P7, p. 4).

This led to a finding that might seem surprising given the social movement’s antipsychiatry roots, because many participants wished to make space *adjacent* to the movement for a biomedicine that was not contradictory to recovery. *Not inside* the movement, because the movement had a social, not medical, orientation, but adjacent to it, where there would be an opportunity for movement leaders to play a role in training mental health professionals. They trusted aspects of psychiatry as currently practiced, including its: diagnostic system (deemed useful); emergency triage procedures (considered life-saving); and psychotropic medications (deemed useful, possibly life-saving). For example, one person asserted, “I was diagnosed with schizoaffective which was very accurate in terms of what I was experiencing” (P10, p. 9). At the same time, psychiatry provoked mixed feelings, with some leaders reflecting soberly that it was a mix of both good and bad. One person reported, although the neuroleptic she had been prescribed caused terrible akathisia, she was willing to accept that it might help others: “I am not saying [it] is a terrible drug. I have heard of people that it really worked well for” (P4, p. 7).

The targets of critique, the impetus for advocacy, were identified as: the mental health professionals’ underlying prejudices; the statutory and informal power, arbitrary and unaccountable, that professionals wielded over consumers and survivors; and the mental health

system's institutional indifference and hierarchy. The upshot was that the movement best take a patient, long term approach to leadership, participants explained, because implementing recovery was very slow, despite our movement's best intentions: "It takes a long time" (P10, p. 32).

Participants and the available documents identified a long list of advocacy tasks, such as decreasing power differentials between the professional and the service user and thinking critically about psychiatry. One leader reported that once on a committee, a senior mental health professional had been very condescending: "I was being dismissed, in terms of my opinion. This one chief psychiatrist...was just so condescending and dismissive" (P7, p. 11). And for many, psychotropic medication was only supplemental to recovery: "I'm doing great [without psychotropics]. I haven't had any symptoms come back" (P12, p. 4).

I begin the chapter with the developmental journey from anomie to self-empowerment, with the notion that self-realization was the basis for genuine leadership. I follow with the idea that the system was as much part of the solution as part of the problem, particularly collaborating and sharing ideas with mental health professionals, using our experiences as consumers and survivors to influence, rather than to fight, the system. At the same time, profoundly negative experiences inside the system lingered, and spurred the participants' ongoing efforts to identify the system's problems. The leaders interviewed voiced extremely varied feelings about the mental health system, ranging from intense anger to somewhat dashed expectations to a warm trust. However, feelings of disappointment were much more numerous than positive experiences. I then describe the participants' approach to recovery, their strategies to implement this field-defining idea in contemporary mental health. Advocating for recovery included critical thinking about psychiatry, identifying stigma as oppression's root cause, and advocating for adequate mental health services. Curiously, many leaders felt that biomedicine retained an

important place in mental healthcare, if professionals enabled hope, not contempt, for their patients. The chapter concludes with a pragmatic, but critical, perspective of leadership, one that many participants viewed as the most realistic. The implication was that social progress in this field would take a lot of time.

Journeying from Victim to Survivor to Inner Warrior

The phrase, from “victim to survivor to [inner] warrior,” was an in vivo code from a participant, which I felt to be especially insightful and descriptive (P10, p. 5). Eleven other leaders, using different words, spoke about a similar journey and developmental process. The phrase seemed to encapsulate seven aspects of leadership development: this was what consumers and survivors wanted in leaders; coming back from the brink of self-annihilation; addictions seemed closely linked with trauma and mental health problems; poverty has taught us, as poverty created our movement; self-realization as leadership’s root; becoming empowered and articulate; and healing the system started with our own healing first.

What Consumers and Survivors Wanted in a Leader

For almost all participants, a leader’s developmental journey, from suffering and distress to finding a way out – in a word, recovery – was central. They suggested this journey was what consumers and survivors sought in a leadership process. One participant explained: “it makes a huge difference when it’s coming from that place because number one, you’re in an environment that, it is not just paying lip service to things like” (P10, p. 17). Another explained that people who have made that journey work with a greater understanding and empathy, because they were basically working with something that they themselves have journeyed through:

They run completely different [than those who have not made this journey]. They run, I would say they run with empathy and understanding, and their Board Members and

Directors usually they have a real-life understanding, so they're dealing with themselves. They're dealing with their families and such, and so their whole strategy of dealing with the community, they're pretty one on one and more connected. (P15, p. 6)

Two participants, both highly experienced in peer support, spoke of the requirement that peer support facilitators must have personal experience with mental health problems (P5, 6). People without personal experience were typically not admitted into the facilitator role. One of them said: "they have to have had the experience. Because the people who come to the group, that's what they want...you are not speaking from a textbook...you know the experience. That's really counts for a lot" (P5, pp. 5-6).

One leader narrated that his personal difficulties with mental distress and his frustrations with the mental health system allowed him to understand and empathize:

going through the trenches, I am a true consumer because...I have gone through the tunnels of the system...and I have been warped and twisted just like any consumer...it gives me a way of empathizing and connecting with people (P7, p. 9)

Coming Back from Self-Annihilation

Participants extensively discussed this topic. Five participants spoke of their past attempts to commit suicide, five of their experience of physical or sexual abuse, and four described family traumas resulting in severe mental distress, some of which would be the abuse referred to above. I understood that the numbers quoted above were underestimated, because there were interviewees who did not speak on the issue in the interview. However, they had publicly disclosed on television and in newspapers that they were survivors of childhood trauma and abuse. Four interviewees stated that their life had changed profoundly, very negatively, after being diagnosed with a mental illness.

Almost all the participants felt that their life had gone completely out of control at the onset of their mental health problems. Most alluded to a personal lack of control, but only three interviewees specified what exactly had occurred (P7, 10, 18). A few interviewees recognized their behavior during that crisis had been “awful” or “horribly angry” (P5, p. 4; P2, p. 4). Two narrated that at that crisis time, they had lost everything of meaning in this world (P10, P16).

Five participants spoke about their suicidal thinking. One person noted that he had made numerous attempts to kill himself: “I tried to take my own life a couple of times...one of those times, I then admitted myself into a mental hospital” (P2, p. 4). He continued: “that was my first [time] and about four, no three months later, I did that [attempted to kill myself] again. I was another three weeks in the hospital” (p. 4). Another described that her voices had led her to near suicide. The crisis worsened because of a medication that produced unbearable side effects, she narrated: “I went to hospital because I made a suicide attempt. Crisis came, my voices...were very critical and nasty voices...they were very nasty...so I made a suicide attempt and then in hospital, I was given a drug that caused akathisia” (P4, pp. 7-8). She continued: “I contemplated suicide to get away from that feeling caused by the medication” (p. 8).

One man described the allure of suicide when he felt that his life had no future: “there was one point I think in January, February, I was in an apartment in downtown Vancouver, and it was raining, and I felt horrible about myself. And I felt dizzy, and I felt that balcony was kind of nice to jump off. I was going, hum, this is kind of dangerous thinking” (P7, p. 6). It was not clear whether the hospital stays that some interviewees described were voluntary or involuntary, but some implied that they had been involuntarily confined to a mental hospital.

At least five people spoke about physical or sexual abuse. One leader spoke in slightly less personal terms on the issue: “I guess we identify ourselves as people with mental illness, but

there are other factors. There's people who are addicted to drugs or that have alcohol, or there's women that have been abused in the past" (P13, p. 5). One man for decades had hidden the fact that he was sexually abused as a child. He hid this from those closest to him, until the truth could not be buried any longer:

my wife knew, for years, and years [laughs]. We are going to be married for fifty years... And for forty years, I never told her about the fact that I was sexually abused as a kid. But she always figured there was something really wrong, but she couldn't put a finger on it. When she asked me questions, I shut her down right away and said, no, you can't do that. Or I'm not going to answer you. So anyway, that's how I sort of slowly, but once I admitted that I had an issue, I began to say, I need more information. (P2, p. 5)

Another man spoke frankly about having lived through an abusive, dire childhood.

Multiple abuses occurred within his family of origin that combined, he perceived, to trigger a mental illness:

I grew up in a highly toxic, shame-based family in which there was unrecognized, undiagnosed mental illness like bipolar disorder. There was a lot of what we called back in those days alcoholism, or addiction to substances, and there was a lot of physical and sometimes sexual abuse. So, we do not know the cause of mental illness, but we know what triggers them. And that is stress. So, the environment I just described was a very stressful, toxic environment. Growing up, it left a lot of wounded emotions on my heart. (P3, p. 5)

He said that mental illness and mental health have always been a keen interest because all his brothers and sisters have experienced mental health problems, which included psychosis and substance misuse. Two of his siblings spent time in prison, he stated, and "my father suicided as

did my brother” (P3, p. 1). Another leader grew up in dire circumstances and felt that she had developed mental health issues to survive and cope with the circumstances:

I have experienced trauma that is so horrific, people don't even know how to hear the stories of what happened to me from the age of 2 all the way up until I took control of my own life, isolated myself away from a lot, and tried to find my own power again and strength. There's a damn reason why I have PTSD, and I don't think there's anything wrong with me. (P16, p. 14)

Profound loss after being diagnosed. Four participants spoke about their life becoming irrevocably altered, negatively, after receiving a diagnosis of mental illness. One spoke about the developmental disruption and identity loss that mental health problems caused in young adulthood: “mental illness strikes people when they are young. It causes people to lose their families, to lose their school, to lose their job, to lose their confidence in their own understanding of reality. It can affect their whole identity” (P4, p. 13). Another participant spoke poignantly about how her career aspirations as a young woman crumbled after becoming psychiatrically hospitalized:

P: I really enjoyed [volunteering]. I wanted to be a doctor and felt so at home there. Until it became like a home in a bad way...it felt like a second home, the psychiatric unit. That was hard. I felt like I was deceiving people by going from school to the unit to meet with the psychiatrist when I was taking first year psychology. It just felt wrong...to me to have that kind of dual thing. I was [hospitalized] quite a few times

I: you are saying it felt wrong to both study psychology and to see a psychiatrist? (P1, p. 5)

I wanted to ask her to elaborate what she meant in, “home in a bad way” (p. 5), but she

did not speak anymore on it. Another person, involuntarily detained in hospital, saw her life collapse. She said that “everything got literally taken away” – her marriage had ended, her house was no longer in her name, and the police had apprehended her with a warrant, so “I got locked up” (P10, p. 9). “Anything that I thought had mattered, it was gone,” she said (p. 9).

Life was going out of control. Almost all participants, eighteen out of the nineteen, spoke of their life going out of control with the onset of mental health problems. For my last interview, number nineteen, because the tape recorder did not work properly the first time, I had interviewed him a second time. I did not ask the same questions so as not to be pedantic, but during the first interview, the man had alluded to his life spinning out of control.

Only three participants spoke directly about their life going out of control. Most others alluded to it by referring to great sadness, feeling personal powerlessness, becoming lost in medical jargon during the diagnostic process, and feeling coerced during involuntary hospitalization. One man reported that when greatly troubled by his symptoms, “life was rapidly cycling out of control” (P7, p.). Another narrated that she had sustained severe injuries in a car accident, including brain injury, and subsequently her mental state deteriorated (P18). Her life went “horribly wrong” (P18, p.). One person said that her long-term use of street drugs had catalyzed a psychosis. Her life spiraled out of control:

my use of chemicals, particularly meth, had reached a point in terms of my coping...all those unconscious behaviors, reached a point where finally...I went into full-blown psychosis...I was diagnosed with schizoaffective which was very accurate in terms of what I was experiencing. (P10, p. 9)

She realized that she could not live her previous life anymore. Within a full-blown crisis, she recognized that the naming of her symptoms, through a psychiatric label, caused both

positive and negative effects (P10). Positively, she had a name for which to call one of her problems in life, and a method to treat that condition – psychiatry. Negatively, she landed in the hospital against her will, and she had lost her former life (P10).

Awful behavior. Two participants described their behavior during their crisis time, leading up to their diagnosis (P2, P5). They admitted having acted negatively, inconsiderately. The reason that I am including this was that I wished to draw attention to their self-awareness, taking responsibility and accountability for one’s actions, good or bad. One man related that in psychotherapy, with family members in the room, he was required to face up to a reality that he had long wished to avoid:

it also made me face up to a reality that I had wanted to avoid [laughs]. The way that I acted and treated [my family]. Because...I’m a nice guy, a good guy, right? [Laughs]. But I don’t always act that way (P2, p. 5)

He used to exhibit episodes of fury: “for some reason, somebody would say something, and I would get horribly angry” (P2, p. 4). Another leader was frank about how she acted during a severe crisis. She did not rationalize or blame people or blame the mental health system:

I: how was your experience initially with the mental health system? Was it okay? Was it bad?

P: it was really rough. At the same time, I was such a mess that I was extremely vulnerable, extremely emotional, in and out of hospital, yeah, my behavior was awful [laughs heartily]

I: okay

P: at that time, right? It was hard for people to deal with me. And it was hard for me to totally get what I needed. (P5, p. 4)

Addictions Were Linked with Trauma and Mental Health Problems

Five participants noted that addictions issues could not be separated from trauma and mental health problems:

when you talk about mental health, you can't talk about mental health without talking about addiction, and when you talk about addiction, you can't not talk about trauma.

There's a triangle there that we like to display body, mind, spirit, and we like to separate them. It can't be. (P10, p. 9)

Several people felt that addictions, for them, was a way to numb emotional pain, after receiving a devastating diagnosis:

I live with addictions, alcohol addiction and cigarettes, but especially the alcohol addiction...I would say escalated when I was diagnosed...so after I got diagnosed, I started experimenting with alcohol, started smoking heavily...Well, this was twenty-seven years ago. I drank for twenty something years, but eventually it caught up to me, so I had to stop. I'm part of a twelve-step program to help me recover from that stuff.

(P7, p. 7)

He understood that he was numbing his emotional pain by drinking. This unhealthy way of coping needed to stop, if he wished to live: "I was self-medicating a lot, even when [my organization] was [running successfully] ...I am so grateful I had found a way out of that. Because it would have killed me" (P7, p. 8).

Having a personal experience with addiction enabled participants to demonstrate empathy for substance users. One leader felt that people with trauma issues have been funneled into addictions programs because the mental health programs would not accept them. She had faced a similar situation herself, being denied treatment in the mental health system:

Addictions [programs] said that they are getting an awful lot of people with trauma...oh my goodness, that's where they are all ending up. People are self-medicating because they couldn't get treatment. Because I couldn't get treatment for my own trauma-related issues (P18, p. 22)

Another person pointed to an ongoing struggle in her workplace, a peer support program, in becoming competent to assess the dynamic interplay of addictions, trauma, and mental health problems. She would like those without an addiction experience to try becoming compassionate towards people with addictions. She drew upon her own life to grasp the complex conflicts within substance users and within her own workplace:

one of the things that has been an ongoing struggle within my workplace over the last while has been a real lack of awareness and compassion around addictions, particularly when you're talking about the polydrug community and people on the street, and a hard-core view because it's hard core coping among other things...in the mental health community they say, you've got to take care of the addiction piece first, so that then we can help you over here. The addictions community says you've got take care of your mental health piece first, and then we can help you. And it's just like, people, this doesn't happen like that. It's an interacting, always interacting thing that you can't separate. (P10, p. 15)

She would offer her knowledge gained through lived experience and a university education to colleagues who had questions on assisting consumers and survivors struggling with addictions: "I had coworkers that would come to me and ask if they could pick my brain because I was honest about my own. I don't have shame behind the path I walked, you know. It got me to where I am today, right?" (P10, p. 25). Another leader corroborated her point about not

feeling shamed with one's journey as a consumer and survivor: "we need to collectively have a self-esteem which is hard when our illness, of course, involves us not having one...it has to be collective self-esteem, and we have to stop feeling threatened" (P18, p. 24). She concluded that it would be helpful to bring one's experiential knowledge to the government and to the people who needed help.

Poverty Taught Us, Poverty Created the Social Movement

Somewhat in contradiction to another point that participants made, poverty being an immense barrier to attaining leadership, five interviewees pointed out that their experience of poverty taught them about empowerment. One man stated that his family had been uneducated and disadvantaged: "I was the first male [person in my family] to graduate high school, and the first [person] period to go to college" (P3, p. 16). He continued that he had met people who had "risen up beyond homelessness and poverty...and they have become very vocal and articulate" (p. 16). Another felt that poverty could create a social movement's grassroots, as it created anger and "the energy to change things" (P7, p. 23).

Although very difficult to be an advocate when absorbed with day-to-day survival, a life she understood from personal experience, one participant suggested an untapped hunger among the poor:

when much of your energy and time goes into day to day survival, there's not a lot left for other stuff...people who are in that place and having lived in that place for a very long time myself, I can definitely speak...there's a conversation happening with tons of people I know. People are very hungry to be a part of social change, a part of doing something that is going to, even if it doesn't change something...for them, then for other people...they are as hungry for that as they are for getting through the day (P10, p. 22)

Self-Realization as the Root of Leadership

Ten participants presented the idea that leadership was rooted in a mature sense of self. Although no participant used the word self-realization, as they all used different words, I settled on the word because it seemed the one that best conveyed the idea across a range of contexts. Participants used words such as “self-compassion” (P5, p. 20), “self-care...self-acceptance” (P5, p. 20), “awareness of yourself” (P5, p. 15), “learning habits, self-habits” (P10, p. 9), “wisdom” (P10, p. 12), “resonating...at heart level...at mind level” (P3, p.). Many participants did not use one word to describe their idea of a mature sense of self but through stories and non-verbal expressions.

Seven participants spoke about something that may be described as self-compassion, although not all of them used this word. Self-compassion seemed a key concept in social movement leadership because many consumers and survivors struggled with accepting themselves as human beings:

I seem to be on this real campaign of self-compassion...most of all but it includes self-care and acceptance. Self-acceptance which is a huge issue for people with mental illness and not with mental illness. It is for all of us humans, right?

...the self-compassion movement...if that can grow bigger, that that will really help us...when we are in psychological stress. I really believe that these concepts are helpful to anybody. And contribute to better mental health by being able to acknowledge ourselves and take care of ourselves well. To be able to accept for the most part who we are...and to live at peace. (P5, p. 20)

This speaker suggested that through accepting oneself, one would lead by functioning as a role model for a life well-lived. The self-compassion techniques can be taught and learned:

“when we are in internal conflict with ourselves, we are in conflict with the whole world...so as human beings, we need to learn how not to be in conflict with ourselves first of all. And how to have compassion for ourselves” (P5, pp. 20-21). She teaches this idea to consumers and survivors: “in my workshop, my first line is, what is a human being and how do I be it well? I just think that is a really fundamental question” (p. 21).

Another leader had for most of his life repressed his childhood experiences of abuse, leading to significant mental health problems. He came to the realization, “if I am going to live any longer, I am going to have to work with [these emotions]” (P2, p. 4). He had lived his life externalizing his emotions and problems, but later realized he must search inside himself for the answers: “I admitted finally to myself...for the first time, I started to get interested in me” (p. 4). He engaged in a journey of self-discovery.

Self-realization required becoming vulnerable. Learning self-compassion and self-realization required vulnerability. One participant had been afraid to join a support group, feeling very vulnerable within the emotional turmoil brought on from being sexual abused. Once she did join that group, however, the learning and the social connection it offered paved the way for her to become a leader (P5). But in the beginning, the support group was scary: “I think probably I felt very vulnerable at that point...that was what was scary” (p. 3).

Another participant spoke about her organization’s peer support groups, which were always led by two facilitators. She described the importance of group facilitators supporting one another, as they might become vulnerable, defensive, or frightened. Managing these feelings, without being overwhelmed by them, within the presence of social supports was a viable modality for personal growth (P6, p. 16).

One man pointed out that effective leaders let down their psychological defenses so they

could talk to people directly about their experiences: “to be a leader in the field of mental health, I think you have to be able to let down your guard, and talk with people frankly about what you have experienced” (P9, p. 17). He provided the example of a Canadian university president who recently divulged his experiences with bipolar depression, opening a useful public conversation.

Becoming articulate, becoming self-empowered. Six participants spoke about learning a language to articulate the hardships and abuse that they have survived, expressing in words and actions their own potential. This learning was part of self-realization. Concepts, such as self-compassion, tapped into universal ideas that were “really helpful to anybody,” as one participant remarked (P5, p. 20). With language, concepts, and practices within their armamentarium, participants embarked on self-empowerment, becoming ready to lead.

The System: As Much Part of the Solution as Part of the Problem

That the system seemed to be as much part of the solution as part of the problem was to say that consumers and survivors ultimately were in the same boat as the professionals and the government policy makers. The phrase, “the system was as much part of the solution as part of the problem,” was a modified quotation from Participant Ten, who believed that if we wanted to intervene effectively to dismantle oppression, we could not neatly separate the oppressors from the oppressed:

every system is made up of people. What we do know about people? Virtually all human beings are confused, and unconscious. We make up their system. Of course, the system is going to be screwed up. No offence, but it’s about being able to look at it and go, okay it is, because we are. How do we heal us, so that we can heal the system? (P10, p. 14)

She did not like the dualistic thinking that bifurcated the world into us versus them. The negativity that activists would fight against, externally, in public, she suggested – aspects of that same negativity resided within them. The pain that many consumers and survivors carried inside, she explained, if they were not self-aware, would become projected onto external entities. Focusing solely on past pain created a negative energy and a negative movement:

I did this [myself], because when you are in a victim-oriented place, you make a lot of things into monsters. You make people into monsters. You make systems into, and you forget that they're made up of people. Like we are surviving, we are those systems. I think that there's a lot more that can be done from when we are working from that place. I think that when you're working for something, fighting for and not fighting against, you also create a different energy (P10, p. 14-15)

She suggested an approach based on *fighting for* something that both consumers and survivors and the mental health professionals valued and worked toward. The approach contrasted with *fighting against* a foe, as defeating your foe did not solve your problem, and there was a good chance one would lose. The fighting for approach, although most participants did not use those exact words, related to what at least ten participants described as: establishing a good relationship, partnering, collaborating, working cooperatively, working together, and walking with a sense of acceptance.

