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Service users' participation in mental health community-based organizations

par

Thanh Truc Huynh

Faculté des sciences infirmières

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Présentée par:
Thanh Truc Huynh

a été évaluée par un jury composé des personnes suivantes :

Chantal Cara, Ph.D., présidente-rapporteure
Lucie Richard, Ph.D., directrice de recherche
Caroline Larue, Ph.D., co-directrice
Jacinthe Pepin, Ph.D., membre du jury
Mélanie Lavoie-Tremblay, Ph.D., examinatrice externe
Chantal Cara, Ph.D., représentante du doyen de la FES

Résumé

La participation des personnes utilisatrices de services au sein des organismes communautaires en santé mentale

Une grande proportion de personnes aux prises avec des problèmes de santé mentale vit dans l'isolement social. Les infirmières en santé communautaire sont interpellées au premier rang pour accompagner ces personnes dans leur processus de rétablissement et pour atténuer leur isolement social. La participation au sein d'organismes communautaires optimise l'expérience de rétablissement, diminue l'isolement social et renforce les réseaux sociaux de personnes ayant des problèmes de santé mentale. Toutefois, la participation des personnes utilisatrices de services dans la structure d'organisation des organismes communautaires est encore peu documentée. Afin de pallier cette lacune, cette étude avait pour objectifs de documenter, décrire la nature de la participation des personnes utilisatrices de services en santé mentale et d'explorer des facteurs facilitatants et des barrières à cette participation.

Un devis de méthodes mixtes, qualitatif et quantitatif, a été utilisé. Dans le premier de deux volets, une enquête impliquant la réalisation d'entretiens semi-dirigés a été menée auprès de douze directeurs d'organismes communautaires œuvrant dans le domaine des services en santé mentale. Une version française du questionnaire « Adapted User Involvement » (Diamond, Parkin, Morris, Bettinis, & Bettesworth, 2003) a été administrée afin de documenter l'étendue de la participation des personnes utilisatrices de services dans les organismes visés. Pour le deuxième volet, deux organismes communautaires ont été sélectionnés à partir des résultats du questionnaire et de l'analyse documentaire de documents publics de ces organismes. Les scores obtenus au questionnaire ont ainsi permis de sélectionner des organismes présentant des résultats contrastés en matière de participation des personnes utilisatrices de services.

Les entretiens semi-dirigés ont été menés avec différents groupes de répondants (membres de conseil d'administration, personnes utilisatrices de services, employés, directeurs) afin de recueillir de l'information sur les thèmes suivants: la nature de la participation des personnes utilisatrices de services, ainsi que les facteurs facilitants et les défis qui y sont associés.

Les résultats de l'analyse montrent que: (1) les facteurs qui favorisent la participation des personnes utilisatrices sont: l'accès à un espace de participation pour les personnes utilisatrices et l'accompagnement de celles-ci par les intervenants de diverses disciplines pendant leur participation au sein des organismes communautaires, (2) les barrières de la participation des personnes utilisatrices au sein des organismes communautaires sont la stigmatisation sociale et les caractéristiques personnelles reliées aux problèmes de santé mentale chez les personnes utilisatrices, et (3) les avantages principaux de la participation des personnes utilisatrices de services se déclinent en services mieux adaptés à leurs besoins et leurs demandes, en leur appropriation du pouvoir (dans leur participation dans l'organisme communautaire) et en leur sentiment d'appartenance à l'organisme. À la lumière des ces constats, l'accompagnement des personnes utilisatrices de services dans leur participation apparaît une avenue prometteuse pour les infirmières en santé mentale communautaire afin de faciliter leur appropriation du pouvoir et d'améliorer leur bien-être.

Mots clés: santé mentale, organisme communautaire, participation, utilisateurs de services, soins infirmiers en santé mentale communautaire

Abstract

Service users' participation in mental health community-based organizations

A large proportion of individuals with mental health problems are affected by social isolation. In the front line, community mental health nurses are called upon to accompany these individuals in their recovery process, and reduce their social isolation. User participation in community-based organizations (CBO) optimizes the recovery process, decreases feelings of social isolation, and consolidates the social support networks of individuals living with mental health problems. However, relatively little is documented on user participation within the organizational structure of mental health CBOs. To address this knowledge gap, the objectives of this study were to document, describe the nature of user participation and explore facilitating and inhibiting factors associated with user participation.

A mixed-method (qualitative and quantitative) design, broken into two phases, was used in this study. In the first phase, a survey of twelve directors from CBOs providing services to individuals with mental health problems was conducted using the format of semi-structured interviews. The French version of the "Adapted User Involvement Questionnaire" (Diamond et al., 2003) was administered in order to document the extent of user participation in the targeted CBOs. In the second phase, two CBOs were selected on the basis of the results of the questionnaire and the findings of the archival data analysis. The scores obtained by the administration of this questionnaire made it possible to choose CBOs with constrasting results on user participation.

Different groups of key informants (members of the governing board of the CBO, service users, CBO staff and directors) from the two CBOs participated in semi-structured interviews to collect detailed information about the following themes: the nature of user participation and facilitators and inhibitors for user participation.

Results of the analysis show that: (1) factors that facilitate user participation are : access to participatory space for service users and professionals of different disciplines supporting service users in user participation activities; (2) factors that inhibit user participation are : social stigmatization of individuals with mental health problems and service users' personal characteristics associated with their mental health problems; and (3) advantages of user participation are: services adapted to users' needs and requests, service user empowerment (in participating in organization of CBO services) and service users' sense of belonging to the CBO. Consequently, the study's findings suggest that accompanying service users in their participation in CBOs, in order to facilitate their empowerment and improve their well-being, is a promising avenue for community mental-health nurses.

Key words: mental health, community-based organization, participation, service users, community mental health nursing.

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List of abbreviations and acronyms

BOD: Board of Directors
CA: Conseil d’Administration
CBO: Community-based organization
DG: Directeur général
PSOC: Programme de Subventions aux Organismes Communautires
UP: User participation

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Dedication

À tous les participant(e)s de l'étude [les personnes utilisatrices de services communautaires en santé mentale, les intervenant(e)s, les animateurs, les directeur (trice)s et les membres des conseils d'administration des organismes communautaires], qui m'ont donné l'opportunité de mieux saisir les enjeux de la participation de personnes utilisatrices de services en santé mentale dans notre communauté et dans la société québécoise.

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Finalement, je ne pourrais passer sous silence ma reconnaissance envers la société québécoise et mes concitoyens. Les valeurs ici fondamentales que sont la démocratie, l'égalité, l'équité sociale et l'inclusion sociale des personnes de tout horizon (notamment des individus ayant des problèmes de santé mentale ou des gens d'origine ethnique étrangère) m'ont permis de m'accomplir pleinement. J'affiche fièrement mon identité québécoise.

Introduction

The *Mental Health Atlas 2011,* published by the World Health Organization (WHO) in October 2011, identifies mental health problems as a major contributing factor to disabilities and premature deaths globally, accounting for 13% of the global burden of illness (World Health Organisation, 2011). The burden of mental illness is calculated in terms of the economic cost of lost productivity due to disability, healthcare expenditures and the reduction in health-related quality of life (e.g., pain, emotional suffering) (Gilmer, Stefancic, Ettner, Manning, & Tsemberis, 2010; Health Canada, 2002). In Canada alone, this cost was estimated at $51 billion in 2003 (Lim, Jacobs, Ohinmaa, Schopflocher, & Dewa, 2008).

Unsurprisingly, mental health problems are among the leading contributors to the overall burden of illness in Canada, accounting for 25% of total years of productive lives lost due to disability and premature mortality (World Health Organization, 2004). Within Quebec, a francophone province in Canada, approximately 23% of the population will deal with a mental health problem over the course of their lives (Lesage, Bernèche, & Bordeleau, 2010).

Consequently, the federal and provincial governments have identified the following top priorities for improving mental health: (1) population-wide mental health promotion and mental illness prevention (also known as primary prevention); (2) mental illness programmes targeting vulnerable subpopulations (secondary prevention); and (3) prevention of further disability and/or psychological rehabilitation for individuals identified or self-identifying as having mental-health problems or who are mental-health service users (tertiary prevention) (Kirby, 2008; Quebec Health and Social Services Ministry, 2012). Therefore, it is timely for this study to address specifically the third-mentioned governmental priority that of the field of tertiary mental health promotion including psychosocial rehabilitation. Psychosocial rehabilitation is considered as a field of study and practice encompassing community mental healthcare approaches to enable the individuals living with serious and persistent mental health problems not only to reside in the community but also to integrate themselves socially within it (Drazenovich, 2004; Tom van, Felling, & Persoon, 2003). Furthermore, this study is in accordance with one of the six strategic directions announced by the Mental Health Commission of Canada in its document entitled “Mental Health Strategy for Canada: Changing Direction, Changing Lives”. Indeed, the Mental Health Commission of Canada puts emphasis on fostering recovery and well-being for people of all ages living with mental health problems, and as well as on service user participation in upholding their right (Mental Health Commission of Canada, 2012). Similarly, the Quebec government in its recent evaluative report on its mental health system underscores the importance of service users’ participation in the organization of service design and delivery within its institutions (Quebec Health and Social Services Ministry, 2012).

Chapter I

Research problem

Within the domain of psychosocial rehabilitation, a predominant intervention approach has been the integration of mental health service users into their communities and neighbourhoods. The body of knowledge in this area has grown steadily (Granerud & Severinsson, 2006; Novella, 2010a; Schön, Denhov, & Topor, 2009; Townley & Kloos, 2011). Several researchers have identified community integration, and the facilitation thereof, as a promising approach (Doughty & Tse, 2011; Jackson et al., 2006; S.P Segal, Silverman, & Temkin, 2010). For the future, the fostering of community integration has been recognized as an important activity for public health professionals in general (R. W. Gibson, D'Aminco, Jaffe, & Arbesman, 2011; Sibitz, Swoboda, Schrank, Priebe, & Amering, 2008) and, more specifically, for community health nurses (M. Barnes & Sharlow, 1997).

Community health nurses belong to one of the eight most trusted professions (Saad, 2006), comprise the largest single category of public health professionals globally and are often the first responders in most types of healthcare delivery (Wand, 2011; World Health Organisation, 2011). Mental health community nurses play a major role in facilitating and accompanying service users during the process of community integration (Henderson, Willis, Walter, & Toffoli, 2008; Huang, Ma, Shih, & Li, 2008; Jubb-Shanley & Shanley, 2007). Front line community mental health nurses collaborate with other health professionals (e.g., occupational therapists, social workers) to support service users not only in their activities of community integration but also in their recovery process (P. Crawford, Carr, Knight, Chambers, & Nolan, 2001; Quebec Health and Social Services Ministry, 2012). They serve as the primary contact point between staff of public mental health institutions and workers in community- based organizations (CBO), hence they are a key pillar in the bridge between the two for service users (Granerud & Severinsson, 2006). Meanwhile specialized psychiatric nurses' role as consultants for frontline nurses and other health professionals has been implemented in several developed countries such as Canada (specifically in Quebec) (Caldwell, Sclafani, Piren, & Torre, 2012; Quebec Health and Social Services Ministry, 2012). Given the above facts, community health nurses are strategically situated to optimize user participation in the mental health services offered by CBOs as well as in public mental health organizations (Borg, Karlsson, & Kim, 2009; Elstad & Hellzen, 2010; Hills, Carroll, & Vollman, 2007; Wand, 2011).

User participation in the organization of mental healthcare services has been conjectured by nurses and other health professionals to be one of the major contributing factors to the effectiveness of community integration/intervention programmes existing in public mental healthcare institutions (e.g., supervised housing, Assertive Community Treatment) (Kidd, Kenny, & Endacott, 2007; Krupa, Eastabrook, Hern, Lee, & al., 2005; Latimer, Bond, & Drake, 2011). Other nursing researchers (Cleary, Horsfall, Hunt, Escott, & Happell, 2011; Elstad & Hellzen, 2010; Jubb-Shanley & Shanley, 2007) have conducted qualitative studies on the process of user participation in the organization of service in public mental healthcare institutions.

Within the discipline of nursing, there exist theories guiding the practice of mental health nursing. Based on psychodynamic tenets, Peplau's (1952, 1997) theory of interpersonal relations postulates that interactions between nurses and individuals with mental health problems are the cornerstone of the mental health nursing interventions (Cahill, Paley, & Hardy, 2012; Peplau, 1952, 1997). Peplau's theory focuses mainly at the individual level and less on the socio-political environment in which a person lives. Similarly, Noiseux and Ricard (2008) developped a middle-range theory of recovery from the perspective of the service users. This theory explicates the service users' participation in their social activities to re-establish their place in the community with the support of mental health nurses and their family members. It underscores the importance of service users' self-determination; nontheless, actual user participation in the organization of activities in their community as one of key elements in their recovery process has not been extensively documented. Provencher (2008), a nursing academic, proposed a conceptual model that outlines the complexity of the organization of recovery oriented mental healthcare services.

Although Provencher's model explicates mental health care and nursing practice at the organizational level, it puts less emphasis on service users' participation in the organization of mental healthcare delivery in publicly funded organizations and CBOs.

User participation in terms of individual perspectives or experiences, in the organization of mental health care in CBOs has not been studied at length (Bee et al., 2008; Broer, Nieboer, & Bal, 2012; Goodwin & Happell, 2006). But user participation is also influenced by other factors, such as political, social and organizational considerations which have not been documented extensively within the CBOs (Karlsson & Markstrom, 2012; Tambuyzer, Pieters, & Van Audenhove, 2011; Tew et al., 2012).

The ecological approach takes into account these different levels of influential factors on user participation. The ecological approach has gained popularity in the field of health promotion (Kok, Gottlieb, Commers, & Smercnik, 2008; Richard, Gauvin, & Raine, 2011) and in the self- management of individuals living with chronic physical problems (Fisher et al., 2005). Nursing studies in public health have been conducted using the ecological approach (Kaiser & Baumann, 2010; Richard et al., 2010). Additionally, it provides a comprehensive conceptual understanding of the facilitation of service users' participation in community based activitites (Kloos & Shah, 2009). For these reasons, it served as the conceptual basis for this study which portrays four levels of factors that influence user participation: the political, social, organizational and individual levels (Tambuyzer et al., 2011).

At the political level, governments of high income countries have elaborated and been implementing and evaluating their policy of user-centered mental services (Piat & Sabetti, 2009, 2012). User participation in the organization of service figures predominantly within these governmental mental healthcare policies (Elstub, 2006; Happell, 2010). Moreover, service users have been recognized as credible information sources in the elaboration of governmental policies (Hodge, 2009; Wakefield, Randall, & Richards, 2011)

At the social level, user participation in CBO services and in their organization (design, delivery and evaluation) has been identified as one of the main facilitating factors in community integration (Aubry & Myner, 1996; Hardiman & Segal, 2003; C. Lloyd, Robert, & Moore, 2010; Nelson et al., 2007; Truman & Raine, 2002; Tsemberis, Moran, Shinn, Asmussen, & Shern, 2003). For example, among people with a mental illness, user participation in housing decisions has been shown to reduce the incidence of homelessness, a chronic problem in the post-deinstitutionalization era (Gilmer et al., 2010; Tsemberis et al., 2003). Moreover, evidence suggests that the increased presence of mental health service users at the community level, hence increased intermingling with the general population, may also lessen the social stigma associated with mental health problems (Pinto-Foltz & Logsdon, 2009).

User participation at the organizational level (e.g., decisions on the design and types of services and their delivery) contributes to the development of mental health services better adapted to the service users' needs (Grant, 2010). Davidson and his collaborators (2004) reported that user participation in the design and evaluation of supported-socialization services is crucial to the increased level of socialization activities of users. Sheppard and his colleagues (2008) concurred and further emphasized that within CBOs user participation, as well as that of their families, plays a major role in creating a culture of organizational responsiveness. Thus, as Faulkner and her collaborators (2008) report, user participation is crucial to evaluating newly-implemented community-based mental health services.

At the individual level, participation in the organization of services within a CBO, also contributes to service users' recovery process and leads to a reduction in mental distress, increased feelings of self-esteem (Felton, 2005; Nelson et al., 2007; Walsh & O'Shea, 2008) and overall improvement in the users' mental health (H. Berry, Rodgers, & Dear, 2007; Folgheraiter & Pasini, 2009; Tambuyzer et al., 2011). User participation has also been associated with the strengthening of individuals' social networks, which in turn has a positive impact on their overall mental health (Mayo & Rooke, 2008; Muir, Fisher, Abello, & Dadich, 2010) and, more significantly, lessens the feeling of being stigmatized (Nelson et al., 2007). Ultimately, user participation results in greater individual and organizational empowerment (Corrigan, 2006; Hughey, Peterson, Lowe, & Oprescu, 2008).

In Canada, as well as in other high income countries, CBOs are considered important partners to public healthcare institutions (Doughty & Tse, 2011; Duperré, 2010; Quebec Health and Social Services Ministry, 2005). Mental health services delivered through CBOs offer several advantages: (1) closer geographic proximity to individuals experiencing mental health problems, (2) low-cost accessibility to quality services, (3) decreased social distancing (i.e., service user interactions with CBO staff, as compared to healthcare professionals, are more informal), (4) a safe social space offering mutual support and the possibility of a collective voice with which to influence the organization, delivery and quality of mental health services, and (5) alternative mental health services that focus on maximizing service users' strengths, a key principle of recovery (Davidson, Chinman, Sells, & Rowe, 2006; Grenier & Fleury, 2009; Morin, 2011). Both user participation and recovery were two, out of the six, principles identified to guide the transformation of the mental health system in the Quebec government's 2005-2010 action plan for mental health (Clément, 2011; Quebec Health and Social Services Ministry, 2005).

