

## PEER SUPPORT: MAKING IT STANDARD PRACTICE

PEER SUPPORT: MAKING IT STANDARD PRACTICE

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## Abstract

Peer support has been shown to benefit individuals with mental health challenges. Yet, peer support has failed to be translated into policy. This study investigates the organizational benefits of peer support, the profound significance to individuals receiving peer support, and the barriers that exist toward formalized implementation of peer support. It offers strategies for overcoming these barriers.

This study combines data from the lived experience of peer supporters and service providers thus offering a unique contribution to the knowledge of peer support. It uses critical disability theory as a lens to frame the research. Findings suggest that personal transformation occurs in the context of relationships in peer support that foster resiliency within individuals. Yet, peer support is undermined due to a lack of utilization in the mental health system.

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Finally, I dedicate this thesis to Dorothy Johns – my mentor. The completion of this thesis marks her ninety-first birthday and time has not waned her zeal and enthusiasm for life. Thank you Dorothy, words sorely fail to express what you have meant to me during this process.

I also dedicate this thesis to the memory of my father and mother.

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### **Introduction**

In the last year of my Bachelor of Social Work degree, a professor approached me about working with a mental health Consumer Survivor Initiative (CSI) in my graduate studies. In this way, I was introduced to the topic of peer support as a subject of analysis. “Peer support” for the purpose of this study will be defined as: the provision of aid by persons with lived experience in the mental health system to other individuals struggling with mental health issues in the context of a formalized setting. Although studying peer support academically was new to me, peer support had been an avenue of growth in my personal life many years ago. It has been my experience that recovery-based peer support emphasizes personal resiliency and stresses that people with mental health impairments can live satisfying lives. In an effort to communicate the depth of self-actualization that has occurred in my own life as a result of journeying with others who experienced the same challenges, I am including the following poem I wrote in March of 1998:

#### **I AM**

I AM

Forming

Little by little the essence I call

“I am”

Is forming.

I am the spiritual substance of my experiences.



I am the spiritual substance of my past.

Little by little this essence I call

“I am”

Is forming.

I am the spiritual substance of my relationships.

I am the spiritual substance of my thoughts.

Forming, emerging, growing...

Forever I am reaching, forever I am duplicating into a

Thousand other selves becoming a single organism

Touch my body and you cannot miss my soul.

Forming.

Little by little this essence I call

“I am”

Is forming.

Cycles of life, death, life are birthing me into a being

Of incredible magnitude

Forming.

Little by little this essence I call

“I am” is defying the imaginary limits of capacity

And

Here

I AM.

The poem demonstrates a level of personal resiliency that occurred in the face of debilitating circumstances and foreshadows the recurring theme in this study of the transformation that occurs in peer relationships. As I spoke to each peer supporter<sup>1</sup> in this study, time and time again I heard how peer support enabled them to defy what I understand to be the “imaginary limits of capacity” that threatened to define them.

After meeting with a Consumer Survivor Initiative (CSI) leader at Teach, Empower, Advocate for Community Health (T.E.A.C.H), I decided to make peer support the topic of my research. T.E.A.C.H is a consumer-run organization located in Milton, in the Halton/Mississauga region, that services people with mental health difficulties. With the help of T.E.A.C.H, I interviewed peer supporters and service providers with a stake in peer support from the region of Halton/Mississauga Local Health Integration Network (LHIN) in Ontario. The central question of this research was to examine how peer support could become standard practice within the Mental Health and Addictions system. This study investigates the organizational benefits of peer support, the profound significance to individuals receiving peer support, and the barriers that exist toward formalized implementation of peer support in this region. It also offers strategies toward overcoming these barriers.

### **Theoretical Perspectives**

To set the stage for a discussion of the research, it is important to first articulate the theoretical perspectives that influenced the design of the study and interpretation of the data.

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<sup>1</sup> A peer supporter in this study is a person that identifies as someone with mental health impairment who has been a receiver or user of mental health services.

## **The Medical Model**

Historically, people with mental health impairments have been viewed through the medical model (Barnes & Mercer, 2010). The medical model emphasizes individual pathology. Individuals are labelled based on the Diagnostic and Statistical Manual of Mental Disorder (DSM) and then essentialized based on that label (Gilson & DePoy, 2002). This is manifested in language when people with specific impairments become defined *as* those impairments: those living with manic depression become “the manic depressive” and those with schizophrenia become “the schizophrenic” for example. In this way, the medical model labels individuals as defective (Beresford, 2002). The medical model assumes that something is wrong with the individual and must be fixed, controlled or treated (Barnes & Mercer, 2010). It is this view of people as defective that led to negative societal understandings of people with mental impairments. A very large, complex medical system developed, geared to cure or care for the mentally ill which involved abusive and harmful treatments (Frese & Davis, 1997).

As a result, the history of people with mental impairments within the medical model has been rooted in oppressive social structures (Bricher, 2000). The disability rights movement began as a reaction against a medical model perspective and consequent institutionalized abuse existing, for example, in the form of demeaning treatment and involuntary confinement (Frese & Davis, 1997). The disability rights movement emerged when the civil rights movement and women’s movement were at their peak (Reaume, 2002). When describing the movement Barnes and Mercer (2010) state:

The exponents of this new disability politics embarked on a struggle for both self-determination and self-definition... disabled people have been isolated, incarcerated, observed, written about, operated on, instructed, implanted, regulated, treated, institutionalized, and controlled to a degree probably unequal to that experienced by any other minority group. Disabled people now highlighted their everyday familiarity with social and environmental barriers, restricted life chances, and negative cultural representations... Disability activists did not deny the positive potential of appropriate medical and allied intervention. Rather, they challenged professional experts who equated disability solely with functional limitations and concentrated service provision on individual rehabilitation and adjustment (p. 2, 3).

It was within this context that the disability rights movement surfaced in the 1960s as an effort towards emancipation for disabled people. A new model of disability emerged during the disability rights movement - the social model.

### **The Social Model**

The Social Model posits that conditions within society create disabling environments rather than disability being the result of individual impairments as the medical model suggests (Oliver, 2004). Society is created “by those with capabilities for those with capabilities” thus excluding those with physical and mental impairments (Barnes & Mercer, 2010 p. 75). This is demonstrated in the ways in which architecture in society fails to address the accessibility needs of those with mobility impairments. The ways in which information tends to be presented mainly in written text excluding those with visual impairments; and the ways in which speech is prioritized as the primary mode of communication thus excluding those with hearing

impairments. In addition, there exist social factors that contribute to the disempowerment of those with impairments. For example, barriers to self-determination include societally created problems such as lack of affordable housing, poverty, prejudice and violence (Cook & Jonikas, 2002). Barnes states (1997), “the biggest obstacle to disabled people’s meaningful inclusion into mainstream community life is negative public attitudes” (p. 10). “Disabled” remains a highly stigmatized identity and is the result of ableist prejudice that favours a particular way of being – physically and mentally ‘able’ – and leads to discriminatory behaviour towards those who are deemed ‘unable’ (Fudge Schormans, 2012). Stigma restricts the activities of people with impairments thus marginalizing them (Thomas, 2004). Corrigan (2004) suggests that people labelled mentally ill, regardless of their specific psychiatric diagnosis or level of impairment, are stigmatized more severely than those with other health conditions. Link and Phelan (2001) describe structural discrimination associated with stigma. They state: “Disabled persons may be limited in their ability to work not so much because of their inherent limitations but because they are exposed to . . . a disabling environment created by barriers to participation that reside in architecture humans have created.” (p. 367). Similarly, when addressing the social construction of work, Finkelstein (2004) states:

It follows from this view [the social model] that poverty does not arise because of physical inability to work and earn a living - but because we are prevented from working by the way work is organized in this society. It is not because of our bodies that we are immobile – but because of the way that the means of mobility is organized that we cannot move. It is not because of our bodies that we live in unsuitable housing - but it is because of the way that our society

organizes its housing provision that we get stuck in badly designed dwellings. It is not because we are physically impaired that we are rejected by society - but because of the way social relationships are organized that we are placed beyond friendships, marriages, and public life. Disability is not something we possess, but something our society possesses. (p. 14)

Thus, the social model posits that disability is not something inherent within individuals. Rather, it is a social construct inherent within the organization of society. Yet, the social model has been criticized for various reasons. For example, the social model is criticized for ignoring the individual experience of people living with impairments by overemphasizing the collective experience (Oliver, 2004). This emphasis on the collective overlooks the diversity among people with impairments thus ignoring other factors such as race, class, gender, ethnicity, and sexual orientation (Mulvany, 2000). Also, the diversity of experience of people living with various types and degrees of severity of impairment is not heard. While the social model is the root of much of disability theorizing, critical theory has had an influence on disability theorizing.

### **Critical Disability Theory**

Critical disability theory is concerned with social transformation and the emancipation of oppressed individuals (Meekosha & Shuttleworth, 2009). It situates social phenomenon in a historical and political context (Neuman, 2011). In addition, power is an important concept within critical disability theory (Hosking, 2008). Critical disability theorists problematize relationships by asking the following questions: whose voice is dominant in mainstream society? Who benefits and why? What are the covert social processes based on race, gender,

ethnicity, sexual orientation, class and location that are governing human interactions and how are these interactions affecting people living with impairments? For example, power imbalances exist between mental health professionals and peer supporters in health-care systems based in the medical model, and these power imbalances are reinforced by its emphasis on pathology within individuals (Bricher, 2000).

As with the social model, a critical disability perspective understands that people living with mental and physical impairments have historically been viewed as deviant (Hiranandani, 2005). This is due, to a significant extent, to how disability has been represented, in both language and visual images within society (Mead & MacNeil, 2006). Consideration of the language used to describe disability and disabled people in research is important because it plays a role in how individuals are perceived and influences values. Although language is often viewed as neutral, it is laden with cultural meanings that stigmatize and marginalize individuals with mental impairments (Mead & MacNeil, 2006). Reaume (2002) argues that language is political and grows out of a specific historical context. He discusses, for example, how political activists with a psychiatric history have influenced the terminology used to label people with mental impairments (Reaume, 2002).

