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A critical analysis of the factors that promote and support leadership and advocacy for people with lived experience with mental health problems or illness.

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A CRITICAL ANALYSIS OF THE FACTORS THAT PROMOTE AND SUPPORT LEADERSHIP AND ADVOCACY FOR PEOPLE WITH LIVED EXPERIENCE WITH MENTAL HEALTH PROBLEMS OR ILLNESS

(Spine title: Leadership for mental health survivors)
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By

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of the requirements for the degree of
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ABSTRACT

Our ways of thinking and acting are complex. Personal and social influences mediate who we are and what we believe. This is particularly true for people who have personal lived experience with mental health problems or illnesses. While mental illness can result in challenges with living, ironically, the challenges increase when people use medical or clinical services. Many people who speak out about their experience describe themselves as “survivors”. Yet, these same experiences with the *care* system effectively inform and evoke leadership and advocacy.

A growing number of survivors recognize that it is important to use their experience to become advocates and leaders for change. In this study, ten people who hold leadership positions that require them to operate from a standpoint of lived experience with mental health problems, engage in critical narrative inquiry to reflect about their experience of becoming leaders and advocates. The personal narratives that participants contribute to this study promote a critical analysis of their journey and the mental health system. They reveal the flaws and injustices that resulted in their silence and caused anger and alienation. They reveal the impact of discrimination. These personal narratives also demonstrate how people adopt alternate understandings about themselves and about the social system.

The study concludes that voice, inclusion and empowerment support leadership and advocacy. This research is unique. It is important in terms of recognizing the effects of personal change, self-determination and empowerment that support leadership and advocacy. We require new understandings to support self-determination and inclusion, and to support survivor leadership in a new mental health system.

Keywords: critical narrative; personal lived experience; empowerment; voice; leadership; advocacy and mental health recovery

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CHAPTER ONE: INTRODUCTION

Overview

People and systems continually adapt and transform. This study examines how ten people use their personal experience with mental illness[1] to adapt and transform. A principle contributor to the transformation of these ten participants is the concept of mental health recovery, which is described in more detail below. The ten survivors who participated in this study are all prominent leaders and advocates. Each participant holds, or has held, executive positions that represent regional, provincial or national organizations. Using critical narrative inquiry (Berman, 1998), these survivors reflect on how they become leaders for change in the mental health system. The narratives provided by participants represent the complexity of personal and system change (Clandinin & Connelly, 2000; Connelly & Clandinin, 1990; Polkinghorne, 1988).

The literature that supports this study considers multiple aspects of personal change. Evidence from the literature presented in Chapter Two describes the social, personal and relationship factors that construct and, therefore, re-construct our self-view and worldview. The literature also provides a framework to explain how we anticipate and understand our experiences. Self-concept, identity and self-awareness also support and influence the process for understanding and interpreting our self-view and worldview. Structural factors shape social relationships and personal development and reciprocally influence our self-view and worldview (Alford & Beck, 1998; Butt, 2008; Clegg, 1989; Foucault, 1980,1988; Freire, 1994; Held & Thompson, 1989; Hinchey, 2001; Kelly, 1955; Nystrand, 1977; Poggi, 2000; Smith, 1991; Stark, 1971).

The experiences and interpretations of the participants in this study are consistent with the literature and demonstrate the effect of personal, social and relational factors as instruments that limit or support change (Butt, 2008; Clegg, 1989; Durkheim, 1966; Foucault, 1980, 1988; Freire, 1994, 1999; hooks, 1994; Jones, 1986; Mezirow, 1990; Poggi, 2000; Stark, 1971). While details regarding the process of selecting and operating this critical narrative inquiry are presented in Chapter Three (Berman, 1998; Clandinin & Connelly, 2000; Cranton, 1994; Freire, 1999; Hall, 1981, 1993; Kamler, 2001; Mezirow, 1990; Polkinghorne, 1988), I will briefly explain that each participant

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[1] As you will read below, mental health recovery does not rely on diagnoses and, therefore, does not require the term “illness”. For that reason, from this point forward, I will use the phrase mental health problem. Similarly, when describing people with lived experience with mental health problems, I will use the terms person in recovery. This phrase is used deliberately to shift language and, therefore, meaning and to balance the power inherent in conventional language such as ‘patient’ or “client”. It is noted that some people in recovery prefer the term consumer and most people in this study group use the term “survivor”.

agreed to audiotape a semi-structured interview that was transcribed and reviewed. Then a Portrait, or an abbreviated version of the narrative, was co-written by the researcher and the participant. These Portraits, which can be found in their entirely in Chapter Four, demonstrate how social, personal and relationship factors affect self-view and worldview. They also explain the factors that mediate and alter these effects.

A common idea articulated in the Portraits is the negative experience of “care” within the mental health system. While the intensity of this experience varied between participants, the frequency of this idea was quite consistent. Despite the conventional system intending to provide “care”, it was certainly not received as “caring” by most participants. The negative experiences of the participants are echoed in other published accounts that add to, and verify the qualitative data contained in the Portraits (Burstow & Weitz, 1988; Capponi, 1992; Chamberlin, 1998; Deegan, 1988; 1995; Everett, 2000; Sky, 2007). Similarly, a national review of the experience of people using the mental health system reported that, “People living with mental illness say that the most devastating impact on their lives came not from the illness itself but from the way others began to treat them” (Kirby, 2006, p.6). These negative experiences angered participants and motivated them to act for change.

The literature regarding social systems and structures assumes that the constructed worldviews that shape our ways of thinking and acting are mediated, interpreted and reinterpreted by experiential forces such as social conventions, regulations and hierarchical structures and relationships that inform, influence and integrate our knowledge and access to knowledge (Clegg, 1989; Durkheim, 1966; Foucault, 1980, 1988; Jones, 1986; Poggi, 2000; Stark, 1971). Our knowledge base affects and nurtures our ways of thinking and acting. In short, what we know influences who we are. According to Kelly (1955) and Butt (2008), the personal constructs that frame how individuals understand and respond in their world and their relationships are best described as a series of hypotheses that a person lives with and tests until the understanding it evokes no longer predicts the same meaning, and new meaning is attributed.

Personal constructs not only affect the way people interpret experience; they also provide a framework of experience from which they anticipate future events (Butt, 1998). The anticipatory effects of personal constructs explain the common expectation that circumstances and relationships will continue as they are. It also explains how people fail to appreciate and respond to oppression or injustice, since these are circumstances they expect to continue (Bishop, 2002). This anticipatory effect explains the tenacity of the social factors that support personal constructs and frameworks of understanding, despite what may logically seem rational. But we know from the participants in this study that under certain circumstances, meaning can be changed and experience can be different.

The shape of personal and collective worldviews or paradigms (Mead & Copeland, 2000; Nystrand, 1977) relies on the integration of knowledge and experience that is mediated by those same social norms, structures and regulations. Worldviews are understood according to the terms of norms, structures and regulations that affect our identities and our relationships (Butt, 2008; Clegg, 1989; Foucault, 1980; Foucault, 1988; Giroux & Purpel, 1983; Green, 1983; Held & Thompson, 1989; Kelly, 1955; Lather, 1991; Poggi, 2000; Nystrand, 1977; Smith 1991; Smith 1999; Stark, 1971). Assuming that our ways of thinking and acting are constructed by factors that inform, influence, shape and integrate them into paradigms (Nystrand, 1977) invites the corresponding assumption that knowledge and understanding can change, grow and transform to new shape and depth. This complex set of assumptions regarding the nature of accruing and changing understanding of personal identity and social structure compels an acceptance of the integral effects of power, including the inherent social, structural and personal dynamics that underlie our worldviews (Clegg, 1989; Foucault, 1980; Foucault, 1988; Giroux & Purpel, 1983; Green, 1983; Held & Thompson, 1989; Lather, 1991; Poggi, 2000; Smith 1991; Smith 1999; Stark, 1971).

Social and structural factors also affect our personal constructs (Kelly, 1955) and, therefore, how we interpret and reinterpret, or attribute meaning as it relates to one self and one self in the surrounding social context (Butt, 2008; Green, 1983; Held & Thompson, 1989; Kelly, 1955; Lather, 1991; Mead & Copeland, 2000; Nystrand, 1977?; Poggi, 2000). In this research study, ten people in recovery examine their personal experience as a critical narrative (Berman, 1998; Kamler, 2001) that considers their view of themselves and their ways of thinking and acting as they have changed within the complex social structures that comprise the mental health system.

The Portraits comprising the abbreviated narratives also detail the factors that supported each participant’s wish to act for change. Chapter Five describes the key themes that operated change: a response to negative experience with the “care” system; voice; inclusion and empowerment. Getting, or being angry initiated the process of change and led to realization of voice. Speaking up and speaking out was important for participants. The experience of feeling heard was transformative. Being heard contributed to inclusion and valuation. Re-valuing one’s self and realizing worth and relevance is the essence of empowerment, or awakening to and appreciating one’s own power. Such changes instil hope. These factors of voice, inclusion and empowerment are essential components of mental health recovery, which is described in more detail below. Recovery is a perspective that informs and supports wellness, self-determination and transformation. All but one of the participants in this study identify as advocates for recovery, although for several the term is used guardedly. The one participant who prefers not to use this language has chosen not to due to its political implications.

The main point of this examination is to consider: What are the experiences of people in recovery in their journey to be leaders and advocates? The secondary questions are: How have people made meaning of their experience, and how have those interpretations shaped their personal constructs and their subsequent ways of thinking and acting? The answers to these questions includes a critical analysis of the social structures that define mental “illness” as well as the system of mental health “care”, especially as it relates to altering the ways of thinking and acting that have resulted in the acquisition of leadership and advocacy roles for people in recovery. In this process of examination, several foci are relevant and necessary to inform both process and outcome: reflection and critique regarding self-view and worldview; the dynamics and influences of the social and power based structures of exclusion; and discrimination and oppression.

Chapter Six describes the conclusions that have been drawn from these data and endorsed by participants. The first finding from the study is that any and all opportunities to liberate voice and inclusion for people in recovery must be exercised to promote and support leadership and advocacy. Second, I propose that the concept of recovery requires a new and collective understanding as a “radical redistribution of responsibility”. With a common understanding of recovery, oppressive and discriminatory experiences are minimized, if not eliminated, and voice and inclusion are welcomed. When recovery is embedded in the system, important survivor operated programs such as self-help and peer support will be properly valued and funded. Finally, support is required for learning the strategic and operational functions of leadership. There is limited education or training for people wishing to work in this distinct field and very limited funding to promote learning. Programs that support recovery, such as the PREFER program (www.cultureofrecovery.org) inherently support strategies to learn new ways of thinking and acting and support both leadership and advocacy.

The composite premises that inform this study include: a general review of the social factors that shape ways of thinking and acting; a systematic critique of the conventional *care* system in mental health; and a specific understanding of mental health recovery as a concept defined by *empowerment*. The role of *voice*, as an instrument for *inclusion*, is presented in terms of defining and shaping identity and personal construct and, therefore, realizing and supporting empowerment. Grassroots ideas regarding what can promote and nurture leadership and advocacy are offered by participants and included in Chapter Six as recommendations. In addition, the personal lived experience of the researcher underlies the construction and interpretations revealed in this study.

Ethics of Care

On the surface, caring is interpreted as a simple matter of kindness. This interpretation, however, is incomplete and recognizes only one imperfect dimension of caring. It is hard to accept that a worthwhile social action such as caring is imperfect or paradoxical. However, accepting this paradox permits critical examination of the less obvious dimensions in the complex social relations and practices related to caring. Acts of caring are not always understood in the way they are intended.

Caring is a particular series of complex, interactive social practices, undertaken and experienced within the relationship of the carer and the cared for (Noddings, 1996, 1999). Caring can be a helpful enterprise that lends support and benefits its recipient. Generally, we assume that caring is the right and kind thing to do to or for another person. However, the act of caring may be distorted. The reflexive critique of problematic inquiry (Smith, 1991, 1999) considers the social relations of caring. This process considers caring in its obvious well intended form as well as caring as its shadow. Despite what the mental health system intends to deliver, many people who use the care system report negative experiences. In order to appreciate the impact of these experiences, the notion of caring must be reconsidered.

In the particular context of this study, given the negative experiences reported by participants, it is important to consider how being a carer and delivering caring to a person who is cared for poses an imbalance in power and privilege. Each of the participants in this study, as well as people who have published accounts of their *care* experience, cite being excluded, alienated, unheard and, in some circumstances, derogated and discriminated against. They note the imbalance of power they experienced in being cared for, and the importance of shifting these interpersonal and structural dynamics (Basset & Stickley 2010; Burstow & Weitz, 1988; Chamberlin, 1998; Deegan, 1988, 1995; Kirby, 2006; Mead & Copeland, 2000; Mead et al, 2001; Pérez Álvarez & García Montes, 2007).

Within the context of relationship and culture, being a *carer* and delivering *caring* to a person who is *cared for* manifests a real or at least perceived difference in power and privilege that can impose, expose and transpose power in relationships (Blizek, 1999). Critiquing the nature of caring as problematic (Smith, 1991, 1999) does not intend that one should not care, or be unkind – it simply suggests that we appreciate that the acts of caring are not innocent. It considers the latent effects of caring. These latent effects reveal the imbalance of power that holds me in a role superior to the person I *care for* reiterating my elite clinical role, rather than inviting a person to engage his or her personal power and competence and supporting self-determination.

While this interpretation may sound contrary to people seeking medical *care* due to physical illness or injury, the underlying principle is consistent. With the exception of acute and obvious corporeal trauma, people generally are in the best position to describe and explain their experiences and contribute to, or be responsible for, solutions to their problems. In my experience, even people who are presenting with severe psychosis can inform a legitimate, if not rational, understanding of what is real to them. These experiences of feeling excluded, unheard and not respected, are well documented (Burstow & Weitz, 1988; Capponi, 1992; Chamberlin, 1998; Deegan, 1988; 1995; Everett, 2000; Kirby, 2006; Segal, et al, 1993; Sky, 2007).

In the experience of the leaders in recovery who inform this study, the dilemma of care is confirmed. Experiences revealing the shadow of care are not isolated in the study group; a national report on mental health conducted by Senators Michael Kirby found that 22% of respondents identify the services they received as more damaging than the cumulative consequences of the illness or condition with which they had been diagnosed (Kirby, 2006). These are the same negative experiences that motivated the leaders in this study to advocate for change. The experience of exclusion, discrimination and oppression revealed by the leaders in this study suggest that true caring, which can only exist within inclusive and shared power, is not the norm.

Voice and Empowerment

Empowerment is a realization of the personal power that lies within each person (Storey, 2007, 2008). Realization of personal power occurs when an existing understanding of powerlessness is re-considered and a new conclusion is reached about how the person, or their situation, is or can be different. Empowerment represents emancipation from existing understandings (Berman, 1998; hooks, 1994). This realization is captured by Freire’s description of *conscientization* - a process of raising awareness, appreciation and the energy for transformation. It is fundamental to empowerment. This understanding of empowerment absolutely contradicts the common notion and usage that one person, generally someone with expert power or privilege based on position, *empowers* another person.

While realization and conscientization may occur as a result of independent and solitary reflection, it more often occurs through participation in conversation or relationship with others (Cranton, 1994; Friere, 1994, 1999: Hall, 1993; hooks, 1994; Kelly, 1955; Mead & Copeland, 2000; Selener, 1997; Storey, 2007). Either way, empowerment is the work of the person, him or herself. The experience of the participants in this study confirms that their work for empowerment was supported by others and they also describe relationships and structures that obstructed their empowerment. In a culture that welcomes and supports empowerment, authentic caring would be defined together. Defining meaning together requires that the voice and experience of the person be heard and accepted. Voice, in this case, means communicating experience and ideas, asking questions and debating outcomes. It is about speaking up for choice and agreeing or disagreeing with a particular strategy.

In this study, the participants clearly link their realization and use of voice to empowerment; similarly, they note that voice can be supported as well as obstructed, thwarted and even negated. Voice is critical to empowerment in that it is a required function of inclusion. It is required in order to operate a process of shared dialectical engagement and the dismantling of privileged knowledge and authority through active challenge and critique of both knowledge and privilege. Inclusion and use of voice established a shift for participants in their sense of internal power and identity. This shift coincides with Fennel's (1999) examination of power within the supervisory social relations, specifically the concept of power with, which represents empowerment – a power sharing, collaborative strategy based on co-constructed meaning and operation, and trust.

Changing the terminology from cared for to caring with, to cite Fennell's usage, accepts, then adjusts the problematic of caring in an unequal relationship to propose that the other person and I care equally, or ascribe an equal caring energy or intention to the end that we are both interested and attentive to. In this case, there is a shared investment in the emancipatory or liberating outcome or change. The caring is acknowledged and open for authentic discussion, examination, and inquiry in terms of the problematic of caring. In caring with a person, he or she must be free to challenge and even decline a service, absolutely or in part. When dialogue between equals is absent, a shadow is cast on *care* and the negative experiences described by the participants in this study and the additional accounts cannot be ignored as a primary flaw in the mental health system.

Mental Health Recovery

Mental health recovery is generally accepted by survivors as a “perspective” or a worldview (Mead & Copeland, 2000) rather than a “model” for care that resembles the medical or academic system it is trying to stand apart from. The recovery perspective values choice, education, wellness and hope. The operational definition of recovery that I use was informed by current literature and research undertaken by people with lived experience (Copeland, 1997; Deegan, 1988; Mead & Copeland, 2000; Onken, et al, 2002) as well as those who studied recovery as allies, which means that these researchers identify as members of the conventional rehabilitation, clinical or academic system rather than as people in recovery (Anthony, 2000, 2004; Casey, 2008; Everett, 2000; Farkas et al, 2005; Jacobson, 2004; Ragins: www.mhavillage.org). I developed this definition as a result of my conversations with other people in recovery and primarily during recovery education workshops (Storey, 2007; Storey, 2008): “*Recovery is the hard work a person does him or herself with the kindness and compassion of the people they choose to support them – in an environment that acknowledges and believes in their potential for wellness*”.

This definition absolutely places the power and responsibility to decide about all aspects accepting or declining service and support, as well as lifestyle and relationships choices, in the hands of the person him or herself. It explains recovery as a *radical redistribution of responsibility* and, therefore, it welcomes and supports empowerment. This understanding of recovery appreciates the complex and multidimensional social and personal realities that challenge one’s mental wellness and the responsibility of oneself as the agent for change. This definition in no way attempts to instruct or prescribe the nature of treatment and support, or the behaviour of providers – other than to insinuate a message for redistribution of responsibility. It cares not for diagnosis, best practice, service targets, or clinical outcomes. While services can support recovery, they cannot “do” recovery. This definition of recovery is primarily concerned only with the work of the person.

The literature related to mental health recovery used in this study is selective. It excludes a comprehensive history of the survivor movement not because it is unimportant, but because it is peripheral to the specific research question. However, since many of the participants identify with it, some detail regarding the survivor movement was reviewed. To summarize, the “movement” was a process through which people who were angry about the treatment they received organized and publicly revealed their experience. The movement itself covers a broad spectrum of interest including opposition to specific treatments such as Electro convulsive treatment (ECT), or involuntary commitment. Finally, all of the concerns and solutions proposed by the movement(s) relate to the importance of respect, empowerment, and recognition of non-clinical services and supports as complementary and alternative to conventional "care".

For more detail regarding the North American perspective of the movement, Segal, Silverman and Temkin (1993) provide a good overview of the process as well as the significance of empowerment and inclusion. Living through mental health care and the community system to support post-care is well described by a leader of the Toronto movement: Pat Capponi (1992). For more detail regarding the provincial perspective, Everett (2000) provides a good overview of the essential points. McKinnon (2003) explains the psychiatric survivor movement in a recovery-oriented overview.

The relevance of the movement relates to the understanding that recovery is a *radical redistribution of responsibility* for those who serve and those who use services and supports. To advance this point, included in the process for triangulation, or verification of the findings from the study, the published experiences of prominent survivor leaders are included to add rigour (Denzin & Lincoln, 1994; Golafshani, 2003; Guba and Lincoln, 1985; Holt, 2003; Thurmond, 2001). Within this context, the operation of redistributing responsibility is the exercise that the participants, and other survivor leaders, have undertaken on a larger scale, in leveraging change in the system of *care*.

Situating the Researcher

The location of the researcher informs the question that drives the research - it identifies the researcher's situationality (Freire, 1999), or "location" in the research. Further, the researcher must situate his/her understanding of social reality in his/her methodology and process. Including my own experience and representing the researcher's voice comprises a practice of auto-ethnography (Holt, 2003) that informs this work. My interest in mental health systems and recovery advocacy and leadership stems from both professional and personal experiences and perspectives. Professionally, I have worked as a clinician, educator and administrator in the conventional mental health system, in progressive front-line and leadership positions, for over 30 years.

During my years of direct service and leadership experience, I not only heard the stories of people receiving care but also the comments and attitudes of enough people providing care and planning the system, to verify for me the negative understandings of many people in recovery. I take responsibility for my elite clinical behaviour and I have used my new interpretation as a ladder to climb onto another plane of understanding about the work I have done, the work that ought to have been done, and the work I want to do. In keeping with an auto-ethnographical sub-text, I declare a level of comfort with, and representation of, the specific issues and contexts surrounding the dominant, conventional care structure as well as personal lived experience as a recipient of that care, leading to a capacity to engage in discourse that is inclusive, invites voice and contemplates alternatives and options for people who may be marginalized by the current structure (Holt, 2003).

About 15 years ago, events conspired to awaken an alternate understanding about how my history, my experience in the mental health fields, and my personal construct for making meaning about that experience drove my way of thinking and acting. For many years I did not access my identity as a family member of someone living with what in those days was called a serious mental illness. One day, in my work as a community clinician, I had to drive an outpatient to hospital to be admitted. Part of this job was to call her daughter at the school where she was a teacher and inform her that I was taking her mother to hospital. The pivotal reality for me, and one that provoked considerable emotions was my memory of the being called at school to be informed that my mother had been taken to hospital. This moment was a turning point for me and for first time, my professional and personal experience was openly and obviously integrating – it shook my identity as a clinician, well bounded by my professional regulations, and it shook my understanding of caring as an empathic versus a compassionate exercise. I no longer understood empathically “as if” the experience where mine, I knew the experience personally, compassionately.

My new appreciation about my likeness to the people I cared for, my growing appreciation of the importance of equalizing these relationships and the opportunity to study more regarding the academic aspects of the ethics of care pressed me to reflect deeply regarding the social and ethical implications of care (Noddings, 1996, 1999). Reframing my understanding to include the shadow of care as an effect that is inherent in the context of my conventional clinical relationships transformed my ways of thinking and acting, not only as a service provider but also as a leader, planning and evaluating mental health service.

By considering the *shadow of care,* I heard the experiences of people differently. I understood their stories differently – more deeply and without feeling a need to interpret according to what I have come to understand is an inherent narcissism in the clinical care structure that assesses, assumes, diagnoses, and constrains. Although I had not yet found my voice in terms of disclosing and operating from a position of personal lived experience, from this first re-understanding, my work and my ‘self’ was forever altered. I also have personal experience as well with mental illness and psychiatric treatment. These were hidden experiences that I had not openly connected to my work. Needless to say, it was very important to me, in my work and role as a system leader, to remain silent about these issues and mask their effects. It was important to remain silent in order to be *like* my professional colleagues and supervisors. Finally, in the safety of relationships with "peers", with other people in recovery with whom I was developing a program to deliver peer support education, I could no longer keep secret about how it was that I did understand the depth of their experience with compassion - I shared similar experiences, both in terms of the *illness* or *symptoms* but also in terms of my experience with *caregivers.*

These shifts in my personal construct (Butt, 2008; Kelly, 1955) promoted new ways of thinking and acting; it promoted speaking up from a personal perspective. Reconstruing or developing a new understanding about the role and power-based nature of my work supported a shift from care to service and from empathy to compassion. These altered ways of thinking and acting led me to more openly critique the administrative structure and relationship at the hospital where I worked as a senior leader, as well as the larger provincial and national system. I continue to use my voice, bolstered by my access to conventional resources and structures for privilege (Held & Thompson, 1989), to work to realign the system and encourage more self-determined and peer-delivered services. My ability to recruit leaders in recovery is evidence of the positive working relationship I enjoyed within the survivor community. My shifted views also influenced my academic and research interests, involving mental health recovery, peer support and now peer leadership. In many ways, my experience parallels that of the participants who share their stories in this study.

My experience in conversation with the leaders I met in this study reminded me of the problems in the care system. My conversations with the leaders in this study reminded me of my own experience and using my voice to advocate for change. These conversations also reminded me that the real interests and opportunities embedded in self-determination continue to be appropriated in a system that, despite relating at the edges regarding recovery and self-determination, remain clinically dominated. Hearing the voices of the leaders who participated in this study convinced me that our system of mental health services and supports requires change.

Relevance to Learning and Education

Knowledge, the accumulation of knowledge, and the understanding of how we use and relate to knowledge are a complex phenomenon. There are no clear and agreed upon answers about how we accumulate knowledge or how knowledge transforms to understanding, appreciation and wisdom. I understand learning as a process of using knowledge and experience for change. Although three of the participants in the study indicate difficulties accessing and benefiting from formal education programs, I did not probe specifically regarding their experience in education. I am aware that several of the participants have completed post-secondary education and that at least two are involved in or have completed graduate programs. All participants noted a wish to learn more about leadership and management, and all expressed a wish to know more about the distinct field of leadership and advocacy from the standpoint of lived experience.

Given the fundamental understandings regarding adult education that welcome learners to build on and enhance their existing understandings (Brookfield, 1987; Freire, 1999; hooks, 1994; Kincheloe, 2007; Kolb, 1984; Knowles, 1980, 2005; MacKeracher, 2004; Malinen, 2000; Mezirow, 1990; Munoz, 1998; Rogers, 1969), these participants are willing to advance their education in general and their specific learning as it relates to their field. For the purpose of this thesis, comprehensive and historical learning theory will not be reviewed. However, considerations of the social and personal variables that affect learning are relevant. These variables include how important accessibility to knowledge or experience is to the person, as well as the significance of personal and environmental receptivity.

Reflecting on my own growth, I appreciate that I have learned most substantially from my multiple experiences and my reflection about experience. My understandings of how people, places and activities in my life, including the place in my own mind, have shaped my thinking and behaviour resonate with Dewey's understanding that "…experience is both personal and social...they are always in relation, always in social context…." Furthermore, Dewey held that one criterion of experience is continuity, namely that "experiences grow out of other experiences, and experiences lead to further experiences" (in Clandinin & Connelly, 2000, p. 2; Munoz & Munoz, 1998; Walford & Pickering, 1998). When I place priority on experience, it is reasonable that in order to truly understand and appreciate how other people have come to be who they are, including their current roles and relationships, I must attend to their own descriptions of their experiences. This explains the use of critical narrative research methodology.

Given the personal nature of the learning examined in this study, it is important to consider how our mental structures or our ways of thinking and acting comprise our experience. Kelly (Mezirow, 1990; Nystrand, 1977) characterizes people as "categorizing animals" (p. 7) who first anticipate their experiences and relevant outcomes, then evaluate, or attribute meaning from their experiences to confirm or reject the correctness of their perceptions. They confirm or reject their perceptions of outcome against anticipation and accept what they expected to understand to attribute new meaning. Kelly's process of adaptation requires retrospection, the evaluation of outcome against anticipation, and the reflective process of construing and reconstruing, to produce cognitive shift. By accepting this perspective, Kelly proposes that living is very like learning because each person brings their past to bear upon the present, to learn from accrued experience (Britton, in Nystrand, 1977, p. 43).

Interestingly, during an evaluation of peer support education (Storey, 2007) people involved in the training concluded that learning about becoming peer supporters and about recovery requires re- or un-learning the "illness identity" which they attributed to their involvement in the conventional mental health and addiction system. Un-learning occurs when one learns how to consider one's experience and the system that shapes experience from a critical perspective, including critique of the influences of power. Transforming requires being critical (Cranton, 1994; Henderson, 1994; Hinchey, 2001; McLaren & Giarelli, 1995).

For participants in this study, the first step in their shift to becoming leaders and advocates is the critical realization regarding the flaws in the system. Awakening the critical mind creates a fertile ground for considering and integrating new and challenging ideas and concepts. Acquiring and analyzing these ideas and concepts leads to new cognitive links and deeper, richer meanings. The process of critical thinking requires an examination of underlying assumptions and contexts, challenging the status quo, discarding inappropriate assumptions and exploring alternative to thinking and living (Brookfield, 1987; Giroux & Purpel, 1983; Green, 1983).

Learning, therefore, is "a process of critical investigation". Knowledge emerges from reflective consideration of our thoughts, feelings and behaviours. Underpinning this thesis is the consideration of personal, social and system change. It is about learning new ways to thinking and new ways of acting. Being different is a learning outcome and commitment. The principles of adult education include recognition of the strengths and resources that the learners brings to the process of changing, whether that be changing levels of knowledge or skill, or accrual of comfort, confidence and understanding (Brookfield, 1987; Knowles, 1987; Selman et al, 1998; Walford & Pickering, 1998). Adult education builds on existing knowledge and skill so that the learner gains new knowledge and understanding, and accrues confidence, competence and, therefore, power (Knowles, 1987; Selman et al, 1998). This study reiterates these principles in a practical context and supports future education programs and strategies that are participatory and survivor-focused.

Summary

This study uses critical narrative inquiry to examine the experience of becoming a leader or advocate for people in recovery. The evidence provided by participants in this research study presents a composite reality of a system of care that is imperfect and has resulted in experiences of faulty, and, in some cases, corrupt self-views or personal constructs. The experience of the study group includes: exclusion, alienation; injustice, discrimination and ineffectiveness. These experiences are understood as common and given the nature of the mental health system, as a power-based structure, that privileges clinical knowledge and expertise.

The rupture between systems of *care* and recipients of care is understandably difficult to avoid. Empowerment strategies that support engagement and self-determination, invite voice. They invite opportunities to speak one's mind freely, to ask, know and debate. They shift the status quo of power (Hall, 1993; Park, 1993). Participant reflections focus on awakening of their critical mind and drawing new conclusions about the care system and about themselves. They describe the factors that supported them to learn to be different (Brookfield, 1987).

According to Clegg (1989), power is a representation of "…the effectiveness of strategies for achieving for oneself a greater scope for action than others implicated by one's strategies" (p. 32). Or, power is action, outcome and benefit. It forms the centre of debate surrounding empowerment and how empowerment operates to realize change. Participants in this study have used their awareness of personal transformation as well as their experience of flaws and injustices in the mental health to awaken their voice and speak out against the structures and practices that disable participation and advocate for changes that advance inclusion, participation and self-determined recovery.

Advocating for change is an exercise of power that forms a crucible for personal change. The experience of personal change described by the participants in this study echoes my own experience. Grasping power is a risky but rewarding exercise and doing so has supported most participants in deepening their own recovery. This line of inquiry, with this population, is not well documented in the literature. We require a new understanding to support individual self-determination and inclusion and to support recovery leadership in the mental health system.

CHAPTER TWO – THEORETICAL FRAMEWORK AND LITERATURE REVIEW

Theoretical Framework

People are influenced by both external and intrinsic forces. Inarguably, our thoughts, beliefs and actions are shaped and regulated by social structures and hierarchies, yet, within the same social context, our ways of interpreting and understanding the social construct can be altered. We can change how we think and how we act – who we are. This study provides a critical analysis of the factors that promote and support leadership and advocacy for people in recovery.

Using a lens that examines and interprets the factors that support an experience of personal change, this study reveals how ten participants altered their ways of thinking and acting and articulates their shift in personal and social identify. Critical narrative inquiry supports the researcher to answer the question: What are the experiences of people in recovery in their journey to become leaders and advocates? The secondary questions are: How have people made meaning of their experience, and how have those interpretations shaped their personal constructs and their subsequent ways of thinking and acting?

The personal changes described by participants present a common etiology of anger and frustration with “care” and identify three key themes that promote and support change: voice, inclusion and empowerment. The narratives present the many points of integration between mental health recovery and leadership and advocacy. As noted in Chapter One, this thesis presents mental health recovery as a *radical redistribution of responsibility* that affects one’s response to mental health problems and the systems that provide support and service. Negotiating this redistribution requires altered ways of thinking, acting and being – personal change.

While people and systems adapt and transform, our collective thinking and behaviour about change is complex. The literature regarding social systems and structures assumes that our ways of thinking and behaving are mediated and interpreted by forces such as social hierarchies, conventions and regulations. Three theoretical areas underpin the research questions. The first area for review relates to learning, or the acquisition, integration and application of knowledge (Clegg, 1989; Foucault, 1980; Foucault, 1988; Giroux & Purpel, 1983; Green, 1983; Held & Thompson, 1989; Lather, 1991; Poggi, 2000; Smith 1991, 1999; Stark, 1971). This aspect of the literature relates closely to the interpretation of systems of meaning (Mezirow, 1990) and Personal Construct Theory (Butt, 2008; Kelly, 1955). The second area of review is the development and application of critical perspective as it relates to learning and change (Brookfield, 1987, 1987; Cranton, 1994; Foucault, 1980; Giroux & Purpel, 1983; Green, 1983; Hinchey, 2001; hooks, 1994; Lather, 1991; McLaren & Giarelli, 1995; Mezirow, 1990; 1995; Smith, 1991). Finally, literature related to strategies that support inclusion and participation (Deegan & Drake, 2006; Freire, 1999; Held & Thompson, 1989; Selener, 1997; Smith, 1991; Starratt, 2003; Tosh, Ralph & Campbell, 2000; Townsend, 1998) is reviewed.

The underlying tension in this study involves the processes for becoming and for change. This study relies on evidence from the literature that supports a dual hypothesis. First, literature defining the *socialization of knowledge* is used to establish that as social beings, we are influenced, some say constructed, based on not just events in our experience but also the nature and culture of our experience. This literature accepts that the extrinsic forces and factors in our society are integral in determining roles and relationships. Within roles and relationships (Durkheim, 1966), we construct an understanding of ourselves and our place in our world, based on a series of experiential hypotheses, from which we attribute meaning (Butt, 2008; Kelly, 1955). Further, it is important to appreciate that our behaviours are shaped and reinforced by not just material but also social rewards and consequences.

Additional literature is used that represents how our interpretation and responses to events and social structure can change when we think and act differently. The literature used in this study indicates that changing our thinking and acting is an outcome of introspection as well as personal and social critique that lead to new ways of understanding meaning, including the related role changes that involve self-determination, or agency. The literature for this study presents a point at which the extrinsic and intrinsic factors driving change intersect.