Mental health CBOs have been at the forefront in advocating greater user participation and empowerment (Clément & Bolduc, 2009; Guberman, Lamoureux, Beeman, Fournier, & Gervais, 2004; Poirel, Corin, & Rodriguez del Barrio, 2011; Robson, Begum, & Locke, 2003a). However, while user participation within public healthcare institutions has been well documented (Abelson et al., 2007; Horrocks, Lyons, & Hopley, 2010), user participation within CBOs has not (Muir et al., 2010). Indeed, little is known about how service users participate within CBOs, be it in the design, planning, delivery or evaluation of services. Fundamental questions about the nature of user participation within CBOs as well as the political, social, organizational and individual factors that facilitate or hinder user participation remain largely unaddressed by the literature on community mental healthcare services (Doughty & Tse, 2011).

Consequently, this study's general objective is to better understandthe process of user participation within mental health CBOs, and specifically to:

1. Document and describe the nature of user participation within CBOs providing mental health services,

2. Explore the individual, organizational, social and political factors that facilitate or hinder user participation within these CBO structures.

Nurses are not targeted in this study as they are not directly involved in CBO structure of service organization; however, they still play a major role in supporting mental-health service users in their participation in community activities. Consequently, this study may enrich the body of community mental health nursing knowledge on the nature of user participation and its facilitators and inhibitors. The study's results may influence the role of mental community health nurses in optimizing user participation within the organization of mental healthcare services. Findings from this study can expand current knowledge on user participation within the context of CBOs and, potentially, identify several key elements of user participation and its influencing factors or determinants. Study results will inform stakeholders (e.g., CBO administrators, managers and service users), including service providers (e.g., nurses and clinicians from other disciplines) about the facilitating and inhibiting factors of user participation. In doing so, mental healthcare programmes within CBOs could be potentially more tailored to optimize user participation in their elaboration, implementation and evaluation.

Chapter II

Literature review

2.1 Method of literature review

Nine reference databases were searched covering the years 1974-2012: Medline, CINAHL, PsycInfo, Web of Science, Social Work Abstracts, Sociological Abstracts, Current Contents/All editions, Embase/Cochrane, Érudit (i.e., a database of scientific peer reviewed articles published by three French–language Quebec universities). The year 1974 was selected as the starting point as the keyword "consumer/user participation" was entered as a Medical Subject Heading (MESH) term in the Medline database during that year. Subsequently, references from pertinent articles as extracted from these databases were manually scanned to identify other relevant articles that might have been missed by a MESH search alone. Additionally, 14 books whose main content is on "citizen/public participation" constitute another credible data source.

The following keywords were entered single and in combination in the aforementioned databases: mental health, community health planning, community mental health, community mental health service, mental health community nursing, psychiatric nursing, public health nursing, voluntary organization, organization, community- based organizations, consumer run organization, consumer/ service user, public, citizen, consumer participation, user involvement. The Medline database was queried first. The Medline search strategy is presented in Appendix 1. This strategy was repeated with some variations in querying other English databases. The French database Érudit was queried using the translation of English keywords to French. Furthermore, grey literature items, such as unpublished reports from governmental or community-based organizations and on-line papers relating to user participation, were included in the review.

The abstracts of 500 articles were read. The selection of these 500 articles was based on the inclusion criterion: namely, the article title indicated at least one of the following single or combined terms: user participation, CBOs, organization of mental health services, community mental health nursing, psychiatric nursing. There were 150 duplicates of articles. The following questions were used at the first level of screening to exclude 273 articles from the review**:** “Does the article deal with user participation in health or mental health services?”, “Does the article discuss user participation in the organization of services existing within public organizations or CBOs?”, “Does the article consider the users’ perspectives, those of community-based staff, those of health care providers and those of CBO managers regarding user participation?”

A total of 77 articles whose authors discuss extensively participation of the health-care service users (including mental health service users) were selected. Then, they were analyzed on the basis of 12 assessment questions (see Appendix 2). These assessment questions were elaborated in line with other scoping review articles on user /public participation (Anderson, Alen, Peckham, & Goodwin, 2008; Mitton, Smith, Peacock, Envoy, & Abelson, 2009). Only English and French articles, books and reports and grey literature were retained. This study focuses on the Quebec mental health CBOs; therefore, data was extracted from French published and grey literature in order to describe the political and social context within which the CBOs are situated.

2.2 Findings from the literature review

As this study focuses on users’ participation in CBO’s organization of their services, the second part of this chapter will describe the pertinent findings from the literature on: (1) mental health CBOs (i.e., historical development, organizational structures and services), (2) user participation, (3) factors influencing user participation at different levels: political, social, organizational and individual, and finally, (4) different conceptual models on participation and the choice of the ecological approach that guides this study.

2.2.1 Mental health community- based organizations.

As the CBOs are of vital importance to this study, it is relevant to examine the Quebec mental health CBOs and CBOs in other high income countries(e.g., United States of America, England, Australia) according to the following elements: a) their historical development, b) their organizational structure, c) their services targeting individuals living with mental health problems.

a) Historical development of CBOs.

In Quebec, from 1894 to 1961, the health care of individuals experiencing major mental health problems took place behind the four walls of asylums administered, for the most part, by various but predominantly Catholic religious congregations (Boudreau, 2003). Underlying the institutionalization of these individuals was an aetiology of mental health problems that emphasized individual and family causes (Bassman, 2001) or "God's will" (Grant, 2007). Individuals (or their families) were blamed for their mental health problems, stigmatized by the general population as being dangerous to public security and forced to live within the physical confines of an asylum (Link & Phelan, 2001; Sacca & Ryan, 2011). During the late 1950s, a small group of individuals made up of medical doctors and other health professionals (e.g., nurses, social service staff) began to challenge the authority of religious leaders and organizations, specifically, their internment and care of persons with mental health problems.

The late 1950s also ushered in a new era of pharmacological treatments for severe mental health distress (i.e., psychotic episodes), thereby attesting to the biological cause of mental health problems and effectively refuting divine and family causes. Accordingly, mental health professionals (e.g., psychiatrists, nurses and social service staff) gradually replaced members of religious congregations as healthcare providers for institutionalized individuals with mental health problems. The effectiveness of pharmacological treatments in alleviating the distressing symptoms of mental health problems also contributed to the establishment of psychiatrists as legitimate and powerful stakeholders in the regulation of care dispensed within state-controlled psychiatric institutions (M. Barnes & Bowl, 2001). Although the biological aetiology of mental health problems partially shifted the blame from the individuals and their families, it only marginally diminished the social labelling of mental health service users as irrational in their decision-making, which continued to negate the credibility of their input regarding healthcare services (Bassman, 2001;

Pescosolido, Martin, Lang, & Sigrun, 2008; Rusch, Lieb, Bohus, & Corrigan, 2006; Tambuyzer et al., 2011).

Supported by psychiatrists and buoyed up by new drug treatments as well as the recommendations of the 1962 Bédard Inquiry Commission on psychiatric hospitals across Quebec (Bédard, Lazure, & Robert, 1962), the deinstitutionalization of psychiatric patients took off in the early 1970s. Public outcry and protests from service user groups and their supporters regarding the dehumanizing treatment of hospitalised psychiatric patients were also significant contributory social forces to this shift away from large in-patient psychiatric hospitals towards smaller outpatient clinics (Poole, 2007; White, Jobin, McCann, & Morin, 2002). Thus, it appears that citizen participation in terms of concerned citizens, mental health service users, their families and supporters played a significant role in the deinstitutionalization movement.

Following the discharge of psychiatric patients into the community, several new social phenomena made their appearance. Among them were three problems worthy of mention: (1) a significant increase in homeless ex-psychiatric patients, (2) a lack of intensive psychosocial support for patients outside the walls of psychiatric hospitals and (3) public resistance to the establishment of group homes for ex-psychiatric patients within certain neighbourhoods (Gostin, 2008; Leiderman et al., 2011; Lub & Uyterlinde, 2012; Novella, 2010b; Robitaille, 2002).

In response to the post deinstitutionalization problems (from the 1970s onwards), numerous informal groupings of individuals, and later CBOs, were created to provide the much needed community services (e.g., adequate housing, suitable employment, socialization) (Battams & Johnson, 2009; Karlsson & Markstrom, 2012) and venues in which to foster mutual support among and for ex-psychiatric patients, now referred to as service users (Beetlestone, Loubières, & Caria, 2011; Green-Hennessy & Hennessy, 2004; Swarbrick, Schmidt, & Pratt, 2009). CBOs, emanating from community grassroots efforts, are considered to be one of the most suitable instruments through which to unravel social problems embedded in the very fabric of a community (Carolan, Onaga, Pernice-Duca, & Jimenez, 2011; Rodriguez del Barrio, 2011). This capacity can be attributed, in part, to community members' knowledge and their ability to identify local social issues, as well as to the physical proximity of CBOs to the communities they serve (Clément & Gélineau, 2009; Emshoff et al., 2007). From their early beginnings as small community groups, mental health CBOs have developed into community service organizations with formalized service delivery structures (Duval, 2005). Nonetheless, despite the formalization of service delivery, these CBOs retain specificities distinct from those of formal public healthcare services. These specificities reside in the fact that community-based services are tailored according to the holistic (ie. physical and psychosocial) needs of service users; equality is emphazised between staff and service users as well as flexibility in the length and intensity of services and user participation (Duval, 2005; Poirel et al., 2011).

In a quantitative study (i.e., a survey assessing the mental health needs of service users), Wallot (1999) found that Quebec CBO service users indicated that mental health CBOs provided for almost half of their needs (i.e., 40%) in terms of leisure and informal mental health services. Further, according to scholars, many CBOs adhere to the principle of collective empowerment among service users both at the organizational level and at the macro-organizational level (i.e., among CBOs) (Brohan, Gauci, Sartorius, & Thornicroft, 2011; Shragge 2007). Many scholars have argued that CBOs are in fact "citizenship schools" rooted in the community inasmuch as they offer accessible and safe social settings in which members can practice and develop political advocacy skills (i.e., public speaking, writing letters to politicians, deliberating and negotiating as members of committees) (Burlone, Andrew, Chiasson, & Harvey, 2008; Clemens, 2007; Shragge 2007; Skocpol, 2003). The development and internalization of their citizenship and rights among mental health service users has been a key influential factor over the past few decades. CBOs also serve as intermediary structures through which philanthropic and government agencies can invest in a targeted group or community (Chaskin, Brown, Venkatesh, & Vidal, 2001; Minkoff, Aisenbrey, & Agnone, 2008).

b) Organizational structure of mental health CBOs.

In Quebec, the official and legal definition of a CBO is that of a moral entity constituted for the pursuit of non-lucrative work in the domain of health and social services. It must be overseen by a board of directors comprised of the director, staff, service users and/or members of the community it serves (Government of Quebec, 1991, code 334). CBO service users pay a minimal fee for membership giving them the right to vote on major issues (e.g., new services, budget) at an annual general assembly. The governing board, otherwise named the board of directors (BOD) retains ultimate accountability for organizational activities or services. Therefore, the role of the BOD has been summarized as follows: overseeing financial management and ensuring adequate resources are in place; ensuring that the services of the organization align with its mission; making long-range plans and establishing major organizational policies; hiring and overseeing the functions of the director; representing the organization to the public (Stone & Ostrower, 2007).

In larger CBOs, the hierarchical structure starts with the BOD and then descends to the director, managers, paid staff and volunteers. In principle, the director is accountable for hiring and managing staff, budgeting and reporting to the BOD. The director is also responsible for preparing and sending the organization's annual reports to governmental funding bodies (Panet-Raymond & Lavoie, 2008).

After analyzing internal annual planning documents, service evaluations and the minutes of staff and board of directors meetings, Duval (2005) observed that the organizational structure within the majority of Quebec CBOs had become increasingly formalized. Further, while a large percentage of staff working for CBOs have university degrees, predominantly in the social sciences (e.g., social work, psycho-education), their salaries are markedly lower than those of healthcare professionals employed by public health institutions (Grenier & Fleury, 2009; Lamoureux, 2007).

There are also different types of CBOs: (1) those providing direct services to individuals with mental health problems, (2) umbrella associations (e.g., the *"Regroupement des ressources alternatives en santé mentale du Québec"*, the "*Association* *des groupes d'intervention en défense de droits en santé mentale du Québec*") that group organizations according to their locality (e.g., Quebec, Montreal, other Quebec cities) or stated mission (i.e., to defend users' rights or to provide services) and (3) coalition networks (e.g., the "*Table des regroupements provinciaux des organismes communautaires et bénévoles*") that regroup CBOs across different sectors (e.g., housing, transport) (Grenier & Fleury, 2009). It has been conjectured that the accessibility and richness of community-based services reside in their large numbers; the mere existence of various types of CBOs ensures a diversity of services and service user choice (Boyle, Donald, Dean, Conrad, & Mutch, 2007; White et al., 2002). Furthermore, in regrouping vertically (from local, municipal, regional to national levels) and horizontally across different service sectors (housing, transport, recreation), Quebec CBOs have established formal lines of communications that enable them to work together towards common goals.

c) Services offered by community-based organizations.

This next section provides a brief description of the activities found within Quebec CBOs along with related studies in the literature on their impact.

As mentioned earlier, CBOs often develop in response to an identified community need; some are specific to the needs of mental healthcare service users, others less so. Nonetheless, CBOs whose membership and services are not exclusively aimed at one specific user group (particularly those that are open to the general public) also have a role in the promotion of social integration, including the provision of opportunities for service users with mental health problems to interact meaningfully with the general population.

Services offered by CBOs can be grouped into two categories: direct and indirect services. There are six types of direct services: (1) social support, (2) community follow-up, (3) training workshops, (4) 24/7 supervised housing, (5) telephone counselling and (6) psychosocial support workshops.

The first and most popular direct service offered by mental health CBOs is that of social support: service users are grouped together around recurrent social activities (e.g., art workshop, sewing or computer classes, support group meetings) or impromptu and informal meetings during drop-in hours (Brown, Matthew, Scott, & Meissen, 2007; Grenier & Fleury, 2009). Within CBOs, social support among service users has been found to be beneficial to their wellbeing, offering a venue for mutual sharing of adverse experiences related to mental health problems, validation, normalization of individual's experiences, exchange of problem resolution processes and positive feedback on one's self-worth (Finn, Bishop, & Sparrow, 2009; Nelson et al., 2007; Solomon, 2004). Focusing on the relationship between those providing the social support and the service users, the literature distinguishes between peer support (i.e., support among service users) and healthcare provider and/or CBO staff support. Peer support enhances feelings of empowerment and confidence among users as compared to those who have not experienced peer support (Carolan et al., 2011; Pistrang, Barker, & Humphreys, 2008; Resnick & Rosenheck, 2008).

The second type of direct service is community follow-up of service users. On a one-on-one basis, service users are accompanied by staff as they pursue their daily living activities, such as looking for suitable housing or counselling in support of returning to work or school (Pigeon & Fortin, 2005; Randall & Wakefield, 2010).

The third type of direct service is the training workshop whereby service users develop essential technical and social skills in order to facilitate integration into the mainstream workforce (Menear et al., 2011); some CBOs even offer an adapted work milieu where service users become employees in a CBO-run venture (e.g., service users are paid to sort and recycle clothing) (Defourny & Nyssens, 2006; Lysaght, Jakobsen, & Granhaug, 2012) .

The fourth type of direct service is 24/7 supervised housing for service users. Within these supportive settings, service users are encouraged to become actively involved in internal committees overseeing the organization of activities (e.g., cooking, recreational activities) (Piat, Ricard, Sabettia, & Beauvaise, 2007).

The fifth type of direct service is telephone counselling, including in-person crisis interventions and temporary respite care (housing) facilities. An American survey (n=393 participants) reported that service users who received crisis intervention services from a CBO evidenced fewer psychiatric symptoms and more service satisfaction than participants who did not receive similar support (Greenfield, Stoneking, Humphreys, Sundby, & Bond, 2008).

The sixth and last type of direct service focuses on the provision of alternative psychosocial support workshops aimed at self development and emotional stability (Petryshen, Hawkins, & Fronchak, 2001; Poirel et al., 2011).

Indirect services offered by CBOs include programmes aimed at the general public: public awareness, such as educational and training activities intended to reduce stigma and discriminatory practices towards individuals with mental health problems (Pinto-Foltz & Logsdon, 2009). Advocacy is another type of indirect service that focuses on making health and social services more accessible to service users (Schmid, Bar, & Nirel, 2008). Additionally, a recently developed mental health CBO in Quebec offers user expertise to researchers and practitioners working in public health institutions and other CBOs during the conception, implementation and evaluation of research projects (Reprendre Pouvoir, 2012)

2.2.2 User participation.

This section reviews the existing literature on user participation: a) the term's definition and b) its characteristics.

a) Definition of user participation.

There are 45 definitions of user participation in the literature (Tambuyzer et al., 2011). Bracht (1990) defines: "User participation as the social process of voluntarily taking part in formal and informal activities and discussions to bring about changes or improvements in a participant's life and service access" (p.110). This definition of user participation is of a contemporary relevance since it focuses on the active role of the individual, as participant, and on the impact of user participation on the individual's life specifically in relation to services in his or her community. User participation can be defined according to the following constituting elements: 1) its characteristics: breadth, depth, the number of users and the duration of user participation, and 2) the form of user participation.