It is important to address the reasoning behind the language used for this thesis. The term ‘people with mental health impairments’ is used deliberately. This decision reflects a social model understanding that differentiates between ‘impairment’ and ‘disability.’ Barnes & Mercer (2010) state: “[the word] impairment [is] classified as a medically bio-physiological condition [which is differentiated] from disability which denotes the social disadvantage experienced by people with an accredited impairment” (p. 11). In this paper, the term service

user (rather than consumer, or patient) is used to describe individuals with mental health impairments accessing psychiatric services. This term has been chosen above the term consumer to deflect notions of commercialism within the mental health system and reinforce aspects of empowerment. I have avoided using the term “patient” because it reinforces the dominant cultural perception of “mental patient” that is associated with negative connotations. In addition, the word “patient” lends itself to a medical model approach that is contrary to the essential objectives of recovery-based peer support. A peer supporter is a service user who is providing supports to a service user. In addition, the term “disabled people” will be used as a description of individuals with mental health impairments. This term is used throughout the literature to describe those living with physical and mental impairments. It is a term that has been reclaimed by those with impairments.

## **Literature Review**

### **Recovery-Based Peer Support**

It has become increasingly clear that interventions rooted in the medical model alone are not sufficient to meet the needs of service users of the mental health system in Ontario (Dennis, 2003). A different type of intervention is needed that is based on principles of empowerment, reciprocity and self-determination. Recovery-based peer support is one such intervention that is currently receiving attention. Consistent with the social model and critical disability theory, recovery-based peer support in mental health originates from a particular historical and political context. It is based in recovery philosophy, which was influenced by the disability rights movement (Solomon, 2004). Recovery philosophy ascertains that people with mental health impairments can recover and lead productive and satisfying lives (Solomon &



Stanhope, 2004). Yet recovery does not mean the absence of the impairment. Jacobson and Greenley (2001) state “it is important to remember that recovery is not synonymous with cure” (p. 483). Rather, recovery allows one to live in the ebb and flow of life’s rhythms, which may include periods of relapse. Setbacks become growth opportunities that strengthen one’s character building resiliency. My understanding of recovery is a process of inner transformation that allows for a deeper connection to the self. This inner connection in turn creates a deeper, more authentic connection with others. For me, recovery can happen even in the midst of the turbulent aspects of the impairment. Recovery is defined in the literature as “internal conditions” that facilitate a personal journey that involves a process of the transformation of self and the renewal of hope (Frese & Davis), 1997; Jacobson & Greenley, 2001; Mead & Copeland, 2000; Townsend & Glasser, 2003).

Furthermore, recovery-based philosophy of peer support is in opposition to the medicalization of individuals with mental impairments and challenges the ways in which people in the mental health system have been “forced into roles” such as “mental patient” (Mead & Hilton, 2001, p. 136). Ideas of empowerment and self-determination are embedded in recovery-based peer support. These ideas are new compared to the old historical views that position mental health service users as dependent on the medical system and incapable of living life without being institutionalized (Charlton, 1998). Mead and Hilton (2001) state:

Many people have learned roles that build a strong sense of identity as a ‘mental patient’. This ‘identity’ leads us to the assumption that the rest of the community can’t understand us and creates an ‘us/them’ split with others. An imbalance of personal power lies at the heart of mental illness. . . In the context of mutually

empathic relationships in peer support environments, we can practice seeking and finding new meaning and seeing ourselves as having personal worth and social power. (p. 135, 136)

Thus, recovery-based peer support encourages the development of personal power and the redefinition of the self within the context of caring relationships. Narratives of lived experience become the foundation of peer relationships that foster reciprocity and resiliency. Whereas services rooted in the medical model reinforce a paternalistic relationship between service users and clinicians (Mead, et al., 2001), recovery-based peer support conversely creates a space for individuals to support one another in the context of understanding and mutual respect (Mead & MacNeil, 2006). Rather than being defined solely by one's symptoms of mental impairment, peer relationships create a safe space for the development of a new vision of oneself (Kruck, Whitaker, Lee, Reed, Jones, & Hammond, 2011). A major aspect of recovery is surrounding oneself with people who can "offer hope, understanding; support; who encourage self-determination and who promote self-actualization" (Frese & Davis, 2009, p. 244). A key aspect of the recovery process is the transformation of the self that occurs in peer relationships. Transformation occurs in the context of relationship as people redefine themselves. Individuals have the opportunity to transform identities entrenched in labels acquired by the medical model. As they transcend these labels, individuals discover gifts they can share with the community.

The growth of recovery-based peer support in the mental health system in North America has been exceptional since the disability rights movement emerged in the 1970s (Nelson et al., 2007). During this time, self-help groups evolved in an effort to support service

users who were protesting their current circumstances. In the last decade in North America, a proliferation of literature has surfaced about the use of recovery-based peer support in the mental health system (Coatsworth-Puspoky, Forchuk, & Ward-Griffin, 2006; Daniels et al., 2010; Holter, Mowbray, Bellamy, MacFarlane, & Dukarski, 2004; Mead & Copeland, 2000; Mead, et al., 2001). Evidence exists that peer support is effective. For example, Solomon (2004) lists the following benefits derived from recovery-based peer support and peer-driven services: reductions in hospitalization and crisis services; improved coping; and higher satisfaction with health (p. 395). Furthermore, in their report on Consumer Survivor Initiatives (CSIs), the Ontario Peer Development Initiative (2009) reported that those who participated in peer-run organizations not only reduced their stay in hospital but also had a reduction in symptom distress and created social supports that reduced isolation in the community. The report also noted that CSIs saved the Ontario (Canada) government more than \$12 million per year through the reduction of hospital stays.

The literature reveals a number of themes that address several important questions. How is peer support defined? What challenges do service users encounter as peer support providers? What counts as knowledge? In the following, I will discuss each of these themes as found within the literature.

### **How is Peer Support Defined?**

It must be made clear that no universal definition of peer support exists in the literature (Bouchard, Montreuil, & Gros, 2010). There does appear to be agreement that peer support involves the mutual support of those with similar life experiences and that a common theme of peer support is one “mental health consumer offering mutually agreed support to another

consumer” (Davidson et al., 1999; Mead, et al., 2001). However, under this umbrella, there exist a vast number of tasks and expectations for those designated as ‘peer supporters’ in peer programs (Repper & Carter, 2010). Funding bodies require a concise definition of peer support. Peer support programs are left vulnerable to lack of funding without an operational definition of peer support. (Bouchard, et al., 2010). Mead, Hilton and Curtis (2001) remind us that in trying to arrive at a common definition, peer support should not be based on “psychiatric models and diagnostic criteria” (p. 134). Rather, at the core of peer support is the understanding “I know where you are because I’ve been there too”.

Solomon (2004) describes different types of peer support: peer employees, peer-delivered services, and peer-run and peer-operated services. Peers of the mental health system who work in the community with other non-peer staff and/or are hired in traditional mental health organizations are commonly referred to as peer employees (Mowbray et al., 1996; Solomon & Draine, 1996). Another common form of peer support services are peer-operated organizations “that are run by and for people with a history of mental illness” (Nelson, et al., 2007). Peer-run or peer-operated services differ from peer-delivered services in that they are services “that are planned, operated, administered and evaluated” by people who identify as having a mental health impairment (Solomon, 2004, p. 393). T.E.A.C.H, the organization involved in this study, is a peer-operated organization known as a Consumer Survivor Initiative (CSI).

CSIs began officially in 1991 with a grant from the provincial government. There are now over 60 CSIs in Ontario. They are organizations typically aimed at the personal empowerment of service users of the mental health system. Nelson et al., (2007) ran a 3 year

longitudinal study using qualitative and quantitative methods to evaluate the effectiveness of CSIs. They discovered that those who participated in CSIs were more likely to score higher in areas such as social support, community integration, personal empowerment and quality of life than those who did not participate in CSIs.

### **What challenges do peer supporters encounter as peer support providers?**

Common challenges peer supporters encounter when providing peer support, which have been identified in the literature, involve problems associated with role conflict; lack of clarity about confidentiality; and attitudinal barriers due to mental health stigma (Carlson, Rapp, & McDiarmid, 2001; Gates & Akabas, 2007). These issues impede the ability to deliver effective services in peer programs.

Role conflicts include challenges associated with unclear boundaries in the form of dual relationships that exist between peer providers and those accessing peer services. For example, mental health peer providers may be exposed to service users with whom they have developed former relationships such as friendships thus creating power imbalances (Carlson, et al., 2001). In such cases, there must be clear boundaries established in order that individuals accessing services are safe from potential exploitation (NASW, 2008).

The second most commonly cited challenge – the lack of clarity regarding confidentiality – is understood to be an outcome stemming from boundary issues that often lead to role conflict (Carlson, et al., 2001). For example, confidentiality may be threatened when peer providers lack knowledge of agency mandates regarding confidentiality. Peer providers may divulge information that could place service recipients at risk (Solomon, Cook, Jonikas, & Kerouac, 1994). Yet, it is important to note that Carlson et al., (2001) state that, “there is no

empirical evidence suggesting that peer providers are more likely to breach confidentiality than non-peers” (p. 34).

In addition, the third challenge to peer support is identified as attitudinal barriers. These attitudinal barriers are believed to originate from mental health stigma and related to misconceptions about peers’ capabilities (Solomon & Draine, 1996). Solomon and Draine (1996) note in their study non-peer case managers “assumed that peer employees would experience more stress, less self-esteem, and greater burn out than non-peer case managers.” Yet, this was not the case. As a result, there exist assumptions about ability or inability that are not present for non-peer staff. For example, in their study Gates and Akabas state:

Some respondents voiced the belief that having a mental health condition, by definition, meant that the individual was ‘sick’ and, therefore, unable to give 100% performance in the workplace. They believed that peers were ‘cheap’ labor who were unable to deal with the stress of working, whose presence on staff had the effect of ‘dumbing down’ professional staff, who were unreliable, who could not go beyond their own perspectives, and who could not respond to emergency situations (p. 297).

These attitudes create barriers for peer providers that challenge their work in peer support.

On occasion, conflict arises between mental health peer providers and non-peer staff as a result of power struggles between the two. Carlson, et al., (2001) state “It has become evident that some amount of discomfort exists on the part of peer providers and non peer staff in developing a working relationship as equals” (p. 206). Mowbray et al., (1996) describe the conflict existing between peer support providers and professionals revealed in a project

designed to expand vocational services for disabled individuals. Peer providers experienced a lack of autonomy in a hierarchal system. Lack of autonomy created feelings of resentment causing peer providers to feel like “second class citizens” (p. 58). In these contexts, peer support providers often must negotiate boundaries in complex relationships.

