Stigma, Discrimination, and PWLE Knowledge

Discussion Report

National Consumer Panel

At Home/Chez Soi Project, Mental Health Commission of Canada

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About the MHCC

The Mental Health Commission of Canada is a non-profit organization created to focus national attention on mental health issues and to work to improve the health and social outcomes of people living with mental illness. As a catalyst for transformative change, the Commission works with stakeholders to change the attitudes of Canadians toward mental health problems, and to improve services and support. Its goal is to help bring about an integrated mental health system centered on people living with mental illness. To this end, the Commission encourages cooperation and collaboration among governments, mental health service providers, employers, the scientific and research communities, as well as Canadians living with mental illness, their families and caregivers.

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Mental Health Commission of Canada — Commission de la santé mentale du Canada

Contributors to NCP Stigma, Discrimination, + PWLE Knowledge Discussion Report

National Consumer Panel (NCP) – March 2011

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Contents

At Home /Chez Soi Project Explanation

The At Home/Chez Soi research demonstration project is based on a Housing First approach. The Housing First model is one approach in housing people with mental health issues who are without homes. It is documented that this approach has produced positive results in other cities in North America where it has been implemented (Levy, Havens, & Modzelewski, 2010; Carol Pearson, Montgomery, & Locke, 2009; Gulcur, Stefancic, Shinn, Tsemberis, & Fische, 2003). The theory is that once a person is given a place to live, they can then better concentrate on other personal issues in their lives. Throughout the course of this study, over 2000 homeless people with mental health issues have participated. As of February 2012, 1,030 people from that group have be given a place to live, and offered services to assist them over the course of the initiative. The remaining participants are receiving the regular services that are currently available in their respective cities. Participants pay a portion of their rent, and will be visited at least once a week by program staff. The project is all about choice, and participants will be able to choose housing within a number of different sites within their cities - including apartments and group homes. They also have access to a service team, and can choose what service providers they would like to work with in order to meet their recovery goals. The overall purpose of the project is to provide evidence about what services and systems could best assist people with mental health issues and who are homeless. At the same time, the project will provide meaningful and practical support for hundreds of vulnerable individuals. Data from this kind of extensive research does not currently exist in Canada. At present, the MHCC project is unique and the largest of its kind undertaken in the world (At Home, n.d).

The National Consumer Panel (NCP), At Home/Chez Soi

This paper discusses stigma and discrimination experienced by people with mental health issues, and is written from a first-person perspective. The work was produced by the National Consumer Panel (NCP). The NCP acts in an advisory capacity for the At Home/Chez Soi project, and is formed by people with lived experience of mental health issues and homelessness who represent peer interests related to the project. The At Home/Chez Soi project has been somewhat unique in its progressive decision to include the consultation of people with mental health issues and homelessness experience in its work. The National Consumer Panel hopes that this discussion allows people to reflect upon the contributions made by people with mental health issues to their own line of work, and consider the perhaps surprising ways in which stigma and discrimination may appear. The NCP further encourages Commission employees to continue to advocate for the inclusion of people with mental health issues in Commission business. The following document is a testimony to the value of experiential knowledge, and its naturalistic quality has been retained to reveal its full significance.

Executive Summary

The National Consumer Panel (NCP) has developed this discussion paper on stigma and discrimination in the At Home/Chez Soi project, as an opportunity to reflect on and value the knowledge produced by the People With Lived Experience (PWLE) community. This paper does not solely focus on individual acts of discrimination, nor seeks to find a definite definition of the terms "stigma" and "discrimination." Rather, we look to explore the ways in which PWLE have produced knowledge at diverse levels of the mental health system including direct service, policy, research, and systems and organizational thinking. By way of this paper, the National Consumer Panel offers a discussion paper on ways to best optimize the knowledge and skills of persons with lived experience of homelessness and/or mental health issues (PWLE) who work within At Home/Chez Soi. It is through exploring these types of knowledge that the NCP hopes to offer and open possibilities for sharing knowledge with the At Home/Chez Soi project from this particular "lived experience" vantage point, and makes recommendations for the project, as well as future ideas for the inclusion of PWLE in projects such as At Home/Chez Soi.

This paper was developed through both direct and indirect contributions of NCP members. Many of the sections in this work are standalone contributions from NCP members in their various areas of expertise and interests. Because of the number of contributors to the paper, each section written by NCP members is introduced through a narrator voice to contextualize each piece within the broader paper. A variety of writing styles were involved in the creation of this work, which hopes to bring to light the diversity of knowledge that PWLE bring to the community, and the larger Canadian mental health and homelessness landscape.

In doing this the NCP recognizes that knowledge transfer is also very much about the way in which you convey knowledge, along with content. For this reason, this document celebrates multiple ways of expressing voice and knowledge through writing, with the understanding that just as there have been dominant socio-political systems at play in the lives of PWLE, the same can be said for dominant and exclusionary communication systems which dictate in what form knowledge should be presented. The NCP is not only looking to make language more accessible through plain language, but also hopes to de-center the traditional way of creating reports and papers. Thus, this discussion report embraces a wide range of voices and writing styles, and leaves it to the reader to draw on their own capacity to value and understand knowledge as it emerges in a variety of forms.

We examine issues at the micro (peer support and peer research), mezzo (local site/committees), and macro (national) levels. We discuss ways to prevent stigma and discrimination, and promote a project-wide environment of inclusion. The paper outlines three main recommendations for utilizing PWLE on the At Home/Chez Soi project:

1) Defining our roles

Perhaps one of the most important points is for a project such as At Home/Chez Soi to define the roles of people with lived experience in the project, so that tokenization is avoided, and people are given clearly articulated expectations as to how they can to fill a position whether voluntarily or in an employment capacity.

2) **The "Next Level" of Peer Positions**

The At Home/Chez Soi project has made great strides already in creating peer positions at a variety of different levels for PWLE. From employing peer support workers and interviewers on the local level, to having a wide variety of advisory positions throughout local sites and nationally, to a number of national positions for PWLE. In terms of moving forward, and thinking about peer positions at even a more elevated level, the NCP recommends that there be a concerted effort to see peer positions on par with the rest of the professionals, and to have more managerial peer positions within the project to evaluate peer workers, interviewers, and other peer positions.

3) **Planning for Peer Involvement**

In looking to the future, and possible initiatives that may rollout of the At Home/Chez Soi project, and the MHCC more broadly, there is a need to develop a type of "peer resource analysis" or a blueprint for the inclusion of PWLE. This envisions that when a project of this size is being planned there needs to be a significant level of PWLE involvement at these early stages, as opposed to in the later stages of planning and in its implementation.

This writing endeavour has truly been a collective one, and the paper hopes to point to the value of peer knowledge within the project and the need to optimize the involvement and value of PWLE in order to prevent stigma and discrimination on the project. We expect that this paper will be circulated to local peer groups with the hopes that it will be taken up and stimulate discussion and further writing from other project peers.

SECTION 1: Defining People with Lived Experience (PWLE) Knowledge and Discrimination towards PWLE.

PWLE Knowledge Historically

The At/Home Chez Soi project has gone to extensive lengths to include the knowledge of PWLE in the process of developing its Research Demonstration Project, through the inclusion of PWLE in the planning, implementation , study and sustainability processes.   However, PWLE knowledge is not a homogeneous concept, and has come in many forms over time. Part of recognizing the knowledge of PWLE in the community has been to retrace and reframe history to uncover the ways in which those with experience of the mental health system have spoke about themselves and the world around them, as seen through their eyes. Spoken and written narratives by PWLE have been published in texts as far back as the 1400s. These autobiographical writings often spoke about a person's personal experience in navigating what was known of as the "asylum", as well and their thoughts about possible changes that needed to be made within the asylum or law more generally (Kempe, 1982; Allen, 1997; Anonymous, 1982). However, these texts would not necessarily be considered works that had a wider scope of thinking that included a sense of PWLE as a community. They often emerged out of the individual's personal struggles, and would often be projects of self-advocacy in proving that the writer was not in fact insane (Packard, 1982). Most often, in these cases the authors would outline the need for the psychiatric system to have better screening and assessment tools to separate the "sane" from the "insane", and consequently devaluing the experiences of many who went through the psychiatric system.

In this way, these early narrative based writings were much of what constituted PWLE for the better part of 500 years through various eras of psychiatry and socioeconomic systems in North America and Europe. This is not to say that collective knowledge wasn't being produced within asylums through organic communities of patients (Reaume, 2000), however this type of thinking was not reflected in texts that were published by PWLE. While these narratives changed in shape and form, the central focus on entering and exiting the mental health system was maintained as an individualizing body of work by PWLE. Meaning that most writings expressed the individual experience of having contact with mental health systems, and did not tie such experience to wider socio-economic and political systems. It was not until the late 1960s and early 1970s that a collective understanding of the mental health system from those who experienced it started to emerge in published texts.

For many the term "peer support" first emerged in a substantial way in the seminal text *On Our Own* written by the late Judi Chamberlin (1978).   While considered a radical work at the time, and still today by many mental health professionals and certain people with lived experience, it became a foundational text which served to exemplify PWLE as a social identity – a marginalized group -- as opposed to simply a group of isolated individuals who each, alone and in isolation, experienced stories of pain, suffering, and pity. Chamberlin articulated the need for psychiatric survivors to create alternatives to the traditional mental health system which in her eyes was broken, abusive, and oppressive. For many, *Own Our Own* was the pivotal book which applied, for the first time, a social science/social justice analysis to the lives and community of psychiatric survivors. Perhaps most importantly, the book was able to merge both a plan of action for the supports and well-being of PWLE, coupled with a biting critique of the psychiatric system. It called for a simplistic, yet well thought out plan to develop groups that were low-cost and self-sustaining, while providing alternative spaces for discussion of the mental health system and everyday life issues.

This critical approach to the issues of mental health and its services was very much a product of the time in which Judi Chamberlin was writing. Many within the psychiatric consumer/survivor movement in the 1970's held a separatist approach as a way to solve the issues of psychiatric oppression, and thought that it was impossible to reconcile the interests of people of lived experience with those of the mental health system. Whether this is a product of the political context of the 1970s, or the high levels of abuse that

occurred in the psychiatric system at the time, psychiatric survivors saw no strategic use in working "with" the mental health system to achieve change at a policy or service level (Duerr, 1996). Regardless of the political stance of the consumer/survivor movement at the time, what is significant in this instance in terms of the knowledge production of PWLE, is that community members began to see themselves as an oppressed group, and in some cases as part of an identity group that should strive for human rights and social change alongside parallel movements (civil rights, feminism, gay rights etc). This was a departure from the individualized narratives that had been prevalent in decades and centuries before, and for the first time knowledge that was produced by those with lived experiences (rather than just those who treated it) was starting to be understood of as having its own value in contributing to and changing social systems.