Thirteen participants thought that collaborative leadership with mental health professionals was a central task of our movement (P2, 3, 4, 5, 6, 7, 9, 10, 12, 14, 15, 16, 18). Eighteen out of nineteen participants identified that some sort of collaboration with mental health professionals was at least obligatory, even if they did not highlight this activity. In contrast, one

participant suggested that a separatist approach, separate from the mental health system, might be more appropriate, but he did not provide specifics as what might be achieved (P8).

One leader reported, “whenever I can work with clinicians, I encourage them to help support our peer support model” (P15, p. 11). Another described a long running program wherein university students would write a term paper based on their learning after carrying out a practicum at her consumer and survivor organization (P18). A participant noted that an influential support group, the Hearing Voices Network, was locally established through an occupational therapist (P4). This group has been a space for an empathic approach to psychosis. Instead of having only one option presented, neuroleptic treatment, as would be practiced in mainstream psychiatry, the Network offered choices: “It is peer led, and we use the New Zealand hearing voices network guidelines, one of which is make no assumption of illness. And the other is you have the freedom to interpret your experience in any way” (P4, p. 5).

The participant suggested that this group might be helping to change both consumers’ and professionals’ beliefs and interventions regarding psychosis (P4). Occupational therapists promoted the group in the community and inside the mental health system. However, the groups themselves were led by consumers and survivors, not mental health professionals.

Several participants aimed to work with psychiatrists and other physicians. A Calgary participant wished to educate future doctors on recovery by asking medical trainees to spend some time shadowing her organization’s staff (P18). A Vancouver participant supported a group of dissident professionals, including psychiatrists, who have raised sharp critiques on mainstream psychiatry and would suggest alternatives, such as the Finnish approach with psychosis called Open Dialogue (P4) (UC San Diego School of Medicine, 2018). A Winnipeg participant was part of a national committee that aimed to promote more effective communication between

patients and physicians. He played a role in identifying that a patient must be asked to provide prior, informed consent for medications, and to educate physicians about this notion (P2). It should be implemented in routine practice, not ignored as it often has been:

there is a better communication and more open communication because in the past, it's happened so often that there has been, a patient or a person with lived experience really does not know what kind of medications they are taking. They don't understand, and the medical community sometimes has failed to even understand that a patient needs to understand [laughs]. (P2, p. 2)

Working together with mental health professionals meant collaborating with the mental health system's management. One man with experience working within Vancouver's mental health system reported that various groups of employees, from line staff to middle managers, had attempted to work with consumers to bring recovery into the mainstream system (P17). I used only the word consumer because this participant did not feel that psychiatric survivors had played, or were offered, much of a role in those attempted reforms. Several Vancouver participants felt that upper management in the Vancouver mental health system had supported recovery, at least in principle, as several opportunities opened for consumers and survivors to be employed as change agents within the system (P4, P12, P14).

Not Fighting, but Joining, Melding

A key component, at the core of this leadership approach, was described as not fighting, but joining, melding, or influencing:

I don't think confrontation is the best way to win a situation at all, without hearing what the other person says. I'm hearing you, and how do we make this work? (P12, p.11)

One man noted that speaking from pure anger did not work for him: “I am not an angry advocate. I am not an adversarial advocate. I don’t believe in that” (P3, p. 7). For another man, a rather gentle approach helped to develop rapport with consumers and survivors. An overbearing approach often triggered defensive reactions, so he would first speak in a low-key manner:

I usually start with information that you may find interesting, rather than saying you need help [laughs]. Here, why don’t you look at this? Do you feel anything? Does this speak to you in some way? Often, they will come back and say, yeah, it did. One of the things that was suggested, and I think I am going to check that out. [laughing heartily] (P2, p. 9)

For some, taking a nonfighting approach was a calculated, strategic choice (P2). For others, it was the best fit for their personality, as they were uncomfortable with confrontation (P7).

Negative Experiences within the Mental Health System

One of the few who answered my research question directly – how leadership experience has affected her perspective on the mental health system – responded that her lens, her perspective, has “expanded exponentially” from leadership experience (P10, p. 13). She meant, in my interpretation, that she could simultaneously appreciate both sides of the picture, not only consumer and survivor grievances against the system, but also the mental health professional’s own sense of frustration and inadequacy.

All participants had given serious, sustained thought on the reason why the mental health system seemed to perform with such mediocrity. A majority thought of the system as a series of checks and balances, at times producing good results, other times mediocre results, and sadly, sometimes failing tragically (all interviewees except P8, 13). The leader I quoted above

surmised that the professionals working within the system were faced with bureaucratic restrictions, rules, and cultural assumptions that loomed over them, overriding their creativity and individual decision making (for an academic perspective, refer to Townsend, 1998). Many professionals then, unfortunately, became progressively more inhibited in their perspective and conduct, in that they could not “even use a healthy approach” anymore (P10, p. 13).

Seventeen out of nineteen participants reported that, historically, the mental health system has been a consistently disempowering force. One explained that certain non-consumer controlled organizations worked in tandem with the formal mental health system to disempower consumers and survivors:

the issue that seems to be predominant within...the [non-consumer controlled organization]. Number one, convincing people that they have [a mental disorder]. Number two, convincing people that they have to take their medication. If you get beyond that, and you listen to people’s stories, you will hear people recovering from not just “mental illness,” but they are recovering from unresolved trauma. They are recovering from a non-recovery oriented mental health system. (P3, p. 3)

Police involvement at involuntary hospitalization added to a possibility of traumatization and stigmatization: “They are recovering from the trauma experienced under the mental health act, where police come, take you out, put you in handcuffs, and take you to the emergency room because you might be suicidal, and you have not even committed a crime” (P3, p. 3). The typical treatments for psychosis came with serious, and for some, debilitating effects. And some mental health professionals still carried stigmatizing and discriminatory attitudes: “People struggle significantly with the side effects of the medications, even the second-generation atypical [neuroleptics]...in terms of metabolic disorder. You hear stories of people talking about the

stigma that still exists within the mental health profession and [within] the community” (P3, p. 3).

Another participant recounted a terrible experience at a mental hospital. She perceived that the neuroleptic the physician prescribed worsened her suicidal ideation due to causing a severe, unbearable akathisia. If she could leave the hospital, then at least she could stop taking the substance responsible for akathisia, putting her in an untenable situation:

because my thinking was slow and foggy, I didn't have a big word like akathisia. I wasn't very articulate about describing how I was feeling [while]...they were increasing the medication dose. In the end, I was contemplating suicide over medication side effects which I think it's a risk the system isn't aware of. When usually someone commits suicide, they blame the illness. But I know of another person who probably did commit suicide over side effects. Anyways...to bring the story to an end, I did get out of hospital. Convinced them that I was better. I still had all the symptoms I went in with...still hearing voices, still thought the voices were real. I thought I was under surveillance. But I convinced them that I didn't, so I got out of the hospital and went off the medication, and all the side effects went away quite quickly. (P4, p. 8)

She narrated a situation where she felt one must lie to a mental health professional to correct an iatrogenic error originating from the professional. She felt that she had received almost no benefit from her hospital treatment. Another leader narrated that a nurse told her, without sound evidence, that surely, she would be taking psychotropic medications the rest of her life (P10). As it turned out, the nurse had been wrong: “my psych nurse, yeah, and she got to see that wasn't true in the end” (P10, p. 10). One participant clearly felt that the power to force

medications onto a patient was abusive, because this practice disregarded prior and informed consent (P4).

One leader recalled times in the psychiatric ward when she would receive an injection, by force, if she became uncooperative. However, she did not feel that this practice had violated her: “my experience in hospital was not traumatizing. Even though I did receive injections if I was not cooperating, and things like that” (P6, p. 4). I thought to myself, I would expect hospital not to traumatize me, or hurt me emotionally – that would be my baseline expectation. This leader concluded that typical hospital treatment and mainstream psychopharmacology were not abusive or traumatizing, but she appreciated that views differed. This person explicitly asserted that she did not identify with antipsychiatry approaches.

Participants differed on these issues. Several felt positively about their psychotropic medication, alongside with some mixed feelings about their drawbacks (P2, P7). The consensus was that medication must involve a positive, respectful relationship with a physician, a listening ear, and room for negotiation from either side. Not having these elements of mutual respect opened opportunities for abusive practices. These participants advocated for exactly these things in their leadership activities.

One woman successfully tapered off her medications and returned to her psychiatric clinic to help facilitate a support group for women at an early stage of recovery. The clinic staff had instructed her not to tell the group that she was not currently taking medication:

I answered questions, but one of the things she said to me before the facilitation, “we need to make sure, don’t tell them you aren’t on medication.” I really had a problem with that, because if there’s anything I want to tell these young women, it’s that I was on a

shitload of medication, on all kinds of stuff, but it doesn't mean you're going have to be doing it all your life, but you need to do it now.

...I just went, I can't do this anymore...because you're asking me [to withhold information], that's my own piece of integrity that's not going work. (P10, p. 11)

The mental health professional did not want her to say an important message she wanted to convey – that recovery was possible, with living proof. This overrule challenged her personal integrity, and she would no longer want to return to the clinic to facilitate groups. A key aspect of her leadership would be to address the lack of voice, and the subtle disrespect, that the system afforded to consumers and survivors.

Ten others pointed out a prevailing attitude of distrust and condescension towards patients in the mental health system (P3, 4, 7, 8, 9, 10, 13, 14, 16, 17, 18). One participant, the founder of an influential mental health organization, recalled his psychiatrist did not seem to have any faith in him. He told his psychiatrist that he planning to start his own organization, and he replied, “you are delusional” (P7, p. 9). When that organization started to operate for real, his psychiatrist came around, said, “I am really impressed that you did this. Because I did not believe in you that you could do it” (p. 9). This leader concluded that his psychiatrist had provided him “a backwards compliment” (p. 9). Within the healthcare system, family physicians, one participant pointed out, at times disregarded physical health complaints coming from consumers and survivors as only somatization (P3).

Advocating for Recovery

Personal experiences of disrespect and negativity within the mental health system, or hearing of such experiences from their colleagues, spurred participants to reform the system. Almost every participant asserted that promoting recovery in the system was their strategy and

mission, although some did not use the same word, but referred instead to critical thinking about medications (P16) or not becoming dependent on the system (P13). One participant, in a minority opinion, suggested that the system was far too corrupted to be reformed (P8). Several definitions of recovery exist within the literature (Deegan, 1987/1996; Morrow, 2013). One leader explained both the system status quo and what a recovery envisioned mental health would mean (P3). The status quo, as described, was symptom management within a chronic illness model. Recovery was living in community, with a sense of purpose, whose main goal would be, quality of life, not reduction of symptoms. Currently, our mental health system in Canada, its primary goal is symptom reduction. Do a quick diagnosis, a fifteen minute to twenty-minute conversation. Tell the person that they will take these very powerful neuroleptics for the rest of their life. And good luck. The goal of the mental health system should be quality of life...to be able to live with a sense of meaning and purpose successfully in community, with social integration and full citizenship (P3, p. 4)

Recovery, it seemed, as a concept and a vocabulary has become well accepted in the mental health system and in government (Morrow, 2013; Vancouver Coastal Health, 2017, n.d.). However, participants told me, health policy planning and healthcare institutions have only just begun to seriously consider and implement recovery principles in actual practices even though the concept has been theorized for three decades (P3, P4, P7, P17, P18). For instance, one leader observed that all the provinces and territories have statements on the meaningful participation of consumers and survivors in the planning, implementing, and evaluating of mental health services (P3). However, he concluded that policies and practices on the ground have yet to change, because recovery was still only a theory on paper, not an actual practice (P3). Five participants

critiqued the mental health system's insincerity. One asserted that talk of recovery can be characterized as politically correct doublespeak (P3):

P: With regional health authorities, different levels of government, it is politically correct to use the word recovery. Very politically correct to say, yeah, we are recovery-oriented. For professionals to say, well, I have always been doing that.

I: [laughing]

P: Which is totally nonsense because if we had been recovery oriented all these years, we would see better results from the mental health system. In terms of less relapse, less trauma, trauma being addressed as part of care. (P3, p. 4)

Given recovery's uneven uptake in the mental health system, most participants were convinced that promoting and implementing recovery's core principles was as important as ever if the consumer and survivor movement was to succeed. No less than seventeen participants indicated that there was a pervasive sense that the power dynamic between mental health professionals and consumers and survivors continued to be unequal, and fraught with distrust and cynicism. One leader indicated that the mental health system operated on a "power over" people principle, as opposed to recovery's "power with" principle: "the mental health system generally operates as power over people rather than power with people. We have to shift from power over, that hierarchy [principle], to power with people" (P3, p. 8).

Such consensus on this topic seemed an indicator of recovery's weakness within the system. Many participants provided accounts of mental health professionals negatively objectifying their patients, with some becoming dismissive and contemptuous (P3, 4, 7, 8, 9, 11, 13, 16). One participant, self-declared as a person who was rarely confrontational, felt dismissed

and looked down upon by senior mental health professionals. He was taking part in a working group with his province's highest-ranking psychologists and psychiatrists:

I was sitting at a group...mostly medical, psychologists, heads of [departments?], it's very high up. Top organizations, top of the chain, I tried to share my honest feelings about the topics that were being discussed. The way I introduced myself: this is a person with schizophrenia, a patient. I didn't say anything about running [my organization] or anything like that. But I was being dismissed, in terms of my opinion...like this one chief psychiatrist guy who was there, was so condescending and dismissive of what I had to say. (P7, p. 11)

Although the setting was a task group, not a clinical encounter, it indicated problematic attitudes amongst some mental health professionals. The attitude of condescension was used to wield power over consumers and survivors (P4, 7, 8, 9, 11). The power that mental health professionals wielded over people with mental health problems was real, sanctioned by provincial mental health law. In British Columbia, Alberta, and Manitoba, a physician, after examining the person, may sign a medical certificate, authorizing the involuntary admission of that person to a psychiatric facility (Canadian Mental Health Association, British Columbia Division, 2017; Sinclair & Turner, 2004). Friends or relatives may escort the person to such a facility, but often, the police were called to find, handcuff, and forcibly detain that person, then transport them to the psychiatric facility (Sinclair & Turner). One participant stated that it meant being treated like a criminal prior to ever having committed a crime (P3, p. 3). I have personally heard mental health staff who, when frustrated, nonchalantly opine that their patient should just be "pink formed" by a physician, involuntarily hospitalized, divested of civil liberties, when the

person with a mental health problem had only been uncooperative or rude, not necessarily a danger to themselves or others.

In cases where a physician was not available to sign a medical certificate, the police in their judgment may take a person, involuntarily, to a psychiatric facility to be detained (Sinclair & Turner, 2004). To be sure, the police typically detained a person under the mental health law only if they found the person to be a danger to themselves or to others, or at risk of very significant deterioration of their health and wellbeing (Mui, 2018). The numbers of people with mental health problems detained by police were very large, according to recent newspaper reports; in Vancouver alone, from 2015 to March 2018, 9,358 persons were detained under the Mental Health Act (Mui). The thought of, the possibility of the police handcuffing and taking oneself to a psychiatric hospital, where one may be injected neuroleptics against one's will, was a frightening prospect for many consumers and survivors (P4, 8).

Critical Thinking about Mainstream Psychiatry

Participants thought critically about the mental health system's assumptions. A few referred to the system as a trap, one that enticed consumers and survivors unwittingly to a life of low expectations and dependency: "the regular [mental health] scene...where people basically sit around and have coffee...[fostering] a dependency on the system" (P13, p. 1). In addition to the services offered by psychiatrists, participants also referred to the drop-in centers, programs run by well-meaning professionals, and activity groups run by occupational therapists, where consumers would sit and drink coffee, eat lunches, make crafts, and smoke cigarettes (P13). They referred to the welfare system, which allowed mental patients to live a life on society's margins. A life of low expectations and diminished opportunities was reason enough to despise the word consumer, living by consuming the system. For one leader, the word signified a

“parasitical,” destructive way of life (P13, p. 4). He said, “I don’t want to be known as someone who’s totally dependent on the system” (p. 4). Another interviewee described their concern about “the trap” one stepped into when resigned to lifelong dependency on the system:

I was really aware of the trap, aware and concerned. I didn’t want to become condemned by that system...I think it was just with me all the time that I was always pawing my way out from the moment I went in. I don’t know how else to put that really. (P10, p. 7)

Critical thinking on medications was important for recovery, as becoming overmedicated seemed a perilous slide into a life of low expectations, lethargy, chronic malaise; in addition, the cascade of weight gain, metabolic syndrome, and diabetes associated with certain neuroleptics (McGorry, Alvarez-Jimenez, & Killackey, 2013; Moncrieff, 2013; Gatov, Rosella, Chiu, & Kurdyak, 2017). For Participant Ten, she decided that she could not risk this slide into long term disempowerment. Two other leaders likewise asserted that they fought for a life lived on their terms, contrary to the expectations of the mental health system (P4, 8). Participant Ten said,

fighting my way out of the system was...recognizing what I wanted for myself, I was not going to find it in terms of the typical path offered to people. I knew that mine needed to be more holistic. I was also told things that I fought against, like you’re going to be on meds for the rest of your life. I’m not [on medications], anymore...There were a lot of things that I knew were not going work for me...it’s challenging because you end up really feeling...alone because [some] people are not supportive. A lot of times your family isn’t either...I’m going to access every damn thing I can. I’m going try everything I can, but it may not be according to the catalogue [laughs] that they want to push on you. (P10)

Yet eighteen participants acknowledged that psychiatric treatment had its rightful place,

with the need to critically weigh its benefits and shortcomings. However, of these eighteen, at least twelve strongly advocated for alternative methods to manage mental distress, including a Finnish approach for psychosis called Open Dialogue, and the Hearing Voices Network. One woman, highly experienced with the Hearing Voices Network, explained that this approach enabled better options and choices for consumers and survivors:

those alternative ways of understanding experience are more personally meaningful than an illness model, which is only a model. They can be more empowering. If you understand your experience as illness, what do you do? You take medications. If you are one of the lucky ones, the medication works well, and then you are okay. I was one of those people. If you are one of the unfortunate people, where the medication doesn't work well, and your voices are distracting, it only helps a little. Where it doesn't help at all, and [where] you believe it is an illness, but you take the medication, it doesn't work. That can leave people feeling very disempowered. Whereas, if you believe it is a spiritual experience, and you have a spiritual relationship with your voices that you can share, for some people that can feel empowering. (P4, p. 5-6)

Hearing Voices Network members can share their feelings and opinions about their psychosis experience, without feeling harshly judged. Another participant facilitated a group with similar principles, but with a different name. She acknowledged that neuroleptics did not work for all people. Her group enabled consumers and survivors to cope with, even thrive, when their hallucinations simply would not go away:

I'm also running a group...for people who experience hallucinations, and medications do not help no matter what, or if they're still fighting those hallucinations. Instead of medicating them when it is not helping and going to hurt their liver or cause diabetes and

all this other stuff, how we can help them to be able to work with those voices, and still live a productive life. How do you silence them? Can you put them in a jar and make them quiet? Can you tell them, I'll talk to you during this time, but right now you're going to leave me alone, because I'm going to school? It's working, right? (P12, p. 5)

It may seem superfluous to state, but all nineteen participants agreed that peer support was an important alternative to psychiatric treatment. For some, it supplanted psychiatry altogether. For one participant, having almost no access to psychiatric services, peer support was the only help available:

we cannot get publicly-funded psychiatric treatment. The letter from the minister has disqualified any psychiatric service or treatment facility in this province from providing us service. So, we have to live in a tremendous amount of emotional pain. If we have anxiety, there is no medical help, there is no clonazepam or Ativan. We have to do everything through peer support. We have had to be in the movement, so there is no medication, no nice doctor, no anything. (P18, p. 7)

At least three participants successfully discontinued neuroleptic medication, although they were careful to maintain a checklist and a safety plan should symptoms arise. Many participants sought to lower their medication dosage. One leader told her story of quietly but diligently advocating to lower, then terminate, her olanzapine regimen (P12). She weighed the pros and cons: "how am I feeling? What are the risks that I take in taking this medication? Is it worth it? The reason why I stopped taking the medication is because...my blood sugar was just like below the 7 marks" (P12, p. 6). Her physician was unsupportive, but she persisted. Another physician cooperated, understanding that she managed well without using that neuroleptic:

I'm well enough that I know my warning signs. I know that I don't want to go back to

when I was [unwell]. If I end up having symptoms, I'm going to go back on medication.

I was at that point where I can reason that out. (P12, p. 7).

In a minority opinion, one participant dismissed psychiatric treatment altogether, reserving grave suspicions about any benefits from psychotropic drugs. He considered neuroleptics especially harmful (P8). In the hospital setting, he understood that neuroleptics may be forcibly injected or imbibed, without prior, informed consent, and he considered this practice reprehensible (P8). On the opposite end of the spectrum, two participants (P6, 12) felt that the mental health system has evolved sufficiently to be neither heavy handed nor domineering going forward: “[in our region], I think that battle has been won. We are working as a team, the professionals and the clients” (P12, p. 3). Hence, Participant Twelve was comfortable working closely with the mental health system and did not seem interested in Mad Pride or any of the contentious politics involving criticism of mainstream formulations of mental health.