There are several structural issues noted in the literature that create challenges for peer supporters working as peer support providers. These issues include the following: ambiguous job descriptions, unequal or low wages, and lack of supervision or training (Gates & Akabas, 2007; Mowbray, Moxley, Thrasher, Bybee, & Harris, 1996). For example Gates and Akabas (2007) note ambiguous job descriptions involve inadequately defined tasks; or “flooding” peer providers with too many tasks thus creating role confusion. In addition, they note that unequal or low wages, compared to non-peer counterparts, lock peer supporters in part time or temporary jobs in which they do not have access to benefits. There is the assumption that peer providers do not want to affect their disability benefit by incurring high wages (Mowbray et al., 1996). Also, role confusion is also noted to emerge when peer providers assume responsibilities without adequate training (Gates & Akabas, 2007). In such cases, peer providers are left with inadequate information to do their jobs. These systemic barriers create challenges for peer providers.

### **What Counts as Knowledge in Mental Health?**

Tensions exist between interventions based upon a recovery model (such as peer support) and contemporary demands for interventions rooted in evidence based practice (EBP). At the root of this tension is the question of what is considered “evidence”. EBP is defined as “. . . an approach to classifying healthcare. . . research according to the quantity and quality of

empirical evidence supporting a particular intervention” (Anthony, Rogers, Farkas, 2003, p. 103). EBP support interventions that rely on experimental designs that have proven effectiveness in research settings. It is historically situated in the medical model as it first appeared in the field of medicine (Claridge & Fabian, 2005). Since that time, EBP has become a global movement (Claridge & Fabian, 2005). Controversy exists in the literature in regards to EBP and the ways in which it can (or cannot) inform recovery-based models such as peer support (Anthony, Rogers, & Farkas, 2003). The outcome-focus of EBP ignores the mechanics of process that is so pertinent in recovery orientated interventions like peer support (Solomon & Stanhope, 2004). Glasby and Beresford (2006) argue that what is considered “evidence” in EBP is situated in the physical sciences and must be expanded to consider other forms of social sciences (p. 271). EBP relies on particular forms of study designs (such as randomized clinical trials), designs that EBP proponents regard as the highest form of evidence. Such designs may not be feasible, nor desired in mental health service research (Anthony, Rogers, & Farkas, 2003, p.104). The combination of certain types of knowledge being more privileged than others and mental health stigma in the attitudes of professionals working in the mental health system has resulted in the devaluation of the lived experience of peer supporters (Bates, Kemp, & Isaac, 2008; Berry, Gerry, Hayward, & Chandler, 2010; Kottsieper, 2009; Murray & Steffen, 1999). As a result, peer support has been underutilized.

### **Methodology**

This research takes an exploratory qualitative interpretive approach. I chose to use qualitative methods as I was concerned to include the voices of peer supporters and service providers with a stake in the question of peer support in Ontario. The decision to involve peer



supporters in my research is also consistent with the values inherent in the philosophy of recovery. These values are based on ideas of empowerment, reciprocity and self-determination. The main message (and title) of James Charlton's (1998) book, *Nothing about Us without Us*, is a powerful slogan that encapsulates the essence of the rights of peer supporter survivors to have a voice in this study. It is interpretive because the study strives to understand "meaningful social action" in the context of peer support (Neuman, 2011, p. 102). I chose to use critical disability theory as the framework for my analysis. Applying a critical lens in the interpretation of the data enabled me to critique issues of power inherent in the dynamics of service providers and peer supporters.

The purpose of my research is to understand the reasons why more formalized use of peer support has failed to be translated into policy in Ontario. The fact that lived experience does not appear to be valued in the mental health system – despite evidence that peer support is effective – indicates that there are deeper structural inequalities at work. Taking into account the history of the fight for rights in the peer supporter movement, my goal in this research is to ascertain the barriers that exist to the implementation of peer support in Halton/Mississauga region. To achieve this, I worked closely with T.E.A.C.H – one of the leading organizations in the field of peer support in this region. They run workshops geared to the holistic development of personhood such as anxiety, self-esteem and leadership training. T.E.A.C.H has supported my work in that most of my data came voluntarily from their members. The T.E.A.C.H. mission statement, found at <http://www.t-e-a-c-h.org>, states the following: The purpose of T.E.A.C.H is to provide community based, peer run support for individuals living with mental illness. T.E.A.C.H is committed to using a person-centered, recovery approach.

### **Recruitment, Ethical Considerations and Participants**

I used purposive sampling because I was interested only in peer supporters and service providers in the mental health system. Participants from this study were recruited through T.E.A.C.H. A variety of strategies were used to recruit participants from the different sub-populations involved in the question of peer support. Populations were divided into two main categories - peer supporters and service providers. I went with these two groups because each brings their own unique perspective on the needs of community in respect to peer support.

To recruit peer supporters, a T.E.A.C.H worker sent a letter of information and consent form to potential participants who accessed their services asking them to contact the investigator directly if they were interested in participating in the study (see Appendix A). This method ensured the confidentiality of those using the services of T.E.A.C.H. (as I did not know who had received the letter) and of future research participants (as T.E.A.C.H. did not know the identity of those who chose to participate). This also allowed participants to self-select which was important in that it worked to mitigate any power imbalances between T.E.A.C.H staff and people using T.E.A.C.H services. The recruitment letter was sent to all members of T.E.A.C.H., including service recipients and volunteers (Appendix A). Interested participants contacted me by email or phone. At the time of contact, I reviewed with them the purpose of the study and the procedures involved, and stressed with them the voluntary nature of the project. If someone indicated a willingness to participate, I arranged for them to take the next step which was an interview.

In order to recruit participants from the service provider group, once again T.E.A.C.H was also directly involved. A T.E.A.C.H worker sent a cover letter, with the information letter/consent form attached, asking potential participants to contact me directly (See Appendix B, C). Again, I utilized a self-selection approach that worked to maintain confidentiality and mitigate any possible feelings of coercion on the part of potential participants. I followed a procedure that was the same as used with peer supporters. The next step involved an interview.

The decision to send letters to the service providers in this study was made in collaboration with the Consumer Survivor Initiative lead, another staff member and the investigator. The service providers who participated represented various stakeholder groups in the community. For example, one individual represented the Local Health Integration Network (LIHN) of the Halton/Mississauga region. There was also a participant who was a community mental health service provider in a national organization. The last participant was a Consumer Survivor Initiative staff member who was both a peer supporter and a service provider who was able to provide a very particular perspective.

The final group of participants included four service providers and four peer supporters. Of the participants, five out of the eight were female. The ages ranged between forty and fifty-five years old. One service provider identified with a mental health disability and one peer supporter identified with other disability issues. All peer supporters identified with mental health impairments and users of mental health services. All participants were Caucasian except one who identified as a race minority. All participants were attached to T.E.A.C.H.

### **Data Collection and Analysis**

Qualitative data was collected using semi-structured, open-ended interviews. My original intention was to conduct a focus group with peer supporters. My first attempted focus group with peer supporters failed because no one attended the group. In the follow-up focus group, I experienced complications with the audio-recording and difficulties with the questions I was asking – I was not confident that the questions were targeting the information that I was after; therefore I asked for, and received, permission from the participants to conduct 1-1 interviews instead. All participants gave written consent to be audio recorded. I interviewed eight people in total - four peer supporters and four service providers. The individual interviews with peer supporters ranged from 45-90 minutes. Interviews with service providers ran for a maximum of 30-45 minutes (as they had made it clear they were busy and I wanted to respect this). Interviews were conducted in their offices. Participants seemed open and comfortable talking about the issues related to peer support. Interviews with peer supporters were conducted at the location of their choice- a coffee shop and the local library. Peer supporters were passionate about the topic of peer support and demonstrated a willingness to share openly.

Although I did not transcribe my own interviews (they were transcribed by a professional transcribe) I was able to engage with the data in depth in the coding process. I used Strauss and Corbin's (2008) method of coding in grounded theory. I decided to code data by hand rather than to take the time required to learn a computer program. First, I went through each of the transcribed interviews one at a time, highlighting significant words, phrases, quotations, or longer pieces of dialogue that I felt were potentially relevant to my study. Secondly, I organized the highlighted data in each transcription into outline form in order to access information in a

more efficient manner. I went through all eight interviews in a similar manner. This was the beginning of a thematic analysis of the data as I began to colour code the major themes that emerged in these outlines. Assigning colour codes enabled me to compare and contrast the themes emerging in the different interviews and to identify major themes reoccurring in the data. The end result was the identification of five major themes that seemed to capture what the participants shared. The identification and analysis of these themes involved using a critical lens to interact with the data and develop meaningful concepts for understanding the issues articulated by participants. The five themes are as follows: benefits of peer support; barriers to peer support; economics (such as funding); understanding peer support related to the definition of peer support; and peer support as an untapped resource.

### **Complexities in Data Collection and Analysis: Insider/Outsider Status**

As a service user myself, I struggled with methodological tensions as I entered into this research based on my membership status as both an insider and an outsider. Yet, as a service user in the mental health system, my insider status also helped create a common bond between some of my research participants and me. I realized I was perceived as someone who could relate to peer supporters in a way in which others could not. This had the potential to work in my favour because there was an environment of trust established based on our commonality.

Conversely, this insider status also came with disadvantages. Self-identifying as a service user invariably associated me with a group that is stigmatized. I had the potential to be marginalized and stigmatized by outsiders due to my association with that group.

Secondly, I could have had trouble analyzing data due to projecting my own undue influence onto participants' stories. Corbin, Dwyer & Buckle (2009) state:

Although [the insider] status can be very beneficial as it affords access, entry and a common ground from which to begin the research, it has the potential to impede the research process as it progresses. It is possible that the participant will make assumptions of similarity and therefore fail to explain their individual experience fully. It is also possible that the researcher's perceptions might be clouded by his or her personal experience and that as a member of the group he or she will have difficulty separating it from that of participants." (p. 58)

This led me to ask the following questions: will I be able to move past emotionally charged narratives that trigger my own painful experiences? How will I be able to identify personal biases that may colour different participants' experiences? Will my interpretation of the data unduly influence the results? How can I mitigate the effects of emotional projections? These questions provoked investigation throughout the research process.

These questions were, in other ways, complicated by my status as an outsider. While interviewing participants in a study on homelessness and HIV, peer research assistants (PRAs) noted that they felt like an outsider when the only connection was based on their disability (Greene et al., 2009). In my case, there were other aspects of my social location that had the potential to make me an outsider from my research population. For example, unlike any of the participants, I identify as a Black, Afro-Canadian woman. The extent of the impact of my social location is unknown.

In addition to being a Black, Afro-Canadian woman, I also held power as a researcher coming from an academic setting. The question for me became: how can I negotiate power in such a way that does not intimidate or shut down the stories of my participants?

As a researcher, I could not avoid the power I held in the research process. I realized a tension for me was negotiating power in the room when I conducted my interviews. Also there were instances (in the case of service providers) where the person I interviewed held more power than I did. The reversals of power dynamic enabled me to relate to peer supporters in this study.