This "separatist" approach prevailed through the 1980s, as psychiatric survivor groups sought change outside of the system, seeing the issues involved with working in the "system" as irreconcilable and unworthy of systemic change due to the fundamental approaches and treatments it offered. Much of the reform work centered on bringing an end to forced drugging and electroshock therapy, and proving the efficacy of alternative treatments to traditional mental health care (Burstow & Weitz, 1988). While there is controversy within the community as to the validity of these arguments, it cannot be denied that the work done to carve out different types of knowledge was an effective one, that provided a level of empowerment to people who experience the mental health system, who'd been told that they were lost causes, never able to find a job or live a meaningful life. Deciding on which approach to take, and where systems change needed to take place became a source for polarization within various PWLE communities, at the same time these types of groups allowed space for critical conversations and dialogue to occur. Although many of the dominant voices were radicalized ones, these groups took up a large amount of political space considering the relatively short history of the political movement. At the very least these voices proved that "mental patients" could stand up for themselves and begin to articulate a struggle, however polarized or problematic they seemed to be. As time went on and the 1980s came to a close, the 1990s brought us an approach that overall lent itself towards more of an integrated approach to changing the mental health system, working with mental health providers and legislators. Some attributed this shift to the mainstream as a result of the lack of funding for the more radical initiatives, while others attributed this fallout to the lack of strong leadership in these organizations (Everett, 2000).

With the disintegration of many groups that were run by psychiatric consumer/survivors, those wishing to do political work in the area of mental health began to find ways in which to work within the system to achieve positive change for service delivery, and mental health policy. During the early to mid-1990s this approach to working within legislative bodies took hold, such as the Ministry of Health in Ontario, as PWLE advocated to be included in governmental committees, boards, and task forces (Church & Reville, 1989). Much of this work was done at the provincial level, as the funding for mental health came from provincial ministries of health, while the federal advocacy work seen today has primarily come from the National Network for Mental Health, which was born out of the Consumer Advisory Council to the Canadian Mental Health Association (CMHA), whose National Board formed in 1985 (Clarke Institute of Psychiatry 1997). PWLE sat on hospital boards, developed patient councils, and worked with the Ministry of Health in places like Ontario to develop funding for businesses and organizations that were run by consumer/survivors (Church, 1997). The difference being that these organizations had a mandate to provide employment, and services to psychiatric consumer survivors, while not having the same type of advocacy focus as was found in the 1980s. Throughout Canada consumer/survivor run organizations maintain their services and structure outside of a directive funding schemes such as the Consumer/Survivor Initiatives in Ontario, but are still able to function and provide supporting services to PWLE. For example, the West Coast Mental Health Network Society continues to be a force as an umbrella group for peer support groups in and around British Columbia, maintaining itself as a survivor run, independent initiative (Purpose Statement, n.d).

Much of the advocacy work today comes from initiatives which are in some way tied to larger organizations. One example is the Empowerment Council at the Center for Addiction and Mental Health

(CAMH) in Toronto, which acts as an autonomous body within the larger organization advocating systemically on behalf of the clients of CAMH (Empowerment Council, 2009). This pattern of consumer involvement has continued through the new millennium, as most of the political work by PWLE has occurred within traditional mental health organizations in community organizing, policy, advisory, and service capacities (Rissmiller & Rissmiller, 2006).

In terms of advocacy specific to housing, PWLE have taken a variety of approaches to impact the ways in which housing policy is implemented by various levels of government. Many in the community have looked to make legislative change in housing to combat the discriminatory attitudes of landlords and neighbourhood organizations. The DREAM Team, made up of people with lived experience, advocate for supported housing in Ontario with an analysis based in personal stories. One of their initiatives has included bringing the issue to the Ontario Human Rights Commission in order to talk about the Not In My Backyard (NIMBY) syndrome, and advocate for systemic change to the policies of the Ministry of Municipal Affairs (DREAM Team, 2007). From a direct action standpoint, the Ontario Coalition Against Poverty (OCAP), among a wide array of activities, has worked to raise public consciousness about abandoned, for-sale City of Toronto buildings which could provide low-cost social housing, but instead are being sold off by the city (Squats, 2006). These two organizations, while different in tactics and strategy, provide a look at the wide scope of action PWLE have taken in advocating for better housing standards at the provincial and municipal levels.

From a service perspective, the influence of PWLE can also be seen in the early Housing First models that emerge out of New York City, as peer specialists have played significant roles in the implementation of housing first models within agencies in the United States since the 1990's. Through examples such as the Pathways to Housing *Resource Centre* in New York City (Hicks 2011, May), the diversity of peer contributions within the model speaks to the way in which "Housing First" initiatives have valued the different types of knowledge PWLE bring to services, and the key role the community plays in relationship to movement-building.

The trajectory of knowledge development by PWLE then, began from a model of personal narratives (pre 1970's), transformed to a sense of an imagined community often on the margins "on the outside looking in" (1970-1980), and finally to a contemporary context which finds much of the knowledge produced by PWLE is coming from within the confines of mental health organizations (present). In this context PWLE deal with the tensions and possibilities of working with those considered "allies" in the movement, working for a more progressive mental health and housing movement within Canada.

It is from this brief history of the consumer/survivor movement and the impetus for peer involvement that PWLE find themselves an integral part of the At Home/Chez Soi project. Many of the primary models for consumer involvement that have evolved during the last couple of decades have been incorporated into the structures of the project, such as the employment of PWLE in policy, research, advisory, and service capacities, as well for the first time bringing PWLE together in a national research project that focuses on drawing knowledge from the lived experiences of homelessness *and* mental health. As seen in figure 1 and figure 2 the At Home/ Chez Soi project has hired PWLE in multiple roles including advisory capacities, research, and service delivery. Through the course of the project thus far, the NCP has had the opportunity to bring together multiple knowledges from experiences of homelessness and the mental health system, something which PWLE have not previously achieved in the national context. This project marks a new era in which PWLE have taken on new ideas around identity to explicitly make a distinction, and simultaneously a connection, between mental health and homelessness. This valuing of multiple experiences has helped produce a dynamic array of individuals across the project who are developing knowledge on the micro, mezzo, and macro levels of the At Home/Chez Soi project. These figures point to how the number of PWLE working on the project rose significantly from 2009 to 2010, with the vast majority of PWLE working in an advisory capacity. Through the hiring of peer support workers, the development of local PWLE advisory committees, having PWLE representatives on all National Committees, peer interviewers on most research teams, and the National Consumer Panel, a constant dialogue is being

facilitated between PWLE and others at all levels and roles on the project. The initiative has also provided a unique space for dialogue between PWLE themselves, and a potential for innovative knowledge production. For a further breakdown of PWLE's role and growth on the project see Appendix A, Appendix B, and Appendix C.
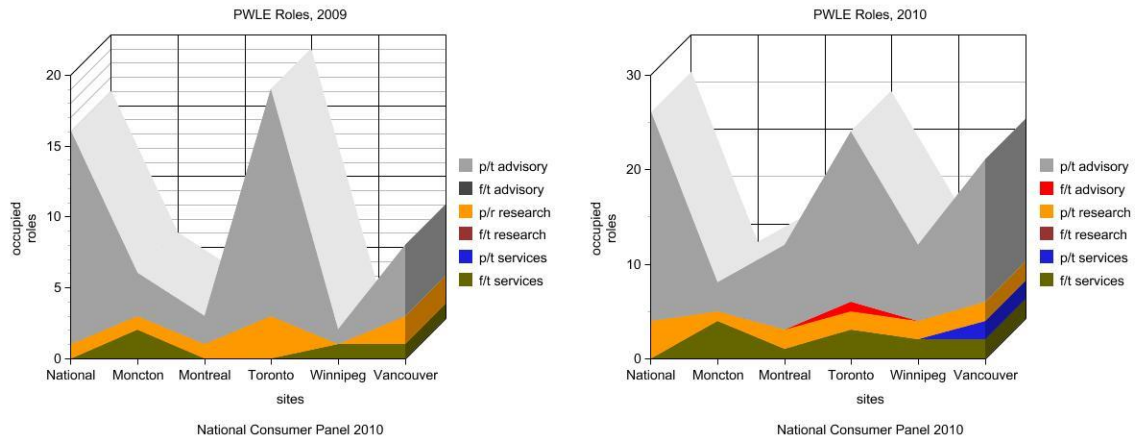

Figure 1. Distribution of PWLE personnel across sites, by type of role, 2009.

Figure 2. Distribution of PWLE personnel across sites, by type of role, 2010.

However, to harness the potential of PWLE on At Home/Chez Soi there must be recognition of the risks that PWLE face when they are in such positions, the ways in which our knowledge can be optimized and utilized to prevent stigma and discrimination on the project, and ongoing work needed to create an environment of inclusion for PWLE working on the At Home/Chez Soi project. The purpose of this discussion paper is to draw on peer knowledge and issues, and engage with them in a way that is productive for all. The NCP feels this is a proactive approach to *preventing,* rather than simply *reacting* to discriminatory beliefs, attitudes, and actions that occur. It is our hope that this examination of the importance of valuing PWLE knowledge promotes a culture of inclusion for individuals and initiatives at all levels of At Home/Chez Soi. Throughout this paper, we account for how peer engagement is progressing – within various _work_ positions, within local environments, and at the national level – to take stock, reflect, and aim for the future. Overall, the NCP hopes to begin a conversation about the value of peer knowledge in all its forms, and shape how PWLE are talked about and understood within the At Home/Chez Soi project.

Language Holds Power by Dawnmarie Harriott

As a way in which to begin the conversation surrounding work and people with lived experience (PWLE) in the context of a research demonstration project such as At Home/Chez Soi, National Consumers Panel (NCP) member Dawnmarie Harriott examines the debate around the use of "peer" in job titles in general, and specifically within the At Home Chez Soi project. Her section helps to call into question the very foundation of the job title and what this means in terms of stigma and discrimination, and helps illuminate the ways in which PWLE must navigate employment situations:

There is no one definition for the term "peer support", however for the purpose of this paper I have chosen the following. "Support provided by individuals with lived experience of the mental health system and/or homelessness to individuals and communities with these same or similar experiences" (Habitat Services, 2010).

Having the word "peer" in a job title for people with lived experience has been a topic that has been debated in the mental health community. While peer support noticeably provides many benefits to consumers and mental health professionals there are individuals who feel strongly that a special position should not be created as it means that people will have to disclose their experience with mental illness and this may cause stigma. On the other hand, there are individuals who believe that having the word "peer" in job titles and descriptions will encourage a greater range of people to apply for certain positions. There are many who are undecided regarding the use of the term peer and use it as default for lack of another term that is widely understood or acknowledged.