One participant considered the issue analytically, viewing the problem as one of systemic oppression at a micro-level: “I really saw the classism and the sexism...even the racism, but particularly the classism within the system...yeah, I used to get quite angry” (P10, p. 8; P17). This person seemed to consider the mental health system's problems as a downstream effect of a corrupt political system. He would like to focus their leadership on reforming the ideas driving that polity, together with intervening in the materialist basis of the social determinants of health (e.g., Vancouver's extreme housing market have put the working poor and the middle class on the brink of homelessness; whereas government intervention in housing, with housing protected as a human right, would yield improved outcomes) (P17).

Stigma: The Root Cause of Oppression

Five participants identified stigma as the root cause of condescending attitudes within the mental health system and the broader society. One man explained that both the Black Civil Rights movement and the consumer and survivor movement had a common foe, discrimination:

if you compare the civil rights movement with the mental health movement or the psychiatric survivor movement, racism is a form of prejudice, as is mentalism...People of color are stigmatized. People with mental illness are stigmatized. Stigma is a caricature based on fear or misunderstanding. Call it prejudice. Prejudicial attitudes always lead to prejudicial actions. Those actions are what we called discrimination. Stigma is an attitude. Discrimination is an action. (P3, p. 19-20)

The stigma regarding mental health problems caused fear and misunderstanding, leading to prejudice. Prejudice led to discrimination. In the mental health system, some professionals, or many of them, depending on one's point of view, exhibited prejudice toward consumers and survivors, revealing itself through subsequent discriminatory actions. The participant concluded, "Our goal is to end the discriminatory action" (P3, p. 20).

Prejudice may arise through misunderstandings within interpersonal interactions. Prejudice on a larger scale arose through parental messages based on unfounded assumptions within one's family:

being told through...our family, through you know if someone is talking to themselves on the street, like be careful, stay away from that person, they might hurt you...

I had these negative, stigmatizing beliefs about mental illness because that is what we are brought up with. (P6, p. 5)

Prejudice arose from media portrayals of people with mental health problems as being violent and unpredictable individuals: "the tendency every time there was a major violent

[crime], to immediately ask the question what [mental disorder] was the person suffering from” (P9, p. 19). The participant narrated that, when first diagnosed with bipolar disorder, he experienced self-stigma, because his only previous knowledge of bipolar had been “news releases of someone doing something erratic and violent” (P9, p. 19). These perceptions were misleading, he explained, as “the majority of individuals with mental illness were more likely to be the victims of crime than the perpetrators” (p. 19).

Advocating for Adequate Mental Health Services

Seven participants discussed the need for adequate mental health services (P2, 4, 6, 8, 9, 16, 18). Mental health services considered inadequate included: prescribing medication without the patient’s prior, informed consent; prescribing medication in which the side effects greatly outweighed the benefits; and denying medical care due to a patient’s psychiatric diagnosis:

They put me on medications that made me suicidal without telling me the side effects...I knew my rights because of my beliefs with the medication. I switched medication, and I got better. The problem was that I didn’t feel that I could tell my doctors how bad it was in my head. (P16, p. 3)

One leader narrated that psychiatric services were almost entirely unavailable to her (P18) (see above). Seventeen participants advocated for an accessible, holistic, humane mental health system, possibly including psychiatry as a major component. One participant seemed indifferent toward psychiatry (P13), and another opposed psychiatry outright (P8).

Several participants advocated for new, emerging mental health supports – trained support dogs, Open Dialogue, Hearing Voices Network, student support groups – because mainstream mental health services were either unavailable, or ineffective for their needs and their community’s needs (University of California, San Diego, 2018). One leader, previously

involved in disaster assistance services, advocated for the availability of psychological counseling for disaster victims. Such services were typically lacking, but very much in demand. He narrated that during a major flood, a person that he had assisted was incapacitated by anxiety, so that he could not even help in the efforts to save his own house: “We have seen that many times in disaster work...we need counselors to be there as well. I have been pushing hard for counselors” (P2).

Peer support received unanimous approval from the leaders interviewed. All nineteen participants advocated for high-quality, accountable, and accessible mental health peer support.

Making Space for Biomedicine

Despite widespread negative experiences within the system, twelve participants concluded that biomedicine was not only a necessary, but an important, part of mental healthcare (P1-7, 10, 12, 15, 18, 19). By biomedicine, I refer to psychiatry and the entire allopathic medical profession, the medical aspects of nursing, all of which saw psychiatric disorders as real, tangible brain disorders with an underlying biological mechanism. It refers to brick and mortar institutions founded on biomedical discourse: general hospitals, psychiatric facilities, and outpatient clinics.

These twelve leaders felt that the consumer and survivor movement ought to be able to work with biomedicine, not inside it, but in tandem, side by side, each with its own principles and methods. One person, drawing on decades of experience within the movement, stated, “biomedical is needed,” but her organization’s acceptance of biological concepts in mental health has drawn the ire of some movement actors: “we are often attacked by other organizations across Canada for being in partnership with the biomedical model” (P18, p. 10). Two

experiences seemed to underlie these leaders' views on biomedicine. First, a mental health professional, such as a psychiatrist, had been pivotal for their recovery. For example:

We had an amazing psychiatrist...This psychiatrist came, and he was one that said, let's get you on the least medication as possible, where you are able to manage and have a good life. That was his policy, to try to wean people off [medication], and though him, I've been off medications for 5 years now. (P12, p. 4)

Second, although fewer participants held this view, was the feeling that psychiatric treatment had saved their life: "If my illness wasn't treated, and I continued on with my psychotic beliefs, at the whim of my highs and lows of bipolar, I might not even be alive today. I might have taken my life" (P6, p. 5).

For participants holding favorable views on biomedicine, they pointed out what they considered its strengths, such as: the clarifying effect of receiving a diagnosis (i.e., one's mental health condition contained certain consistencies, and a diagnosis usefully drew parameters around what it was, and what it was not); the formulation of a treatment plan based on a coherent methodology; and the ameliorative effects of psychotropic medications. One interviewee stated that her diagnosis was "very accurate" in terms of what she was experiencing (P10, p. 9). This person understood that getting hospitalized psychiatrically meant that her old life was literally taken away. While she had lost everything, it paradoxically was the beginning of getting her life back:

when I was hospitalized, they dealt with police and a warrant. I got locked up, and that was the beginning of the journey for me, because it was also the start of getting my life back, because everything got literally taken away. When I went into the hospital, I was here for, gosh not long enough. (P10, p. 9)

She felt that her stay in the hospital had in fact been too brief, but that fortunately, she was referred to an outpatient clinic. She understood that her hospitalization had to happen, because her life had spun out of control (P10, p. 9).

One leader appreciated the clarifying effect of a diagnosis. She suggested a diagnosis would be a roadmap for helping people to get back their employment, housing, and benefits, rather than be lost in a fog of vague speculation regarding symptoms and what to do about them:

if you don't think it's a disability, what would you like to call it? Again, the DSM [Diagnostic and Statistical Manual of Mental Disorders], the whole row of them over there [pointing to the book shelf], because, in our house here at [organization], if you are here with [my staff], behind the computer on any given day of the week, he'd throw up his hands in frustration and say, oh my God, it's a disability! (P18, p. 19)

She seemed to understand the disadvantages of medicalization discourse as well, but she asserted that without a diagnosis, a treatment plan, or community supports, consumers and survivors with complex needs ended up homeless:

People are losing their homes. They are losing their jobs. They are losing income. Our people meet the criteria 100 percent for complex care. They have mental illness, physical barriers, more than one mental illness. They've got addiction, and PDD [Pervasive Developmental Disorder], and most of them are physically compromised as well. There is not one person who walks through this door with [only] one issue [strong tone]. (P18, p. 19)

Another person, highly critical of what he termed “biomedical reductionism,” nonetheless reported that psychotropic medications were a significant boon for many consumers and survivors (P3, p. 4). Recounting decades of experience as a patient within the mental health

system, another participant reported that he often disagreed with the system. Ultimately, however, he respected the methodology of medical science, which allowed him to adhere to his psychiatric treatment despite these criticisms: “My faith in science...has been a strong motivator to continue [working] with psychiatry” (P7, p. 9).

Seven participants felt that their psychiatrist or another mental health professional has been pivotal to their recovery (P1, 2, 3, 5, 6, 10, 12). They might describe this mental health professional as either “amazing” or as highly dedicated to their wellbeing (P1, p. 4; P12, p. 4). When one participant was hospitalized, he felt heartened by the dedication and care provided:

I met with him about five times each week. Which was almost every day, and I still meet with him once every three months. He is going to be retiring now. We are going to see how I can be transition to a different psychiatrist. Yeah, but the system has been wonderful. Just wonderful and smooth sailing really through it all. But like I say, I know that sure isn't everyone else's experience. (P2, p. 6)

I found it noteworthy that his caveat acknowledged that not all people experienced, or perceived themselves to experience, genuine care and dedication from a mental health professional. Of all participants interviewed, this man was the most effusive about psychiatry, from his personal experience of “smooth sailing really through it all;” nonetheless, he took seriously the complaints of others concerning psychiatry (P2, p. 6). One person out of nineteen in the current study outright rejected psychiatry, with eighteen leaders ranging in their attitudes on psychiatry from a grudging acknowledgement of its existence to outright enthusiasm.

For those who felt psychiatry to be helpful, a typical opinion of its benefits would go something like the following: “talking to the holistic oriented psychiatrist made a world of difference in my living beyond depression and having a sense of meaning and purpose” (P3, p.

5). The implication seemed to be that a caring mental health professional was just that, one who was dedicated to caring about their patient, having the appropriate technical skills to carry out effective interventions, who considered a patient's needs and wellbeing holistically, and, in the final analysis, who respected their patient's personhood and dignity (P10, p. 12).

Several felt that their mental health professional offered wise counsel (P1, 2, 10). Several people mentioned that their psychiatrist offered useful advice about living a balanced life. A psychiatrist had simply reminded him to get adequate sleep, a basic health principle. The participant found this to be true:

One of the things I have found personally for myself is rest. I need lots of rest. I need my ten hours of sleep. I know that sounds ridiculous. My psychiatrist told me that, from the first day, I think, within the first twenty minutes of talking with him. He said, I think you need a lot of rest. And it's true. I function best with rest. (P2, p. 15)

One especially poignant moment in my interviews occurred when a participant narrated about the way her mental health professional had taught her to self-advocate. This person helped the participant to reclaim her personhood, as her power and dignity had been ripped from her through the ordeal of involuntary hospitalization:

Simply by living by example, because she did. She advocated for me in [many] ways...there were times when she truly did have to do things for me, in places where I didn't have the ability or capacity to be challenging certain people on systems and situations. But she also informed me so that I knew how to do this myself, and so that I knew how to do this with other people in the future...just she really taught well in that way, because she didn't just treat me like a client. She...treated me like a peer in that way and sharing her knowledge and wisdom. (P10, pp. 11-12)

The mental health system gave her back some of her power, when the outpatient clinic she attended asked her to teach them, the professionals, how to work with their patients, signifying to her that wisdom resided within oneself:

One of the things I will never forget about [the outpatient clinic] was the psychiatrist that I had constantly reminded me that we need your feedback. You're the one with the wisdom in teaching us how to work with our other clients, how to do things right...I knew I actually had a lot of voice. I think that gave me power back. I can tell that matters because tears come. When you've been stripped of your power, and your voice in particular, because that's the thing that took a long time to find, they're saying this has value, and we want it. (P10, p. 12)

Other participants noted that their mental health professionals had encouraged them to seek out community resources to heal and empower themselves. As such, several individuals spoke of reaching out and getting involved in sexual abuse survivor groups, with one person eventually becoming a nationally recognized public speaker on the topic (P2, 5).

Four participants felt that psychiatric treatment had saved their lives (P5, 6, 7, 10). One leader told me, "if I had not been hooked up with [early psychosis prevention and intervention], I can tell you I wouldn't be alive today" (P10, p. 9). At least nine participants reported either to me or to a newspaper reporter that their life had essentially crashed, and they were subsequently admitted to a psychiatric facility. I surmised that several more of the leaders I interviewed had also been hospitalized, although not all of them spoke on the topic. One leader, a survivor of sexual abuse, narrated that in one terrible year, when things completely fell apart for her, life was "scary, really scary," and she was in and out of all four of the hospitals in her city (P5, p. 4). Another participant concluded that his mental condition, if untreated, was literally a dead end:

I found relief because the opposite direction...was so painful. I had no control at all in my life. I knew that was a dead end. The journey of untreated schizophrenia was a dead end. When I started taking medications, I found that that was a doorway. I also found relief. (P7, p. 5)

Here, too, the participant understood that his psychiatric treatment was less than perfect, that it came with unwanted and rather serious side effects: “I have been warped and twisted just like any consumer...I have never enjoyed the weight gain and side effects that come with the drugs” (P7, p. 9). However, in sum, he felt that treatment’s advantages outweighed its disadvantages. Several participants noted that they experienced concurrent substance abuse as well as to mental health problems when they were in severe distress. Had one or the other not been adequately treated, they might not have survived: “I might have gotten involved with dangerous things, and got really involved with drugs, because I was heading down that path in a way” (P6, p. 5). One said, “I drank for twenty something years, but eventually it caught up to me. I had to stop” (P7, p. 7).

A Pragmatic, but Critical, Approach to Leadership

Most participants emphasized that a persistent, long term approach to leadership was the most realistic one. Given that the leaders I interviewed were, for the most part, rather moderate individuals, by no means firebrands, in my opinion, this leadership approach was not surprising. One participant explained that we cannot expect the system to do what we as individuals often could not:

It takes a long time. If you look at the course of human history, I mean it is the evolution...we evolve...look at one individual. It’s evolution – to be able to understand

why the system takes so long to evolve, if we're not doing it ourselves, why are we expecting the system to be doing it for us? (P10, p. 32)

What she was alluded to was stated in different form by several others: as people with mental health problems, if we were self-aware, we knew that many of us have in the past behaved less than adequately. This might have taken the form of anger, substance abuse, and causing others worry and grief. For example, one person acknowledged that his use of alcohol caused great concern in his family: "My parents saw me dealing with stuff [coping] through alcohol. That had to be hard on them" (P7, p. 7).

We may not have always sublimated our intense feelings into prosocial purposes, at times expressing them in raw, possibly hurtful, ways. A few participants felt that although the system had been "rough" in its treatment of patients, at times "traumatizing," they nonetheless understood what part their own actions played in how the system reacted (P5, p. 4; P10, p. 8). One found the capacity to acknowledge her strengths and shortcomings, laughing at herself, self-compassionately: "At the same time, I was such a mess that I was extremely vulnerable, extremely emotional...in and out of hospital...my behavior was awful [laughs heartily]" (P5, p. 4). One participant, through reflection and self-examination, realized that the system had acted in the way that it was designed to do (P10):

when you're talking about institutionalization or any of the pieces, from my own experience in the system, that were overly traumatizing; in retrospect, I can speak about it in a completely different light. Because I know that what happened to me needed to happen, every damn piece of it. How it happened, that's what I'm dealing with today... That is where the problems are – how to benefit people, help people to move forward, because it is not being done in a way that empowers people. (P10, p. 8)

I interpreted her experience as the understanding that, however painful the past might have been, she would use her experiences to help others on a similar journey get to a better place. Part of her vocation was perhaps reshaping the mental health system into a more human institution, that would speak to its patients like human beings, not like objects.

The consideration of biomedical knowledge, curiously for a movement that began as an anti-psychiatry one, seemed to be a case in point. An opinion existed, among a group of the participants, that biomedical discourse was both necessary and helpful (see above). At the same time, eighteen out of nineteen participants identified the mental health system's ongoing oppressive practices. Drawing from self-awareness, self-compassion, dialogue with both movement and system actors, and a careful consideration of the evidence, the upshot seemed that an *us versus them* mentality, between the system, labelled as bad, and us, the courageous consumers and survivors, would be a mirage (P2, 3, 4, 5, 6, 7, 10, 12, 14, 18). We are part of the system, and the system is partly us – one participant explained briefly that her thinking on this issue has evolved, from victim centered to something more comprehensive:

I think before, coming from an especially victim-oriented [perspective], that experience, is a system that's against everyone. You start seeing...it is, they [the systems] are a part of, they are suffering too is what I am trying to say. All of us are in it together. This isn't a separate. (P10, p. 13)

If we, as individuals, as consumers and survivors, were expected to take some time, through concerted efforts, to work toward self-awareness and self-empowerment, it would be reasonable to expect the mental health system to take a considerable time to reform (P10, p. 32). For all participants, they had no illusions as to the pureness of biomedical knowledge. Biomedicine contained the potential to alleviate pain and offer coherent explanations for

phenomena, but that it also contained inaccuracies, tended to overlook its own biases and misconceptions, and historically has supported some truly monstrous practices (P3) (Chabasinski, 2012; Chamberlin, 2012; Pelka, 2012). At least two participants would disagree with a reconciliatory approach with biomedicine, as they felt chasm between the mental health professional and the psychiatric survivor was too wide to bridge (P8, 13). One person steadfastly upheld that most mental health professionals were, in his perception, the oppressors, he the victim, but his leadership formulation was vague, aside from broadly suggesting the idea of psychiatric survivor separatism from mainstream mental health (P8).

Many participants, nonetheless, had no time to waste regarding the oppression within mainstream systems. One told me, “we are not speaking, enough, louder” about the root causes of mental distress, and the sequelae of homelessness, addiction, and early mortality (P18, p. 22). Another asserted that she had no time for oppression, for the voices of the oppressed needed to be heard inside the boardrooms and corridors of power (P10). She explained that consumers and survivors must speak assertively, diplomatically, backed by well-thought out arguments, to mental health professionals and government policy makers:

I’m also someone who doesn’t have the time to wait for changes to take place, especially the people who are going through this every day, thinking whether they’re going to get through another day because of what they’re being put through, or what they’re experiencing. I’m also someone who’s on the other end, who is going to give voice to, in support of other people, and doing voice is a huge fucking problem, excuse my language. People so need to be saying something about it, because why it is not changing is that these voices are not being listened to. They’re not being heard or believed. (P10, p. 13)

The mental health system has been slow to reform, participants suggested, due to its conservative nature, its tokenism and co-optation of consumer knowledge, and its leadership by politicians who lack the vision and the will to make reforms happen (P3, 4, 7, 10, 14, 16, 18). One leader felt that her provincial department of health was “very conservative. I think the health authority is moving away from a biopsychosocial spiritual [holistic view of health] ...they are cutting the programs...that are recovery oriented looking at the whole person” (P4). Another participant from the same city concluded that “tokenism is alive and well” in their mental health system (P14, p. 1). A leader with thirty years of experience in the movement noted that the Ontario advocacy commission, which began in 1994, was halted several years later: “There was a lot of opposition to it by opposing [political] parties. They thought it was a waste of money” (P3, p. 10) (History in Practice, 2015). He concluded that politicians lacked vision and incentive to bring legislative and structural change, because the masses were not yet ready to rise: “We lack that political will of our leaders nationally and provincially and civically, because there is no social will and there is no massive uprising of the oppressed” (p. 20).

Summary

The nineteen participants offered an astounding amount of organizational narratives and leadership lessons. Most interviewees initially answered my research question the other way around, looking first at how their experience within the mental health system has affected their leadership practice. They reflected on their personal experiences around mental health issues, and then applied those lessons to leadership practice. Later, many did reflect upon how their leadership practice has changed their view on the mental health system (P1, 2, 3, 5, 6, 7, 9, 10, 12, 13, 14, 16, 18). Most suggested that leadership has broadened their perspective (P2, 3, 5, 9, 10, 12, 14). A few turned to their psychiatrist as their primary support (P1). Conversely, a few

turned to peer support and activities outside the mental health system for healing (P13, 16, 18). Some did both (P2, 5, 9, 12). Some felt empowered and emboldened to speak to their psychiatrist or other professionals as an equal (P2, 12, 16, 18). Some felt that they became privy to disclosures of even greater oppression within the system than they had previously imagined (P7, 16, 18). A number felt that leadership experience has humanized and softened their view of mental health professionals, seeing them as fellow travelers in a suffering society (P3, 5, 10, 12).

Many participants emerged from trauma, violence, and profound psychic distress within their families of origin and during their young adulthood. Many were literally on the brink of self-annihilation. They transformed those harrowing experiences, catalyzing a thirst for understanding themselves and for fighting for justice with like-minded individuals. These budding leaders then listened, learned, and found a language, a conceptual vocabulary, to express themselves, a voice, and an action. They found their personal voice and their political voice. They were becoming self-empowered.

Quite a few participants understood that their journey into addiction cannot be separated from their mental health concerns and their unique response to trauma. Allowing an empathic perspective to addiction led the participants to understand themselves, both their positive and negative behaviors, helping to lead others to offer greater compassion for substance users. They wished to translate personal experiences with addictions into well-thought out policy initiatives.

Self-realization, or a mature sense of self, may be the basis for leadership, participants suggested. Self-realization includes self-awareness, self-compassion, and wisdom. Self-aware leaders admit where they have gone wrong and where they have done right. Self-compassion seems to build a robust personality capable of accepting one's accomplishments and successes and not letting periodic failures crush oneself. The road to self-realization involves first

becoming vulnerable. Vulnerability forms the basis of the learning process in the movement's archetypal modality, peer support, providing for an identity-based leadership. Participants may speak their personal truth – experiences of marginalization, abuse, and neglect within their family, community, and civic institutions – to the polity, leading from their identity as an oppressed minority (as a person with mental health problems, with a disability, as a woman, so on). Wisdom lies in mastering self-awareness and self-compassion, reaping the fruits of those learning journeys, reflected in the soundness of an action or decision. None of the leaders said that they have reached self-realization or wisdom, but several said that they were working on it.