Characteritics of user participation.

The following questions regarding user participation are examined in depth in this study: to what extent do users penetrate into CBO organizational and service delivery structures (i.e., depth of user participation), what is their length of involvement (i.e., duration of user participation), and to what extent do one or more users influence the organizational decision-making process (i.e., breadth of user participation). Consequently, within this study, user participation is conceptualized in terms of the breadth, depth and duration of the participation it engenders (Peck, Gulliver, & Towel, 2002; Robson, Begum, & Locke, 2003b; Webb, 2008). The first three characteristics of user participation (i.e., breadth, depth and duration) are discussed below, followed by a discussion on the form of user participation (i.e., user as information-receiver, consultant, partner and decision-maker); the latter (i.e., form of user participation) having been studied at length in the literature, is more extensively developed than other characteristics of user participation.

The breadth of participation refers to the influence of user participation in a specific CBO's decision-making instances. User participation can be seen as an interpersonal process encompassing a bi-directional flow of information among users, staff and managers based on their expectations, mutual trust, and majority consensus. In these decision-making instances (e.g., CBO committee, BOD), service users are often in a minority position (Cornwall, 2008; Webb, 2008). The number of service users on a working committee or BOD has been shown to be significant, in that the presence of more than one service user can provide mutual support to other service users' perspectives (Binet, Clément, & Labelle, 2004; Bréchat, Jourdain, Schaetzel, & Monnet, 2005; Clément, 2011; S. McDaid, 2009; Tritter & McCallum, 2006). Furthermore, the number of service users (i.e., more than one on a BOD or committee) can have a positive impact on service user motivation and duration of participation, as well as on users' influence on the final decisions made by the CBO administrators (M. Barnes & Coelho, 2009; Binet et al., 2004; Connor & Wilson, 2006; Robson et al., 2003b).

Depth refers to the extent to which users penetrate into a CBO's organizational structure (e.g., board of directors, committees) and their role within that structure. Depth encapsulates the degree to which service users are involved in and at which stage of service delivery: the initial issue identification or needs assessment to the design, planning, allocation of resources, service implementation and service evaluation stages (Cornwall, 2008; Maier & Meyer, 2011). Additionally, the depth of user participation refers to the degree of service user involvement in the management and evaluation of human and financial resources. As such, depth is measured by the involvement of service users in organizational activities such as staff recruitment and evaluations, budget planning, grant application submissions, periodic and annual reporting to funding bodies and liaison with other CBOs (Diamond et al., 2003; Grant, 2007; Kent & Read, 1998).

The third aspect, duration, looks at the length of time service users are involved in a CBO (Noam, 2005; Ochocka, Nelson, & Janzen, 2006). It has been argued that the length of service user involvement (i.e., duration) within a CBO influences the type of organizational activities (Nelson & Lomotey, 2006). The longer a service user utilizes, hence becomes familiar with a CBO's structure and services, the more likely it is that he or she will participate in higher-level activities such as budget reporting or public speaking as a representative of the CBO in comparison with regular (low-engagement level) CBO activities such as volunteering or assisting CBO staff (Restall, Cooper, & Kaufert, 2011).

Different forms of user participation.

The classic and often-cited typology of user participation as described in Arnstein's ladder of participation (i.e., users as followers, consultants and decision-makers) advances a unique dimension relative to the power dynamics between service users and the professional gatekeeper of public services (Arnstein, 1969). At the bottom of Arnstein's ladder, service users, in the role of passive followers, comply with the plans of action as predetermined by a professional. In the middle of the ladder, service users are consulted, but the final decision on the types of programmes or activities is still made by a professional. At the top of the ladder, service users have the autonomy to decide on the types of programmes or activities. Several authors have criticized the linear and hierarchical aspect of Arnstein's work, which progresses from a state of complete powerlessness of the service user to absolute control, with little consideration given to the complexity of the situation, the evolution in the degree of user participation and the service user's capacity for personal development and adaptation to an organization (Cornwall, 2008; Litva, Canvin, Shepherd, Jacoby, & Gabbay, 2009; Tritter & McCallum, 2006).

Other scholars have shifted attention away from the valuation of participation implicit in Arnstein's ladder, whereby user participation is seen to be universally beneficial independent of the socio-cultural context (Litva et al., 2002). Some go as far as to argue that user participation as a feel-good concept is tyrannical in that non-participants are further marginalized (Lammers & Happell, 2003) when in fact, in many instances, service users' non-participation is more plausibly the end result of the inadequacies of services to meet service their needs or the outcome of service users' resistance to professional interventions (Cooke & Kothari, 2001; Reid & Nikel, 2008). In other words, the benefits of user participation should be viewed as multifaceted and context dependent (Beeble & Salem, 2009). Nevertheless, the literature indicates a continuum of user participation ranging from passive form - information receiver, service-user consultant, to a more active form– service user partner (as an expert by lived experience) collaborating on equal footing with the healthcare professionals in the decision-making process (Bennetts, Cross, & Bloomer, 2011; Cornwall, 2008; Lammers & Happell, 2003; Tambuyzer et al., 2011).

Globally, user consultation is the most widely applied form of user participation (Cornwall & Coelho, 2007). In most instances, user consultation is said to occur when public institutions convene service users or the general population to participate in public forums in order to solicit input on pre-specified issues (M. Barnes, Newman, Knops, & Sullivan, 2003; Mitton et al., 2009; VanKemenade & Fréchette, 2007). Further, within institutions, ongoing committees also create a venue for user consultations, allowing service users as committee members to contribute their perspectives on a regular basis (Milewa, Buxton, & Hanney, 2008). In one of the largest studies on user participation, which examined the relationship between 74 user groups and 18 public mental-health institutions serving over 7.4 million residents, Crawford and colleagues (2003) found that user consultation was perceived as a positive and satisfying experience by service users. Rijckmans and colleagues (2007) concurred that user consultation is perceived as meaningful by service users when their perspectives are respected and taken into consideration in the decision-making processes (by staff and managers). Moreover, within user consultation sessions, issues to be discussed are elaborated in partnership with all participants, service users and professionals; and the minutes of the meetings are written up and validated with the participating service users. Furthermore, during debates, service users and officials are encouraged to voice their perspectives and concerns, then put their individual views aside in order to reinterpret and incorporate the combined contributions into a common standpoint (Lehoux, Daudelin, Demers-Payette, & Boivin, 2009). In one qualitative study, user consultation was considered to be optimal when service users' perspectives were integrated into the final outcome and, in instances where the input was deemed inappropriate or unfeasible, a legitimate justification for exclusion/rejection was presented by the decision-makers to the users (Litva et al., 2009).

Another form of user participation, the user as partner, which involves the service user in active partnership with health professionals in the process of deciding the service user's community care or treatment plan, is also well documented in the literature (Corrigan et al., 2012; Curtis et al., 2010). Moreover, the recovery movement has been successful in coalescing service users, researchers, health professionals and decision-makers around a shared viewpoint implicit in the user-as-partner approach. In fact, individuals with serious and persistent mental health problems can lead satisfying and productive lives despite the chronic nature and severity of those problems. Consequently, the user-partner form of user participation is increasingly present in service users' interactions with health professionals, not only in relation to their own care and life projects, but also in the organization and evaluation of services, research programmes, the education of mental-health professionals and policy-making processes within the mental health system (D. Barnes, Carpenter, & Dickinson, 2006; Goodwin & Happell, 2007; Karlsson & Markstrom, 2012; Mahone et al., 2011; M. K. Watson, Bonham, Willging, & Hough, 2011).

2.2.3 Factors that influence user participation.

Inspired by the ecological approach (Finn et al., 2009; Richard et al., 2011), the factors influencing user participation can be classified into four levels: political, social, organizational, and individual.

a) The political level.

In Quebec, mental health CBOs founded by concerned community leaders or service users and supported by mental-health professionals (e.g., physicians, nurses) were recognized as pioneering, creating a network of community-based health services for the general population (Ellis, 2000; Jette, 2008). Rooted in the deinstitutionalization movement, these autonomous social entities gained momentum and recognition, as evidenced by recurrent funding from both the Quebec government and large charity associations (e.g., Centraide) and the public acknowledgement in government documents and policy papers of their contributions to the health of the population (Grenier & Fleury, 2009; White, 2008).

The majority of published articles give credence to the fact that within developed nations the current political context favours user participation in public healthcare institutions (e.g., Australia, Canada, England, New Zealand, United States of America) (M. Barnes, Newman, & Sullivan, 2007; Gauld, 2010; Happell & Roper, 2006; Piat & Sabetti, 2009; Restall et al., 2011; Rodriguez del Barrio, Bourgeois, Landry, Guay, & Pinard, 2006; Toiviainen, Vuorenkoski, & Hemminki, 2010). Government policy documents state clearly that service users have a critical role to play in influencing the organization concerning the implementation and evaluation of healthcare service (New Freedom Commission, 2003; Quebec Health and Social Services Ministry, 2005). However, some scholars have cautionned against governments and instituions to implement the ideology of user participation as a political strategy to rationalize and legitimatize unpopular decisions (e.g., cut in mental health services) (A. Gibson, Britten, & Lynch, 2012; White, 2000).

Most Quebec mental health CBOs receive minimal financial contributions from their service users (e.g., on average, a $10 annual membership or user fee). During 1989 to 1998, an exponential growth in the ranks of mental health CBOs followed the adoption and application of the 1989 government policy "*La politique de la santé mentale*," [Mental health policy] and again in 1991 with Act 120, in which the government officially recognized CBOs as social entities providing essential community mental health services to the general population. Currently, eighty percent (80%) of Quebec CBOs receive government subsidies. In the fiscal period 2006-2007, some 430 CBOs were recognized as mental health CBOs, thus comprising 20% of the total 3,200 community-based organizations. Healthcare CBOs receive a combined total of more than $300 million from the "*Programme de Soutien aux Organismes Communautaires*" (PSOC) [Funding programmes for CBOs]; 23% of the PSOC funding was allocated to mental health CBOs in 2008 (Jette, 2008).

Within the field of mental health services, most CBOs in Montreal, the largest city in Quebec, are funded by the Montreal Agency of Health and Social Services under the PSOC provincial programme. Further, CBOs with a mission to provide training, work and support for mental health service user integration or re-integration into the labour market can also receive concurrent funding from the Quebec Ministry of Labour and Solidarity and the Quebec Ministry of Health and Social Services. Government subsidized CBOs are required to send an annual report of their activities and services as well as a detailed account of financial expenditures to the PSOC.

In providing recurrent annual funding to CBOs based on their stated mission, and not as a limited contractual service, the government contributes to their sustainability as organizations situated in the community that provide accessible health and social services (White, 2008). On one hand, despite this growing financial dependency on the government, most CBOs are determined to preserve their autonomy in programming and service delivery (Jette, 2008). On the other hand, the government is striving to structure integrated healthcare services by establishing a hierarchy of such services from first-line services (in which CBOs play a major role) to second- and third-line services (i.e., specialized, mainly psychiatric in-patient treatment services) (Marquis, 2006). In return, CBOs are increasingly called upon to collaborate with public institutions by offering specific community services that support users' mental health needs (e.g., community follow-up services, support for daily life activities such as applying for low-income housing) (Vallée et al., 2009). Indeed several CBOs have developed close ties to psychiatric hospitals within predefined geographical boundaries and are called upon to offer services to individuals referred by emergency rooms or discharged from hospital wards, local health centres and social service centres.

Nevertheless, some CBOs aspire to change certain governmental regulations on social issues (e.g., accessibility of housing facilities for service users); thus, these CBOs espouse the ideal of social transformation (Church, Shragge, Fontan, & Ng, 2008; Corin, Poirel, & Rodriguez del Barrio, 2011; Schmid et al., 2008). As a result, a few CBOs, ill-inclined to assume the role of complementary partner or government "subcontractor" to public health institutions, have pointedly affirmed their autonomy in service provision; however, these generally receive little or no government funding (Burlone et al., 2008).

Earlier Quebec government documents, such as the "*Plan d'action pour la transformation des services en santé mentale*" [Action plan for the transformation of mental health services] (1998) clearly state that service users have to be consulted on the organization of mental health services as offered by public institutions and CBOs (Rodriguez del Barrio et al., 2006). Conversely, a more recent document entitled "*Plan d'action en santé mentale 2005-2010: La force des liens*" [Action plan in mental health 2005-2010: The strength of networks] (Quebec Health and Social Services Ministry, 2005) puts the emphasis on the passive role of service users as patients, to be medically and socially managed (liberal translation of the French phrase "*la prise en charge*") by health professionals. Furthermore, within the Quebec context, there is some concern that the role of the service users in the organization of general healthcare services is in fact diminishing (Forest, Abelson, Gauvin, Martin, & Eyles, 2003; Jette, 2008; Tremblay, 2007). For example, in 2000, new legislation, Act 24, actually abolished the election of user representatives on the governing boards of regional health agencies. The number of reserved seats for users on the governing boards of healthcare institutions was also cut (Tremblay, 2007). According to government documents, the official reason for these changes is the disappointingly low user participation rate in electing representatives (Jette, 2008). Moreover, another fact worthy of mention is that the functions of an officer of the BOD may represent an unfair or excessive burden on the average or typical service user from the perspective of government officials (Jette, 2008).

In one study that surveyed the practice of user participation in a large public health institution in England, Martin (2008) pointed out that ambiguity in government policy as to the objective of user participation, coupled with a top-down user participation implementation process, inhibited user participation. In a Canadian qualitative study looking into community health promotion programmes, Boyce (2002) reported that despite the efforts of health promotion professionals to encourage participation from community members at the local level, actual participation from groups of disfranchised individuals was minimal due to high-level government decision-makers' emphasis on intervention efficiency and effectiveness.

Despite the above, some scholars (Doughty & Tse, 2011; Morin, 2011; Resnick & Rosenheck, 2008; Salyers et al., 2010; Wang, 2011) point to government support, in terms of administrative directives and financing, in developing some mental health CBOs that are specifically mandated to establish user participatory spaces or to enhance more active user participation in public healthcare institutions.

b) The social level.

A survey of the sociological and community mental health literature reveals two ideologies of user participation: a consumer versus a citizen accessing a right (M. Barnes & Coelho, 2009). Indeed, as a consumer of mental healthcare services, the service user has a right to have a say in the quality and responsiveness of healthcare service to service users (for public institutions and CBOs). As a citizen, the user also possesses the right to hold society and its politicians accountable to the highest standard of mental health care (Buchanan, Abbott, Bentley, Lanceley, & Meyer, 2005; Toiviainen et al., 2010; M. K. Watson et al., 2011). Whether the mental health service users are consumers or citizens, their participation in the organization of mental health service has been greatly influenced by the recovery movement (Browne & Hemsley, 2010; Marshall, Crowe, Oades, Deane, & Kavanagh, 2007; Zubritsky, Mullahy, Allen, & Alfano, 2006). Consequently the recovery movement is discussed in relation to user participation.

The recovery movement.

The recovery movement, as a social movement, has been gaining political recognition for the past three decades, all the while influencing government policies and the mental healthcare system (Jordan & Court, 2010). The ensuing transformation from a pharmaceutical treatment model, based on the biomedical model, to a recovery-oriented mental health service model seeking to enable service users to take greater control over their lives continues to evolve (Corrigan et al., 2012; Davidson, Ridgway, Kidd, Topor, & Borg, 2008; Latimer et al., 2011). Recovery as a social movement reaffirms that service users lead a productive life in their society and that, as citizens, they have a right to participate not only in their care but also in the design, delivery and evaluation of healthcare services. In doing so, they contribute positively to their community of residence (Harding, Brown, Hayward, & Pettinari, 2010; Weinstein, 2006). In existence for more than forty years, mental health CBOs in Canada and other developed nations have played a major role in humanizing mental health services and in advancing the recovery movement (Doughty & Tse, 2011; Duval, 2007; Grant, 2010; Hughey et al., 2008; Toiviainen et al., 2010).

At the social level, recovery also signifies the awakening of both the individual and collective consciences regarding social prejudice against mental health service users (Provencher, 2002; M. K. Watson et al., 2011). Other authors write extensively about the ultimate responsibility of a society and its decision-makers not only to faciltitate the recovery of the service users but also to acknowledge the importance of their recovery as a valuable contribution to the whole community (Hopper, 2007). In other words, not only should service users have easy access to services in public institutions and CBOs in order to optimize their capabilities (e.g., to participate in community activities, to reconnect with others in their neighbourhood), but their participation in the community should be valued at the same level as the involvement of the general population in the organization of medical and social services (Sen, 1993; Ware, Hopper, Tugenberg, Hickey, & Fisher, 2008).

Furthermore, as a concept and a principle of practice, recovery has made some inroads into mental health professionals’ discourse (Huckshorn, 2007; Krupa & Clark, 2009; Tsai, Salyers, & Mcguire, 2011). The existing gap between the body of knowledge on “psycho-biomedical treatment” and the social recognition of service users’ experiential knowledge is being narrowed by a growing number of government funded or supported programmes that train and employ service users as peer providers, peer specialists or peer coaches (i.e., user participation in service delivery). These are being delivered in conjunction with in-service training for health professionals on user participation and recovery oriented mental health care (Beetlestone et al., 2011; Bennetts et al., 2011; Restall et al., 2011). Mental health CBOs also offer services modelled on the principle of recovery inasmuch as service users are assisted (e.g., training workshops for acquiring technical skills) in their efforts to integrate into the community through CBO work, volunteer or leisure activities (Brown, Shepherd, Merkle, Wituk, & Meisser, 2008; Corrigan, 2006; Nelson, Lord, & Ochocka, 2001).