Listed below are some of the main discussions related to the use of the term "peer" should or should not be added to a job title, as well as a breakdown of peer and non-peer positions (employment and voluntary) in Figure 3.

Roles identified as peer in title

National Consumer Panel 2010
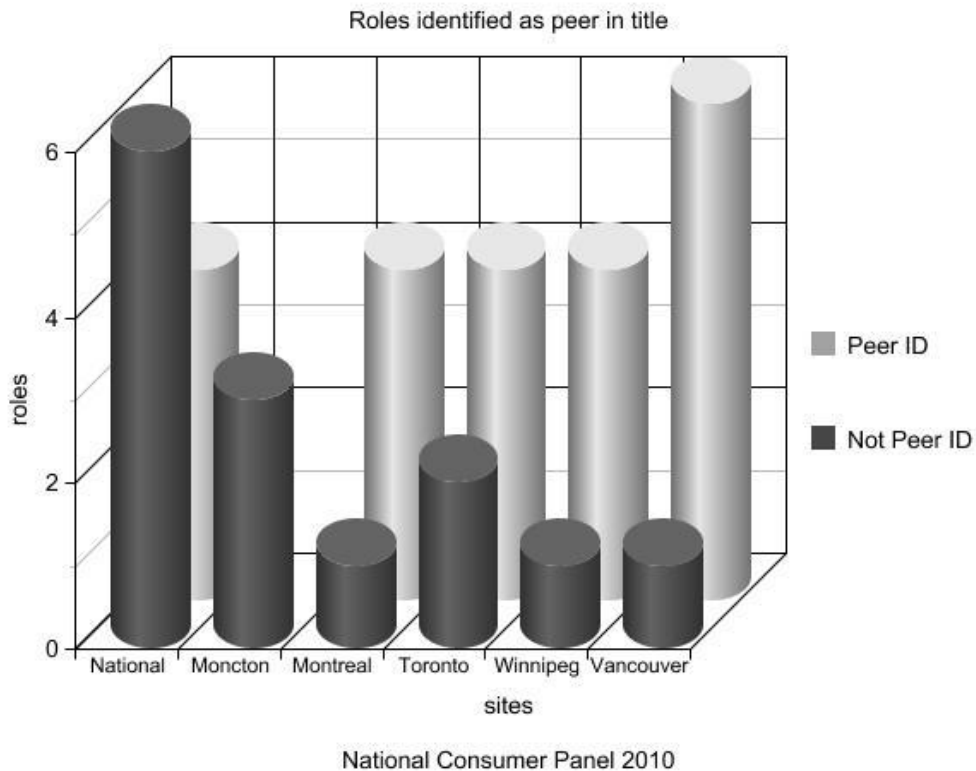
Figure 3. Roles identified as peer in title

Reasons not to have the word "peer" in a job title:

- Using the term peer in a job title identifies someone as being a person with lived experience which sets them apart from all other staff. Some believe, individuals should be hired for a job based on their qualifications. Having lived experience should be viewed as an invisible bonus; this way people can choose to disclose their experience at their own discretion.
- Many agree that if a position only involves traditional "peer" work; for example going for a chat over coffee or accompanying someone to an appointment, then having the term "peer support" in the job title is acceptable; however , identical job descriptions within an organization should not be separated by the "peer" term, for example Housing Worker and Peer Housing Worker. There is also the possibility that the stigma of the word peer can move from job to job on a resume.

- People working under the peer title can be viewed as having lesser status than professionals. Consumer Survivors (C/S) may not want to speak to a person who has peer in their job title. C/S may not feel that a peer would be qualified enough to provide assistance, but rather they trust their doctors and "professional" staff instead.

Reasons the word "peer" is beneficial in a job title:

- The peer title differentiates people with lived experience from clinical staff and allows consumers survivors to be aware of other models of recovery. Individuals using the service are able to speak to a person who has gone through a similar circumstance which create a "safe space" and discourages isolation.
- The peer title indicates a particular type of expertise and trustworthiness which allows for the positive impact of role modeling. People with mental health experiences are able to get encouragement from others with the hope that one day they may hold a peer position as well. (Wellesley Institute, 2010)
- Hiring peer workers who identify with mental health experience, creates a more diverse organization which can create learning opportunities for both peers and professional staff. Professionals are challenged to take advice from people who may have a better understanding of a situation through their personal experience.
- Plainly classifying job positions as "peer" will enable applicants to apply for positions they may not have otherwise thought to. This will assist staff in organizations to reflect the community they serve.

Conclusion

The prior mentioned points illustrate excellent reasons to think through both the use and the elimination of the term "peer" in a job title; what is most important is that agencies include people from the communities they serve in multiple job positions, at all levels of the organization, which is demonstrated in the At Home/Chez Soi project. This makes it easier for people with lived experience of mental illness to be involved and have a sense of belonging and a feeling of contributing. In keeping with the MHCC's anti stigma and discrimination mandate, engagement with peer workers and professionals should be encouraged by means of training sessions on how to effectively work together.

 Self-disclosure can be a stigmatizing process, however it can to be very powerful to assist peer workers and professionals in building trust and encourage hope for recovery.

Understandings of Stigma and Discrimination

Emerging from Harriott's applied example of the ways in which PWLE must learn to navigate arenas of potential stigma and discrimination, we pulled back now to a broader look at the tensions that surrounds the reality of stigma and discrimination.

The following pieces look directly at more traditional and personal notions of discrimination, through both narrative *and* analysis, along with a number of insights concerning what it can be like working with "professionals" for people with lived experience. This contrasts with the framework of this paper overall which is examining what it means for people it PWLE to produce knowledge, and how bodies of work and understandings are left out of much of the mental health and homelessness landscape. In the works of Francis, Petitpas, and Gingras what begins to come clear is that the understandings of stigma and discrimination for people with lived experience are diverse both in content and ways of understanding. In the following passage Francis examines the relationship between professionals and PWLE, and first looks at legislation surrounding discrimination in Canadian law.

Stigma and Discrimination by Jerry Francis

It's fine and dandy to look at doctors with all their academics and words of technicality; I certainly understand we need to do that for the bureaucrats, but we need to start from the origins of history (surrounding notions of how dominant and subordinate groups interact) to avoid the problems from continuing. According to a lot of research, stigma and discrimination is not new around the circle of mental health but there was never an address to the issue of saying "There is a solution" and I know we're looking for that now. With much thought to this jumping full steam ahead makes me kind of wonder that there is a lot to think about for both sides: both professionals and peers. We also have to consider "defamation of character" on both sides. I've been reading up on a lot regarding this subject (including human rights Federal and Provincial standards) also some background history with the current subjects of this matter that we're dealing with (Stigma and discrimination and peer involvement) . I'm also looking at it from a simplified way, and from documents that use every day common language not university academics or million dollar words. Coming from street life and seeking shelter from rain or storms, meaning at times sleeping in a dumpster or a portable toilet would be no way to address my concerns of academics, now that I'm in recovery. At my age I am slow at academics and there is a lot of reading material with common everyday language that does give very good explanations and examples to people who don't have academic comprehension! If this can be considered it would be very much appreciated. After all it would go for us too that we don't want to discriminate or form prejudice for those that are slow to learn or are behind. I know we have to move further on the matter, but let us do it right from grassroots ways. Forgive me, so far I don't see this now as we have to assert to mental health professionals, because some of us come from severe trauma. My grandmother used to tell us patience is the virtue of understanding and that's the holistic teachings of First Nations. When you ask, they show you the conception which is appreciated. If this can be done in some way, I would have a lot of respect for those that are hard at work for this matter. "Peer support" and "Stigma and discrimination" can have several different meanings, and it's good to dissect how a document is relating to these terms. We need to read between the lines because if we don't the principles can be lost.

Stigma and Discrimination Hurts By Johanne Petitpas

Stigma is a way that a person judges others, a group of people judge others or a way of thinking that if an individual doesn't think or act or believe like you, there is something wrong. This way of thinking isn't fair. For myself, I try to always use the saying "judge not less you be judged." Stigma is the cause of guilt, shame, isolation and self-esteem problems.   When someone with a mental health issue has a stigma and discrimination problem anywhere outside of the home it hinders their progress in getting the help they need. Delayed access to treatment is what stops you from getting better. It stops you from seeing friends and may cause problems with work performance and also increases the chances of unemployment.

If you have respect and dignity you will treat others with the same. No matter who you are; what race or religion; if you treat others the way you want to be treated that's one good step. When you are living with mental illness and you are discriminated against it will stop you from getting the proper help you need.

Stigma and discrimination: the reality of mental illness by Cylvie Gingras

As a person with lived experience of mental illness (PWLE), I have seen good changes with the project Chez Soi/At Home. For me, I had experienced a lot of examples of stigma and discrimination in my life about my homosexuality and the fact that I've spent a few years in jail. Since I have been hired to work for the project Chez Soi/At Home, my mental illness became an issue. Due to my mental illness which is my bipolarity, my anxiety, my few phobias and my chronic insomnia, I realized that all the people I meet on different committees listen to me, consult me, take me seriously and they are respectful toward me.

For me, it is very important to be listened to, because in Montreal, I'm the one who has the best evaluation about the homeless people living on the streets, especially the homeless women. For example, I'm the one who proposed at the Direction committee that our participants must be financially administrated. Due to my own experience, I told them that hard drug abuse and alcoholism goes with homelessness, so I related to them my own story: "When I rented my little apartment, I asked that my counsellor administrate my

welfare cheque, which she did for two years. Every month, she gave a cheque to my landlord for my rent and every week when she came to visit, she gave me money for my groceries. Instead of purchasing food, I felt so isolated that I went back to the neighbourhood where my street friends were staying and with my grocery money, I bought hard drugs and had a nice "trip" with them. I didn't tell them where I was living, because I didn't want my apartment to become a "crack house" or a "shooting gallery". My counsellor and I worked on harm reduction and slowly but surely, it came to a time that I was tired of being hungry and I started to cook instead of doing hard drugs.

Being financially administrated helped me to become more stable. It worked for me, because it's been 16 years that I'm living in the same neighbourhood.

There's something else: to be hired for the project Chez Soi/At Home, there were two major conditions: having experienced homelessness and suffering of mental illness. The people who hired me should have had the expectation concerning the fact that in three years, it would be possible that I could be hospitalized in a psychiatric hospital for different reasons. Before my first hospitalization which happened four months after I had been working on the project, I was told since I work part time, I would not be paid. I had to write a letter to tell them: "Hey, listen folks! What do you expect when your mentally ill employees are sick?" and they revised their policy.