The literature that contributes to the methodology for the study supports the use of critical narrative inquiry as a means to appreciate the experience of participants. Underlying the choice to apply these theories of inquiry is an essential nature of both inclusion and the importance of fostering participants to respond from a critical perspective. The narrative data provided by the study group substantiates the claims in the literature regarding both intrinsic and extrinsic factors as responsible for their previous as well as their current ways of thinking, acting and being.

In the case of this study, people in recovery describe how they were excluded, alienated and demeaned because of the collective belief regarding their deficits and absence of personal potential. They describe the factors leading to changes in how they personally think and act – as well as changes in how they are thought of and related to. They describe the social and intrinsic factors that influenced who they were and who they became. The social factors that influence our ways of thinking and acting resist simple characterization as external social forces; their effects are insidious and can be embedded so deeply into our identity, self-view, and contribute to the development of our personal construct (Kelly, 1955) or meaning structure (Mezirow, 1981, 1990). Over time, and with multiple factors and forces, it is hard to separate the force from its effect; it is hard to notice what we respond to and what, if any, our pure responses are. The participants in this study elaborate their experience and describe these changes.

Core Assumptions for the Study

The purpose of this research is to examine, the experience of becoming a leader or advocate for people in recovery. Using narrative inquiry I examine how the experiences related to mental "illness" and mental health recovery influence advocacy and leadership for people in recovery? How does being a leader or an advocate influence a person's recovery? How does one's understanding of his or her identity influence both interest and engagement in advocacy and leadership? What are the experiences that influence how people in recovery establish meaning about the mental health system and service, leadership, and advocacy?

In order to proceed to inquire, consider and interpret the question proposed by this study regarding how people in recovery have become leaders in the mental health system, I must accurately articulate my assumptions regarding content and process. Laying this groundwork at the outset is essential for effectively presenting and arguing rationale, methodology, findings and interpretations. While I am accountable for disclosing my personal assumptions regarding this study, I believe it is fair to say that my understandings are consistent, in some cases identical, to those already articulated in literature regarding mental health recovery (Copeland 1997; Deegan, 1988; Everett, 2000; Fisher, 1994; Jacobson, 2004; Mead & Copeland, 2000; Onken, et al, 2002; Storey & Shute 2009).

1. The first core assumption of this study is that our social experiences and relationships shape and sculpt our ways of thinking and acting, and construct our identities. Specifically, for the cohort in this study, the influences of conventional clinical understandings of mental illness and social prejudice in general shaped and constricted their identity, and, therefore, their ongoing interpretations about experience. This primary assumption regarding the determining effects of social and cultural influence is not intended to be pessimistic. Rather, it is a realistic understanding and interpretation based on literature and experience. In fact, believing that people's sense of 'being', or

their identities, are shaped and sculpted must optimistically accept that change is possible. The participants in this study are proof that given certain conditions if one can be shaped, reshaping is also possible, leading to the second core assumption.

2. The second core assumption is that factors that influence or force particular ways of thinking, acting and being are not always sustained socially or intrinsically, and new influencing forces replace them. New influences may be welcomed under circumstances where the person invites alternate explanations and learns new understandings. New cultures and new influences may be accepted and tolerated in situations where one must learn to be different or understand differently to serve a goal. In others instances, one becomes different, thinks and acts differently, when he or she reattributes experience and produces alternate meaning. Personal agency, empowerment and self-determination are the pillars that lend resolution to the act of thinking, acting and being different.

3. Being different involves understanding where and how one's self-view, or identity is influenced by our worldview. Establishing a new way of understanding oneself involves actively changing our understanding, or interpretations of, and relationships with the social structures and hierarchies that intersect our lives. Therefore, the third core assumption for this study involves the function of challenging or questioning the veracity of what we have come to know as a requirement to reconsidering another way to think, to act and to be. This assumption necessitates an understanding that being different requires a new way of knowing and learning and a new way of interacting and relating. To be different requires a transparent awareness and reflection regarding how and why we have become who we are, and with whom we are. It requires a critical understanding of our experiences - the forces that constrain or liberate our self-view, both the inherent personal beliefs as well as the underlying societal factors that influence our self-view as well as the self and world-views of the people, relationships and structures within which we exist.

The following sections articulate these three assumptions more clearly, including an analysis of the tensions between the social and the personal instruments for being and changing. Scholarly evidence from the literature is presented that supports these points as they relate to this study. In this specific study, the participants are people in recovery. They have been diagnosed and received *care* for "mental illness". They have also experienced a transition in their ways of thinking, acting and being. They have become leaders and advocates motivated to assure that others do not re-experience the social and institutional factors and forces that negatively shaped their being or identity. Literature to specifically address this population and this particular set of experiences is limited to conventional peer-reviewed (in this case peers are academic peers) and scholarly articles, so most of the references have been interpreted to support the basic arguments of this thesis. There is, however, growing interest in “survivor research” (Rapp, et al. 1993).

Review of the Literature: Process and Selection for Reviewing the Literature

As noted above, there are intersecting fields in the literature that inform and contribute to this study. Layers of knowledge and theory frame the human processes of learning, interpreting knowledge and experience, and transforming ways of being. The first field of literature is the role of socialization as it relates to learning. Specifically, this literature considers the acquisition, integration and application of knowledge (Clegg, 1989; Foucault, 1980; Foucault, 1988; Giddens, 1984; Giroux & Purpel, 1983; Green, 1983; Held & Thompson, 1989; Lather, 1991; Poggi, 2000; Smith 1991; Smith 1999; Stark, 1971). The selections for examples within this literature included use of material that was recommended in the Policy and Leadership and Ethics of Care studies in the Joint PhD program as well as selected in consultation with my academic supervisor, who has expertise in this area.

The literature related to the socialization of knowledge is closely related to the interpretation of systems of meaning (Mezirow, 1990) and Personal Construct Theory (Butt, 2008; Kelly, 1955). Learning, in this case include ones interpretation or reinterpretation of knowledge or experience. To support my position regarding the socialization of knowledge, I chose to include literature that considers the development and application of critical perspective as it relates to learning and change (Brookfield, 1987a, 1987b; Cranton, 1994; Foucault, 1980; Giroux & Purpel, 1983; Green, 1983; Hinchey, 2001; hooks, 1994; Lather, 1991; McLaren & Giarelli, 1995; Mezirow, 1990; 1995; Smith, 1991). Selections for examples from this field of the literature were also informed from the Policy and Leadership studies in the Joint PhD program as well as recommendations from academic advisors for this thesis. Some additional material relating to the specific links between experience and interpretation (Munoz & Munoz, 1998; Walford & Pickering, 1998; Walker, 2006) were retrieved using search questions related to experiential learning using data bases at the Faculty of Education library as the University of Western Ontario.

The literature that guided the design of the study and the development of methods and operation of the study were purposefully selected to accommodate the interactive nature of the work. The literature related to qualitative methods and critical narrative inquiry (Berman 1998; Denzin, 1989; Denzin & Lincoln, 1994; Glaser & Strauss, 1973; Golafshani, 2003; Guba & Lincoln, 1985;

Hamilton, 1994; Holt, 2003; Kamler, 2001; Kirby & McKenna, 1989; Lincoln & Guba, 1985; Maguire, 1987; Miles & Huberman, 1984; Mitchell & Radford, 1996; Oakley, 2000; O' Reilly-Fleming, 1993; Schram, 2003; Spradely, 1980).Storey, 2007; Thurmond, 2001) was selected from processes I had used in previous research, recommendations by colleagues, professors and advisors. In particular, I appreciate the guidance provided by Dr. Bonnie Burstow regarding the process I developed for data analysis. In addition computer searches were used within the Education Resources Information Centre (ERIC) data bases at the Faculty of Education library as the University of Western Ontario.

Literature that considers mental health recovery and its values was retrieved using the following data bases: PsychINFO; CINAHL; Psychology & Behavioural Sciences Collection and PsychARTICLES database. The key words for searching were: mental health recovery; empowerment; voice and leadership. Many of these searches produced articles that profiled the primacy of service providers and competencies to practice recovery, which included how to "empower" and how to manage symptoms. They also included consideration of aspect of "care" such as medication, seclusion and restraint. In some cases, the resources addressed issues of supported housing and employment. This search reiterated the observations of participants regarding the over and in some cases misuse of the term recovery. Where the search produced resources that took into account a consumer-survivor perspective of recovery, and did not represent a "testimonial" story describing an illness process, the resource was reviewed.

Given my working relationships with survivors and consumer operated programs, frequently the literature I found most relevant was provided by people with whom I was discussing this work, including some of the participants. Many of these pieces included recovery narratives (Basset & Stickley, 2010; Burstow & Weitz, 1988; Capponi, 1992; Chamberlin, 1998; Deegan, 1988; 1995; Everett, 2000; Sky, 2007; Wandrei, 2003). If this presents a particular bias, I propose it is the bias that represents the participants who hope to change the existing knowledge base.

Similarly, literature related to strategies that support inclusion and participation (Deegan & Drake, 2006; Freire, 1999; Hall, 1981, 19992, 1993; Held & Thompson, 1989; hooks, 1994; Selener, 1997; Smith, 1991; Starratt, 2003; Tosh, Ralph & Campbell, 2000; Townsend, 1998) was retrieved using the search tools listed above as well as using resources utilized in previous graduate studies. Recommendations by academic advisors also played a key role in reviewing and selecting foundational literature related to the process of the study. While all of these resources informed the study, not all are referenced.

Structures and Socialization of Knowledge: Extrinsic Forces Binding Personal Meaning

As much as we may glorify choice and personal responsibility, the experience of participants suggests that it is hard won. Social rules, roles and norms insidiously and perpetually affect our experiences and how we interpret them. Agency, or working as one's own agent in navigating and negotiating the socialized landscape represents a transformative function in realizing free will. According to Wandrei (2003), agency defines a person as "a proactive meaning-maker and hypothesis tester who contributes to his or her own life course" (p. 289). When we choose, or learn agency, it must be negotiated against a framework, or network of intersecting and integrating social relationships, hierarchies and related authorities that organize ways of thinking, acting and being. Based on our interactions and experiences with and within our social network, we develop a worldview, a personal construct (Kelly, 1955), or a meaning structure (Mezirow, 1981; 1990) from which we predict, anticipate and attribute meaning, and into which we fit our identity. Through experience, and specifically by reflecting and reconsidering our experience, including problems and dilemmas we encounter, we learn new ways of thinking, acting and being. Based on our reflective reconsideration, we alter our self and worldview, personal construct or meaning structure – we are different, transformed.

One interpretation regarding the far reaching impact of the socialization of knowledge insists that our society's belief that we are free thinking and rational people is false (Foucault, 1975, 1980, 1988; Giroux & Purpel, 1983; Stark, 1971). Foucault's analysis, in particular, pessimistically concludes that obvious social forces, such as social hierarchies dominate and control knowledge. In addition, more covert factors, such as his concept of *surveillance* proposes that people are essentially programed to behave in ways that preserve the dominant ideology of normal social function, relations and language, and directly produce and regulate ways of thinking, acting and being.

Less extreme views conclude that our personal and collective impressions and understandings derive from, and are controlled by the intended and unintended 'teachings' we encounter and experience that are presented and sanctioned by both social and cultural apparatus (Cranton, 1994; Foucault, 1988; Smith, 1991; Townsend, 1998). Social and institutional structures and hierarchies are linked as both antecedents and sequelae of interpersonal as well as grand scale system relationships, including our sense of control and access to resources. Social rules, expectations and norms are forces that incubate, influence and shape self and world views, in response to individual and group interests and other artefacts in society (Clegg, 1989; Foucault, 1980, 1988; Held & Thompson, 1989; Lather, 1991; Nystrand, 1977; Poggi, 2000; Smith 1991, 1999; Stark, 1971).

Societal norms and associated social forces establish, transmit, monitor and uphold the social norms and values that guide and sanction the collective roles and behaviours acted out by people - our individual and group ways of thinking and acting (Durkheim, 1964; Jones, 1989; Poggi, 2000). Durkheim proposes that these norms or rules are required to preserve the *normal* function of society. Collective norms, roles and role contingencies develop and maintain the relationships, structures and institutions that govern and support social operation (Poggi, 2000; Stark, 1971) and represent the collective meaning or explanation of human and material relationships produced and transmitted by what Durkheim names a distinctive, authoritative and collective social entity that shapes and sanctions the acquisition of ways of thinking and acting expected from its members (Poggi, 2000; p 59 and 60). Societal forces comprise the cognitive and relational relevance for being, knowing and interacting in society.

From a more moderate perspective, social structures have the pervasive capacity to be instructive and generative in terms of social function but by this definition, their impact also holds reductive, destructive and oppressive sway. As noted above, it is apparent that sometimes we “learn” to accept beliefs and behaviours perpetuate discrimination and marginalization. The common understandings of mental “illness” would be an example of this phenomenon. However, Durkheim (1964) proposed that although society is the sum of its norms and it exists in so far as people comply with norms, there is also a personal capacity for “self-transcendence” if one is socialized to do so (Poggi, 2000, p. 91). Having noted the potential for self-transcendence, Durkheim also lamented that our society and its institutions are reluctant to establish and empower the arrangements required to support self-transcendence (Poggi, 2000, p. 92). Rather than liberating and supporting transcendence, our societies more accurately perpetuate the collective understandings that support the norms and agreements determined by the dominant discourse, which are articulated by the dominant groups in society – primarily those with agency, voice, or access to both. In this instance, it is important to ask: what is the *normal social function* that, according to Durkheim, must be upheld.

Presumed supremacy in ideation, knowledge and the normalization of social function, assumes a power embedded in a society that assigns arrogant priority to its own interests and satisfaction. Interests in this case represent the personal focus and desire expressed and understood collectively by its people that support and maintain ‘established’ understandings and interpretations and satisfaction as the degree to which those interests are achieved. As an example of what Durkheim refers to as “social facts” (Jones, 1989 p. 60) or the elements that define social phenomena and our ways of thinking based on the exercise of control, is the Christian idea about creation.

A prevailing religious belief that humans were created at the same time as all the animals, during a seven day period, was information that was accepted by Christians as true in part due to the absence of scientific evidence to the contrary, but also due to the instruction of dominant authorities. Now, despite scientific evidence to the contrary, these beliefs are still held as true by some, also due to the prevailing support and instruction by those same authorities. Similar patterns of collective belief that are contrary to logic or science have occurred when dominant social powers benefit from a particular view or outcome: for instance, slavery was perpetuated by the capital interests of plantation owners and people using the cheaply produced material sold by slave-owners based on a collective belief that people of colour were not fully human or entitled to human rights. Again, despite scientific evidence to the contrary, people of colour remain racialized today. Interestingly, the longevity of these core concepts, despite evidence and logic, proves the strengths of the arguments proposed regarding the socialization and social structure of knowledge.

Integral to this particular understanding and interpretation of knowledge, and, therefore, being, is the effect of social, structural and relational power, specifically an appreciation of the power to exclude, marginalize and discriminate against. Psychiatric structures of discipline and *surveillance*, as explained by Foucault (1980), factor greatly in how people in recovery experience and mitigate their history. It affects how they interpret, reinterpret, negotiate and adjust prior unjust relationships to ones of inclusion and shared responsibility. Power is at the centre of debate surrounding operational structures and must be understood in order to propose change.

An obvious example of ideological supremacy is patriarchy, the interpersonal and institutional restrictions on activity, opportunity and liberty, based on gender that was, and still is in many ways, a socially accepted form of truth established, upheld and sustained by historically dominant male discourses. Considering this more deeply, in North American society, we may be self-congratulatory about feminism and gender equality. However, when viewed through commercial, familial and interpersonal lenses, there are still many collective but obscured understandings about women that sexualize and constrain activity, opportunity and liberty – we have simply tricked ourselves into deciding that women make choices with their own free will, which, as proposed, is systematically erroneous. For instance, many are increasingly opposed to what we presume is the restrictive and depersonalizing burhka, yet we have not thought deeply about the more overt sexualizing of breast implants. I propose that these apparently diverse *social facts* are really identical definitive interpretations of women's role in a given society. Socialized gender discrimination, obvious or obscured, is a parallel experience of socialized discrimination described by the participants in this study, specifically the insidious and unjust clinical interpretations and treatments described by participants that marginalized, limited and demeaned their self-view, experience, and potential.

To the point of this study, as social functions, clinical relationships must also be determined by norms understood by all parties about role, function and responsibilities. Durkheim's understanding of the role commitment, or more precisely, role contingency, posits that the role of one group is mirrored and supported by its relation to that of its partner (Poggi, 2000 p. 92). In this case, being "cared for" by a controlled system of relationships by definition requires agreement regarding the understanding of the person`s disorder or deficit. The narratives in this study are clear. Understandings that require disorder and deficit depersonalize and stigmatize people. The role of the person with 'mental illness' is defined in relation to the clinician caring for him or her, and in order for one to change substantially, both must change.

Changing roles and norms is not only difficult, it is resisted. Durkheim asserted that "the conduct of individuals is necessarily and materially oriented by norms and sets of expectations which society sets upon those individuals and sanctions" (Poggi, 2000, p. 58). Furthermore, society exercises its authority to impart to individuals not just the rules of conduct for their actions but more significantly, the cognitive understandings related to how we perceive or understand our conduct (Poggi, 2000, p. 87) and how we understand the consequences of being outside the rules and norms. Durkheim conceptualizes society as "the set of minded patterns affecting the interactions of human individuals. Society exists for Durkheim, in so far as those interactions are controlled by mental, [cognitive] images, rather than by laws of matter or instincts" (Poggi, 2000, p. 87).

The process of socialization, therefore, is based on both the minded patterns, exemplified by roles and norms. Consequences and sanctions for non-compliance with rules and performance of norms, privilege how we collectively perceive and accept the circumstances and roles that mediate how we think and act in society. These understandings of adherence, performance and consequence may trump our cognitive, physical or instinctual realities.

Intersecting Extrinsic Forces and Intrinsic Factors as a Means for Change

To accept that we are socialized beings that think and act in ways we are socialized to believe are correct, and that we are rewarded for conforming and discouraged from non-compliance, is to accept that relevant knowledge is generated, transmitted and sustained by a hegemonic system of discourse and ideology. External social and structural forces set the stage for identity and being. This socialized system of knowing operates with the apparent agreement of its subordinates, namely all of us, under the guise of our collective and interpretive mind, or consciousness (Poggi, 2000; Smith 1991,1999; Stark, 1971). This understanding is concerned with the origin and perpetuation of ideas, rather than the truth or validity of ideas (Stark, 1971, p. 152; Giroux & Purpel, 1983). By its definition, this composite understanding also opens opportunities to expose social and cultural factors that discriminate, invalidate and oppress, which nurture the intersecting intrinsic factors for the person, and support them to compete against the extrinsic factors. Similarly, to accept that norms are contingent, assumes that ideology, operated through norms and roles can be changed; that both collective and self-transcendence is possible.

How can ideology be understood, exposed and corrected? If there is no pure being that is uninfluenced by his or her environment and relationship, then ideas are also never pure (Stark, 1971). Ideas must be apprehended against the context of the environment that mirrors them – the norms and roles that operate them. Ideas must also be apprehended within their context of social hierarchy and supporting bulwark of governance and regulation. Leveraging context, ideas are transitive. Ideas comprise essential, developmental constituents of theory and knowledge. The participants in this study agree that at one time in their lives, they were bound by a set of roles and norms that defined their experience as disordered, untrustworthy, excluded and subordinate; these experiences were justified and sustained within the ideas that comprise the conventions of the medical/clinical system of care. *Caring* is a component of power; there is a passive role of *cared for* insinuating a less capable being and a *carer* who can *take care* of one less capable or fortunate. As the participants of the study reveal, care is not always accepted as it was intended. Care is also not always delivered as we hoped it had been intended. Yet, each of these people leveraged the context of their experience with *care* by questioning its validity and relevance. They considered alternate understandings regarding their experiences and constructed a new way of being.

Similarly, theories of empowerment and liberation, as posed by Freire (1994, 1999) and hooks (1994), propose corrective strategies about engagement and participation which produce new ideas about power, empowerment and self-determination. More recent analysis regarding empowerment and agency (Berman 1998; Storey, 2007; Wandrei, 2003) verify the compelling importance of participation as a function of acquiring the critical perspective that supports introspection and personal change. In addition, Giddens' (1984) concept of agency requires not just intention to be different but also capability of being different, including access to resources that promote and support change which further substantiates the importance of participation and elaboration of alternate ways of thinking and acting. Giddens' (as cited in Held & Thompson, 1989; Clegg, 1989) *structuration theory*, proposes a matrix of duality, comprising longitudinal and durable rules and resources that constitute, guide and reproduce agency in the power relations of intellectual, practical, ideological and moral relationships and practices (Clegg, 1989; Green, 1983).

Agency, in Giddens' theory of structuration of power, is defined by an intentional or unintentional outcome, conceived in the transformation of power, as exercised through the medium of resources (Clegg, 1989; Giddens, 1984). Giddens' model of reproducible, but durable transformations of power, endorses Kelly's concept of personal construct and suggests that identity is recursive; it is reproduced through successive situated social practices and outcomes, by which it is organized, articulated and defined. For the participates in this study, their self-view, identity or construct, therefore, is a product of, and is reproduced by, the social rules that ascribe and define power and privilege, within clinical relationships; in some cases, the outcomes produced, or reproduced, match the intention through which they were enacted but in some cases they do not. The social versus personal construction tension is mitigated using personal construct theory, which acknowledges social forces and influences, yet also assumes that individuals actively use these events and experiences to construct and reconstruct frameworks of understanding from which they anticipate, predict and respond. (Kelly, 1955; Poggi, 2000)

If we agree that societies create, understand and transfer knowledge, presupposing that this reflects the determination based on the voice, experience and resources of the dominant group, we have one ideological perspective about who we are and what we think based on what we are told we are and what to think. Taking this one step further, we 'know' or more likely understand what we can be, what our potential is understood to be. As noted above, ideas, roles and norms are valuated with, and confirm social meaning. In order to expose the sociological underpinnings of ideas and knowledge, critical reflection and deconstruction at all levels are required in order to attend to the root of theory and, therefore, potentiate change. Participants endorse the effects of critique as altering their responses to injustice and liberating their voice. They also describe the personal realization of power and effectiveness that characterizes empowerment. They became different. They established new roles and they worked for new knowledge and norms.

The literature as presented suggests that social forces or constructs inform and sustain how societies establish, understand and transfer knowledge, and how societies implement rules and allocate resources. If we agree that knowledge, rules and resources reflect the voice and experience of the dominant or most influential group (Clegg, 1989; Foucault, 1980; Foucault, 1988; Giroux & Purpel, 1983; Held and Thompson, 1989; Lather, 1991; Nystrand, 1977; Poggi, 2000; Smith 1991; Smith 1999; Stark, 1971), we can also agree that who we are, what we think and how we behave is based on who society teaches us to be. It is clear that our socialized interpretation of mental illness governs the ways we think about and act toward people "with mental illness" but it is also clear from this study that these same forces have governed how people think about themselves, if they believe they are "mentally ill" – it affects their self-view and how it integrates with their worldview.

Our Systems for Attributing Meaning to Our Experiences

There are many factors that affect how we as human beings attribute meaning to our experiences. Attributing meaning is the process by which we understand who we are and how we fit into our worlds. According to Kelly (1955), Personal Construct Theory articulates a framework of sequential development, based on experience and interpretations about experience that explains and makes meaning of events and supports people to anticipate meaning. Personal constructs comprise the way in which individuals understand, respond and use their experiences in their world and their relationships (Kelly, 1955). One's personal construct is not a rigid or hierarchical system of development. Rather, it is a series of hypotheses that a person tests, or lives with until the understanding it evokes no longer predicts the same meaning, and new meaning is attributed. Personal Construct Theory was established by George Kelly (1955) as a result of his clinical observations as a humanist therapist (Butt, 2008). Kelly theorizes that personal constructs are cognitive templates of understanding that individuals develop in order to predict or explain their experiences (Kelly, 1955). Kelly's position is based on his understanding that "[a]ll thinking is based, in part, on prior conviction" (Kelly, 1955, p.6). He describes convictions as complex and relational patterns of belief and behaviour that become correctly or erroneously validated and embedded in cognition when they are attributed to match subsequent events or behaviours (Kelly, 1955). Personal constructs, therefore, function as filters that anticipate and interpret experience and attribute meaning (Butt, 2008).

Kelly suggests that we develop our personal constructs by either collecting “new nuggets of truth” (Butt, 2008, p.20), known as “accumulative fragmentalism” or by revising or replacing our interpretations of truth, which Kelly calls “constructive alternatives” (Kelly, 1955, p. 15). In the first explanation, what is, simply is; in the second explanation, we have an opportunity to change our minds. Kelly accepts that constructs are both personal and social, reckoning that there is social and cultural influence in our interpretations and our templates for understanding our own behaviour, and the effects of the behaviour of others. Similarly, Mezirow (1981; 1990) recognizes that people strive to make meaning of their experiences. Mezirow’s theory requires development of a critical perspective (1981) from which a person reflects and reconsiders one’s experience against what is already understood and where it is not consistent, new meaning is attributed. This is seen as a process of learning new ways of thinking because these new interpretations affect beliefs and values and activate personal transformation.

In the case of this study, personal constructs, or meaning structures are the templates of understanding that shape a person’s interpretation and understanding of their own experience as a mental illness or a mental health problem, and its relation to assuming a passive or leadership role. It also shapes how that person will engage with others holding similar or varying constructs. Social constructs, including prejudice, disease and defect, or optimism effect one’s initial construal of meaning as well as the subsequent revision or replacing of attributed meaning. In my personal case, I can attest that I held a personal construct that understood that people with “mental illness” were disordered and required care and treatment by experts; with a reattributed understanding, and adopting a construct that understands recovery, I saw my own mental health issues as a cognitive and emotional variance or a response to social forces rather than a disorder. I recognized a personal expertise and responsibility for my wellness, and, therefore, felt safe to disclose an experience that I had previously interpreted as an indication of inability or even unworthiness.

Kelly’s theory, embedded as it is in his clinical work as a therapist and emerging at a time of relative cultural homogeneity in the United States, does not articulate as strongly on the social and cultural aspects of individual construct development and revision as it does on the process for individuals. When I interpret Kelly’s theory in relation to stronger social and cultural influences, as he might do himself today, in a different time, we can consider how the sociology and structure of knowledge guides and explicates how people seek and make meaning. We can build on personal construct theory and how people make sense of, and attribute meaning for their experiences in the context of their world, and their worldview. A theorist from a similar time, Carl Rogers (1961, 1980) recognized the role of introspection and reconsideration of inherent beliefs about one's self and one's experiences, yet he too might appreciate his suggestions about the role of an independent self differently now if he were to deconstruct the oppressive experiences people describe regarding their mental health *care*.

The writings of Piaget, Kelly and Kuhn (in Nystrand, 1977) converge with respect to their premise that people adapt to their environment according to personal constructs and social factors. All of these theories describe how people construct, organize, engage, shape, attribute and shift the meaning of their experiences and the events that surround them. The underpinning assumption is that people adapt and change. People can change their personal and collective understandings, or paradigms, and these changes alter the internal conditions that operate their thinking and behaviour, such as their personal constructs.

Kelly (in Nystrand, 1977) uses the word paradigm to characterize the instrument of socially constructed but generally ineluctable unit of meaning that encapsulates and governs our personal as well as our collective thinking. In his therapeutic work, Kelly draws on the humanists Rogers and Jung (Butt, 2008) so his interpretation of a paradigm as an instrument that defines and drives our personal and collective behaviour is characteristic of his personal construct. The relevance to this proposal is that a paradigm is chosen, upheld and sustained by the "assent of the relevant community" (Nystrand, 1977, p. 28), which is generally the dominant voice in society, or as Smith (1991, 1999) proposes: the ruling apparatus. Therefore, the link between dominant social pressure and personal and collective thinking is revealed. Essentially, we decide what we believe based on our understanding, including our predictions for, and explanations of what our social experiences indicate we ought to believe.

While people differ from each other in the way they interpret or attribute experience, it is common for people to construct meaning by making what Kelly calls an "elaborative choice" from which they can safely anticipate future events (Butt, 1998). This meaning of "choice" is useful in understanding the effects of oppression or injustice, as described by the participants in this study. Most describe a period of understanding themselves and their environment in a longitudinal, submerged (Kelly, 1955) way that attributes their situation as outside of their control, or that events are occurring due to their fault – while it is hard to conceptualize this as a choice per se, it was clearly a way of understanding their world at a point in time, and may have been a convenient understanding in the absence of internal and external supports for change.

Submergence is a way of construing meaning that prevents the construct from being put to the test and being validated (Walker, 2002). In the case of this study, participants initially submerge what might seem a rational or typical way of anticipating and relating to their world, to be safe from realizing the oppressive or unjust experiences. In most narratives, participants acknowledge that for extended times, they accepted and believed the messages about their disorder, their disability and their limitations. In their later experience of leadership, the reluctance of participants to identify as leaders may provide a safe view from which to engage in system change fully anticipating the real consequences of the oppression and injustice they have realized in the past. Is the risk for these leaders a matter of presenting themselves in a way that is so unlike their understanding of themselves and so aligned with the dominant oppressor, or is it a construct of humility, bred from a history of personal uncertainty?

Merriam (1993) and Malinen (2000) have analysed the theories of Mezirow as well as Kolb. The chief difference between Kolb (in Merriam, 1993) and both Mezirow and Kelly is his focus on the transformative effects resulting from reconstrual of meaning subsequent to problem-solving, or I would add: encountering and negotiating a dilemma. These theories cohere around the point that we reconsider the meaning of experience when our existing meaning for that experience does not align with our current understanding. As such, we become aware of the problem, or dilemma associated with this new meaning and by operating reflexive introspection, and, perhaps, experimenting with new meaning through dialogue with others, promotes a new understanding. We learn a new way of knowing and doing, and our personal construct is fundamentally changed.

Personal Construct Theory, in particular (Kelly, 1955) elaborates the idea of socialized knowledge and the impact of social forces and influences by explaining the impact that these influences have on how people understand who they are, in terms of identity and not only what they ought to do in terms of roles and norms but also what they can do in terms of restricted or emancipated opportunities. Kelly certainly supports an ideology of choice rather than a perception of control, as we find with Foucault.

In keeping with the premise of agency as fundamental to assuming a critical perspective and empowerment, Kelly asserts that while people do not always take responsibility for their choices, people always have a choice of options along a continuum, punctuated by opposing poles. Having said this, the narratives in this study will demonstrate that while this understanding may be true in theory, its operation can be suppressed or deferred. For instance, when a person is informed by an *authority* that she is not capable of education, her construct predicts that this must be true. Over time, as long as this meaning is interpreted from the socialized force, it is true; the person's ways of thinking and acting confirm and perpetuate their understanding, because it does not happen. In this case, it seems wrong to suggest that the person is not choosing responsibly; however, when circumstances shift, and social structures and process are understood alternatively, that constructed hypothesis can fail. At this point, new meaning is assigned and new ways of relating occur. People have learned to choose, to overcome control.

Participatory Processes

People can awaken to change in isolation, however if I accept the social nature of knowledge construction and integration, and personal construct theory including transformation and re-construal of understandings or constructs (Butt, 2008; Clandinin & Connelly, 2000; Cranton, 1994; Freire, 1999; Hall, 1981, 1992, 1993; Kelly, 1955; Mezirow, 1990; Selener, 1998; Vio Grossi, 1981) then I must lean toward strategies for transformation that are interpersonal, reflective and participatory. In fact, the narratives of the participants of this study support the operative effect of voice as a transformative element, which obviates the interactive, dialectical conditions that support change.

Participation is a dialectical process that includes interaction and reflection. It values common, popular or indigenous knowledge as fundamental to understanding and assigning meaning to experience (Hall, 1981; Hall, 1975; Selener, 1998; Schram, 2003). Reflective participation creates a space and opportunity to be sceptical; to openly consider not only current practice and belief but also to consider and propose alternative practices and beliefs. Interpersonal reflection is realized or tangible in conversation, dialogue, and debate, and it also changes experience and meaning. An obvious requirement for this dialectic is earnest and respectful 'hearing' of the experienced voice. By this I mean hearing the message of the people with whom you wish to learn about an experience. The participants in this study confirm the role of voice. They cite the experience of being heard, authentically and safely, as a transformative factor in their personal change. Voice was a prerequisite to inclusion.

People who have experienced "mental illness" and mental health care have been required to *trust* without question the processes and authorities that decide about and deliver service to them;

they are the *cared for*. Trust in this case may not involve believing the experience is true but as I heard from survivors, it may well mean behaving as though it is true. Exploring the structures that disable participation and identifying the structures that advance participation expose the underbelly of traditional power structures and frameworks. Toppling faith, as a factor in obedience, challenges hegemony and establishes a transformative base for organizations to realize the knowledge capacity within it.

Giddens' articulation of structuration (Held &Thompson, 1989) explains that without regular and consistent access to the power structure and the resources inherent in this system, people are also prevented from shaping the values which define services they receive, informing their delivery and application, and effectively negotiating and realizing their effect. Without full access to meaningful inclusion and contribution, people who are 'cared for' report low acceptance and satisfaction with care (Kirby, 2006).

According to Tosh (2000) and Valentine (1989), advocates want more inclusion in decision-making forums such as Boards of Directors, committees and work groups. One way to address this claim is to prescribe representation by people who used services. This prescribed allocation of representatives which Vroom and Jago (1988) defined as "legislated participation" is indirect; its effect has not upset or altered conventional power structures. This strategy is also known as "tokenism" (Bishop, 2002). The demeaning and frustrating effects of 'tokenism' are reiterated by participants in this study. They described discrepancies in power and influence, lack of perceived credibility, decision-making structures that do not easily invite and engage critique and challenge, and their experience confirms the limited support by the conventional system to prepare their leadership and business skills (Valentine, 1989, Brydon-Miller, 1982), further undermining their comfort or confidence in the role.

An important premise for this study is to understand the process and effects of participation; it pairs with assuming a critical perspective in dialogue – effecting change. Using a framework of critique presented by Foucault (1980) and supported by Giroux and Purpel (1983), which asserts the importance of apprehending fully the systems of constraint and control, as well as by asking critical questions, and especially by listening to the answers, an initial understanding of how participation in the mental health system can be formed. Collaborative questioning and challenging processes that are not only free of reprisal, but more particularly welcomed and embraced form a deeper approach to participation.