Corbin Dwyer & Buckle (2009) speak of “the space in between” insider and outsider positioning. For example, they state:

...insider and outsider are understood as a binary of two separate pre-existing entities, which can be bridged or brought together with a hyphen. This hyphen can be viewed not as a path but as a dwelling place for people. This hyphen acts as a third space, a space between, a space of paradox, ambiguity and ambivalence, as well as conjunction and dis-conjunction...There are complexities inherent in occupying the space between. (p. 60, 61)

I felt the space in between was an important concept because it enabled me to acknowledge that there exists a murky area that is not so clear cut as the concepts of insider and outsider may suggest. Rather there exists a place in between that appreciates the “the multilayered complexities of human experience” (Corbin Dwyer & Buckle, 2009 p. 60). Haviland, Johnson, Orr, & Lienert (2005) state, “Insider and outsider are not clear cut categories, but rather they involve complex and often shifting positions” (p. 11). This would suggest that at any given time people move in and out of the insider-outsider position depending on the circumstances.

Depending on issues of gender, ability/disability, sexual orientation, class and race one’s status as an insider or outsider are multi-layered combinations that create the space in between.

It was within this space that I brought all the complexities of who I am (as did the participants). Realizing that I co-exist among these multi-facets of identity created a continual shifting of my membership status. Holding this space, I realized I would not resolve the tensions I face regarding power or how others in the research process viewed me but I could sit with these tensions and allow them to expand my ability to be a better researcher

### **Findings and Discussion**

In the following section, I used literature to expand on the words and ideas of participants.

#### **Benefits of Peer Support to Peer supporters**

Peer support is recognized by peer supporters to be beneficial to service users. Through interviews with the peer supporters in this study, the value of peer support in the lives of service users is affirmed. Peer supporters (who were also service users) spoke passionately about the ways in which peer support transformed, empowered and enabled them to cope. In this study, service providers generally only spoke of the benefit to service users. Kirby and Keon (2006), in their federal report, document that service users in Canada are requesting peer support as a means to deal with the debilitating aspects of mental illness. Their report includes the voices of service users who indicate that peer support is valuable tool for recovery. Goldstrom et al., (2006) reveal that throughout the USA, Canada, UK, Australia, New Zealand, Greece, Peru and Argentina thousands of peer support services are described in the grey literature. The fact that so many exist would seem to support the idea that service users benefit tremendously from peer support. Participant #8 (peer supporter) refers to the impact peer support has had on her/his life in the following:



[Peer support] has impacted my life because when I am facilitating a group I am constantly referring to the tools and it is a constant refresher in my head that I need to keep moving forward. . . it ingrains into my head that I have come so far because sometimes we forget how far we have come in our recovery; it keeps me in that frame of mind of moving forward because if I did not have to constantly think about it in a weekly setting in a group... I would kind of probably slack off. . . I probably would not think about it but I know that recovery is a constant learning experience and being around other people it is very easy to think positively because you are surrounded by people who are in the same situation as you.

This participant frames recovery as a continuous growth process that reflects inner transformation. S/he indicates “moving forward” in life is a priority and refers to “tools of recovery” which enable her/him to cope.

Participant #4 (peer supporter) reiterates the value of peer support. She states that peer support was more value to the groups she co-facilitated than those meetings with clinicians:

In my own recovery . . . peer support . . . gave me the momentum to keep going and in fact enter the field that I have entered . . . I was a co-facilitator in peer support and was able to take from the groups that I was co-facilitating... the participants that were there found that this kind of peer support was more valuable to them [than] any of their clinicians.

### **Peer Support as Bridges between Peer supporters and the System**

Participants spoke to the benefits of peer support to people within the system. Peer support could be beneficial to people by enabling users to negotiate a complex system thus creating a bridge between service users and the system. Participants have identified navigating the system as an important issue for service users. There is a need for system navigation because “people fall between the cracks”; this was stated by Participant #1 (service provider) in the following:

Within all the LHIN’s there are always gaps so you have 12 providers [within the Halton/Mississauga LHINs]. People fall between the cracks, people cannot navigate the system. . . getting the right care at the right time by the right person when you need it is not always there, that is the goal but we do not have a seamless system. . . in terms of navigating the system and getting the care when they need it. And every door is not the right door so when they tap into one it is maybe not the right door for them, they will be directed and connected with the appropriate door and appropriate service as opposed to being told “sorry we don’t provide that service” and the door closed. They make it very difficult for someone in a time of need to get the care and the risk is that they do not get the care and then exacerbate and get worse.

The confusion embedded in the mental health system is reiterated by Participant # 2 (service provider) who recommends peer support as a way to navigate it:

What would be great would be navigation, system navigation, that is what we spend a lot of time. . . the complaints that we get, the work that we are trying to

do with all of our community partners and the other hospitals in the region, the satisfaction surveys that we get from patients it is all about people do not know where to go. . . . How do I find my way in the system? How do I enter the system? I got an e-mail today from a school in Burlington, “I had a kid sent to your emerg, he was discharged, things got worse, then they took him to Hamilton emerg and they admitted him. Why did you not admit him? Where am I supposed to send him?” . . . That is what people are very confused about, where to go when you have an issue and how to access the system, so what would be really tremendous is you know more people available to help with this whole navigation around “where do I go?”, and that would be a great role for a peer support worker. It is working alongside the clients and their families, supporting them through the process of entering and existing different systems.

Participant # 3 (service provider) indicated that having a comprehensive understanding of services would be a challenge for most peer supporters. For example s/he stated:

I know all 12 agencies in Halton but I do not really know what makes them different. I know what the brochures say, I know what it means but I cannot understand why I would choose so-and-so’s organization over so-and-so’s. There is not clear enough data. So, I think that while peer support would be wonderful to help navigate, I do not know how those peer support workers would do it.

Further, an understanding of services from the vantage point of a service provider without experiential knowledge may be different from those who have lived experience. It may not be

possible to have comprehensive knowledge of every service but lived experience adds emotional depth to knowledge that can be communicated only by one peer supporter to another. It is this sense of empathy of one who has walked in your shoes and understands how to climb bureaucratic walls that peer supporters can give to another person in the mental health system. However, service provider participants are suggesting that while they think peer support would be a good way to assist users to navigate the system, they are not sure this is happening yet and worry that it might actually be a challenging task.

Participant #6 (service provider and peer supporter) mentioned both the necessity of service users learning how to navigate the system and the benefits of access to the useful skills of those service users (as peer providers) who had experiential knowledge of the system:

[P]eer navigation was identified as being extremely valuable. . . What better person than an individual who not only understands this system but has experienced their own challenges and had to sort of find their own direction there is that type of understanding and empathy that would be extremely beneficial. Beneficial in a number of ways, not only to the person at that critical point in time for their own recovery but by connecting people with the services at the right time you are potentially easing the burden in emergency departments revisits or a duplication of an individual taking the same services over and over without getting any traction when there potentially could be not only a better fit for them but also a seat has opened for someone else who could use that service.

There seems to be support in the literature that peer supporters' knowledge can be valuable in negotiating the system. For example: Solomon (2004) states that "peer providers

are adept at negotiating the diversity of systems and agencies on behalf of others, due to their own experiences and encounters with societal and system barriers.” (p. 397) Peer support is a place to generate peer supporters’ knowledge that can feed back to the system and make the system more navigable.

Chinman, Weingarten, Stayner and Davidson (2001) found additional benefits to the system which include peers providing a ‘bridge’ between the mental health system and the patient to improve service delivery; they also believed that the peer support worker could also help the professionals and patients get a better understanding of each other’s needs” (Cited in Repper & Carter, 2010, p. 11)

Yet, all this puts the onus on service users to become informed in order to access the system. There are inherent inaccessibility problems within the system that must be addressed. It is still about changing people and not addressing the inherent structural issues embedded within the system. The focus needs to be on changing the system instead of changing individuals. In their study, Saraceno et al., (2007) state “the way in which mental health services are organized affects treatment coverage. . . ” (p.1167). The fact that services in Ontario are so decentralized has a bearing on the accessibility of mental health services. The centralization of services could reduce the complexity of the system thus making it more navigable.”

As has been articulated, system navigation is one such benefit which, if done properly, not only supports service users to learn to more effectively navigate a complex system but (if service user feedback is implemented) allows for the creation of a more user-friendly system.

In addition to the above, participants highlighted the following benefits in this study: alleviation from isolation, recovery education, normalization, safety, and transformation of the self.

### **Alleviation of Isolation and Recovery Education**

Three peer supporters and one service provider who is also a peer supporter spoke about peer support as an avenue to alleviate isolation. Participant #5 (peer supporter) mentioned that people with mental health impairments may be prone to disconnection from the community:

“. . . People with mental health issues really feel disconnected from the community and this peer stuff for me it is so nice to be able to connect again with people.”

It is documented in the literature that people with mental health impairments living on low incomes are likely to feel more isolated and disconnected from others. For example Crooks (2004), in her study on women with mental health impairments living on the Ontario Disability Support Program, indicates the commonality of isolation for people living with a mental health impairment and a limited income. Similarly, the following peer supporter described the pain of being isolated in a large High School during her teenage years. She indicated that a peer supportive relationship enabled her to cope with the debilitating effects of her/his “illness” before diagnosis. Participant #8 (peer supporter) stated:

I first developed symptoms of a mental illness when I was 18, in high school. I did not know what it was at the time and I was not diagnosed with a mental illness until I was 23 so I went five years not knowing what was going on with me until many years later. Peer support was really important for me because I went to a very large high school and I honestly thought I was the only person

that was suffering and when I found out that a friend of a friend or someone that I worked with went through the same thing I really latched onto them because I thought at least someone kind of knew what I was talking about and it made a world of difference knowing that I was not alone. So that was I guess the turning point for me in recovery.”

One gets a sense of the depth of meaning peer support had for this participant through her statement: “it made a world of difference knowing that I was not alone”. It is important to grasp the emotion embedded in the language of this participant.

Being drawn out of isolation for another participant meant learning more about the day-to-day manifestation of her/his impairment. Participant # 7 (peer supporter) stated:

For me, I guess one of the big things is when I was having difficulty, I have bipolar disorder and when it became unmanageable and I had to go to the hospital and. . . it kind of seemed like this was only happening to me. I was alone in this, you know? I didn't know what I was going up against. . . I did not have a lot of information about it... the hospital provides a bit of information and I did a bit of reading but I guess when I first started doing peer support activities it is just comforting to know that there are people that understand how you feel.