Because I had been hired to work three days per week, I do not get paid for holidays. For example, this year the 24th of June and the 1st of July were two holiday days, on my pay cheque they cut those two days of salary. It meant $320 out of my budget and I had to pay my rent. Because I had been hired to work three days per week, I do not get paid for holidays. For example, this year the 24th of June and the 1st of July were two holiday days, on my pay cheque they cut those two days of salary. It meant $320 out of my budget and I had to pay my rent. Because I have a nice job, I decided to improve my quality of life by moving into a real home which it costs $275 more than the apartment I lived in for 14 years.

The part of work which makes me feel very well, comfortable, loved, listened to, consulted with and respected is with the National Consumer Panel members. With them, I feel as good as I feel with my colleagues from the street newspaper L'Itinéraire, where I have written a column for the past 15 years. I wish I had the same passion within Chez Soi/At Home, but since mid-July, the Conseil des pairs came across a difficult crisis, because a lack of structure and training. A subcommittee has been created to guide us with peers to support us and to keep track of our hours within a new structure. I hope that this change will settle things down because since July, I have not been happy at work.

In Montreal, we are a total of seven consumers and we will recruit two more people. As a PWLE, it is important to share my knowledge with people who have not experienced what I have. I used to say that I am educating those persons.

For me, it is important to be listened to and to be considered and respected, because it makes me feel useful and it's good for my self-esteem. Within the project Chez Soi/At Home, I have the great opportunity to pay back indirectly the people who helped me when I was living in the streets. I want to prove and show them that harm reduction works. In my case, I stopped using hard drugs two years ago and it's been nine months that I have stopped drinking. I want to tell homeless people that recovery is a goal which can be reached with some help.

SECTION 2: Optimizing Peer support Workers and Peer Interviewers

Having worked through some fundamentals surrounding PWLE knowledge and the ways in which knowledge is transferred and language around mental health holds power, we now turn to examining at the micro level the ways in which peer knowledge can be valued and optimized through work delivered by peer support workers and peer researchers.   Just as PWLE knowledge holds various ways of thinking and framing experience, oppression, and action, peer support work emanates from various different places across geography, analysis systems, and experience. Peer support workers are not one homogeneous group of people, neither are they recipients of sheltered employment, as seems to be the common misconception of peer support work within far too many parts of mental health systems across much of North America (O'Hagan 2010).   Some models that emerge out of the United States have taken on varying levels of employment certification, most notably the Georgia model which certifies peer support workers under a certain framework of practice, and is the gold standard in many parts of the US for peer support work (Sabin & Daniels 2003). There is peer support work that occurs within consumer survivor initiatives, which takes on a different flavor as peer support is all encompassing and is the service that is delivered, rather than one discipline among other disciplines on a traditional mental health team. Peer support work also occurs on various community based assertive community treatment teams, intensive case management teams, outpatient clinics, and Internet-based services. Even these types of peer support work seem a far cry from that of the work done by peer support workers on inpatient units which requires a further re-framing of the work considering the various mental health acts, and levels of involuntary commitment that are at play.   These tensions surrounding location of peer support in the mental health system seemed to ring true in the MHCC *Making the Case for Peer Support* report released in 2010:

"People were very clear that the mainstream management of peer support initiatives could only work if this was done in a spirit of partnership with the peer workers in organizations that 'get' peer support values. Unfortunately, it's more common that peer workers in these settings feel over-controlled and under-respected by their professional and management colleagues."(O'Hagan et al 2010)

To situate the peer support work done on At Home/Chez Soi, PSW's work on either ACT, or ICM teams. These PSW's also work under the Housing First model, where much of the work centers around the negotiation of acquiring housing for participants, dialogue with landlords, and applying a peer support analysis to the various aspects of a housing model that involves difficult decision-making processes surrounding the re-housing of participants and the distribution of resources.

The nature of At Home/Chez Soi has brought about an intriguing employment situation in terms of how peer support workers have come on board to traditional mental health teams as a result of a national project. Whereas the definition of an ACT team does involve the inclusion of a peer support worker on the team, this is far from reality on most ACT teams across North America. However, the At Home/Chez Soi project uses fidelity measures in which to make sure that there are peer support workers on all of its ACT teams, ensuring a level of accountability towards peer support locally. This has meant that peer support workers are negotiating working within the mental health team, and working from a housing first model, and now having a more formal national connection, through the Peer Support Workers Communities of Practice (PSW CoP), as a community of peer support workers developing their practice and supporting each other.

At Home/Chez Soi peer support workers represent the first wave of Housing First PSW's in the five demonstration sites. The nature of the project has also meant that the idea of PWLE is an expanded concept to explicitly signify both experience of the mental health system, and or homelessness. Usually, peer support work has only had the prerequisite of having experience of the mental health system in doing

the work, but by adding another "social location"(having experienced homelessness) as an explicitly valued criteria of At Home/Chez Soi, a number of its PSW's (but not all) draw on such experiential knowledge as well.

Examining Peer Support Worker Knowledge

Just as PWLE knowledge overall has moved away from an individualized narrative, the base of practice knowledge of PSW's is not directly correlated to their individual experience in the work they do. While personal stories and knowledge are highly valued in the work PSW's do on At Home/Chez Soi, and generally in the mental health field, it is also the worker's analysis of this experience and how their thinking relates to a community history, empowerment, oppression, and the practice of peer support work in decades past. It must be made abundantly clear that peer support work is not sheltered employment but a discipline and practice in and of itself, as peer support workers come from a variety of backgrounds and education in arriving at the work that they do and work for a range of employers.

As has been discussed, peer support has a long history, and has come in many forms both informally and formally, paid and unpaid, inside and outside the mental health system. In terms of issues that have arisen on the project which need to be addressed from a knowledge perspective, the NCP can identify a few areas of improvement and development. With NCP members holding various roles as peer support and peer research on the project, a number of key areas will be addressed in the following section: access to training, inappropriate assessment tools, lack of disability accommodations, and the current peer support culture of professionalization. As an introduction to the section, NCP member Jerry Francis contemplates the relationship between peer support, stigma and discrimination, and how this relates to discrimination against aboriginal people. Jerry's analysis is echoed by NCP member Diane LeBlanc who helps weave together concepts of stigma and discrimination, and how this relates to being a peer support worker on a project ACT team:

Stigma and Discrimination -- PWLE / Member of the ACT team – Diane Leblanc

The shame and discrimination associated with mental illness is still true today. In the past, people with mental illness were locked away in mental institutions, sometimes for the rest of their lives. These people were seen as "mentally defective" and incurable. Depression was seen as a sign of personal weakness and some were refused work based on this belief. Today this is still true for many who believe that depressed people can "snap out of it".   People with mental illness don't want to be labeled as "apparently defective" and most feel misunderstood and fear rejection from others. Sadly, in many cases, they are right. Indirect and evident discrimination against mental disorders continue to be documented by social scientists regarding employment, education, housing, parenting, criminal justice, immigration and other areas of social and community life.

Negative stereotypes of people with mental disorders such as "they are lazy, have nothing to contribute, or cannot recover", fuel misconceptions regarding these disorders and maintain prejudice and discrimination.

Prejudice and discrimination are based primarily on ignorance, myth and intolerance. The best solution for this is targeted, community based education combined with direct positive contact with individuals who have suffered with a mental disorder. It's also time to start calling stigma what it is---prejudice and discrimination. Stigma implies there is something wrong with the person while discrimination focuses on the individuals and institutions that practice it.

I am a 52 year old woman who has suffered with mental illness (depression, generalized anxiety and panic disorder) since the age of 16. I have been stigmatized, discriminated against, ridiculed, mistreated and misdiagnosed. I know too well the devastating and lasting effects of stigma and discrimination.

Today I am still struggling with mental illness and have to constantly remind myself that this condition doesn't define who I am. I am a human being who deserves to be treated with respect and dignity and will treat others the same.   I am not a victim but a survivor. I refuse to be over-medicated because I choose to live a productive and fulfilled life and be a positive role model within my community.

I currently work as a Human Services Counselor with the ACT Team of the At Home/ Chez-Soi project. This project is a homelessness initiative which practices the Housing First model. Since I've been working with this project I have learned many things, especially about people. Each participant I meet brings me so much knowledge and understanding as regards to their lived experiences, behaviors, thoughts patterns and beliefs. Each one is unique, each one has specific needs. We cannot compare them to others; what works for one may not work for another. We have to assess each person individually so we can offer them the best treatment possible.

I have a special connection with each participant and have the ability to win their trust. I see the pain on their faces and hear the fear in their voices. They have difficulty trusting others, even the ones who want to help them, because they have been let down one too many times. Some receive the help and support they need and are able to experience success within their lives, others do not; I can't understand why. I do not speak of those who refuse our help but those who accept it. People still fall through the cracks of a "system" which makes many promises but does not always deliver. I have to constantly remind myself that I am part of that system and can make a huge difference in people's lives. As a front- line worker I need to make accurate assessments of people's needs, situations, and challenges. I have to take each participant's statements seriously including threats of suicide. There is no place for assumptions where people's lives are concerned. We have all heard someone say "Oh, he always threatens to kill himself but he won't do it" or "It's always the same old story…." What if he goes through with it? Can we live with the knowledge that we might have been able to save his life? If we have lost one soul it is one too many.

In November, 2010, we lost one of our participants to suicide, even though there were many red flags, the system still failed him; we failed him.

We must realize that we are dealing with people's lives; this is a great honor which carries great responsibility. I do not believe we truly understand the significance of it all. We cannot afford to take anything for granted. We need to listen more and talk less. We need to open up our eyes and hearts to their pain and suffering so we can have a clearer understanding of what needs to be done. We need to work together for the good of all.

Peer Support and Professionalization by Janina Komaroff

Many working as peer support workers with the At Home/Chez Soi project want their work valued for what it is. Peer support workers have accumulated significant experiential knowledge of mental illness and/or homelessness and have trudged the hard road to recovery. The depth of knowledge and level of sensitivity peers can bring to the table is invaluable, unique, and unmatched with the skill set of those who have gained their credentials through formal training. The unprecedented nature of the position also demands innovative and quick thinking on the part of the peer support worker.

Peer support workers often convey the ideas of hope, empowerment and strength to their clients. They play the role of recovery advocates simply by virtue of their lived experience, and knowing how they have been treated and how they would have liked to have been treated while undergoing rehabilitation. They also have a better idea of the capacity of people to take on new challenges while recovering and learning new skills. This points to a need to reaffirm the importance of the central experience of recovery and the sophistication of experiential knowledge.