Finally the recovery approach can be defined as a complex process involving intrinsic, non-linear progress, primarily and actively generated by individuals, in order to rebuild a sense of self and to manage the imbalance between internal and external forces with the overarching objective of charting a path through the social world and gaining a sense of wellbeing on all bio-psychosocial levels (Noiseux & Ricard, 2008). Conversely, in a recent Canadian multisite qualitative study of 54 service users, recovery was perceived by some service users and mental health professionals as stability in a service users’ mental health status due, at least partially, to their adherence to medications (Piat et al., 2009). Despite different conceptualizations of recovery, there exists a consensus in the literature on the importance of service users’ active participation in striving for control in their lives, to sustain their personal recovery and in playing an active role in shaping mental health services (Liberman, Kopelwicz, Ventura, & Gutkind, 2002; Piat & Sabetti, 2009; Tanenbaum, 2011).

c) Organizational level.

As aforementioned, community mental health nurses are one of the largest professional group at the forefront providing mental health services to service users

(Beinecke & Huxley, 2009; Happell, Hoey, & Gaskin, 2012). Consequently, it is timely to conduct a literature review on the practice of community mental health nursing, and specifically on their influence on user participation.

Community mental health nursing.

According to Canadian community nursing standards, nursing practice should be geared towards enabling service users to develop their participatory capacities in community activities and to work alongside with them in the recovery process (Community Health Nurses Association of Canada, 2003; Forchuk, Martin, Chan, & Yensen, 2005; Repper & Perkins, 2003). Nurses play an increasingly significant role in ensuring the continuity of mental health care for service users in hospital settings; accompanying them in their recovery process, including fluctuations in the intensity of their mental health problems during the transition from in-patient settings to community dwellings; and enhancing their participation in community activities (Bee et al., 2008). The role of community mental health nurses as care coordinators or case managers for individuals with serious and persistent mental health problems living in the community is well documented (Huang et al., 2008; Nutt & Hungerford, 2010; M. Stewart, Wilson, Bergquist, & Thorburn, 2012; Wells et al., 2006).

The practice of mental health nursing rests essentially upon the therapeutic nature of the relationship between the nurse and the service user, regardless of the setting, be it hospital or community (Comité d'experts sur la pratique infirmière en santé mentale et en soins psychiatriques, 2009; Cookson, Daffern, & Foley, 2012; Cutcliffe, 2008; Larivière et al., 2009; Peplau, 1997). Indeed, the supportive relationship between nurses and service users has been found to facilitate active user participation in their individualized health care and in healthcare service organizations (Goodwin & Happell, 2007; McCann, 2002; Repper & Perkins, 2003).

Furthermore, some authors (Happell, Palmer, & Tennent, 2011) emphasize nurses’ distinct professional perspective as compared to other healthcare disciplines (e.g., psychologist, social service staff) in that nurses play a major role, in providing holistic (i.e., physical and mental) and humanistic health care for service users in their daily life activities in the community. Nurses not only support service users in their daily management of mental illness symptoms but they also work alongside with service users in dealing with social issues (e.g., access to adequate housing, public financial assistance, employment) (Brimblecombea, Tingle, Tunmore, & Murrells, 2007; Crowe, O'Malley, & Gordon, 2001; Mahone et al., 2011).

The past few decades have seen a gradual shift within community mental health nursing practice from that of a paternalistic standpoint and patient advocate towards greater promotion of service user autonomy and self-determination (Caldwell et al., 2012). On the evidence from a qualitative study of user participation that analyzed the perspectives of different stakeholders within two large London-based public regional institutions (users, managers, staff, chief executive officers), Rutter and colleagues (2004) argue for measures promoting nurse empowerment (e.g., allocating sufficient time and resources for nurses to affect incremental changes in the organizational structure in order to render it more accessible for user participation). These authors conjecture that concrete strategies to empower nurses in creating organizational initiatives (e.g., creation of a user committee) may be more effective in enhancing active user participation than educational sessions on the value and practice of user participation. Empowered mental health nurses are better equipped to empower service users to voice their experiential knowledge, to influence and even to shape the delivery of healthcare services (Goodwin & Happell, 2008; Handsley & Stocks, 2009; McCann, Baird, Clark, & Lu, 2008; Warne & McAndrew, 2007).

Two additional qualitative studies (Langton, Barnes, Haslehurst, Rimmer, & Turton, 2003; Middeton, Stanton, & Renouf, 2004) report that mental health nurses believe that systemic barriers, such as lack of organizational support, ambiguity regarding the objectives of user participation and limited resources have to be addressed in order to facilitate nurses’ work in optimizing user participation

Having discussed the relation of community mental health nurses with user participation, the following section discusses other organizational factors within CBOs and public institutions, specifically regarding CBOs staff (of different disciplines other than the nursing profession) and how these factors interrelate and influence user participation: (1)

the interpersonal dimensions or perceptions of organizational staff and (2) service users (i.e., differences in their perceptions vis-à-vis the credibility of the service users' experiential knowledge and the legitimacy of user participation), (3) the social climate, (4) leadership style, (5) formal space for user participation and (6) differential treatment of service users.

Perceptions of the organizational staff.

The literature on user participation is rich in empirical studies that document the gulf between organizational staff and service user perceptions regarding the credibility and legitimacy of user participation in the organization, delivery and evaluation of services as well as the governing of public health institutions (Cleary et al., 2011). The practice of user participation is marginalized by health professionals who undermine the legitimacy of service users as representative of other users (Happell, 2010; Martin, 2008). Frequently, health professionals and government officials question whether the user representative in a consultation or on a service user committee can be said really to represent all service users rather than simply their own unique life experiences (Brohan et al., 2011; Daykin, Sanidas, Tritter, Rimmer, & Evans, 2004). Taking this further, some professionals argue that middle-class service users represent a privileged "elite" group within the actual service user group. The fact that they are often more articulate and less "emotional" in their arguments makes them more persuasive and obscures the voices of less-advantaged members; in other words, they do not represent the voice of the average or typical user (M. Barnes & Bowl, 2001; Robert, Hardacre, Locock, Bate, & Glasby, 2003). More significantly, the same oppositional view is also voiced by family members who question the credibility of user representativeness or even reject service users' voices, claiming they are more representative of particular interest groups (Nelson et al., 2001). However, Crawford and Rutter (2004) reported in their cross-sectional survey (n= 139) that the views of service users who represented other service users on work committees and BODs did not differ from those of "ordinary" mental health service users.

Nonetheless, the credibility of user participation within public institutions and CBOs resides, essentially, upon the mental health professionals' (staff) recognition and valuation of the service users' experiences [(i.e., the daily coping mechanism of users with mental health problems and their experiences of using mental health services (Rise, Grimstad, Solbjor, & Steinsbekk, 2011)]. Although there has been progress in implementing consumer-advocate, peer-consultant, and peer-support roles for service users within public and community mental health organizations (Migdole et al., 2011), there are key challenges that have to be worked on to optimize user participation, such as health professionals' negative perception of service users' experiential knowledge, as well as the differential value placed on academic knowledge versus lay expertise often embedded in organizational structures (Hernandez, Robson, & Sampson, 2010).

The service users' perception.

User representatives assert that they speak for other people who have similar life experiences (M. Barnes et al., 2007). They believe that their perspective is not only essential to improving the responsiveness of the healthcare system but also crucial for the common good of the greater community (Clément & Gélineau, 2009; S. McDaid, 2009).

Regardless of their status as an "ordinary" or "elite" user, service users argue for the legitimacy of their participation: their first-hand knowledge of the mental health experience and services is a source of experiential expertise and a vital source of information for improving healthcare systems (Alm Andreassen, 2008; Beal et al., 2007; Borg, Karlsson, Lofthus, & Davidson, 2011; F. Brooks, 2008; Restall et al., 2011). Further, they believe that their experiences should modulate professional practices and serve as strong evidence for social transformation (Alm Andreassen, 2008; Beal et al., 2007; Borg et al., 2011; F. Brooks, 2008; Restall et al., 2011). An added value of user participation, noted in the literature, resides in the fact that despite social stigmatization of their mental health problems, participating in service design and delivery allows service users to exercise their democratic right as citizens.

Finally, investigators have also found that the quality of participation is more significant in terms of its impact on organizational or social change than the issue of user representativeness (M. Barnes, 2007; Hutchison, Arai, Pedlar, Lord, & Yuen, 2007).

Social climate within community-based organizations.

Social climate is viewed as an organizational dimension that is constitutued of staff attitudes towards service users and social cohesion (conceptualized as the sense of belonging to a specific organization that results from a positive relationship among the individuals within the organization) (Moos, 2003). In her qualitative study of a consumer-run organization, Felton (2005) found that a common belief in recovery from mental health illnesses shared strongly by staff and users contributed to social cohesion. Other studies indicate that user participation is not only enhanced but sustained by social cohesion (evidenced by mutual interpersonal support) between staff and users (Norman, 2006; Schutt & Rogers, 2009; Waegemakers Schiff, Coleman, & Miner, 2008). On the other hand, a negative attitude towards user participation among health professionals (i.e., where health professionals demonstrate little belief in the importance of user participation) is reported to have a downbeat influence on their interactions and relationships with service users (Gordon, 2005; Grant, 2007; McCann et al., 2008). Meanwhile, in conducting a quantitative survey of CBO service users (n=561), Hughey and colleagues (2008) concluded that social cohesion, a key element in an organization's social climate, is positively associated with user participation.

In general, social climate has been studied more extensively in residential substance-addiction (Moos, 2003), neighbourhood associations (Wandersman & Florin, 2000) and school settings (Way, Reddy, & Rhodes, 2007) than within mental health CBOs. Nonetheless, there is some evidence that a social climate favourable to user participation exists within organizations whose members share a common vision and whose leadership is inclusive and democratic (Allen, 2005; Kegler, Norton, & Aronson, 2008).

Leadership style.

Individuals in leadership roles, such as CBO directors, are influential in setting the tone of an organization's culture as one that enables or constrains user participation (Brown et al., 2008). In view of this fact, CBO directors are often called upon to have a clear vision of the organization's mandate and how best to accomplish it (Schmid, 2007). However, the charisma of some director-founders can overshadow the actual work of the community-based organization (Rhéaume, Tremblay, Dumais, Brunet, & Vaillancourt, 2007).

Additionally, some scholars have observed that the more leadership is decentralized in decision-making processes, the more positive the organizational climate is in terms of the staff's work satisfaction (Aarons & Sawitzky, 2006; Lord, Ochocka, Czamy, & MacGillivary, 1998). Furthermore, it has been noted that within CBOs, a transformative leadership style emanates from directors who act as role models in their determination to meet organizational objectives, often against a backdrop of scarce financial resources; such leaders have the ability to mobilize and motivate their staff in the smooth and fluid functioning of the organization (Schmid, 2007). It is worth noting that a user-focused and democratic leadership style is also effective in cultivating innovative practices, such as widening the depth of user participation within an organization (Baldwin, 2008).

Space for user participation.

Quebec CBOs reserve three types of spaces for users (Lachapelle, 2007): (1) user-consultants in the design of alternative health-service programmes (e.g., day centre, art therapy workshop, etc.), (2) user representatives on ad-hoc working committees to plan community services or special projects or to liaise with other organizations (e.g., public institutions, other CBOs) and (3) user representatives on the board of directors. In Quebec, CBOs are legally required to reserve seats on their governing boards for service user representation (Jette, 2008), thereby allowing users an opportunity to dialogue with organizational staff and directors within the organization's ultimate decision-making body. However, some scholars (M. Barnes et al., 2007; S. McDaid, 2009; Stern & Green, 2008) caution that this reserved space, while essential, is not in and of itself sufficient to ensure influential user participation.

In fact, it is conjectured that despite the reserving of official space in most public institutions and CBOs, actual user participation remains less than optimal in the decision-making processes in terms of planning and daily operations (Daykin et al., 2004; Stern & Green, 2008; Tremblay, 2007). This fact is attributed, in part, to the formalization of roles (i.e., staff as helper and service user as "helpee") and the centralization of the decision-making process in the hands the CBO directors or public institutional administrators (M. Barnes, 2007). Furthermore, Moss (2003) argues that the more structured an organization is, the more it encourages conformity amongst its members (i.e., organizational staff and users) and the more likely it is to be less open to user participation and input. Brown and colleagues (2007) concur with Moos (2003). The larger a CBO is, hence a higher formalized role structure, the less service users have any say in administrative decision-making; consequently, they are less inclined to participate in the organization's higher level activities (e.g., service planning).

The following analysis, found in the literature, summarizes the enabling factors that maximise user participation within formal reserved spaces for users. Beyond giving users the opportunity to speak, the organizational staff and directors have to be willing to listen and engage with service users in a reciprocal dialogue (Cornwall & Coelho, 2007). Reserved space for service users on the governing boards has to be complemented by real structural change within the organizational culture, such as instances whereby service users, staff and directors dialogue on equal terms, moving beyond the boundaries of their personal knowledge base (i.e., experiential and lay knowledge versus professional knowledge) (Church et al., 2008; Harding et al., 2010). The literature suggests other enabling organizational strategies for creating a conducive organizational space for service users such as (1) financial compensation for user-representatives in recognition for their input (Clément & Bolduc, 2009; Cornwall, 2008), (2) opportunities for users to acquire communications skills (e.g., communications workshops), (3) instrument/tool appropriateness (e.g., user-friendly documentation), (4) emotional support for user-representatives who participate in decision-making processes (e.g., debriefing at the beginning and the end of formal meetings) (Brown, 2009; Grant, 2007; Harding, Pettinari, Brown, Hayward, & Taylor, 2011), (5) clear communication between user representatives and CBO staff regarding their beliefs and perceptions about the purpose of their roles and inputs (Martin, 2008), and (6) educational training for organizational staff on the benefits and modalities of user participation (Diamond et al., 2003). Finally, it should be noted that the literature review also highlighted a definitive gap in terms of an absence of research focused on implementing these strategies and evaluating the outcomes.

Differential treatment towards service users.

Two organizational factors found to constrain user participation are the lack of financial compensation for user representatives (Alm Andreassen, 2008; Cornwall, 2008) and the differential social credibility regarding professional versus lay (or experiential) knowledge (Harding et al., 2011). As a group, service users are often financially disadvantaged, yet they receive little, often only symbolic, monetary recompense for their participation on temporary or permanent committees in public health institutions or CBOs. Conversely, organizational staff and health professionals are paid for their presence and input. Despite considerable progress in government efforts to compensate user participation adequately during national or regional public consultation fora, insufficient funding to compensate service users in their participatory endeavours remains an obstacle at the local level (Thomas, Wilson, & Jones, 2010). Although several authors have documented stakeholders', researchers' and health professionals' positive valuation of service users' experience-based know-how, bio-medical-based knowledge is still perceived to be more credible than service users' experiential knowledge (Jordan & Court, 2010; McLaughlin, 2008; Petersen, Hounsgaard, Borg, & Nielsen, 2012).

d) Individual level.

This section examines the individual factors in relation to user participation in public institutions and CBOs. The literature indicates that service users with a well-developed sense of belonging to the communities in which they reside participate more actively in the community (Elstad & Eide, 2009; Townley & Kloos, 2011; Walsh & O'Shea, 2008). Furthermore, several authors (Muir et al., 2010; Wynaden, Barr, Omari, & Fulton, 2012) assert that the driving force underpinning user participation is service users' self-confidence in their capability to participate in community services. Segal and colleagues (2002) concur that user participation in CBOs is more prevalent among service users with greater self-esteem and a higher level of social functioning in the community, as compared with other service users.

Other motivational factors, identified by mental health service users who actively participated in CBOs and public institutions, divide into individual or personal motivators (e.g., to expand social and friendship networks, to obtain exclusive membership in an organization, to get personalized service) and altruistic or collectivistic motivators (e.g., speaking for the common good of other users) (Brown et al., 2008; Sheppard et al., 2008; Tritter & McCallum, 2006). Other authors, (Attree et al., 2011; Lowndes, Pratchett, & Stoker, 2001; Simmons & Birchall, 2003) examining the motivation of service users as a cost-benefit ratio, found that user participation is more likely when benefits outweigh costs. Notwithstanding this fact, collectivistic motivations (e.g., participation in order to promote change in service) consistently stand out as one of the main motivational factors cited by active service users (M. Barnes et al., 2003; Netting, 2007; Schutt & Rogers, 2009).

Additionally, Nelson and his collaborators (2001) ascertained from their qualitative study of three Canadian CBOs that service users who actively participate in CBOs have the following personal characteristics: (1) insight (i.e., self-awareness pertaining to their conscious or subconscious drive to participate and the root of their mental health problems (M. Cunningham, 2010)]) and (2) belief in their capability to recover from irregular periods of mental health crises, coupled with (3) the presence of a stable support system (e.g., family members and friends, organizational staff or personal healthcare professionals). Waegmember and colleagues (2008) also reported that user participation is associated with service user's readiness to engage in interpersonal interactions and their desire to function maximally within the constraints of their mental health problems.