The reduction of isolation occurs in the context of peer support when members share their life experiences with one another. Without this connection, service users in isolation feel as though illness is only happening to them. Empathy seems to be an important factor among service users' connection to one another. Pistrang, Barker, and Humphreys (2008) mention in their

work the benefits of social interactions with others in peer support. These benefits include findings similar to those of this study: The benefit of empathy - a connection with someone who, due to sharing similar experiences, can relate in a compassionate and empathic way - is a resource specially found in peer support. As a result, people “feel less isolated and more understood” (p. 111).

In addition to the alleviation of isolation, participants spoke of the value of peer support in terms of accessing and sharing knowledge and skills. Two service providers (one also being a peer supporter), and one peer supporter identified recovery education as an important component to the benefits of peer support to service users. Recovery education is defined by participant #6 (service provider and peer supporter) as:

. . . .Education can come in the way of workshops or taking courses but there is also a real education in the reciprocity of . . . being present and listening to other peoples’ experiences and processing them, either for better or for the worse, or just being discerning and say ‘oh well this worked for one person, this did not work for another person, how could this work for me?’, and giving me some ideas or tactics to be able to try.

Participant #5 (peer supporter) mentions the reciprocal benefits of sharing knowledge and skills in peer support. For example s/he stated:

I was introduced to a peer mentorship program where we could share experiences with other people who were in recovery and I think that this has a huge benefit to those who are in the infancy of their recovery because they have someone that they can relate to and in my case my recovery was very self-



directed and I was able to share a lot of strategies with my peer pairing and I think it was also great for me.

Mead and Copeland (2000) confirm that sharing knowledge, strategies and skills with one another are an important aspects of recovery. It is the sharing of knowledge, strategies and skills that are understood to enable peer supporters to learn and grow from one another in a way that feels comfortable.

### **Normalization as a Process in Peer Support**

In addition to alleviation of isolation and recovery education, three out of four peer supporters spoke about the process of normalization that occurs in the context of peer supportive relationships. This process makes traumatic experiences less abnormal. Mead, Hilton and Curtis (2001) state that peer support is about normalizing what others have named abnormal in the lives of people with mental impairments. Repper and Carter (2010) highlight the dimensions of normalization when they acknowledge that in this process service users are allowed to explore intense feelings without being pathologized. Participant #5 (peer supporter) implied that peer supportive relationships that foster a sense of normalcy leading to a sense of hope that there is an opportunity to get better:

[Peer mentoring] was also great for me it was kind of a way to acknowledge that I had made progress and for the other person they can see that, yeah, there is normalcy. There is an opportunity to get better and things were well, all is good.

Interestingly, Participant #6 (peer supporter and service provider) connects the normalization process that occurs in peer supportive relationships to recovery:

. . . wherever there are folks who are struggling with mental illness or they are experiencing mental fatigue, peer support can be that conduit to bringing them back. . . again, it is that any instance where the process of normalizing can help a person to attain some confidence, to re-center and to move themselves forward in their own recovery there is a role for peer support.

Participant #4 (peer supporter) clearly speaks to how peer support can be normalizing:

What the participants were saying is that, you know, they go to the psychiatrist and the psychiatrist, a lot of psychiatrists are not really counselling psychiatrists and so it is more on a medication line, and also they are MD's or whatever so a lot of the clinicians they are not particularly counsellors, and also a lot of the clinicians do not have life experience in this area. So when [the participants] come to the self-help group they are dealing with people who have had the life experience and, once the group gets to know each other, some of the participants feel safe enough in the group to share some very personal knowledge about their mental health, their status, some of the things that have happened to them, and all of a sudden you see around the group that you know this is really hitting a chord with some other people and they are able to voice that and almost feel relief that they are not going crazy, that other people have experienced the same thing.

The sense that they are not “going crazy”, they are not alone and that in fact people have experienced similar life events, s/he connects to the understanding that arises among service users who reach deep emotional connections due to shared life experience. This participant also

points to how the normalizing experience that takes place in these relationships seems to facilitate a feeling of safety for service users. Safe environments are created in peer supportive relationships that enable service users to mirror one another in ways that allow them to take risks.

### **Safety in Peer Support**

Mead and MacNeil (2006), discuss the issue of safety in peer support. They differentiate between the traditional mental health care system's meaning of safety and the meaning of safety in the context of peer support. They state:

We cannot talk about doing something fundamentally different until we address the topic of safety and the fact that it's simply come to mean risk assessment in the field of mental health. We've been asked, "Are you safe, will you be safe, will you sign a safety contract?" . . . For most people a sense of safety happens in the context of mutually responsible, trusting relationships. It happens when we don't judge or make assumptions about each other. It happens when someone trusts/believes in us (even when they're uncomfortable), and it happens when we are honest with each other and own our own discomfort. It is with this interpretation of safety that we can begin to take risks and practice alternative ways of responding. We can choose who to be with and when and we can begin to talk about shared risk... We talk about how we each are likely to react when we feel untrusting or disconnected. We begin to pave the way for negotiating the relationship during potentially difficult situations. This level of honesty works

well in trusting relationships but is critical to the health of a peer support group or program (p. 15).

It is this sense of shared experience that creates a feeling of safety: a bond among service users that works to normalize traumatic life experiences.

Participant #6 (service provider and peer supporter) similarly attests to the importance of a sense of safety that is created in a normalizing peer supportive relationship when s/he stated the following:

. . . the whole normalizing aspect of not being the only person to have to manage what you have shamefully or with difficulty been trying to figure out. . . you cannot transfer a clinical didactic from clinician to a patient or peer supporter to service provider. Peer support has the street credibility of a person having walked the walk and it is absolutely integral.

Importantly, this participant also addresses how this typically does not occur in hierarchical service user-clinician relationships. This sentiment was echoed by participant #8 (peer supporter) who stated:

I would rather deal with someone who knows what I am going through, has felt was I was going through and has empathy towards what I am going through as opposed to someone who has read it in a book. It is two completely different dynamics and I have had experiences in a clinical setting where you know doctors are like, okay, these are the symptoms you are supposed to have and these are the pills you are going to take and these are the ways you are going to get over it, but you know he has never sat in my shoes and does not know how

difficult it is. . . [to]come to terms with even just getting diagnosed with a mental illness.

Participant #4 (peer supporter) also addressed how this process cannot easily be transferred in hierarchical relationships. For example, s/he mentioned that psychiatrists are focused primarily on adjusting medications for service users with mental health disabilities.

### **Transformation of the Self**

My study revealed a level of transformation that occurs within the core self of services users receiving peer support and of those providing peer support. Two out of four peer supporters described an inner journey that involves transformation to the level of personal self-actualization. Participant #5 (peer supporter) describes her/his peer-mentoring relationship with another service user in the following quote:

I thought this was a culmination of her re-building herself. . . and re-building yourself does not mean building the way you were before because that is part of the reason why you crashed. Re-building yourself . . . in a more resilient way; to build yourself up and back to a place where it is a healthy you. It is not a person that is going back to the old mentality; the old habits. So a lot of it [the process of peer mentoring] was informal but was very deliberate [for example] establishing goals, finding out what they wanted to do... it led to self-actualization.

Note how the above peer supporter speaks to the concepts of inner growth as well as emotional and spiritual transformation. S/he mentions the idea of re-building one's life from a state of devastation to a place of health and resiliency. Yet there appears to be little literature about the

concept of self-actualization in the context of peer support. Kruck, Whitaker Lee, Reed, Jones and Hammond (2011) mention it. They state:

Providing peer support may be a powerful growth experience for both parties. Peer support can help a person gain a sense of self-determination, rekindle ambition, and provide real-life solutions based on their experiences. Peer support provides dynamic nurturing process in a non-competitive environment that promotes independence and self-actualization. (p. 4)

Echoing this literature, participant #4 (peer supporter) stated that her/his experience as a group facilitator at a peer supporter run organization was both career-altering and life-changing. S/he stated:

. . . as a facilitator I learned a lot from the group on a professional level, I guess, from the sharing that went on, but also on a personal level because it allowed me to also share and talk about my experiences that related to whatever was going on in the group discussion. So it was helpful that way. . . it is really satisfying to be able to give of yourself and know that you are helping another individual or a group of individuals . . . This has been career altering for me. . . when I decided to go and take formal studies in the areas of addiction, mental health and self-esteem because those three to me are very much intertwined and you usually do not have one without the other. It has been life changing to be able to participate as a volunteer . . . in the self-help mental health groups; it kind of just solidified that, yeah, this is really what I want [to do].

For this participant, healing self-esteem through career changes that created more meaningful activity in her life was the key issue that led to transformation. This occurred in the context of group members sharing experience, strength and hope.

Peer support is a valuable tool for the recovery of service users. Peer supportive relationships create deep emotional connections that alleviate isolation. Service users learn important skills through recovery education, and develop a sense of normalcy that encourages a sense of safety. Also, peer supportive relationships encourage the transformation of the self. As one participant so wisely put it, peer support is about “being present to one another” in a way that supports dynamic change in the individual.

Furthermore, benefits of peer support could involve easier accessibility to the system through peer navigation. The mental health system is not seamless and there exists a danger of service users falling through the cracks.

### **Peer Support as an Untapped Resource**

Although, participants stated that peer support has many benefits, it was identified as an untapped resource in this study. Participant #1(service provider) stated that peer support is a resource that benefits service users but is not utilized enough. S/he states:

I think peer support is a great avenue by which knowledge is exchanged . . . people learn well from their peers. It . . . also validates them and their experiences so I think it is a good tool that we probably do not use enough.

In this study, peer support was challenged to become more evidence-based and it was this perceived lack of ‘evidence’ that resulted in peer support being an untapped resource. The under-utilization of peer support seems to be rooted in an insistence within the health care

system that all interventions be evidenced-based. Participant # 1 (service provider) insisted that the role of the funding body s/he represented only funded programs that were evidence-based. As a result, peer support would have to be proven to be evidence-based in order to tap into much needed resources. Participant #2 (service provider) reiterated that peer support as an intervention must produce “documented” evidence that it can achieve outcomes. Finally, participant #3 (service provider) stated that focusing on “hard outcomes” is what is required from peer support. There is literature that supports this insistence that programs be evidence-based in order to be funded and utilized (Sackett & Rosenberg, 1995; Solomon & Stanhope, 2004).