Peer support workers within the At Home/Chez Soi project have raised the fact that often they must defend their legitimacy as part and parcel of a mental health team. Experiential knowledge is not seen as valid as formal training given our society's emphasis on credentials and adherence to competency profiles. In fact, as peer support workers slowly do become recognized as valued contributors to mental health teams, the job description of "peer support worker" has continued to expand, currently mirroring the requirements of a professional. The latter phenomenon is one that will continue given the job itself is being redefined each time someone is hired. Greater interest in the concept has also led to greater professionalization of peer support workers (for example Support, Time and Recovery workers in the United Kingdom).

One must question, however, the increasing bureaucratization of the position. As the job becomes more formalized, barriers to entry to the position are created. Formal training is expensive and time consuming. Many people who see the position as an opportunity to re-enter the job market, or put their hard earned knowledge to use, may be turned off. Moreover, the focus on the human experience of recovery can get lost amongst the desire to achieve rehabilitation "goals." The necessity of the continuity of the support function can easily get subsumed in the desire of mental health teams to complete timely interventions.

Peer support workers and their colleagues should remain cognizant of the fact that their legitimacy and raison d'être rests on the acknowledgement of their lived experience. Their support function is long-term. Their contribution has unequalled value. While the current framework of rehabilitation may force peer support workers to adhere to certain rehabilitation norms, "focus on strengths, establish goals, return to work or school, develop social skills" etc., the creativity of the peer support worker cannot be lost. Whether the peer support worker believes that accompaniment through painful emotional states is paramount, or has the ability to communicate with people in states of psychosis, or has their own tricks of how to reduce difficulty however it appears, that knowledge should be respected. The peer support worker incarnates recovery and gives a client hope.

The above discussion points to the fact that peer support workers should occupy a central place in terms of the structure of governance and organization of the project. While this has been stated in the project documentation, it is often not adhered to in practice. Peers have had to fight to have their voice heard and are rarely consulted before decisions are taken. They are called on to "react" instead of "act" when there is a decision to be taken. This type of attitude is also reflected in the peer's function within the mental health team.

It stands to reason that the greater personal difficulty one has had with mental illness and homelessness, the greater the depth of understanding of those who have recovered. That knowledge must be targeted and harnessed. Peer support workers and potential peer support workers should be made to feel comfortable defending this knowledge. The inexorable drive towards professionalization must be accompanied by means to facilitate the entry of people with lived experience into the position, and have the value of their knowledge reinforced through organizational structure.

To quote from the Mental Health Commission of Canada's (MHCC) literature review on peer involvement:

"The importance of self-determination is often exhibited by fears within the consumer/survivor movement of 'co-optation', a process of traditional systems using the language and structures of peer support without change in the underlying power imbalance between 'psychiatrized' and other people. For advocates, not only is 'consumer control (…) an essential organizational characteristic', it has also been shown to be the 'best predictor of personal empowerment and social functioning' (Segal and Silverman, in Brown, Shepherd, Wituk and Meissen, 2007)."

Challenges of Peer Research and Interviewing

Having worked to develop an understanding of PWLE knowledge more broadly, as well as an understanding of peer support knowledge, one of the areas in which PWLE knowledge is vastly undervalued in mainstream mental health and homelessness arenas is PWLE research. Similar to peer support work, the idea of PWLE research is not simply research done in the traditional manner by PWLE, but a research paradigm framed out of the experiences and thinking of the PWLE community. Using lived experiences as the point of departure, members of the community have done research inside and outside of academia in the areas of history, law, sociology, and public policy. Whether it's an examination of Mad People's history through the lens of inmates of the Toronto Insane Asylum (Reaume 2000), or an analysis of Community Treatment Orders as "Tranquil Prisons"(Fabris 2011) to name a couple of examples, PWLE have been doing extensive research from the paradigm of lived of experience for some time.   Housing specific research by PWLE has also begun to take shape, as the Dream team has also been involved in community research through the Wellesley institute in Toronto. In 2008, the Dream Team collaborated with the organization to evaluate the impact of social housing on community, social, economic and

attitudinal change (Wellesley Institute 2008). This look at past PWLE research is significant for the development of the At Home/Chez Soi project, as the initiative has provided a number of possibilities for peer researchers and other PWLE on the project to develop research and writing from various PWLE community standpoints.

A specific example of this is how peers have been hired within research teams. The project has a National Research Team, as well as local research teams in each site. Jijian Voronka sits on both the National Research Team and the National Qualitative Research Team, in order to ensure that there is a peer perspective at the table. There are also a number of other National Research Team subcommittees which don't have a peer presence. To make up for that lack, the NCP is often asked to consult on research issues that arise within the quantitative side of things, and so far our input has been considered and often implemented in a variety of ways. A few of the things the NCP has done include:

- Created a discussion paper on possible ways to increase TAU retention.
- Provided suggestions on appropriateness of language in research questions (for mental health issues, for street work and economies, trauma).
- Reviewed proposed scales (Trauma scales, victimization scales)
- Participated in focus groups (OHQS)

Local peer groups have also been active in engaging with local research teams. The quantitative research team has also consulted with participants in the pre-testing of its scales to provide feedback on the appropriateness and relevance of the quantitative research questions.

Local research teams have hired peer interviewers/researchers on their local teams, and some sites have had more success than others in drawing on and benefiting from the knowledge that peer researchers bring. The benefits of peer researchers are many, including that peers "know what it feels like "to undergo treatments and their various side effects; they have ideas about what questions should be asked and how questions may be asked differently. Furthermore, if the needs and views of users are reflected in research, results are more likely to be obtained which can be used to improve health and social care practice" (Leiba, 2010: 155).

Some peer researchers working on the project come with a wealth of university experience and are used to working within the culture of academic research teams. Others come with a wealth of informally acquired knowledge and lived experiences, but are new to the particular dynamics that research teams often work within. Two-way learning is a must, and oftentimes the expectation is that the peer is to conform to the existing research culture. It's imperative that when 'researching with' the community under study, that the culture of that study is valued within every tier of the process, including between peer and non-peer co-workers on research teams.

Peers as interviewers on research teams have met with mixed success. Some are also working in other areas of the process, like parsing and creating themes. Fewer are involved in data analysis and writing, but we are working towards ensuring optimal inclusion on that front.   To that effect, peers were invited to become co-authors on the national research papers whose authorship is in the process of being determined. We also expect that peers in some sites will be invited into the process of co-authoring local research papers. The Toronto PWLE Caucus is undertaking a research project of its own. Further, a Peer Qualitative Research Group is being formed in Fall 2011, which will be a peer-only group that will write an article based on the baseline qualitative consumer narratives that have been collected.

Some recommendations that have been identified by peers working within research teams include:

- When researchers are given training e.g. trauma-informed care or suicide prevention, it would be good to see peer researchers given an opportunity to have that training as they are dealing with the very same issues and problems in the field as the researchers. It doesn't make sense to give

the researcher the tools to deal with a situation and not the peer, that's like sending the peer into battle with a gun and no bullets and expecting them to come back safe!

- Sometimes professionals forget that the peer has their own diagnoses which can show itself at varying times. These should be taken as the reason why the peer might struggle with certain situations instead of just that they can't do the job.

SECTION 3: Optimizing PWLE Knowledge on the Local Committees and in Local Sites

Overview

In the previous section, NCP members worked through the various levels of knowledge involved in doing peer support work, and understanding the practice based on personal and community experience. Changing gears, we now focus on local peer involvement. Representatives from all five sites of the NCP have worked to give outlines of their perceptions of peer involvement across each site, and described how peer knowledge is being used in an advisory capacity, and to what extent PWLE are employed or volunteering in each site. It's important to note that these are reflections from particular people on the project, and if others from local sites were to do write-ups, they might look quite different. Regardless, each report provides a sense of the uniqueness of each site and the successes and challenges faced in including PWLE in the processes on the At Home/Chez Soi project:

Moncton Peer Involvement

There are PWLE on local committees in Moncton and working on the project at the site level, as there are 5 or 6 people on the ACT committee, and 3 working at the Manse where the service staff and all support workers are.

Here in Moncton involvement in all levels of the site project is going really well, the researchers are working well together and things at the University is all good. We had a meeting with the researchers and they thanked us for all that we had done. They do have their problems at times but they are working things out, there will always be issues but in order to get the project going well you have to be willing to let some things go.

The ACT team at the Moncton site consists of a multitude of disciplines including social work, healthcare professionals, Human Service Counsellors, and administrative staff. Unfortunately, there are no "peer support workers" positions on the team, but two of the full-time human service counsellors are recognized as "peers" because of their lived experiences of homelessness and/or mental health issues. There exists a common bond and mutual respect between peers and the participants which bring many possibilities for success. By sharing their personal stories of hope with participants the "peers" have the ability of gaining their trust. This is an essential part of the recovery process and enables healthy communication between "peers" and participants. It is very important for the "peers" to assess the participants' needs and goals to be able to offer them the best possible support. Participants are also encouraged to focus on their strengths, and make positive changes within their lives.

There may be not enough people with PWLE but we think that some are saying no because they are too busy with their own lives. We also think that maybe some are being asked but are saying no because of other factors. Systemic discrimination we all think that this is not happening with all the talk and from talking to all of the staff.

Lack of peer hiring this is not happening in Moncton as far as we know all people that have being hired were hired from hospitals French and English and at the Detox Center and of course professionals had to be hired. Over all there is lack of peer hiring but there are some leaving for better jobs or long lasting jobs.

Montreal Peer Involvement

The 2010 year started off slowly for a number of reasons, including organizing and gaining access to the budget. In addition, the Conseil des pairs (Peers Committee) did not have an equipped work space prior to June 2010. Peers sat in on the vast majority of committee meetings, but it was mostly the same people doing the work. From January to June 2010, motivation and morale were low. From April to August 2010,

peer employees of the project recruited three new Peer Workers on an honoraria basis. The new recruits were not put to full use however, and the projects the Conseil were aiming to achieve did not fully materialize (i.e., monthly welcome activities for new At Home/Chez Soi participants, newsletters, recovery training sessions, etc.).

With the recent hiring of the Assertive Community Treatment (ACT) Team's Peer Support Worker, the Conseil des Pairs now have an additional peer on board. In December 2010, our Site Coordinator began to work directly with us, which has helped in terms of organization. In addition, our budget administration centre has since switched from the Centre de Santé et Services Sociaux (CSSS) Jeanne-Mance to the Douglas Institute, meaning access to financing instantly facilitated logistics. As a result, we were able to call six meetings of the Conseil between December 2010 and January 2011. Attendance by peers receiving honoraria was exemplary. Overall, enthusiasm levels are at a comfortable high, and peers are showing great initiative.