The perspective of mental health recovery values participation and specifically participation in relationships as a tool for critique of power, oppression and discrimination toward a hopeful end of wellness, empowerment and personal responsibility (Copeland 1997; Deegan, 1988; Mead & Copeland, 2000; Onken, et al, 2002; Storey & Shute 2009; Storey, 2007; Storey et al, 2008; Storey & Shute 2009). Recovery-supporting thinking and activities require meaningful and generative engagement and participation, which Freire (1999) has described as conscientization, or a process of raising awareness, appreciation and the energy for transformation with liberating effects. The generation of knowledge using a participatory process represents a new truth.

Critical Realization as it Relates to Adjusting Individual and System Perspectives

The sociology of knowledge and Personal Construct Theory converge to underpin our understanding that thoughts and actions are socially constructed, mediated and sustained (Stark, 1971), and presume that we can and do construct, reconstruct and change our thoughts and actions (Kelly, 1955; Mezirow, 1990; Nystrand, 1977; Poggi, 2000). For my purposes, the constructed ways of thinking and acting toward people with “mental illness” restrict their inclusion as partners and leaders. To recognize that our impressions and understandings derive from, and are controlled by the intended and unintended teachings, and sanctioned by the collective social and cultural apparatus, attributes meaning about exclusion, oppression and discrimination but it is also hopeful, assuming reconstruction is an available remedy.

Kelly’s theory is not specific in describing a critical perspective but his arguments about theory and theory-making include pragmatism and an acceptance that the recursive operation of reconstruing and revising meaning, which has been described as a “sceptical approach” (Butt, 2008), is clearly consistent with critical theory. Again, Kelly’s personal construct theory supports more strongly the idea of agency and optimism for personal autonomy in terms of construing meaning and revising one’s construct, and it does not accept the idea of social hegemony, or dominance with the same strength as other authors. Similarly, although the socialization of knowledge states that social structures and process shape and sustain self-view and worldview, the mechanism or conditions that provoke a change from the status quo are not as well documented in that body of literature.

The absolute and essential influence of social dominance cum influence is countered by the concept of agency embedded in Personal Construct Theory and these points elaborate the literature supporting how the development of a critical perspective articulates hope for emancipatory learning, thus, personal and system change (Berman, 1998; Brookfield, 1987; Clandinin & Connelly, 2000;

Cranton, 1994; Henderson, 1994; Hinchey, 2001; hooks, 1994; Lather, 1991; McLaren & Giarelli, 1995; Mezirow, 1990; Smith, 1991, 1999). Developing a critical perspective liberates individuals and systems to engage and, therefore, supports and sustains both personal and systemic transformation. Developing a critical perspective is operative for empowerment.

Critical thinking is a personal capacity to encourage, support and utilize the processes of questioning, analyzing and challenging social influences related to knowledge, learning and social relationships (Cranton, 1994; Hinchey, 2001; hooks, 1994). Reflection about experience supports critical thinking; reflection can be personal as well as interpersonal, and it can change meaning, or construal (Berman, 1998; Brookfield, 1987; Henderson, 1994; McLaren & Giarelli, 1995; Mezirow, 1990; Smith, 1991, 1999).

If social structures and processes establish, transmit, monitor and uphold social norms and values that guide and sanction the roles and behaviours acted out by people in society (Poggi, 2000; Stark, 1971), then, shifting perceptions of these structures and processes can transform their relevance. Participants quite rightly concluded that they have adapted to, and were operating from a particular socially constructed understanding of mental illness and their experience of voice and inclusion liberated an alternative view of their experience, which required re- or un-learning their “illness identity”.

Un-learning occurs when one learns how to consider and contemplate one’s collective experience, and the system that shapes experience, from a critical perspective, including a critique of the influences of power. Transforming requires being critical (Cranton, 1994; Henderson, 1994; Hinchey, 2001; McLaren & Giarelli, 1995). Transforming power leads to empowerment. Supporting people to think about both their experience from a critical perspective exposes the underlying forces or worldviews that sustain their self-view and interpretations - their personal constructs. This exercise can also expose the alternative, liberating interpretations that revise our constructs and, therefore, change our ways of thinking and acting.

The exercise of reflecting, questioning, and reconsidering is the process of critique. This exercise is especially apparent when people are sceptical and question personal and social roles and structures, which opens and invites alternatives to accepted roles, identities and relationships. Realigned perceptions that also realign power from the system to the person are emancipatory and effect empowerment – the realization of power from within. The process of empowerment is pertinent to this study because it has shifted the role of participants from conventional recipient of ‘care’ to self-determined people in recovery and advocates for change in the conventional care delivery system – people advocating for, and leading others to alternate interpretations and constructs.

Summary

Social factors and forces shape our self-view and world-view. Our experiences are assembled as personal constructs that influence how we anticipate and interpret events and interactions. These assumptions affect people in recovery in particular ways. First, the prevailing societal construction of *mental illness* as a disordered or even dangerous condition affects both how the person understands him or herself as well as how they are understood, and regarded by others (Mead, 2001; Pérez Álvarez & García Montes, 2007; Szasz, 1961; Walker, 2006) . Second, an illness orientation precludes full appreciation of the social factors that affect the experience of *symptoms* or *illness* that dictates how the system provides *care.*

When the reasons for “symptoms” are wrong, then logically, the prescription of treatment based on those symptoms will also be wrong. For example, an interesting conversation ensued during the focus group surrounding how shock and grief after acute trauma, such as violent assault, or chronic trauma such as abuse or homelessness, are more effectively addressed by considering the etiology rather than simple interpretation of presenting symptoms. Without inclusive, dialogically oriented “assessment” clinicians appear to jump to illness oriented conclusions, such as “depression”.

By accepting that self-views and world-views are constructed, one must agree that they can also change. Opening and supporting authentic dialogue with people about the forces and factors that influence self-view and world-view can induce people to question and challenge social and structural factors that sustain the dominant mental health system. People in recovery, who are leaders and advocates for change in the mental health system, comprise the participant group for this study. This study draws on the evidence regarding: socialization of knowledge; Personal Construct Theory, critical realization and participatory processes to describe their experiences of becoming different. Clearly, the experiences of the participants in this study demonstrate the tensions inherent in becoming different. All participants describe how extrinsic social factors and attitudes not only shaped but also limited their full participation in their lives and their full understanding and appreciation of who they were and their potential. Their experience also demonstrates that changes are possible. They describe how societal circumstances, as well as internal reconsideration of both circumstances and self, supported that change.

CHAPTER THREE—METHODOLOGY AND RESEARCH DESIGN

Introduction

The focus of this examination is to consider how people in recovery become leaders in the system that served them. Specifically, I seek to answer the question: What are the experiences of ten people in recovery in their journey to become leaders and advocates? This question requires personal disclosure and reflection. The answer will comprise a composite of responses that may not be identical. Underlying this question are aspects of the experience that are relevant to accurate conclusions. One such aspect is a critical analysis of mental “illness” and the mental health system, especially as it relates to acquisition of leadership and advocacy roles for people in recovery. In this process of examination, several things are relevant and necessary to inform both process and outcome: reflection and critique regarding self-view and worldview; the dynamics and influences of the social and power based structures of exclusion; and discrimination and oppression.

Regardless of theoretical orientation or methodology, I believe the intent of research is to prepare a systematic and critical investigation that includes the collection of information, the analysis and critical interpretation of that information, including the verification of the interpretation and meaning of the data, and the drawing of conclusions. Research informs and adds academic or practical understanding to an area of study and identifies areas for social change and strategies for action. Further, scholarly research requires critical examination of areas of study that contribute to the knowledge and theory base in the field. In this case, there is limited research and literatures regarding the experience of leadership for people in recovery and this study will shape new theory or add to the sketch of existing interpretations in the field.

Research Question(s)

The research question applied to this study is: What are the experiences of people in recovery in their journey to be leaders and advocates? The secondary questions are: How have people made meaning of their experience, and how have those interpretations shaped their personal constructs and their subsequent ways of thinking and acting?

Choosing Methods to Appropriately Address the Question(s)

Research *methodology* refers to the underlying rationale and philosophical assumptions that shape the particular *methods* chosen to undertake the study. Interest in research relating to aspects of human behaviour, values and relationships assumes that discovery and understanding of the research problems, questions and findings (Lincoln & Guba, 1985) are more readily available using qualitative methods. In the case of this study, my task was to discover and critically examine the experiences of people in recovery and how they have interpreted and integrated the meaning of their experience into ways of thinking and acting, using qualitative research methods.

Learning and knowing are complex phenomena. People choose, or are attracted to certain ways of knowing and learning and this forms the basis for what theories and practices we believe are "true". People who are comfortable with absolute or "provable" knowledge are more likely to choose ways of understanding that rely on quantification. Such researchers contribute to society by determining cause and effect in science. Researchers are knowledge brokers. They are the people who have the power to construct legitimating arguments for or against ideas, theories or practices. They are collectors of information and interpreters of meaning, which can be used for, or against the interests of those they are researching. Knowledge acquisition, processing and brokering again depends on the perspective of the researcher, and his/her ways of knowing (Belenky, 1986; Oakly, 2000).

People who are more comfortable managing complex and inseparable information, and who are satisfied without definitive cause and effect, are more likely to choose ways of understanding that rely on qualification. Such researchers contribute to society by facilitating an appreciation of the meaning of social issues or problems and whose work is designed to change and improve the structure of society. The impact of mental health problems, and the personal transformation required to become leaders for system change is one of those complex social issues that requires a way of understanding that relies on "qualification". It is a problem and an opportunity that affects people who report they have been treated unjustly and subjected to oppressive environments.

Using Qualitative Methodology

Attraction to styles and philosophies of learning and being influence how a researcher chooses the process of critical investigation. Depending on his/her perspectival creation of reality, his/her personal construct (Kelly, 1955) or his/her structure of meaning (Mezirow, 1990) a researcher can choose any one of a variety of methodologies to pursue the information he/she needs, or to uncover a response to a question he/she has posed. In this case, my background as a mental health clinician is relevant. Specifically, I draw on my additional training and experience in the practice of cognitive behaviour therapy, dialectical behaviour therapy and narrative therapy (Alford & Beck, 1998; Beck, 1979; White & Epston, 1990), and my grounding in a humanistic approach (Rogers, 1961, 1980). I am drawn to, and comfortable with, methods that engage in conversation and relationships, and which seek to understand in a participatory format, appreciating the accounts and experiences of the people who I am listening to. For these reasons, I am drawn to qualitative methodology.

Qualitative research literature suggests that to focus on ascribing causation diminishes the complex nature of social and intrapersonal realities (Denzin & Lincoln, 1994; Mitchell & Radford, 1996; Schram, 2003). Qualitative research draws on multiple personal and social perspectives and philosophical backgrounds, specifically relating to perceptions that highlight "practical reason" rather than science (Hamilton, 1994). Qualitative research offers the opportunity to focus on finding answers to questions centred on human experience, such as how it is created and how it lends meaning to life (Denzin & Lincoln, 1994). Complexity and multiple influences are accepted.

Qualitative research relies on "rich description" (Denzin, 1989; O' Reilly-Fleming, 1993) to be sensitive to context and to build and develop theory. Triangulation, a method of using multiple approaches or sources to contribute to, or to confirm interpretations, provides trustworthiness and credibility to interpretations and conclusions and adds to the richness of the description and depth to the meaning (Golafshani, 2003; Guba and Lincoln, 1985; Denzin & Lincoln, 1994; Holt, 2003; Thurmond, 2001). The process of attending to description, in this case varying descriptions of experience, and the importance of context and personal meaning differs from and the more precise processes expected by the quantitative model, where data can be more standardized and outcomes are more measurable. The nature and context of experiences of participants resist quantification. Yet the comprehensively systematic approach of qualitative methods is equally but differently rigorous.

Qualitative research methods better suit a study such as this, where the context that defines experience is important. For this study, people and their thoughts and experience must be considered within their context and constructs because to approach it differently would strip away the capacity to attribute and understand meaning. Qualitative research represents an epistemological shift in terms of what and how we know issues, including their context and meaning and how we value discovering their nature as wisdom shared by the people included in the research.

Critical Narrative Inquiry as a Preferred Method

"Narrative method, in its simplest terms, is the description and restorying of the structure and variety of experience" (Clandinin & Connelly, 2000, p. 89). When I consider my own narrative, I appreciate that the most substantial turning points in my construct development, and revisions in meaning, emerge from my personal experiences. Specifically I draw on my own personal construct development and revision regarding mental health, mental illness and recovery. My conventional professional training forms the preamble to my story and frames an acceptance of the clinical model of expertise and care. Subsequent clinical experience and ongoing professional and academic education provoked me to develop the sceptical, critical awareness I required to question and challenge embedded constructs, thoughts and actions. My personal understanding recovery shifted my interpretation once more. I established a construct or cognitive template to explain the failings of the system as I had experienced them, and how I witnessed others who were experiencing them.

My understandings of the role and importance of how people, places and activities in my life have shaped my thinking and behaviour resonates with Dewey's understanding that "…experience is both personal and social...they are always in relation, always in social context…." Furthermore, Dewey (in Clandinin & Connelly, 2000) held that one criterion of experience is continuity, namely that "experiences grow out of other experiences, and experiences lead to further experiences" (p. 2). When I place priority on experience, it is reasonable that if I want to truly understand and appreciate how other people have come to be who they are, including their current roles and relationships, I must attend to their own descriptions of and interpretations of their experiences (Rogers, 1961).

Therefore, qualitative methods support engagement and participation that I seek, and it invites the multiple perspectives required to consider and appreciate the individual understandings and meanings proposed by this study (Schram, 2003). In particular, the narrative inquiry that forms the basis of the conversational interviews with participants and verifies the understandings and meanings that indicate the phenomenon of being a leader in recovery (Clandinin & Connelly, 2000; Connelly & Clandinin, 1990; Jardine, 1992; Krall, 1988; Polkinghorn, 1988; Smith, 1987) are critical in nature. Critical narrative recognizes the multiple perspectives that contribute to the accrual of experience that forms the story of personal narrative and it also presses for reflection and critical interpretation regarding experience, in this case the experience of becoming a leader (Berman, 1998, Kamler, 2001).

Considering the multiple perspectives of personal narrative and the transformative operation arising from reflection and critique, I also accept Polkinghorne's (1988) premise that a person's story, or personal narrative, unifies his or her way of perceiving, thinking and acting. This unification forms, or supports and sustains the formation of a person's identity. This aspect of narrative as a mirror for identity is important in my inquiry because the research questions relate to a transition and/or transformation of identity. Therefore, to assure that the stories of participant experience ground my understanding, choosing narrative inquiry as a qualitative method is a reasonable decision.

I am aware of a risk in this decision from my own experiences. People in recovery have almost always been in a situation where they have revealed their "story" to a professional clinician who has probed and guided their disclosures to meet clinical ends. It is my experience both in professional interactions as well as casual conversations that people in recovery can revert to a story that is over inclusive of clinical detail and reveals more than I would intend to ask in this context. In fact, the conventional system has exploited this tendency, in my opinion, when they ask people who have used the system to "tell their story" in public as a way to promote understanding of illness, services or even worse, fundraising. While I have taken this perspective on public story-telling, and I am also aware that some people feel liberated and validated when they "tell their story", this is not the effect I aim for in this research.

Another risk to the proposed research in using narrative inquiry is the relationship of the work with theory. I have assumed that several theories will be relevant to the study; however narrative inquiry resists reliance on formal theoretical infrastructure which can create tension for both the listener and the teller of the story (Clandinin & Connelly, 2000). The essential idea of narrative inquiry, according to Clandinin and Connelly, and supported in the writing of Polkinghorn (1988), is to create a relational space that invites participants to describe their past experiences as well as their hopes and goals from both a nature of chronicling and detail, as well as from a reflective and aesthetic stance that provides commentary and critique. The "telling my story" activities I describe above as exploitive, in my opinion, are not narrative inquiry. It will be my task to guide people from the familiarity of this activity to the less familiar process of meaningful inquiry.

In addition, Clandinin identifies the interpretive quality of narrative inquiry given that our stories are embedded in particular cultures and histories (Connelly & Clandinin, 1990). In the case of the research that I propose, it is important to assume that the story of lived experience will contain examples that support and challenge each person's own recovery as well as containing examples that impact on their system advocacy and leadership. I accept that each person's story is both their own narrative biography as well as a shared story; it is shared with me and then I will share it with others in order to make certain points about people in recovery as leaders. It is crucial that I understand and appreciate the nature of the stories well, and that we agree about content and the intent of the content (Clandinin & Connelly, 2000).

In narrative method and this study, the details as well as the nature of the personal story are relevant. We all, researcher and participant, bring our biases and personal lived experience to bear on the subject under discussion. This is particularly relevant given the co-construction of Portraits that abbreviated the original narrative. When I as the researcher hear the narrative, I become interested in aspects of the story for which I feel affiliation and relevance. Given the application of critical narrative inquiry, that presses for interpretation and critique in real time, I am not a blank slate in this regard. My interpretations can and ought to presage in part the elicitation of and analysis of the data. I noticed this phenomenon when trends began to emerge after the first few interviews which I then used to draw out more detail regarding similarities or discrepancies in participant experience.

The task of the researcher in this exercise is to honour the personal narrative as it is revealed and not inadvertently force a predetermined outcome. By focussing primarily on the particular experiences of leadership and advocacy I was mindful of the importance of hearing the depth of experience while legitimately attending to the key points for the study. In particular, the narratives provided by participants contribute to an inquiry that both describes and critiques the phenomenon and process of becoming a leader in recovery (Clandinin & Connelly, 2000; Connelly & Clandinin, 1990; Jardine, 1992; Krall, 1988; Polkinghorn, 1988; Smith, 1987). Therefore, critical understandings about the system or context within which the participant became a leader are required to effectively answer the research question.

Critical narrative recognizes the multiple perspectives that contribute to the accrual of experience which, according to Kelly (1955), revise our interpretations and support the appreciations of constructive alternatives. In addition, Clandinin identifies the interpretive quality of narrative inquiry given that our stories are embedded in particular cultures and histories (Connelly & Clandinin, 1990). Attending to alternative considerations presses participants for reflection and critical interpretation regarding their experience of becoming a leader (Berman, 1998; Kamler 2001). In the case of this research, the function of critique is essential, given the premise that assuming a critical perspective advances transformation.

Relevant Ethical Considerations

Ethical review and approval is an essential component of this study due to university obligations articulated in the Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans (www.pre.ethics.ca). The process is equally compelling for me because the personal value I append to this work and these relationships also requires that I assure fair and just inclusion and participation. The subjective ethics of this work are more compelling based on the personal relationships I hold with many of the participants, as well as my considerable respect and admiration for their work in leveraging system change and advancing an environment of recovery for their peers. Therefore, in this research, I openly acknowledge the flexible and permeable boundary between the researcher and participant's roles that support joint construction and verification of the narrative through conversation.

The specific ethical components embedded in this study include respect for the dignity of participants, including fully informed consent and respect for their agreement to voluntarily participate in the study, or not. The issue of the *vulnerability* of this group is of interest. According to Tri-Council guidelines, people who have been diagnosed and treated for mental illness typically exceed the threshold that defines a *vulnerable* population. Clearly, I described the potential risk associated with the process for people as they "tell their story" however, as I anticipated, this population was well able to bear the burden of this inquiry. In the event that there were untoward effects from constructing and discussing their narratives, the ethics approval required information to be provided regarding professional supports, despite my first wish that this group of people in recovery, who value peer support, would prefer and find more effective a peer support resource. The program that I chose to refer participants to if they experienced distress was the Gerstein Centre in Toronto, knowing that this program could access peer support subsequent to their *professional* assessment. This choice was noted with interest by participants. Given the significance of the Tri-Council Policy regarding Ethical Conduct for Research Involving Humans, for the purpose of this study, vulnerability was accepted but given the nature of the research question and the population, it deserves further debate at a later time.

For the participants of this study, anonymity would be difficult to assure as a requirement to the inquiry. In most cases, the participants have openly and publically disclosed their personal histories. The consent process included a discussion regarding the risks of disclosure and offered participants an option to have their identity obscured; however, each participant acknowledged the challenge in doing so and agreed to have their identity disclosed. Having said this, my choice is to use pseudonyms to identify participants in this thesis. I realize, as do they, that their stories will be recognizable when the findings are disseminated in public forums and within subsequent publications. Therefore, accuracy of information is essential; ample opportunities were embedded in the process for participants to review, clarify and correct, verify and contribute to the body of information that was be produced.

Underlying Principles Consistent With Participatory Engagement

Participatory engagement in this research process is defined by the principles of Participatory Research (Hall, 1981, 1992, 1993; Selener, 1998). Participatory research is intended to challenge basic structures of society, especially the structures which generate and sustain exploitation and oppression of people who are marginalized. It is an inherently political methodology that sees participants in the research as equal determiners of social action. Participation is a dialectical process which values common, popular or indigenous knowledge as fundamental to understanding and assigning meaning to experience and to the prescription of resolution (Hall, 1981; Selener, 1998). Social action, or a transformation of the social structure, is the desired outcome. The basis of social action is knowledge – both knowledge provided by the participants to the researchers, as well as knowledge provided to the participants by the researchers.

"Knowledge has to be unearthed in each individual, collectively reformulated, and analyzed, so that it can be applied in collective actions to benefit a group or community" (Selener, 1998, p. 25). Knowledge informs and supports social action. Reflection by all parties in the research is an essential step toward the outcome action (Freire, 1999; hooks, 1994). Participatory Research relies on the relationship between the "researcher" and the "researched" to achieve its three principle activities: research, education, and action (Hall, 1975, 1981; Jackson & Kassam, 1981; Maguire, 1987; Selener, 1998). In the research process, there is equity of power; the researcher does not recapitulate the oppression of the dominant social structure by doing research on "subjects". In Participatory research the role of the researcher is to appreciate the potential of common knowledge, or "organic intelligence" (Hall 1981), and to catalyze the community's organizational capacity to implement action (Selener, 1998).

Conducting the Research

Using qualitative methodology requires the researcher to be comfortable with a level of ambiguity in terms of expectations and process. Schram (2003) suggests that qualitative researchers "do not frame and follow a research design as much as they 'orchestrate and clarify connections among the various raw materials and thought-about perspectives that feed into their developing inquiry. Their task, in other words, is ……to develop strategies for holding on to, making sense of, and forging links among the ideas that are prompting and guiding their inquiry". (p. 14-15).

Appreciating the potentially ambiguous nature of this process, I conducted this research with an open mind, hoping to learn as much as I could about the experience of participants as they became leaders.

The design of the proposed research hinges on the important assumption that people who have experienced “mental illness” are capable and competent leaders, with a unique and significant perspective. The focus of the research is to facilitate and support a respectful and safe process, through which people in recovery, who are in leadership roles, self-reflect, consider, and articulate the experiences that define their role and function both with their peers and with the conventional system. Within the scope of literature produced by either people in recovery or conventional clinical or academic researchers, there is very limited content related to recovery leadership or advocacy. Therefore, this research is important in terms of supporting the self-determination and empowerment of people in recovery to become equal partners in contributing to decision-making in the service system which affects them.

To answer the research questions regarding their experiences in their role as leaders and advocates, participants engaged in a recorded conversation with the researcher. In the course of describing their experiences leading to and being a leader, participants were also asked to describe the impact of these experiences on them personally as well as in terms of their interest in advocacy and leadership. All participants formally consented to participate in an audio-taped conversational interview and focus group as well as contribute written reflections and impressions about their experience (Kamler, 2001; Morgan & Krueger, 1993).

The Participants

Ten people were selected to participate in this study from a purposeful sample of recognized leaders of regional, provincial and national organizations, who were known to represent themselves from a standpoint of personal lived experience with mental health problems. Some of the participants disclosed substantial experience within institutions and others described alternative or peripheral ways of addressing their mental health problems. Knowing that a focus group was a required element of the process, I deliberately recruited participants for whom travel to a central location would not be onerous. Therefore, the group comprised participants from South-west Ontario (London and Kitchener-Waterloo), Simcoe County (Midland and Penetanguishene), York Region and Toronto. One of the participants completed the interview and part of the reflective journaling before she had to withdraw for health reasons; it was her wish that the details she had provided to date be included in the study. One other participant was unable to attend the focus group but she provided subsequent feedback that added to those data. The location of the focus group was decided based on one participant’s limitations with respect to transportation.

In most cases, I had a prior relationship with participants due to my current work in the field but in some cases, despite having heard them speak publicly, I was meeting participants personally for the first time. Although I did not recruit a specific demographic group, it is notable that most of the participants were in their 40’s to 50’s with an age range between 35 and 70 years of age. All of the participants were apparently Caucasian. The demography of the group was not important to me at the time however, participants themselves noted an absence of youth both in the group and in their ranks in the field. They also noted the absence of ethno-racial diversity of their group.

Recruitment and Informed Consent

Participants were contacted in person, by email or telephone. One person who was contacted declined due to his pre-existing obligations. All other recruits accepted and agreed to the conditions described in the informed consent. In order to assure that participants fully understood these conditions, each person was provided the questions that guided the interview in advance. Information was reviewed again verbally at the first meeting and opportunities to ask questions and confirm understandings were invited.

Research participants freely decided to contribute to this inquiry based on full disclosure of the purpose, the process and the anticipated outcomes. Each participant arranged a space for the conversation where they were comfortable. I travelled to meet with them at the location of their choice, including workplaces, homes and neutral sites. Each person seriously considered the implications of his or her participation, given the challenges regarding anonymity and heavy workload. Each person accepted that by participating, their story could be identified and they waived the requirement for anonymity embedded in the consent. Nevertheless, in an attempt to protect their identity, pseudonyms were used. Compliance with ethical process ensured that all participants were fully informed of the risks and benefits associated with participation.

Semi-Structured Interviews

Participants were invited to meet with the researcher at a location convenient to them. Prior to these meetings, the list of questions in Table 1 below was provided by email, with an explanation that these questions formed a structure for the conversations but where not intended to limit or direct what and how participants wanted to share their experience nor were they intended to interfere with a natural flow and exchange of information. Participants provided additional and relevant information that supported as well as challenged or clearly refuted anticipated themes. These additional rich descriptions were welcomed (Denzin & Lincoln, 1994).

Table 1*: Interview Questions*

What is your history with the mental health system/recovery community?
How did you become a leader?
Tell me about your interests in advocacy and leadership
What is the nature of your work?
How long have you been in this or other leadership roles?
How do you think about yourself as a leader/advocate?
How does your understanding of recovery affect your leadership?

Data Collection, Management and Analysis

The qualitative data in this study comprise information acquired from four sources: audio-taped interviews with participants that were transcribed into narrative summaries, journal entries, correspondence and a review of published accounts from other people in recovery who were in leadership roles. The collection of data involved transcribing the descriptive narrative (Polkinghorne, 1988) that heard each person's story as a unique experience. At the same time, the nature of the conversations facilitated inquiry regarding explanatory narrative (Polkinghorne, 1988) that focussed on why their experiences had occurred as they reported. Explanatory narrative inquiry uses the person's interpretations of meaning, and the contributing factors and influences they report to add relevance and significance. It supports revelations of personal, social, cultural and, potentially, institutional factors that affect the roles of advocacy or leadership for people in recovery. Critical narrative inquiry presses for reflective critique regarding experience and its interpretation. These narrative data led to a transcript of the conversation.

Each participant reviewed his or her transcript to ensure authenticity and accuracy which improves reliability and credibility of the findings (Denzin & Lincoln, 1994; Guba, 1981; Lincoln & Guba, 1985). To manage the volume of data for the ease of both the researcher and the participants, the descriptive narrative was then reiterated in mutually constructed brief summaries, or collaborated stories, which Clandinin and Connelly (2000) refer to as *plots*, and I have named Portraits. The Portraits offer details that answer the research question as well as contributing detail that defines the narrative. Despite the risk of being reductive, the portraits were endorsed by participants to ensure authenticity and accuracy and to improve reliability and credibility of the findings.

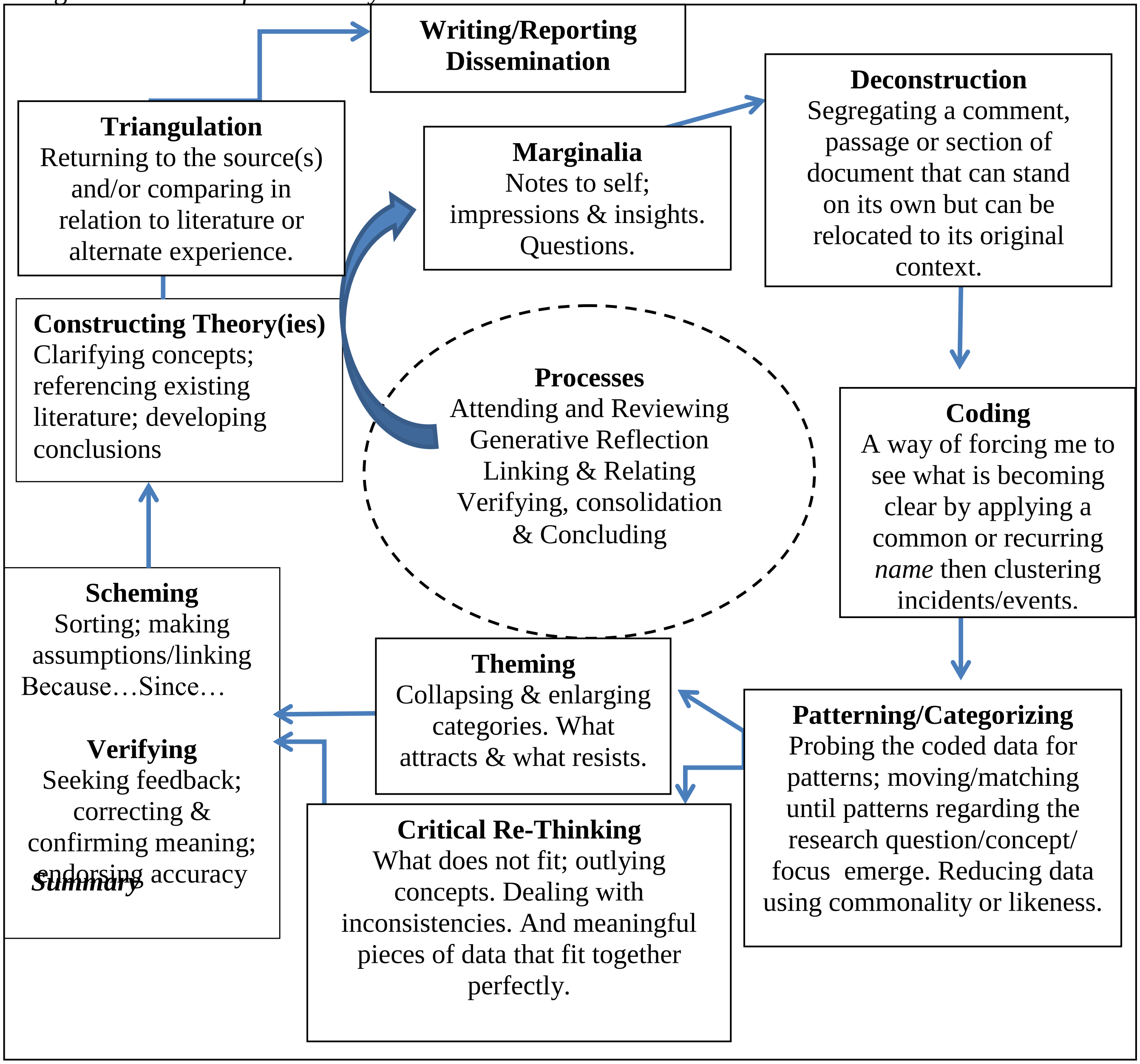
Once each participant had endorsed his or her portrait, a single focus group meeting was scheduled to bring together participants in order to clarify, confirm or correct preliminary interpretations of the themes that emerged from the conversations (Morgan, 1993; Morgan & Krueger, 1993). Prior to this meeting, preliminary themes emerging from the interviews and portraits were circulated to support participants in their preparation. Participants were also invited to direct any areas of disagreement or corrections to me in advance of the focus group, a process that allowed participants an opportunity to obscure their identity from the other if they so choose. The focus group was held in Toronto and all but one participant attended. The absent participant provided feedback in advance and subsequent to the meeting. Participants also agreed to provide written information in the form of *journaling.* This aspect of their participation was weak. Only three participants contributed additional data.

In terms of data analysis, "[t]he purpose of descriptive research is to present the narrative schemes the storyteller has intended" (Polkinghorne, 1988). The role of the researcher is to listen carefully to the story, probe for content and context, and clarify meaning. Understanding qualitative data requires an involved and thoughtful process of deconstructing context, identifying and assembling patterns, reconstructing collective meaning, developing theory and proposing conclusions. Techniques for recognizing themes and patterns in the narrative and comparing and analyzing data are established, and facilitate the researcher's intent to use data to answer the research question, so that theory about the issue is developed, or enhanced (Crabtree & Miller, 1992; Denzin & Lincoln, 1994; Kirby & McKenna, 1989; Marshall & Rossman, 1989; Miles & Huberman, 1984; Polkinghorne, 1988; Schram, 2003). The process that I have used for qualitative analysis can be found in Diagram 1 below. It demonstrates a systematic relationship of interaction and reflection (Denzin & Lincoln, 1994; Glaser & Strauss, 1973; Hamilton, 1994; Kirby & McKenna, 1989; Lincoln & Guba, 1985; Maguire, 1987; Miles & Huberman, 1984; Oakley, 2000; Spradely, 1980).

In keeping with the importance of collaborative meaning-making that is evident in qualitative research in general, and participatory and critical narrative inquiry specifically, participants must play an active role in not only confirming their own contribution but also in the broader functions of verification, clarification or correction of data to assure there is agreement regarding the ideas and concepts (Lincoln & Guba, 1985; Polkinghorne, 1988). Each participant endorsed a Portrait that captured the principal themes and events included in their narrative transcript. Preliminary themes were presented to the participants collectively and guided the group conversation that clarified, enhanced and verified the interpretations (Diagram 1).