Finally, the severity of or periodic instability ensuing from mental health problems (i.e., having a psychotic episode, low energy levels) affecting service users' social functioning also deters them from interacting with others, hence from participating in community activities and in consultative forums on mental health policies (Binet et al., 2004; Kidd et al., 2007; Magliano, Fiorillo, Malangone, Del Vecchio, & Maj, 2008; Petersen, Hounsgaard, & Nielsen, 2008).

2.2.4 Conceptual models of user participation.

User participation is a social innovation in that the participation of service users in the design, delivery and evaluation of healthcare services has been recently valued and actively promoted within the public healthcare system, a direct outcome of the emergence of the democratic, patient empowerment and recovery paradigm (M. Lloyd & Carson, 2012; Nelson, Janzen, Trainor, & Ochocka, 2008). User participation in service organizations (and its potential benefits) has only recently been introduced into the community mental health domain; thus, as a social innovation, user participation continues to confront several challenges or resistance to its adoption as a practice (Bréchat et al., 2005; Nilsen, Oxman, Johansen, Myrhaug, & Oliver, 2006). Consequently, it is unsurprising to find that the empirical findings on user participation in many studies are well documented in terms of hindering factors (M. Crawford et al., 2003; Gordon, 2005; S. Stewart, Watson, Montague, & Stevenson, 2008).

Facilitating factors of user participation are less studied and often emerge only in recommendations, rather than in studies reporting empirical findings (M. Barnes, 2007; Boote, Telforda, & Coopera, 2002; Daykin et al., 2004; Diamond et al., 2003; Gordon, 2005). Most of the barriers to user participation can be categorized under the organizational level (Bennetts et al., 2011; S. Stewart et al., 2008). Other factors can also be found in the social and political levels.

There exist some theoretical frameworks of user participation that deal specifically with the following dimensions of user participation: a) the aims of user participation (Tritter & McCallum, 2006), b) socio-political and organizational structures within which user participation is embedded (Abelson, 2001), c) user participation processes (Charles & DeMaio, 1993; Gauvin, Abelson, Giamartino, Eyles, & Lavis, 2010; Guo & Musso, 2007; Tritter, 2009), and d) power relation between users/ citizen and professionals and/or decision-makers. Along the power dimension, the first and widely cited model is the ladder of participation, as elaborated by Arnstein (1969) in urban planning, followed by Charles and Maio (1993) and Hickey and Kipping (1998) in healthcare services, and Choguill (1996) in community development within low income nations.

Many other authors present conceptual models of user participation with a strong focus on the following issues: (1) equity in accessing social resources (Rifkin, Muller, & Bichmann, 1988), (2) social and organizational factors (Abelson, 2001; Thurston et al., 2005), (3) the role of the service user as citizen, healthcare consumer and principal stakeholder, (4) the means of participation (Stevens, Bur, & Young, 2003; Tremblay, 2007) and (5) the process of decision-making by consumers in health service research (Oliver et al., 2008). Concurrently, nursing scholars detail their conceptual frameworks of mental health nursing care with some emphasis on user participation (Carlyle, Crowe, & Deering, 2012; Hickey & Kipping, 1998). The recent typology of user participation is based on one comparative study across European (e.g,. England, Norway) and North American countries (Tritter, 2009).

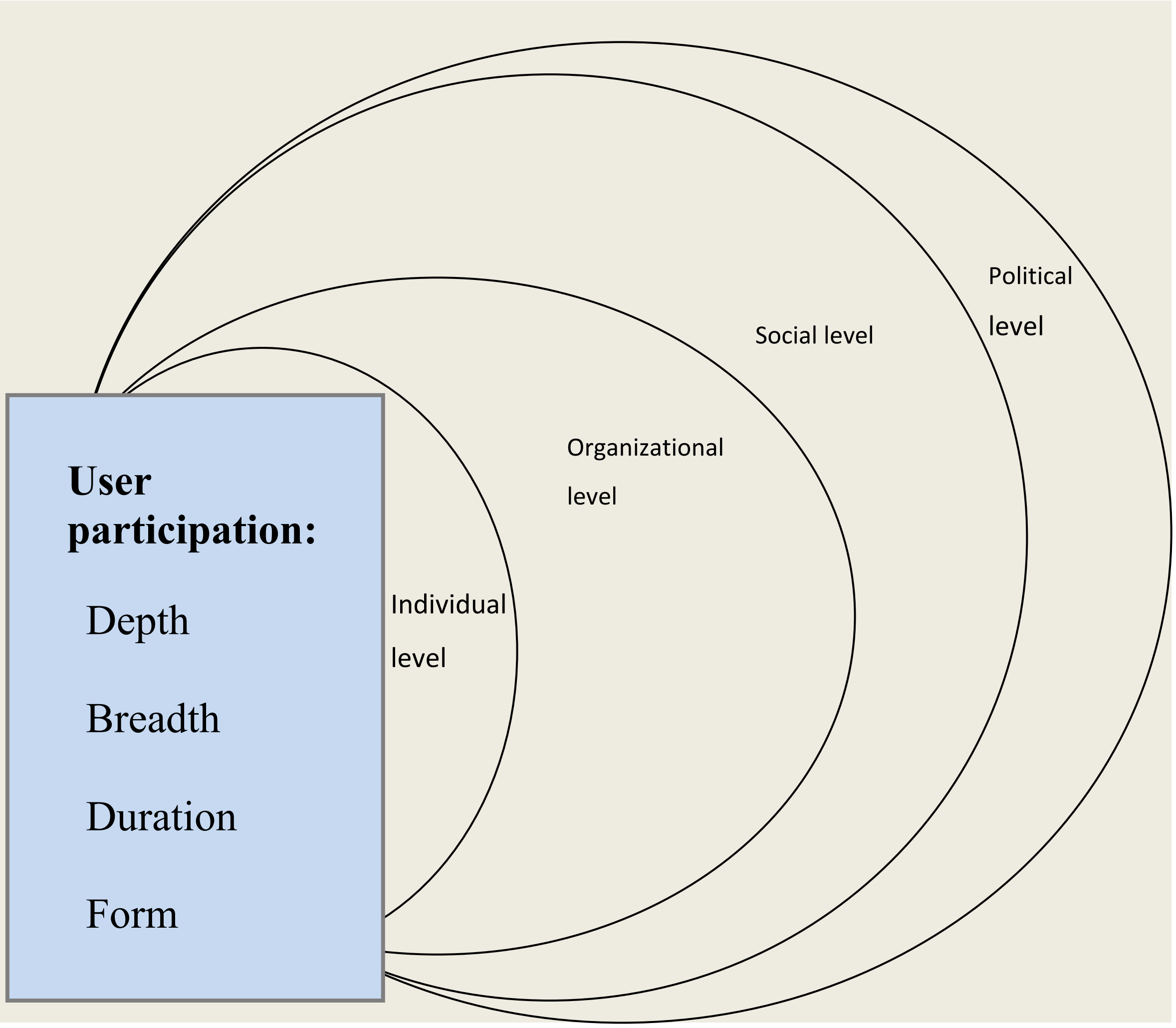
The existence of the aforementioned frameworks reflects the complexity of user participation, yet none explicates the nature of user participation within CBOs. Moreover, although CBOs are playing an increasingly major role as social and health service providers, they remain largely understudied as to their organizational structure in relation to the participation of their service users in the mental health and public health literature (Grant, 2010; Peterson et al., 2008; Taylor, Jones, Reilly, Oldfield, & Blackburn, 2010). This study is an attempt to understand user participation in CBOs (within which few nurses are currently working).

Taking into account this literature review, Figure 1 was designed to illustrate user participation in mental health community-based organizations based on the ecological approach (Kloos & Shah, 2009; Moos, 2003). User participation is defined as a social and interpersonal process that the mental health service user undertakes within a CBO. As depicted in Figure 1, this schema comprises two essential components illustrated by (1) the rectangle depicting user participation (its characteristics and form) and (2) four circles depicting the four levels within which the factors influencing user participation in CBO are situated: political, social, organizational and individual (Hernandez et al., 2010). As mentioned earlier, this schema of user participation is inspired by the ecological approach (Kloss & Townley, 2011; Pelletier et al., 2013; Richard et al., 2011). This ecological approach has been utilized by Kloss and Townley's study (2011) on the impact of community settings and housing facilities on the mental wellbeing of individuals living with mental health problems as well as Richard and colleagues (2011), in their review of studies on the promotion of health lifestyles.

Thus, to address the first study objective—to document and describe the nature of user participation—user participation in mental health CBOs was viewed according to its characteristics: depth (i.e., the degree of service users' penetration into a CBO's organizational structure), breadth (i.e., the extent of user involvement in a CBO's decision-making processes, which is closely associated with the number of service users present during decision-making instances), duration (i.e., the length in time that service users participate in the organization of CBO services), and form (i.e., the user as recipient of information [from CBO staff/managers], consultant or partner).

In line with the study's second objective—to explore the factors that hinder or facilitate user participation—various factors were classified according to four levels: political, social, organizational and individual. The political level is defined as the context within which the government and its representative bodies (e.g., the Ministry of Health and Social Services) influence the organization of mental health services within a mental health CBOs. Thus, governmental policies regarding CBO funding and promotion of user participation within a CBO's organizational structure must be considered. The social level is defined as the context in which the recovery phenomenon influences user participation. The organizational level is defined as the context within which: (a) community mental health nurses interact with service users in relation to the latter' participation in the CBOs and (b) the CBO, as an entity, in combination with its staff and managers interact among themselves and with the service users to organize services. The individual level is defined as factors related specifically to service users, such as their socio-demographic characteristics, their recovery process, and their motivation to participate in the organizational structure of a CBO.

Figure 1: Schema " User participation in mental health CBO"



Chapter III

Method

3.1 Study design

This study's design is that of an exploratory study. Since the literature review reveals few empirical studies on the nature of user participation within the context of mental health CBOs, the general objective of this study is to explore the complexity of user participation and to document empirically the multiple levels of influencing factors on user participation (Creswell, 2007). The research consisted of two phases. The objective specific to the first phase was to ascertain the nature of user participatory activities across a population of mental health CBOs situated in a specific urban district of Montreal serviced by a psychiatric teaching hospital. The objective of the second phase was to explore different elements (e.g., form of user participation) of user participation as outlined in the literature review and the factors found to influence it across different levels (i.e., political, social, organizational and individual) within two CBOs showing constrasting results in terms of service user participation.

In its first phase the researcher collected data by the administration of a questionnaire. Indeed, central to the first phase was the administration of a questionnaire entitled "Adapted User Involvement Questionnaire" (French version) to the CBO directors who agreed to participate in the study. This questionnaire was adapted from Diamond's User Involvement Questionnaire (Diamond et al., 2003) (see Appendix 3[a]) and translated by the student-researcher and her supervisors (see Appendix 3 [b]). The questionnaire focuses specifically on the nature of user participation within the hierarchical organizational structures of CBOs: from service users' participatory activities in daily CBO services, side by side with CBO staff, to their participation in the CBO's governing board. Moreover, it operationalizes user participation as service users' involvement in the organization of CBO services (design, planning, delivery and evaluation) as well as in the management of CBO staff.

Additionally, archival data (e.g., CBO websites, annual reports) were analyzed as a secondary source of complementary data in order to extract data about the organizational characteristics of the participating CBOs (e.g., the number of seats reserved for service user on the BOD, the plethora of their services, actual volume of participatory activities).

The study's second phase examines in depth the facilitators and inhibitors for user participation from the perspectives of CBO directors, members of the Board of Directors (BOD), CBO workers and CBO service users from two selected CBOs. Using the scores obtained by the administration of the questionnaires to CBO directors in combination with the archival data analysis and the interview data with the CBO directors, two CBOs were selected according to a maximum variation sampling strategy, that is, one CBO with a high level of user participation versus another CBO with a more limited level of participation (Patton, 2002).

3.2 The first phase of the study

This section describes: 1) the study population, 2) the exclusion and inclusion criteria, 3) the recruitment process of CBOs, 4) characteristics of participating CBOs, 5) the scores obtained by the administration of the Adapted User Involvement Questionnaire.

3.2.1 Study population of the first study phase.

The study population of CBOs comprises 23 CBOs located within the predefined territory serviced by a university psychiatric teaching hospital. These CBOs were identified from the list of two umbrella organizations (*Réseau alternative et communautaire des organismes en santé mentale de l'Île de Montréal* – RACOR – and *Regroupement des ressources alternatives en santé mentale du Québec* – RRASMQ), both of which regroup mental health CBOs located within the target area. The rationale for selecting CBOs linked to a university psychiatric teaching hospital was based on two facts: (1) given the existing ties between these CBOs and the hospital, it was likely that the CBO directors would be more amenable to participating in a study conducted by a student- researcher under the supervision of two professors affiliated with the hospital's research centre; and (2) no known published study has been conducted on user participation in CBOs in this community. Furthermore according to the statistical data compiled for the year 2005-2006, the residents of this community were shown to have a higher rate of mental health care utilization than the general Montreal population, as evidenced by the following facts: 7.7% of the people residing in this district had at least one medical consultation for their mental health problem in comparison with 7.5% of general Montreal population (Agence de la santé et des services sociaux de Montréal, 2008). The residents of this community had a higher rate of emergency room visits for psychiatric problems (4% vs 3%). Six percent of the people residing in this community required hospitalisation for mental health problems as compared to 5% of the general Montreal population (Agence de la santé et des services sociaux de Montréal, 2008*)*.

3.2.2 Inclusion and exclusion criteria.

This section describes the inclusion and exclusion criteria.

a) Inclusion criteria.

The inclusion criteria for the sampling of 23 CBOs were:

a. The organization is situated within the district served by the psychiatric teaching hospital, an affiliate of the *Université de Montréal*.

b. The organization has legal status as a moral entity under Quebec law (article 334 of the Health and Social Service Act).

c. The organization operates within the domain of community mental health, offers direct services to users and receives a government subsidy.

d. The organizational structure formally comprises an executive director, staff and users.

e. The director is accountable to the BOD.

b) Exclusion criteria.

As the intent of this study is to examine the nature of service user participation within mental health CBOs, the exclusion criteria primarily address those organizations that do not offer services to users as follows:

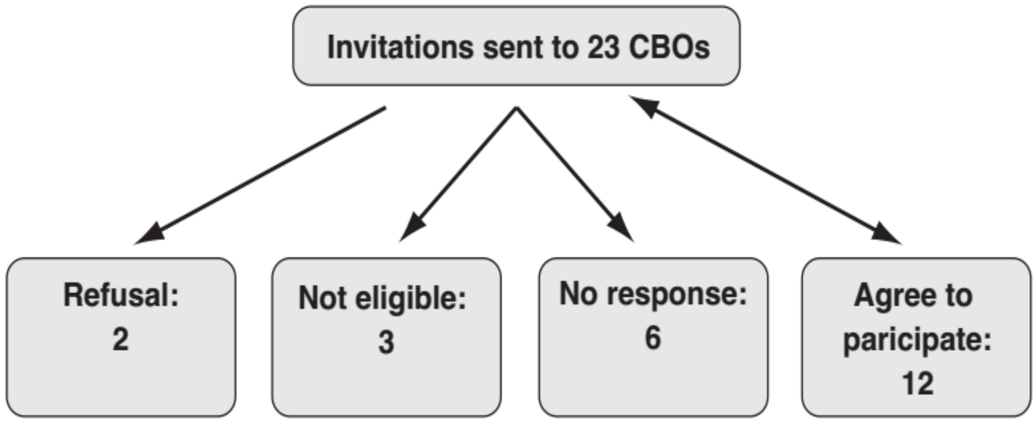
a. Any CBO that represents a grouping of local CBOs at the Regional Health Agency or Ministry level (e.g., *Réseau alternative et communautaire des organismes en santé mentale de l'Île de Montréal* – RACOR, *Regroupement des ressources alternatives en santé mentale du Québec* – RRASMQ) was excluded.

b. CBOs that offer support services specifically to service users' family members and significant others were excluded because the study focuses exclusively on the mental health service users themselves and their participation within the CBO and not on the involvement of users' caregivers or their family members in CBO services.

3.2.3 The recruitment process of first study phase.

As an initial contact, general information about the study and a consent form were mailed to the directors of each CBO (Appendix 4: a, b). Within two weeks of the mail-out, the student-researcher contacted director by phone to inquire about his or her interest in participating in the study and to provide a detailed verbal description of the study (e.g., study objectives, data collection procedure). Twenty three CBOs received invitations to take part in the study. Twenty CBOs met the inclusion criteria; among these, the directors of 12 CBOs consented to participate in the study, giving a response rate of 60% (Diagram 1).

Diagram 1: Participating CBOs



The sampled CBOs were coded as CBO A to CBO K. They offer direct services within the three types of mission: (1) community integration, (2) socio-professional integration and (3) advocacy. Examples of person-to-person services within the first two missions are as follows: recreational activities, personal development classes or adapted workplace. The third mission (advocacy) of one particular CBO is viewed as CBO staff supporting service users in accessing health care and social services adapted to their needs. The participating mental health CBOs have been in existence for more than a decade. Further characteristics of the sampled CBOs will be described in chapter IV.

3.2.4 Data collection during the first study phase.

The student-researcher employed two data collection devices: the Adapted User Involvement Questionnaire (Diamond et al., 2003) and the Analytic Grid of archival data. The questionnaire was chosen based on its parsimony and clarity in operationalizing the participatory activities of service users within the organizational structure of the CBOs.