To date, the Conseil has agreed on our team mandate and the role of the Conseil Coordinator. Each peer has expressed his/her preferences in terms of what they would like to contribute to the Conseil. In recent months, the Conseil has had particular interest in the Montreal Site Discharge Protocol. A member now sits on the Appeals Committee for decisions taken to discharge participants who are deemed negligent on their commitments to the project. In July 2011, a new Conseil Coordinator came on board, along with three more Conseil members. At present, the total now stands at eight members.

Toronto Peer Involvement

The People with Lived Experience (PWLE) Caucus is an advisory group to the Toronto Site of the At Home/Chez Soi Research Demonstration Project of the Mental Health Commission of Canada. Our goal is to empower and support PWLE Caucus members while to making positive recommendations to improve the project based upon members experience with mental health, addictions and housing to promote more successful project implementation. Members act as a sounding board to air concerns and propose solutions on issues raised within the At Home/Chez Soi project. The Caucus has worked together to create terms of reference, guidelines and suggesting roles and responsibility of the Caucus for the project. Individuals with various backgrounds, cultures and experience with the mental health system, addictions and homelessness were selected to reflect the ethno-specific view of the Toronto site.

Caucus members attend diversity sessions to learn about the challenges different ethnicities face regarding housing and mental health. Members also participate in leadership skills building sessions to enable them to better advocate on the behalf of others.

One to three Caucus members participate in each of the committees and workgroups in the Toronto site of the At Home project and provide input and feedback at all levels. These groups consist of the National Consumer Panel, Site Operations Team, Sustainability, Ethno-specific, Housing, Services, Research, Referrals and Local Advisory Committees. Monthly Caucus meetings are held to report on all committees and workshops to ensure everyone is informed and up to date on current issues.

The Caucus has created change within the project by advocating for the Treatment as Usual (Control) group to receive higher honoraria as well as transit funding for each research interview visit. This was approved and retro-active reimbursement has been provided to participants of the project. Planned move in dates for participants were being delayed due to non-furniture arrival. Another recommendation was suggested that Canadian Tire cards be handed out to purchase air mattresses if furniture was delayed. It was pointed out that the most important thing to someone was moving into a home not the furniture that was there.

Caucus members also participate, sometimes as requested, sometimes through Caucus initiative, on related local and national initiatives related to the project. For example, in July 2010 Members hosted a "Mix and Mingle" for the National Consumer Panel in Toronto, as well as shared personal stories at several events. Moving toward sustainability a Caucus member has been selected to Co-host an event to secure

funding from government officials while three different Caucus members are members of a Sustainability Working Group planning the March 7, 2010 event.

Currently there are two peer support workers for the Act Mental Health Crisis Assessment & Treatment Team and one for Across Boundaries. Their duties include the following:

- Act as a teacher and role model for our clients. Provide a consumer perspective on mental health programs and provide clients with informal counselling and group support services.
- The Peer Support Worker provides household management, personal care, assistance with routine daily living activities, socialization and emotional support for clients. All activities are performed to encourage client independence and respect client choices. There is also one part-time peer researcher working with the local research team on the qualitative data collection and analysis.

Winnipeg Peer Involvement

From my perspective, as a Peer Research Interview Assistant, I and my colleagues feel fully appreciated that we are making a tremendous contribution to the At Home/Chez Soi Research Project. Further, the fact that we are being listened to as "peers" and are being taken serious is another unique aspect of this project. That our ideas, observations, suggestions and contributions are given equal consideration and acceptance makes us feel as a valuable entity to the success of the overall project.

We look at the project as a whole as a new and ever-changing entity and work around issues until we find a common ground or something that works for everyone concerned. I believe it all stems from the fact that when human beings are involved, one can anticipate various levels of cooperation and flexibility or even restraint and constraint. My observations concluded from a "peer" perspective that we are here for the benefit of one another and more importantly, the target group that they are working with. It is very satisfying to see my "fellow peers" advocating in the spirit of unity and camaraderie on their behalf.

As for the contribution that our knowledge as "peer support" workers lends to the overall effectiveness of the project, it should be emphasized that such knowledge and experience that we bring to the table is paramount in that the participants are more apt to share their direct experience and inner-most thoughts and feelings. It should also be noted that the knowledge that people with lived experience actually working on the job in the capacity as an Interviewer is extremely valuable in that we are the first line of communication that that target group come in to contact with. That being said, it is crucial that a good strong base of trust be established very early in the process. I firmly believe that "trust" is probably the single-most important element in such a research project, because, the Winnipeg Site target group draws heavily on the aboriginal component, and this particular segment of society have been studied and researched more than any other ethnic group in the past, with a great deal of them slough it off as just another study, until someone like me, or my colleagues confide in them that "we" have lived their life too and know of what they speak! I also believe that we are looked up by the target group as "role models" as someone who has been there, has survived and moved on, and that with the supports of the project, they can too!

As for this major research topic of Peer Qualitative Research, we very much appreciate the opportunity for us being allowed to participate in all aspects of this research paper either as a contributor or a full writer as we as "persons with lived experience" in the mental health field do come with a certain set of "street smarts" and know of what we speak. We, as "peer" interviewers never anticipated that our living the difficult life we've lived would one day would make a valuable contribution to someone else's lot in life and for that, we are up for the take!

Vancouver Peer Involvement

PWLE participation in the Vancouver site began with focus groups conducted by researchers during the early project planning phases.

Later, four PWLE were engaged as part of the Local Advisory Committee (LAC) that formed with a mandate to meet quarterly. A full time Peer Engagement Coordinator and Aboriginal Support Specialist were hired by the ACT team that began treating participants in October, 2009. Two part-time Peer Co-Interviewers were retained by the field research office. One Co-Interviewer became a member of the National Working Group, and the Safety & Adverse Events Committee. The Peer Engagement Coordinator and one PWLE from the LAC went on to become members of the National Consumer Panel.

As time went on, the ACT service provider left the project and was replaced on the NCP by Vancouver's other Peer Interviewer (no longer titled "co-interviewer"). A replacement ACT Peer Support Specialist was hired, and later a second half-time worker was added in the same role. A part-time Peer Advocate was also brought onto the ICM team, in recognition that one participant with "moderate needs" needed more support.

The Peer Reference Group (PRG) was formed in 2010. Consisting of eight members, they comprise some (but not all) PWLEs working on the project as well as PWLE community members and representatives from peer agencies. The PRG is chaired by the Peer Coordinator, who was hired part time to oversee Vancouver PWLE activities.

 Tokenism is an ever-present concern to guard against. At each monthly meeting, the PRG receives a one-way presentation from a project team. It is our desire to be more engaged in decision-making, an original intended function of the group.

SECTION 4: The Dinner Party: National PWLE Involvement

In shifting from local updates on how peer involvement has emerged in each of the five sites on At Home/Chez Soi, we now move to a discussion of how peer involvement has emerged nationally. There are two national "peer-exclusive" groups that meet, as well as peers that sit in advisory capacities or as work members on all national committees (the National Working Group, the National Research Team, the National Qualitative Research Team, the Project Team) as well as a number of subcommittees. For a brief on peer roles on a national level, please refer to Appendix A & B.

The National Consumer Panel

The National Consumer Panel, formed in Summer 2009, meets on a monthly basis and acts in an advisory capacity to the project. As of late, we have consulted on a number of topics, including:

- Providing input on the development of the Objective Housing Quality Scale, which is currently being field-tested by researchers to use at the 21-month follow-up.
- Offering advice to research teams on how to optimize Treatment as Usual (TAU) follow-up, highlighting suggestions such as the need for peer driven outreach in locating TAU participants for follow-up interviews and increasing the price of honorariums as an incentive
- Working with the National Project Team to advise on issues of consent, editorial control and representation as they relate to the upcoming NFB documentary on the project.

Last year, the NCP finalized its Media Discussion Paper, which helped inform project principles and procedures on People with Lived Experience (PWLE) and participant media involvement. We worked in collaboration with the MHCC Communications Department to develop documents that provide guidelines for the media, for partners approaching participants to speak to the media, as well as a pamphlet for participants to read and consider before speaking to the media. These documents are available as a resource to all sites: contact Nujma Bond at nbond@mentalhealthcommission.ca

In this section Jijian Voronka, who helped establish the NCP in 2009, recounts how the NCP came to be, the challenges they face, and the work and consideration required to pull together a national advisory board constituted by people with lived experience.

The text that follows is taken from a talk called "User Involvement: The National Consumer Panel" given at the National Forum on Intervention in Homelessness, at the University of Quebec at Montreal, in Montreal, in October of 2010. It details the processes of community-building within a fixed context, and the dedication to "make it work" that is required systemically as well as individually in building something differently.

A wise old activist friend of mine once said that being invited to a dinner is very different that having a dinner party of your own. In that respect, the Chez Soi project has a National Consumer Panel – constituted and run by users -- which I played a foundational role in developing. The thing with new initiatives is that if you can get in at the foundational moments, when money and resources are being broken up and down and allocated – opportunity for doing things differently, especially in the age of "user participation" as a best practice – can fall into your lap. And this was really how the opportunity for the NCP unfolded – sitting in a board room with very important people developing the bare bones framework for a huge $110 million project. What national committees would be created? One for research, one as a working group, on and on with subcommittees – and then the question of a user-only group? A yes, please, from my perspective eventually resulted in being handed the task of creating a National Consumer Panel constituted for and by people with lived experiences of mental health and homelessness. Suddenly, I was asked to hold a dinner party of own – now, who to invite, where to hold it and most of all – what to serve?

I'm going to talk about the making of the NCP – and what sort of practical and practice issues we as a panel have faced, and how we are in ongoing resolve. First of all – having a user-only advisory panel is a practice in and of itself. All of us having a variety of shared experience of Mental Health and/or homeless issues resolves one huge issue when trying to organize users – it absolves the power differential between users & "chronically normal" professionals. While power still of course circulates, all of us identify as peers, and that in itself allows us to talk frankly about issues that we are often forced to speak less frankly about in mixed circles.

In July of 2009 the NCP had its first meeting. I decided that the group should be made up of both users who work within the project, as well as users who work in an advisory role on the project. Often times, when you work for an employer and are pay check dependent, you feel less freedom to speak from the position of critique. For that reason, I felt it important to also have people on the panel that were community advisors, a little more arms length from the project and able to speak from a more independent position. As a whole, the NCP as it currently stands has 14 members, and a mix of peer support workers, peer researchers, peer organizers, a social media expert, anti-poverty activists, and so on. We come from 5 different sites across Canada – Vancouver, Winnipeg, Toronto, Montreal and Moncton --, and have a strong mix of individuals who are able to speak from positions of racial, sexual, Aboriginal, language, gender, ability, and geographic-specific positions. So, basically – by insisting on complexity – we invited a guest list of troublemakers to the dinner party.