It is essential to assure that the information provided by participants, and the conclusions that emerge from these data, are accurate, trustworthy and credible. Guba and Lincoln (1985) and Denzin and Lincoln (1994) describe four modes of triangulation to assure credibility: sources, methods, investigators, and theories. Given the multiple sources for the collection of qualitative data, including the focus group review and revision of preliminary themes and conclusions, credibility of the information was assured (Golafshani, 2003). In addition, comparing the themes identified in the narratives of this study against those apparent in published accounts by other leaders in recovery reinforced the veracity of the interpretations. Finally, comparing the responses to the research questions against the theoretical concepts that informed the development of the research problem provided another venue to triangulate for trustworthiness of the data and conclusions.

Figure 1. *Process of Data Analysis*



Summary

Participants formally consented to participate in audio-taped conversational interviews and in a focus group. While they also agreed to contribute written reflections and impressions about their experience (Kamler, 2001; Morgan & Krueger, 1993), this aspect of the study was not as strong as the level of commitment given to the interpersonal components of the study. Individual and group conversations were structured so participants would reveal their experiences and the related meaning of those experiences in terms of their engagement and participation as advocates and leaders. I anticipated that in the course of these conversations, participants would raise and consider the impact of historical, existing and potential structures and systems of power that affect the mental health system. I also anticipated that participants would observe that becoming an advocate or leader influenced their own recovery. I was not disappointed.

Within the scope of literature produced by either people in recovery or conventional clinical or academic researchers, there is very limited content related to recovery leadership or advocacy. Therefore, this research is important in terms of supporting the self-determination and empowerment of people in recovery to become equal partners in contributing to decision-making in the service system which affects and concerns them.

CHAPTER FOUR – PARTICIPANTS’ EXPERIENCES: EFFECTS OF THE MENTAL HEALTH SYSTEM ON PERSONAL TRANSFORMATION

Who Are The Participants?

The focus of this study is to examine the experience of people in recovery, who have made the personal transition to roles of leadership and advocacy. The participants comprise a purposeful sample of ten recognized leaders. All but one participant were employed by regional, provincial and national organizations, and held positions that required them to operate from a standpoint of personal lived experience with mental health problems. The questions that guided the inquiry include: What is your history with the mental health system/recovery community? How did you become a leader? Tell me about your interests in advocacy and leadership. What is the nature of your work? How long have you been in this or other leadership roles? How do you think about yourself as a leader/advocate? and, how does your understanding of recovery affect your leadership? Given the conversational nature of the interviews, there were many rich digressions.

The degree of experience with the formal and institutional system varied within the study group. Some disclosed substantial experience within institutions while other say they “skirted around it”. All of the participants also describe experience as a family member of someone who was involved in the mental health system and these experiences affected their own engagement and response to “care”. All of the participants knew of each other, and many had strong pre-existing relationships. I had pre-existing relationships with most of the participants. I did not recruit a specific demographic group and age, and racial homogeneity of the group was noted by participants.

The participants agreed to an audiotaped interview which was transcribed. Based on the transcript of the interview, an abbreviated narrative, or Portrait, was developed that noted the elements of each person`s journey to becoming a leader or advocate. The Portraits, which can be read in their entirety in this Chapter 4, were analysed for common themes, which were provided to the participants for review before the single focus group meeting that was held to enhance, correct and verify the themes. The format of the focus group was conversational but intended to address the following questions: What has your experience been in this study? Do you agree with the analysis of themes and patterns? What would you add or change? What advice or recommendation for other leaders and advocates do you see emerging from this research? And, what other issues and topics are important for you to feel that your stories have been heard and appreciated?

The key themes that emerged from the Portraits, and which were confirmed and verified by the participants during the focus group are: an underlying negative experience with the “care” system, and the significance of voice, inclusion and empowerment. Additional themes that emerged during the focus group included a growing concern regarding appropriation of ideas and programs and a corresponding corruption of their meaning. More detail regarding the findings and their interpretations can be found in Chapters Five and Six.

The profile and prominence of most participants was an issue with respect to ensuring anonymity. Each of the participants had already disclosed their story in a variety of forums. Knowing that for most participants their stories were already part of the public record, everyone declined efforts to ensure anonymity. They indicated that their names could be used in the final publication or in presentations. Nevertheless, because this thesis will be a more complete document than subsequent publications or presentations, in an attempt for anonymity, pseudonyms are used. All of the participants were eager to participate. Interestingly, most were surprised that I considered asking them to contribute to a study regarding leadership. They do not see themselves as leaders, per se.

Commonalities and Integrative Factors

Participants described many common experiences during their transition to roles of leadership and advocacy. They described commonalities in terms of what motivated them to work for system change. The primary motivation was dissatisfaction with the services they received. In part, they described services as lacking in availability and responsiveness. More specifically, they articulated anger and resentment regarding experiences of exclusion, oppression and discrimination which incited their passion to act for change. Their wish to correct the system included advocating for, and developing alternative programs and supports.

For many, moving into a role that advocated for change was serendipitous; however, the effect was quick and profound. They described accepting invitations to participate in activities that welcomed questions and feedback. While they were generally reluctant to participate at first, the effect of speaking up was significant. These activities were opportunities to liberate their “voice”. The importance of being listened to and having their observations and opinions valued was transformative. Voice, in their experience, was a vehicle that supported the development and utilization of a critical perspective by nurturing their questioning natures.

Every participant described involvement as members on Boards of Directors. While these appointments provided an introduction to the leadership process, for too many of the participants, they felt there was inadequate training and support. The sense that they lacked preparation is echoed in their comfort and confidence in the management and operational function required for their jobs. They described the orientation to their work as a “trial by fire”. They referred to the grind of learning on-the-job, and they cited persistent doubt about their performance. They described their strengths as their ability to motivate and influence others and create a vision for change. They described a commitment to collaborative leadership that involves leading with others and leveraging relationships with allies. They articulated an approach that values collectivity and peer engagement. In fact, they were reluctant to ascribe the term leadership to their work because they saw themselves as working collectively to lead but to build the strong support of their peers and allies.

The work of peer leadership and mental health advocacy is difficult. Their programs are poorly funded and not openly valued by a system privileged by a clinical elite. Nevertheless, they recognize that their work has yielded positive results. However, there is a sense, that since some of their programs and supports such as peer support are proving effective, they are being appropriated by conventional services. At the focus group, there was extensive dialogue regarding the “take-over” of survivor operated programs and the “co-opting” of recovery. Participants expressed resentment regarding how their experiences were exploited as the system appropriates the language of “recovery”. They were clear that peer operated programs must be autonomous.

In addition to the people who participated in the study, published narratives are included from prominent survivors who have also transformed their experiences with the mental health system to advocate and lead for change. The stories of these survivors mirror those of the participant group, adding rigour to the results. These people also described negative experiences that produced anger, resentment and a will to change the system. They endorsed the experiences of being unheard, alienated, excluded and characterized as deficient. These experiences were characterized as oppressive and extinguishing hope. These additional narratives reiterate the importance of realizing one’s voice and being listened to. As activists motivating their peers, they invite challenge and a rebellious perspective that encourages risk. They also describe an environment that fails to inform and engage meaningful choice, including information about alternatives. Each of these survivors has exercised their voice to become leaders who believe in, and are hopeful about the reality of recovery.

Finally, most participants described their work as “healing”. Advocacy frames their personal recovery. They acknowledged the pressure to appear “well” in order to be seen as legitimate leaders in the system. They have also experienced underlying discrimination when others are suspicious if they are “too well” and their survivor-identity is questioned. For some, their role as an advocate and leader, especially given the public nature and pressure of their work, has compromised their own recovery.

Participant Portraits – Abbreviated Narratives

For each participant in the study, transcripts of the semi-structured interviews were reviewed for salient points and collective themes that answered the research question. Portraits that comprise an abbreviated narrative were developed jointly by the researcher and the participant. Each of the following Portraits was endorsed by the participant, verifying its accuracy. Even though, in the process of informed consent, participants did not require anonymity, efforts to protect their identity have been taken by using pseudonyms. This measure may not guarantee that the details won’t be recognizable. The published accounts that provide verification and triangulation are clearly ascribed to their author.

Portrait 1 – Art

My experience covers many perspectives. I am a consumer and a family member, and before I experienced my first hospitalization, I was employed in the conventional system. My personal experience with mental health problems has framed my professional work.

We don’t have a collective understanding of recovery. I shudder when I hear people say, yes, we do recovery. Programs like OCAN require you to set goals – The word goal-setting has so much baggage - it becomes another mechanism for services to control.

I became a leader because I was not satisfied with the system and I wanted to work for change. The system is custodial; fear and ignorance result in discrimination and prejudice which prevent complete citizenship. Our system is not based on a shared vision; there are too many camps, bickering about whose version of the truth is most accurate. One of the barriers to shared vision is a subtext of capacity - that consumers don’t have the capacity for clear thinking.

I was working in the field at the same time and was an open advocate for families but I had not disclosed my personal experience. My position within the conventional system provided some credibility but it also tainted my leadership. I started by leading family support and advocacy groups then moved to a provincial forum assuming a role as board member. Board membership provided a larger platform for advocacy and the opportunity to make important connections to advance.

I see my work as leading for recovery. I do this as a board member, charting the course of the organization, and as a program administrator. I talk about recovery; I have and promote the *honest conversations we must have about the supports, services, options, tools and resources required to make informed choices about how we "get on with our lives".*

We provoke change by talking about how we learn from our experiences of profound trauma, or depression, or the voices you hear. I do this by leading our organization, speaking and writing, and doing standup comedy - You loosen people up then poke this thing called mental illness. I want to more work to deconstruct consumer/survivor identity. What are the common elements or our experience that frame our mad identity? In some ways the system has done a better job of engaging and including people and we're seeing benefits of the good work that we have done. The oppression of the system is less overwhelming.

As a leader I seek to build consensus. I see strength in common ground. I have experience working from a common vision, principles and a shared dream. This process requires getting rid of your ego either as an individual or an agency; disagreement is unavoidable but to argue means that we're talking about it. There is competitiveness in our community; we can beat the shit out of each other. While this may be no different than leadership in conventional sectors, I have seen that if somebody experiences some successes and stuff we throw bricks. It's annoying; we're too hard on ourselves.

I am concerned that we leaders and advocates in recovery are aging. In part this points to the new experience for people coming through the system; It's absolutely different. Most of the folks who are newer to the system seem to say this isn't who I am I just want to get on with my life. We also don't fully understand the experience of mental health from a cultural perspective. We need to appreciate and engage cultural communities in leadership.

My work is healing; it gives me a different way of framing my experience. Recovery gave me a different lens in which to view my madness for me. However, it's hard in this sector to balance the public and the private. There is pressure to be uber [super] consumer who can manage their mental illness, the system and their home life all in one fell swoop while not breaking a sweat; we're not allowed to slip.

My personal recovery has been affected because I've been a leader. People forget or discount the hard work it took me to get, and stay well – it didn't happen overnight and it continues to fluctuate. Sometimes I need to disengage, to spend quiet time. The most severe form of discrimination is exposed when our competence is seen as evidence that we could not have experienced illness at all. It's disrespectful, it's disempowering - you don't know jack.

Portrait 2 – Carol

I struggled with - I still struggle with mental health issues, mostly depression. I am also a family member. I identify as a survivor of the system. When I had a negative experience with my first contact, I withdrew from the system. I went back into survival mode until I was almost 40 when I experienced problems coping and I had problems continuing to work. I met the Coordinator of the Council and because I had personal lived experience they hired me on a part time basis to do bookkeeping and be administrative assistant.

A turning point for me was my involvement in a drop in program where I felt accepted as normal; if I cried or showed emotions it was okay and you got a hug. I could be a friend there. The strength of support of one another, peer support kept me here in this position. I recognized the significance of that personal connection. I had a personal experience of wellness that I wanted to share.

My mental health problems interrupted my education in business admin. I found office work and that's where I stayed. My depression never went away, I just became kind of creative in how I managed it but it took everything I had and I got by and survived.

I grew into this leadership role during a time that I was working on my mental health. I noticed quite a change in my comfort and confidence and my ability to cope. I believed I could deal with the job so I applied for it and earned it. Early in my work I was involved with the Mental Health Task Force; I naively believed that it was changing for the better and I would be along for the ride.

At first I didn't have much varied experience with the mental health system. Now, as I get more involved in the recovery community, I am lifting my head outside of the mire and I have developed relationship. My cooperative way of interacting is well-known and accepted.

For me, advocacy is about relationships, and if you're sitting in the office filing and doing paperwork and the bookkeeping and the other you're not forging those relationships. When we had more staff, we could divide the work to suit our skillsets. Dividing the workload also allowed me time to forge relationships as well as time for reflection, planning, and follow up - I am more effective when I build time into my day to reflect and plan; I need this to be fresher to be a better leader.

I lead by doing. The reality for consumer survivor initiatives[2] *and that's that there is so much work to do, and you see all the work that needs to be done, but there is so little support in terms of funding and staffing to do the job. There are so many tasks that need to be done to keep the*

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[2] A Consumer Survivor Initiative (CSI) is a program operated and staffed by people in recovery.

program operating and leadership isn't all about getting all the work done; it's about fulfilling a message, a vision.

I am the leader of a consumer-survivor program run by a Board of Directors who are all consumer-survivors. At first this work provided me the simple pleasure of accomplishment. Bookkeeping never ends: when you clear one pile, there's another pile waiting. I never realized how important accomplishing a task was to me; it was like opening my eyes to another whole world.

I am changing now to make more conscious choices about my life, to be more strategic about consumerism, to bring the council to a better understanding of consumerism. I think to move forward I need to take stock of my strengths and weaknesses, set goals, set agendas, set some timelines and so on. I want to do so much more around the bigger picture. To do this I have to educate and motivate the Board to shift their perspective. I don't feel confident in my role, although others would say I do a good job. I have a good reputation. I think in some ways it's too good in that I don't challenge them enough because I haven't got the strength to.

When I first became a leader, I was already on the path of recovery. My involvement in recovery groups resulted in big strides in my own recovery. Over time, I am more overwhelmed by the work required to build and sustain the relationships required to lead the program and advocate for change, at the same time as orienting and steering the board toward the bigger picture, and supporting new peer support initiatives – and be well in my own recovery.

If I had not had this opportunity to work as a leader and an advocate I might not be facing these kind of personal crises but I don't think I would have grown as much either. Sometimes we need the trial by fire, right? You have to crackle a little bit. Once you have become a leader in recovery it's hard to sustain it. I get the support from my staff but when I am overwhelmed I find it very difficult to direct someone else to do what needs to be done. It takes more time to explain it than to do it myself, so I keep pushing through. If I take time off – no one is doing it. On a personal level, I carry all the balls: house, mortgage, insurance and everything. I have responsibility in every aspect of my life.

Portrait 3 – Delia

I am a consumer survivor and a family member. I would probably continue to use services to support my recovery if I needed them, but have not needed them for some years now – and do hope not to need them again because the one service that worked best for me was privately paid talk therapy. My working involvement with the system involved a 13 year tenure as a public member with *a panel where formal decisions about people's care and treatment were made. I identified with the people more than the panel, and felt that I "heard" their comments very differently than the other members - it touched my own lived experience. Membership on the panel broadened my view beyond my personal and family experience; it taught me the prevalence of some wrong ways of thinking, including stigma.*

While I was traveling with the panel, I noticed signs in one hospital recruiting for new groups involving peer support – Consumer-Survivor Initiatives (CSI's). Later, when my mental health experience affected my ability to work, I recalled those notices and got involved. My previous experience with leadership in a non-profit, with entrepreneurship through a business I had owned, and with that panel laid down my roots in leadership and advocacy. Because my position on that panel placed me in what could be seen as a power role, I was already comfortable relating to formal power-brokers and I wasn't intimidated by psychiatrists. My history with the panel improved my understanding about rights and how we apply them. My business background and my solid strength in public speaking also supported leadership capacity. I see advocacy in mental health and recovery as critically important; it is often political. Advocating to justifying your funding grants every year can wear you down.

I am the Executive Director (ED) of a consumer-survivor operated organization. Leadership in this position responds to the needs of the membership and the wishes of the Board of Directors (BOD). Organizations founded on recovery principles are built on relationships versus a hierarchy of structures. When I became ED, liaising with a board of directors in this way was definitely new for me because in the past I had always been on the board side of the relationship. Also new for me was being in charge of staff. Becoming a boss was a huge learning curve; I made some mistakes and I learned some lessons.

One challenge for leadership in CSI's is assuring employee wellness. While all employers face challenges related to employee health and wellness, CSI's philosophically appreciate that people require time off to get or to stay well. But for most programs, the staff pool is not deep and any absence leaves people hanging on by their fingernails to hold the fort down. Small organizations cannot afford to provide EAP services and in any event, EAP's tend to allow just enough hours to open wounds, then leave folks walking around bleeding.

Another challenge for leadership in CSI's is an absence of data about ourselves as a sector. In part we lack staffing capacity to participate in surveys but I think some of us are also reluctant to *share data about staffing levels or pay scales, even though these would support advocacy. This reluctance could be due to suspicion that data may be used to de-fund or to force co-opting (I have seen that happen) but there might also be general suspiciousness about: who are you to ask me this; some consumers may say I'm not going to answer you because I don't have to, and I just like to exercise my right not to have to. We do after all come from a sector that has traditionally found that everything one says will end up on some chart or record and be used against one.*

Suspiciousness about being co-opted by mainstream programs is real. Compounding this fear is the lack of information about programs that have been taken-over. All of a sudden they are being subsumed by some supposedly more responsible body, and we can't know why. When you hear the scuttlebutt, you decide it's probably better to keep your head low and not attract attention.

The LHIN environment has exacerbated these fears because they have clearly articulated a specific agenda to reduce the number of organizations. These messages make you wonder what will happen if I'm the littlest or least funded program or if the advocacy I do is seen as "rocking the boat" by the community. OPDI used to provide mentorship and support for leadership and Board functioning, and this function needs to be resumed. If an ED is struggling with Board leadership or staffing, now there is no affordable support and certainly none that is geared toward how folks in our sector have identified as their ideal or preferred ways of learning. We need more peer-support for leaders; support that appreciates the distinct role and purpose of CSI's. Currently, and for too long, ED's and Boards of Directors of CSI's have had nowhere to turn except to the kinds of organizations that would love to take them over.

I struggle with seeing myself as a leader. The word is onerous and the concept seems somewhat self-aggrandizing. I see my role to be a collective voice of our membership. To collect the multiple voices, I have to stay in touch. I try to be adaptable. In a member-driven organization, consensus can be really difficult. Sometimes there are ideas by members of the organization or board, or staff that I cannot abide or that have nothing to do with recovery, or that are great ideas but simply not doable. I rely on membership consultation, while recognizing and working around the constraints of funding, staffing, Board expertise and the suspiciousness I noted above. From consultation you can recognize trends and patterns of both positive and negative experience. I continuously orient people to the role of our organization and what kind of support or advocacy we can provide. Often they might not think it's enough but that again is about mandate, about funding and about capacity. We can't be everything to everyone and it is unrealistic to try.

I'm not sure what my "leadership style" is. I am so busy hitting the ground and running that I'm not even sure that I've given it any thought. Sometimes I gear my leadership or advocacy approach to the issue at hand or to what is missing from the "agenda" and one always wonders about any "hidden agenda". Also, I adjust based on the audience – I may need to tone down or be stronger with my messages just to ensure certain people will continue to listen.

I have learned to appreciate that my wellness affects how I relate to everybody. I worry sometimes that me or our organization is a target – because I've witnessed other leaders where that is absolutely the case. I think it is particularly true that leaders in the consumer survivor movement can get chewed up and spit out. I use self-reflection to think about how I act or I think. I find you have to be careful reaching out for support because if you show your weak belly people may take advantage. This is especially true in a system where everyone is starving.

My recovery has been affected by conflict I encountered in my leadership role, during a time that I was particularly vulnerable due to grief. In retrospect, this problem could have been minimized or resolved by better orientation and education about governance, roles and responsibilities and by me recognizing sooner, how the person was affecting my basic nature and way of relating. I used this situation to learn when to draw a line in the sand; I think we all need to learn our boundaries and limits – how much we are going to take from people and how much we are going to let ourselves give, or give back.

Leaders in recovery are not here because we have to be, we're her because we want to be. Having said that, the reality is that to be on a Board or to be a member of a CSI, you have to identify as a consumer-survivor; when you become the staff or ED or whatever of one of those organizations that just ups the visibility. And that is as it should be if CSI's are going to remain true to their values. You are OK with being "out" but you wonder who's not OK with it… what if I might like to choose down the road to apply for work in some other sector? There's tremendous pressure to be a role model. Recently after a regional meeting someone said: you were very quiet in there and I thought: was that a clinical question; was that a criticism, or was that just a passing comment; does she think I'm not OK? Then I thought oh to hell with it – never mind she observed I was quiet – get over it.

I would like to see autonomy restored for all the CSI's and they would all be required to have a board of directors and be membership driven.

Portrait 4 – Lee (withdrew from the study for medical reasons before the focus group but wanted her narrative included)

My experience of mental illness took me very deeply into the system for over 20 years. I saw the system at its best and certainly at its worst. I've told my story across the country many times, for many audiences. My message is that people with mental illness are resilient, courageous, and we fight enormous battles. I aim to change attitudes. Currently, I am in full, joyous, blessed, recovery. It just feels like I've been given my life back.

Leadership with the association came from a very personal place, not necessarily the most positive place. When I talked openly about my experience on the psych ward, I was accused of airing dirty laundry – I rebelled against that and, as part of my own recovery, I pondered: what and why was I hiding? When I experienced remission I decided to honour my story and give back, repaying my karmic debt. I drew on leadership skills that I developed in my community development work. One of the things I say in my talks is that coming here was like I'd been on this journey to come to this place…this is my destiny.

I am Executive Director (ED) of a provincial association. While I am not convinced that the lived experience is a must to be the ED of this association - I think my personal lived experience adds a deeper "get it" factor. "Getting it" leads to real openness for people walking through the door; you are more likely to be open about what's happening to you, or your family, because the person at the helm willingly acknowledges she has lived experience and there is absolute safety in disclosing. I've never personally experienced the reverse that people would not trust me as an ED because of my lived experiences.

I have the best job in the world - I get to reach out and touch so many people with a message of recovery and hope. To me, recovery has two dimensions. The first dimension considers "who are you" - you are a person not a patient or client; you are a person, a mother or a teenager or a senior. The second dimension involves a quote by Bob Lester, from his own learning: "Life is not about waiting for the storm to pass, it's about learning to dance in the rain". That quote struck me between the eyes – that's what we do; we teach people how to lead their lives while coping with a serious illness. We teach them how to dance in the rain.

My background is in teaching. I had experience as a leader before I came to the association. I began in community development and assumed increasingly managerial roles. Because I had the skill set, I became an ED for many years with regional and interagency councils. Leadership is my nature. I started as a volunteer with this association in 1997. Later I became a member, then president of the Board of Directors. I became the Executive Director in January 2001.

Part of my leadership is to keep trying to push that envelope and respond to opportunities to attack stigma. I was always dramatic – I was always the entertainer. My dad used to call me – not Sarah Bernhardt but Sarah Heartburn, so for me, speaking and entertaining and getting people to laugh and cry just fed into my nature. I am comfortable with risk and pushing the envelope.

My strongest suit in leadership is vision; innovation and motivating people to engage. I enjoy working the turn of phrase that captures key messages and provokes change. My weakest area is HR management because I'm a bit of a softy. Day-to-day-operations is not my passion. I wear that pretty heavily; the pressure I place on the association to address awareness, education and advocacy. My lived experience, combined with my personality, drove this association; if I had been constricted to simply running our peer support groups, I would have just died.

I've been in therapy long enough – I think I have a realistic sense of my strengths and my limitations. I recognize that I have personal charisma, or touch, or whatever - that can get people engaged, committed and passionate about working together. Therapy built me up when I was pretty beaten down; I found my sense of worth and comfort with my skills. I learned to navigate my triggers, like conflict. People don't see the turmoil under my calm exterior.

I have a very good, supportive relationship with the Board of Directors; they realize I am thinking of staged retirement and we've started doing succession planning here, although I'd like to continue to do visionary work and public speaking and education.

Any organization will say that the elements of good leadership are skill sets and personal attributes; does that mean the experience of living with the illness adds to skill and attributes? There's no false modesty – I think I've shaped and branded and changed the organization for the good because based on my experience. I "get it".

I note the work of Bill Wilkerson, who engaged economic leaders to address mental health in the workplace; I was stunned when he did not disclose his own lived experience with severe depression until he retired. I thought: You're there trying to beat back stigma with a stick and yet you perpetuate it by assuming that people will think less of you because you have had the lived experience. It took me back to an early experience at our association when our return address was not on our envelopes because people wouldn't want that in their mailbox; I said: "You have to be frickin' kidding me!"

Portrait 5 – Lorne

For many years I had mood swings but declined medications. Instead, I worked with research to track my biorhythms. I used alcohol to take out the peaks and valleys. When I was thrown in jail, I gave up my drinking habit; this forced me to deal differently with the incredible mood swings. I decided to use medications that were recommended ten years prior that I declined because I didn't have the wherewithal to recognize I needed support. The effects of these medications were catastrophic; I no longer had fine motor skills to do art work and that broke my heart because I derived joy from my art.

I had a very negative way of thinking; I disliked myself and the world at large. My mind was filled with loathing. I didn't need anyone else to tell me how to run my life. I masked my self-dislike by attempting to become perfect; I was an over achiever in my work. I was trying so hard to be something else, trying not to deal with my personal issues.

I had an epiphany one day. I was reading a book and when I got to the last page of the chapter I wrote the word God, then when I turned over the next page the first word on the next page happened to be God. And an inner voice was saying to me, Lorne, listen up: I'll always be here for you. I recall it as being the first time in my life I did not feel alone, isolated and unworthy.

So, I decided to join DMDAO and the support group; I thought no one would understand, however I was mistaken because they did understand and also walked the path. Self-help was the best choice because I was a rebel; I really fought the system all the way down the line. I said, aha, here is a pathway to wellness and recovery which led me to take a year off work to volunteer – and I never returned to conventional work.

My background is in business leadership. When I was a boss, my job was to make sure my staff were happy in their work; that their ambitions and their hopes could be recognized. Really, they were the boss - sometimes I think we lose sight of that. I believe things need to trickle up rather than continue to trickle down because when it trickles up you get a deeper understanding of what really the needs are of the people you serve.

I believe that my illness was not an affliction so much as it was a gift; it demonstrated my humanness, a deep sense of connection and compassion, rather than my previous experience of being somewhat robotic. My relationships with people with lived experience reinforced my understanding that there was a great void; I felt people should participate more in shaping and designing their own treatment. I saw people who were being mistreated by a controlling system. I saw the pure injustice.

I acted for change in my roles as a member and chairperson on over 40 consumer-survivor and mainstream Boards of Directors at the local, regional and provincial level.

I simply love what I do. I am vigilant about my responsibilities. I honour and respect differences of opinion. I aim to work together with mainstream so they get greater satisfaction from a professional perspective, then I can walk away knowing that I've been dealing with someone who was willing to hear me rather than tell me what to do. I have social comfort; I never felt less or more than anybody. Here I am. I respect you, I'm grateful for you, here's my message.

Currently I lead a LHIN funded consumer program. Moreso I work as a recovery educator. I develop and facilitate programs to support people to take back control of their lives. My job is to say: help yourself to whatever I'm offering, leave behind what you don't want. I don't use the word help because if I'm helping you I had to see you as lesser than who I am. That's why I cling to the word service. I felt my job is to serve you; I bring to the table the skills or whatever it may be that I have acquired - and help yourself to it. You owe me nothing.

There is hostility in the conventional system without them knowing that they're hostile. In part I think this is because really, they have no control over what people actually do or think – how well we are. Whereas, in recovery we introduce a pathway to follow that recognizes a sense of well-being and self-acceptance.

Serving shapes me as a leader. My job is to simply listen. And if you ask me where I'm coming from these many years in the role of a leader my leadership is simply because I care and love; working from the heart. My job's not to – my work's not to tell people how to live their life but it's to be with them when they are living their life.

I come to my work from a deeper, philosophical perspective - the essence of service rather than the tasks or the relationship? I felt I was a token and my dissatisfaction with this pushed me on and on. I never believed in taking a revolutionary approach to things. I always felt that things would evolve by working with people respectfully – recognizing their understanding and bringing them to our understanding as well.

I say my message in my own annoyable way. I recognize that clinicians work in accordance with their credentials and their learning; they were doing the best that they could but not at the exclusion of the participation of the people that you are serving. I reframe the limitations of their expertise; they have not lived the experience.

I insist we are not our illness dammit. We're people. We have hopes, we have dreams, we have ambitions. In terms of advocacy, I've never backed away from the thorny issues. You don't have to accept what I'm saying I'm just sharing it with you in accordance with the question you've asked. But don't feel compelled, you know, to embrace my philosophy of my way of life. You have to do what you feel is right for you.

I really struggle sometimes but I do my struggles alone, despite having a wonderful support network. I keep my spirits up doing the work because when I'm with a group of people, this may sound strange, I always feel loved and accepted. The role of being an advocate and a leader was my pathway to recovery.

Portrait 6 – Sam

I have experienced mental health problems, employment consequences due to my mental health problems, and homelessness. I could not find services to address my particular problem. Because I had never been hospitalized, I was excluded from some services. I got involved in the consumer movement through my experience of frustration about the lack of services and the hurdles in the system. Here I recognized the importance of being with people who have similar experience, and receiving support. I was the first consumer-survivor clubhouse worker in Ontario.

My advocacy was a response to my quest for services and support. My seeking led me to the consumer-survivor initiative. This was pivotal. I became a volunteer at the CSI then a board member. Serendipitously I became president of the Board of Directors. The ED was a strong leader. She recognized my potential and encouraged and mentored me. I don't see myself as a leader, I led with others, like osmosis…but you know birds of a feather flock together.

I developed a critical perspective and became involved at a grassroots level, hearing about the real issues like the poverty, homelessness and exclusion. I was shocked at first to realize these applied to me.

I see myself as more of an advocate than a leader. I took on a formal leadership role by default. In retrospect, my role was to question; I was curious. I wanted to get to the truth; I wanted fairness. I wanted people to be heard and to have respect for one another.

I led by rolling up my sleeves; I was stimulated by meaningful projects and it was awesome to be supported by members and colleagues, who really helped me to grow. I enjoyed rising to the challenge. I was looking for responsibility to confirm my worth; I didn't have faith in myself. I was *able to get an infrastructure in place, with a grant for peer support, before I was reorganized back out of the system.*

I have worked in the trenches as a peer advocate and an executive director. I have worked through development and reorganization related to effectiveness governance and leadership. I drew on my inquisitive and sometimes challenging nature to push the envelope for change. Even though I stood out and I gravitated to leadership, I don't feel very confident as a leader. I am able to analyze and distil multiple messages down to the salient point. I think I am more adversarial than most people.

I enjoy connecting, engaging and motivating with people and I am confident around conflict resolution and community development. I prefer the creativity side of the work. I was less confident around governance and operations; it was not my nature. By the end, I made my point. Services have been developed are far beyond where I had even though back then; I feel like I've done my job.

At the beginning of the movement, we shared the same sentiment: give us resources, dammit! But supporting change was like pushing the rock up the hill. There were strong and passionate voices but no collective strategy or funding. Once people were listening, our statement broadened and disparity in terms of strategy was inevitable. There was disparity between economic development and support programs such as drop in and self-help.

Funding didn't come with expectations to sustain. They never taught our community well because they didn't expect us to succeed. Separate funding sources led to mistrust and lack of voice for many who felt less strong, who feared they would be subsumed and lose their interests. There were some fractious relationships and jockeying for position regarding systemic advocacy. Collectivity wasn't encouraged by the funders so stronger voices prevailed. One of the challenges of leadership is having others pull you back or sabotage you, and that experience eventually came along! We destroy our leaders; we eat them.

My advocacy led to a series of relationships that supported my recovery; however, the leadership role did not support my recovery at all. I was naïve. I didn't realize how fractious this sector can be; how politicized. We eat our leaders. I respect the passionate voices in the movement but I think I expected more sensitivity and compassion. I couldn't wait to get the hell out.

There is discrimination from within our community that doesn't accept wellness. We don't accept past struggles, only current proof. You're damned if you do, damned if you don't - you hide *behind a façade because if you show your vulnerability they'll eat you up; if you don't show it you have no credit.*

Things went further downhill after a personal loss. I needed to step away from the burden of responsibility for a while and think about where I'd been and what I wanted to be involved in. I don't feel healed; I've moved on. Now, while I'm quite comfortable to offer an opinion or some insight and make recommendations, I don't want to be a leader ever, ever, ever again.

It's not so much a workload as it is having to be on all the time that just grinds away at you. I was a voracious reader of systemic and mental health material in my last leadership role; when you do that you talk more about it and you put things together in your head - so you're on it all the time. Now I can't do it. I just can't focus, my mind's wandering and I think there's a part of me that's burnt out. Being a leader has taken its toll.

Portrait 7 – Tara (unable to attend the focus group but provided feedback regarding themes)

My personal lived experience includes the conventional medical system, which never provided any information or support other than medication. When I understood the survivor movement I began using recovery-supporting alternatives to medication.

When I first started working in this sector, I had no idea about the consumer survivor movement. I immersed myself in the movement when I saw that our program was failing its community. My experience with the movement opened my eyes to our common experiences and alternative perspectives. I knew that to be more credible we had to start working with this movement.

I think the movement is really evolving. People are leaving a sense of it behind and people are gathering new stuff. I'm terrified about when the strong voice of our leaders and advocates is gone. This generation though didn't have the very negative experiences that we can't forget, like 300mgs a day of Haldol. Not that its less oppressive now - I just think the stick changes shape maybe. People are savvier at a younger age.

My interest in advocacy and leadership grew out of my work. As I became socially and politically active, I challenged our programs ways of thinking and acting that duplicated conventional practices. I started to slowly incorporate an alternate worldview for our program. Six years later I was recruited to implement these changes as the executive director.

Survivor leaders often have interesting relationships with our boards because members are usually peers who often have no orientation, board development training, no role clarity. Often Boards of Directors put their fingers in places that they shouldn't. My board was really good in *terms of saying: let us know when you need us. But at the same time I wanted more direction and support.*

Due to circumstances, I was thrown right into the role of leader. The board knew I didn't have core operational skills but they supported me to develop my leadership capacity. Because funds and time for training was limited, I took online financial management and employment standards courses at night. I learned on-the-job.

I felt alone; leadership is lonely. I wanted support, supervision or coaching. The available training or support/advice is based on conventional thinking; there's nothing that meets our philosophy. We do poverty work - where can I reconcile my leadership skills for that? I had no relationships with survivor leaders; I was just some young kid up in the suburbs running a CSI. I relied on my friends who were really radical social workers.