Consumer and survivor leaders collaborated and shared ideas with mental health professionals, challenged the professionals on their unfounded assumptions, and for the most part refrained from head-on confrontations with the mental health system, preferring to meld with and influence the system. Participants voiced striking experiences of pessimism, bleakness, and disappointment within the mental health system. A small minority, on the contrary, voiced unalloyed trust in the system. Experiences, whether positive or negative, spurred the participants to advocacy, and the list of responsibilities and tasks which they took on was impressive, indeed daunting. I have not described all the activities that these leaders carried out in regard to recovery, wishing to keep the discussion to a reasonable length, but they included advocacy for a guaranteed annual income, for affordable housing, for barrier-free education, educating about addictions, speaking at deliberations in Parliament and at the United Nations, giving interviews on television news, maintaining a web presence, providing crisis intervention services for consumers and survivors, finding housing for the homeless, and teaching and practicing psychosocial rehabilitation. Advocating for recovery and implementing it in actual policies and practices, so it would become a reality, was the goal. In a sense, exposure to leadership

opportunities has deepened the participants' involvement, in a critical, reforming capacity, in the system.

A key plank of recovery is an ongoing critique of biomedical assumptions and routine psychiatric practices, without necessarily aiming to destroy these discourses, but identifying their inconsistencies, gaps, and where reforms ought to happen. Curiously, various leaders narrated that formative experiences in their encounters with psychiatry laid the seeds for their recovery, even if it was not what they had wanted at the time. The extremely varied experiences of this group of leaders made their stories difficult to summarize. Warm, trusting, humanistic helping relationships characterized a portion of these experiences. At the same time, leaders spoke about, with the literature corroborating, significant problems in current psychiatric practice, the “soft bigotry of low expectations” and consistently shorter lifespans of people with schizophrenia, in part due to iatrogenesis, as compared to the rest of the population (Gatov, Rosella, Chiu, & Kurdyak, 2017; McGorry, Alvarez-Jimenez, & Killackey, 2013, p. 898). Generally, involvement with movement leadership seemed to increase the participants' affinity for the mental health system. Yet simultaneously, involvement with leadership enabled participants to focus their critique and impetus for reforms on aspects of the system judged to be unacceptably oppressive, discriminatory, and ineffective.

The final piece that struck me was an acceptance of vulnerability, the self-compassion that enables a person to accept themselves, that most participants conveyed. Self-compassion did not seem to hamper their ability to engage in radical thought, because the thinking that participants referred to was not a superficially saccharine mentality but a nuanced, deeply examined consideration of one's personal history, strengths, and shortcomings, receptive to the possibilities of healing and personal growth. Self-compassion worked to humanize their

relationships with fellow consumers and survivors, to authority figures in the mental health system, leading to a pragmatic, but critical, view of leadership. Congruent to the above, most interviewees did not seem consumed by anger or negativity. I am not certain whether self-compassion preceded or was concurrent with the participants' entry into leadership activity, but this mode of thought seemed to increase the accuracy of their judgements on the strengths and the shortcomings of the mental health system and improve the creativity and rigor of their proposed solutions.

Not all participants believed in self-compassion, however. Keep in mind that I interviewed most participants only once, so by no means was this a long-term study that might reveal any one individual's inconsistencies in practice. Two persons interviewed would likely not agree with the above, as they felt that they could not help but be angry at a system, and at a mental health problem, that had taken so much from their life.

Chapter Seven

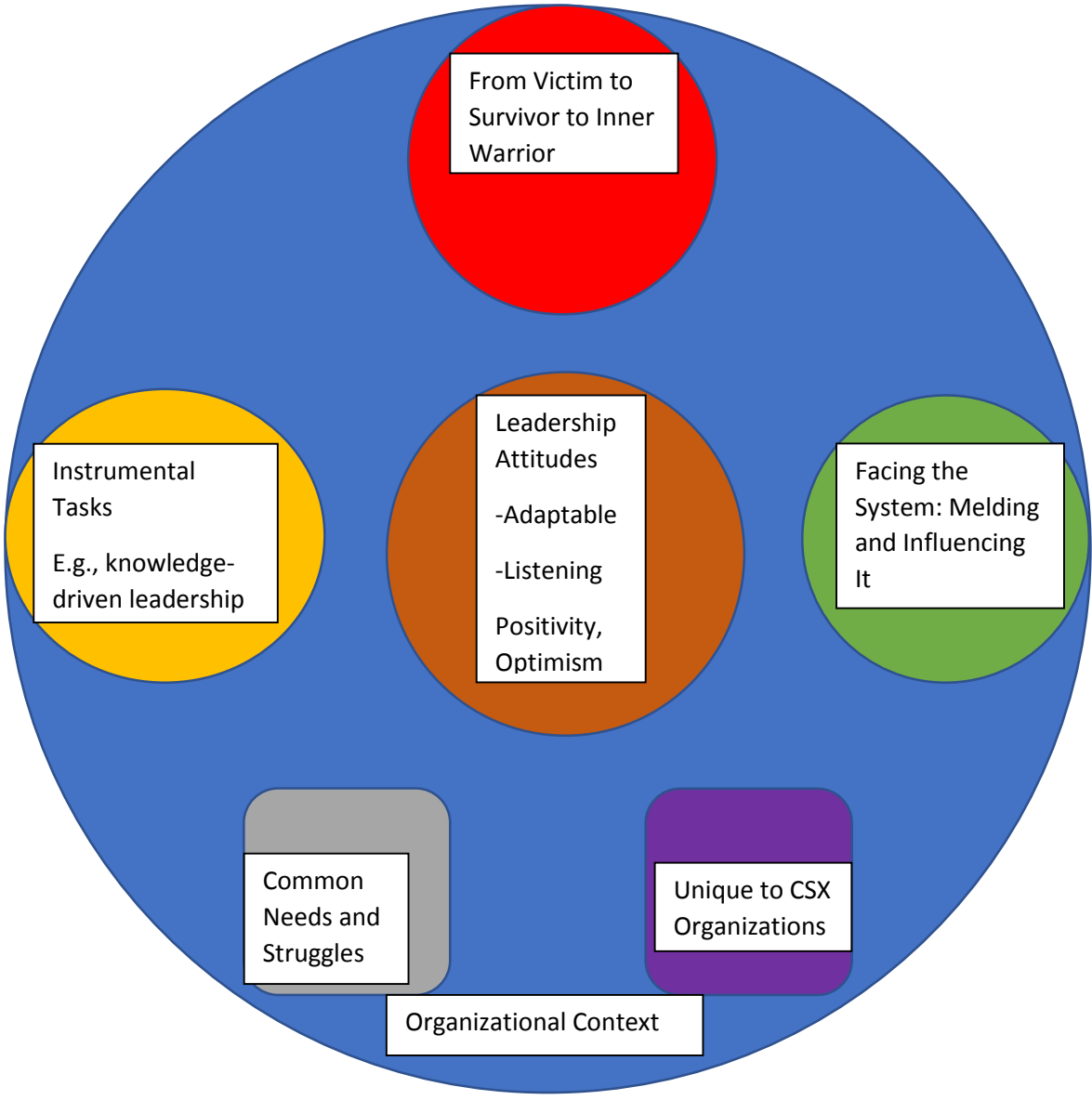
Discussion

In this chapter, I discuss the study's major findings, taking care to highlight any surprising findings. It compares the way different participants interpret and resolve the problem studied (Stringer, 2014). I then compare the participants' perspectives with those in the research literature. The overall conceptual framework derived from the findings is presented in Figure 2.

In answering the first research question, how is leadership practiced differently, or not, within psychiatric consumer and survivor-controlled organizations compared to non-consumer-controlled organizations, participants indicated that there were many commonalities. First, both consumer and survivor-controlled organizations and non-consumer controlled organizations required leadership that promoted accessibility and flexibility in organizational procedures. Body, behavioral, and emotional variation would need to be accepted if consumers and survivors are expected to enter and to maintain leadership responsibilities. Otherwise, I believe, organizations would replicate the inaccessibility and haughty condescension of the mental health system. Second, both consumer and survivor organizations and non-consumer controlled organizations required the practice of common leadership tasks, including mentorship, peer support, and changing public discourse through recovery stories.

Participants talked about peer support both as an organizational service and as a social dynamic amongst movement leaders. Four participants suggested their peer support networks became like a family or a set of confidants, although not all of them used the word "family." The intimacy, vulnerability, and the profound meaning they found within peer support reminded me of my own interactions with consumer and survivor leaders who had motivated and supported me throughout the research project. My deeply positive experience in peer support

Figure 2: The Conceptual Framework of Leadership



was one of the reasons I had embarked on this research and the participants' depictions reinforced my starting convictions. I was not surprised that peer support was described as empathic, intimate, and absolutely pivotal as a practice modality for both consumer and survivor organizations and non-consumer controlled organizations (Wulff, Bernstein, & Taylor, 2015). Of the four participants speaking on the issue, two came from consumer and survivor organizations and two came from non-consumer controlled organizations.

I did not hear critical voices regarding peer support except from two participants (P8, 18). Most others attributed peer support to be a wholly benevolent activity. Of these two critical voices, one person felt that most peer support programs explicitly embraced biomedical understandings of mental distress, understandings which he would disavow. The second person perceived that non-consumer controlled organizations have usurped the peer support knowledge originating from consumer and survivor organizations. She suggested that there was a significant political difference between the two types of organizations. Both critical voices felt that mainstream conceptions of peer support may sap the movement's vitality, although for quite different reasons. Participant Eight did not want movement leadership to be tied to biomedical discourse. He posited that our strongest leadership would take a separatist, antagonistic position vis a vis the mental health system. Participant Eighteen felt that the non-consumer controlled organizations operationalized peer support to be palatable to the dominant culture but in the process had disengaged the modality from its grassroots, communal roots. She suggested that leadership which did not originate from the grassroots, often from the most marginalized sectors of society, would betray the trust and hope that rank and file consumers and survivors placed in the movement.

Changing public discourse through stories of recovery seemed to be a crucial leadership task in both types of organizations. Given that this modality has been well established, from the autobiographical discourse of Judi Chamberlin (1978) to the recent Bell Let's Talk campaign, I was not surprised. Participants disagreed on whether outing oneself, individually, was a strategy that brought us closer to solving the root causes of mental distress. Some felt that telling recovery stories in well-publicized campaigns opened space for an empathic response among Canadians. Other participants critiqued the White, middle-class orientation of many recovery speakers: "It is evident to me that the white middle-class agenda is very marketable. That's lovely, and it gets money, but it's not addressing the problems" (P10, p. 25). One person added, "when you look at class, at who is the speaker that's put out front, it's always somebody who presents well in these campaigns" (P16, p. 12). These criticisms suggested that a recovery discourse that did not critique the mental health system, or class and colonial oppression, would not address the root causes of mental distress because it sought narrowly individualistic solutions to societal problems. The literature suggested that recovery, shorn of its political implications, was likely a smokescreen for a neoliberal logic allowing for individual self-expression but simultaneously buttressing the dominant culture's capitalist, colonialist foundations (Morrow, 2013; Voronka, 2015).

The marketability of the white middle-class agenda, Participant Ten suggested, inferred a framing contest between a poor peoples' movement, responsive to rank and file consumers and survivors' needs and aspirations, and framing mental health as an issue caused by structural oppression, and a celebrity-driven, corporate-led neoliberal mental health movement, detached from the voices of ordinary consumers and survivors, framing mental health as a nonpolitical issue requiring only friendly talking and clinical attention (Linton, 2018; McAdam, McCarthy, &

Zald, 1996). The organizations affiliated with the participants, whether consumer and survivor controlled or not, and their respective framing of the mental health agenda did not necessarily pose such a stark dichotomy between the class interests of the working class and the poor and the ruling and upper middle classes, but instances of class struggle did occur and are further discussed later in the chapter. As I said, there was more in common than opposed between the two types of organizations, and I interviewed middle-class leaders as well as working-class leaders. What is clear is that stories of recovery are just as political as they are deeply personal, and I argue that these self-change narratives form the raw materials for motivation, tactical repertoire, dramaturgy, and strategic judgement in leadership (Johnson, 2001). The recovery stories were a mix of radical thought and age-old wisdom (although the two could be the same), self-insight and political commentary, caution on innovation and change mixed with an impetus to take risks. An eclectic mix of conservatism and progressivism in recovery narratives, without any of them adhering to a precise dichotomy between the two types of organizations, spoke about the kind of leadership that people practiced. As eclecticism goes, so does the movement leadership, which I perceive to be a significant strength.

Common Struggles

Acquiring and maintaining funding has been a struggle for most participants in their work within both types of organizations. This was not surprising, given a steady slate of government cutbacks the past thirty years, and for some organizations, a matching move to private fundraising (Lord, 2010; Prince, 2009). Organizations, participants reported, were understaffed and at risk for discontinuing their programs due to decreases in funding. One participant seemed resigned to the reality that his organization might always be on the verge of shutting down due to a sudden cutoff of funds (P15): “We’re always on the edge of being shut-down” (p. 9).

Funding cuts to Vancouver-based organizations have been the most severe, according to study participants and media coverage (Hladikova, 2015). Information about organizations that have closed due to funding cuts came from sources outside of those organizations. Five out of the total seven Vancouver participants worked at the three organizations that were subject to recent funding cuts (P4, 5, 6, 9, 13), and these organizations included both the non-consumer controlled and consumer and survivor controlled. All seven Vancouver participants were aware of these funding cuts, and their opinions on this phenomenon ranged from feeling bleak (P4) to acceptance (P12, 14) to a strengthened motivation for improving their grant writing (P6, 9). One person, whose organization had suffered a major financial setback, offered an unexpected opinion. He offered a contrarian view, that it may be a good thing to lose one's funding, because it forced one to rethink and innovate one's strategy:

That's actually a good thing in some ways when you think about it...Because it makes people take more care about what they're doing, and think more about where they're getting their money, what they have to do to provide this certain point of view. That's the irony of it. It's an opportunity rather than a real problem, or at least that's the way I see it. It's not good to be totally dependent. (P13, p. 8)

The participant did not elaborate on the specifics of turning this problem into an opportunity. He questioned, however, the strategy of completely relying on the government for one's financial existence. He suggested such a strategy would curtail creativity and freedom.

However, from my experiences within the movement, and as a former health authority employee, I considered these funding cuts a result of the British Columbia government's neoliberal ideology. One Vancouver-based organization whose funding was eliminated was a consumer and survivor-controlled group that accepted anti-psychiatry perspectives. It has been –

or, more accurately, its newsletter has been – very critical of the local health authority and the provincial government (Shimrat, 2011, 2013, 2015).

The Corporatization of Mental Health

The ethical dilemmas that arose from fundraising were an interesting issue that participants touched upon. One participant (P5) spoke about the business orientation of her governance committee, in her perception completely geared to fundraising, whereas she would prefer a more holistic approach. The dominance of business matters alienated her from her fellow committee members. She felt like she belonged to a different class, whereas other committee members were either successful businessmen or highly educated professionals. The implication seemed that a commercial approach to leadership excluded the consumers and survivors living on disability benefits and without extensive contacts within wealthy circles. This incident pointed to the possibility that in her organization, non-consumer controlled, rank and file consumers and survivors could not cross the class barrier, isolating leadership opportunities to the upper middle-class.

Corporate influence was a concerning phenomenon at both types of organizations, participants indicated (P1, 3, 5, 7, 10, 16, 18, 19). Three leaders were troubled about pharmaceutical companies providing money to mental health organizations, as they felt that such financial relationships promoted a corporate biomedical discourse and sapped energy away from grassroots efforts (P3, 7, 19). They believed this funding relationship was not innocent and might serve as advertisements for pharmaceutical products, a significant concern as many participants understood that people with mental health problems were already overmedicated. One participant diplomatically described what he perceived as a serious ethical breach, as a

pharmaceutical company had negotiated with various community groups to help advertise its neuroleptic products, under a funding agreement negotiated and signed in secret.

Corporate sponsorship and advertising of mental health issues are familiar to Canadians; recently, Bell, Great West Life, TD Bank, amongst other corporations, have sponsored nationwide mental health awareness campaigns, the most well-known being Bell Let's Talk (Linton, 2018). Hypocrisy surfaced, according to news reports, as some of these companies were alleged to have engaged in emotionally abusive management practices towards their employees, contradictory to their mental health campaigns (Johnson, 2017a, 2017b, 2017c). One may argue that these corporations, in telecommunications, life insurance, and banking, as central pillars of Canada's capitalist system, were routinely creating the conditions for widespread mental distress through enacting capitalist values of self-interested individualism and valorization of profit whilst ignoring social and environmental responsibilities and wellbeing (Loreto, 2015; Mullaly, 2007). Thus, it may be argued that corporate giving to mental health organizations was a two-faced public relations exercise. One Bell employee told CBC News: "They have the Let's Talk initiative, but Bell doesn't walk the talk" (Johnson, 2017c). A participant (P16) argued that mental health organizations may ethically make use of corporate sponsorship, by turning the money into stronger community supports, and working from the ground up to create structures that buffer the harmful effects of capitalism (for a similar argument, refer to Loreto, 2015).

If the movement began to support wholesale the corporate discourse on mental health, this would suggest a transfer of the movement's framing processes from consumer and survivor organizations to corporate boardrooms. Consumers and survivors continued to shape mental health phenomenology, through their recovery discourse, public demonstrations, policy and legislative advocacy, academic research, movement newsletters and zines, cultural products such

as songs, poetry, and visual art – even if outmatched by the more powerful biomedical and governmentality discourses (Morrow, 2013; White & Pike, 2013). Yet corporate discourse has a long history of occupying space within biomedical discourse (Crowe, 2017; Fickweiler, Fickweiler, & Urbach, 2017; Hodges, 1995), and corporate discourse would now co-opt what previously had been considered radical language, shifting the meaning of recovery, empowerment, self-determination to commercial consumerism, product placements, self-branding (Linton, 2018; Morrow, 2013; Voronka, 2015). Asking consumers and survivors to become happy by so-called talking (Bell Canada, 2018) while ignoring the structural determinants of mental health, when the root causes of alienation and ill health might in part be placed at decisions made in corporate boardrooms, was aptly named by one participant as “so damned cliched!” (P11, p. 10). I would go further and call it a neoliberal co-optation.

Some Mental Health Organizations: Disempowering and Discriminatory

Historically, various mental health organizations, controlled by philanthropic and medical interests, acted in patronizing, discriminatory ways toward consumers and survivors, while publicly professing to support mental health. The consumer and survivor movement has identified such organizational discourses as a significant problem, analogous to the disability movement’s criticism of the charities which depicted people with disabilities as wretched unfortunates, only worthy of society’s pity and sympathy (Longmore, 2009). Several participants reported that the non-consumer controlled organizations have made earnest attempts to remedy these hurtful historical legacies, acknowledging the wrongs and working together with consumer and survivor groups to correct organizational practices.

Participants commented that such attempts at reconciliation seemed genuine, yet a few organizations continued to depict people with mental health problems as helpless, pathological,

and criminal. There were also more subtle instances of disempowerment that several participants pointed out, although not directly refuting recovery, these implicitly depicted consumers and survivors as incompetent beings. Instances of subtle disempowerment were difficult to identify and remedy, participants suggested, because these behaviors were supported by otherwise rational sounding organizational procedures and strategies (P3, 18, 19). Both overt discrimination and subtle biases regarding mental health mainly occurred within the non-consumer controlled organizations. It was not a common struggle for both sets of organizations. Nonetheless, their effects were readily felt within the consumer and survivor groups.

The implication was a framing battle between disempowering organizations that voiced contempt for recovery and organizations that promoted recovery (which included both non-consumer controlled and consumer and survivor organizations). Some leaders grappled with the question of what the public would believe – a pathology-oriented discourse compared to a recovery discourse – and this battle of ideas caused some angst for participants (P1, 3, 7, 9, 10, 16, 18). Disempowering organizations received a portion of the government's allocation of funds, leaving a smaller share for recovery-oriented organizations, many of which were continually struggling for sufficient funds. One leader reported that one organization, during a provincial election, had circulated a letter highlighting several cases of violence involving people with mental health problems (P4). This letter encouraged voters to call or write their legislative representative, asking them to support involuntary psychiatric treatment. She felt this letter writing campaign was a very stigmatizing way of bringing mental health issues into the public eye. Especially galling for her was that this organization had recently secured a large funding increase from the province, while her organization had slashed funding to its peer support programs.

The leaders of the organization spearheading the letter-writing campaign were mainly mental health professionals and the parents and family members of those with mental health problems, and the organization purported to speak for people with mental health problems while upholding the principle that the family perspective remained paramount and that people with mental health problems first belonged within their family. Two participants, however, opined that family-driven organizations doubtful of recovery were not a countermovement, nor an enemy, but people with a different perspective who may share common goals with consumers and survivors (P1, 7). I agree with this perspective.

Although a legacy of stigmatization and discrimination existed, I would argue there existed more in common than opposed between the family member groups and the consumer and survivor groups (Neufeldt, 2003; U.S. Department of Health and Human Services, 1999). The avowedly anti-recovery organizations were few, and most family-oriented organizations blended into their structure consumer and survivor leadership, with varying degrees of acceptance on recovery (Mood Disorders Society of Canada, 2018; Singer, 2018). A pooling together of resources occurred between the two groups, although some participants might reject such a strategy. As one participant said, many consumers and survivors were relatives of people with mental health problems. For her, the sister of a sibling diagnosed with bipolar depression and addiction issues, she has “felt the worry, the struggle of family members” (P1, p. 9). She gained insight about her family’s confusion and frustration in reaction to her own mental health problems. Her sister’s struggle gave her a clearer self-awareness. I interpreted this participant’s response as implying that a separatist, us versus them approach to managing relations with a supposed countermovement and perceived enemy was politically counterproductive, impractical, and emotionally underdeveloped.