But the theoretical complexity of user organizing – which I am always so intent on focusing – soon became secondary to the very primal practicality of adventuring to meaningfully engage across a landscape such as Canada. The question of how to compensate people for their time became of issue. Those who were employed by the project, we asked that their employer consider NCP work to be part of their job description. This, was a complication. Far greater a complication was getting honorarium to people who were not employed by the project – most of whom are on disability or social assistance. Some of whom do not have bank accounts. How do we get money to people without them being punished for it? This requires flexibility, a flexibility that most accounting practices do not have to be reflexive about. As I stated earlier – ongoing resolve …

As a start-up, the NCP was expected to organize and communicate in the same ways as the other Chez Soi committees. Email, phone, and in-and-out travel to in-person meetings across Canada. Most communication, agendas, summary and action items, issues of relevance would be through email circulation. While many of our members are very computer savvy, some of our members were not online. This was a problem. I at first relied heavily on Canada Post to communicate with some members. We had monthly meetings that were to be held by teleconference – some of our members did not have phones, others only cell phones that accrued cost even when dialling a 1-800 number. These foundational wedges set a cog in our organizational plan. Luckily, we had resources, and both locally and nationally we organized to provide technology and basic training for people who were without. This financial "answer" to user participation is hard to come by, but usually the solution to improve user participation is – that Jerry McGuire moment of "show me the money." And the Commission has always been flexible in allowing us to figure out what are various needs are, and accommodating us to enable us to get the work done.

With emails and teleconferences set up, we began to develop a routine of meetings that resembled business as usual ways that committees organize – Terms of Reference, guidelines, dates and times. But we realized that business as usual doesn't work for people who have histories of exclusion. So I framed the teleconferences as across sites instead of across topics – so that the couple of people from each city were each assured a designated time to speak. We also EXTENDED the time of the teleconference to 2 ½ hours – a long time, but it ensures that everyone has the time to speak reflectively on a topic, so that we can avoid people feeling that they are being silenced.

Then came the in-person meetings, of which we have 3 a year. Passports and other ID, credit cards, hotel stays in fancy venues, all day meetings, and stressful airport security encounters – many people getting on

a plane for a first time. The work of "getting together" was unravelling for many. It was clear from the get go that plane tickets and hotel rooms had to be booked in advance by the Commission, and that the business as usual of out of pocket expenses and waiting for reimbursement was not an option. Travel advances for meals and taxis are sent out prior to meetings. Sometimes, they don't arrive in time, and so we Western Union the money out. One of the many issues that we continue to struggle with is the continued insistence by hotel front desks upon check-in to ask people automatically for a credit card for incidentals. All we can do is continue to call the hotel ahead of time and ask that they not. To put notes next to the reservations held that there is no need to ask for credit cards. This – continues to be an ongoing struggle. Big business is built for business as usual.

A few of our members have found, because of various reasons, that they don't want to or are unable to travel for the in-person meetings. In that case, we keep them as members and add an alternate from the site who is able to travel. The ways in which the "chronically normal" Commission meetings are held are often 12 hour days, a few of them back to back, with the expectation for most that you fly out the evening that the meetings end. Our TOR's promise that a meeting will last no longer than 5 hours a day and no more than 2 days in a row. If people ask for an extra hotel night to rest before getting back on the plane, they get it.

The practical issues of getting and staying together takes a lot of effort. For the first ten months of the project I did it alone, and one of the unanticipated results was that much of my work became peer support. I don't have great boundaries and am prone to answering the phone if it rings at 3 am. How do I support someone in distress long distance? How do I keep this group running, along with my plethora of other work and school commitments. I asked for help from the Commission, and we hired on a peer facilitator who is a trained peer support worker – something that some NCP members need to help them from time to time.

Finally, with all guests gathered and hungry for content – what do we serve? Well, we don't. Instead – it's a potluck. I'm positioned nationally, and so bring information that I gather on issues such as peer involvement, research, service provision, etc. to the group. In turn, local users bring local issues to the table and share across sites. Often times, issues that come up in one city are of issue to others. Sometimes local solutions in one site have helped other sites, and users can go back with ideas to their local teams with resolve. One of the developments from this networking is that members realized that a strong plan and budget for a local user group in Toronto had been planned and executed, and members from other sites began to push for the development of local user groups. So while the NCP covers all sites, Vancouver now has a peer reference group, Winnipeg has the lived experience circle, Toronto has the PWLE Caucus, and Montreal has the committee de ex-pairs.

Oftentimes, as a group we have things that we identify as of great import, and arrange to have meetings with leads on other teams. An example of this is some concerns that we had about some research practices, and some of our members had consults with the lead Principle Investigator's on the project, making clear our concerns. Sometimes things change, sometimes they do not – but we are heard. Other times teams consult with us – sharing research questions and asking us to consult on them to ensure that they are suitable and respectful to ask. There have been research tools that we have identified as unacceptable, and they were not implemented into the research study. We are consulted, a lot.

An example of one issue that the NCP took great interest in was the issue of media. The media and the commission itself are of course interested in getting press on the project as it moves forward. Everyone, always, wants to talk to PWLE as well as participants who have been housed by the project. While the benefits of this happening are obvious – it makes a great story for a reporter, and it makes a press release for the Commission. But what does it do for the users themselves, to have their names, their photos, their often framed "tragic" stories out in the media? The NCP took the initiative to write a 20 page report on this issue, which discussed not just the benefits of doing this – but also the drawbacks – the easiest one to grasp the fact that for years – if not forever – if an employer or anyone else for that matter were to Google your name, that story – and the story of mental illness, homelessness, drug use etc would be forever

attached to you. Something to consider. From that report, the commission communications department has well considered our input, it has influenced commission policy on media communication, and our pamphlet "So, you're thinking about talking to the media?" is in press, available for hand-out to any user or participant to read and consider before they take the media plunge.

We are currently writing a report on stigma and discrimination [this is it!!]. We have done a lot of presentations, a lot of learning – a lot of what is often called capacity-building. What has been the most important part of this work is the capacity-building that the Commission has done in learning that business as usual doesn't work in this context, as they capacity-build to learn how to accommodate and learn from doing business differently!

Peer Support Workers Community of Practice

Another national peer group that has developed out of expressed need is The Peer Support Workers Community of Practice (PSWCoP). They had its first meeting via teleconference in January 2011. The group brings together peer support workers from across the five sites of the project. While those in the group occupy various job titles, including human resource counsellor and peer support specialist, the group recognizes that there are commonalities of peer support work across these different job positions, and works towards best practices through discussion of local practice issues and broader peer support principles. The group will meet in-person for the first time at the Vancouver training event in May 2011.

SECTION 5: Conclusions and Recommendations

In looking at the diversity and depth of PWLE knowledge, this paper has spanned across a number of locations within the At Home/Chez Soi project, and identified a number of different ways in which PWLE contribute to the agenda of working towards ending homelessness in Canada for people who have experienced the mental health system. In this final section, the NCP will attempt to bring together all the various points of knowledge that have been explored in this piece, and come up with some well grounded recommendations for ways in which the project can move forward in including PWLE in decision-making processes.

Defining our roles

As was explored in the opening section on PWLE knowledge and its history, perhaps one of the most important points is for a project such as At Home/Chez Soi to define the roles of people with lived experience in the project, so that tokenization is avoided, and people are given clearly articulated expectations as to how they can to fill a position whether voluntarily or in an employment capacity. Far too often PWLE are given positions on advisory boards, indirect service roles, or outreach positions which have a wide scope in terms of responsibilities, but often don't have clarity for the ways in which people with lived experience can draw on their knowledge and expertise to contribute in a truly meaningful way (Repper & Carter 2010). Too often it is heard around a variety of mental health organizations and bodies that "we need a peer, don't we?" The inclusion of PWLE shouldn't be some sort of legitimizing strategy for dominant mental health organization interests to fulfill predetermined goals that they articulate in their interest to appear to have a progressive mental health service, scheme, policy, or program. By looking at the diversity of ways in which PWLE contribute to the larger mental health and homelessness knowledge base, job descriptions and roles should point to what type of PWLE knowledge are being used in a given capacity, and clear expectations defined in terms of skill sets and responsibilities. This is a recognition not only of how job descriptions and roles should state that someone must have lived experience of the mental health system or homelessness, but should point to how the person has taken up this analysis in their previous experiences whether it be from a direct service, community organizing, research, or policy framework. The assumption should not be that people have no prior experience in this type of thinking, but rather that PWLE in these positions have some connection to how their lived experience relates to a broader community which has a history, and a large knowledge base. While there are many people with lived experience who are employed across the project, work roles identified as "peer" mean that one of their primary tasks is to lead with the knowledge that derives from such experience in their work. This means that people in peer roles must draw on their own experience as well as have a familiarity with the consumer/survivor community's approach, analysis, and community history within the field. And when these roles are defined, people will have a greater sense of empowerment and responsibility within these positions, and will be able to contribute at a variety of levels in a more meaningful and thorough way. It's through this process of meaningful and explicitly recognized "peer" contribution, that the possibilities for acts of discrimination or stigmatization is greatly reduced. When an organization and its employees/volunteers are engaged with PWLE knowledge in a real way, and peer positions and roles are supported in being defined in relation to non-peer positions, the unequal power dynamic between peer and non-peer is greatly reduced.

The "Next Level" of Peer Positions

The At Home/Chez Soi project has made great strides already in creating peer positions at a variety of different levels for PWLE. From employing peer support workers and interviewers on the local level, to having a wide variety of advisory positions throughout local sites and nationally, to a number of national positions for PWLE. In terms of moving forward, and thinking about peer positions at even a more elevated level, the NCP recommends that there be a concerted effort to see peer positions on par with the rest of the professionals, and to have more managerial peer positions within the project to evaluate peer workers,

interviewers, and other peer positions. This type of thinking has been echoed by O'Hagan et al (2010) in their findings as, "People were also emphatic that supervision and performance appraisals of peer workers inside mainstream agencies should be done by other peers and not professionals."