My vision was to bring the movement home – to create a community agency run by survivors, with a different intentionality - a social service agency like any other but from a different standpoint. And we're doing it - we're a legit community agency and that's the way we're treated. I've only now started to give myself credit for the impact I've had. I'm walking out the door knowing I "brought the movement" home to our program. We are recognized as leaders in our own sector as well as provincial and national circles.

To make change, you've got to be a leader in your organization, in your organization's community and you've got to be a leader in the mental health system. And I don't think a CSI can be really successful unless they're a leader in all three.

We have to recognize the power we have when we are the ED. It doesn't matter if you're a peer, you're the ED and people understand how it works. You need to lead with credibility. You need to balance your mainstream credibility without losing your survivor credibility - which means sometimes advocating against the mainstream and still being able to keep all your professional relationships intact; it's about leveraging relationships.

To bring the movement home I had already established myself as a critic. And there's no way to not be critical; everything about the job is political. I think I'm pretty charming but if I wasn't a little bit sharp edged we wouldn't be here; charm with an edge means you can get more of your edge out. It's a critical anti-aggression perspective. You can have all the bright ideas you want but you must also be engaging.

A good leader hires good people. And then that's even a dilemma, you can't just hire "uber" survivors. People want to see you hire people that can sound like them and give them opportunities. Staffing a CSI must be both representative and developmental. A mainstream leader might say how do I minimize the damage whereas a survivor leader looks at the person with absolute acceptance and trusts that what needs to be done will get done. This has never interfered with work. It's only enhanced it. No one has ever taken advantage of it and no one's ever performed less than amazingly afterwards. I am frustrated when I hear conventional leaders consider employment for survivors - I've got 11 disabled staff - Are any of you talking to me about any lessons learned? No!

I had to tame my ego; I had a fancy title and I could hobnob with ED's of other large organization but I was still a tiny fish in a very tiny, little pond in terms of CSI's. You don't get into this work for career advancement; it doesn't sit well in the survivor movement. People in the survivor movement can smell someone they can't trust from miles away. They've honed that skill, right? We are standing on a whole community of people to which you're going to be accountable to. This is a steep pedestal to fall off; people are watching.

In terms of my own recovery, it's about balancing acts; there are a lot of dialectics in this work. I've been wondering as I change careers: when is a person no longer a consumer survivor. Is it when they decide? Or is it when they've been, you know, free of challenges, concerns or labels for a certain amount of time? Is it when you stop using your medication? Is there an expiry date?

My recovery has been wrapped up in this job. There isn't anything better for my recovery than to be effective and successful at my job. Work also created the diversion I need when things were tough for me; working a 12 hour day is a great way to not focus on the weird thoughts that are going on in your head. The external pressure was good for me; I had people I couldn't let down. I think my mental health recovery only comes when I am satisfied, effective and I have purpose. My experience is out there. I'm surrounded by a whole bunch of people that won't let anything happen to me. I work with my friends, with people that really care about me. There's safety in this environment that has allowed me to be immersed in my recovery.

Portrait 8 – Resi

My connection with the mental health system began at a very young age. It includes very long and recurring hospital stays. In my experience in hospital, I was isolated from the other patients. I was always behind this locked door, looking out so they figured I'd done something really, really bad - that's why you were locked up.

I was sparked by anger about the way I was treated, and the way others were treated. Part of the reason I've become a leader was to tell people who had taken away my hope, who had given up on me that they need to believe there is hope for people. I saw that they had written me off. They said I wasn't capable of education or work. They threw up their hands thinking we've done all we can; you are going to end up committing suicide – now take this prescription, it's the best we are going to offer.

Being an example is important for my peers but it is important in different ways for the "treaters". I needed to address injustice and discrimination. I knew this was wrong; it did not sit right with me.

I did not actively seek leadership, I sort of fell into it; I had this lucky star following me. When the hospital held an open forum for patients to share their experiences I was invited to attend. Not being anybody's fool, I went because I knew I would get my clothes, and be able to get out of my room! The forum was intimidating but with the facilitator's support, by the end I had agreed to continue with this group - the seed was planted.

It took me a very long time to find my voice. I found my voice to speak out for others first, then, because I saw my voice was valued, I began to value myself. I started to educate myself by attending workshops and extending my network of relationships with key people in the system. I became a member then Chair of a Board of Directors. I was nominated to be leader of a provincial consumer council by a peer who recognized my strengths in encouraging people to participate. I accepted these volunteer roles because I remained convinced that I would never be employed. But I wanted to do more. My work on Boards of Directors helped improve my communication skills, to be a better listener.

I've been employed as leader with our hospital's council for 15 years. I have a strong vision for peer support. I know that connecting with people who share the same experiences is supportive. I wanted to create a place that encourages people to seek their own wellness rather than stay stuck in a system that tells us what we can't do and keeps us in poverty.

I am constantly surprised when people see strengths in me. I'm not comfortable saying I'm a leader; I see myself as having influence. At first it was a shock that people were actually listening to what I had to say. I knew that with the power to influence and I must be careful to be clear about what is my own perspective and what has worked for me. I say: you can understand the lessons learned in that but you have to find and understand what works for you.

In terms of being a leader, I strive to set the example – I share my experience moving forward and how much more rewarding it is than staying where I was. I know how bad it has been, but I also know how good it can be. I don't want to let people down; once I make a commitment, I work hard to do my best so I don't disappoint people. It is part of my nature to step up when there was a problem. My approach is that although I am the chair, the group does the work; I encourage leadership within the group because that becomes my support as well.

I started in this work as the voice for others and then I developed my own voice. Now I support others to develop their own voice. My leadership strategy is to build and support leadership in others. It's about being available and being authentic, honest and open - sharing what I know. Courage is the ability to stand up and voice yourself – but its also knowing the time to sit down and listen. Some of the peers I have "led with" have become strong advocates and leaders on their own journey of recovery.

I see my role as supporting people to realize that they have the power to effect change. My message is that the power of voice effects change; people will change when they hear themselves – when they speak out. In my understanding of recovery I realize that empowerment has to come from within me. I strive to create an environment in which people can find and liberate their own power. I believe that when we fail in life, we learn. When the opportunity to risk or to fail is taken away from us by clinical paternalism, it is easy to fall into or stay in that comfortable role of being "taken care of". I hope that by being strong in my recovery I can inspire others to find strength within themselves, to assume personal responsibility.

It is difficult to be a leader and an advocate. Being recognized as a very public voice has caused people to treat me differently. The people who really believed in me stuck with me and the people who weren't so sure didn't stick with me. It is difficult for my family because they don't always understand what I do; they would like me to move on.

Advocacy was a big part of my recovery. That's how leadership came for me, through advocacy. I was trying to understand how and why things happened the way they did and to change things that were unjust. As I felt valued, respected and gratified as an advocate, I became more confident and comfortable. Over time I noticed I was starting to feel better; I wasn't using any of my old, harmful coping mechanisms. I don't know where I would be if I didn't have the opportunity to develop my skills and work as a peer leader.

I am strong in my recovery now, which guards me from burnout but earlier on I wish I had paid more attention to it because it led to re-hospitalization. Eventually, I became tired of being in the hospital and I realized that being in the hospital made my situation worse. Part of my recovery has been to say yes I have a mental illness and I'm in recovery and I am doing well. These staff had one picture of me and now they see me as a very confident, successful person. I share this perspective with psychology and social work students.

Portrait 9 – Brenda

I have both a personal and a family history. I learned of the mental health system through stories about inhumane treatments like ice water baths, hosing people down; about hiding people away. I wrestled with my own mental health issues. Even though my emotions and experiences were accumulating, I kept hiding it until I got to the point where I was completely suicidal.

I hid my distress because I thought I should be able to fix myself and I thought I should be happy. People thought I had such a great life; one that most people would see as ideal. I was married, children, a home in the country and we owned two businesses.

I put a lot of family pressure on myself; my responsibilities were such a huge weight on me. After I was hospitalized, the relationship with my family dramatically changed due to a lack of education and ignorance of mental health problems. It damaged my relationship with my children and affected many things in my future life. My parenting was undermined. It was a tremendous loss. At one point a family member said if she's not going to get any better then we might as well find a home and put her in there. The environment in my home did not support my recovery. I was given messages that I wasn't trying hard enough or that if I really wanted to get better I would try certain medications or ECT[3]*. I got angry, which was against my nature. And then three of my children dealt with mental health problems.*

As far as the recovery community, I feel I am very connected through-out the province and elsewhere. When you feel strongly about something, you become connected to those people who are on the same wave.

I always had a healthy curiosity or critique of systems; I homeschooled three of my five children. I began to question the mental health system from my first contact. Many of my experiences in the system were negative. I did not feel informed or included in my treatment. I was terribly scared about all the medications because they were not explained to me. I had to slink down the hallway to

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[3] Electro-convulsive Therapy ("shock treatment")

find a quiet place to sleep. I was accused of not wanting to get better when I declined shock treatment. I was told not to talk with other patients because that's going to hinder your wellness, even though I knew intuitively that most of my healing came from my peers who had the same experience. It made me think I could do something to make this different; it was the training ground for leadership.

I attended a couple of patient council meetings and I thought: I've got skills to be a good leader so I just stepped up to the plate and almost immediately became the chair. I come by public speaking kind of naturally in some ways because my dad was a story teller and I learned that art from him. I went from somebody who was secretive to the point where I said: enough, we need to get this out in the open and sort it out. I'm a giver; I like to help make things better and to make things happen. I joined the Volunteer Association at the hospital and I helped with various craft programs. I heard so much from other clients that made me want to help even more.

I became a leader intuitively at a grass roots level. I learned to value lived experience and I started to then value myself more. I advocated to have my work compensated. It impacted my wellness when I shared my ideas with people in the system and they were accepted and valued. I began to realize that they needed me and the input I brought. Now that I'm in a formal leadership role I see my role as building recognition for lived experience and promoting system change, especially around increasing peer supports as well as inclusion of people with lived experience in planning and decision making - nothing about us without us. I have strongly advocated for people to be recognized and compensated for their work in this area.

I'm not an activist because I see that as more political but I think I'm an advocate who challenges in a quieter way. I don't know if I even still see myself as a leader. But I know I am a leader with skills to mobilize other people; building strength among others. I'm using my experience of leadership to support my recovery but I'm also using my experience as a leader and advocate to support my recovery. I'm pushing myself in a new direction and taking on broader leadership roles in the region and in the province, including contributing to policy development.

The work that I do is from my heart. It's very tied up in my own experience and my wish and desire for things to be different and for integrity and autonomy for survivor organizations. My challenge is a lack of formal education at the university level; I don't have a CV, so there's certain things that I'd like to do, like survivor research, but I don't feel qualified. I would really like to see a coalition, like around the Emergency Department Diversion Project where we come together to *share our experiences and maybe there's a common model or common wisdom in there or maybe not. I'd like to bring people together without the old turf wars.*

You don't just talk about recovery, you have to do it. I don't accept the "try harder" message that I was given; the recovery message is "try different". I began to value myself more when my ideas and contributions were valued – my wellness improved as I became more involved and used my voice. My foundational belief is that I lost a couple of years in my life and it was horrible; I don't want that to be lost in not utilizing my experience for change.

Portrait 10 – Dylann

I have personal lived experience with mental health problems. I was once hospitalized where I now work. I knew then what would happen to me if I created any issues. When I left against medical advice they didn't stop me.

After I left hospital, I lived in rooming and boarding homes; it was horrible. That experience got me angry and I made a very strong commitment that I would do whatever I could to help people help themselves. I wanted to go back to school but there was no support from my workers who were adamant I should be content with my welfare cheque. This made me want to do it even more. It was always blaming the individual as opposed to our structures and systems that create classes, like we were losers.

After I learned I'd been accepted in school, I was on the streetcar, coming back to the rooming house, feeling so pleased with myself - then it all went up in the air when I saw lice crawling out of my daughter's hair. Seeing that lice was a turning point for me, the beginning of me not accepting what was the status quo. I started really questioning all these frigging professionals. It made it clear to me that society didn't value any of us. That's what made me angry.

I began working at an affirmative business run by consumers. It was a thrill; I learned so much and we were very successful developing and coordinating alternative businesses that demonstrated that people have skills and abilities. When we received a large grant to expand our work program I spoke at a big event at where all the bureaucrats came out - they had to wait for me to invite them up on the podium. One survivor came up to me outside on the sidewalk and said, "can you believe it, look at all these people - I think I'm proud." I'll never forget that day.

I always thirsted to make things right; social justice. I've witnessed people getting a light in their eye or the light bulb goes off. People used to call me angry and bitter and, yes I was, and that was good motivation. I didn't want to blow places up but I did want to see change. I used to just yell *at people all the time and get their backs up and that was kind of not worth it. It made me feel good but it didn't achieve anything. So now that I'm older I try to look at the bigger picture and what that's going to turn into in the long run. My biggest skill now is my ability to communicate across differences.*

I coordinate employment for people with lived experience in a conventional mental health institution. This initiative recruits and supports retention for people with mental health and addiction challenges and provides education and support to managers, directors, supervisors. Staff are physically shocked to see someone that they "worked" with clinically who is now healthier and more together. It changes staff perspective.

People are so surprised with our competence; it takes their breath away. When I started in this job, the suits they would stutter because I didn't speak their language, I didn't have my people (from the movement) who gave me strength. I was trying to be polite, trying not to be the crazy person, trying to have a voice, trying to work. It took them at least five years to be comfortable with me; just now they are asking me questions and being up front with me.

I miss my day to day interactions in the community (of survivors); I miss some of that camaraderie but I've replaced a lot of it with camaraderie here which is neat. And I have those ties with the people in power.

I don't feel comfortable with leadership because I'm not one person - I really draw on the survivor community. I'm just a cog in the wheel; the wheel is what you hop on to make your personal change. We're on each other's shoulders here. I have a lot of survivor skills that are easily transferable to the work that I do today.

My nature is to question. I notice injustice. In school, others wrote down what was said without question. I was stunned at their apathy and middle-classness. I was passionate in my arguing. My reality and what was being talked about in the academic world didn't match, at all.

Working on the inside has shaped my skills more around consensus building; solving the problem by working together for the middle ground. I re-coined the phrase poverty of soul. I see it not only in our population but I also see a lot of the victims of our workforces, right? As a leader and advocate I watch for teachable moments, when I can raise awareness and shift an attitude. It's getting people to a comfort level where they engage, being instinctive as a leader - using your gut.

It's hard to make the history of the movement clear to people entering the system now. I have what I call my matching furniture story; even though we had a grant to run our program, our power *was tenuous. We got it through partnerships and collaborations with people that cared and had the power. Younger survivors have a different experience; they don't have an understanding of that. They just saw the matching furniture and didn't see the struggle to get there; the fight to get there. And I think that's when the survivor movement started to fall apart. We need to know where we all came from.*

Care in psychiatric facilities is still not right. It's going to take years to shift this attitude. Saying they're adopting recovery principles is a joke; the resistance to change is significant. It's a buzz word. Recovery implies client direction; it implies a focus on social determinants of health and the value of experiential knowledge. Those with power won't let go of it. People need to have something to be proud about; they need to see a light at the end of the tunnel - they need the tunnel. I'm talking about getting the hope to hope.

Professionals say they need to learn about the real experience. In the last six years I've learned that it's a dog eat dog world. Stabbing in the back is very common. But if you give professionals an opportunity to support one another, to create change, that can be beautiful too. And the people who benefit are my folks (other survivors).

Published accounts: Judi Chamberlin (1998)

"Being a patient was the most devastating experience of my life. At a time when I was already fragile and vulnerable, being labeled and treated only confirmed to me that I was worthless. It was clear my thoughts, feelings and opinions counted for little…it was clear…[that I needed] professionals [making decisions and] running my life for me. For this total disregard of my wishes and feelings, I was expected to be appreciative and grateful. [I saw what happened to bad patients so] I told staff what they wanted to hear….In short, I lied. I did not cry and scream and tell them I hated them, their hospital, their drugs and their diagnoses, even though that was how I really felt….I was outraged. …My only aim during my…hospital stay…was to get out. [I]nside I nurtured a secret rebellion…in which an army of former patients marched on the hospital, emptied it of patients and staff, and then burned all the buildings to the ground…[while we] joined hands and danced around this bonfire of oppression.

"One of the elements that make recovery possible is regaining belief in oneself. Patients are constantly indoctrinated with the message, explicit or implicit, that we are defective human beings who should not aim too high. In fact, there are diagnostic labels, including "grandiosity" and "lack of insight" to remind us that our dreams and hopes are barriers to recovery instead of one of its vital

components…[t]here is something about being a "good patient" that is unintentionally perhaps, incompatible with recovery and empowerment.

"When many of us who have become leaders in the consumer/survivor movement compare notes, we find one of the factors we usually have in common is that we were labelled "bad patients". We were "uncooperative", "noncompliant", "manipulative" or "lacked insight"….[W]e were told we would never get better…But 25 years of activism in the consumer/survivor movement has been the key element in my own process of recovery. Let's celebrate the spirit of noncompliance that is the self struggling to survive. Let's celebrate the unbowed head, the heart that still has dreams, the voice that refuses to be silent."

Pat Deegan (2001)

"Prior to becoming active participants in our own recovery process, many of us find ourselves in a time of great apathy and indifference. It is a time of having a hardened heart. Of not caring anymore. It is a time when we feel ourselves to be among the living dead: alone, abandoned and adrift on a dead and silent sea without course or bearing. If I turn my gaze back I can see myself at seventeen years old, diagnosed with chronic schizophrenia, drugged on Haldol and sitting in a chair. As I conjure the image the first thing I can see are the girls yellow, nicotine stained fingers. I can see her shuffled, stiff, drugged walk. Her eyes do not dance. The dancer has collapsed and her eyes are dark and they stare endlessly into nowhere.

"During this time people would try to motivate me. But nothing anyone did touched me or moved me or mattered to me. I had given up. Giving up was a solution for me. The fact that I was "unmotivated" was seen as a problem by the people who worked with me. But for me, giving up was not a problem, it was a solution. It was a solution because it protected me from wanting anything. If I didn't want anything, then it couldn't be taken away. If I didn't try, then I wouldn't have to undergo another failure. If I didn't care, then nothing could hurt me again. My heart became hardened.

"[In my work now as an educator] I try to help students understand that although they do not have the power to change or motivate the person with a psychiatric disability who is hard of heart, they do have the power to change the environment, including the human interactive environment, in which that person is surviving…[E]nvironments must include opportunities for people to have accurate information. Information is power and information sharing is power sharing.

"People who feel powerless can increase their sense of self-efficacy by having access to information. People who feel powerless also feel that what they say does not matter. Taking the time

to listen to people and to help them find their own unique voice is important. Having a voice in developing rules as well as having a say in the hiring and evaluation of staff are important ways of exercising a voice which for too long has been silenced. Finally, it is important to have other people with psychiatric disabilities working as paid staff (peer support).

Role models provide hope that maybe I, too, can break out of this hardened heart and begin to care again.

"I cannot remember a specific moment when I turned that corner from surviving to becoming an active participant in my own recovery process…I know that anger, especially angry indignation played a big role in that transition. When that psychiatrist told me the best I could hope for was to take my medications, avoid stress and cope, I became enraged. (However, I was not smart enough to keep my angry indignation to myself because the #1 rule is never get enraged in a psychiatrist's office if you're being labelled with chronic schizophrenia!) I also remember that just after that visit I made up my mind to become "a doctor". I was so outraged at the things that had been done to me against my will in the hospital as well as the things I saw happen to other people, that I decided that I wanted to get a powerful degree and have enough credentials to run a healing place myself.

"In effect I had a survivor mission that I felt passionately about. Imagine what my psychiatrist would have said to me if I had announced at age 18, having virtually flunked out of high school, with a combined GRE score of under 800, with a diagnosis of chronic schizophrenia, that I was planning on getting my Ph.D. in clinical psychology. "Delusions of Grandeur!" But in essence that is precisely what I did.

"Recovery does not mean "cure". It does not mean stabilization or maintenance. Rather recovery is an attitude, a stance, and a way of approaching the day's challenges. It is a self-directed process of reclaiming meaning and purpose in life. It is a process that is marked by human resilience in the face of adversity. It is not a perfectly linear journey. There are times of rapid gains and disappointing setbacks…Each person's journey of recovery is unique.

Each person must find what works for them. This means that we must have the opportunity to try and to fail and to try again. In order to support the recovery process mental health professionals must not rob us of the opportunity to fail. Professionals must embrace the concept of the dignity of risk and the right to failure if they are to be supportive of us."

Mary Ellen Copeland (Mead and Copeland, 2000)

"When I was first diagnosed with manic depression at the age of 37, I was told that if I just kept taking these pills - pills that I would need to take for the rest of my life - I would be OK. So I did just that. And I was "OK" for about 10 years until a stomach virus caused severe lithium toxicity. After that I could no longer take the medication. During the time I was taking the medication I could have been learning how to manage my moods. I could have been learning that relaxation and stress reduction techniques and fun activities can help reduce the symptoms. I could have been learning that I would probably feel a lot better if my life wasn't so hectic and chaotic, if I wasn't living with an abusive husband, if I spent more time with people who affirmed and validated me, and that support from other people who have experienced these symptoms helps a lot.

"I was never told that I could learn how to relieve, reduce and even get rid of troubling feelings and perceptions. Perhaps if I had learned these things and had been exposed to others who were working their way through these kinds of symptoms, I would not have spent weeks, months and years experiencing extreme psychotic mood swings while doctors searched diligently to find effective medications.

"No one is beyond hope. Everyone has the ability to make choices. Even though health care professionals have traditionally been asked to define treatment and prognosis, they have to look through the layers of learned helplessness, years of institutionalization, and difficult behaviors. Then they can creatively begin to help a person reconstruct a life narrative that is defined by hope, challenge, accountability, mutual relationship and an ever changing self-concept.

Summary

These narratives represent the complex experiences disclosed by participants as they answered questions regarding their journey to become leaders and advocates. While all are distinct and unique, there are many commonalities that coalesce in themes. The key themes that emerge and are analysed in detail in Chapter Five are: a negative experience with the "care" system; the importance of voice and inclusion; and the significance of empowerment. These themes represent the factors that affect changes in thinking and acting, and contribute to a deeper understanding about how experience motivates and supports transformation. The themes will be addressed more deeply but it is clear that they can inform recommendations regarding the care environment, specifically strategies and practices that can support recovery and promote survivor leadership.

CHAPTER FIVE - DATA ANALYSIS: THEMES, FOCUS GROUPS AND MODEL VERIFICATION

Introduction

The research question used to frame this study is: What are the experiences of people in recovery in their journey to become leaders and advocates? The secondary questions that contribute to the systematic investigation are: How have people made meaning of their experience, and how have those interpretations shaped their personal constructs and their subsequent ways of thinking and acting? Qualitative methods were used to support participation and invite the multiple perspectives required to consider and appreciate the individual understandings and meanings proposed by this study (Schram, 2003).

Ten people in recovery participated in a semi-structured interview to describe their experience with the mental health system/recovery community. They also provided a description of how they became a leader or advocate. All but one of the participants is currently employed in a leadership role, working for organizations that expect them to operate from the standpoint of personal lived experience with mental health problems. During the interview, they were also asked to describe how they performed in leadership roles. Given the conversational nature of the interview, there were many rich digressions. The responses they provided described the impact of their experiences as it related to how they became involved in advocacy and leadership as well as the factors that support them in in these roles.

Narrative inquiry formed the basis of the semi-structured, conversational interviews. Narrative inquiry also supported verification of the expressed understandings and meanings relevant to the research questions (Clandinin & Connelly, 2000; Connelly & Clandinin, 1990; Jardine, 1992; Kamler, 2001; Krall, 1988; Polkinghorn, 1988; Smith, 1987). More specifically, critical narrative inquiry revealed the multiple and sometimes competing perspectives, experiences and dilemmas. Using a critical narrative perspective supported introspective critique for participants regarding their interpretations about becoming a leader (Berman, 1998) as well as their negative experiences with the “care” system.

In terms of process, each person participated in a semi-structured interview which allowed for relevant digression and in-time clarification of meaning. The interviews were transcribed then collaboratively reconstructed as abbreviated narrative accounts, or Portraits. Participants reviewed and approved the content of their Portraits, which were presented in Chapter Four. The analysis of the data included the thoughtful process of deconstructing context, identifying and assembling patterns, reconstructing collective meaning, developing theory and proposing conclusions.

The analysis of the data was undertaken using a variety of techniques and activities. The process I used demonstrates a systematic relationship of interaction and reflection (Denzin & Lincoln, 1994; Glaser & Strauss, 1973; Hamilton, 1994; Kirby & McKenna, 1989; Lincoln & Guba, 1985; Maguire, 1987; Miles & Huberman, 1984; Oakley, 2000; Spradely, 1980). In the course of developing the Portraits, full transcripts were carefully and repetitively reviewed and abbreviated. During this process, emerging themes and patterns in the narrative were recognized, compared and clustered into ideas that were similar and those that were singular (Crabtree & Miller, 1992; Denzin & Lincoln, 1994; Kirby & McKenna, 1989; Marshall & Rossman, 1989; Miles & Huberman, 1984; Polkinghorne, 1988; Schram, 2003).

The process that I used to undertake qualitative analysis can be found in Figure 1. (see Chapter 3). In most cases, the ideas presented in the narratives were consistent and little interpretation was required to decide regarding the themes. However, in keeping with the importance of collaborative meaning-making that is evident in qualitative research in general, and participatory and critical narrative inquiry specifically, participants must play an active role in not only confirming their own contribution but also in the broader functions of verification, clarification or correction of data and analysis to assure there is agreement regarding the ideas and concepts (Lincoln & Guba, 1985; Polkinghorne, 1988). Each participant endorsed a Portrait that captured the principal themes and events included in their narrative transcript. Preliminary themes were presented to the participants collectively and guided the group conversation that clarified, enhanced and verified the interpretations.

The key themes that emerged from the analysis of the Portraits are: a negative experience with the “care” system; a serendipitous entry into leadership roles; the significance of voice and inclusion as an operative factor in becoming a leader; and the underlying importance of empowerment. Another common element of the analysis was the reluctance of participants to describe themselves as “leaders”. In fact, many of them were surprised to be identified as such, despite their roles within their organizations. An overview of these key themes was provided to the participants in advance of a focus group in order to support their preparation regarding verification and enhancement of the data.

A single focus group was held to review the themes that were extracted from the Portraits and to correct, enhance or verify these conclusions. As noted above, the key themes were provided to participants in advance of the focus group so they could give thought to the collective impressions in advance and prepare (Figure 2). The focus group itself was a lively discussion confirming the themes identified from the Portraits. The participants also added detail that can be best described as the single theme of "appropriation". Appropriation will be described further below, however to summarize briefly: as a group, participants expressed concern regarding the popularization of "recovery" and the "take over" of programs and supports such as Consumer-Survivor Initiatives, self-help, and peer support.

A Consumer-Survivor Initiative is a program or organization that is governed and operated by people in recovery. These programs are currently funded by the Ministry of Health but funding is described as inadequate and "dooming them to failure" – hence the divestment of many such programs to conventional community mental health programs (Strong, 2009). The programs and supports delivered by Consumer-Survivor Initiatives (CSI's) have been identified as effective and now they see them being "subsumed" by conventional mental health programs which essentially corrupts their intention as consumer-survivor delivered. Appropriation appears to be related to an understanding of recovery that is more clinically oriented and an inability to appreciate the autonomy of peer operated and delivered supports.

Following the focus group, the final task for participants was to submit personal reflections in the form of responses to journal questions. This component of the study was completed inconsistently, despite several reminders and additional requests for information. Only four of the ten participants contributed to this component of the task. Of those who provided written observations, two participants provided a consolidated report that was a retrospective review of the four week period, rather than four separate reflections over the course of the period. Participants were apologetic in correspondence and cited their workload and time constraints as factors obstructing their completion of this task. It was decided by the investigator that the data collected by those who did submit would be taken into consideration, since it reiterated many of the themes noted in the interviews/portraits and, therefore, contributed to triangulating and verifying the findings.

Key Themes Revealed

a) Negative experience with the mental health system

A predominant theme that emerged from the participants' narratives is the common experience of negative and unsatisfactory experience with the medical/mental health system. While participants described some examples of positive or supportive "treatment", the prevailing experience was, and remains, negative. A subtheme of exclusion and a sense of not being heard or understood underlies the negative experiences. Examples of these experiences are provided below.

"The system is custodial; fear and ignorance result in discrimination and prejudice which prevents complete citizenship" (Art)

"When I had a negative experience with my first contact, I withdrew from the system". (Carol)

"The effects of these medications were catastrophic; I no longer had fine motor skills to do art work and that broke my heart because I derived joy from my art… There is hostility in the conventional system without them knowing that they're hostile." (Lorne)

"I got involved in the consumer movement through my experience of frustration about the lack of services and the hurdles in the system". (Sam)

"My personal lived experience includes the conventional medical system, which never provided any information or support other than medication". (Tara)

"I saw that they had written me off. They said I wasn't capable of education or work. They threw up their hands thinking we've done all we can; you are going to end up committing suicide – now take this prescription, it's the best we are going to offer". (Resi)

"Many of my experiences in the system were negative. I did not feel informed or included in my treatment. I was terribly scared about all the medications because they were not explained to me. I had to slink down the hallway to find a quiet place to sleep. I was accused of not wanting to get better when I declined shock treatment". (Brenda)

"After I left hospital, I lived in rooming and boarding homes; it was horrible… It made it clear to me that society didn't value any of us. That's what made me angry… Care in psychiatric facilities is still not right. It's going to take years to shift this attitude". (Dylann)

""Being a patient was the most devastating experience of my life… For this total disregard of my wishes and feelings, I was expected to be appreciative and grateful". (Judi Chamberlin,1998)

b) Evocation of anger as a motivator for change

Negative experiences with the mental health system evoked frustration, injustice and anger. These feelings became a motivator to change the system. A primary factor motivating change was to assure that other people would not have to endure the same negative experiences. For some, the wish to change the system was also related to protecting family members from the same fate. Examples of these comments can be found below.

"My advocacy was a response to my quest for services and support. My seeking led me to the consumer-survivor initiative". (Sam)

"I became a leader because I was not satisfied with the system and I wanted to work for change". (Art)

"I was sparked by anger about the way I was treated, and the way others were treated". (Resi)

"…[my] experience got me angry and I made a very strong commitment that I would do whatever I could to help people help themselves…I always thirsted to make things right; social justice. I've witnessed people getting a light in their eye or the light bulb goes off. People used to call me angry and bitter and, yes I was, and that was good motivation". (Dylann)

"I was so outraged at the things that had been done to me against my will in the hospital as well as the things I saw happen to other people, that I decided that I wanted to get a powerful degree and have enough credentials to run a healing place myself". (Pat Deegan)

c) Voice, inclusion and empowerment as a vehicle for leadership and advocacy

Essential components for effectively mobilizing anger and addressing injustice and dissatisfaction are *voice* and *inclusion*. For the participants in this study, it was important to hear and be heard. Initially, voice was realized through spontaneous or serendipitous engagement. The experience of feeling heard was transformative. Over time, participants noted that their voices have become more focussed and directed at broader audiences. Inclusion was often identified as serendipitous, which suggests that invitations to become involved or to share experiences were not strategic activities within the system. Similarly, except for a few experiences where there was a prior leadership relationship, participants seemed to "fall into" roles on Boards of Directors or Councils. In retrospect, although they did not feel well prepared for these positions, the participants see these experiences as pivotal in their current role.

The functions and activities that facilitate voice and inclusion relate directly to the realization of personal power from within: empowerment. This process is best described by Resi: *"In my understanding of recovery I realize that empowerment has to come from within me. I strive to create an environment in which people can find and liberate their own power. I believe that when we fail in life, we learn. When the opportunity to risk or to fail is taken away from us by clinical paternalism, it is easy to fall into or stay in that comfortable role of being "taken care of". I hope that by being strong in my recovery I can inspire others to find strength within themselves, to assume personal responsibility".*

Being public about their experiences occurred serendipitously for most participants when they were invited or included in activities which asked to hear their experience. *"Board membership provided a larger platform for advocacy and the opportunity to make important connections to advance" (Art).* When these activities felt safe, or productive, they liberated the person's voice. In the words of one participant: "*I did not actively seek leadership, I sort of fell into it; I had this lucky star following me. When the hospital held an open forum for patients to share their experiences I was invited to attend. Not being anybody's fool, I went because I knew I would get my clothes, and be able to get out of my room! The forum was intimidating but with the facilitator's support, by the end I had agreed to continue with this group - the seed was planted*" (Resi).

Voice is related to worth. Leading is associated with recognizing and supporting the voice and worth of others. Voice is personal and voice is collective. Clearly, it is important to use one's voice to talk about the experience of "illness", oppression and recovery. Examples of the impact of liberating one's voice are found below. The essential nature of voice and reluctant inclusion is well described by one participant who states: *"I took on a formal leadership role by default. In retrospect, my role was to question; I was curious. I wanted to get to the truth; I wanted fairness. I wanted people to be heard and to have respect for one another" (Sam).* Additional examples regarding voice, inclusion and empowerment are included below.

"We provoke change by talking about how we learn from our experiences of profound trauma, or depression, or the voices you hear… You loosen people up then poke this thing called mental illness. I want to work more to deconstruct consumer/survivor identity". (Art)

It took me a very long time to find my voice. I found my voice to speak out for others first, then, because I saw my voice was valued, I began to value myself…I started in this work as the voice for others and then I developed my own voice. Now I support others to develop their own voice… My message is that the power of voice effects change; people will change when they hear themselves – when they speak out". (Resi)

"I started really questioning all these frigging professionals". (Dylann)

"…[I] heard [peers] very differently than the other[s] - it touched my own lived experience… I see my role to be a collective voice of our membership". (Delia)

"I went from somebody who was secretive to the point where I said: enough, we need to get this out in the open and sort it out". (Brenda)

“Taking the time to listen to people and to help them find their own unique voice is important. Having a voice in developing rules as well as having a say in the hiring and evaluation of staff are important ways of exercising a voice which for too long has been silenced”. (Pat Deegan)

Despite developing leadership and advocacy for change, facilitated by voice, people did not feel fully prepared, and in most cases are not well supported in their new roles. *“Part of the reason I’ve become a leader was to tell people who had taken away my hope, who had given up on me, that they need to believe there is hope for people”*(Resi). Being a voice for hope and to speak up about injustice is only part of the function for these leaders in recovery. Each of them also holds a position of leadership at a funded organization or program. Therefore, a tension is created between doing what is wanted, such as using voice for change, and what is required, namely: functional operation of a program.

d) Preparation for the role

Participants describe very limited preparation for their work leading organizations. Participants clearly note that operational management is not only a struggle but also a barrier to their effective use of voice, or supporting liberation of voice with their peers. The pressure of running the organization restricts advocacy because it is time consuming and it stifles confidence. The credentials of lived experience are not well valued by conventional systems and institutions. Brenda indicates that lack of these “*CV factors*” affects confidence in the role. The journal submissions addressed more of the grinding day-to-day interactions and experiences. They reiterated and confirmed the accounts of the interviews, portraits and group. In addition, comments in the journal submissions articulate how the burden of operations negatively affects engagement and recognizes the art of balancing resistance. Working in a system where prevailing conventional ideas and planning may not be relevant to the task of operating a peer operated program produces a risk of having funds withdrawn. More examples are below.