Lacking Acceptance of Cultural Diversity

To end the discussion of common struggles, five participants said that both non-consumer and consumer and survivor organizations struggled, and often failed, to appreciate and accept cultural diversity. They suggested that the consumer and survivor movement, analogous to the disability movement, continued to function mainly as a White Canadian enterprise, recovering for White bodies the rights and entitlements that disability had deprived them of (Bell, 2010; Galloway, 2001/2012). The moves toward corporate fundraising and greater legitimacy within institutional politics may further reinforce a middle-class White-centric movement. Modern corporations have endorsed policies favoring multiculturalism, to strengthen corporate business acumen among various ethnic communities (Shafi, 2016). The Mental Health Commission of Canada, which some participants suggested would serve as a vehicle to carry movement actors toward political legitimacy and influence, has actively endorsed cultural diversity, competency, and safety (Cultural Safety Working Group, 2011; Mental Health Commission of Canada, 2016; O'Hagan, Cyr, McKee, & Priest, 2010). However, corporate friendly mental health campaigns reinforced Whiteness through framing recovery spokespersons as white, wealthy, and respectable (Shafi). As one participant asserted, the “white middle-class agenda” in mental health is very marketable, and corporations seem intent to seize this market (P10, p. 25).

One participant, identifying as an ethnic minority immigrant, stated poignantly that he did not feel that belonged anywhere. His ethnic community did not accept him, due to ableism, and the movement did not understand him, due to his ethnicity. He could not imagine a solution for his quandary, although I had referred him, with his consent, to several of my contacts who led ethno-racial mental health organizations.

Two participants spoke about the lack of Indigenous leaders within the movement (P10, 16). These two interviewees felt this to be a major shortcoming, although tentative steps have been taken in national disability organizations to include Indigenous leaders (National Network for Mental Health, 2018). I attempted but could not secure any Indigenous participants for the current study. A non-Indigenous participant suggested that due to the complexity of issues within Indigenous communities – colonial oppression, a lack of housing, a lack of clean water – the idea of joining a disability-specific movement may not be high on peoples’ priorities (P16).

Without Indigenous perspectives on leadership in this study, and few Indigenous leaders in the movement overall, important issues would be neglected, or not given full consideration, including: the relationship between human mental health and the natural world’s wellbeing, given the understanding that we depend on non-human entities for our survival; the likely consequences of the ruling colonialist capitalist system on the mental health of both Indigenous and non-Indigenous Canadians; Indigenous leadership’s novel, creative, holistic alternatives to colonial capitalism, developed from both Indigenous legal systems and Canadian constitutional law (Borrows, 2016; Makokis, 2008; University of Victoria, 2018; Yellow bird, 2005).

Leadership Issues Specific to Consumer and Survivor Organizations

Poverty thwarted empowerment, participants said. Poverty meant material and social deprivation. Several interviewees noted that a reason why the movement has achieved only limited success was because most consumers and survivors were poor. As one participant explained, being closed off from opportunities for socialization and education, one did not “become educated on anything outside of [one’s] own exact moment and experience” (P16, p. 11). The narrowness of perspective that poverty produced negated social movement possibilities, because “you cannot have a movement from one person’s exact experience” (p. 11).

In my interpretation of these participants' views, social movements required a social imagination, and without education, dialogue, reflection, and practice, poverty killed the imagination, intellect, and spirit necessary for self and community empowerment.

One participant understood that self-actualization, which he proposed to be a leadership necessity, required living at a higher level of psychological fulfillment than mere subsistence (P7). Bass and Bass (2008) stated that leaders, compared to non-leaders, tended to self-actualize more. This participant (P7) based his claim on Maslow's needs hierarchy, notwithstanding that Maslow's concept lacked supporting evidence (Wahba & Bridwell, 1976). Other participants believed in the possibility of poor people becoming leaders, despite their adverse living conditions. One participant (P9) identified that with government funding, a welcoming, nonjudgmental organization, a robust training program, and linkages to further work opportunities, poor people who grasp these opportunities may become self-empowered, becoming potential leaders. He, with another participant (P13), suggested that these potential leaders may still struggle with other aspects correlated with poverty, such as addictions and family violence, but these barriers would not stop them. The implication of this opinion is that the poor, with sufficient supports, could self-organize into politically effective groups that would create economically sustainable work, identify society's problems and produce viable solutions, and maintain a sense of dignity and a self-made culture.

Social movements led by poor people have been less successful than middle-class oriented movements (Clemens & Minkoff, 2004; Staggenborg, 2012). The literature suggested that social movement organizations which are moderate, reform-oriented, or aimed at middle-class interests tended to dominate any given social movement's organizational network. They were given greater access to institutional polity, accompanied by greater access to resources,

whereas poor peoples' organizations tended to struggle in maintaining, and often losing, their political influence and mobilization machinery (Clemens & Minkoff, 2004; Edwards & McCarthy, 2004).

The organizations affiliated with the study's participants did not always lend themselves to be sharply divided between middle-class or poor people oriented, as many were a mix of both. And participants mentioned several middle-class oriented organizations that had run into severe difficulties or had dissolved. Those organizations composed of and led by poor people, affiliated with participants, might have had their struggles, but did not dissolve. I would conclude that the study did not corroborate the literature's claim of middle class ascendancy within a network of movement organizations, even if some participants asserted that this was the case.

Organizational structure may be interpreted as a signal to the wider movement about a group's chosen identity and ideology (Clemens & Minkoff, 2004). I found the idea and the implementation of the flat, nonhierarchical organization, two of them in the current study, to be an exciting phenomenon. Clemens and Minkoff theorized that choices of organizational form might be simultaneously vehicles for mobilization, signals of identity to opponents and possible future allies, and etiquettes for collective action. The three participants involved in these two nonhierarchical organizations did not delve into these factors in detail. One participant (P13) suggested that their organization was rooted in the culture and economics of Vancouver's downtown eastside, within what I interpreted as a radical tradition of psychiatric survivor organizing stemming from the historic Mental Patient's Association (Beckman & Davies, 2013; Chamberlin, 1978). That tradition included a commitment to participatory democracy (Beckman & Davies; Chamberlin). This participant emphasized his organization's democratic nature.

Still a Radical Flank?

The consumer and survivor movement originated in the contentious era of the 1960s, as other liberation movements such as Black Civil Rights sprang into action, and during the 1970s and 1980s the movement borrowed strategy, language, organizational forms, and street tactics from its neighbor, the disability movement (Chabasiniski, n.d./2012; Chamberlin, 2012; Oaks, 2012; Pelka, 2012). For example, radical flank actions in the disability movement in 1977 and 1980, the result of shrewd strategy and broad coalition building, had garnered great successes, forcing the government to recognize disability in national legislation and helping to change the definition of disability from tragedy to human rights in the minds of Americans and Canadians (Enns & Fricke, 2003; Schweik, 2011). These successes coincided with the rise of a prototype user-led organizational form (Enns & Fricke; Lord, 2010).

What are the radical elements doing now? None of the organizations affiliated with participants, be it a flat, nonhierarchical organization or a conventional hierarchical organization, put much effort into high pressure tactics, such as civil disobedience, to press their claims. No organization could be considered militant or extreme, and I cannot find a radical flank among them, or among any participant (save one interviewee, who unfortunately declined to provide substantive answers to any of my leadership questions) (McAdam, McCarthy, & Zald, 1996).

A Vancouver-based consumer and survivor organization, with which none of the study's participants were affiliated, seemed to contain elements of a radical flank. While the organization itself worked in a cooperative manner with the government and the local health authority, individuals belonging to the organization advocated rather radical, if not always the most realistic, agendas. These opinions and platforms were expressed within the organization's newsletter. The organization lost most of its government funding in 2013, downsized its operations the next year, and has almost ceased operations as of 2018 (West Coast Mental Health

Network, 2013). Because no one from this organization participated in the study, I could not ask them about radical flank possibilities and strategies.

Another Vancouver-based organization, consumer and survivor controlled and affiliated with two interviewees, engaged in activism premised on a radical politics, but neither civil disobedience nor public challenges to politicians had ever been part of their repertoire. The organization promoted the culture and history of Vancouver's downtown eastside and took a leading role in neighborhood festivals and cultural life. It encouraged and facilitated people living in dire poverty to self-educate, engage in cultural work, take part in democratic deliberations. This organization had endured a major funding setback at around the same time as the organization mentioned above, yet it managed to survive. There was a strong possibility that the threat and reality of government cutbacks discouraged both consumer and survivor controlled and non-controlled organizations from considering any strategy that would publicly embarrass or antagonize the government.

Consumer and Survivor Organizations: Not More Contentious than Others

The two nonhierarchical organizations encountered in the current study seemed to operate quite efficiently, according to three participants, although one participant suggested that previously organizational upheavals in one organization have occurred (P6, 9, 13). Because details on the nuts and bolts of organizational decision-making were scarce, in part due to the unavailability of documents, I am not able to comment on organizational functions beyond what participants offered. The three participants all indicated that their two organizations functioned smoothly, but I wondered if these opinions amounted to impression management.

No participants voiced any concerns about the studious avoidance of leadership, a so-called tyranny of structurelessness (Clay, 2005a; Clemens & Minkoff, 2004; Hanisch, 2001), in

organizations that they had affiliations to, which was contrary to my expectations based on the literature on radical organizations (Everett, 2000; Staggenborg, 2012). Hanisch (2001), speaking about American radical feminist organizations in the 1960s and 1970s, asserted that many women taking leadership positions had been unfairly ridiculed and slandered, as leadership was perceived by critics to be un-feminist, male-centric, and a usurpation of feminist democracy. Power was to be distributed equally, and any woman who took charge of an issue could be deemed selfish and put under ideological suspicion (Hanisch). However, it was practically impossible to equally and randomly distribute all organizational tasks amongst the membership, and a lack of communication and lack of central authority meant that the organization's work was at times ineffective and other times ground to a halt (Hanisch). Clemens and Minkoff (2004) wrote that social movement organizations beyond the feminist movement have had frustrating encounters with this phenomenon of structurelessness, and Clay (2005a) reported on specific instances of the phenomenon within consumer and survivor organizations.

Either participants would not mention existing examples of the above, as this study did not focus on organizational structure, because they were not directly asked, one possibility, or because examples did exist but only within organizations not affiliated with any participant. The third possibility would be that a tyranny of structurelessness once did exist within the consumer and survivor organizations that I studied but not currently because they have learned from past examples and improved their administrative practices. Although participants may not have formally studied the leadership struggles and lessons of past consumer and survivor organizations, several interviewees alluded to me that they have heard such leadership narratives and the caution and insights these tales offered (e.g., Beckman & Davies, 2013; Chamberlin, 1978, 2012; Clay, 2005b; Morrison, 2005; Shimrat, 1997; Silverman, 1997) (P3, 16, 18).

Dissension and polarization are customary features of social movements throughout the modern era, and I expected such features be present to some degree within consumer and survivor-controlled organizations (McAdam, McCarthy, & Zald, 1996). Within the consumer and survivor organizations affiliated with the study's participants, no one pointed to severe ideological struggles within their own organization. A participant pointed to some conflict between moderate views and an antipsychiatry view within a consumer and survivor organization that he worked with on a casual basis (P9). Within his own consumer and survivor organization, he said, no conflict of this sort existed (P9). However, at least seven participants pointed to sustained ideological conflict, dissension, and polarization within the overall movement, wherein people clustered into groups or organizations based on similar views but would not speak to those with dissenting views. Movement polarization meant that it was difficult, if not impossible, to speak to mental health professionals and to government with a unified agenda and message. Although dissension occurs in all social movements (Rucht, 2004), the perceived invisibility of the consumer and survivor movement within the established polity and its perceived inability to steer the legislative agenda in the direction of movement goals frustrated participants, some of whom felt that unity was the only answer (P3, 14).

Curiously, just as many participants mentioned major ideological and interpersonal conflicts within the non-consumer controlled organizations (P1, 3, 4, 5, 7, 10, 19). Conflicts over the politics of fundraising, the legitimacy of medical discourse, the role of medications, the nature of mental illness, and meaning of recovery were some of the issues that have shaped the development of these non-consumer organizations. It was possible that some of these groups accepted a wide ideological spectrum within its membership, leading to debates on these issues. However, the result that non-consumer controlled organizations seemed to register as much

dissension and polarization as consumer and survivor controlled organizations challenged Everett's (2000) contention that the latter organizations were, at times, functionally unsound due to a lack of ideological consensus. This finding suggests that consumer and survivor leaders may have enhanced their leadership skills and produced stronger administrative structures, so there appeared to be no leadership disparity between consumer and survivor organizations and more mainstream mental health organizations.

Identity in the Context of Belonging to Something Greater

Participants spoke about their identity, the words they used to describe themselves, and how identity was related to the movement's internal dynamics. People described themselves as consumers of psychiatry, survivors of psychiatry, both consumers and survivors, survivors of childhood abuse or trauma, or none of the above. Naming and identity signified the relationship between one's personal experience to one's political commitments. This phenomenon of naming and identity seemed equivalent to Snow's (2004) concept of framing processes. These are people's conscious strategic efforts to fashion shared understandings of society and of themselves so that it *legitimizes* and *motivates* collective action (McAdam, McCarthy, & Zald, 1996; Snow, 2004). Within the ongoing work of a social movement, framing processes become shaped by conscious, strategic decisions on the part of individuals and social movement organizations, the subject of intense contestation between rival movement leaders, and between movement leaders and existing counter movements (McAdam, McCarthy, & Zald).

Burstow (2013) argued that naming and identity within the consumer and survivor movement was a binary process, signifying either a political commitment to radical change or acquiescence to the status quo. Diamond (2013) provided a more nuanced reading of identity within the movement, seeing greater fluidity and a relational ethics. Although two participants

(P8, 15) adamantly rejected identities and political commitments espousing values opposed to their own, they were a minority opinion, as most participants expressed a fluid, circumstantial use of identity. A participant may deem themselves a consumer in one context, and a survivor in another, without feeling that they have in any way contradicted themselves (P7, 10, 18).

The upshot seemed to be that participants, as the leaders of a movement, emphasized the need to work with others despite differences. To paraphrase several participants' ideas (P2, 16), it was impossible to have the exact same life story and experience between two individuals, but it was equally impossible to build a social movement from one person's exact experience. To build a movement required collective dialogue, which was often messy, emotional, but full of learning potential. The question, for some participants, remained: How does one argue with others without wounding them? It would be hard to refute that dualism is a part of movement work: Us versus them, the oppressed versus the oppressors, trailblazing radicals versus staid moderates. Yet this could be slippery slope into turning "people into monsters," as one participant explained (P10, p. 15), a dynamic which would undermine a movement's effectiveness more than it would galvanize it, as antagonism and hatred took hold within people and between people, impeding people from learning about themselves and others. The consensus among participants suggested that leaders in the movement must bring people together, whether or not they shared identical ideological stripes.

Not Fragile

My question on the perceived fragility of consumer and survivor organizations did not produce a consensus (Everett, 2000). Some interviewees agreed with the descriptor, whereas others thought that there was insufficient evidence to make this judgment. The only consensus was that all mental health organizations were subject to major leadership crises. There was some

veiled criticism, and for one participant (P14) direct disapproval, at the antipsychiatry approach, suggesting that this wing of the movement enfeebled the movement because its anger alienated potential compatriots and allies, and its arguments lacked substance. Three participants (P2, 4, 16) commented that a rigid, fundamentalist orientation would lead to fragile organizations and a fragile movement because rigid approaches would not address the needs and opportunities offered by a fast-changing mental health field. Because organizational fragility was not only confined to consumer and survivor controlled organizations, I interpreted this to mean that Everett's (2000) notion of movement fragility was, for the groups studied herein, no longer a convincing argument. My caveat to this conclusion would be that organizations that have collapsed did not send any participants to join the study, as my sample consisted of those working in organizations that have survived.

Balance and Discernment: Leadership when Faced with Oppression

In answering the second research question, in what way do dynamics within the movement influence outcomes, many participants emphasized listening and humbleness. This was an encouraging sign. Evidence from other studies suggested that leaders who underrated themselves on their abilities but consistently pursued their leadership tasks, while remaining open to criticism, were more likely to be successful than the opposite (Atwater & Yammarino, 1997, as cited in Bass & Bass, 2008).

Entering the Political Opportunity Structure

The remainder of the leadership tasks described by participants corresponded well to the main concepts of resource mobilization theory. Cultivating powerful allies was a task referred to by thirteen participants, and this task pointed to the political opportunities and constraints confronting a social movement (McAdam, McCarthy, & Zald, 1996). Three leaders narrated

about their involvement with the Mental Health Commission of Canada. One participant spoke effusively about his close working relationship with a member of the provincial legislature (P2). Other participants worked with federal cabinet ministers and senior bureaucrats (P16).

Tarrow (1998) suggested there were five dimensions of political opportunity for a movement: the *polity's openness or closure*; *shifting political alignments*; *presence or absence of elite allies*; *divisions within the elite*; and a *lack of state repression*. It was difficult to accurately gauge these dimensions without interviewing a much larger sample, using an instrument calibrated to assess the five dimensions. The polity overall seemed quite open to the movement, as more participants than not indicated that there were many opportunities to find powerful allies (approximately 10 out of 19 participants). I am defining polity to mean the government and its supporting civil service bureaucracy, the quasi-governmental agencies (e.g., the health authorities), and the political party apparatus (the government and opposition parties, party fundraisers, political marketers). Participants tended to speak about their government and mental health system connections, but rarely about the political party machinery.

If participants would comment on shifts in political alignment, they referred to election results and a government coming to power, and, except for one participant (P16), never the subtle power struggles and gamesmanship within a governing party, an opposition party, or between several parties. However, one participant seemed adept at assessing these microprocesses of political alignment (P16). Participants commented that to some extent, all three provincial governments within the study's mandate, British Columbia, Alberta, and Manitoba, evidenced a rhetorical shift towards recognition of mental health concerns, but this talk was often not followed through in either policy initiatives or funding. Six out of the seven Vancouver leaders (eight in total if a participant living in the interior was included) indicated that

British Columbia's government showed a history of especially severe funding cutbacks directed at mental health organizations. Government discourse supportive of mental health literacy in British Columbia did not deter the province from withdrawing support to both consumer and survivor and non-consumer controlled organizations, as a neoliberal, fiscally conservative retrenchment agenda prevailed (Hladikova, 2015; Mitchell, 2004; Rowe, 2013). Nonetheless, many Vancouver participants were optimistic that political alignments, if not exactly in their favor, would shift from neutral to auspicious. Although no one commented on the province's new NDP-Green minority government, elected in 2017, this new government might serve as the reason. At the federal level, participants who opted to comment on Canada's Liberal government felt that Prime Minister Trudeau and his ministers would take mental health seriously and offer the appropriate support to the consumer and survivor movement.

If I broadened the definition of political alignment to include the workings of quasi-governmental agencies (e.g., the health authorities) and powerful institutions with powers comparable to a municipal government (e.g., the universities), participants would have a lot to say about political alignment shifts. Many participants paid close attention to power shifts within their local health authorities. For instance, I found no consensus for the seven Vancouver participants (eight if a former Vancouver resident would be included) in their views about their local health authorities (the organization encompassing their mental health system). Three participants (P4, 9, 17) were pessimistic about their mental health system's political prospects and alignments in relation to the consumer and survivor movement, whereas three participants were optimistic (P6, 12, 14). Regarding the possibility of universities aligning themselves to support the movement, two interviewees felt very positive about this prospect.

Most participants indicated that elite allies were present. One participant spoke about a university president actively advocating for mental health (P9), while another participant reported that she regularly met with federal cabinet ministers and senior federal bureaucrats (P16). It was unclear whether elite allies would champion the movement's cause in both good times and in challenging times, or if their support was only a fair-weather phenomenon, superficial and out of convenience. The federal government's determination to pass national disability legislation, including ongoing consultations with consumer and survivor groups, spoke to the possibility of a pivotal elite-movement alliance (Mcquigge, 2017, 2018). There was little consensus among participants as to the extent to which elite allies would support the movement's attempts at structural reform. Many interviewees understood that elite allies may well support mental health awareness and anti-stigma campaigns, targeting the social exclusion aspects of the social determinants of health, as such matters were already within the Mental Health Commission of Canada's agenda (Standing Senate Committee, 2006). Interviewees were much less optimistic about the willingness of elite allies to champion the materialist framework of the social determinants of health: equity in income distribution, equity in educational access, full employment, housing outside of a purely capitalist paradigm.

Some participants felt that elites may work on initiatives to improve the material conditions causal to mental health if given sufficient opportunity, or at least there was a possibility they would (P2, 7). Others felt this hope was unrealistic, given the elite allies' class interests which ran against an equitable distribution of power and wealth (P18). Some felt equivocal about the issue (P3, 16). Albee (2005) maintained that very few members of the ruling class wished to work on primary prevention regarding the material aspects of the social determinants of health, because such actions would contradict their class interests.

No participants commented on possible divisions within the elite. Possibly, this lacuna was due to the movement being only a minor player within the polity, insufficiently influential to be invited to engage in the power struggles amongst political party leaders and other elites.

No one talked about state repression. Radical activists in the movement have spoken of such matters (Burstow, 1992; Morrison, 2005). None of the current participants did, and I assumed that they deemed this issue irrelevant.

Choosing one's compatriots and allies wisely became very important when entering institutional politics, several participants pointed out. By compatriots, I meant people and groups who identified as consumers and survivors. In contrast, allies referred to those who did not identify as a consumer or survivor but were interested in helping the movement. One needed to ask, what groups would one align oneself to? How radical should one's compatriots be, or should there be a mix of radical and moderate voices? How would these alliances influence the process and the outcome of the negotiations with the government?