Yet, the demand that peer support be evidence-based does not fit a service user-centered approach. There exist philosophical and ideological differences. For example, evidence-based practice stems from medical model ideologies while recovery stems from a political frame of reference that rejected the principles of the medical model in an effort to emancipate people from oppressive definitions of disability. Solomon and Stanhope (2004) state:

. . . recovery vision represents a significant shift away from the medical model... Instead the focus of service moves beyond symptoms and pathology to the individual, who may have different treatment goals from those of the clinician. Some peer supporters have argued that “programs based on evidence have tended to ignore peer supporter feedback, especially in the area of medication side effects.” (p 313, 314)

There are also other inconsistencies regarding values between evidence-based practice (EBP) models and service user-centered recovery-based visions. For example, EBP emphasizes



the importance of outcomes. Yet these outcomes do not always align with service user-centered values. Participant #2 (service provider) identified the following outcomes that are consistent with EBP: dealing with acuity, hospitalization prevention, and reduced visits to emergency (all of which were touched on in this study). On the other hand, service users' values are based on issues of inclusion such as membership in a community, valued work, decent housing, and enrolment in school (Anthony, et al., 2003). Furthermore, the processes of change that are important aspects of healing via relationships have no way of being accounted for in EBP. For example, "Deegan, a psychologist and consumer, describes recovery as a deeply personal 'process' that involves wrestling with the reality of mental illness but includes finding a new sense of self and feeling of hope, while understanding the limitations of psychiatric disability" (Cited in P. Solomon & Stanhope, 2004, p. 313). This inner transformation that occurs in relationships has no way of being quantified in EBP(Anthony, et al., 2003).

Therefore, Solomon and Stanhope (2004) suggest that recovery should inform EBP for a more holistic paradigm that can meet individual needs. This will require EBP models to incorporate a broader definition of what is considered to be "evidence". Due to the fact that formal peer support is still in its infancy, and may always defy quantification, evidence will need to be considered which now lies outside the realm of formal evidence-based practice.

### **Barriers**

Existing barriers that impede the implementation of peer support are manifested in stigmatizing attitudes toward peer support, such as the devaluation of lived experience, the devaluation of peer support as work, and barriers related to the effects of economic constraints due to funding.

### **Devaluation of Lived Experience**

The root cause of the devaluation of lived experience is the culture and attitudes in society that promote oppressive perceptions of service users. Berry, Gerry, Hayward, and Chandler (2010) state:

. . . stigma and discrimination contribute to the social exclusion of people with mental health problems; and there is a culture of thinking among clinicians and people who are in the profession that if you're a peer supporter, you don't amount to much very much. (p. 413)

Although this cannot be said of all clinicians, this general culture among clinicians is believed to contribute to the systemic barriers manifested as the devaluation of lived experience.

Two service providers (one of whom is also a peer supporter) and one peer supporter spoke about the devaluation of lived experience. For these participants, devaluation of lived experience is connected to oppressive structural perceptions that deem the knowledge and experience of peer supporters less valuable than those of clinicians with post secondary education. This idea was clearly expressed by Participant #2 (service provider) who stated:

[T]here are systemic barriers and that is about perception, stigma, you know, this perceived sense that people's personal experience is not as valuable as you know my five years University degree and my knowledge base so I think those are barriers.

For this participant oppressive perceptions are embedded in attitudes that lived experience of peer supporters is less valuable than knowledge gained in academia. Participant #8 (peer

supporter) explains the ways this plays out in the lives of peer supporters in a practical way creating limited opportunities. S/he stated:

I [have] learned from experience as opposed to learning from a book where these people went to school... there is a big line that is drawn in the sand that. . . you are either educated this way or you are educated that way and it is hard to cross each side... I think that this is a problem that I am dealing with right now personally because I am going to school to get certified so I can actually become a social worker and not be stigmatized... I get pigeon-holed... because I suffered [from a mental illness] and I am not [perceived] as being as good as somebody [else]. I still think there is stigma behind that in a clinical setting.

This participant experiences oppression manifested in the devaluation of lived experience of peer supporters as social exclusion. For example, her/his metaphor of the big line in the sand that separates those with lived experience and the privilege of those with higher education communicates her/his sense of exclusion. This exclusion leads her/his to feeling of being pigeon-holed. This image demonstrates a sense of constraint. Therefore, this peer supporter experiences the devaluation of lived experience as oppression. S/he believes going to school will emancipate her/him to live a fuller life. Yet, the issue does not lie in peer supporters getting education – its roots run much deeper.

Participant #6 (service provider and peer supporter) describes stigmatizing attitudes that lie at the root of the devaluation of lived experience as an egoist hierarchical wedge between clinicians and peer supporters thus further expanding on the meaning of stigma and exclusion that occurs in this insidious systemic barrier. For example s/he stated:

Part of the grassroots with peer support is that in order to be able to provide peer support there is absolutely no educational requirement to do so... A peer supporter's education, their PhD... comes through their own life experience so being able to impart at the appropriate time a mentor's experience with a mentee... [it] is a skill. [This is] where the challenges in the system lie... [T]he healthcare system, being very hierarchical...there clearly is a stratification... within the healthcare system. Egos come into play...it makes clinical professionals anxious and this is actually something that drives people with lived experience up the wall because it just takes for granted the experience that people have had [in] their own recovery; so there is this egoist hierarchical wedge.

Again, this peer supporter reiterates the tensions that exist between the clinical healthcare system and those with lived experience in recovery. S/he points out that it takes skill to impart life experience in such a way that enables, empowers and supports fellow peer supporters; and the fact that life experience is not valued undermines people in their recovery and the years of expertise within recovery. S/he addresses the frustration peer supporters experience by stating this devaluation of life experience "drives people with lived experience up the wall". In addition, s/he points out that there exists a hierarchical stratification within the healthcare system in which "egos come into play". Stigma is embedded in this egotist hierarchical wedge that separates those with experiential knowledge as avenues of healing in healthcare system. There is research that mental health professionals can and do hold stigmatizing attitudes toward

service users (Jorm, Korten, Jacomb, Christensen, & Henderson, 1999; Kottsieper, 2009).

Sriram and Jabbarpour (2005) state:

We may be practicing a double standard – expecting peer supporters and the public to cast off stigmatizing beliefs but harbouring those beliefs ourselves... Our educational efforts should not stop at targeting the public and peer supporters of mental services; professionals should also be included... transformation of the mental health system... should also address stigmatizing beliefs of mental health professionals. (p. 610)

Perhaps it is these stigmatizing beliefs that the above peer supporter describes as a egotist hierarchical wedge that separates clinicians and peer supporters in the mental health system. For these peer supporters the devaluation of lived experience is experienced as social exclusion stemming from oppression in the form of stigma.

### **Peer Support as Legitimate Work**

A second significant barrier related to stigma articulated by the participants was the devaluation of peer support as work. Two peer supporters in this study identified that not having financial compensation for their work was way of losing a sense of legitimacy for the work they do as peers. Participant # 8 (peer supporter) noted the importance of giving back to the community when one is recuperating from illness but once one gets better there is a need for money to support oneself. S/he stated:

Most peer support is voluntary and while you are still in recovery you are not working and you have other supports; it is okay to give back. But once you get better and you know you need to support yourself, it is very difficult to give 100

percent or . . . give some of your time to a voluntary service because you have to support yourself. So, I mean if there was some kind of a program where they offered some kind of financial assistance to help other peers... it would make a world of difference.

This peer supporter addressed the conflict volunteers face as they learn new skills and become healthier and the ongoing need to sustain livelihoods.

Participant #5 (peer supporter) puts this very succinctly when s/he stated:

A lot of peers are trying to work or trying to earn some income. . . you can't be volunteering your life away without getting some kind of compensation so you can sustain yourself.

Although the benefit of providing peer support to others is immense and individuals facilitating peer mentoring programs gain very valuable skills, the fact remains that peer support is not paid labour and there exist a loss of legitimacy to the work. Shankar, Barlow, and Khalem (2011) state: "a robust body of literature shows that people who experience mental illness perceive work as central to their recovery (p. 268). They address benefits to employment such as "financial gains, personal growth, and improved health" (p. 268).

It is important to point out that people are at various stages of recovery. Peer support on a volunteer basis is great for people who are not ready for employment but need an avenue to build skills. Those who are further along in recovery soon become restless as their desire and need to re-enter the paid workforce increases.

## **Funding**

A discussion of the barriers to peer support would not be complete without attention given to lack of funding. Five out of the eight participants (three service providers and two peer supporters) in this study mentioned that funding was a barrier to the implementation of peer support in their region. Although this is not surprising, what became evident in this study was how lack of funding has been affecting peer support in the Mississauga/Halton region. Setting up the scene, Participant # 6 (service provider and peer supporter) describes the growing need for peer-led programs in this region. S/he stated:

There definitely is a need [for peer support]. Using current data of residences of the Mississauga/ Halton region [this region]. . . covers from south Etobicoke across the geographical boundary of Mississauga and into Halton hills which is Georgetown, Acton in the north and in the north, and Milton . . . [which is ] the fastest growing community in Canada. . . . This LHIN services 1.1 million residents and currently there is only one peer supporter service initiative...that is serving the needs of 1.1 million people.

People with mental health impairments are experiencing the devastating effects of the lack of services in this region. For example, Participant # 5 describes his/her experience as a vacuum in the system. S/he stated:

. . . I really found a big vacuum in the mental health field . . . There was really not a lot help and I had to be basically self-directed...I feel that if you do not take control of your own recovery, you will likely stay in a negative cycle in the medical system.

The above quote is important because it demonstrates how the lack of services in this region is causing a vacuum for service users. This vacuum is forcing service users to seek services on their own behalf or else fall through the cracks. This peer supporter had the skills to search out services on her/his own behalf but many service users get stuck in a bio-medical model that blames the individual for her/his dis-ease. This perpetuates feelings of helplessness and isolation thus solidifying the patient-clinician hierarchy. Mead, et al., (2001) state:

We, as users of the mental health services, often referred to as 'consumers', are forced to understand our problems as solely a biological matter. This denies the social and environmental factors that may have precipitated or contributed to the distress. Having been marginalized by this model we have adopted roles as 'mental patients' some of us have accepted this role, while others of us have not.  
(p. 135)

The lack of peer-led services due to funding constraints led to service users recycling existing services over and over in order to maintain wellness Participant # 4 (peer supporter) in this study who was also a facilitator described the panic that ensued at the ending of workshops in the one peer-led service in the region. For example s/he stated:

I know that as we were closing up the anxiety and self-esteem sessions towards the end of December, the groups almost went into a panic because of what was out there for them after that... We need to have somewhere we can just come; where we know there is going to be a place where we can come on a regular basis and just share if we are having difficulties and get that support from group members... It was... frightening to see these people were panicking because



they felt like... after this: “I do not have anything other than my clinicians and, Oh God, am I going to fall back into the dark hole that I was in and how am I going to pull myself out?”. . . you have people who immediately want to register for the next group and do the whole 12 weeks over again. . . They are wanting to continue to the degree that they just want to sign up for the same group that they just participated in just so that they can keep going and have that thread to the sunnier side of life.