“Becoming a boss was a huge learning curve; I made some mistakes and I learned some lessons”. (Delia)

“I prefer the creativity side of the work. I was less confident around governance and operations; it was not my nature… They never taught our community well because they didn’t expect us to succeed”. (Sam)

“…I was thrown right into the role of leader. The board knew I didn’t have core operational skills but they supported me to develop my leadership capacity...funds and time for training [were limited so] I took online financial management and employment standards courses at night. I learned on-the-job…I felt alone; leadership is lonely. I wanted support, supervision or coaching. The available

training or support/advice is based on conventional thinking; there's nothing that meets our philosophy". (Tara)

"My challenge is a lack of formal education at the university level; I don't have a CV, so there are certain things that I'd like to do, like survivor research, but I don't feel qualified". (Brenda)

As leaders and advocates, participants use their interpersonal skills to facilitate change. Change is difficult because they feel like outsiders, working from a position of lived experience that is not shared by their leader-partners in the conventional systems. It is difficult work because as Tara notes above: "*training or support/advice [about how to do the job of recovery leadership] is based on conventional thinking; there's nothing that meets our philosophy*". So, these leaders must use each other as supports to remain coherent in their approach, and this increases the difficulty because both their skills and their message is not well recognized by the dominant institutional structures.

"To bring the movement home I had already established myself as a critic. And there's no way to not be critical; everything about the job is political. I think I'm pretty charming but if I wasn't a little bit sharp edged we wouldn't be here; charm with an edge means you can get more of your edge out. It's a critical anti-aggression perspective. You can have all the bright ideas you want but you must also be engaging." (Tara)

"Our system is not based on a shared vision; there are too many camps, bickering about whose version of the truth is most accurate. One of the barriers to shared vision is a subtext of capacity - that consumers don't have the capacity for clear thinking". (Art)

"Early in my work I was involved with the Mental Health Task Force; I naively believed that it was changing for the better and I would be along for the ride". (Carol)

"…being collaborative and cooperative seems to be getting us nowhere just lately"; "I'm saddened when I see where they are conflicted between serving folks they are supporting within a system of barriers"; "So little of our work will ever be public knowledge". (In the presentation of data retrieved from journal submissions, participants will not be identified because the number of contributors was too limited. These comments represent consolidated journal submissions from three separate participants).

"Advocating to justifying your funding grants every year can wear you down". (Delia)

"Day-to-day-operations is not my passion. I wear that pretty heavily". (Lee)

"People are so surprised with our competence; it takes their breath away. When I started in this job, the 'suits' would stutter because I didn't speak their language, I didn't have my people (from the movement) who gave me strength. I was trying to be polite, trying not to be the crazy person, trying to have a voice, trying to work. It took them at least five years to be comfortable with me; just now they are asking me questions and being up front with me". (Dylann)

e) Reluctant leadership

Leadership is a title that participants have assumed with trepidation. There is a clear reluctance for people to name themselves leaders. In part, this reluctance relates to suspicion of labels themselves. But for most, the reluctance is related to their view of themselves as part of a shared process, with shared responsibility. This sentiment is well expressed by Dylann who states *"I don't feel comfortable with leadership because I'm not one person - I really draw on the survivor community. I'm just a cog in the wheel; the wheel is what you hop on to make your personal change. We're on each other's shoulders here".* This idea is further developed by Art: *"As a leader I seek to build consensus. I see strength in common ground. I have experience working from a common vision, principles and a shared dream".* Delia explains the functional differences between conventional and peer operated programs when she notes that: "*Organizations founded on recovery principles are built on relationships versus a hierarchy of structures".*

Interestingly, almost all of the participants were surprised when they were asked to contribute to this study. They did not see themselves as leaders. Also interestingly, before the focus group when they met the other participants, they frequently recommended each other as examples of leaders in the field. So, while they recognize leadership in each other, they are reluctant to recognize it themselves.

f) Recovery leadership

The idea of leadership is seen differently by participants. They see their work as different to leadership they have experienced in conventional mental health and social systems. For these leaders in recovery, they are *"not here because we have to be, we're here because we want to be"* (Delia). For these leaders, their work is their passion, their vision: "*The work that I do is from my heart. It's very tied up in my own experience and my wish and desire for things to be different and for integrity and autonomy for survivor organizations".* (Brenda)

The primary difference they note is the idea of leading "with" or leading by "example" to inform and influence people – but recognizing the power and responsibility inherent in their role (Fennell, 1999). Their wish is to build consensus and motivate agreement on principle then realize change collectively, by acting, recognizing as Deborah states "consensus can be really difficult". Resi expresses both her discomfort in being labeled a leader as well as providing an excellent description of the mantle of power and responsibility that is carried with the role: *"I am constantly surprised when people see strengths in me. I'm not comfortable saying I'm a leader; I see myself as* *having influence. At first it was a shock that people were actually listening to what I had to say. I knew that with the power to influence, I must be careful to be clear about what is my own perspective and what has worked for me. I say: you can understand the lessons learned in that but you have to find and understand what works for you".*

The lived experience of these leaders is essential to being effective in their work. As described by Lee: *"I think my personal lived experience adds a deeper "get it" factor. "Getting it" leads to real openness for people walking through the door; you are more likely to be open about what's happening to you, or your family, because the person at the helm willingly acknowledges she has lived experience and there is absolute safety in disclosing".* Yet, the work poses positive and negative consequences in the personal recovery for these leaders:

*"My work is healing; it gives me a different way of framing my experience. Recovery gave me a different lens in which to view my madness for me". (*Art*)*

"I lead by doing. The reality for consumer survivor initiatives and that's that there is so much work to do, and you see all the work that needs to be done, but there is so little support in terms of funding and staffing to do the job". (Carol)

"If I had not had this opportunity to work as a leader and an advocate I might not be facing these kind of personal crises but I don't think I would have grown as much either. Sometimes we need the trial by fire, right? You have to crackle a little bit". (Carol)

"My recovery has been wrapped up in this job. There isn't anything better for my recovery than to be effective and successful at my job. Work also created the diversion I need when things were tough for me; working a 12 hour day is a great way to not focus on the weird thoughts that are going on in your head". (Tara)

g) Tensions within the community

The confidence of leadership is undermined for some by the lack of coherent support and message from their own community. As one participant states: *"There is discrimination from within our community that doesn't accept wellness. We don't accept past struggles, only current proof. You're damned if you do, damned if you don't - you hide behind a façade because if you show your vulnerability they'll eat you up; if you don't show it you have no credit"* (Sam). Relevant to this understanding is the historical and reality of suspicion that Delia acknowledges: *"We do after all come from a sector that has traditionally found that everything one says will end up on some chart or record and be used against one".*

For some participants, this is about how they are defined – what are the criteria to be identified as a person in recovery, a person living with mental health problems or mental illness? Tara asks this question: *"…when is a person no longer a consumer survivor. Is it when they decide? Or is it when they've been, you know, free of challenges, concerns or labels for a certain amount of time? Is it when you stop using your medication? Is there an expiry date?"*

The most dangerous discrimination I have known is to hear that a person with lived experience, who has become a leader, cannot possibly be a "consumer" because they are too well. This insidious opinion is also apparent within the community. As one participant states: *"People forget or discount the hard work it took me to get, and stay well – it didn't happen overnight and it continues to fluctuate. Sometimes I need to disengage, to spend quiet time. The most severe form of discrimination is exposed when our competence is seen as evidence that we could not have experienced illness at all. It's disrespectful, it's disempowering - you don't know jack"* (Art). This reality is echoed by another participant who states: *"I find you have to be careful reaching out for support because if you show your weak belly people may take advantage. This is especially true in a system where everyone is starving"* (Delia). And, gaps in collective approach are noted by another participant: *"…supporting change was like pushing the rock up the hill. There were strong and passionate voices but no collective strategy or funding"* (Sam).

h) Appropriation of programs and ideas

Finally, participants express fear about competing for resources in a system where "*everyone is starving*" (a comment endorsed by all participants during the focus group). This may result in leaders within the consumer/survivor sector to "betray" (journal note) their peers or to articulate a message that is not coherent with the inclusive principles of recovery-supporting leadership. These breeches of faith from within the peer group of leaders in recovery increases the risk of being "co-opted" by conventional programs or organizations. Co-opting in this case is well understood by participants to mean that funding and, therefore, autonomy of peer operated and delivered programs are gradually being eroded and reallocated to conventional organizations. This understanding regarding appropriation and "co-opting" programs and ideas is well reiterated by Trevedi (in Chapter 13, Basset & Stickley, 2010). She characterizes her observation using analogy to The Emperor's New Clothes to articulate the inconsistencies between authentic ideology and practice.

Furthermore, language and terms are being used by the conventional system to mean something other than was intended – to the detriment of the survivor community. In the focus group, participants cited several “take-overs” of programs as well as their disappointment, and, in some cases, disgust with the appropriation of ideas such as recovery and peer support by the conventional system, and the misuse of these new ideas against their community (Strong, 2009). One participant is clear in her portrait: *“I would like to see autonomy restored for all the CSI’s and they would all be required to have a board of directors and be membership driven”* (Delia).

Based on the qualitative data extracted from the portraits and the preliminary interpretations articulated above, the theme Figure 2 below was produced and shared with participants in advance of the focus group. This Figure, and a description of the process that generated it, provided the participants with the consolidated experience of the group and proposed meaning that was emerging from all of the narratives. These consolidated themes facilitated participants to appreciate their experience in the context of their peers. It created a document to contemplate prior to our discussion and a guide for the conversation.

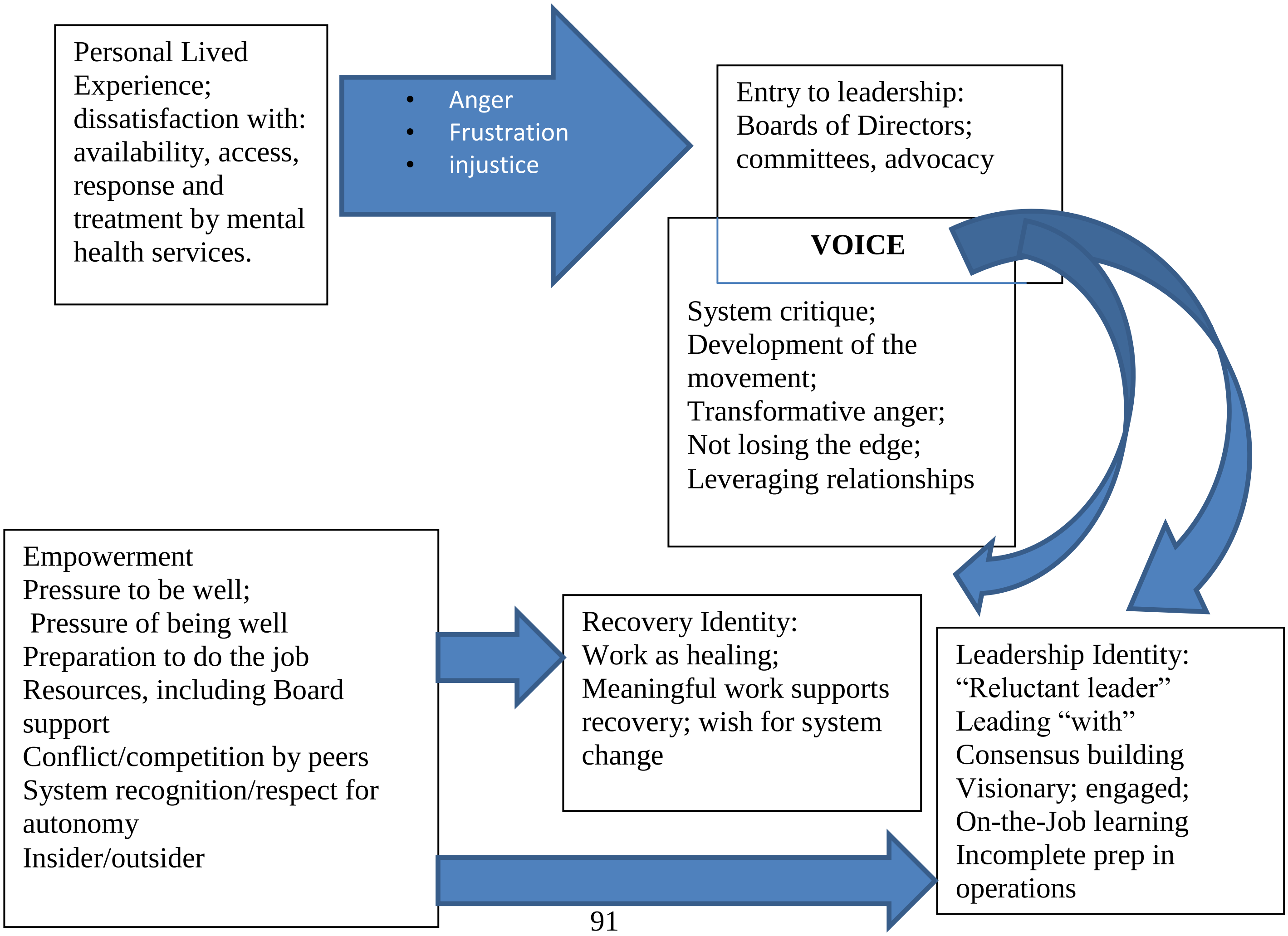
All participants were invited to attend a focus group. The purpose of the focus group was to review the emerging themes from the data and expand on preliminary interpretations. The focus group also provided a venue to correct and endorse the material. Two participants were not able to attend; one due to illness and one due to a scheduling conflict. The focus group was held in a central location in space agreed upon by the group. Lunch and refreshments were provided. Additional paper copies of the theme Figure (Figure 2) were available at the focus group. In addition, with the permission of the participants, one paper copy of each Portrait was posted on the wall of the meeting room so that narratives could be shared within the group. The group was scheduled for a two hour period, however in order to adequately represent all the voices and interpretations of the participants, with everyone’s agreement the session lasted three hours. Although the theme Figure was intended to frame the conversation, certain points of clarification were required. The voices of the participants have not been identified specifically. When several people agreed regarding experience or content, the “quotes” were merged.

Agreeing About Recovery

The first point of clarification the group wanted to address related to the concept of recovery. According to the group, recovery as a concept has been appropriated and popularized by the mainstream and conventional system. Although popularization of the term may demonstrate that survivors have been heard, all of the participants believe its meaning has been compromised. For some, the meaning of recovery is tenuous in the first place. It belies the medical origins of "recovered" which presumes one is moving along a continuum, which is simply a linear hierarchy denoting "improvement". Participants note that hierarchies have loaded meaning in the conventional, power-based interpretation. Participants agree that recovery represents a change of culture and language that requires more than just lip service and that they need to hold the system accountable for "walking the talk".

At least two participants resist understanding recovery as a categorization of "wellness" or a standard against one's wellness is appraised. The current use of the word recovery does not make obvious the importance of "taking control of your life" or "getting on with life". In terms of how the concept of recovery relates to this study, the group suggests that the idea must be deconstructed and the key points of "control" and "ownership" must be highlighted. Making obvious the person as the point of "control" will expose how the term recovery has been appropriated by the system as a tool to continue an agenda or model of care versus recognition of the person's journey of "taking back control of our lives".

Figure 2.*Themes and Themes Formation Process*



The Focus Group

Every participant has been involved with committees and boards of directors, as members and as leaders/chairs. This experience of leadership produced changes in the way they think about themselves or changes in the way they operate in the system. For some, the experience of leadership promoted system critique and "leading for" or "leveraging" change. For others, it was more about negotiating, nudging or gently pushing the system until it changed. Almost everyone said that using their *voice* for change, and being engaged/ involved in change, benefited their recovery. Recovery embraces and creates hope for change. A recovery identity shapes leadership because it accepts who we are. Therefore, comfort with oneself is realized and it supports people to use lived experience as a tool for change. Additional consolidated comments are below.

"I think the sense of ownership and control is fundamental. You know, we talked about self-determination and really it means that I'm in the driver's seat and that I am the one that decides what resources and what things I may do...I choose the environments, I choose the people who will be with me; we cannot have a recovery oriented process with coercion."

"I don't consider myself in recovery, whatever the hell recovery is. Recovery implies that someone's recovered or they're better; I'm the same person I was 30 years ago."

"We don't want to lose the critical deconstruction of recovery; it's about survivors leading for change; unfortunately it's become so watered down and it becomes something that people do to somebody as opposed to something I do myself."

"Recovery in so many ways is another buzz word; the phrase is being absorbed by the mental health industry."

The bottom line for survivors is getting on with life; more and more people want to measure recovery or quantify it add all sorts of weird shit to it.

A summary of the focus group was circulated to all participants and the following feedback was received: *Is appropriation of an idea like recovery actually a step toward shaping change; when ideas are appropriated, it acknowledges that the originators of the idea have been heard. Being heard, however, is not the same as being understood – it's about adopting our talk without the walk. This is an insider-outsider tension – to work on the inside for change, you have to meet the prevailing power (for lack of a better word) where they "talk" and push them out to the "walk". The insider (system) perspective is incomplete, it requires the outsider (survivor) perspective to realize meaning…but it is hard to penetrate [the conventional insider perspective] because they have* *the resources (power, funding, and privilege) and inclusion of outsiders requires an invitation – not just an invite but an honest will to hear and understand. This moves appropriation from an arrogant and simple application of a term like recovery to a mission statement (talking) to a real wish to change the on-the-ground experience of the people who the insiders are serving (walking).*

Clearly, concepts such as recovery are deeply embedded in experience and, therefore, impossible for people who have not experienced recovery to either appreciate or assume. To access the concept, one participant (Delia) was clear: those without the experience (outsiders) require an experienced interpreter (insider) to realize meaning. This proposed understanding from the focus group, adds more poignancy to the reality that the term recovery is branding institutional care and interventions. It also explains the obvious fears that all that "the movement" has accomplished is being appropriated and used against them. Finally, the definition of recovery that we agreed to as a group is: "*Recovery is the hard work a person does him or herself to reclaim/claim control over their lives, with the kindness and compassion of the people they choose to support them – in an environment that believes "I can*". This definition speaks to the essence of control and choice inherent in self-determination. It represents the *radical redistribution of responsibility* that I propose defines recovery. It clearly articulates the importance of hope and belief that *"I can".*

Agreeing About the Term Leadership

The second point of clarification required with the group related to the term leadership. As noted above, participants resisted being categorized as leaders. Most participants said the word leadership is tainted by the conventional understanding of leadership and power. In part, this is resistance to the conventional understanding of leadership as power and controlling others. In part, it is a realization that control has been exerted against them, with negative consequences, and they do not want to be associated with the term. More significantly, leadership suggests independent action which is not a way of thinking or acting for this group. With the exception of agreed upon tasks or jobs that require "leadership", participants in the study group do not identify as leaders. Additional comments from the focus group regarding leadership are noted below.

"the journaling is a real challenge. I don't think like that when I do my work. So I don't think, what's my leadership skill here? I can't relate to it…my thought process is on whatever outcomes I'm hoping to achieve on any particular day or issue or whatever."

"It's our experience as folks who use service that shapes the values and principles for the work that we do; so leadership is driven by our commitment and our passion for change"

“I don’t see myself as a leader. This is what I do. This is who I am. My experience has shaken me and given me focus. This is what I do.”

“Are we saying we rebel against power, a position of power? We’ve been in situations where we’ve been disempowered where other people have had power - do we refuse to take that position of power that says I’m a leader? But we’re not leading from a position of power…maybe I don’t want to say I’m a leader because then it sounds like I’m better than people or that I’m more powerful than somebody. I’m rebelling against that terminology because of the position of authority or power that it seems to bring.”

“leadership is being responsible – I think we’re all being responsible in trying to change what’s not working and trying to address the human right abuses”

“I’d like to enter the idea that everyone is a leader, that everyone has a potential to be a leader. Once a person can think about it and to take in information, educate themselves, have choice, then they become a ready – they’re in the process of developing their own leadership, their self-identified leadership”.

“Whenever you take a step forward, whenever you fearlessly use your voice, whenever you make – have more choice, whenever you exercise your own wishes, you are leading yourself.”

“People with inherent skills and abilities to take on a role are people who can exercise their own choice, their own judgment, their own whatever, when and how they want to do it. That to me is a leadership role…It’s a collective leadership not an individual leadership – unless it’s a task, then there is a responsibility; sometimes a burden”.

“I see leadership in the context of the movement... For me it’s about injustice and it’s about human rights…people do not believe the atrocities that still go on…”

“The idea of leadership is tainted. I think there is this false expectation in a subversion of process because if you’re painted as a consumer leader then by defacto, well, you’re the consumer - we’ll have you on this committee. And it’s like, wait a minute here. I don’t presume to speak for hundreds of thousands of other people. That’s disrespectful and that’s – that to me is a perversion of community and of collectivity. I speak from my own experience and I really would say you need to get more voices around the table.”

“Our leadership is not about different forms or different styles. It’s driven by personal experience. And it’s not in the literature.”

“I don’t want to be a role model but I hope that by what I say and what I do someone would be inspired to make a positive change. If I can inspire someone to see a strength within themselves to make a positive change then that’s what it’s all about…its inspiring hope; There’s the concept of power –If I’m a model then I’m expecting you to be like me. But if I’m inspiring I’m just putting it there and you can take what parts of it you want, right?”

“It’s about more than inspiration; it’s also practical - this is how I did it, perhaps you can do it too; You don’t have to do it my way but you can do it too”.

"It's about naming the problem but also identifying possible solutions. And it really is through telling stories and being an inspiration that perhaps that's maybe where the leadership is… we're willing to tell our stories and share our learning and basically say, yes. I've skinned my knees quite a number of times. And that's part of it as well."

In terms of doing leadership, the group does not endorse a conventional linear strategy of setting and working toward goals, objectives and targets. Rather, underlying all of the narratives and included in the focus group conversation was the idea of leveraging relationships and seizing opportunities to make change. The leadership that they describe is quite apart from their experience of conventional leadership, which they have experienced as neither authentically inclusive nor supportive. Tokenism and "*lip service*" compromise the real impact of their perspective and wisdom (Bishop, 2002). Recovery leadership is different. It is about being a person who is engaged and promoting a vision for change versus taking on the identity of being a leader.

Ideally, according to their descriptions, participants believe that there is more value in the means than in the ends. And yet, the reality for many is that the job of "leadership" in terms of their task or position is solitary because it is hard to engage others. In the feedback recruited subsequent to the focus group, the participants endorsed the following definition of leadership: "*People with personal lived experience appreciate that relationship and voice are critical tools to make obvious the need for system change. Working collectively, in relationships, leverages influence. Voice exposes the need for change. People use their personal lived experience, their experience of controlling their own lives, to provoke awareness and lead for justice and change*.

The Essential Role of Voice

A key factor in leveraging relationships is connecting with both the "inside" and the "outside" community, and this requires voice. Participants describe voice as operative. It is the first change that people recognize when they became involved. It is attached to the realization that "people listened". For the group, voice, especially common voice, validates similar or common experiences. Voice includes the dissatisfied or angry voice – demanding change and knowing it is the right thing to do. Voice was used to disclose personal experience; to make obvious the errors, problems and injustice in the system. Outrage and anger was articulated as a very common experience. At the same time, the group is suspicious of how voice can be exploited when a person's "personal story" is used for purposes that advance the system and are not intended to support recovery, when it is “taken to advance the system and not the person”. Additional descriptions of voice are below.

“I don’t see it as leadership, I see it as finding my voice - and not being afraid to use it. Each of us leads from that ‘we’ within ourselves”...It is critical to find opportunities to air our voice.”

“for a lot of folks finding voice starts with peer support”.

“one of my first experiences...was to hear psychiatric survivors saying, yes, I’m crazy…that whole time was just such an eye opener. And so not only was it inspiring but I think the important part is that it gave me permission. Because nobody was saying I could speak up. There was modeling… modeling a way of being that had been completely stifled because of what had gone on for me; what was going on for me. Modeling allowed me to find permission in myself with my newfound reality and gave me permission to act, to find my voice. So it’s not just inspiration, it is permission.”

“If you use your voice to make obvious the things that – or make legitimate the things that have not been just then suddenly the other person feels validated and inspired because you’re saying to them this wasn’t good and they’re thinking: I thought I was the only one that thought that.

“still they want to hear your personal story because it’s so inspirational; But I’m tired of telling my story; stories are exploited; People tell their story and I’m standing there like, go back to your organizations and talk to the people that are using your services…I worry about a lot of people going in and telling their stories…We’ll, pull you on the stage and let you bleed in front of everybody and no band-aid. It’s such ugliness.

“Voice is supported by being included in the conversation in the first place.... those having conversations need to be aware that we have a role and recognize when to invite us.”

“Voice is supported by information and the appropriate sharing of it – we often have no input or ineffectual input to events or plans, because of the Cone of Silence around processes.... Advisory groups for example – we invest so much time and effort, influence group recommendations, negotiate things to a place where we can support them... only to have bureaucratic process beyond our control completely change the group’s messaging to suit a political agenda or a plan that was predetermined in the first place – or worse we find that powerful subsets of the group or team have moved behind the scenes to secure self-serving outcomes.

“Voice is supported by breath. In our sector we are underfunded, understaffed, are running to keep up with ever growing and changing accountability mechanisms, and have simply not got the lung capacity to yell while we are running.”

Connection as it Relates to Voice and Leadership

Participants endorse a process of leading and advocacy that is collective. They describe being strong enough, or compelled enough, to speak up and be active in change because they were affected by others they met and connected with along the way. Every participant describes a common experience of anger, injustice or frustration, ranging from disenchantment to outrage. Using voice to disclose feelings of anger and justice or frustration led participants into “connections” with others. The other people were frequently peers and, sometimes allies within the conventional system. For some in the group, it led to the collective activism of “the movement”. For some it was serendipitous. People happened to meet the right person at the right time, or it was seeing a poster or being invited to a meeting. It was that opportunity to develop, to realize and use their voice to exercise that anger or injustice, frustration. Speaking out loud meant “*connecting with other people*.” Change happened in relationship. More comments regarding the change process are below.

“I wasn’t able to start to make sense of stuff until I started talking to other people who’d been there. And you can’t talk about recovery or whatever it is and the consumer experience – without talking about the connection to a community of peers”

“I couldn’t have done by myself. You just don’t go buy a book and all of a sudden everything is hunky dory. That’s what the culture would like us to believe. Or take a pill. Another thing you do on your own, right?”

“The whole leadership thing doesn’t come without a context. It’s not something that we just do. And this is why it’s hard to answer those questions because anything we do is done in relationship to someone or something else. Sometimes it’s being reactive but often it’s also being proactive. But it’s always got a relation to something else. And I think that’s what makes – for me that’s what makes it a little bit of different and harder to sort of grapple with because it’s done in relationships.”

“…we live our life but I make sense of my experiences through meeting other people. So we can’t forget the value of peers.”

The Tensions Related to Personal Lived Experience/identity

Participants describe a deep respect for their own personal experience. They also realize that they can never impose that experience onto someone else. The group sees a need to create environments where people can get in touch with, and use their own experiences to develop and exercise their own voice. Participants see their personal lived experience as a tool – something that they have used for personal change. Sharing their experience is a tool for others to change. There are various viewpoints on the definition and language of what is survivor and what is not. Being labeled a survivor is difficult. There is pressure to be well but not too well; there is pressure to be representative, not an individual. The importance of lived experience and the role of consumer, survivor, or person in recovery is expanded in the comments below.

"It's our insider knowledge that's important…I don't want to waste what happened to me even though it was really horrible; is there some way I can use that in the future to make it better not only for me but for others...it's making use of what happened."

"Although it was a terrible experience it set me in a new direction, a new path to my life. It channelled me in a different direction. The experiences that we've gone through have changed us…I never would have been here if it hadn't been for this experience."

"You are a survivor as long as you live, I guess…I don't think you change your identity; I don't define myself as a leader at all"

"There's the pressure of being identified in the role. It's like every word you say, if it's not quite recovery, you know, or it's not quite this, you're critiqued about everything…if we get ill and have to enter a program it's like, oh my God, you have failed so badly...we are so disappointed -- You can't do this kind of stuff because obviously it's too stressful for you."

"…it's a steep pedestal to fall off; Maybe that's why we don't want to take the name leadership because it's so far to fall… It's not a pedestal all the time. Sometimes it's a hole; A consumer identity creates big barriers and hurdles…There is pressure to be well or if you are in control of your life and you are functioning, then some people were saying then you're not a survivor; because you're perfect now; or you've never been that sick; you don't look like somebody with bipolar disorder don'tcha know; You must have been misdiagnosed, right?"

"I had to entertain three docs from Europe this past summer and they looked at me and said, well, obviously you didn't have a serious mental illness; it was said with such a calmness, assertion, arrogance, oppressive, basically these people were denying – at least ten people were at this group denying everybody's experience, right? It's like if you can say a word with four syllables then you don't have a mental health problem."

"But we do it to each other as well. I've had people say you're not really consumer enough. You don't have enough street credit. What does that mean then? Is my whole experience denied just because I managed not to let the system get me? Just because by shit luck I managed to stay out of it."

Leading for the Future

There was a strong sentiment during the focus group that it was important for this group to be together, in many cases: together again. Reconnecting and retelling experiences evoked a sense that the history of the survivor movement must be honoured and documented. "*The history is rather awesome and very worthwhile knowing, but we are losing it". "People need to know where we've come from to know where we're going*". Many members of the group were active in the original survivor movement in Ontario and they regret that "*essentially there is no movement today*". There is a sense that this is "*because there's no history; we don't call ourselves together anymore"*.

There was a sense within the group that people had lost their understanding about how "the movement" effected change. People do not understand how tenuous change is. There is a loss of memory about the "constant struggle" in the movement. Dylann recounted her "*matching furniture story*". When her program was finally funded and all the furniture matched, peers who had not been part of the struggle could not appreciate just how important this was.

Knowledge of the movement and its work is particularly lacking for people new to the system. In addition, the study group acknowledges that even though the work done collectively by the movement, and by this leadership group, has leveraged some change, it has not been enough. Nevertheless, some of the participants believe there has been enough change as a result of the movement's work so that people entering the system now are not experiencing as much anger and justice frustration.

Other members of the study group believe the intent of the dominant clinical system has not truly changed but it appears more engaging and humane. The number and availability of services have increased, which the group sees as a double edged sword "*because we are systematizing people earlier, so younger people don't understand the language". They don't understand the term survivor, consumer survivor. What does that mean? It doesn't really resonate". The group hopes to "figure out ways to find those voices that are wanting to be heard..."*

The idea that people with "mental illness" are part of "*mental health industry*" was proposed. "*It's really dawned on me the last few years – we're a market, right? We're a commodity and we're used for income generation to – or used to validate a science that's not a science and the agendas…it's the mental health industry*" (Dylann, with agreement from the group). This idea presents a new direction for anger and reiterates the complex and legitimate mistrust involved in appropriation. "*I see it every day… how they take words like recovery and talk about we're going to change a model of care that includes recovery…. So you really see what they're doing is marketing madness*" (echoed by several participants).

The impact of advocacy that increases services, demands inclusion, and attempts to normalize mental health problems has a consequence according to the participant group. They expressed concerns about over- and early- diagnosis and the ongoing reliance on medical and pharmaceutical interventions. The group wrestled with the idea that popularizing the terms depression and anxiety as a way to explain normal experiences such as loss and grief, or social problems such as abuse and poverty, further appropriates their authentic experience of intense and prolonged mental health problems. While they are reluctant to discount another person's experience of pain, they are also mindful that being diagnosed does not always correspond to their shared experience.

There is a sense of betrayal that their work has been appropriated and realigned to support ideals they do not, and cannot hold. Practices appear more inclusive and available but they have changed little – "*the language they use to oppress has changed*". Inevitably, when autonomous peer support and survivor operated services struggle to thrive on their minimal funding, they are *rescued* or divested to conventional organizations in the interests of commercial efficiency. The group expressed a sense of "*betrayal*" regarding the programs that have been "*lost*" to, or "*taken over by*" [conventional organizations].

Summary

Each participant co-created a Portrait representing their personal narrative. The qualitative data collected from portraits provided relevant information in terms of answering the research questions. The key themes that emerged were: a negative experience with the system which evoked anger, frustration and a sense of injustice that motivated each person to advocate for change. Essential to the function of advocacy was realization of voice and inclusion. Inclusion occurred serendipitously, for the most part, and comprised experiences that introduced leadership, including involvement on committee and boards of directors, which supported empowerment.

The focus group feedback deepened meaning regarding the idea of recovery and leadership, and verified the essential role of voice and self-determination. While the issue of preparation for the job of leading was raised in the portraits, the grind of working in an institutionally-based system was more prominent in the focus group. My own observations were that the group was generally well-acquainted prior to this meeting and many had close relationships in the survivor movement. There was a common tone to the voice of the group. In some cases, people were able to finish sentences for each other and say the same things at the same time. They were clear, as a group, about how the system appears to have changed but really they believe it has simply reconstructed how we see it, or want to see it.

These leaders in recovery struggle with a system that they believe does not easily welcome or value the critique they provide as a result of their experience. They note real fear that a system that does not recognize the distinctness and autonomy of peer operated and delivered services and appropriates concepts such as recovery and peer support will continue to "take-over" their work. The sense I was left with following the focus group was how important this group felt it was to reconnect at a time when they have been harbouring similar fears and advocating in isolation.