The second device, the Analytic Grid of archival data (see Appendix 5), was elaborated by the student-researcher. It is a table that is used to examine public documents for written text segments indicating evidence of users' participatory activities in the organization of CBO services and any factors that facilitate or hinder user participation. The examined public documents were CBOs' mission statements, promotional hand-outs and /or videos, annual reports and CBOs' annual programmes of service. Concurrently, the websites of the participating CBOs were examined and analyzed using the same analytic grid.

a) The Adapted User Involvement Questionnaire.

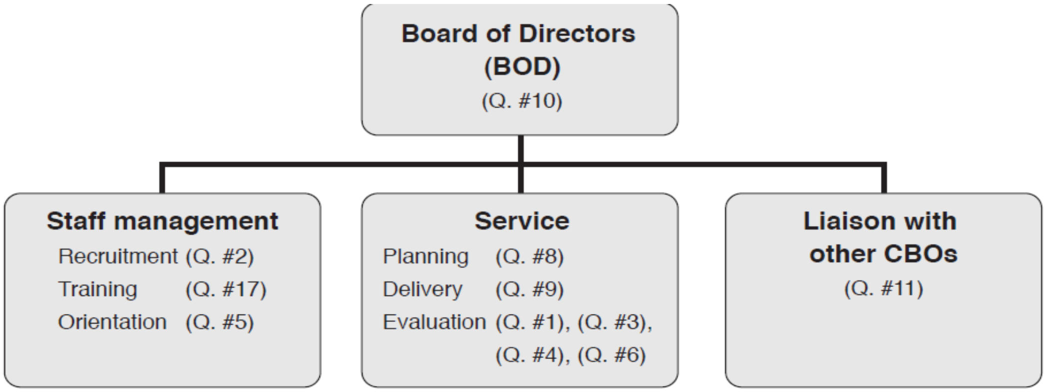
Face-to-face interviews were arranged with the directors of those organizations consenting to participate in the study. The interviews were recorded and transcribed by the student-researcher to obtain the contextual information pertinent to explicating the director's response (e.g,. the directors' statement about organizational factors that may influence his or her response to each question of the questionnaire). The 12 interviews with the directors or their representatives were conducted essentially to query them about the items in the Adapted User Involvement Questionnaire. However, the format of these interviews was semi-structured since the directors were invited to explain the contextual factors or rationales that led to their responses. During these 12 interviews, the adapted French version of the User Involvement Questionnaire (Diamond et al., 2003) (Appendix 3 [b]) was administered. The average duration of the interviews was sixty minutes.

The original User Involvement Questionnaire was conceived by Diamond, a clinical psychologist, in partnership with a local network of service users and researchers. It has been used as an audit tool to survey the level of implementation of service user involvement standards across a large mental health rehabilitation service centre located in Nottingham, England (Diamond et al., 2003). Service user involvement standards, as established by the Nottingham Health Trust (the equivalent of the 17 Agencies of Health and Social Services in Quebec), specify that service users are to be involved in all areas of public mental health service institutions: staff recruitment, regular evaluation of service user needs, staff training on service user involvement, and service evaluation, design and delivery. Diamond and colleagues (2003) argue that the face validity of this questionnaire resides in the fact that service users were involved in the design, modified substantially the questionnaire, and administered it themselves during the interviews with the organization's staff, managers and other service users. No other information was provided on the psychometric properties of this instrument by Diamond (2003).

Keeping in mind that the original questionnaire was intended for staff of a public healthcare institution in England, two questions were deemed irrelevant and eliminated. The first, which focused on the service users' role in modifying their treatment plan in the hospital setting, was not pertinent since this study focuses on CBOs. The second, which related to staff contact with the advocacy team (equivalent of the service users' committee in Quebec hospitals), was removed due to the absence of an equivalent advocacy committee in Quebec CBOs. One question on service users' meetings was modified in order to clarify the purpose of these meetings. In the modified question, the purpose of the service users' meetings was specifically defined as a meeting to discuss the provision (design and execution) of CBO services in order to exclude service user meetings intended to promote informal socialization. Three new questions were also added to the adapted version: the official role of service users on the BOD, the service users' role in service delivery, and the service users' role in networking with other CBOs and public mental health institutions.

Consequently, the adapted version of the directors' questionnaire comprised 11 questions, answerable with "yes", "no" or "non-applicable," based on the four dimensions of user participation (Diagram 2): (1) the official role of service users on the governing board of directors (question 10); (2) in staff management issues (i.e., question 2: staff recruitment, question 7: staff training, and question 5: staff orientation); (3) in the organization of CBO services (i.e., service question 8: planning, question 9: service delivery, and questions 1,3,4 and 6: service evaluation); and (4) in networking with public mental health institutions and other CBOs (question 11).

Diagram 2: Four dimensions of the Adapted User Involvement Questionnaire



a) Analytic document grid

Public documents from the CBOs (e.g., websites, the annual reports) constituted a second data source. These documents were reviewed in order to locate segments related to the following information: CBO services, existing organizational structures that may influence user participation (e.g., presence of user meetings), actual roles of service users within the organizational structure, types of participatory activities (i.e., service planning, delivery and evaluation) that service users are involved in, and the actual actions of staff and CBO directors associated with these participatory activities. These two methods (i.e., questionnaire and analytic grid) of data collection were combined in order to obtain the most representative nature of user participation existing in the participating CBOs. For example, in the case of a CBO whose director responded positively to the question about user involvement in staff recruiting, the annual report of this CBO also reported the presence of service users on the selection committee for hiring staff.

3.2.5 Data analysis of the first study phase.

This section presents the data analysis of the archival data and scores from the Adapted User Involvement Questionnaire. The eleven-item Questionnaire addressed the four aforementioned dimensions of user participation. The responses from the directors were scored as follows: 0 (zero) for a negative response and 1 for a positive response; “non-applicable” responses were discarded. The final score for each CBO was obtained by adding the response scores and dividing the result by the number of questions applicable to that specific CBO.

The final scores were deemed to reflect the nature of user participation in the organizational structure of each CBO and were plotted on a continuum from the lowest to highest score. Two CBOs, one with a high (CBO F) and one with a low (CBO G) user participation score, were invited to take part in the second phase of the study. The decision as to which CBOs to invite was based on two criteria derived from the analyses of the CBOs' archival data: 1) a commonality of services within their stated missions to provide community integration services and 2) their similarities in terms of their organizational structures and service design, delivery and evaluation.

The transcripts of the interviews with the CBO directors were also analyzed to ascertain the contextual factors behind their answers to the Questionnaire. Most of the contextual factors were ascertained to be at the organizational level (e.g., low staff turnover leading to the fact that the question of user participation in staff recruiting is not applicable in certain CBOs).

3.3 The second phase of the study

The objective of this phase was to explore, in depth, user participation within two contrasting CBOs and the factors that influence user participation within each.

3.3.1 The inclusion criteria of the second phase study.

The inclusion criterion for the directors, governing board presidents and staff was the length of employment or involvement in the CBO, defined as a minimum of six months. This criterion of the duration of employment was determined because some authors (Hughey et al., 2008; Turner, 2008) in organizational sociology concur that the newly hired employee and manager may require this length of time to become familiar with the organization (its structure, its staff, the relations between staff members).

The inclusion criteria for the service users was 18 years or older, being mentally stable (as assessed by the CBO staff), residing in the community, being autonomous in the activities of daily living, involved in the CBO for a minimum of six months and willingness to share their experience vis-à-vis the CBO. Study informant inclusion criteria were based on other user participation studies in the literature (Nelson et al., 2001; Perkins et al., 2007). Further, scholars (Church et al., 2008; Duperré, 2010; Guberman et al., 2004; Nelson, Ochocka, Janzen, & Trainor, 2006), have correlated informants' knowledge regarding a CBO's organizational structure and activities to the duration of their respective roles within a given CBO. The service users' stability in mental health was used as an inclusion criterion because some studies reported that service user discussions about their lived experiences could be simultaneously empowering and emotionally laden (Lewis, 2012).

3.3.2 The recruitment process of the second study phase.

When they signed their consent to participate in the first phase of the study, the directors of the selected CBOs were also made aware of the second phase of the study. A second letter and information sheet was mailed to the two selected CBOs [see Appendix 7 (a), (b)] Two weeks later, the student-researcher contacted the directors by phone to arrange an interview.

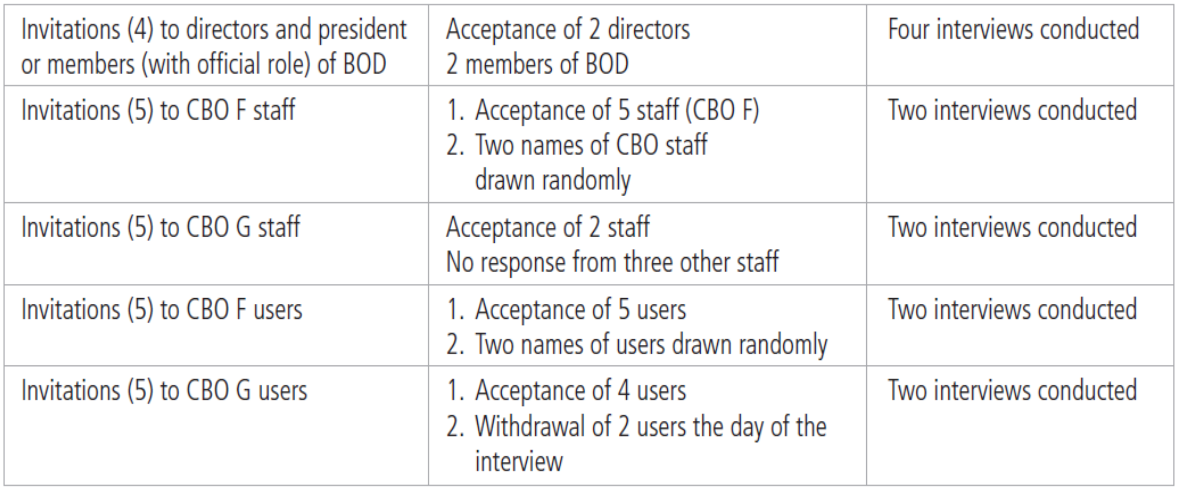
The packages, containing the information sheet explaining the study and the consent forms, were mailed to the president of the BOD for CBO F (see Appendix 8). However, because the director of the CBO G is also the president of the BOD, the director suggested the BOD secretary as an alternative study participant. The CBO staff information package was given to the staff coordinator in CBO G and the CBO receptionist in CBO F.

Within two to four weeks of mailing the information package, the student-researcher contacted the CBO F president of the BOD, BOD secretary of CBO G and the staff of both CBOs by phone to inquire about the informants' interest in participating in the study and to schedule an appointment for the interview. For the service users, in CBO F, the CBO staff approached service users regarding their interest in participating in the study. Subsequent to their agreement, the student-researcher phoned both to schedule an interview.

In CBO G, a CBO staff introduced the student-researcher to service users during a large informal gathering, subsequent to which the student-researcher was approached by service users interested in participating in the study; the ensuing interviews between service users and student-researcher were scheduled in person.

Five CBO staff of low-scoring CBO G received invitations to participate; two responded positively. In high-scoring CBO F, all five staff agreed to participate; however, for parity with the CBO G staff, two staff names were selected randomly. In the users' group, five users of high-scoring CBO F also agreed to participate and two names were chosen randomly. In low-scoring CBO G, four users accepted the invitation to take part in the study, but two changed their mind on the day of the interview. Table I presents detailed information on the recruitment process and the final numbers of participants for each category.

Table I: Recruitment during the second phase of the study



Invitations (4) to directors and president or members (with official role) of BOD	Acceptance of 2 directors 2 members of BOD	Four interviews conducted
Invitations (5) to CBO F staff	1. Acceptance of 5 staff (CBO F) 2. Two names of CBO staff drawn randomly	Two interviews conducted
Invitations (5) to CBO G staff	Acceptance of 2 staff No response from three other staff	Two interviews conducted
Invitations (5) to CBO F users	1. Acceptance of 5 users 2. Two names of users drawn randomly	Two interviews conducted
Invitations (5) to CBO G users	1. Acceptance of 4 users 2. Withdrawal of 2 users the day of the interview	Two interviews conducted

A total of 12 semi-structured interviews were conducted with two directors, one president and the secretary of the BOD, 4 staff (two from each CBO) and 4 service users (two from each CBO). The average interview length was 45 minutes. Study informants chose the locale for the interviews. All interviews with the CBO directors and staff took place at the CBO headquarters. Interviews with three service users were conducted away from the CBO premises, and for one service user from CBO G on the CBO premises. Eleven interviews were recorded and transcribed *verbatim* by a professional French-speaking transcriptor. There is no transcript for one interview since the informant refused a recording. Accordingly, the student-researcher took notes of the informant's responses. Additional meetings with the directors, presidents, staff, and service users were not required.

3.3.3 Data collection of the second study phase.

During the second phase of this study, the student-researcher interviewed the three different groups of key informants from each CBO. Based on the schema of user participation (Figure 1) and the findings of the literature review on the determinants of user participation, general questions about user participation and its determinants were elaborated by the student-researcher. These questions involved the numbers of service users involved in organizational activities, the specific activities, the form of their participatory role. Addtionally, the informants were asked by the student-researcher to elaborate on the facilitating factors and challenges at the political, social, organizational and individual levels that have an impact on user participation. The use of these questions was not intended to limit or structure the informants' responses. They served to guide the student-researcher in her efforts to harmonize her questions during the semi-structured interviews with the three different groups of informants across the two CBOs. More importantly, the informants were invited to talk extensively about their lived experience of user participation in their respective roles of director, member of the BOD, CBO staff and service user.

The following section explicates the questions addressed when possible to the three different groups of informants. The first group of informants: board members (i.e., director, president, user representative) were questioned about the participatory activities of the user representative on the BOD, interpersonal interactions among board members and other individual and organizational factors that enabled or hindered service user participation on the BOD. Looking more broadly (beyond the BOD) at user participation in CBO activities, the directors were invited to comment on their perspective about user participation within the structure of service design, delivery and evaluation. Queries were also made regarding possible facilitating factors and challenges at the political, social, organizational and individual levels that influenced user participation in the two CBOs.

Staff were queried on the specific participatory activities of service users (e.g., conducting/facilitating workshops with other service users). Questions about influencing factors, specifically at the organizational and individual levels, were asked.

Service users were queried regarding their participatory activities, their actions and responsibilities linked with these activities and their specific role. Questions included perceptions regarding their interactions with other service users, the director, staff, organizational level, and individual factors that might influence their participation. Moreover, service users were invited to discuss at length the outcome or the influence of their participatory activities on their recovery, as well as on the organization of CBO services (see Appendices 11, 12 and 13 for schedule of semi-structured interviews with the three groups of informants: the administrative team, staff and service users).

3.3.4 Data analysis of second study phase.

As outlined in chapter II, user participation within CBOs might be explored at several levels: the individual, organizational, social and political levels. Codes were constructed based on the research questions regarding the nature of user participation and its determinants. In order to respond to the first research question, codes were applied to segments of *verbatim* that identify the constituting elements of user participation at the individual level. Guided by the schema on the nature and determinants of user participation, transcripts were coded and grouped into elements (i.e., organizational, social and individual levels). As the coding of transcripts of all informants was performed, some codes were retained and new codes were added and regrouped into new themes with their constituent sub-themes and elements. Chapter IV presents in detail the organization of coded data into elements, sub-elements, sub-themes and themes.

As there are three different groups of informants (i.e., the administrators, staff, and service users), data analysis was conducted separately for each group. Coding of text segments and reorganization of coded segments was done using the QDA miner software package (version 3.1). Included in the data sources are the student-researcher's field notes on the physical space of the interview and the interviewee's body language.

Inspired by the analytic procedures described by Miles and Huberman (1994), the process for coding the transcripts was as follows: (1) data immersion (i.e., intensive reading and rereading of the interview data, reflection on its meaning and writing descriptive memos), (2) the organization of transcripts into segments, (3) the writing of memos (descriptive, inferential) on codes, (4) the construction of a list of codes, (5) the writing up of code definitions, (6) the coding of segments according to the list of the codes, (7) codes are regrouped into common sub-elements (e.g,. specific participatory activities of the service user) with associated *verbatim*, (8) the regrouping of sub-elements into the elements with attached *verbatim* segments, (9) the regrouping of elements into subthemes with attached *verbatim* segments, (10) the writing up of relations between the subthemes to identify themes, (11) the construction of different graphical diagrams illustrating links between sub-elements, elements, subthemes and themes, and finally (12) an integrated diagrams of themes and their constituent subthemes, elements and sub-elements was constructed based on the ecological approach (Pelletier, Davidson, Roelandt, & Daumerie, 2009; Sanders, Fitzgerald, & Bratteli, 2008).