One participant drew on the example of Martin Luther King Junior and the nonviolent focus of Southern Christian Leadership Convention, noting that "King shrewdly did not align himself with groups that he felt could not [work] in a more peaceful way" (P3, p. 18). King expressed reservations about the principles and tactics of militant groups, such as the Black Panther Party, that these groups might misguide the movement that he was building (Martin Luther King Junior Encyclopedia, n.d.). However, if all members of a movement alliance were moderates, the option of the radical flank would be unavailable. One participant suggested that angry and radical consumers and survivors in the 1970s and 1980s wisely steered both the movement and the mental health system away from total dependence on the medical model (P6). However, two participants concluded that radicals – specifically antipsychiatry activists –

seemed to have made a negligible impact on current mental health practice and policy (P14, 15). However, others disagreed, suggesting that the impact of movement radicals was difficult to measure, but should not be underestimated (P3, 4, 7, 9, 10, 13, 16, 18).

It is difficult to make conclusions about the utility or necessity of exercising the radical flank in this movement. Clay (2005b) presciently wrote that what angry radicals demanded in 1983 seemed “hopelessly angry and radical,” but in 2003 would form the basis for the policy direction of a United States federal agency, albeit in milder, more diplomatic language (p. 257). Leadership effects cannot always be predicted. My caveat to this point remains that the components of authentic leadership theory, to which the perspectives of the study’s participants serendipitously converge on, suggest careful, balanced information processing during leadership decision making (Caza & Jackson, 2011). This would suggest that becoming radical, even confrontational, toward the polity must be done only after thorough calculation and strategic planning, to maximize its chances of success. Strategy should involve Tarrow’s (1998) five elements of political opportunity, looking at how a radical flank action would connect with the opportunities, or lack thereof, granted by these five factors. On a psychological level, radical actions need to be consistent with the notions of self-awareness, relationship transparency, and the inner moral compass mentioned by participants.

The Risks of Institutional Politics

Government initiatives, and more broadly involvement with political and business elites, may sow discord within a social movement, participants suggested (P1, 5, 16, 18, 19). Thus, involvement in the polity could be dangerous. The power struggles within government, within a political party, and the outcome of such struggles, who the eventual victors would be, were outside of what our movement can effectively influence, one leader suggested (P16). Perhaps

this was an indication of the consumer and survivor movement's relative weakness, but whatever the case, the powers that be within the government – typically, the cabinet ministers favored by the Prime Minister or the Premier – have been afforded the power to take up or discard the agenda of a social movement. Whether they consulted with the public about such decisions, or not, this participant explained, was immaterial, as the government would still make the final decision. The material consequence of the political decision was expressed in what organizations the government would fund, and which organizations that they would stop funding. When the pot of money offered became smaller, or nonexistent, participants suggested that mental health organizations may begin to distrust one another, even fight, to get at the remaining money (P16).

What participants suggested was that they were often looking over their shoulders, at what the government response might be, prior to making strategic decisions. Social movement organizations tap the pulse of the government, as any shift or slight movement by the government colossus meant reverberations and consequences in movement organizations. Just as movement organizations may exploit divisions in the polity to their advantage (Tarrow, 1998), government and elites may create divisions inside a social movement, within and between organizations, as they reinforce their hold over the institutional and cultural field. The sowing of discord might be intentional, as some participants suggested (P4, 16, 18), or unintentional, only a side effect of government agenda and policy. Participants noted that none of the current provincial governments were antagonistic toward the consumer and survivor movement, and since the changeover, the Liberal federal government has been willing to work with the movement (P2, 3, 7, 12, 15, 16, 18, 19). Yet given the consumer and survivor movement's lack of influence within the polity, I interpret that leaders try their best to strengthen their respective

organizations and the network comprising the movement but must hope for the best regarding the government's intentions and actions. One participant surmised that no matter what the government did, movement leaders and organizations must stand together in unity, because if divided, they would lose what little influence they had (P3).

Knowledge as Leadership's Foundation

The data indicated that enrolling in formal education was both a foundation for leadership skills and an opportunity for recovery. Many participants had been treated negatively in the mental health system, some had their civil rights taken away, and enrolling in post-secondary education seemed to assist them to regain self-efficacy and a measure of belonging in mainstream society. Education was an opportunity to reflect upon their experiences in the mental health system, their recovery journey, and engage with others' perspective and theories. All these things would be helpful, in my interpretation, for leading a social movement. As participants have stated, one cannot base a social movement on a purely individual experience, as a movement requires a socialization into a community wherein one's views would be supported as well as challenged. Formal education is an ideal space for this socialization, in my interpretation, and it may also provide training in critical thinking, promoting the balanced information processing identified in authentic leadership theory (Caza & Jackson, 2011). Reflection upon their recovery experiences may propel participants to become self-aware, and closer possibly to self-realization, psychological substrates of leadership that I will discuss later in this chapter.

Many participants drew upon research to inform their leadership or engaged in research themselves. The data suggested that research provided a ballast to these participants, something to anchor their practice beyond a purely subjective interpretation of their own and others'

immediate experience. Similar to enrolling in formal education, research provided a space to reflect upon how their personal experiences would relate to the theories and the empirical studies that purport to explain their experiences. For some, after being put under examination by nurses and physicians in the mental health system, psychologically held down and exposed, research became an opportunity to take some power back in relation to these health professionals, and I believed this would fortify their self-efficacy. For example, participants early in their mental illness experience felt that they had no choice but to comply with their nurses and psychiatrists, carrying their authoritative psychological assessments and directives and buttressed by their professional privilege (P6, 7, 10, 12, 14, 16, 18).

Further into their recovery journey, becoming educated on medical theory, psychopharmacology, and recovery, they spotted various options and choices that had not explained to them previously, bringing the possibility they would assert and advocate for themselves, partly the result of their post-secondary education. This ability to no longer allow mental health professionals to talk over them or allow themselves to become merely passive objects of a medical gaze, in my interpretation, transfers into self-efficacy, then self-advocacy and systemic advocacy, as well as improving one's general confidence. Becoming educated and speaking one's knowledge and wisdom corroborates with two of Hutchison et al.'s (2007) leadership components, strong individual leadership and being grounded in liberation values.

Many participants emphasized knowledge as leadership's foundation. Although my findings corroborate aspects of Hutchison and colleagues' (2007) leadership framework in the Canadian disability movement, there are also significant differences. Hutchison et al.'s leadership model emphasized identity leadership, rooted in the disability community and the oppressions that people have survived, with less of an emphasis on empirical knowledge. This

study's findings suggest the requirement that leadership be based on evidence and research, in tandem with identity leadership. It infuses the subjective, interpersonal, emotional aspects of leadership, admittedly crucial, with an analytical component. The findings focused on the lessons from social movement history, often based on the intersections between the leaders' identity, challenges of mobilizing diverse groups of followers and allies, and realpolitik calculations within the polity. In that manner, among many, if not all, of the participants, there would be a trust placed on empirical knowledge, in guiding leadership, and less reliance on identity than has been previously theorized. Speaking out, talking back to psychiatry (Morrison, 2005), and becoming the authentic voice of consumers and survivors (Hutchison et al., 2007) has been tempered with reasoned argument and self-knowledge tested by critical thinking.

Leading Organizations and Supporting Each Other

As expected, all participants took some role in leading their respective organizations. Participants rarely expressed what I expected to be the pressures, anxieties, and interpersonal conflicts that often accompany organizational leadership. If they did, it was often through a tangential reference. Thirteen participants spoke in a cerebral and analytical way about managing conflict, in response to dealing with organizational hierarchies, disorganized leadership, political differences, colleagues with difficult personalities, and receiving hate mail (P1, 2, 3, 4, 5, 7, 8, 10, 11, 15, 16, 18, 19). Perhaps this was to be expected, as the current study had the quality of appreciative inquiry, and participants would not wish to speak about interpersonal feuds. Among six interviewees, however, obvious frustration with organizational dilemmas and difficult personalities arose (P4, 5, 8, 11, 18, 19). One interviewee, in a minority opinion, devoted almost the entire interview to detailed narration about, in his perception, the vindictive nature of mental health professionals.

In forming thought leaders, participants expressed a need to learn inter-generationally. This finding was consistent with Hutchison et al. (2007)'s framework, that past leaders of vision would inform the current generation. The participants' emphasis on knowledge networks was consistent with Hutchison et al.'s discussion of relational ties and mobilizing capacity – resource mobilization in McAdam, McCarthy, & Zald's (1996) theoretical formulation. Unlike Hutchison et al., however, participants were not overly concerned about future leadership capacity, nor did they harken back to past visionaries (except for one participant).

Many participants emphasized that personal wellness was essential to a sustainable leadership career. The key to wellness was peer support with other leaders and with friends and family. One leader said that his wellness activities – outdoor activities and woodworking – were not just things to do but ensured his psychic survival. Wellness and emotional support was not emphasized in Hutchison et al. (2007), who focused instead on instrumental, task-oriented support for developing strong policy leaders. Everett (2000) hinted at the need for wellness, as she detailed grave psychological deterioration among some Ontario movement leaders. As peer support was the movement's cornerstone, it seemed evident to apply the same approach among leaders who indeed were first introduced to their role through peer support.

Faced with an Indifferent, Disempowering System: Pragmatism and Wisdom

In answering the third research question, how has leadership practice in the movement affected one's experience within the mental health system, participants acknowledged that living with mental distress and embarking on recovery constituted an authentic foundation for leaders. This was akin to Hutchison et al.'s (2007) emphasis on representing an authentic voice, to help others living in oppression to become empowered and have the confidence to speak out. Authentic voice was a political, identity-driven process:

marginalized by mainstream cultural values... they represent a critique of wider culture. The sources of oppression are seen to be the very nature of personal and familial relationships... Reevaluating personal histories and experiences is seen to be the essence of the movement toward change: the personal becomes the political. (Hills, 1998, cited in Hutchison et al.)

The participants wished to create a holistic modality to address personal pain and intergenerational trauma, via the vehicle of a social movement. They voiced criticism of the mental health system, revolving around the system's separation of the mind from the body, of the individual from society, a compartmentalized approach that alienated many consumers and survivors. Mental health problems and addictions came from intergenerational trauma, several interviewees explained, which was further enmeshed in patriarchal oppression, within a colonialist, capitalist state (P3, 10, 16, 18). The suggestion, from some, was that a social movement could address these factors underlying mental distress.

Some interviewees felt that they were staffing the frontline in addictions, in the context of a Canadian opioid epidemic (Barnsley & Smith, 2017). In Vancouver, Fentanyl use has exacerbated fatalities within an ongoing street drug epidemic (Barnsley & Smith; MacDonald, 2017). Participants said that they assisted various desperate consumers and survivors addicted to Fentanyl and other substances, who have been unable to access mental health treatment because they did not fit within such programs' behavioral criteria (P10, 18). All participants who spoke on this topic said that addictions are joined to mental health problems and individual and family trauma, and some interviewees noted that people with addictions were stigmatized and avoided even within the consumer and survivor movement. Movement leadership sought to instill an ethic of care and mutual assistance vis a vis people deemed incorrigible and unrecoverable, that

no one's life is to be thrown away, as many participants had personally lived and survived a life of addictions themselves. Thus, these leaders practiced the peer principle: that in helping others to heal, they healed within themselves, while not underestimating that the structural forces producing addictions were not within the individual, but an interface between an individual personality and a societal structure premised on patriarchy, colonialism, and neoliberalism (Clay, 2005a; hooks, 1981; Morrow, 2013).

Self-Realization: A Pragmatic Basis for Leadership

Participants spoke evocatively on their process of self-awareness, self-compassion, self-empowerment, and engaging with their vulnerability. I realized that all these things spoken pointed to an overarching concept, self-realization. Embarking on a journey of self-realization was not a new idea in leadership. As Burns (1978) explained within his transformational leadership theory, a psychologically mature leader would cultivate realization and moral uplift in followers (Bass & Bass, 2008). Maslow (Wahba & Bridwell, 1976) posited the similar concept of self-actualization, which has been readily used in leadership studies (Bass & Bass). Siebers (2008) wished to craft a theory of pain from the perspective of people with disabilities, a theory with personal and political orientation, not a biomedical one, that would have practical benefit for disabled people. Siebers emphasized a self-compassion and self-acceptance of the non-normative body, although he himself did not use these words to describe his argument. He did not, however, make any explicit link with leadership theory.

The study participants made vivid connections between surviving trauma and abuse, engaging in self-development, and leading a social movement. Most indicated that without having survived harrowing experiences, they would not have been qualified to lead the consumer and survivor movement, because it required, one person stated, “a real-life understanding” as the

font of knowledge was located within themselves (P15, p. 6). They indicated, to effectively understand and assist someone facing self-annihilation, who was suicidal, for instance, required a helper whom had faced self-annihilation themselves but embarked on a recovery journey.

To compound the difficulty, many consumers and survivors, during their most vulnerable time, when they had felt totally out of control, had to deal with what they perceived as a negative and narrow-minded mental health system. Participants who have made this journey evinced a depth of compassion and understanding, becoming a role model, with individual vision, provided that they identified, learned, and practiced psychological maturity, a process akin to Hutchison et al.'s (2007) concept of strong individual leaders. Hutchison et al., however, focused less on self-realization, but rather more on the instrumental aspects of leadership. Given the consumer and survivor movement's emphasis on a subjective life of the mind, whereas the disability movement tends to prioritize rather concrete issues, the psychological processes underlying leadership ought to be *a priori*.

One interpretation from the leadership literature is that self-realization necessitates taking responsibility for one's gifts as well as one's mistakes (Bass & Bass, 2008; Caza & Jackson, 2011; Northouse, 2013). Everett (2000) mentioned that psychiatric survivor leaders acknowledged that they had made major mistakes and squandered opportunities in the movement, leading to a sense of pessimism. The current study's participants indicated that self-compassion, even open-ended optimism and positivity, rather than pessimism, would be a stronger psychological foundation for movement activities. I must mention that this was only one perspective on leadership psychology, as other radical movement leaders dismissed the idea of psychological maturity due to its sanist connotation, preferring the idea of behavioral diversity and acceptance of extreme emotional states (Burstow, 2013; Fabris, 2012; Ingram, 2005;

Shimrat, 1997).

Taking a nonfighting approach, or fighting only selectively and judiciously, flowed from the self-realized mind. To be sure, nonfighting and self-realization, were ideals not all participants achieved or would practice consistently. However, the notion of the system being the problem as well as the solution seemed a powerful idea. On a practical level, a social movement would not have any chance of securing lasting, positive changes if it did not work inside the polity, according to resource mobilization theory (McAdam, McCarthy, & Zald, 1996). Another aspect, akin to the situation faced within the disability movement, was that most consumers and survivors tended to return in some capacity back to governmental programs and the mental health system, even if self-declaring to have favored a separatist approach (Carten, 2006).

On a philosophical level, one participant explained that oppression and liberation embodied within one's self would in turn relate to self-realization, because an accurate assessment of oneself would not only perceive strength and goodness, but some fear and negativity as well (P10). The mix of positivity and negativity within one's unconscious, this leader suggested, applied just as much to the professionals within the mental health system, whom embodied a mix of courage and fear, positivity and negativity. I interpret this to mean that whether mental health professionals were our allies, antagonists, friends, hero figures, or our bitter enemies, if we, as consumers and survivors, understood ourselves and our movement, we could understand them. Everett (2000) suggested as much, and the current participants advised that if we understood us, we could work with them, and the movement, joining forces, would be a powerful one indeed.

Recovery: Only Talk, Little Action

Participants spoke at length about their negative experiences within the mental health system. Pervasive negativity amongst the staff, disrespect toward patients, a lack of informed consent in medical decision-making – these problems, identified by Shimrat (2013) in the Vancouver system, Everett (2000) in the Ontario system, and Morrison (2005) in the United States mental health system – seemed to have continued unabated. Right now, recovery has not yet been implemented in actual policies and practices of the mental health system, participants noted. One man suggested that recovery was only a “paper” phenomenon, not an actual practice in the system (P3, p. 14). Another participant felt very frustrated that her local health authority seemed to have broken its promises about supporting recovery, exemplified in cutting funding to recovery-oriented organizations (P4). Some disagreed. Three Vancouver participants felt that the mental health system supported recovery, although irregularities remained, and predicted that peer support within and outside of the system would begin to flourish (P6, 12, 14). These participants generally felt that their own psychiatric treatment has been helpful.

Three participants suggested that the mental health system’s talk of recovery was akin to politically correct doublespeak (P3, 17, 18), despite three decades of attempted dialogue with consumers and survivors. The underlying dynamic between consumers and survivors and the professionals remained “power over people,” not “power with people” (P3, p. 8). Given that three decades have elapsed, it was a disappointing outcome. Several leaders pointed out that the mental health system assumed that patients would succumb to a life of lethargy, unemployment, malaise, low expectations, what one person called “the trap” (P10, p. 7). Movement leaders fought against this trap: the professionals’ attitude of low expectations; and the institutional mechanisms that supported it, such as overmedicated regimens, physical sequelae of neuroleptics – weight gain, metabolic syndrome, diabetes, an array of drop-in programs and clubhouses where

people idly “sit around” (P13, p. 1); and employer discrimination and psychologically unhealthy workplaces (Gatov, Rosella, Chiu, & Kurdyak, 2017; Johnson, 2017a, 2017b, 2017c; Linton, 2018). With other options seemingly inaccessible, many consumers and survivors lived their life in poverty, unemployed and melancholic (according to P13). In that sense, this situation reinforced the mental health professionals’ subtle condescension and low expectations for their patients.

Morrow (2013) indicated that recovery as a concept usually lacked an appreciation of mental distress’s root causes. In contrast, almost all participants conceived recovery as a structural intervention – including innovations such as a guaranteed annual income, socialized housing, Indigenous resurgence and land title – into a historically inequitable and discriminatory Canadian state. The implication was that movement leadership would not be satisfied with purely cosmetic, superficial interventions in mental health – the corporate campaigns to just talk nicely about mental illness comes to mind as an action that is not good enough. If we are serious in making a dent in lowering the distress and pain that Canadians experience, recovery must include an intervention into the social determinants of mental health, as well as intervening in the microsystems that cause mental distress (e.g., unhealthy workplaces) and connecting with adjacent social movements geared to changing the geopolitical structure, at a scale greater than simply health, such as the decolonization of Canada’s political and legal regime (Albee, 2005; McAdam, 2015). Not all participants would agree with this discussion, as several felt that what currently sufficed for recovery at health authorities and provincial governments was adequate. However, many more participants, even if they would not out of hand dismiss the possibility of good coming out of corporate campaigns such as Bell’s Let’s Talk, would still work for the more radical meanings that recovery entails to give recovery the greatest potency possible.

Advocating for Biomedicine?

The finding that many avowed consumer and survivor activists would advocate for biomedicine having a strong place in the future of mental health might seem surprising, even odd. I did not find another result in the academic literature wherein movement actors supported such a theme, as the literature usually posited a clear dichotomy. Most psychiatric literature, as expected, tended to support biomedical discourse (Carpenter & Buchanan, 2002; Ghaemi, 2012; Lewis, 2010). Disability studies literature, citing consumer and survivor voices, typically opposed biomedical discourse (for example, refer to Burstow, 2013; Fabris, 2013; Morrow, 2013; Shimrat, 2013). Yet the participants here suggested a bridging voice, not a binary. This was not a new phenomenon in the movement if one looked carefully. Morrison (2003), in her study of the American psychiatric consumer and survivor movement, said that she expected her interviewees to be very radical, but “some were much more conservative than I had imagined” (p. 76). She explained, “these individuals were not anti-psychiatry per se. They were resisting the imposition of definitions and constraints on their lives, even if they agreed with the definitions themselves” (p. 76). Morrison cited David Oaks, a prominent American movement leader, in his 2002 speech,

Our movement can be big enough for choice and different points of view. When one person says psychiatric drugs saved my life and helped me recover, and another person answers, psychiatric drugs poisoned me...that is not necessarily an argument. It is the sign of a strong movement. (Oaks, 2002, cited in Morrison, p. 125)

One participant asserted, setting aside her strong criticisms of the system for the moment, that “what happened to me [inside the system] needed to happen, every damn piece of it” (P10, p. 8). Others corroborated similar views, that the system did what it was designed to do, and that

consumers and survivors must be realistic in assessing their own situations prior to assigning blame (P2, 5, 6, 7). Participant Ten disagreed with the word survivor because it denoted a wounded identity, which I interpreted as a rejection of social identities based on powerlessness, an unchangeable past, a perpetual woundedness. I interpreted four interviewees' emphasis on first taking responsibility for one's own actions as a method of starting to take back power, to an internal locus of control, rather than feeling constantly besieged by powerful others (P2, 5, 6, 7). In that sense, biomedicine, unlike the survivor's formulation of it as omnipresent, implacable threat, was treated by these participants as simply another feature of modern society, neither all good nor all bad, to be used at one's own risk with a critical eye.

This was not to sweep away the detailed criticisms that many voiced about the mental health system. Everett (1997) reflected that for a self-aware, critical thinking professional, the mental health system was "nothing if not a tale of violence and tragedy" – the violence engendered when they forced patients, at their most vulnerable, into locked wards, against their will (p. 349). She explained, "in the mental health system, our endorsement of involuntary commitment and forced treatment colors all that we do" (p. 350). Everett (1997) painted a picture of commonplace ethical malaise as mental health professionals mocked their patients' harrowing stories of poverty, abuse, and discrimination, in front of the patient or amongst themselves in the staff lounge.

Yet for some participants, they, upon reflection, almost expected this kind of treatment: Mental health staffs were human beings after all, are they not, with common frailties, aggressive impulses, frustrations, ego needs (P3, 10)? Why would one assume that professionals were any different, more decent than an average human being, one leader suggested (P10)? This seemed a pragmatic, if not uncritical, perspective. At the same time, participants asserted strongly that

lacking human rights protections inside the mental hospital, lacking the service user voice in decision-making at individual and policy levels, and the system's dismissal of the social determinants of mental health, these factors were an open door for unsatisfactory outcomes, hopelessness, and professional misconduct and abuse. For at least five participants (P3, 4, 10, 16, 18), biomedicine's convention for individualistic assumptions, without thinking seriously about structural determinants and acting judiciously to intervene in these, was simply not acceptable (Morrow, 2013).