Finally, the experience of these leaders in recovery is verified by the experience of Judi Chamberlin, who became a strong leader for recovery and system change in the United States. Her comments reflect the importance of reconsidering the usefulness of labels that denote defectiveness and the destruction of hope by people who do not understand the importance of believing in the potential of recovery. She verifies the significance of questioning apparent authority and power and using voice to speak out against the ways we have been “indoctrinated” to understand “mental illness” and recovery:

“When many of us who have become leaders in the consumer/survivor movement compare notes, we find one of the factors we usually have in common is that we were labelled “bad patients”. We were “uncooperative”, “noncompliant”, “manipulative” or “lacked insight”....[W]e were told we would never get better… But 25 years of activism in the consumer/survivor movement has been the key element in my own process of recovery. Let’s celebrate the spirit of noncompliance that is the self struggling to survive. Let’s celebrate the unbowed head, the heart that still has dreams, the voice that refuses to be silent…“One of the elements that makes recovery possible is regaining belief in oneself. Patients are constantly indoctrinated with the message, explicit or implicit, that we are defective human beings who should not aim too high. In fact, there are diagnostic labels, including “grandiosity” and “lack of insight” to remind us that our dreams and hopes are barriers to recovery instead of vital components…[t]here is something about being a “good patient” that is unintentionally perhaps, incompatible with recovery and empowerment” (Judi Chamberlin, 1998).

CHAPTER SIX – RESEARCH SIGNIFICANCE AND IMPLCATIONS

In this study, people who identify lived experience with mental health problems were asked to reflect and share their experience of becoming leaders and advocates in the mental health system. Nine of the ten participants in the study were, at the time of data collection, employed as leaders in regional and provincial organizations that expect them to operate from the standpoint of their personal lived experience. One of the participants held several executive volunteer leadership positions. Several of the participants were actively involved in prominent provincial as well as national initiatives related to the mental health system. Participants provided narrative data in semi-structured interviews that were jointly abbreviated to produce Portraits that can be found in Chapter Four.

From these Portraits, the following key themes related to initiating and supporting leadership and advocacy emerged: a negative experience with the “care” system; a serendipitous entry into leadership roles; the significance of voice and inclusion as an operative factor in becoming a leader; and the underlying importance of empowerment. In addition, participants expressed a common concern regarding “appropriation” of concepts such as recovery and effective programs such as self-help and peer support. In addition, participants acknowledge limited preparation for their roles and suggest that relevant education is required to promote and sustain leadership and advocacy in the consumer-survivor field.

Within the scope of literature produced by either people in recovery or conventional clinical or academic researchers, there is very limited content related to recovery leadership or the factors that affect its development. Therefore, this research is important in terms of recognizing the effects of self-determination and empowerment that support people in recovery to become leaders and advocates who contribute to decision-making in the service system that concerns them. As noted, there are very limited programs for learning about advocacy and leadership, and specifically the supervisory and management skills required to operate a peer-operated organization.

What are the experiences of people in recovery in their role as leaders and advocates? How have people in recovery used experience to re-shape their ways of thinking and acting as leaders and advocates? Qualitative methods, specifically critical narrative inquiry, supported participants to reveal the multiple perspectives that affected their transition to becoming a leader. Collective meaning was verified in the focus group conversations regarding the factors that initiated advocacy and leadership: negative experience with the “care” system that produced anger and a will for change. Similarly, the factors that support and sustain leadership were also collective: the importance of voice, inclusion and empowerment.

Published accounts of well-known leaders and advocates lend additional weight to the "rich description" (Denzin, 1989; O' Reilly-Fleming, 1993) provided by the study group. The use of these existing accounts further confirms the interpretations. This process of "triangulation" provides trustworthiness and credibility to conclusions. It also adds richness to the description and depth to the meaning (Denzin, 1989; Denzin & Lincoln, 1994; Golafshani, 2003; Guba & Lincoln, 1985). Using published accounts verifies the interpretations derived from the experience of the study group against examples of similar experience (Denzin & Lincoln, 1994; Miles & Huberman, 1984).

In the course of semi-structured conversations, participants described their experience with the mental health system. They reflected on their experience of being diagnosed or labelled and provided commentary regarding their *care.* These accounts are poignant and reveal how devastating and isolating the experience of mental health *care* was for them. The narratives in this study are very similar to the experiences described by people who contributed to the Kirby Commission in their review of mental health services in Canada (Kirby, 2006). People responding to the Kirby commission also reveal frustration, anger and resentment about the *care* they were given by the conventional mental health system.

While recognition of anger and resentment led participants to awareness and introspection, a turning point for most participants was realizing their *voice* to speak up for change. Voice, or the process of speaking up and speaking out about their experiences, led to inclusion and empowerment. In this study, inclusion is interpreted as an appreciation and utilization of the experience of people affected by the system, and an authentic wish to understand the thoughts and ideas of people in recovery. In this study, empowerment is understood as an internal reckoning of strength, the will to act for personal and system change, and a belief in one's potential. Participants described how these factors influenced them to become leaders, or advocates within the system. The published accounts echo both the sentiment and the importance of voice, inclusion and empowerment.

During the focus group meeting, participants collectively endorsed and enhanced the themes emerging from the individual narratives. Specifically, participants confirmed a negative experience with the mental health system that was, and remains self-defeating. Frustration and growing appreciation about the injustice of these experiences provoked anger and a will for system change. The participants realized that their voice, and having their voice validated, contributed to their motivation to assume roles as advocates and leaders. Voice, empowerment and inclusion are interrelated components supporting leadership and advocacy. The essential elements of participant experience is supported by evidence in the literature that personal and world views are substantially influenced by forces such as social hierarchies, conventions and regulations (Clegg, 1989; Foucault, 1980; Foucault, 1988; Held & Thompson, 1989; Lather, 1991; Poggi, 2000; Smith 1991, 1999; Stark, 1971), and mediated by participation (Freire, 1999; Hall, 1981; Hall, 1975; Selener, 1998).

Theoretical Arguments for Thematic Agreements

a) Frustration, injustice and anger as a motivator to change the system

The primary factors that inspired advocacy and leadership for the participant group were frustration, anger and a sense of injustice regarding their experiences in the system. Judi Chamberlin, a survivor from the 1990's expresses it succinctly: "*Being a patient was the most devastating experience of my life… For this total disregard of my wishes and feelings, I was expected to be appreciative and grateful*" (Chamberlin, 1998). The devastating effects are echoed by participant Resa: "*I saw that they had written me off. They said I wasn't capable of education or work. They threw up their hands thinking we've done all we can…*" Participants understand that their identity or who they were was constructed and reinforced by a dominant discourse (Clegg, 1989; Foucault, 1980; Foucault, 1988; Lather, 1991; Pérez and Montes, 2007; Smith 1991, 1999; Stark, 1971; Walker, 2006) that was illness and deficit oriented. The idea that there is something "wrong" with them produced and sustained hopelessness and shame. Their identity, or how they interpreted their personal construct, was based on how they were perceived (Butt, 2008; Kelly, 1955; Mezirow, 1990). Their reflections also recognized that oppressive environments and relationships extinguish hope and fuel discrimination.

Discrimination and oppression formed a part of the participant's negative experiences within conventional mental health services. They described experiences of disrespect and disregard that compounded feelings of being deficient. Their strengths and capabilities went unrecognized. According to Carol: "*A turning point for me was my involvement in a [peer] drop in program where I felt accepted as normal….*" Each participant expressed anger and resentment about the *care* they received and the clinical impressions that limited their recovery. Deegan (1995) describes the experience as "*outrage*". Participants in the study described themselves as "*sparked by anger*" (Tara) and "*thirsting to make things right*" (Delia). They knew this *care* was not supporting them to grow and they did not want others to endure the same treatment. They wished for acceptance and respect for their histories; they wished to be heard and included. They hoped for justice and self-determination.

One resource for additional published narratives that endorse and verify the experience and interpretations of the participants in the study group is found in a collection of stories called “Shrink Resistant” (Burstow &Weitz, 1988). In the preface, legal advocate Carla McKague states that the stories document “experience [that] is, with few exceptions, one of degradation, depersonalization, forcible and extremely unpleasant treatment, and deprivation of almost every right that people in the community take for granted” (Burstow &Weitz, 1988, p. 15-16). These narratives disclose examples of experience that led to the development of the survivor movement that many of the study group became a part of.

I am touched by these stories because I was part of some of them. As a student and a young nurse, I worked in some of the facilities cited and I knew some of the narrators personally. Dr. Burstow (1988) was a professor I studied with. These narratives were hard to read and easy to doubt but in the final telling, I had to appreciate them and their authentic account of what these experiences really meant to the people affected. This is the task of the listener – to hear the voice. To believe that, regardless of my interpretation, the meaning held by the teller is accepted as inherently true. This differs from the role of the therapist, which is to deconstruct, reconfigure and re-align thinking, or cognition toward rationality (Alford & Beck, 1998; McNamee & Gergen, 2004; White & Epstein, 1990).

A significant moment of reckoning for me reiterates the importance of accepting the truth of the person. On the most extreme edge of the literature reviewed for this study are the accounts of people who describe abuse at the hands of care providers and those who established the Ontario Coalition to Stop Electroshock (Burstow &Weitz, 1988). While it is unheard of now, when I began my career as a mental health nurse, Electro Convulsive Therapy (ECT) was administered in the “sunroom” on the ward, with no drapes or privacy. Later, we were more aware of privacy and used a treatment room down the hall from the ward. I did not question this practice but accepted my duties of assisting in the procedure. Assisting meant intubating, placing electrodes on the temples and counting the seconds during which the seizure lasted.

Many years later when I was working in the community, I was asked to “back up” a colleague who was going on maternity leave. One of her clients, who had been involved with the hospital and in our outpatient program for many years, indicated that she preferred that I not be her case manager. I was shocked; I thought we had a good relationship after these many years. The departing case manager informed me that this woman was haunted by my face, which was the last thing she saw before each treatment, bending over and getting ready to assist. She did not wish to discuss this with me and I accepted her wish. Now, in retrospect, after realizing how important it had been for her to disclose this experience, I wish I had taken the time to apologize to her. I use this experience of regret to show how complicated a history of *caring* and being *cared for* is – and how important it is to reveal and correct the wrongs.

b) Voice as access to inclusion and empowerment

While participants were becoming aware of the injustice and oppression in their experience, they also held self-identities or constructs that assumed they were not capable, or worthy. These identities silenced them until various and often serendipitous events occurred to provide a forum to speak up and realize their voice. By speaking up, the participants developed and communicated their critical perspectives and questioned and reconsidered their experiences. Consistent with the literature, speaking up facilitated both introspective reflection and empowerment. (Brookfield, 1987; Cranton, 1994; Foucault, 1980; Hinchey, 2001; Lather, 1991; McLaren & Giarelli, 1995; Mezirow, 1990; 1995; Smith, 1991).

Speaking up, speaking out, and being heard was noted as a turning point for most participants. Voice became the essential component for effectively mobilizing anger. The experience of feeling heard was also transformative. Voice and inclusion supported them to advocate. It supported them to actively question injustice and dissatisfaction (Brookfield, 1987; Hinchey, 2001; Lather, 1991; McLaren & Giarelli, 1995). Burstow (1988) also recognized the significance of voice when she stated that "professionals use speech to oppress people who…have no say about what happens to them, and they are not listened to and believed" (p. 22). Although the experiences collected by Burstow and Weitz represent the mental health system of twenty to thirty years ago, these comments echo the narratives of the participants – the significance of voice is also reiterated.

The narratives demonstrate the impact of how using voice and facilitating inclusion relate directly to the realization of personal power from within: empowerment. Voice, in their experience, was a vehicle that supported the development and utilization of a critical perspective and its questioning nature. As Resa explained earlier, when she "*saw my voice was valued, I began to value myself…In my understanding of recovery I realize that empowerment has to come from within me. I* *strive to create an environment in which people can find and liberate their own power."* In effect, Resa became different; she (re)established her identity or construct.

c) Inclusion: the function of participatory processes

Finally, realization of voice facilitated engaged participation (Deegan & Drake, 2006; Freire, 1999; Held & Thompson, 1989; Selener, 1997; Smith, 1991; Starratt, 2003; Tosh, Ralph & Campbell, 2000; Townsend, 1998). Effective realization of voice was not just the action of speaking up or speaking out. Participants also cite the importance of being heard, both by their peers as well as by care providers. Voice and being heard supported empowerment. Many participants specifically describe thinking *"I can"* and *"I will"* in terms of re-valuing themselves and reclaiming their hopes.

Participants agreed that experiences of voice influence one's sense of value. The act of speaking up and the results of being heard resulted in their interpretation, or belief, that their environments supported expression of ideas. Supportive environments facilitate inclusion and welcomes new ideas. Consideration of new ideas supports acquisition, integration and application of new knowledge (Clegg, 1989; Held & Thompson, 1989; Lather, 1991; Poggi, 2000; Smith 1991, 1999; Stark, 1971). Reflective critique and reconsideration of ideas produced new systems of meaning (Mezirow, 1990) for participants. By thinking and acting differently, and by realizing and interpreting new experiences, participants re-attributed and re-configured how they interpreted themselves (Butt, 2008; Kelly, 1955), and developed identities as advocates and leaders. Voice and inclusion led to relationships with peers and service providers that supported personal shifts in role and identity.

Several of the participants described this transformation in terms of becoming passionate about the vision for change then building strong and inclusive relationships to advocate for change. Inclusivity meant both individual and collective voice. Inclusivity and collectivity meant that peers agreed change was important and it meant that there was shared commitment to make it happen. This is the phenomenon that supported "*the movement*" (Dylann; Sam; Art & Lorne) leading to the development of peer-operated programs and organizations in Ontario. Many of these programs are still viable but according to participants, their continued autonomy and their ability to compete for funding are threatened (Strong, 2009).

Inclusion is an important commitment in the work of the study group. They describe their leadership and advocacy as grounded in participatory and empowerment focused principles. Literature regarding the social nature of knowledge construction (Butt, 2008; Clandinin & Connelly, 2000; Cranton, 1994; Freire, 1999; Hall, 1981, 1992, 1993; Kelly, 1955; Mezirow, 1990; Selener, 1998; Vio Grossi, 1981) accepts that strategies for transformation are interpersonal, reflective and participatory. The narratives in this study support the operative effect of voice as a transformative element. For these leaders, as in their recovery, they appreciate that change occurs in relationship, and their leadership strives to develop relationships for change. The stories expose the interactive, dialectical conditions that are evident in relationships, and support change.

Participation is a dialectical process that values experiential knowledge as fundamental to understanding and meaning (Hall, 1981, 1975; hooks, 1994; Schram, 2003; Selener, 1998). Inclusive participation requires safe and authentic opportunities to be curious or even sceptical. Genuine and equal dialogue invites and facilitates open consideration of current circumstances and it also poses consideration of alternative understandings. Participants reiterate Giddens' theory of *structuration* (Held &Thompson, 1989) when they indicate the essential nature of inclusion. People in recovery require fair access to the power structure (Delia) and the resources inherent in the system in order to meaningfully inform the delivery, of services and supports, and effectively negotiate and evaluate their effect.

The experience of this study group suggests that the conventional power structures that control information and choice disable participation and restrict resources. Participants clearly state that people in recovery, and specifically leaders of survivor organizations, must be included as equals in the structures that affect information and choice. A perspective of mental health recovery values participation as a tool not just for personal growth but also as a means to critique power. In this way, participation addresses oppression and discrimination toward a hopeful end of wellness, empowerment and personal responsibility (Copeland 1997; Deegan, 1988; Mead & Copeland, 2000; Onken, et al, 2002; Storey & Shute 2009; Storey, 2007; Storey, Shute & Thompson, 2008; Storey & Shute 2009). Recovery-supporting thinking and activities require meaningful and generative engagement and participation.   Freire (1999) describes these as conscientization, or a process of raising awareness for transformation with liberating effects. The individual and collective narratives in this study confirm the impact of participatory engagement and the process of conscientization in the development of "*the movement*" of psychiatric survivors. They endorse the generation of knowledge through a participatory process.

Shifting Identities Through Role Reconfiguration

The participants in this study confirmed the role of voice and the experience of being heard, authentically and safely, as a transformative factor in their personal change. Voice precipitated the feeling of inclusion. Inclusion helped them establish their collective voice, through which they became activists and advocates for change. Becoming an advocate and leader represented a change in thinking, attitude and behaviour. This change required adjustment in the understanding and application of the social roles and norms to which these participants had become accustomed and into which they had to fit.

Adjusting roles within a social structure that has nurtured and sustained them is no mean feat. According to Durkheim (1966), collective representations convey the way in which a group understands itself and its understanding of itself depends on its relation to the nature of the environment, or its society. Participants understood themselves as deficient, disordered and "wrong" because this was the message, or the norm, within which they lived. Their identity was consistent with how they were seen and accepted by others. When their understanding of self began to shift, the social understandings that were previously accepted, dissipated. When they became represented as a "*movement*" they acquired a new understanding of themselves in a new set of norms and roles. Durkheim describes this existential transition of moving through normlessness as anomie (Neves, 2003; Poggi, 2000).

The conflict faced by a person experiencing anomie is that one cannot respond to two sets of norms or expectations. One cannot be a silent mental patient and an advocate who speaks up. A shift must occur to realign and bring integrity to one's role. New light is shed on the insidiously socialized understanding of process and language. As an example, in my clinical work I have witnessed people change the meaning they ascribe to events and experiences. I have worked with people who have experienced sexual or physical trauma who often feel they are to blame or responsible for the abuse. They assume they were provocative or "willing" when in fact they were in a power-based social setting in which they could not compete with the (often adult) perpetrator. In therapy, I have supported people to awaken to the social factors and norms of power and obedience and (re)consider their experience.

We are not generally aware of our socialization. This is what makes it such a powerful element of our social construction. And this is what makes moving through anomie a difficult process. We become aware that we were being socialized when we begin to critique our experiences and our environments. We operationalize this critique using voice and inclusion. Participant experience mirrors Durkheim's theoretical explanation. Role change aligns norms and attempts to bring integrity to the obvious and not-so-obvious network of social understandings.

This is the shift that Carol notes: "*I noticed quite a change in my comfort and confidence, and my ability to cope. I believed I could deal with the job so I applied for it and earned it*". The journey for Sam included his shift in appreciating his capabilities: "*I enjoyed rising to the challenge. I was looking for responsibility to confirm my worth; I didn't have faith in myself*". Resa reiterates the transition of role as it relates to redefining her norms: "*As I felt valued, respected and gratified as an advocate, I became more confident and comfortable. Over time I noticed I was starting to feel better; I wasn't using any of my old, harmful coping mechanisms. I don't know where I would be if I didn't have the opportunity to develop my skills and work as a peer leader*".

Becoming different for the participants was a function of being aware and active in their social understandings. They negotiated transitions. As Kelly suggests, we develop our personal constructs by accepting and collecting new and alternative truths (cited in Butt, 2008) that reconcile personal and social influences and interpretations. Each participant changed in their journey to advocacy and leadership. The change reflects their competence, confidence and comfort. Through voice, inclusion and empowerment their sense of personal and systemic responsibility has been radically redistributed.

Practical Realizations and Implications

Voice and empowerment awakened participants to become active but the group was almost unanimous in recalling that they felt unprepared, unsupported and frustrated in the early stages of their work. They persevered and "learned on the job" but for several, they were unable to access the training they needed to produce a real sense of competence in the role. Even though these people are now accepted as effective advocates and leaders, they have underlying doubts about their abilities. They indicated a certain reluctance to identify as a "leader". In part, this theme supports a recovery perspective. Their strong commitment to inclusivity and collectivity affirms values that they see as different to the conventional clinical hierarchies they were/are motivated to change. In "leadership" their hope is to radically redistribute responsibilities.

To effectively redistribute responsibilities, people in recovery must realize, address and overcome imbalances in power. On one hand, they must awaken and appreciate intrinsic factors, or their inner strengths, to realize empowerment. On the other hand, they must account for extrinsic factors and infiltrate relationships that position them to seize power. Intrinsic and extrinsic factors merge in the experiences described by participants in this study. They became different. They engaged differently with others. These changes are consistent with Freire's (1989) theories of empowerment and liberation which propose that extrinsic factors such as engagement and participation alter the power base and support empowerment and self-determination.

Most members of this study group endorsed a serendipitous or simultaneous operation of inclusion and empowerment, primarily through the experience and function of voice. Invitations to participate and speak up about their frustrations with "care" were turning points in their capacity to effectively critique and challenge the mental health system. Inclusion, realizing voice and adopting a critical perspective altered their identities and their appreciation of personal and collective agency. Their experiences verified that empowerment and agency (Berman, 1998; Storey, 2007; Wandrei, 2003) are a function of acquiring the critical perspective that supports introspection and personal change.

Supporting Change

The narratives shared by the participants demonstrate that change is complex. Their narratives also describe the social and systemic barriers to change. These observations are consistent with Giddens' (1984) concept of agency and its connection to personal change. Agency is an outcome of empowerment that supports self-determination. It requires access to resources that promote and support change and transform power (Clegg, 1989; Giddens, 1984; Held & Thompson, 1989). The participants affirm the importance of resources as a requirement for a *redistribution of power and responsibility*. In part, the resources they require are personal and support their ongoing recovery. Resources are also required to support ongoing participation. Resources such as funding are essential to effectively support their work. In this study, personal change preceded systemic change. Yet, systemic factors are both catalysts as well as outcomes of one's changed ways of thinking and acting - one's construct or identity.

Giddens and Kelly endorse recursive transformations of identity. Our ways of knowing and understanding ourselves is reproduced and defined through successive situated social practices and outcomes. For the participants in this study, their self-view, identity or construct was (re)produced by the social rules that ascribe and define power and privilege, within the context of being identified with, and being given *care* for their mental illness. Voice and inclusive participation promoted empowerment and transformed identity. Based on the recency of participant descriptions, the system has not yet risen to support the next point of change, transforming itself.

The resources that are required to sustain personal, collective and systemic change are not fully available to leaders in recovery. According to participants, programs are poorly funded, investments in leadership education and support are minimal to non-existent and the value of peer support and peer leadership remains undervalued. Peer leaders need an infrastructure of resources to advocate for change. They require resources to sustain a strong network within their ranks to support the inclusive representation and collectivity that is vital to their recovery perspective.

Leadership Challenges from Within

Collectivity is messy. Participants note that critical appreciation of the system and willingness to speak out is not consistent within their ranks. While participants were respectfully guarded about their internal relationships, almost everyone described peers who were either unfamiliar with the historical struggle of their movement or who were perhaps less informed or advanced in their critique of the system. Tensions emerge when resources are scarce and when agreement is difficult to reach.

Collective debate and agreement for some people is trumped by funding or service allegiances. It is difficult to disagree with or critique the hand that feeds you. These situations reiterate the power imbalance and undermine the critical perspective that supports recovery. They fragment the peer group, which threatens genuine collectivity. Fragmentation of a peer group occurs in the absence of resources that bring people together, particularly when the getting together relates to an autonomous agenda.

Participants note that invitations to participate can in fact be invitations to nod and support programs, plans or ideas for which no real advice or consultation has been sought. This group of participants was seasoned in their work. They were aware of the politics of the role. They were reluctant to criticise or deprecate a peer who held opposing beliefs but in their discussion of internal challenges, I interpreted otherwise. There is a sense that peers who were not operating from positions of empowerment and self-determination had been used as vehicles to support the conventional system agenda. By default, this undermines a strong consumer-survivor agenda. The reverse was also described: peers with lived experience who supported a conventional agenda did not fully support an alternative perspective, for a variety of reasons including socialized understandings.

Leadership Challenges from Without

Recovery leadership is just that – leadership operated by people in recovery. Identification for this role requires a person to disclose personal lived experience and lead from a standpoint that values this experience as a factor for change. It is the lived experience that accounts for the difference in understanding and approach in the role. But this experience is not always believed. For instance, participants all described situations where their experience of mental health problems had been discounted because they were now "well" or they must "never have been sick".

Delia recounted an experience of orienting a group of prominent international psychiatrists to her program. After assessing her as a competent guide, they discounted her life and work experience, insisting that her diagnoses must be wrong. Tara described being told she was "*not consumer enough*" to be a peer representative at a regional planning table. Personally, I have encountered scepticism about my own lived experience. Certainly, a doctoral student could not have mental health problems; there must be another explanation.

Stereotypic views that characterize people who have lived experience with mental health "diagnoses" and "treatments" as incapable of critical thought or articulation of alternate ideas indicates deep and insidious discrimination. The assumption that a capable person could not have lived experience because they don't "look" or "sound' the part, reveals equally insidious discrimination. A person who has been participating in peer recovery education revealed in a conversation recently that she had become aware of the praise and recognition she received for completing tasks, which in some cases were routine. As with the participants in this study, her new understanding of this paternalism had been instrumental in awakening her voice and her advocacy.

Being included and using voice supports empowerment and wellness, yet wellness is often tenuous. While most participants saw their advocacy and leadership work as healing, many also reported that the work can produce set-backs to their wellness. In particular, participants noted that pressure to perform and produce in the absence of resources conflicted with their work to support their recovery and self-determination. Self-doubt about their preparation for, and ability to do the job also affected their recovery. The work of these leaders is unique. They are leading programs that support people facing multiple social problems. Tara was clear that there was no training to do "*poverty work*". Nor was/is there training to navigate the various issues related to their standpoint regarding homelessness, criminalization, and trauma. The work is hard and the pressure to be well and strong in recovery is met by the paradox noted above. Current wellness discounts previous experiences of despair and suffering.

Appropriation of Programs and Ideas

Finally, these participants realized that many of their hopes and wishes are apparent in the concepts and programs that had emerged from their own movement. They knew the effectiveness of self-help and peer support. They appreciated the nuance of recovery as a personal journey and not a clinical approach or model of care. They saw that a recovery perspective required a *radical redistribution of responsibility.* Having *recovery* become a focal and branding point for conventional services is a double-edged sword. On the one side, if the conventional system uses the idea of *recovery* to assure inclusive, compassionate and self-determined *care*, then the objective of these leaders and advocates has been met. As feedback from the focus group suggests, *"…the idea of recovery is actually a step toward shaping change; when ideas are appropriated, it acknowledges that the originators of the idea have been heard...*"

On the other hand, as Delia says: "*Being heard is not the same as being understood – it's about adopting our talk without the walk*". The group expressed doubt and, in some cases, scepticism that the system truly understands the nuance of recovery. Without real understanding, the word is used but the intended change is stalled. When a system that does not appreciate the nuance of recovery decides to orient its patients and clients to the concept, the understandings are further corrupted. To appreciate the nuance and align its true wish for change, the system must hear and value the experience of people in recovery, specifically the leaders and advocates. The system needs to listen to the real experience.

Everett (2000) cites survivor feedback: Professionals "*don't really mean it….I don't think a lot of injustices are purposely done. I don't think [clinicians] set out to be unjust. It's just something that happened by chance or happened because they didn't take the time to listen. They didn't take the time to analyse the situation*" (p. 121). The system is like me, it needs to hear and know how its work intentionally or unintentionally effects the people it is meant to "*serve*". It needs to hear that people are haunted by your face because you were party to their ECT, or their involuntary commitment or their inability to obtain life insurance, and so on. It needs to appreciate how, despite compassionate people, its machinery dehumanizes and systemically discriminates.

As the focus group summary feedback indicates "*The insider (system) perspective is incomplete, it requires the outsider (survivor) perspective to realize meaning…but it is hard to* *penetrate [the conventional insider perspective] because they have the resources (power, funding, privilege) and inclusion of outsiders requires an invitation – not just an invite but an honest will to hear and understand. This moves appropriation from an arrogant and simple application of a term like recovery to a mission statement (talking) to a real wish to change the on-the-ground experience of the people who the insiders are serving (walking)".*

Another alternative understanding of "walking" together is that people in recovery are resources for each other and that self-help and peer support are effective components of recovery (Fukui, 2010; 2011). Autonomous peer support requires peer leadership and program operation. Peer support that is operated by conventional programs may not be free to serve the agenda and wishes of the people it is meant to support (Strong, 2009). Preliminary evaluation of the Peer Recovery Education For Employment & Resilience (PREFER) Program notes significant impact for peers participating in WRAP, Pathways to Recovery; Gaining Autonomy with Medication (GAM) and Like Minds Peer Support Education (www.cultureofrecovery.org). Appropriation of peer programs was hotly debated in the focus group. Participants shared stories about which Consumer Survivor Initiatives and peer operated programs had, or were about to be "*taken over*" by conventional organizations.

Appropriation of peer programs proves the system's misunderstanding regarding the nuance of recovery. It disregards the *insider* expertise. It verifies a disbelief in the capacity of peers to deliver effective alternative support. One reason participants say they are given to explain "*take overs*" relates to consolidation of "*administrative functions*" (Strong, 2009). This explanation reiterates the misunderstanding of nuance and fails to recognize and appreciate the power imbalance. Based on the feedback by the study group, the system is disconnected at an authentic level with their intended vision for reform and how it can be achieved.

Interpreting the Findings as Recommendations

1. Appreciating recovery as a radical redistribution of responsibility

While participants wrestled with their collective understanding about the concept of recovery, and, in one case, an unwillingness to use the term, it was clear that their interpretation of recovery is a process of transformation that includes choice and empowerment. Based on the experience described by participants, although they hear some basic recognition and support regarding the concept of recovery, the conventional system is not operating with the same understanding of recovery as consumer-survivors. As Art notes: “*We don’t have a collective understanding of recovery. I shudder when I hear people say, yes, we do recovery*”.

For some participants, there was a stronger belief that the system is exploiting (my interpretation of their general conversation) recovery to enhance a vision of a reformed system. “*Saying they’re adopting recovery principles is a joke; the resistance to change is significant. It’s a buzz word. Recovery implies client direction; it implies a focus on social determinants of health and the value of experiential knowledge. Those with power won’t let go of it*” (Dylann). For some other participants, there is hope that the system is becoming gentler and more inclusive. Nevertheless, there is no coherent understanding of what is wished, what is intended, and what is possible. Perhaps it is ambitious to expect such agreement.

The agreements that ought to be pursued relate to what a recovery-supporting system looks like or how recovery-supporting programs function (Onken et al, 2002). Language that states “recovery-supporting” is significant because it makes apparent that the person is responsible for his/her own recovery and the services that support it. This is the nuance that participants doubt many in the conventional system appreciate. Debate regarding what recovery means to people who are doing it and how it can be supported, is important. Brenda states: “*You don’t just talk about recovery, you have to do it. I don’t accept the “try harder” message that I was given; the recovery message is “try different*”. Orienting partners and peers to recovery ought to be the role of recovery leaders and advocates. Proper orientation requires adequate funding.

2. Opportunities for voice and inclusion

Being included and being heard were turning points for most participants. As Brenda states in her Portrait: “*I began to value myself more when my ideas and contributions were valued – my wellness improved as I became more involved and used my voice*”. In each of the narratives, participants indicated that they were motivated to speak up to make clear that processes were unwanted or unjust and to work toward correcting the problems. Most of the opportunities for inclusion were serendipitous and participants gradually learned on their own how to realize and exercise their voice. The function of voice and participation complimented empowerment and deepened inclusion. Being heard validated a new personal construct or identity for participants.

To promote leadership for people in recovery, opportunities for voice and inclusion at all points of service are critical (Janzen & Ochocka, in press). It is equally, if not more important, to welcome voice and inclusion at points before a person engages with conventional services. At these early points, peer delivered supports and navigation can certainly make a difference. Participants in the study, as well as the published accounts I have included, suggest that they were not asked about their circumstances or their experiences in a way that was meaningful to clinical understanding or informing *care.* Sharing decision making (Deegan & Drake, 2006; Crickard, 2010; Rapp, 2010) is a collaborative process that requires accessible information, attention to power-based barriers and adequate time to support dialogue. There are frequent references to practices that “silence” people in the unbalanced power structures that comprise clinical relationships. In order to support emerging advocates and leaders, services should be based on strategies that promote self-determination and empowerment, and that invite and welcome questions, discussions and especially challenges and even disagreement.

Consumer-Survivor initiatives and peer support programs demonstrate to people that voice and inclusion are possible. Having these opportunities accessible for more people can promote and support use of voice and meaningful inclusion. Evidence from peer support education I have been involved in suggests that participation in meaningful and critical discussion with peers has an emancipatory effect (Storey, 2007). For most of the participants, involvement in Boards and committees presented the opportunities for engagement and participation in the system. Peer support for members of Boards and committees can facilitate the development of confidence and skill in speaking up and using voice.

The participants were generally not supportive of “testimonial stories” that adhere to conventional agendas and rely more on illness orientation than recovery and wellness. Some participants found them exploitive and no longer respond to requests to “tell their story”. A new format to “stories” would unfold with an agreement about recovery as a redistribution of responsibility. People would share more about their strengths, their hopes and their recovery than about their diagnoses, hospitalizations and challenging behaviours. Stories in this case would promote recovery-supporting use of voice. Developing a strategy for voice and inclusion would be a reasonable task for recovery leaders to undertake collectively.

3. Realigning planning and programming

With a common understanding about recovery, planning and programming would focus on engaging and understanding. It would be important to recognize, utilize and develop strengths, and support self-determination. Services would be inclusive and invite voice. Common approaches to treatment such as psychotropic medication would be introduced and recommended in alternative ways. Medication is a choice that many people *use* to support their recovery. This statement articulates the nuance of self-determination and the active function of "use" not "take. Mueser et al. (2002) completed an extensive review of the literature regarding illness management using medication and recovery. Interestingly, their conclusions support the idea that people must understand not just what medication they are "given" but why they are "using it". They note the importance of self-awareness to appreciate the intended and unintended effects of medications, which support the person to use it. Mueser's study found that when people are invited to discuss and compare experiences, and when they are supported to critically assess and consider treatments like medication which supports the realization of self-determination, there is a better effect.

These findings are consistent with the theoretical underpinnings of this study and, I propose, would be replicable with treatments and services other than medications. Participants in this study and the people represented by published narratives repeat their experiences of being medicated as a routine or first line of *care* without full understanding or inclusion in discussion – essentially without informed choice. Informed consent is an interactive process. Service planning and programming ought to be an interactive process. Despite that, in my experience, the language and message of services is to be client driven and to be "partners in care", the actual experience of the participants does not align. As Dylann described (abbreviated in the portrait but reiterated in the focus group): "*Care in psychiatric facilities is still not right. It's going to take years to shift this attitude"*.