With input from the supervisors, the construction of codes was undertaken by the student-researcher on the basis of the schema of user participation within CBOs and the literature review on its determinants. The student-researcher coded all of the interview transcripts. Intra-coder reliability (Miles & Huberman, 1994) was done by the student-researcher throughout the data analysis process for each group of informants. An interview transcript from one informant from each group was coded twice after all the transcripts for each group had been coded. The reason for the second coding of each transcript was to determine intra-coder reliability, which might be influenced by the passage of time and the diversity of informants' perspectives (Miles & Huberman, 1994). In this study,the intra-coder reliability value of 0.87 has been found to be reasonable according to the nursing and health literature (Jones, Turner, Singleton, & Ramsay, 2009 ; McKinley & Middleton, 1999). Moreover, in order to assess inter-coder reliability, coding of a transcript from a long interview with one of the informants (30 pages of dense data) was undertaken by one of the supervisors. The inter-coder reliability was found to be 83%, which is deemed acceptable (Creswell, 2007; Miles & Huberman, 1994). The retaining of codes, the introduction of new codes, the regrouping of these codes into sub-elements, elements, subthemes and themes were discussed during meetings between the student-researcher and the two supervisors. Any divergent opinion about the sub-elements, elements, subthemes and themes was discussed until a consensus was reached among the sudent-researcher and her supervisors.

As recommended by Miles and Huberman (1994), data analysis was undertaken once the interviews with the CBO directors were finished so as to refine the questions addressed during subsequent interviews with the other groups of informants.

3.4 Ethical considerations

The service users are considered members of a vulnerable subpopulation due to their mental health problems; hence, the recruitment process has to be performed with much attention to their mental health status. Thus, the recruitment of user informants was undertaken with the assistance of CBO staff as intermediaries because of their familiarity with and knowledge of the service users' mental health status. Moreover, as an additional step, the CBO staff acquired the service users' permission for the student-researcher to approach them (see Appendix 9). Furthermore, the student-researcher obtained information from CBO staff regarding the service users' mental health stablility before she could approach service users for their acceptance to participate.

The interview was conducted only after the service users granted the student-researcher permission to invite them to take part in the study. An intentional delay between the granting of permission, the telephone or in-person follow-up and the scheduled interview allowed the user informants ample opportunity to reflect on the decision and to change their minds without undue pressure from the CBO staff. Additionnally, the student-researcher was reassured by the CBO staff of their presence and support in the case if any adverse incident would happen during or after the interviews with user-informants. No adverse event occurred during the interviews.

Based on the principles described by the Tri-Council Policy Statement (2005), respect for human dignity was demonstrated through full, upfront disclosure about the study and the study's objectives. The commitment of study participants was explained in the introductory letter and again as part of the student-researcher's oral presentation during the first interview. Participants were asked to sign a consent form only after the student-researcher ascertained that user informants understood the study's aims, the structure of the interviews and that their consent to participate was of their own choice.

The study protocol was examined and approved by the *Comité d'éthique de la recherche en santé de l'Université de Montréal* [Ethical Review Board of the *Université de Montréal*] before the first contact with the CBO director was initiated. Informants were assured of the confidentiality of their responses. Participants were informed of their right to stop the interview at any time. Tapes, transcripts and the list of contact people will be kept in a secure location for seven years. Participants were assigned numbers; no names were retained. A small monetary donation ($25) was offered to the service users in order to compensate for expenses (e.g., transport cost) related to their participation in the study.

Chapter IV

Results

This chapter presents the findings of the study. The first part of this chapter describes the findings of the first phase. The second part of the chapter looks at the findings of the second study phase.

4.1 Results of the first study phase

4.1.1 CBOs' characteristics.

Three data sources contributed to developing an overall portrait of the participating CBOs: (1) an in-depth analysis of the 12 CBOs' websites; (2) their annual reports for 2009-2010, except for one CBO for which only the 2006-2007 report was available; and (3) the recorded interviews between the CBO directors (or their representative) and the student-researcher. Table II, a synthesized analysis of the archival data, presents the CBOs' characteristics relative to the following dimensions: operational budget, mission, number of staff, number of members, type of services, and number of users working as staff.

The sampled CBOs represented three types of mission categories: (1) community integration, (2) socio-professional integration and (3) advocacy (individual and collective). Eleven CBOs pursued one or both of the first 2 mission categories, which are more individualized in nature compared to the third, advocacy. Only one CBO pursued advocacy as a mission.

Based on the description of CBO services, community integration as a mission objective has diverse applications. Some CBOs defined it as providing a secure, autonomous or semi-autonomous place of residence as opposed to institutionalization) for service users with persistent and serious mental health problems (CBOs G and H). Once housing and food needs are met, for some CBOs community integration also includes the provision of services such as self-development activities, social skills enhancement programmes and recreational or artistic activities (e.g., CBOs A, D and H).

The mission objective of socio-professional integration was found in the social mandates of five CBOs providing pre-employment training and adapted workplace environments (referred to as "*plateau de travail*" in French) tailored to the service users' capacities (CBOs C, G, H, K and L). Socio-professional integration, as delivered by these CBOs, also included socio-psychological support for post-secondary students having situational mental health problems during the school year. One of the CBOs pursued advocacy as a mission objective; this included individual advocacy (i.e., supporting service users to voice their concerns) and collective more politically orientated advocacy (e.g., defending the collective rights of mental health service users).

During the 2009-2010 fiscal year, 82.5% of the total governmental PSOC *(Programme de Subventions des Organismes Communautaires)* budget was distributed to CBOs on the basis of their global missions, as opposed to project-specific funding (Secrétariat à l'Action Communautaire autonome et aux initiatives sociales, 2011). The remaining 17.5% was distributed to non-recurrent projects (e.g., one CBO received funds to implement a service user committee for mental health users in a health and social service centre, referred to as a CSSS in French). All but one, the interviewed CBOs received additional funding from other sources (e.g., *Centraide*, private foundations).

The 12 CBOs have been in operation of more than a decade (ranging from 10 to 34 years of operation). On the whole, more than 2000 individuals benefit annually from services provided by these 12 CBOs. There are four CBOs that came into existence during the late 1970s, three during the 1980s and five during the 1990s. The socio-demographic characteristics (i.e., age, gender, educational level, civil status, ethnic origin, income) of their service users were too disparate to identify commonalities. The majority of the service users live in the comunity, not in psychiatric institutions.

According to all of the directors (including two staff designates) and some of their annual reports, most of these service users receive public financial assistance and can be grouped into two categories according to the impact of their mental health problem upon their activities of daily living: (1) individuals with transient or situational mental health problems (e.g., a large proportion of service users in CBOs D and F) and (2) individual living with enduring and serious mental health problems (e.g., service users in CBOs A, C, E and G). In 11 CBOs, the service users are required to pay a symbolic service user fee annually except for CBO K (which is a CBO offering adapted work environment). Some service users work as unpaid volunteers or as remunerated staff (generally these receive a small premium for assuming duties such as receptionist, maintenance worker, etc.).

In one CBO, K, service users do not identify themselves as mental health service consumers but as employees. This is reflected in the CBO's dual mandates: (1) to provide an adaptive and supportive working environment for their employees with mental health problems and (2) to produce goods in a competitive market without making a profit while concurrently upholding the CBO's social mission (i.e., to integrate service users into the mainstream workforce).

A detailed examination of the CBOs' websites and annual reports for the preceding three fiscal years yielded a large array of diverse community services that are also in constant evolution (e.g., art or computer classes, informal coffee club discussion or social-support meetings, structured self-development classes). Combined, the 12 CBOs employed a total of 103 permanent or contractual staff, who provided person-to-person psychosocial services or run group sessions for the CBO users. It was not possible to obtain the exact percentage of full-time versus part-time employees as numbers varied throughout the year because of CBO budget fluctuations. According to the 12 directors, approximately 80% of their staff were college or university graduates trained in psychosocial interventions or group animation, in addition to several years of work experience in the community..

Table II: CBO characteristics

Name	Budget (PSOC) (2009-2010)	Mission	Nb of staff (2009-2010) [1]	Nb of users (2009-2010)	Types of services	Nb of users involved in dispensing services
A	≥$100000	Community integration	1	101	Art workshop; Improvisation class Publication of in-house newsletter, bingo Summer camp	6
B	$100 000 – $199 000	Community integration	6	97	Art class Computer class “Sharing expertise” (e.g., cooking, knitting) workshop	3
C	$100 000 – $199 000	Socio-professional integration	7	159	Occupational workshop	3
D	$200000-$299 000	Community integration	6	197	Computer class Sessions of self-development and management of interpersonal interactions	0
E	$100 000 – $199 000	Community integration	4	107	Support group Anger management class Recreation activities (e.g., karaoke, bowling)	0
F	≥$400 000	Community integration Socio-professional integration	21	373	Workshop on medication management, on anxiety, support for post-secondary studies and preparing for the workforce, self-development workshop	16
G	≥$400 000	Community integration Socio-professional integration	18	583	Supervision of group homes Day centre: literacy Sport activities Internet café	18
H	$100 000 – $199 000	Community integration Socio-professional integration	60	76	Supervision of group homes Supervision of work (housekeeping, painting)	0
I	$300 000-$399 000	Advocacy	7	242	Training in mental health rights Represent users at provincial decisional level on collective causes	Not available

Table II (cont.) : CBO characteristics

Name	Budget (PSOC) (2009-2010)	Mission	Nb of staff (2009-2010) [1]	Nb of users (2009-2010)	Types of services	Nb of users involved in dispensing services
J	\$100 000 – \$199 000	Community integration	4	74	Establish friendship links between persons with mental health problems and people with no mental health problems	0
K	≥\$400000	Socio-professional integration	N/A	56	A work environment that is similar to other working environments for the general public	Not applicable
L	\$100 000 – \$199 000	Community integration Socio-professional integration	10	70	Offer training sessions to the general public and persons with mental health problems such as literacy, citizenship	0

[1] The annual reports of the 12 CBOs did not specify whether their workers are working full time or part time, except for the fact that they are of permanent status or have a renewable or non-renewable contract.

4.1.2 Participation scores.

As discussed in chapter III, user participation within mental health service organizations, as outlined by the Adapted User Involvement Questionnaire, was assessed according to four dimensions, corresponding to four subscales: (a) the official role of the service user on the BOD; (b) service users' involvement in the recruiting, training and orientation of staff; (c) service users' involvement in the planning, delivery and evaluation of services; and (d) service users' involvement in networking with other CBOs and public institutions. The 11 equally-weighted questions were used to calculate CBO's final user participation score.

Subscale scores for the Adapted User Involvement Questionnaire.

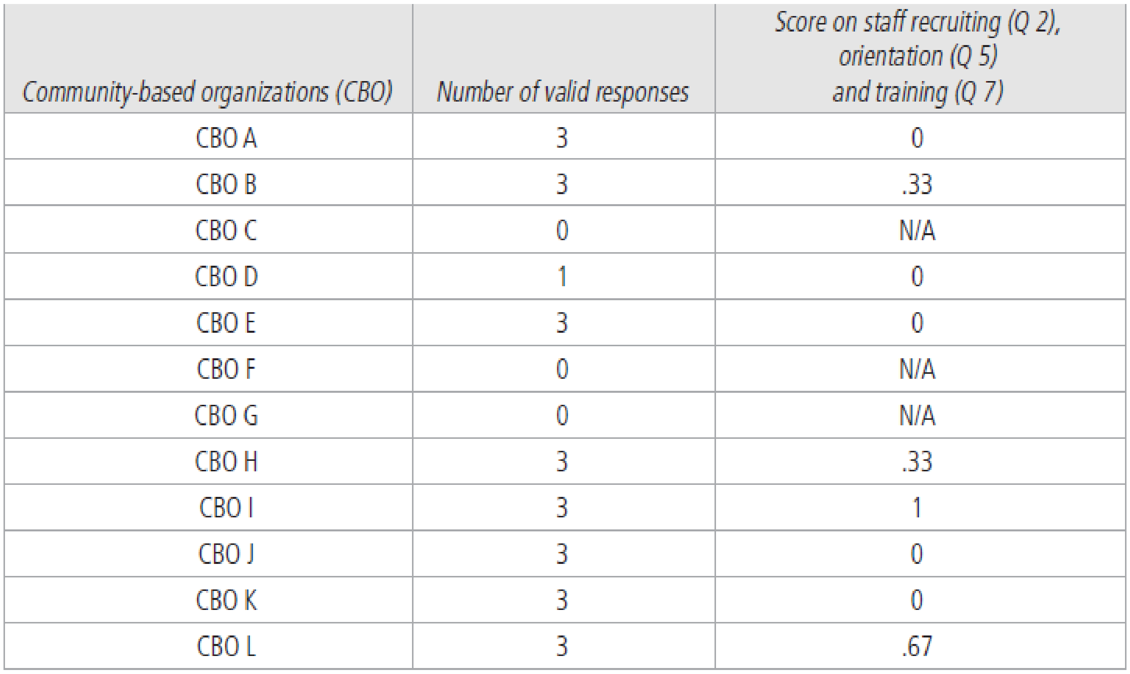
First dimension: Users' official role on the Board of Directors.

The first dimension examined the possibility for users to assume an official BOD role, such as president, vice-president, secretary or treasurer. As this was queried by only one question it is not presented in tabular format. Four out of the 12 CBOs responded positively to this question, indicating users could fulfil official BOD roles. Nonetheless, only one of the four CBOs had service users holding an official BOD role, and these users were in the two CBOs (CBO I and CBO L) that required a 100% service user membership in the BODs. CBO L offers services to persons with or without mental health problems. Additionally, these two directors had no voting power on the BOD.

Second dimension: User participation in staff management.

The results for the second dimension, user participation (UP) in the management of CBO staff, are presented in Table III. Three CBOs indicated that they had not recruited new staff in the last 5 years; this is represented by the notation "not applicable" (N/A) in Table III; thus 9 CBOs were able to respond to Questions 2, 5 and 7. Two CBOs (I and L) responded positively to Question 2, which elicited information on user participation in staff recruitment. Only CBO I indicated user participation in staff trainings; the remaining eight did not. Four CBOs affirmed that service users are involved in some aspects of staff orientation (e.g., staff's orientation to the physical workspace). Thus, based on a scoring of 1 (positive response) or zero (negative response), only 1 CBO could be said to involve their service users in staff management issues.

Table III: Scores obtained at the second subscale of UP in staff management

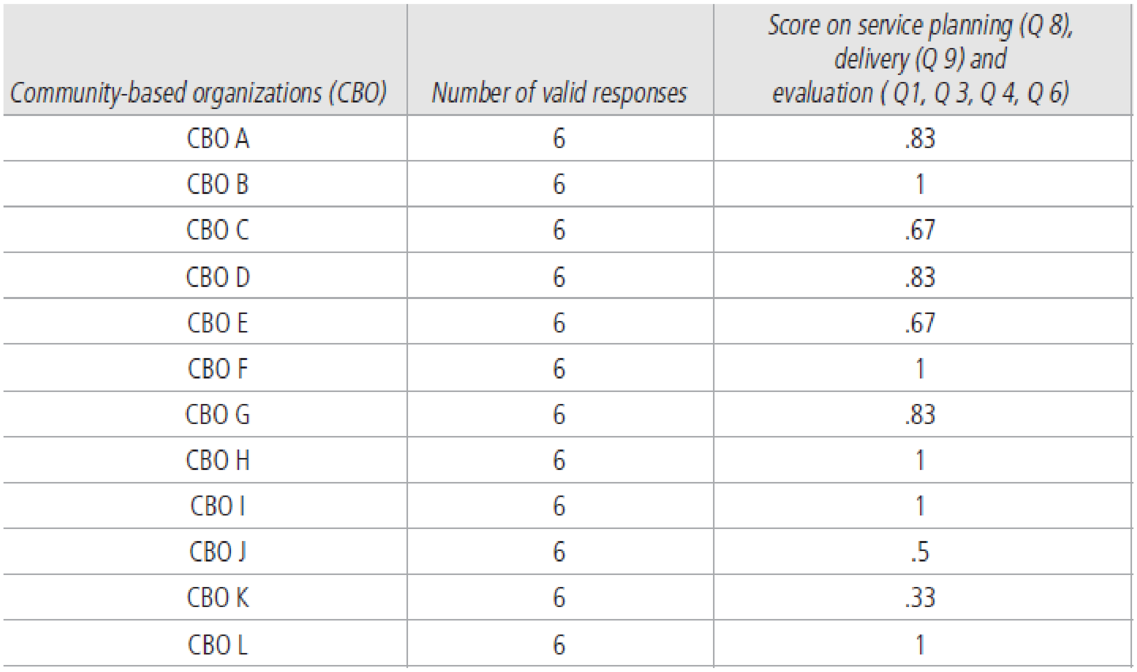


Community-based organizations (CBO)	*Number of valid responses*	*Score on staff recruiting (Q 2), orientation (Q 5) and training (Q 7)*
CBO A	3	0
CBO B	3	.33
CBO C	0	N/A
CBO D	1	0
CBO E	3	0
CBO F	0	N/A
CBO G	0	N/A
CBO H	3	.33
CBO I	3	1
CBO J	3	0
CBO K	3	0
CBO L	3	.67

Third dimension: User participation in service planning, delivery and evaluation.

The third dimension, user participation in organizing CBO services, was queried through questions 1, 3, 4, 6, 8 and 9; the results are presented in Table IV. Concerning the question on user participation in service delivery, seven CBOs indicated that users are involved in at least some form of service delivery. On the issue of user participation in service evaluation delineating users' concerns related to CBO services, all CBO directors (or designates) responded positively. Indeed, the CBO directors (or designates) emphasized repeatedly that team meetings between directors and staff centred on user concerns. Service evaluation by service users via written feedback forms, informal oral sessions or organization-wide surveys was present in ten of the CBOs**.** Eight CBOs also affirmed the existence of informal service user meetings, which are also venues for facilitating user participation in service evaluations, particularly in CBOs that have no formal user committees. In sum, all 12 CBOs included service users in service evaluations either verbally or in writing.