One can sense the urgency participants in this workshop felt at the close of the sessions. Having found an avenue to explore and share on a deep and profound level, as well as support for one another in the context of a peer mentoring program, they express panic and anxiety that the prospect of losing their sense of connection with one another. Also, they realize that the relationship they have with clinicians is not enough to sustain healthy recovery. As the above peer supporter puts it, they need peer support so they can have “that thread to the sunnier side of life”.

The fact that there exists lack of funding is not surprising during this harsh economic climate where there have been deep cuts to services. Yet, the effects of funding cuts have had deep psychological consequences for peer supporters.

### **Implications for Research and Practice**

#### **Implications for Social Work**

It is important to address some of the implications drawn from this study for social work. It became apparent that the knowledge possessed by the service provider who was also a service user was much more in-depth than those who were service providers alone.

Implications for social work involve educating future social workers about disability issues – including mental health disabilities – in post-secondary education. Disability studies must become a priority in the curriculum. Without a foundation in education the system reproduces social workers that do not have the knowledge and skills to understand and challenge the devaluation and stigmatization of service users both within society and the profession.

### **Peer Support as an Untapped Resource**

The challenge for peer support to be evidence-based creates barriers, and makes it an underutilized resource as previously discussed. As a result, peer support is not a priority in the healthcare system. The main thrust seems to be what counts as evidence in EBP. More research could be done on how peer support and EBP could inform one another. For example, peer supporter research has the potential to create bridges between models of evidence-based practice research that could be mutually beneficial. In order for EBP to inform recovery and ultimately include peer support, evidence must be expanded to include other forms of evidence.

Anthony, et al., (2003) state:

Future evidence based practice research in the recovery era must focus on outcomes that are critical to people's recovery. Qualitative and non-traditional measures of studying important processes and outcomes related to recovery must be used and the influence of non-randomized trials for the development of EBP must be acknowledged... if evidence based practice research is to inform the development of recovery based services, the concept of EBP must be broadened.

(p. 112)

Other forms of research could include, but are not limited to, research now used in the social sciences like qualitative research, ethnographic research and participatory action research (Anthony, et al., 2003).

As a result of EBP being heavily based on academic and medical approaches, there often exists a gap between research and practice (Reed & Reed, 2008). For example, the heart of recovery is process orientated and occurs in the context of relationship. This study confirmed the importance of peer supportive relationships as exemplified in the process of the transformation of the self. Anthony et al. (2003) affirm that EBP does not address the importance of relationship in facilitating the change process for mental health peer supporters. Solomon and Stanhope (2004) state:

. . . recovery's heart and soul is in the process of change which cannot be reduced to the structural components of services and their outcomes. These social and psychological factors tend to go unstudied and as a result contributes to the error variance in clinical effectiveness research... The challenge of EBP are to capture this process, which. . . [has] made the difference between effective case management and ineffective case management. (p. 316)

In addition, certain types of knowledge have become privileged as more valid than others (Berry, et al., 2010). This further exacerbates issues of power between service users and peer supporters in the mental health system and clinicians. Glabsy and Beresford (2006) suggest that all types of knowledge be considered as valuable forms of evidence including knowledge of lived experience. Recommendations of this study advise peer support programs to develop a

best practice approach and, at the same time, work towards an expansion of what is considered evidence in evidence-based practice.

### **De-Stigmatizing Peer supporters' Experience**

As a result of those with the most power assigning value hierarchies to knowledge, service user' and peer supporters' lived experience has been marginalized. Also, systemic barriers create stigma which further compromise users of the mental health system.

Stigma has devastating effects on individuals, users of the mental health system who are one of the groups in society with the least amount of power. My study illustrates that stigma, embedded in attitudes of mental health professionals, is related to the devaluation of lived experience in peer support. The imbalance of power between peer supporters and service providers is a serious matter exacting a heavy toll in suffering and, very likely, even loss of life.

My study scratched only the surface of the complications of mental health professionals' stigmatizing attitudes toward service users and peer supporters. More research needs to be done on how systemic oppression is manifested in the mental health system and how these barriers affect peer supporters. Lauber et al (2006) confirm that mental health professionals do have stigmatizing stereotypes of people with mental impairments. Yet, their study does not address the ways in which these attitudes create oppressive barriers for peer supporters. Participants in this study listed social exclusion, limiting opportunities and frustration as key consequences of this oppression.

Education about stigma is needed for mental health professionals at every level. It is essential that peer supporters take the lead in this training. As Murray and Steffen's (1999) study shows, increased training has proven to positively affect mental health professionals'

attitudes toward people with mental health impairments. In addition, Bates, Kemp, and Isaac (2008) state:

Despite a strong body of evidence that mutual support is beneficial and widely accepted, this resource has been either underutilized or ignored in the mental health field. . . . The biggest obstacle is a perceived lack of credibility: the perception that peer supporters have little useful to offer because they have a mental illness. Yet research has shown that peer support programs can be successful when mental health clinicians are educated about the benefits of peer support in recovery. (p. 22)

The devaluation of lived experience is prevalent in peer support and must be addressed as a major barrier to peer supporters. The underlying assumption among mental health professionals that peer supporters do not have much to contribute must be challenged. These assumptions are rooted in ableist attitudes that emerge from society's conceptions of disability and have far reaching implications for practice.

### **Definition**

Defining peer support in such a way that it is universally operationalized was identified as an area needing further research in this study. There is a need for clarity and a more broadly based definition in order to accommodate various roles and tasks that fall under the umbrella of peer support. Bouchard, Montreuil, and Gros, (2010) state that, "a clear understanding of peer support is crucial for its development and utilization however this concept is inconsistently defined in the literature." (p. 590) Because peer support is poorly defined, it has meant

confusion for those who are distant from its process – a finding this study confirmed. This has implications for research and practice.

More research is needed to develop a broad and flexible definition of peer support. It needs to be broad enough that it incorporates the key values of peer support and at the same time flexible to adapt to the various roles and tasks involved. The result of a broad-based definition of peer support could be that people will begin talking the same language and service users would be able to communicate more effectively the ways in which peer support benefits their recovery. As stated in this research, there was an emotional depth that service users communicated when they spoke of peer support.

An inconsistent definition of peer support affects practical issue such as funding. For example, accessing funding becomes problematic for agencies (such as T.E.A.C.H.) using peer support as its main service for service users. Funding bodies want clear and concise measurements, outcomes and definitions in order to provide monies to a project. As stated earlier, without a standardized definition, peer support is understood to be a nebulous idea and it is this that challenges its legitimacy. Much needed services become restricted and phased out of the community due to lack of funds. As a result, the region becomes a vacuum for mental health services for service users looking for peer support services. This is a devastating implication for those struggling with mental health disabilities. There must be an operationalized definition of peer support.

**Limitations of this study**

The limitations of this study include a small sample size, which does not allow the findings to be generalized. It was an unfunded study, which constrained the scope of the study, and, in addition there were time constraints imposed as a result of this research being conducted as part of an M.S.W. program of study. Both of these factors limited, for example, the sample size.

**Conclusion**

This research adds to our knowledge of peer support. What has been of particular interest to me has been coming to this research as an insider. I return here to some of the ideas stated in the insider status portion of my methodology section. I believe that my presence as a Black, Afro-Canadian woman with mental health impairment affected the process of the research in subtle yet definite ways. For example, in many ways I found myself occupying the space in-between; the murky area that appreciates the multi-layered definitions of who I am. This was manifested in the role of power within interview process.

Power played a dynamic role in the process. In the case of peer supporters, I believe I was able to facilitate the balance of power within the interviews in such a way that enabled participants to share important aspects of their stories – in large part because of my identification as a service user. In addition, I was aware when the dynamics of power levied heavier on the other side of the table, in the case of interviews with service providers.

The process of doing this research has had a profound impact on me as I have been struck by the recurring theme of transformation that emerged from conversations with peer supporters. The strength and resiliency that peer supporters demonstrated in the face of debilitating life

challenges resonated deeply with me. I was also very encouraged by the work of service providers who genuinely cared about the people they served within the community. The process of doing this research has had a transformative effect on my own personal growth as both a person and researcher in the field of peer support.



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DATE: \_\_\_\_\_

**Appendix A**

**Peer supporters**

**LETTER OF INFORMATION / CONSENT**

**Working toward Standardized Practices for Peer Support in Ontario**

**Investigators:**

**Student Investigator:**

Yolisa Nongauza

Department of Social Work

McMaster University

Hamilton, Ontario, Canada

( 905)523-6458

E-mail: [nongauy@mcmaster.ca](mailto:nongauy@mcmaster.ca)

**Faculty Supervisor:**

Dr. Ann Fudge Schormans

Department of Social Work

McMaster University

Hamilton, Ontario, Canada

(905) 525-9140 ext. 23790

Email: [fschorm@mcmaster.ca](mailto:fschorm@mcmaster.ca)

Dear Friends

Yolisa Nongauza, a McMaster student, has contacted T.E.A.C.H asking us to tell our contacts about a study she is doing on peer support. The following is a brief description on her study. If you are interested in getting more information about taking part in Yolisa's study,

PLEASE CONTACT HER DIRECTLY by using her McMaster email address: [nongauy@mcmaster.ca](mailto:nongauy@mcmaster.ca) or her telephone number 1 905 524-3663.

### **Purpose of the Study**

Strong evidence exists that peer support is effective. Although the evidence of the effectiveness of peer support is strong, it has not yet translated into peer support being integrated into Mental Health and Addictions services in Ontario. Using the Halton/Mississauga LHIN region in Ontario as an example, the central question of this research will be to examine how peer support can become standard practice within the Mental Health and Addictions system. This research will investigate the barriers that exist toward implementation in this region and recommend strategies toward overcoming these barriers.

### **Procedures involved in the Research**

I am seeking 12 consumers with lived experience in the Mental Health and Addictions systems who are/or have been involved in peer support as part of their recovery process.

If you agree to be in this study, you will be asked to take part in one of two focus groups (6 in each focus group) during which you will be asked to talk about your experiences of peer support. It will take place in with a location that is safe and stigma free. With your permission, the focus group will be audio-recorded and these recordings will be transcribed by myself. After the information is analyzed, a summary report will be written. You are welcome to see this document and your feedback on it would be appreciated.

I would like to retain the transcripts to use for my Master's thesis.