Participants indicate that their personal recovery work provides a basis from which they gather and utilize strength. Recovery-supporting programs are required components of all systemic service planning. Recovery occurs in relationships, therefore, interactive approaches and activities ought to form the basis of service planning and programming. A common understanding for the participant group was the essential nature of peer support and self-help as a complimentary or alternative component of recovery. Several of the participants are educators in peer support programs or operate peer support/self-help programs. All planning for recovery-supporting programs must, therefore, include peer support and self-help. Participants were also certain that peer support and self-help programs should be operated by peers. Delia's belief was validated in the focus group: "*I would like to see autonomy restored for all the CSI's and they would all be required to have a board of directors and be membership driven*".

Autonomous peer support provides an internal infrastructure of support for role and skill development as well as comfort and confidence. Peer operated programs can broker service to conventional programs to provide coverage. This not only assures integrity in meaning regarding recovery, it also promotes employment and leadership development. Recovery happens in real life. As Art suggests: "*I see my work as leading for recovery... I talk about recovery; I have and promote the honest conversations we must have about the supports, services, options, tools and resources required to make informed choices about how we "get on with our lives*". Planning for services and supports must take into account the world, the social experiences, in which people live. It must consider the effects of poverty (Tara) and the multiple barriers and discriminations people in recovery face. According to Rapp et al (1993), empowerment-oriented outcomes in service must address community, citizen and environmental impacts.

4. Supporting recovery leadership – Relevance of education

Leadership roles for people in recovery are important. They promote the standpoint of lived experience and verify the expertise of experience. As Delia states above, the conventional system is incomplete. It needs the insider perspective to plan, deliver and evaluate its *care.* Leaders are models that demonstrate the potential of recovery. Advocates provoke alternate ways of thinking and doing related to a particular understanding of the issues, based on their personal lived experience with mental health problems and the mental health system.

Leadership is understood by participants as a power-based activity or one that ascribes a solitary or representative authority for systems and tasks. They see their function as leaders to: inform; promote discussion and understanding; and negotiate consensus. Their perspective on leadership is tainted by negative experiences in a power-based clinical system. As such, while participants in this study identify as people advocating for change, they reluctantly identify as leaders. A distinct appreciation of recovery leadership is lacking.

Most of the participants describe minimal preparation for their work as leaders. Specifically, there is little education regarding the nature of leadership in the field of peer operated, recovery programs. Tara put it well in her comments: "*I felt alone; leadership is lonely. I wanted support, supervision or coaching. The available training or support/advice is based on conventional thinking; there's nothing that meets our philosophy. We do poverty work - where can I reconcile my leadership skills for that?*" In addition to the core business of supporting peers, participants said they had little orientation to the role and lacked formal training on critical elements of the job (e.g., budgeting, project management and human resource management). They learned on the job. Because most leaders work for Boards of Directors that are not well prepared formally for these roles, conflict and confusion is common. Specific education, training, and support for emerging leaders are important to realize the full potential in these positions. For integrity in the role, training and support should be provided by peer leaders, perhaps using a mentorship model and including a network of support.

Table 2: Interpreting the Findings as Advice

1. Establish a collective appreciation of recovery as a radical redistribution of responsibility
2. Create and promote opportunities for Voice and Inclusion
3. Realign system/service planning and programing
4. Support recovery leadership

Research Limitations

This research involved ten people who have personal lived experience with mental health problems and as recipients of service provided by the mental health system, primarily in Ontario. The experience of the study group mirrors that of many others who have publically published accounts of their mental health care. This group was motivated by negative experience. Their purpose was to advocate and lead for corrective change. There are likely other motivating factors that affect people in recovery to become leaders and advocates – motivation based on vocational aspiration, positive experience with the system and hopes for continuance of current practice. There was no intention to deliberately recruit people who had negative experiences but leaders and advocates operating from a positive experience are not represented in this study. Therefore, it is not possible to imply that the emergence of voice, inclusion and empowerment would follow the same course in a different sample.

Future Research

In order to optimize what was learned in this research, deeper understandings about the effects of inclusive and self-determined relationships with the conventional care system are required. Specifically, it is important to consider people who engage and speak up as a result of positive experiences. More detail about the nature of voice and inclusion would inform future planning. In particular, research by people in recovery is required to profile the unique experience they can offer (Rapp, 1993).

Summary and Implications

The socialized system of knowing operates with the apparent agreement of its subordinates, namely; all of us, as we have learned to do (Stark, 1971). This composite understanding opens an opportunity to expose social and cultural factors that discriminate, invalidate and oppress. Similarly, to accept that norms are contingent, assumes that norms and roles can be changed; that both collective and self-transcendence is possible. If our system contributes to what we believe, and if what we believe contributes to what we do, then we can change what we do if we reconsider what is true.

It is important to (re)consider our ideas against the context of the environment that mirrors them – the often invisible norms and roles that operationalize them, and the intangible social hierarchy that supports them. The participants in this study agree that at one time in their identities or constructs, they were bound by a set of roles and norms that defined their experience as disordered, untrustworthy, excluded and subordinate. These experiences were justified and sustained within the norms and roles that we as a society have agreed comprise the conventions of the medical/clinical system of *care*. Raising awareness of the inconsistencies of these ideas and understanding arose for this group in the form of anger and frustration at injustice and discrimination. This led each of these people to question the validity and relevance of their *care* and the system that provides it. In so doing, they (re)considered alternate understandings and constructed a new way of being. Their realization of inner strength and personal commitment and empowerment, sparked their “passion” to participate in changing the system.

Theories of empowerment and liberation, (Berman 1998; Freire, 1989; hooks, 1994; Wandrei, 2003) verify the compelling importance of participation as a function of acquiring the critical perspective that supports introspection and personal change. Giddens’ (1984) concept of agency requires intention and capability of being different, citing the significance of access to resources that promote and support change. This further substantiates the importance of participation and elaboration of alternate ways of thinking and acting. Giddens (1984) and Kelly (1955) propose a plastic and transformable identity which is recursive; it is reproduced through successive situated social practices and outcomes, by which it is organized, articulated and defined. For the participants in this study, their self-view, identity or construct, therefore, is a product of, and is reproduced by, the social rules that ascribe and define power and privilege, within clinical relationships. In some cases, the outcomes produced, or reproduced, match the intention by which they were enacted. In some cases they do not.

An underlying assumption for this study is that our social experiences and relationships shape and drive our ways of thinking and acting. Therefore, both obvious and intangible social experiences contribute to the construction of our identities. Specifically, for the participants in this study, conventional social and clinical understandings of mental illness constricted their identities, and they experienced discrimination and oppression. Yet, when we assume that social factors and influences shape experience and construct identity, it is understood that experience and identity can be reconstructed. The participants in this study are proof that given certain conditions, specifically voice, empowerment and inclusion, change is possible.

This study also reviewed the infiltrating processes that operate change. The premise, based on the assumptions for the study, is that in order to change, a person must notice and respond to the factors that influence their particular ways of thinking, acting and being. Openness to new influencing invites alternate explanations and new meaning. We become different when we reattribute experience and produce alternate meaning. Participants in this study are clear. Their realization of voice supported inclusion. The effect of being heard and included supported a new faith in themselves and their strength. Voice, inclusion and empowerment are the pillars that support the emerging role of advocate and leader.

Becoming different, therefore, involves understanding how self-view or identity is influenced by our interaction and interpretation of society, or worldview. Establishing a new way of understanding oneself involves actively changing our understanding and relationships with the social structures and hierarchies that intersect our lives. Therefore, the third key assumption for this study involved the function of challenging or questioning social truth. In this case the social truth involved the experience of mental health care and advocacy and leadership within the system.

To be different requires a transparent awareness and reflection regarding how and why we have become who we are, and with whom we are. It requires a critical understanding of our experiences. Participants describe their awaking critique of their care and the systemic factors that supported the ideas of “care”. In so doing, participants recognized their anger and frustration and mobilized these feelings to counter what they experienced as injustice and discrimination. Exercising a critical perspective and speaking up to express their vision and hope for change propelled them to new, and, in some cases, unsought roles as advocates and leaders.

Conclusions

The research question applied to this study is: What are the experiences of people in recovery in their journey to be leaders and advocates? The secondary questions are: How have people made meaning of their experience, and how have those interpretations shaped their personal constructs and their subsequent ways of thinking and acting? Ten people participated in the study. Their narratives were used to identify themes regarding their experience. A focus group meeting enhanced and verified collective interpretations of the themes. Published accounts by prominent advocates added credibility, or triangulation, to the data provided by the study group.

While I expected to learn that participants had encountered some negative experiences, I was surprised to hear the extent. While I expected to learn that inclusion and empowerment were foundational to becoming a leader, I did not anticipate the critical role of voice. While I expected disclosures regarding lack of preparation for the work of leadership, I did not anticipate the self-doubt and reluctance that participants disclosed. I was not surprised to hear the concern about appropriation or the tensions that exists between peers and between system partners.

The experiences of the participant group are consistent with the theoretical evidence that was presented. However, their narratives add a new dimension to this literature by demonstrating how the three factors of voice, inclusion and empowerment merge to support changes in self-concept or identity as well as role acquisition. The findings suggest that leadership can be realized when structures that support voice, inclusion and empowerment are in place. To sustain leadership, education to prepare people for the nature and intensity of the work is required and the resources to support the work must be available.

These participants and the advocates represented in the published accounts have been transformed. Their message is clear and their vision is strong. Recovery is an important and hopeful vision. It represents a *radical redistribution of responsibility* that insists on voice, inclusion and empowerment. Simply put, based on the experience of these participants, as well as the collateral, published narratives, their advice to services intending to support recovery is: be kind, act gently, listen deeply, invite curiosity, and believe. Recovery is not well understood as a personal journey. As such, it has been appropriated as a clinical function or model of “care”. To advance recovery leadership, common ground must be found; these advocates and leaders are prepared to be guides.

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APPENDIX A: ETHICS APPROVAL

THE UNIVERSITY OF WESTERN ONTARIO
FACULTY OF EDUCATION

USE OF HUMAN SUBJECTS ETHICS APPROVAL NOTICE

Review Number: 1002-4
Principal Investigator: Ron Hansen
Student Name: Kathryn Storey
Title: *Becoming a leader: The experience of people in recovery. A narrative inquiry that supports a leadership role for people in recovery*
Expiry Date: August 31, 2010
Type: PhD Thesis
Ethics Approval Date: April 15, 2010
Revision #:
Document Reviewed & Approved: UWO Protocol, Letters of Information & Consent

This is to notify you that the Faculty of Education Sub-Research Ethics Board (REB), which operates under the authority of The University of Western Ontario Research Ethics Board for Non-Medical Research Involving Human Subjects, according to the Tri-Council Policy Statement and the applicable laws and regulations of Ontario has granted approval to the above named research study on the date noted above. The approval shall remain valid until the expiry date noted above assuming timely and acceptable responses to the REB's periodic requests for surveillance and monitoring information.

During the course of the research, no deviations from, or changes to, the study or information/consent documents may be initiated without prior written approval from the REB, except for minor administrative aspects. Participants must receive a copy of the signed information/consent documentation. Investigators must promptly report to the Chair of the Faculty Sub-REB any adverse or unexpected experiences or events that are both serious and unexpected, and any new information which may adversely affect the safety of the subjects or the conduct of the study. In the event that any changes require a change in the information/consent documentation and/or recruitment advertisement, newly revised documents must be submitted to the Sub-REB for approval.

Dr. Jason Brown (Chair)

2009-2010 Faculty of Education Sub-Research Ethics Board

Dr. Jason Brown	**Faculty (Chair)**
Dr. Elizabeth Nowicki	**Faculty**
Dr. Jacqueline Specht	**Faculty**
Dr. Farahnaz Faez	**Faculty**
Dr. Wayne Martino	**Faculty**
Dr. George Gadanidis	**Faculty**
Dr. Robert Macmillan	**Assoc Dean, Graduate Programs & Research (*ex officio*)**
Dr. Jerry Paquette	**UWO Non-Medical Research Ethics Board (*ex officio*)**

The Faculty of Education
1137 Western Rd.
London, ON N6G 1G7

Karen Kueneman, Research Officer
Faculty of Education Building

APPENDIX B: LETTER OF INFORMATION

Becoming a leader: The experience of people in recovery
A narrative inquiry that supports a leadership role for people in recovery

Kathryn Storey
Faculty of Education, The University of Western Ontario, London, Ontario

Introduction

My name is Kathryn (Kate) Storey and I am a doctoral student at the Faculty of Education at The University of Western Ontario. I am currently conducting research into: the experience of people in recovery in leadership roles and I would like to invite you to participate in this study. In this study, I define people in recovery as people who identify a personal lived experience with mental health problems, or mental illness.

Purpose of the study

The aims of this study are: People in recovery are under-represented as contributors to the system that plans, provides and evaluates mental health services. This research is intended to advance understanding and significance regarding the role of personal lived experience in how people in recovery realize leadership roles. This research examines lived experience and personal stories, and interprets meaning based on that lived experience.

If you agree to participate

If you agree to participate in this study you will be asked to:

1) engage in a semi-structured personal interview lasting between 30-90 minutes that situates you in terms of your history and your role. The location of this interview will be negotiated with you to assure your convenience. This interview will be audiotaped and transcribed into written format – you will be given an opportunity to review and confirm or correct the text of the interview;

2) work with the researcher to construction of a brief (1-2 page) summary of your story that will be shared with other participants and will contribute to research findings and conclusions;

3) submit weekly on-line journal entries and engage in additional on-line correspondence that provides evidence of deeper reflection about your experience in and conditions affecting your role;

4) participate in face to face or teleconferenced focus groups lasting up to 90 minutes, that will review, confirm, correct, or enrich findings and conclusions at both the midway and the final points of the research; the focus groups will be audiotaped and transcribed to written format.

Confidentiality

The information collected will be used for research purposes only. As a leaders and advocates with personal lived experience with mental health problems, you may well have already disclosed your story in public. Therefore, while the use of aggregate themes and narratives can protect your identity, specific stories may be recognizable. Focus Groups are scheduled to be held at the Krasman Centre in Richmond Hill; it is likely that by attending sessions at this site you will be recognized by employees or people attending there and if this is problematic for you alternative such as teleconference from a satellite location can be provided. Quotations from your interviews, journal submission or correspondence, or observations about your participation, will appear in the thesis that will be written about this study and they may also appear in future conference papers or published articles about the study. You may choose to identify yourself or your direct quotes and observations by name and position, or you can choose to be unnamed. If you choose to have your name and position included in the research, you will be asked to provide specific consent. In terms of information collected about and from you during the study, notes, on-line/emails including journal submissions will be saved to CD and all identifiers will be removed.

Risks & Benefits

There is potential risk of emotional and or social discomfort for participants due to the requirement in this study for self reflection regarding the impact of personal lived experience related to your leadership or advocacy role. These risks will be acknowledged and discussed at the first meeting. Opportunities to link to peer support within the group will be negotiated. You can discuss stressful responses with the researcher and a list of appropriate agencies and mental health professionals will be provided in the event that you experience stress as a result of participating in the research study.

Voluntary Participation

Participation in this study is voluntary. You may refuse to participate, refuse to answer any questions or withdraw from the study at any time. All costs associated with participation are the responsibility of the participant; there is no funding to support this study.

Questions

If you have any questions about the conduct of this study or your rights as a research participant you may contact the Manager, Office of Research Ethics, The University of Western Ontario at (phone number) or (email). If you have any questions about this study, please contact:

Kathryn (Kate) Storey (address, phone number, email)
or
Dr. Ron Hansen (address, phone number, email)

This letter is yours to keep for future reference.

Kathryn Storey

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APPENDIX C: CONSENT FORM

Becoming a leader: The experience of people in recovery
A narrative inquiry that supports a leadership role for people in recovery

Kathryn Storey
Faculty of Education, The University of Western Ontario, London, Ontario

CONSENT FORM

I have read the Letter of Information, have had the nature of the study explained to me and I agree to participate. All questions have been answered to my satisfaction.

Name (please print):

Signature: Date:

Please initial your choice:

__ My name may be used to identify quotes or information obtained from me during the course of the study in publications and presentations resulting from the research.

__ Do not use my name in publications and presentations resulting from the study.

Signature: Date:

Name of Person Obtaining Informed Consent:

Signature of Person Obtaining Informed Consent:

Date:

CURRICULUM VITAE

Academic History

A) Post Secondary Education:

- Current – University of Western Ontario, PhD candidate – Faculty of Education; Policy and Leadership
- Ontario Hospital Association: Hospital Management Diploma, December 2008
- OISE/University of Toronto - Master's Degree: Adult Education: Counseling Psychology 2002
- University of Waterloo –Bachelor of Arts: Psychology 1992
- Durham College - Post Graduate Psychiatric Nursing; Clinical Specialty 1980
- Centennial College - Registered Nursing 1978

B) Workshops and Certificates:

- Georgian College - Certificate: Teaching and Training Adults - 1988
- Trauma and Abuse: 2 day Workshop; Sandra Butler - 1995
- Cognitive Behaviour Therapy for Clinicians: with Dr. Greg DuBord – Toronto, 1997
- Relationship Management of the Borderline Patient - Level 1: with Dr. D. Dawson – Orillia, 1997
- Continuous Quality Improvement; certificate - 1997
- Solution Focused Counseling: certification, Dr. R. Warner (OISE), 1998
- Cognitive Behaviour Therapy and Depression: with Dr. D. Burns – Toronto, 1998
- Cognitive Behaviour Therapy for Anxiety Disorders: with Dr. G. Dubord – Toronto, 1998
- Women, Trauma and Abuse Issues: 2 day Workshop - 1998
- Cognitive Behaviour Therapy and Trauma: with Dr. D. Meichenbaum – Toronto, 1998
- Shared Care: Integrating Psychiatry and Family Practice - Dr. T. Turner – Toronto, 2000
- Working with High Performing Teams – Dr. Marilyn Laiken – Toronto, 2001
- Roles and Boundaries – Leading Edge Seminars – Toronto, May 2004
- Cognitive Behaviour Therapy and Trauma – Dr. Don Meichenbaum – Toronto, September 2004
- Leadership and Change: Brenda Zimmerman (with Jane Jacobs) – Toronto, November 2004
- International Recovery Perspectives: Building Alternatives (3 day) Toronto, September 2007
- Knowledge Integration: Transitional Discharge Model (Cheryl Forchuk) - London, Nov. 2007
- Peer Support – A Distinct Support: with Shery Mead – Newmarket, January 2008
- Manager as Coach: Ontario Public Service. Midland, February 2008
- Creating Inter-professional Collaborative Teams for Comprehensive Mental Health Services (Cheryl Forchuk) – London, May 2008
- International Recovery Perspectives: Action on Alternatives (3 day) Toronto, June 2008
- JEMH Conference on Ethics in Mental Health - *Theme* - *"True Colours"* Lakefield, October 2008
- Meditation/Yoga Retreat – building capacity in therapy. Oaxaca, Mexico, March 2009
- Recovery Programs: one day Institute with Mark Raggins, MD, Thunder Bay, Ont. Sept. 2009
- Psychosocial Rehabilitation National Conference. Thunder Bay, Ont. Sept. 2009

Employment History in Health Care

1979-1983 - Front-line clinician at the Mental Health Centre Penetanguishene (MHCP); Registered Nurse providing direct service in both acute care and forensic specialty programs; Demonstrated clinical competence and leadership resulting in promotion.

1983-1986 - Nurse Educator at MHCP; developed, coordinated, delivered and evaluated educational programs to professional staff and the community at large; affiliated faculty at Georgian College, Barrie and Durham College, Oshawa.

1986-1987 - Nurse Clinician at MHCP-Oak Ridge Division; hired to develop and implement a significant “change management project” intended to facilitate the move from custodial care to more progressive psychiatric nursing practice.

1987-1992 - MHCP Program Director - Behaviour Therapy Unit: Oak Ridge; key functions included coordinating a Multi-disciplinary team to provide service to offenders with a mental illness in a maximum security setting; responding to clinical/legal issues; Leadership within a Matrix Management structure, this position required high level interpersonal skills to influence, negotiate and direct without direct reporting authority.

1992-2000 - MHCP Program Director: Outpatient Services Program; Directly responsible for the administration of a community-based mental health program. Program/Service development and evaluation, as well as organizational influence, were significant requirements of this role. Partnership and community development were critical components of this position.

2001-2004 – part-time instructor: Georgian College – Orillia (Psychology) and Midland Campus (developing curriculum and delivering the “Skills of Helping” program and Introductory Sociology).

2003-present – private therapist/educator: Osprey Training and Consulting. Private clinical practice including: Critical Incident Debriefings; and individual, couple and group therapy using the following methods of treatment: CBT, Solution Focused Therapy and Narrative Therapy, with emphasis on a recovery perspective. Approved therapist for: Aspiria/Link EAP, Criminal Injuries Compensation Board; Shepell FGI; Active Health Management; Ontario Teachers Insurance Plan; PsyPro EAP; Ministry of Community and Social Services, as well as direct payment. In addition, psychometric services provided in the preparation of psycho/vocational and educational assessments.

2000- March 2009 - Division Chief: Acute and Community Care at MHCP – This is an executive position within a large health organization. There is significant responsibility for both fiscal and service outcomes. This position required systemic organizational oversight, review and implementation of constructive change. This leadership role was instrumental for policy development at both the local and regional levels

January 2007 – April 2008 – Project Manager: seconded from home position to lead a project to regionalize acute mental health services in the North Simcoe – Muskoka LHIN; key deliverables are the development and implementation of a bed registry; establishing standardized referral/admissions and discharge protocols; and implementing a psychiatry on-call service.

June 2007 – present: Recovery Educator/Consultant – consulting and planning with programs/organizations to shift system and practice dimensions of mental health service to a recovery-supporting focus. Includes development and delivery of education to consumer/survivors and allies as well as evaluation of established self-help and clinical services. Examples include:

- Program Design/Evaluation: Peer Recovery Education For Employment & Resilience (PREFER) – a Trillium Funded program to improve employment outcomes with a focus on recovery
- Recovery Education for Allies: two one day workshops for the Royal Victoria Hospital – Barrie. May, 2010
- Psychiatric Survivors of Ottawa (PSO) - comprehensive evaluation of WRAP

  - South Riverdale Health Centre – design a comprehensive evaluation for a new program addressing diabetes and mental health
  - Program evaluation – Community Crisis Services; St. Elizabeth Health Care, York Region, including peer support for Emergency Department Diversion (EDD).
  - Recovery Education for Allies – Peel Region CMHA
  - Program Design/Evaluation – Peer Recovery Education for Employment and Resilience (PREFER) a four year employment education program funded by The Ontario Trillium Foundation
  - Program Design and Evaluation - Peer Support for Housing: Toronto Community Housing Corporation – funded by TCHC: Social Investment Fund
  - Inclusive Employment: Workforce Reflection – Houselink Community Homes
  - Recovery-Supporting Medication Education Strategies - Canadian Mental Health Association: Peel Region

February 2010 – April 2010: North Simcoe-Muskoka Local Health Integration Network (LHIN) and MHCP Geriatric Services Program. Project Management – Aging at Home: Acute Geriatric Mental Health Initiative. Research and proposal regarding development of a comprehensive strategy for cognitive assessment tools to determine appropriate identification of service needs and treatment placement. Development of a train-the-trainer process to assure utility of the assessment manual. Construction of an evaluative framework for the program.

September 2010 – January 2011: Accreditation Educator/Coordinator Mental Health Centre Penetanguishene. Designing, delivering and evaluating a multidimensional strategy to prepare employees at a large psychiatric hospital, with successful outcomes.

March 2011 – April 2011: North Simcoe-Muskoka Local Health Integration Network (LHIN) and Waypoint Centre of Mental Health Care Geriatric Services Program. Program Evaluation – Behaviour Intervention Response Team (BIRT) – funded by the Again at Home Initiative.

September 2003 – present: independent **therapist/consultant/educator**: owner/operator: Osprey Training and Consulting. Private clinical practice including: Critical Incident Debriefings; and individual, couple and group therapy using the following methods of treatment: CBT, Solution Focused Therapy and Narrative Therapy, with emphasis on a recovery perspective. Approved therapist for: Aspiria/Link EAP, Criminal Injuries Compensation Board; Shepell FGI; Active Health Management; Ontario Teachers Insurance Plan; PsyPro EAP; Ministry of Community and Social Services, as well as direct payment. In addition, psychometric services provided to Dr. Jacqueline Cimbura, clinical psychologist, in the preparation of psycho/ vocational and educational assessments for the Ontario Disability Support Program.

December 2010 – present: Nurse Shift Manager – Mental Health Centre Penetanguishene; officer in charge after hours.

Community Organizations and Participation

Women's' Resources of Simcoe County (Huronia Transition Homes) – Board member 1986-1990 and again 2004-2006; Board Chair 2006 to 2010; Past Chair 2010 to 2011

Volunteer: Mental Health Centre Penetanguishene; specific to a relationship with the Patient/Client and Family Council and as an educator in the Like Minds: Peer support Education Program

Culture of Recovery (www.cultureofrecovery.org): co-founder and member; support and education coalition to advance a shift in perspective for people and organizations that that provide mental health and substance services, as well as to promote a recovery and wellness perspective and lifestyle for people with lived experience. June 2005 to present.

Shambala Sun – Editorial Advisor: provided feedback and advice regarding articles for publication in this monthly Buddhist journal. November 2005 – December 2007

Extra Ordinary People (Sky Works Charitable Foundation) consultant and development partner for this antidiscrimination documentary. Coordinating author of the training manual that accompanied the documentary. Co-lead for facilitator training. (2007 to present).

National Commission for Mental Health (Kirby Commission): member of the Anti-Stigma Campaign. Specifically, a participant consultant to the education and research component of the Commission relating to education for clinicians – based on the Culture of Recovery evaluation of Extra Ordinary People. (2009-present)

Canadian Mental Health Association - Barrie/Simcoe Branch - Board of Directors 1988 to 2003; includes 3 year tenure as Board Chair; also Chair of the Program Advisory Committee

Central East Region (Penetanguishene) Mental Health Implementation Task Force; member Intensive Services and Public Education sub-group (2002-2004)

Simcoe County Alliance to End Homelessness; original alliance member; Past Chair of Public Awareness Sub-committee; Member of the Research and Evaluation Committee

Co-lead: Simcoe Homelessness Action Research Project (SHARP)

Simcoe County District Health Council (1994-2006); former Member of the Crisis Co-ordination Group – which established regionalized crisis services; System-Design/Planning Groups; Early Psychosis Intervention. Led the review of Lead Agencies for the System Management Group: member of the Evaluation Committee, implementing Program Logic Models for community programs.

Regional Action Group for Mental Health – North Simcoe – Muskoka LHIN (Jan. 2007-2009)

Former member of the Regional Acute Mental Health Service Steering Committee – member of the group who developed the model for regionalization of acute mental health services for Simcoe/ Muskoka Local Health Integration Network.

Central East Mental Health Committee – a time-limited group designed to decide regarding re-allocation of unspent Mental Health Implementation Task Force funds – which led to: the development of the "Culture of Recovery Project" – steering the culture shift for Simcoe Muskoka related to consumer empowerment and establishing a culture of recovery in service delivery; co-lead of Peer Support Training Group; Consumer/Survivor Leaders Network; and member of the Public Education Strategy work group

Dominican Nursing Mission (May 2005 and May 2006) – direct community/outreach nursing and health promotion/education at San Jose de Ocoa, Dominican Republic.

Peer Reviewer – International Studies Association on Teachers and Teaching: Annual Conference; reviews submitted for concurrent paper presentations. April, 2007

Ontario Hospital Association – Provincial Mental Health Working Group: providing consultation and advice to the overarching provincial steering committee regarding policy and service development.

Mental Health Commission of Canada – invited participant: Anti Stigma program development (Toronto: Sept, 2009); Recovery Roundtable (Ottawa, 2010).

PREFER Steering Committee – guiding, implementing and evaluating a comprehensive employment program for people in recovery.

Research and Practice Interests:

- Mental Health Recovery Education; Politics of recovery and reform
- Peer Support
- Social Justice
- Transformative pedagogy

Professional Presentations/Publications (* peer reviewed)

The Criminalization of the Mentally Ill - presentation to the assembled Community Advisory Boards of Ontario Provincial Psychiatric Hospitals – Midland, November, 1989.

People with Schizophrenia Say the Strangest Things: What They Mean and How to Respond - Schizophrenia 1990: Poised for Discovery - Vancouver, B.C. – July, 1990.

Woman Abuse: Interventions of the Physician - Annual Psychiatric Residents Conference – Horseshoe Valley, May, 1991

* *Partnerships or Relationships: Working Together to Provide Better Service and More Resources* - International Association of Psychosocial Rehabilitation (IAPSRS) Conference- Barrie, June, 1995

Crisis Response in a Rural Community - CMHA National Conference, Hamilton, Ontario – June, 1996

Women and Poverty and *Poverty and the Seriously Mentally Ill* - two panel presentations to the Simcoe County Health Unit – February, 1997

Building Longitudinal Relationships Between Sectors: Linking Inpatient and Community Forensic Services (Co-presenter with Dr. R. Fleming) - CMHA National Conference, Vancouver, B.C. – July, 1999

*Creating Service Integration through Partnerships - The North Simcoe Experience (*Panel Presentation) - CMHA National Conference, Vancouver B.C. – July, 1999

Simcoe Homelessness Action Research Project – (co-author: Gail Saulnier) A Participatory Research project designed to increase awareness and appreciation of the experience of homelessness, and to bring forward the advice of people who have experienced homelessness in the solution-building process – including creating an environment that encourages and supports people who have experienced homelessness to sit as equal participants in the formal service and advocacy structure. This report was released in March 2002.

* *Collective Wisdom: How the experience of people who are homeless inform structure and process* - Poster presentation, National Conference on Homelessness, York University, May 2005

Empowering Clinical Processes: Improving Primary Care through Shared Care - Reinventing Primary Health Care http://www.federatedpress.com/FPWeb/Events/ConferenceReports/tabid/308/mid/380/ProjectId/123/wildRC/1/Default.aspx#Kathe%20Storey) – Federated Press. Toronto, December 2005

Like Minds: Building a Framework of Experience. Panel presentation. The Power of Experience Conference. Barrie, February 23, 2006

<u>Like Minds: Peer Support Education</u> – educator/curriculum design; 3 day course; peer support education; (2006 to present)

**Like Minds: Peer Support Education - Education designed and delivered by peers, for peers, to support mental health and wellness for all* panel presentation; - Making Gains in Mental Health and Addiction. Toronto, November, 2006.

* *Like Minds: a model of empowerment education* – paper presentation and internal publication; International Studies Association on Teachers and Teaching: Annual Conference, (Brock University) (http://www.isatt.org/ISATT-papers/ISATT-papers/Storey_LikeMinds.pdf) St. Catherine's, Ontario. July, 2007.

Building a Culture of Recovery - Internal publication: Ontario Recovers Campaign, provincial on-line list-serve and Ontario Peer Development Initiative (OPDI) provincial magazine (September, 2007).

Extra Ordinary People – Education Guide: a manual to support facilitated discussion of the discrimination experienced by people with mental illness and addiction; supporting the documentary Extra Ordinary People, produced by Sky Work Charitable Foundation

Recovery: A learning to live by – poster presentation: University of Western Ontario Faculty of Education Research Day. London, March 2008.

* *Building Culture of Recovery: A Comprehensive Recovery Education Strategy*. Journal of Ethics in Mental Health:
http://65.39.131.180/ContentPage.aspx?name=Journal_of_Ethics_in_Mental_Health_Vol_3_No_1_Building_A_Culture_of_Recovery

** Building a Regional Acute Mental health and Addiction Service: Meeting Community Needs Through Integrated Health Care.* Program Exemplar accepted for presentation at - Celebrating Innovations in Health Care Expo. Toronto, March 2008.

Regional Acute Mental Health and Addiction Service – Building Partnerships to Improve Integration. Celebrating Innovation In Healthcare – exemplar project. May, 2008

Regional Acute Mental Health & Addiction Services: project overview. The First Canadian Healthcare Registry – on-line conference: http://thefirstcanadianhealthcareregistry.ca/whois/index.php/Details/Storey-Kathryn May, 2008

Building a Culture of Recovery in Central East Ontario. Conference presentation: International RECOVERY Perspectives: Action on Alternatives. Toronto, June 2008.

Wellness Recovery Action Plan: Retrospective self assessment of change. Program Evaluation related to delivery of WRAP to participants in Ontario. (www.cultureofrecovery.org) June, 2008

** Building a compassionate citizenship: Ending discrimination for people who have experienced mental health or substance abuse problems.* (OISE); Learning Democracy by Doing: Alternative Practices in Citizenship Learning and Participatory Democracy, Toronto: October, 2008.

Diversity in Action: implementing respectful work environments (corporate education; presentation of the program evaluation to senior Ministry of Health team, including Assistant Deputy Minister). A series of interactive workshops to shift attitudes regarding ways of thinking and acting related to: people of colour; people with alternate abilities; Aboriginal people as people with variant sexual orientation, gender identity and gender fluidity. Penetanguishene and Toronto, June – August 2008

Diversity Conversations. Interactive presentations discussions designed to shift perspectives regarding : people of colour; people with alternate abilities; Aboriginal people as people with varying sexual orientation, gender identity and gender fluidity. November, 2008.

Comprehensive Recovery Education and Support Strategies: a Culture of Recovery! Invited presentation at "Canadian Innovations in Recovery Conference". Sponsored by the Self-Help Alliance at Kitchener, November, 2008.

Extra Ordinary People: Compassion trumps Discrimination – educating to end discrimination. National Conference for Psychosocial Rehabilitation - Recovery: Practicing in Partnerships; September 2009.

Reclaiming Peer Support: A critical perspective regarding peer recovery relationships. National Conference for Psychosocial Rehabilitation - Recovery: Practicing in Partnerships; September 2009

Recovery Politics: Tensions and Opportunities: Toronto, November 2009. Available at www.cutureofrecovery.org

Building healthy consumer/survivor organizations: Ottawa, 2011 – invited guest. Development of a strategy to advance autonomous peer operated services and supports for users of mental health services in the province of Ontario.

PREFER Summit – presentation of Year 1 outcomes for a recovery education program for employment; April 1011. Available at www.cultureofrecovery.org

Professional Registrations

- Licensed by the College of Nurses of Ontario;
- Certificate of Competence Number: 79-0281 0
- Active member of the Registered Nurses Association of Ontario (RNAO) including the Mental Health Interest Group as well as the Nurse Educator and Research Interest Groups.