I interpret the mental health system to be a collection of frail, all too human characters, interspersed with elements of expertise, within a culture of middle-class normativity and ableism. Participants suggested that a multifaceted, nuanced perspective on the mental health system, employing self-awareness and humility, allowed oneself to step beyond a victim-centered, anger-driven leadership. Yet by itself, a cadre of self-aware, psychologically balanced, humble leaders, although a boon, would be insufficient to change the structural conditions which produce mental distress, hopelessness, self-annihilation. Changes involving alterations in the political power structure and diminishment of class privilege would be necessary, an area that mainstream allopathic medicine has showed disinterest, if not outright hostility toward, so I argue an uncritical pursuit of the medical paradigm would accomplish nothing (Kirk, 2005; Takakuwa, Rubashkin, & Herzig, 2004). To have a chance of success, participants suggested, we need to produce a cadre of gentle, self-aware, humble leaders producing future thought leaders working together to intervene in the polity, targeting the social determinants of mental health with practical arguments and well-thought out policy proposals – with biomedicine as a partner, as pragmatism might suggest, or, without it.

A Pragmatic, but Critical, View of Leadership

Most participants suggested that they did not wish to craft a movement based on a woundedness identity, on pain, even though they spoke extensively about their ordeals and traumas. They seemed to show a pragmatic orientation that the only thing that they can do would be to change the future because the past could not be altered. They drew on the past to inform their current activities and future strategies. They believed, for the most part, in recovery, self-awareness, and self-realization. These three concepts were modalities for leaders to fruitfully transmute past struggle, pain, and learning into a current consciousness and preparation for a happier, more just, and equitable future.

Siebers (2008) suggested that a minority identity, a disability identity, offered epistemic privilege, so that one may recognize the illusionary veil dominant society has draped over us, that most people accepted and conceded to (Alcoff, 2006). Siebers reasoned that this illusionary veil would not “permit the thought of contradiction necessary to question it, it sutured together opposites, smoothing over contradictions, and made unrecognizable any perspective that would offer a critique” (p. 8). Marxist theorist Gramsci called this veil hegemony (Sassoon, 1991a, 1991b). Critical theorists named the illusionary veil variously the discourse of the colonialist white supremacist capitalist patriarchy (hooks, 1981), or simply neoliberalism (Whyte, 2010). Consumers and survivors, recovering their self-awareness, living with a disability identity, may also cut through the illusion. Cutting through it prompted a reevaluation of personal histories and experiences, identifying the sources of oppression, and engaging in recovery of the self. All these activities were templates for reimagining the relation between the personal and the political, drawing upon one’s own recovery to understand, and, if possible, aid others’ recovery.

Theorizing and arguing about hegemony are difficult tasks, as Marxist theorists and revolutionaries have learned over the years, with at times disastrous results (Shandro, 2001).

The leaders interviewed took a pragmatic, but unlike some Marxists, a heart-centered approach, wherein they used their own life lessons, their strength and vulnerability, to illustrate the possibilities for personal and social liberation (for published examples, refer to Pelka, 2012). The participants were not, for the most part, theorists intent on philosophizing, nor were they coercive and heavy-handed, lambasting those who held a different ideological orientation. Generally, they were leaders who worked with rank and file consumers and survivors where they were located, physically, psychologically, ideologically, and educated each other on notions such as liberation in friendly, street wise language.

However, participants suggested that leadership based on identity alone was insufficient. A reliance on identity politics to power the movement, expressed in the studies of Everett (2000), Fabris, (2012), Ingram (2005), Morrison (2005), and the autobiographical works of O'Hagan (2014) and Shimrat (1997), was understood by most participants to lack sufficient robustness. Participants generally felt that identity work needed to be accompanied by: self-knowledge; movement knowledge; a realistic appraisal of the field; practical, step by step methods in accessing the polity; relationship building with allies; and self-care. Identity politics fashioned into an instrument for rage, for head-on attacks against perceived enemies, and the obliteration of the antagonist – the mental health system – were strategies that were generally out of favor with the leaders interviewed.

Twenty years after Everett (2000) had studied the Ontario consumer and survivor movement, movement leaders in Western Canada voiced that identity politics was not enough. Other elements must be in place for the movement to find success. Even with a robust, multifaceted repertoire for the movement, success may still be stymied. One participant, likely the most prominent movement leader of the nineteen interviewed, suggested that despite the lip

service given by provincial and federal governments to mental health reforms, the political opportunity structure remained closed to proposals for structural changes in Canadian society that would improve the social determinants of health (Albee, 2005). This was a striking comment, as this person was consulted frequently by senior civil servants and government ministers. He concluded: “We lack the political will of our leaders nationally, provincially, civically, because there is no social will, there is no massive uprising of the oppressed” (P3, p. 20).

The implication, if the conclusion by this participant is prescient, is that the sharpest, most astute leadership, at the current time, can only achieve limited gains due to the polity’s closure, perhaps in tandem with Prince’s (2009) notion of progressive incrementalism in Canadian social policy, but just as likely to result in no decisive successes, no changes resulting in alteration of the root causes of mental distress. I would assuage such a cautious conclusion, however, with McAdam, McCarthy, and Zald’s (1996) prognostication that while movements are largely born of environmental opportunities, their fate is “shaped by their own actions” (p. 15). Tarrow (1998) strongly argued that social movements produced their political opportunities, seeing the political opportunity structure as a dependent rather than independent variable, through organizational acumen and sound strategy; in a word, leadership. For instance, in June 1980, few outsiders would have predicted that a group of people with disabilities, convening at Winnipeg’s Convention Center, would over the next ten years decisively help to reshape Canadians’ views on disability from one of personal shame to a protected human right, to include disability in the Charter of Rights and Freedoms in 1982, and to recruit and negotiate with government officials, at the highest reaches of the federal cabinet, to create a national network of disability rights organizations, funded by Ottawa (Enns & Fricke, 2003; Lord, 2010).

Similarity to Authentic Leadership Theory

The study's findings corresponded to authentic leadership theory (Caza & Jackson, 2011). This was a serendipitous result. The sensitizing ideas I had been exposed to while proposing this study were distinct from authenticity leadership. Authentic leadership theory comprises of four elements: self-awareness, internalized moral perspective, balanced information processing, and relational transparency (Caza & Jackson; Kernis, 2003; Northouse, 2013). The findings corroborated three out of the four elements of authentic leadership. Self-awareness was a foundational component of self-realization, as expressed by study participants. Self-awareness included reflecting on one's core values, identity, motives, and goals, and understanding how one's personality came to be (Northouse, 2013). As per Kernis (2003), study participants strongly felt that self-awareness involved being aware of and trusting one's feelings. People tended to rate leaders with self-awareness as more authentic (Northouse).

Self-realization and journeying from victim to survivor to inner warrior, conceptual categories emerging from the data, corresponded to authentic leadership's internalized moral perspective. Authentic leadership theory proposes that individuals use their internal moral standards and values to guide their behavior rather than allow outside pressures to control them (Northouse, 2013). Participants clearly stated that their own journey of struggle and healing grounded them in a strong set of values, and these values guided and sustained their movement leadership.

The conceptual category knowledge-driven leadership corresponds to authentic leadership's balanced information processing. Participants who spoke on this stated that they understood academic training, participating in research, learning from the history of social movements, and using the results of empirical studies to be an important foundation for

leadership practice. Without knowledge, they said, leadership would go awry. Authentic leadership theory refers to balanced information processing in a similar vein, as a self-regulatory behavior wherein an individual analyzes information without undue bias and explores a full range of perspectives before deciding (Northouse, 2013).

The fourth element in authentic leadership, relational transparency, refers to being open and honest in presenting one's true self to others (Northouse, 2013). The conceptual category journeying from victim to survivor to inner warrior, and its constituent category, coming from the brink of self-annihilation, seems to partly fit authentic leadership's relational transparency, as participants spoke candidly about their struggles. Relational transparency includes showing both positive and negative aspects of themselves to others (Northouse). Participants did not consistently speak about showing both positivity and negativity in their leadership. Some participants emphasized openly communicating both positivity and negativity (P5, 7, 9, 10, 16). Others emphasized only one aspect (P4, 8, 11, 12). Many did not feel the need to do either. Thus, the relational transparency criterion was only partially supported by the data.

In addition to theory's four main elements, there are three antecedents to authentic leadership: critical life events, moral reasoning, and positive psychological capabilities (Covelli & Mason, 2017; Northouse, 2013; Robinson, 2017). Two of these three antecedents correspond to similar ideas within the conceptual framework derived from the current study (Figure 2 in Appendix). Critical life events correspond directly to the participants' striking concept of journeying from victim to survivor to inner warrior, especially the idea of coming back from the brink of self-annihilation. Moral reasoning does not correspond to only one category in the framework, but a conglomeration of categories, including self-realization, melding rather than fighting, advocacy for recovery, supporting one another, and journeying from victim to survivor

to inner warrior. Indeed, the conceptual framework is largely based on the notion of moral reasoning, sharpening the correspondence between the findings and the authentic leadership antecedent.

I do not consider the correspondence between positive psychological capabilities and the conceptual framework to be sufficiently strong to merit its inclusion. Northouse (2013) referred to these positive psychological capabilities as confidence, hope, optimism, and resilience. Although the framework's espoused leadership attitude of optimism and positivity identifies a similar psychological state, given that participants and other consumer and survivor leaders often struggle with hopelessness and have bodies and minds that are not consistently resilient, I would conclude that this antecedent only partially corresponds to the study findings (consistent with the perspectives of participants 1, 4, 7, 9, 16, 18).

The correlation of the study's conceptual categories to authentic leadership theory is an important finding. Although theorists necessitate that all four components of authentic leadership should be present to be considered an authentic leader, the current study's finding suggests an important theory to position and focus the movement's leadership practices and a focus for further movement research (Aviolo, Walumbwa, & Weber, 2009). Authentic leadership theory is a construct attracting significant interest in the leadership literature and is buttressed by an increasingly robust empirical base (Banks, McCauley, Gardner, & Guler, 2016; Peus, Wesche, Streicher, Braun, & Frey, 2012). Authentic leadership may predict team potency and team success (Rego, Vitoria, Magalhaes, Ribeiro, & e Cunha, 2013), reduce leaders' stress and increase their work engagement (Weiss, Razinskas, Backmann, & Hoegl, 2018), and promote followers' extra efforts (Peus et al., 2012). Although beyond the study's scope, future

research may wish to verify the association of these possible beneficial effects to leadership processes and outcomes in a social movement.

The Negative Side of Leadership

My presentation of the study's leadership conceptual framework thus far and its association to authentic leadership theory has focused on the positive aspects of leadership. There is an argument that leadership, in its role as a mood manager and a motivator for followers to do things that they might not otherwise do, may easily slide into manipulation (Ashkanasy & Humphrey, 2011). Leadership that is overtly political, as is the case in social movement organizations, is especially susceptible to sliding into manipulation, because of its appeals to group emotions and fighting for a larger set of values that validates one's current arduous labor and even personal sacrifice. The historical record presents us with no shortage of leadership personalities, originally working in the context of social movements before rising to power, who revealed themselves to be manipulative, dishonest, less than benign, and some malevolent and cruel, to their followers: Lenin, Hitler, Mao. Although it can be argued that these leaders were in fact not authentic, but falsely transformational, leaders, the point is that politicized leadership, with its influence over the moods of its followers and its control over organizational discourse and micro-culture, can easily slide from benign to manipulative (Ashkanasy & Humphrey).

Given that the current study is of an appreciative nature, wherein I interpret my participants' the words and behaviors as authentic representations of reality, it is possible that leadership's negative aspects are glossed over. I had suspected that leadership's controversial or negative aspects would be indicated within documents relating to organizational change and restructuring, as well as in the unofficial conversations movement leaders would have with me outside of the recorded interviews. The lack of internal organizational documents did not allow

me to explore these areas. Unofficial conversations were outside the study's terms of reference and cannot be counted as data.

In summary, the study explored leadership knowledge, attitudes, and tasks that seemed exemplary in the context of a social movement and attempted to link specific leadership approaches to movement outcomes through participants' self-reports. The study focused on what worked in leadership and how participants' experiences may be explained at a higher level of abstraction through authentic leadership theory.

Chapter Eight

Implications and Conclusion

The last chapter covers the implications of the study findings for research and practice in social movement leadership. It reviews the main findings. It discusses the study's strengths and weaknesses. The chapter ends with directions for future research and a personal reflection on the leadership problematic.

This study originated in my unease and anger as a social worker within the mental health system, where I saw health professionals practice routine discrimination against people with mental health problems. It also originated from my positive experiences in the disability movement, which at its best demonstrated to me the fruits of a strong organizational structure and a pragmatic, yet critical minded, leadership. I wanted to combine what I perceived to be a pressing need for organizing skills within an oppressed group – the psychiatric consumers and survivors – to strengths within a neighboring social movement, the disability movement, which would be their cognitive template for leadership with their demonstrated track record of success in individual and policy advocacy and the recruitment of elite allies. I am not the first person to think in this way (Chamberlin, 2012; Deegan, 1992). Indeed, it is the basis of cross-disability movement leadership, with a fifty-year pedigree (Enns & Fricke, 2003; Lord, 2010; Pelka, 2012).

As I conducted preliminary inquiries and established working relationships with potential participants, including visits to movement leaders' homes and many long conversations, I realized that the psychiatric consumer and survivor movement had formulated its own leadership models. These models were derived from experiences and knowledge inside the movement and simultaneously from the leadership knowledge of neighboring progressive movements, including civil rights, feminism, Indigenous resurgence, anti-capitalism, and disability, and from

mainstream leadership practices in healthcare and government. This eclectic blend of leadership knowledge was intriguing, although oftentimes presented in an anecdotal and highly subjective manner. Unlike what earlier treatises have suggested, that psychiatric consumers and survivors are in a uniquely isolated and oppressed location (Chamberlin, 1978; Everett, 2000), I found that movement leaders swim in a sea rich with leadership knowledge, although the variety of discourses and opinions that one becomes immersed in may confuse. I became even more motivated to document these diverse cognitive schemas and practices as I embarked on formally conducting my research interviews and grounded theory analysis, seeing what would result when an amorphous collection of leadership knowledge was subjected to systematic inquiry.

For the methodology, I chose constructivist grounded theory because I wanted a way to create knowledge that would be useful for the consumer and survivor movement. I sought the help of research participants and academics with lived experiences of mental health problems in crafting my research questions. It turned out that the participants had difficulty with coming up with an entire research question themselves, but they offered helpful hints in what I should pursue: one, the co-optation of the movement by corporate forces; and two, what happens at the intersection of the grassroots movement, composed of mainly poor people, to the top-down movement, composed of wealthy leaders with lived experience of mental health problems, backed by government ministers and philanthropists with deep pockets. With the assistance of Geoffrey Reaume, a noted Toronto-based mental health activist and academic, I crafted three research questions to reflect the need for practical application, the concerns of the grassroots, and the influence of capitalism (G. Reaume, personal communication, May 30, 2016).

Summary of the Findings

Addressing the first research question, how is leadership practiced differently (or not) within psychiatric consumer and survivor-controlled organizations compared to within non-consumer controlled organizations, I found much more in common than differing when comparing the leadership practices of these two types of organizations. Both types of organizations required competence in administrative and leadership tasks and that they be designed for accessibility for people with diverse needs. All organizations carried out essential activities such as mentoring future leaders, creating a viable peer support system, and, through the medium of recovery narratives, intervening in the public discourse. Both types of organizations must face the challenges of fundraising, organizational ethics, acceptance of cultural diversity, and the historical and current implications of ableism. For both types, interviewees indicated that a purely middle-class leadership would fall short of the movement's structural reform goals, although some participants would disagree.

Initially, I had supposed that there had been an orchestrated effort by provincial governments and their health authority subsidiaries to channel resources and legitimacy into middle-class controlled organizations at the expense of poor peoples' organizations. Participants indicated that the issue was not so neatly bifurcated, given the commonalities between consumer and survivor-controlled organizations and non-consumer controlled organizations, where both struggled to develop organizational stability, influence in the field, marketing strategies, funding, and access to the polity. Some participants held that middle-class organizations, the name-brand mental health organizations most familiar to Canadians, were granted an unfair proportion of resources and elite patronage due to class privilege, but the consensus among interviewees did not reflect this opinion.

Poverty remains a formidable barrier for the rank and file consumer and survivor aiming to step into a leadership role. Without an amelioration of poverty among the masses, grassroots leadership is unlikely. Yet poverty also created systemic injustice and widespread anger, the raw material upon which social movements are built. Lastly, consumer and survivor organizations resulted from the conceptualization of a minority social identity and are continually influenced by these ideas and their identity politics practices. While debates and disagreements over identity terminology and the politics of representation pervade over consumer and survivor organizations, participants did not indicate dissension and factionalism to be more prevalent in their organizations as compared to non-consumer controlled organizations.

Ospina et al.'s (2012) finding that vertical and horizontal leadership can functionally co-exist in successful organizations is an issue that the study was unable to adequately explore. The study was not designed to probe organizational processes and the participants whom I asked about this issue were uninterested in providing detailed explanations. The unavailability of organizational documents made it especially difficult to study the issue. The consensus among participants was that governments and health authorities made important decisions and served as the final arbiter regardless of the citizenry's views; in short, for governmental entities, democratic deliberation was minimal. Participants' responses about the coexistence of vertical and democratic deliberation in both consumer and survivor and non-consumer controlled organizations were nebulous, possibly reflecting, in my opinion, the sensitivity of this topic in regards to their own leadership.

For the second research question, in what way do dynamics within the movement influence outcomes (successes, failures, compromises), the data indicated three attitudes underlying effective movement leadership. First, leaders would need to be adaptable, balancing

between different agendas, dancing with disparate personalities and social forces, open to changing their ways as circumstances changed. Second, leaders must listen carefully to the collective, to their followers, and at appropriate times become a follower themselves (for example, Johnson, 2001). Some leaders would be doing the behind the scenes work, out of the spotlight. Among many of the leaders interviewed, humbleness prevailed. Third, a positive and optimistic attitude is integral because it is contagious (for example, Cone, 1996-1998/2012). People worked consistently to build the movement in good times and in tough times, with a view that they will succeed. As one can see, mastering these three attitudes would be a very considerable challenge.

Participants then delineated numerous leadership tasks, complex and multidimensional endeavors requiring discernment, experience, and wisdom. Among the most important tasks for a social movement leader are cultivating allies and entering the polity. To successfully recruit a broad base of allies, including elites, and to deftly enter the polity without becoming co-opted would go a long way for the movement to finally achieve some of its goals. Participants gave much thought to ally-ship approaches, and many indicated allies would be readily found. Entry into the polity was a difficult endeavor, and the data indicated that movement leadership did not wield sufficient political clout to exploit possible divisions within the ruling class, or for elites to even recognize the movement as a challenger group.

Interviewees indicated that both the knowledge generated by social movements and those gained from post-secondary education provided a foundation for leadership practice, buttressed by research and evidence. A key aspect of leadership would be training thought leaders and building a network of thought leaders. In leading organizations, some leaders built up both local groups and maintained a national presence. Steering organizational development, with its

complex functions and variegated tasks, was extremely important, inclusive of the intricacies of organizational demands, administrative competencies, and organizational outcomes. Lastly, helping other leaders across organizational boundaries and throughout the movement was necessary for leadership to be sustainable, as peer support and family support enabled the participants to persevere when the tasks seemed daunting. My hunch that peer support enables effective leadership is corroborated by participants' experiences.

The third research question, how has leadership practice in the movement affected one's experiences within the mental health system, garnered evocative responses. Participants asserted that what consumers and survivors wanted in a leader was someone who had journeyed from being a victim to a survivor to an inner warrior, as self-awareness and self-empowerment would be the basis for leadership. This journey of self-development led to an ethic of self-compassion and an approach based on melding and influencing instead of clashing and fighting. There was the sense that the mental health system was as much part of the solution as part of the problem, leading to the strategy of collaborating with mental health professionals while identifying the system's unremitting problems. Leaders advocated for recovery while some curiously made space for biomedicine, in tandem with, but outside of, the social movement. Lastly, participants felt that a pragmatic, but critical, approach to leadership was the most realistic, taking a long-term view of system reform analogous to the gradual self-development of individual consumers and survivors.

Knowledge Contributions

Calls for reinvigoration of a broad-based coalition, led by creative and innovative leadership, involving both the very poor and elite allies, have resounded in the past ten years within the psychiatric consumer and survivor movement and its neighboring challenger group,

the disability movement (Lord, 2010; Pelka, 2012; Schweik, 2011; Withers, 2012). The lack of success in the movement's structural reform goals has caused considerable frustration, even as the greater social acceptance of mental health problems achieved by grassroots groups, working together with mainstream mental health organizations and backed by elite allies, has been encouraging (Chai & Nicolas, 2017; Pietrus, 2013). The relative closure of the polity to the movement's entreaties on structural change, despite rising hopes in 2002 when Senator Kirby had chaired the nationwide testimonies that led to the creation of the Mental Health Commission of Canada, prompts what I believe as a need to study the contextual factors and the leadership performance factors underlying this impasse. This study attempted to do both: to examine current movement dynamics and the broader geopolitical context governing movement outcomes and to provide the movement's leadership cadre an empirically-derived knowledge base to stimulate dialogue and development of their practice.