**Potential Harms, Risks or Discomforts:**

The risks involved in participating in this study are minimal. However, the interview may raise issues that you find difficult to think and talk about. You may also worry about how others will react to what you say. Please know that you do not need to answer questions that make you uncomfortable or that you do not want to answer. And you can stop taking part in this study at any time. I will also work to ensure the focus group is a safe and respectful place.

While every effort will be given to protect the identity and confidentiality of participants, some may still worry their identity and confidentiality will be compromised. Please see the section below on confidentiality

**Potential Benefits**

There may not be direct benefit to you for participating in this research study beyond having the opportunity to share your story. However, your participation may help enhance peer support services.

**Reimbursement**

There is no material benefit to you in participating in this study. However, you will receive a thank you card as a token of appreciation and light refreshments will be served during the focus group.

### **Confidentiality**

We will undertake to safeguard the confidentiality of the discussion in the focus group. We will ask other members of the focus group to keep what you say confidential, but we cannot guarantee that they will do so. Your audio-recorded interview file will be transferred and stored in a password protected computer file or encrypted computer storage device which will, in turn, be locked in a file cabinet (along with the completed short questionnaire). Only I will have access to the locked cabinet. I will not use your name on any documents (it will be replaced with a code name) or any information that would allow you to be identified on the data (such as transcripts and field notes on computer files). Anything that could identify you will not be published or told to anyone else without your permission. The only other person who will have access to the data will be my supervisor, Ann Fudge Schormans.

I respect your privacy. No information about you will be given to anyone without your permission, unless the law requires so, as for example if there is immediate harm to you or someone else.

Audio files of interview will be erased once they are transcribed. Following completion of the research study the transcripts of interview will be kept for 5 years and then be destroyed.

### **Participation and Withdrawal**

Your participation in this study is voluntary. It is your choice to be part of the study or not. If you decide to be part of the study, you can decide to stop at any time, even after signing the consent form or part-way through the study. If you decide to withdraw, there will be no consequences to you. In cases of withdrawal, the information you have shared up to the point of your withdrawal will need to remain part of the data because it will be part of the focus group discussion and, therefore, is not able to be removed. If you do not want to answer some of the questions you do not have to, but you can still be in the study.

You will be given a copy of this consent form for your record.

### **Information about the Study Results**

If you would like to receive the summary personally, please let me know how you would like me to send it to you.

### **Questions about the Study**

If you have questions or need more information about the study itself, you may contact:

**Yolisa Nongauza** (Investigator): (905)523-6458 or e-mail:nongauy@mcmaster.ca

**Dr. Ann Fudge-Schormans** (Supervisor): 905-525-9140 x 23790 or e-mail:  
fschorm@mcmaster.ca

This study has been reviewed by the McMaster University Research Ethics Board and received ethics clearance. If you have concerns or questions about your rights as a participant or about the way the study is conducted, please contact:

McMaster Research Ethics Secretariat

Telephone: (905) 525-9140 ext. 23142

c/o Research Office for Administrative Development and Support

E-mail: [ethicsoffice@mcmaster.ca](mailto:ethicsoffice@mcmaster.ca)

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## CONSENT

By signing this form:

1. I agree that you have explained the study, the possible harms and benefits of participation, and my right to withdraw from the study at any time even after I have signed the consent without reason being asked. You have answered all my questions.

2. I agree that the interview be audio-recorded.                      Yes                      No

3. I agree that I have been told that my records will remain private. You will not give my information to anyone, unless the law requires you to.

4. I agree that I have read and understood pages 1 to 3 of this consent form. I agree, or consent, to take part in this study.

\_\_\_\_\_

\_\_\_\_\_ Research participant's Name      Research participant's Signature

Date

\_\_\_\_\_

Phone No.

\_\_\_\_\_

Name of Person Obtaining Consent      Signature

\_\_\_\_\_

Date

\_\_\_\_\_

Phone No.

**Appendix B**

**Service Provider Cover Letter**

**Working Toward Standardized Practice in Ontario**

**T.E.A.C.H.**

**Teach, Empower, Advocate for Community Health**

348 Bronte St. S., Unit 12 Milton, ON L9T 5B6

Tel.: 905-693-8771; Fax: 905-693-9278

[www.t-e-a-c-h.org](http://www.t-e-a-c-h.org) Email: [teach@shhalton.org](mailto:teach@shhalton.org)

Date:

Dear Colleague,

You are invited to participate in a study that examines barriers to the implementation of peer support programs in the mental health and addictions systems in Halton region. T.E.A.C.H. has been providing peer support to individuals dealing with mental health and substance use issues for more than six years. During this time we have expanded our programs to include all of Halton region and to cover a myriad of mental health and substance use issues. Evaluation of these programs shows that they are very effective in supporting people through their mental health recovery.

Yet, peer support programs are still not prevalent among mental health and addiction services available to Halton residents.



Please read the attached letter from Yolisa Nongauza, an independent researcher from McMaster University, describing the purpose of her study and the need for expanded peer support programs through the mental health and addictions system in Halton region. The study has received ethics clearance from the McMaster Research Ethics Board at McMaster University in Hamilton.

T.E.A.C.H. fully supports this project, and we will benefit from the recommendations that emerge from the information collected.

Please consider participating in this project. Your voice is important and your participation matters.

Please contact Yolisa Nongauza directly if you would like more information or to participate in this important study: [nongauy@mcmaster.ca](mailto:nongauy@mcmaster.ca) or 1-905-524-3663.

Thank you!

Debbie Jones, MSW

Recovery/Volunteer Coordinator

**Appendix C**  
**Service Providers**

**LETTER OF INFORMATION / CONSENT**

Working toward Standardized Practice for Peer Support in Ontario

**Investigators:**

**Student Investigator:**

Yolisa Nongauza

Department of Social Work

McMaster University

Hamilton, Ontario, Canada

(905)523-6458

E-mail: [nongauy@mcmaster.ca](mailto:nongauy@mcmaster.ca)

**Faculty Supervisor:**

Dr. Ann Fudge-Schormans

Department of Social Work

McMaster University

Hamilton, Ontario, Canada

(905) 525-9140 ext. 23790

Email: [fschorm@mcmaster.ca](mailto:fschorm@mcmaster.ca)

Dear Colleagues,

Yolisa Nongauza, a McMaster student, has contacted T.E.A.C.H asking us to tell our contacts about a study she is doing on peer support. The following is a brief description on her study. If you are interested in getting more information about taking part in Yolisa's study,

PLEASE CONTACT HER DIRECTLY by using her McMaster email address: [nongaay@mcmaster.ca](mailto:nongaay@mcmaster.ca) or her telephone number 1 905 524-3663.

**Purpose of the Study** While the evidence of the effectiveness of peer support is strong, it has not yet translated into peer support being integrated into mental health and addictions services in Ontario. Using the Halton/Mississauga LHIN region in Ontario as an example, the central question of this research will be to examine how peer support can become standard policy within the Mental Health and Addictions system. This research will investigate the barriers that exist toward implementation in this region and recommend strategies toward overcoming these barriers.

**Procedures involved in the Research:** I am seeking service providers, decision makers and other key stakeholders in the Halton/Mississauga LHIN region in Ontario.

If you agree to be in this study, you will be asked to take part in an interview for approximately 30 minutes to discuss the accessibility of peer support services in the Halton/Mississauga LHIN region in Ontario. It will take place in any location you feel comfortable with. I will take hand written notes and with your permission, the interview will be digitally-recorded. After the information is analyzed, a summary report will be written. If you would like to receive the summary personally, please let me know how you would like me to send it to you. Your feedback on it would be appreciated. I would like to retain the transcripts to use for my Master's thesis.

**Potential Harms, Risks or Discomforts:** I do not foresee any potential harms, risks or discomforts this interview may cause you.

**Potential Benefits**

There may not be direct benefit to you for participating in this research study. However, the information you provide may help enhance services for consumer-survivors.

**Reimbursement:** There is no material benefit to you in participating in this study. However, you will receive a thank you card as a token of appreciation.

**Confidentiality:** Every effort will be given to protect your identity and confidentiality. Your audio-recorded interview file will be transferred and stored in a password protected or encrypted drive, and the drive will in turn be locked in a file cabinet (along with the completed short questionnaire). Only I will have access to the locked cabinet. I will not use your name (will be replaced with a code name) or any information that would allow you to be identified on the data such as transcripts and field notes on computer files. Anything that could personally identify you will not be published or told to anyone else without your permission. In addition, your employer will not know that you participated in the study.

I respect your privacy. No information about you will be given to anyone without your permission, unless the law requires so, as for example if during the research there is immediate harm to you or someone else.

Audio files of my interview with you will be erased once they are transcribed. Following completion of the research study the transcripts of interview will be kept for 5 years and then be destroyed.

**Participation and Withdrawal:** Your participation in this study is voluntary. It is your choice to be part of the study or not. If you decide to be part of the study, you can decide to stop at any time, even after signing the consent form or part-way through the study. If you decide to withdraw, there will be no consequences to you. In cases of withdrawal, the information you have shared up to the point of your withdrawal can either stay with the research study or be erased according to your wish. If you do not want to answer some of the questions you do not have to, but you can still be in the study.

You will be given a copy of this consent form for your record

**Questions about the Study:** If you have questions or need more information about the study itself, you may contact: Yolisa Nongauza (Researcher): 905-524-3663 or by e-mail: [nongauy@mcmaster.ca](mailto:nongauy@mcmaster.ca)

OR Dr. Ann Fudge-Schormans (Supervisor): 905-525-9140 x 23790 or by e-mail: [fschorm@mcmaster.ca](mailto:fschorm@mcmaster.ca)

This study has been reviewed by the McMaster University Research Ethics Board and received ethics clearance. If you have concerns or questions about your rights as a participant or about the way the study is conducted, please contact:

McMaster Research Ethics Secretariat

Telephone: (905) 525-9140 ext. 23142

c/o Research Office for Administrative Development and Support

E-mail: ethicsoffice@mcmaster

## CONSENT

By signing this form:

5. I agree that you have explained the study, the possible harms and benefits of participation, and my rights to withdraw from the study at any time even after I have signed the consent without reason being asked. You have answered all my questions.

6. I agree that the interview be audio-recorded.                      Yes                      No

7. I agree that I have been told that my records will remain private. You will not give my information to anyone, unless the law requires you to.

8. I agree that I have read and understood pages 1 to 3 of this consent form. I agree, or consent, to take part in this study.

\_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

Research participant's Name

\_\_\_\_\_

Research participant's Signature

Phone No.

Date

\_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

Name of Person Obtaining Consent

\_\_\_\_\_

Signature

Phone No.

Date