One of the first places to start in terms of recognizing the professional designation of peer positions is that of peer support workers on the project. While there is a recognition of trainings and experience of peer support workers, the formation of a PSW discipline is still something which could use support and guidance from the At Home/Chez Soi project in actualizing PSW's as a discipline along with social work, nursing, psychiatry, occupational therapy, and recreational therapy. The emergence of the PSW CoP has been a huge step in connecting PSW's and using that connection in creating a sense of a discipline, and the NCP is encouraged by this type of initiative. In terms of developing peer supervisory roles, this may also be a place in which to start the conversation, as having people in positions who have experience as a PSW in evaluating other PSW's could go long way in improving service delivery, and enhancing the role of PSW's.

Within the context of the At Home/Chez Soi project, peer supervisory roles have emerged in the form of coordinators that supervise local PWLE groups, as well as peer supervised positions on the National Team which include peers overseeing the work of site-wide PWLE bodies. This has shown that the project is committed to having peers managing peers, which could in turn, set the stage for looking at local service and research teams in achieving a similar workplace dynamic in the future. Because of the nature of ACT and ICM teams, there isn't necessarily a place for a peer designated supervisory role that could achieve the desired effect, but would instead rely on finding a way in which to incorporate an analysis of PWLE knowledge into hiring practices. While many positions in the mental health field are advertised encouraging applicants from various social locations, including PWLE, the next step could include hiring managers and team leads who have *worked* from a place of lived experience in past roles. For example, the hiring of a team lead on an ACT team could include interviewing applicants who have had experience as a Peer Support Worker. This practice would create the advantage of having a team leader whose knowledge of Peer Support Work would give them a unique skill base in managing someone who works in the position of PSW. While the position of team lead is not explicitly "peer," hiring someone who has experience as a PSW could go a long way in not only working with PSW's, but would help promote a broader lived experience perspective within mental health service teams. The same can also be said of other positions on the project including for peer researchers, who would also greatly benefit from having supervisors who have knowledge as people with lived experience, and a research background which draws on their analysis of PWLE communities.

From a purely managerial standpoint, in both these cases, sometimes non-PWLE are placed in an awkward position when needing to discipline or direct people who are in peer positions because they don't want to seem unaccommodating. PWLE can have added insight into the ways in which to get the most out of people with similar experiences, and also have knowledge of when best to "draw the line" with people they are managing. These points speak to how the development of professionalizing and structuring in peer supervisory roles can work to accommodate and access PWLE knowledge. In building on the ways in which defining roles helps balance unequal power dynamics of role description, viewing peer positions in the same professional realm as the interdisciplinary mental health and research teams shifts the way mental health service and research is delivered, and materially situates peer positions in the same category as traditional disciplines. This type of thinking, hopefully will lead to the final abolition of seeing peer roles as sheltered employment schemes, but rather as a place of true knowledge production and service delivery. This structural shift, then, will no doubt go a long way into reducing both systemic discrimination, and individual acts of prejudice as people in peer positions will have the resources, power, and exist in a workplace culture to better shift decision-making processes within the At Home/Chez Soi project. However, for these roles to truly develop and reach their full potential there will be a need for peer supervisory roles in order to truly develop people in these positions, and ensure that PWLE knowledge is being valued, expectations are being met, and the PWLE is being transferred through working relationships between supervisors and employees.

Planning for Peer Involvement

In looking to the future, and possible initiatives that may rollout of the At Home/Chez Soi project, the MHCC more broadly, and the fields of mental health and homelessness in general, there is a need to develop a type of "peer resource analysis" or a blueprint for the inclusion of PWLE. This envisions that when a project of this size is being planned there needs to be a significant level of PWLE involvement at these early stages, as opposed to in the later stages of planning and in its implementation. Far too often are PWLE brought into projects, initiatives, and organizations when many of the final decisions for conception, proposal and implementation have already been made. Projects the size of At Home/Chez Soi need to draw on the past experiences of PWLE involvement, and provide the resources needed for PWLE to have a real impact, and be granted a level of representation within a project.

The project can be used as a resource for future projects, to draw on learnings such as what you need to have in place in order to involve PWLE in peer positions, and ensure an inclusive and empowering organizational culture. By having things in place before an initiative is operational, the "growing pains" of stigma and discrimination towards PWLE can be better avoided. When these early missteps can be avoided, it lays the groundwork for greater possibilities of knowledge development, and contributions of PWLE as individual and systemic acts of discrimination can only work to silence and discourage the participation of PWLE as a project unfolds and takes shape. This process then works to prevent stigma and discrimination, recognizes the history of PWLE knowledge, and can foster a climate where the most innovative work takes place. For many people in the PWLE community, the idea of various projects around mental health and homelessness in their current form, are only a reminder of how history continues to repeat itself. The At Home/Chez Soi project has already gone to lengths to recognize the diversity of knowledge of PWLE, and furthering the development of an agenda which works from this framework can not only go further in preventing stigma and discrimination on the project for PWLE, but also greatly increase the goals of the At Home/Chez Soi project.

Appendices

Please note that peers often occupy multiple roles, and the total number of roles is greater than the total number of people employed or volunteering.

Appendix A. 2009 Roles of Persons with Lived Experience, At Home/Chez Soi

As of Nov. 16, 09	Title	Type	Part/full	Roles
National	Consumer Research Consultant	r	p	1
16	National Consumer Panel Member	a	p	10
	National Work Group Member	a	p	5
Moncton	Assistant Qualitatif	r	p	1
4	Local Advisory Committee Member	a	p	3
	Human Services Counsellor, ACT	s	f	2
Montreal	Organisateur Communautaire	a	p	2
3	Research Assistant	r	p	1
Toronto	Local Advisory Committee Member	a	p	4
19	Consumer Caucus Member	a	p	12
	Qualitative Interviewer	r	p	2
	Research Assistant	r	p	1
Vancouver	Local Advisory Committee Member	a	p	4
9	Peer Engagement Coordinator, ACT	s	f	1
	Aboriginal Specialist, ACT	s	f	1
	Peer Co-interviewer	r	p	2
	Peer Reference Group Member	a	p	1
Winnipeg	Peer Support Specialist – ACT	s	f	1
2	Local Advisory Committee Member	a	p	1
Total				**55**

Legend: Type, r/a/s = research, advisory, or services, in part/full time work.

Appendix B. 2010 Roles of Persons with Lived Experience, At Home/Chez Soi

As of Dec. 6, 2010	Title	Type	Part/full	Roles
National	National Research Team Member	r	p	1
26	Consumer Research Consultant	r	p	1

	Peer Worker Community of Practice Facilitator	a	p	1
	National Consumer Panel Facilitator	a	p	1
	National Consumer Panel Member	a	p	12
	National Working Group Member	a	p	5
	National Project Team Member	r	p	1
	National Qualitative Research Team Member	r	p	1
	National Training Subcommittee Member	a	p	1
	Safety &Adverse Affects Committee Member	a	p	2
Moncton	Assistant Qualitatif	r	p	1
8	Local Advisory Committee Member	a	p	3
	Human Services Counsellor, ACT	s	f	4
Montreal	Organisateur Communautaire	a	p	1
12	Communications Peer	a	p	1
	Peer Research Assistant (Qualitative)	r	p	1
	Peer Interviewer (Qualitative)	r	p	1
	Participer au comité conseil	a	p	7
	Peer worker, ACT	s	f	1
Toronto	Local Advisory Committee Member	a	p	4
24	Persons With Lived Experience Caucus Member	a	p	14
	Persons With Lived Experience Caucus Coordinator	a	F	1
	Qualitative Interviewer	r	P	2
	Peer Specialist, Ethno-racial team	s	F	1
	Peer Workers, ACT	s	F	2
Vancouver	Local Advisory Committee Member	a	P	6
21	Peer Support Specialist, ACT	s	F	1
	Peer Support Specialist, ACT (half time)	s	P	1
	Aboriginal Services Coordinator, ACT	s	F	1
	Peer Advocate, ICM	s	P	1
	Peer Interviewer	r	P	2
	Peer Organizer	a	P	1

	Peer Reference Group Member	a	P	8
Winnipeg	Peer Support Specialist, ICM	s	F	1
12	Peer Support Specialist, ACT	s	F	1
	Assistant Tech I, Peer Research Interview Assistant	r	P	2
	Local Advisory Committee Member	a	P	3
	Lived Experience Circle Member	a	P	5
Total				**103**

Legend: Type, r/a/s = research, advisory, or services, in part/full time work.

Appendix C. mid-2011 Roles of Persons with Lived Experience, At Home/Chez Soi

As of May 17, 2011	Title	Type	Part/full	Roles
National	National Research Team Member	r	P	1
27	Consumer Research Consultant	r	P	1
	Peer Worker Community of Practice Facilitator	a	P	1
	National Consumer Panel Facilitator	a	P	1
	National Consumer Panel Member	a	P	12
	National Working Group Member	a	P	6
	National Project Team Member	r	P	1
	National Qualitative Research Team Member	r	P	1
	National Training Subcommittee Member	a	P	1
	Safety &Adverse Affects Committee Member	a	P	2
Moncton	Peer interviewer, qualitative	r	P	1
8	Local Advisory Committee Member	a	P	3
	Human Services Counsellor, ACT	s	F	4
Montreal	Organisateur Communautaire	a	P	1
11	Communications Peer	a	P	1
	Peer Research Assistant (Qualitative)	r	P	1
	Participer au comité conseil	a	P	7
	Peer worker, ACT	s	F	1

Toronto	Local Advisory Committee Member	a	P	4
24	Persons With Lived Experience Caucus Member	a	P	14
	Persons With Lived Experience Caucus Coordinator	a	F	1
	Qualitative Interviewer	r	P	2
	Peer Specialist, Ethno-racial team	s	F	1
	Peer Workers, ACT	s	F	2
Vancouver	Local Advisory Committee Member	a	P	6
21	Peer Support Specialist, ACT	s	F	1
	Peer Support Specialist, ACT (half time)	s	P	1
	Aboriginal Services Coordinator, ACT	s	F	1
	Peer Advocate, ICM	s	P	1
	Peer Interviewer	r	P	2
	Peer Organizer	a	P	1
	Peer Reference Group Member	a	P	8
Winnipeg	Peer Support Specialist, ICM	s	F	1
31	Peer Support Specialist, ACT	s	F	1
	Peer Support Advocate, Third Arm	s	F	1
	Peer Support Worker, Third Arm	s	F	4
	Assistant Tech I, Peer Research Interview Assistant	r	P	5
	Local Advisory Committee Member	a	P	3
	Aboriginal Cultural Lens Committee member	a	p	1
	Service Team Lead PWLE member	s	p	1
	Project Consultant	a	F	1
	Lived Experience Circle Member	a	P	12
Total				**122**

Legend: Type, r/a/s = research, advisory, or services, in part/full time work.

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