The study is one of the few Canadian studies to examine leadership processes in the consumer and survivor movement. Previous leadership studies have focused on the Ontario movement, although they also paid close attention to the political context (Everett, 2000; Nelson, Lord, Ochocka, 2001; Voronka, 2015). In contrast, Storey (2011) focused on leaders' personal constructs of their experiences rather than leadership's instrumental tasks. The current study seeks to advance thinking on the relationship between instrumental practices and the thoughts and personal histories underlying leadership, within a political field characterized by indifference and *realpolitik*. Its contribution is to document and analyze movement leadership from a comparative perspective in Western Canada, in Vancouver, Calgary, and Winnipeg, hitherto not previously attempted. The study also contributes to developing a usable, empirically-derived conceptual framework for leadership practice. There is a remarkable association between the

participants' concepts of self-awareness, self-development, and an internalized ethical compass countercultural to the dominant culture's norms to three out of the four components of authentic leadership theory (Caza & Jackson, 2011). This association has promising implications for practice, education, and further research.

In Chapter One, I posed the question whether the marginal, even abject, knowledge forms expressed by people experiencing mental distress can make any contribution to theory development. The conceptual categories expressed by most participants were mainstream, characterized as structural-functional in the sociological nomenclature. Participants did not wish to jettison the system entirely. This result may be a function of sample selection, as militant and uncompromising leaders may not have felt drawn to my study. It may be a function of the radical organizations ceasing to exist, due to government cutbacks, or lacking a physical presence, existing mainly in cyberspace, so procuring participants from these groups was not straightforward.

I asked in Chapter One, is it possible for people with mental health problems to produce unique knowledge forms that destabilize and reinvent what is commonly known as sound mental health and sound leadership in bureaucratic auspices? The answer is both yes and no. The knowledge identified by participants was not unique to psychiatric consumers and survivors. Many ideas raised would be found in the techniques, wisdom, philosophy practiced by people from all walks of life, who have drawn from stories of experience. Yet these ideas challenge the assumptions and the contradictions embodied in the practices of both the mental health system and social movement organizations. I would argue that the conceptual framework raised by the participants contains politically orthodox elements – for e.g., working with the system – and radical ideas – doing whatever it takes to achieve self-realization and collective liberation,

besting an adversary *by not fighting them* – and the combination of these two elements might disorient and disarm the dominant society’s tactic of ridiculing, repressing, or co-opting challenger groups.

Recommendations

The participants indicated that peer support seems to be leadership’s foundation. Enthusiasm for peer support from nearly all the study participants suggests that a robust peer support modality be maintained as it serves as an incubator and as nourishment for movement leaders (also as a core service for all people). This includes both the more intimate, family-like relationships in peer support espoused by some as well as the office-based, formal, and programmatic peer support offered by mainstream organizations (Wulff, Bernstein, & Taylor, 2015).

Participants spoke much on self-compassion and self-empowerment. I would like to emphasize the importance of self-care. Leadership is often a stressful endeavor. As the participants indicated, self-care and critical reflection are crucial for leadership longevity. The intimate aspects of peer support mentioned above can be very helpful, as well as wellness activities outside of movement auspices (Wulff, Bernstein, & Taylor, 2015). What the movement must avoid is the interpersonal rancor and psychological deterioration that Everett (2000) had observed, which led to burnout and a sense of defeatism.

The movement’s lack of acceptance of cultural diversity, as indicated by some participants, seems quite problematic. I would recommend that movement leaders reach out to Indigenous communities, racialized communities, and recent immigrants to learn and seek guidance from them, akin to the way non-consumer mental health organizations have reached out and sought guidance from consumers and survivors. A possible goal is to increase the numbers

of Indigenous and racialized people serving as movement leaders on organizational boards and committees to something approaching fifty percent of the total.

Recruitment of a wide assortment of allies, from federal politicians to local community groups, is crucial to a movement's success (McAdam, 1996b; McAdam, McCarthy, & Zald, 1996). To work effectively, several participants suggested that one must speak a language that allies can understand, approaching the issue from their perspective (McAdam, 1996b). For example, how can your project help the government save time and money? To talk to allies, in the words of one leader, the communication "really lands for them and meets them and speaks to them personally (P10, p. 27). I would emphasize this approach means that a leader talks to allies, especially privileged allies, by first listening, talking only after one has achieved some empathy for their position. It avoids labeling allies as privileged or oppressive at the outset. It is talk that does not wound (P16). Such an approach does not make one a doormat, nor does it preclude speaking truth to power or making allies uncomfortable at times. It simply avoids the pitfalls that come when one does not listen, assuming the other person is politically retrograde and requiring correction (Harnish, 2017). Challenging assumptions and prejudices would still occur, but only after the establishment of a robust working relationship.

I would also recommend that leaders focus their policy advocacy on structural reform, targeting materialist factors in the social determinants of mental health (for example, greater equity in income distribution through a guaranteed universal income). The polity and elite allies currently seem comfortable with a politics of recognition (of mental health) but demonstrate a weakening commitment to structural reform (Prince, 2009; Raphael, 2016; Raphael & Curry-Stevens, 2016). I would reaffirm that the movement should focus on structural interventions to remediate social inequality because this approach shares similar goals with other progressive

movements – disability rights, labor, socialism, feminism, Indigenous resurgence – enabling a broad-based alliance (Staggenborg, 2012; Withers, 2012). Leadership effectiveness would be increased, in my view, by adopting the principles of authentic leadership theory, especially balanced information processing. The social determinants of health have a strong empirical foundation (Raphael). Participants suggested that policy advocacy based on research and evidence in combination with discourses of recovery, including personal stories, can be quite effective.

Lastly, I would suggest the movement explore training based on authentic leadership theory. Given the correspondence between the study's findings and authentic leadership theory, the purported benefits of authentic leadership may be a good fit with the movement's needs. Purported benefits include improved team potency and reduction in leaders' stress (Peus et al., 2012; Rego et al., 2013; Weiss et al., 2018). Any training should be adapted for the movement's characteristics and local conditions, not be imposed as a one-size fits all solution.

Assessment of the Study's Rigor

I refer to two important aspects of trustworthiness, credibility and transferability, to assess the quality and rigor of the study (Marshall & Rossman, 2011). The study has demonstrated credibility by achieving familiarity with the setting and topic (Charmaz, 2006). In the case of the Calgary-based consumer and survivor organization and its affiliated participants, I believe I have achieved intimate familiarity due to maintaining a strong working relationship with them, including phone calls, conference calls, meetings, joint authorship of a discussion paper, and home visits. For the other participants, familiarity was less involved but at least for the duration of their interviews, participants generally seemed comfortable to state their views

and claims. Initial coding brought forth numerous repeated references to robust rapport and interpersonal sharing between the interviewer and interviewees.

The volume and specificity of the data have been sufficient to merit the study's claims, given the large number of observations within the database, and I have made systematic comparisons between observations and categories, through the listed references – excerpts from transcripts – comprising each category (Charmaz). For instance, the initial coding yielded 478 individual codes. I believe that there were strong logical links between the data and my argument and analysis, provided through focused coding wherein I raised initial codes to categories as determined by the significance of the code's meaning and the number of references supporting the category (Charmaz). I performed these operations in NVivo, resulting in a list of categories, and I grouped these categories into conceptual categories based on the three research questions and the emerging meaning structure.

Also, to assess credibility, I asked all participants to review their own transcripts and correct any misinterpretations. I asked thirteen participants to comment upon my analysis of their responses and further explain a concept or technique that they had mentioned. I asked 18 participants to provide feedback, interpretations, and corrections to the conceptual framework of leadership emerging from the study.

It is difficult to assess the findings' transferability. As I have provided a description of the study's methodology, context, and activities, it would be possible for researchers and readers to determine if another practice context would be sufficiently similar for the findings to be transferable (Everett, 1997; Stringer, 2014). To truly demonstrate transferability and create a robust middle-range theory, further research would involve replication with new participants but

similar characteristics – leaders of the same social movement – and then replication studies with leaders of other social movements, of healthcare and government, and in international contexts.

Lastly, the study demonstrated considerable usefulness; that is, the study offered interpretations that social movement leaders can use in their everyday worlds (Charmaz, 2014). A primary goal of the study is to generate knowledge that helps people think critically about their practices and offer concrete suggestions for practice improvement (Kemmis & McTaggart, 1988). The study charted linkages between self-development (from victim to survivor to inner warrior) and strategies to catalyze institutional change (melding and influencing instead of head-on fighting), which may aid others in becoming self-critical learners (Kemmis & McTaggart). The similarity between the participants' conceptualization of leadership and authentic leadership theory offers an opportunity to compare theory with field data, a chance to both recalibrate theory based on field observations and improve practice based on theoretical principles. The comparison between participants' experiences and authentic leadership theory validates their experiences and authentic leadership principles have been demonstrated to contribute to leaders' wellbeing, followers' ethical behavior, and team effectiveness (Banks et al., 2016; Rego et al., 2013; Weiss et al., 2018).

Strengths and Limitations of the Study

Several factors strengthened the study. First, as an insider to the movement, I established strong working relationships with movement leaders and potential study participants. My identity as a user of psychiatry and a survivor of childhood abuse helped me to garner trust and supported my legitimacy as a researcher. In addition to conducting the study, I worked with movement leaders on various projects within their organizations. I did not establish longitudinal relationships with all interviewees, as many of them I would meet once and may never see again,

but for the few leaders and organizations whom I established long-term associations, it has provided a wider, panoramic perspective on the field.

Second, the comparative perspective between three different geographic locations provided an opportunity to examine differences and nuances in movement characteristics and political regimes. The data suggested that the Vancouver, Calgary, and Winnipeg leadership and their respective polities contained much in common, with all three cities exhibiting a neoliberal governmentality within their polities, yet regime differences and movement variations can be found. For instance, it was a viable argument to suggest that in Vancouver, cutbacks to mental health organizations have been the most severe, a result of two decades of right-wing government. Unfortunately, given the study's small size, the limited number of participants in each city, robust comparisons of leadership style and polity characteristics are not feasible.

Third, the study's applied orientation, aiming to construct a conceptual framework for leadership practice useable and applicable to movement personnel on the field, was a significant strength. Several study participants and several movement leaders not involved with the study have told me that this knowledge was sorely needed as leaders wished to ground their practice in empirical data and struggled to find blueprints for success after repeated frustrations. The unexpected association between the participants' conceptual contributions and authentic leadership theory enables future verification, testing, and development of authentic leadership theory vis a vis consumer and survivor leadership processes.

The study contained several weaknesses. One, the study was small, given the resource constraints of a doctoral dissertation. A larger study, encompassing thirty to fifty interviewees and documentary case studies – for example, on documents relating to the decision making of the polity and the intra-organizational dynamics of movement organizations – would allow a robust

comparative analysis of geographic differences in movement leadership and polity characteristics.

Two, I was not able to secure the participation of Indigenous leadership. Although the study was not designed to investigate Indigenous perspectives on leadership, the causal factors of mental distress in Canada directly relate to historical forces of settler capitalism, white supremacy, the colonization and commodification of the land and water, problems on which Indigenous leadership would be insightful and knowledgeable (Kelm, 1998; Kirmayer, 2007; Senier, 2013; Senier & Barker, 2013). Several interviewees stated that the lack of Indigenous voices in the movement was not acceptable, with the implication that Indigenous personnel should lead the movement, given that Western Canada is wholly Indigenous territory, with British Columbia mainly bereft of treaty relations and should be considered as stolen land and water (Ray, 2011). This is not to diminish the principle of nation-to-nation relationships between the settler state and Indigenous sovereignties with an option of Indigenous leaders creating social movements and mental health services within a tribal context and outside of settler interference.

Directions for Future Research

The logical follow-up to the current study would be an implementation project, applying the constructed knowledge framework to a current question or problem in the field (Stringer, 2014). This may involve a leadership workshop or a strategic planning forum, together with an evaluation of outcome. Testing authentic leadership theory in this implementation project would be helpful, particularly in outcome evaluation involving the claimed benefits of authentic leadership: team success, reduction of leaders' stress, and improving leaders' work engagement (Peus et al., 2012; Rego et al, 2013; Weiss et al., 2018).

An action research study, encompassing thirty to fifty interviews with movement leaders, a comprehensive documentary research component, and an implementation phase in the field, can extend and test the concepts constructed in the current study. Furthermore, to build a grounded theory within a field and then across substantive areas, a direction for future research may involve comparative study of movement leadership in other geopolitical locations, such as smaller cities and rural areas. It can be extended to compare with leadership processes in other social movements and ultimately in social change leadership in institutional contexts – professional associations, hospitals, and governments (Glaser & Strauss, 1967; McAdam, McCarthy, & Zald, 1996). These large projects would require multiple researchers coordinating with numerous movement leaders across language and national boundaries. Together theory generation, these large projects may compare the explanatory and predictive powers of various leadership theories, in addition to authentic leadership theory.

Conclusion

Everett (1997) concluded her study of consumer and survivor leadership by stating that the field of mental health “has effectively resisted reform for over two centuries, creating over and over again, conditions under which nothing changes and no one gets better” (p. 363). In the twenty years since Everett’s study, the mental health field has made some remarkable reforms, yet remained mired in negative, oppressive practices, as both study participants and recent published reports have indicated (Community Legal Assistance Society, 2017). I began this dissertation pointing out that the progressive segment of the social work profession wanted the mainstream system to change and wanted social work itself to change, in its underlying values and the practices flowing out of those values (Mullaly, 2009). Progressive social workers wanted to be freed from the practices and policies enfolded within the bondage of oppression and

the dominant relations of ruling, normalized as the status quo in their clinical mental health workplaces and in the broader governmental and societal systems underwriting the mental health system (Johansson, 2001; West, 2014). As a person identifying as a psychiatric consumer and a survivor of childhood abuse, I crossed the divide between the professional and the consumer and survivor, with a role as both a professional ally and one of the quieter leaders in the movement, in addition to the researcher role. Perhaps this insider-outsider social location enabled me to speak with consumers and survivors in a more relaxed manner.

The remarkable conservativeness and stubbornness of the mental health system has effectively resisted change, as Everett (1997) underlined, but consumer and survivor leaders' tenacity and perseverance in chipping away at and remodeling the mental health edifice has been equally noteworthy, voiced by the current study's participants. She wrote that her interviewed leaders had found "a healthy outlet for their anger" (p. 363). Thus, they begun a journey into social movement formation. The current study's participants acknowledged anger to be one catalyst for movement formation, but they have also stepped ahead, going beyond anger as a basis for identity politics and identity leadership. They employed self-compassion, self-realization, a tempered and balanced decision-making system, research and evidence, and a way of fighting the system without fighting it head-on, opening the possibility of a win-win for both the protagonist and antagonist. An identity leadership based on anger and separatism, if employed at all, was only a supplement to their overall leadership repertoire.

Everett, in 1997, concluded some consumer and survivor leaders stated that they were having the time of their lives because they had discovered their purpose in life. At the same time, she noted that movement leaders were fearful of their own psychic survival, of being thrown back into the mental hospital, and fearful for their social movement's fragility. Twenty

years later, some leaders I interviewed worried about their psychic survival, yes, but they held this worry in perspective, as only one factor in a larger scheme of things. The current generation of leaders interviewed quietly said that their time is *now*, not a “political identity in search of a future” (Everett, 1997, p. 357), but a current political movement building for the future, not afraid to lose, but working, *working* (!), making decisions, evaluating the results, and able to carry on.

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Appendix A

Interview Questions (First Iteration)

- Introductions

- Which organization are you affiliated with? Are you affiliated with other organizations? How long have you worked for this organization?
- How did you happen to join this organization?

- How did you happen to join the consumer and survivor movement?
- What was [the above] like?
- What did you think then?

- What was going on in your life then?
- How is life now?

- How did you get connected with the mental health system? As a patient? As a worker? Or a committee member? How would you characterize your experience?
- Has activism or leadership changed your perspective on the mental health system?

- From your perspective, how is the consumer and survivor movement faring? What are the contributing factors? Some have called the movement “fragile” – what do you think?
- Is there a difference between how work and politics are done within consumer and survivor controlled organizations and in non-consumer controlled ones? Why is this so? Have you worked in both?

- What resources do you require in your work? Do you have enough? Who or what can help?

- What is your [or your organization's] relationship with government? Is it the espoused "partnership" that the Mental Health Commission of Canada endorses?
- Given that most consumers and survivors are poor people, what effect might poverty have on how we do activism? On who becomes an activist (or "leader")?

- Tell me about your communication strategies, how you share ideas with colleagues [members, consumers] and with external agencies [the media, government, other community organizations].

- In the end, what does "leadership" mean to you? How would you describe your "practice" of it? What kinds of relationships are necessary for leadership to flourish (e.g., peer support; a higher purpose; connecting with nature; family)?

- Some have said having outside allies is essential to how a social movement will fare. What do you think? Who might these allies be? Can social work be considered an ally?

- What do you think the future holds for the movement?

- Virtual Tour: How does your group usually work? (when meeting with government, giving a presentation, etc.)
- Can you tell me about [pivotal leadership event]?

- Actual Guided Tour: Could you show me around your [office, art studio]?
- Tell me about this part.

- Is there anything you would like to add?

Appendix B: Interview Context

Participant Initials:

Where the interview took place:

Date of recording:

Time:

Interview number:

Total interview length:

Sound condition (background noise):

Other people present:

Body language and process:

Notes about the interview (key points, contradictory points):

- What is your [or your organization's] relationship with government? Is it the espoused "partnership" that the Mental Health Commission of Canada endorses?
- Given that most consumers and survivors are poor people, what effect might poverty have on how we do activism? On who becomes an activist (or "leader")?

- How do you present your ideas to win support, gain members, and gather resources?

- In the end, what does "leadership" mean to you? How would you describe your "practice" of it? What kinds of relationships are necessary for leadership to flourish (e.g., peer support; a higher purpose; connecting with nature; family)?

- Some have said having outside allies is essential to how a social movement will fare. What do you think? Who might these allies be? Can social work be considered an ally?

- What do you think the future holds for the movement?

- Virtual Tour: How does your group usually work? (when meeting with government, giving a presentation, etc.)
- Can you tell me about [pivotal leadership event]?

- Actual Guided Tour: Could you show me around your [office, art studio]?
- Tell me about this part.

- Is there anything you would like to add?

Figure 1 (adapted from Ospina et al., 2012, p. 256)

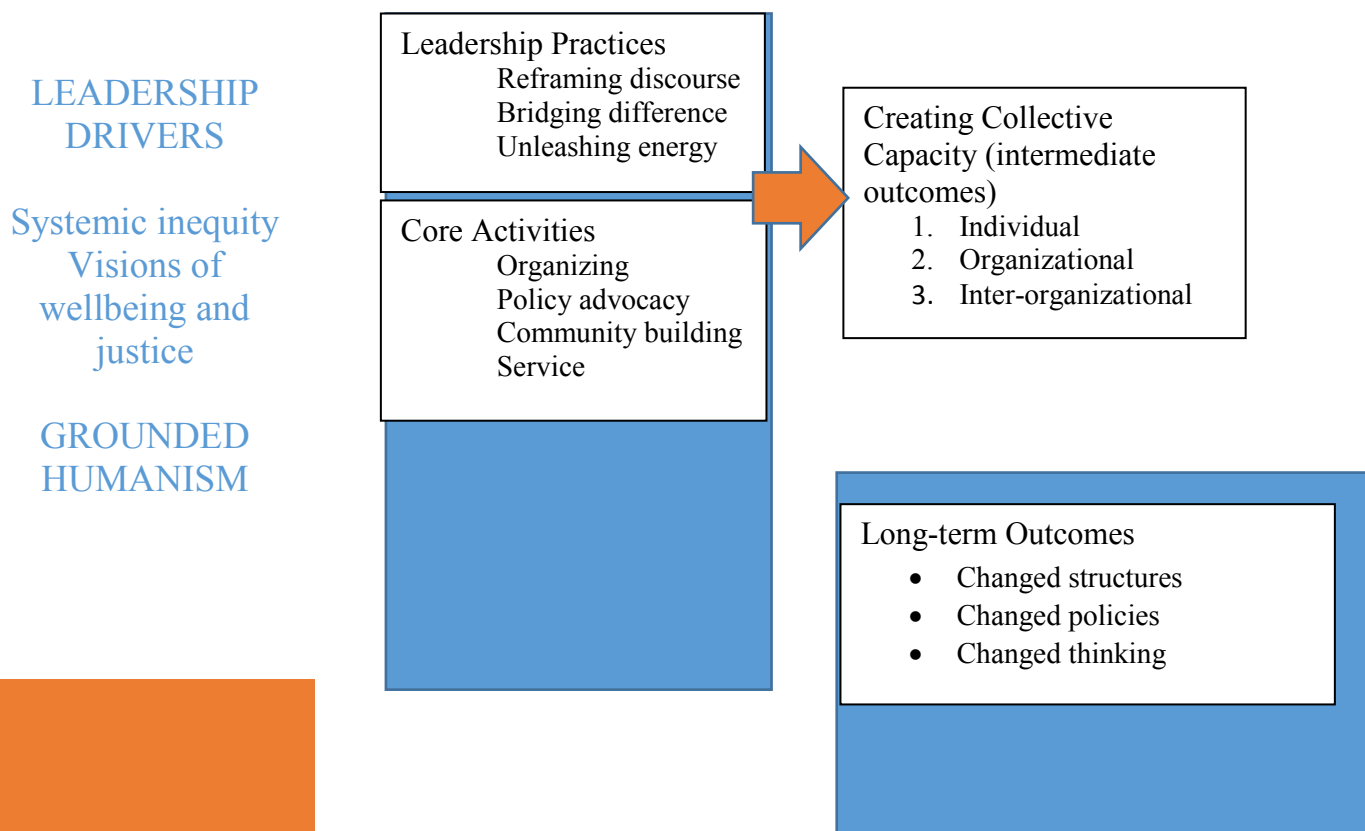


Figure 2: The Conceptual Framework of Leadership