Table IV: Scores obtained at the third subscale of UP in service organization



Community-based organizations (CBO)	*Number of valid responses*	*Score on service planning (Q 8), delivery (Q 9) and evaluation (Q1, Q 3, Q 4, Q 6)*
CBO A	6	.83
CBO B	6	1
CBO C	6	.67
CBO D	6	.83
CBO E	6	.67
CBO F	6	1
CBO G	6	.83
CBO H	6	1
CBO I	6	1
CBO J	6	.5
CBO K	6	.33
CBO L	6	1

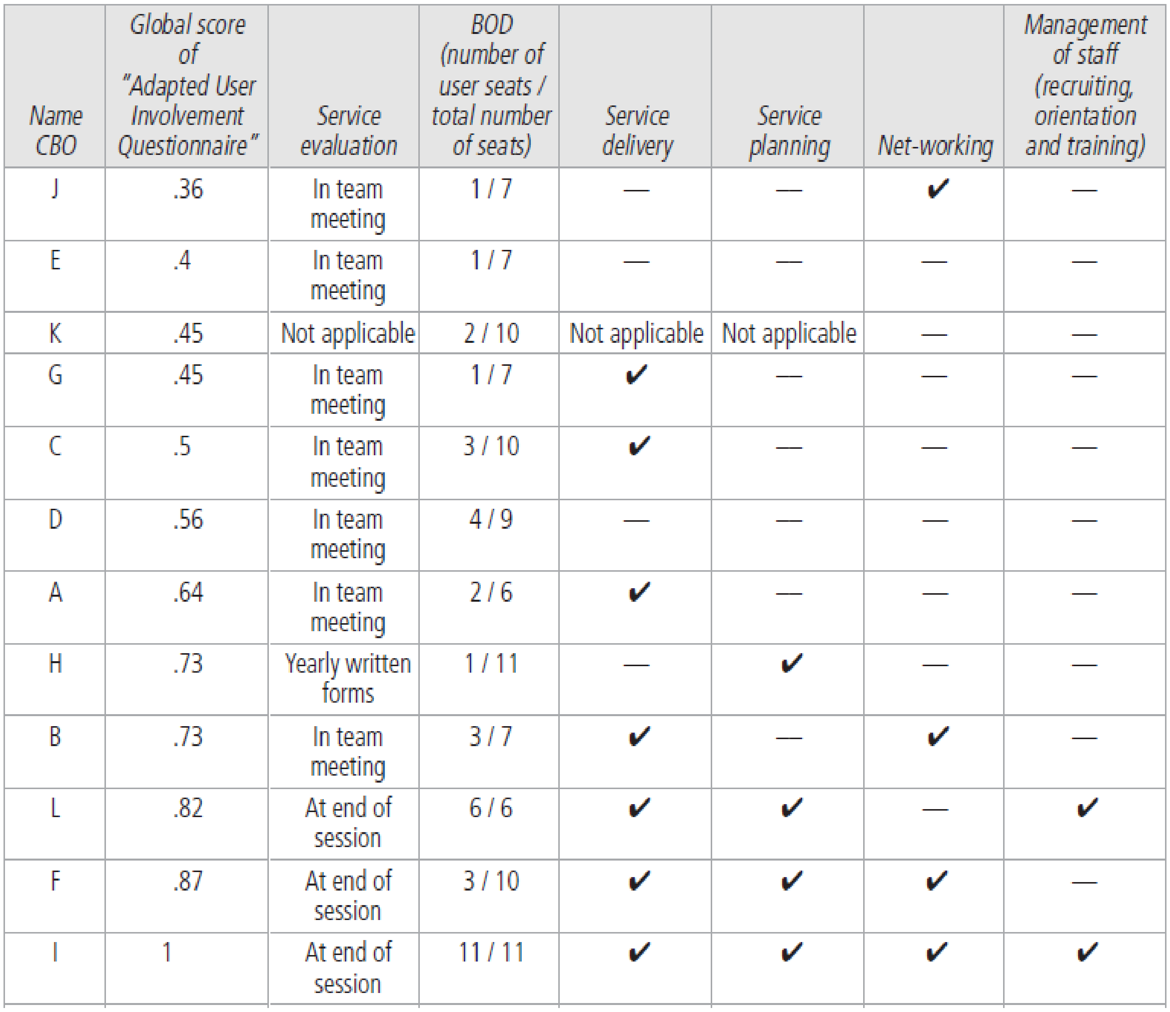
Fourth dimension: User participation in networking with other CBOs or institutions.

User participation in CBO networking has significant symbolic value. It suggests users' voices and opinions are valued and that they are trusted to represent the CBO at official public consultative forums with other CBOs and government healthcare services within the mental health domain as well as in other social service sector meetings (e.g., housing board, recreation services in the users' neighbourhood) (Panet-Raymond & Lavoie, 2008). As this was queried by only one question it is not presented in tabular format. Six CBOs asked their service users to represent them in various networking situations; for the remainder, this function was assumed by the directors or their representatives.

4.1.3 Relations between CBO scores and characteristics.

The results of the Adapted User Involvement Questionnaire revealed differences between the CBOs in term of user participation. Table V summarizes the CBO scores in relation to the CBOs' provision of user space within formal organizational structures. In other words, the extent to which users can participate in a CBO's decision-making around service planning, delivery, and service evaluation, staff selection and training, and representing the CBO in forums with other agencies. The lowest score, obtained by CBO J, indicates there is no formal space within the organizational structure for user participation. The highest score, obtained by CBO I, is exemplary of a CBO within which service users have access to and representation in all organizational structures, and specifically in the administrative affairs of hiring and training new staff.

Table V: Comparative table of CBO's final score in relation with UP



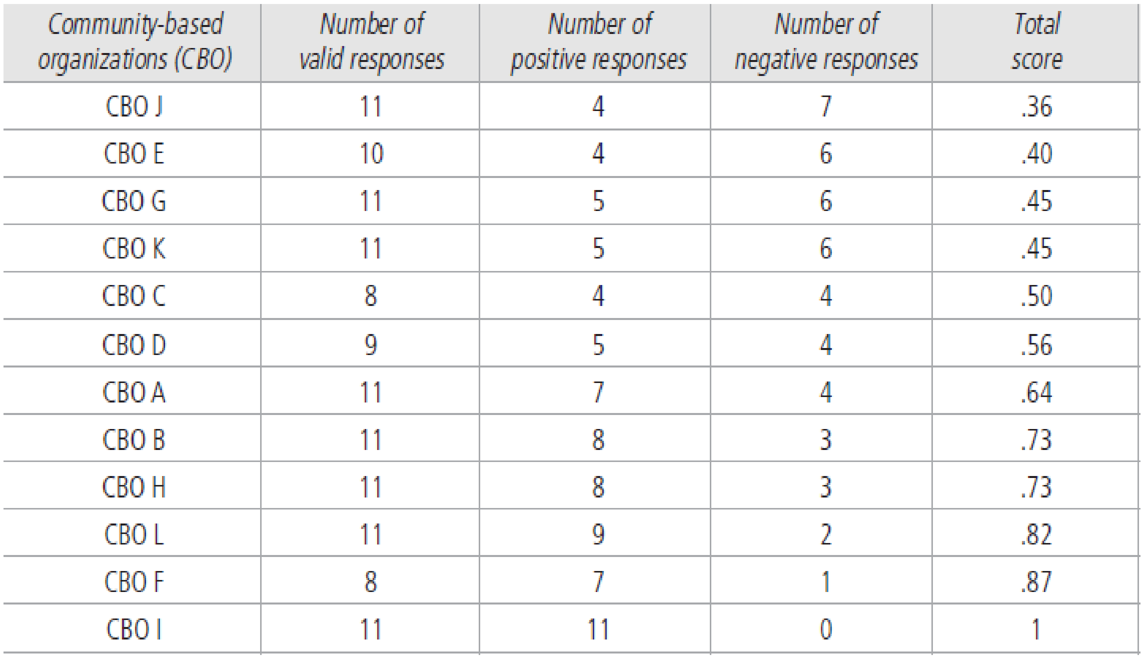
Name CBO	Global score of "Adapted User Involvement Questionnaire"	Service evaluation	BOD (number of user seats / total number of seats)	Service delivery	Service planning	Net-working	Management of staff (recruiting, orientation and training)
J	.36	In team meeting	1 / 7	—	—	✓	—
E	.4	In team meeting	1 / 7	—	—	—	—
K	.45	Not applicable	2 / 10	Not applicable	Not applicable	—	—
G	.45	In team meeting	1 / 7	✓	—	—	—
C	.5	In team meeting	3 / 10	✓	—	—	—
D	.56	In team meeting	4 / 9	—	—	—	—
A	.64	In team meeting	2 / 6	✓	—	—	—
H	.73	Yearly written forms	1 / 11	—	✓	—	—
B	.73	In team meeting	3 / 7	✓	—	✓	—
L	.82	At end of session	6 / 6	✓	✓	—	✓
F	.87	At end of session	3 / 10	✓	✓	✓	—
I	1	At end of session	11 / 11	✓	✓	✓	✓

An examination of Table V gives rise to the following observations: three of the low-scoring (i.e., score ≤.5) CBOs have only one seat reserved for service user on the BOD; conversely, all but one of the higher-scoring CBOs have reserved at least two BOD seats. Noteworthy, the difference in user participation between CBO I (highest score) and CBO F (second-highest score) is the absence of UP in staff management. It can be conjectured that UP in staff management might be one of the most relevant indicators of depth of UP in mental health CBOs (i.e., the presence of service users and their degree of involvement during decision-making instances). Service users' involvement in service planning also correlates to higher scores (.73-1) in four CBOs. However, UP in service planning is not as predominant as it is in service delivery and evaluation. Consequently, UP in service planning may be a compelling indicator differentiating CBOs with active UP from CBOs with a more passive form of UP. As indicated in the Table V, UP in service delivery predominates in seven out of 12 CBOs. A conjecture, based on these observations, is that UP can be viewed as a continuum: where, beginning at one end, UP is included in service evaluation, then service delivery and service planning, and ultimately in staff management.

4.1.4 Analysis of CBO scores on user participation.

Table VI summarizes each CBO's combined score for the four dimensions of user participation. The mean score was 0.62. The lowest score, 0.36, was obtained by CBO J, reflecting only four positive responses. The highest score, 1, was obtained by CBO I, which responded positively to all 11 questions. This table suggests that the use of the questionnaire "Adapted User Involvement" (Diamond et al., 2003) [developed originally in England] to assess the nature of UP is relevant within this study context (i.e., a Canadian urban setting) based on the finding that the global score of each CBO reflects the variation of UP depth.

Table VI: Final scores of 12 CBOs



Community-based organizations (CBO)	Number of valid responses	Number of positive responses	Number of negative responses	Total score
CBO J	11	4	7	.36
CBO E	10	4	6	.40
CBO G	11	5	6	.45
CBO K	11	5	6	.45
CBO C	8	4	4	.50
CBO D	9	5	4	.56
CBO A	11	7	4	.64
CBO B	11	8	3	.73
CBO H	11	8	3	.73
CBO L	11	9	2	.82
CBO F	8	7	1	.87
CBO I	11	11	0	1

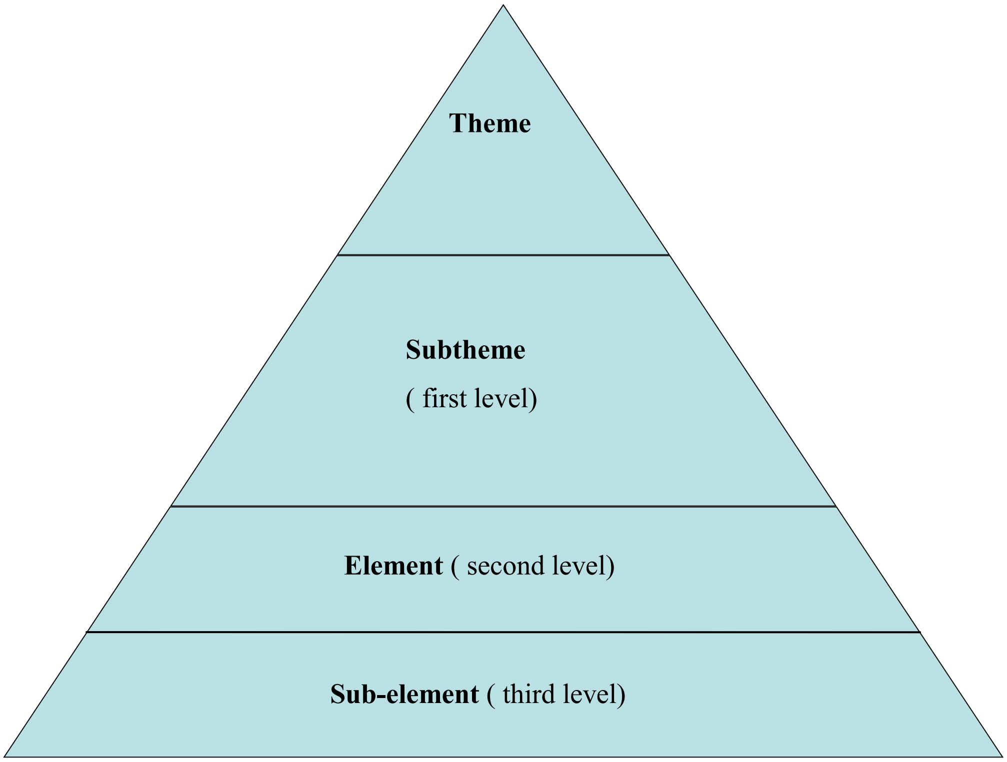
4.2 Results of the second study phase

4.2.1 Study themes.

After going through the process of code construction, coding transcripts and regrouping codes with attached *verbatim* into sub-elements, elements, sub-themes and themes, three themes were constructed based on the research questions and were found to be convergent with the raw data collected from the three different groups of informants during the second study phase. The fourth theme, the advantages of user participation, was constructed mainly from the coded segments of transcripts from the three different groups of informants across two CBOs.

Each theme has its own matrix comprising one to three levels to delineate its complexity (refer to figure 2). The first theme, the Process of user participation, is examined as interpersonal processes at the individual level; thus, it has one level or subtheme. The second theme, the Facilitating factors for user participation, and the fourth theme, the Advantages of user participation, include three levels: the individual, organizational and social levels. These three levels are identified as sub-themes that are further made up of multiple elements and sub-elements. For example, the individual level of the fourth theme is divided into four elements; one of these four elements, citizen participation, is further divided into 2 sub-elements (i.e., holding a socially-accepted role in the CBO and establishment of other social space for user participation in other CBOs and public institutions).

Figure 2: The study theme matrix



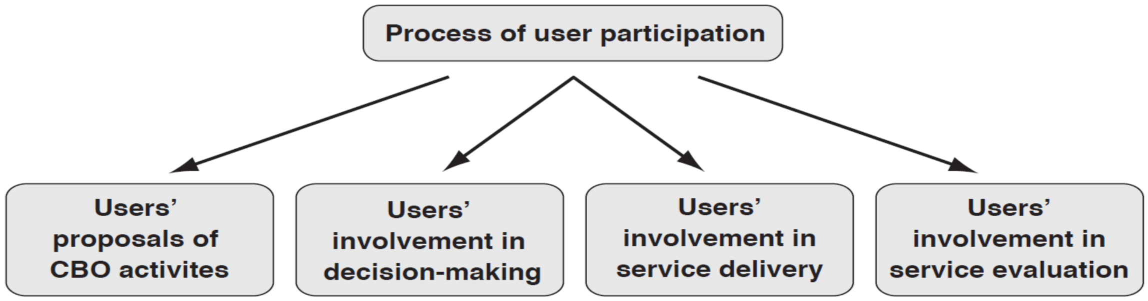
4.2.2 Description of the components of the four themes.

The following sections detail the four themes across applicable subthemes, elements and subthemes. The four themes were finalized after two rounds of coding by the student-researcher and several discussions between the student-researcher and her supervisors. They are depicted vertically and explained textually from top down in diagrams 3 to 6 to illustrate their constituent subthemes, elements and sub-elements. Each theme and its components are delineated as illustrated by quotes from the three groups of informants from CBO F, the CBO with a high user participation score (Tables VII to X) and from CBO G, the CBO with a low user participation score (Tables X to XIV).

Theme one: Process of user participation.

The first theme as illustrated in Diagram 3, the Process of User Participation, comprises four subthemes around user involvement in all aspects of service delivery from design to evaluation: users' involvement in (1) proposing CBOs' activities/services, (2) in decision-making processes regarding services, (3) in the implementation of CBO services and (4) in the evaluation of services. The four subthemes are illustrative of the actual actions as performed and described by the service users. These four participative actions were also reported by the other two groups of informants (i.e., directors and staff). This theme depicted clearly the service users' actions in terms of their involvement in the organization of CBO services, either on a recurrent or an irregular basis. Noteworthy, user participation in the organisation of CBO services began with users' proposing new activities or changes to existing activities. Subsequently, users' proposals were discussed and deliberated in formal or informal meetings. The most prevalent user participative actions are of an evaluative nature centred on users' service satisfaction.

Diagram 3: The process of user participation



Theme two: Facilitating factors for user participation.

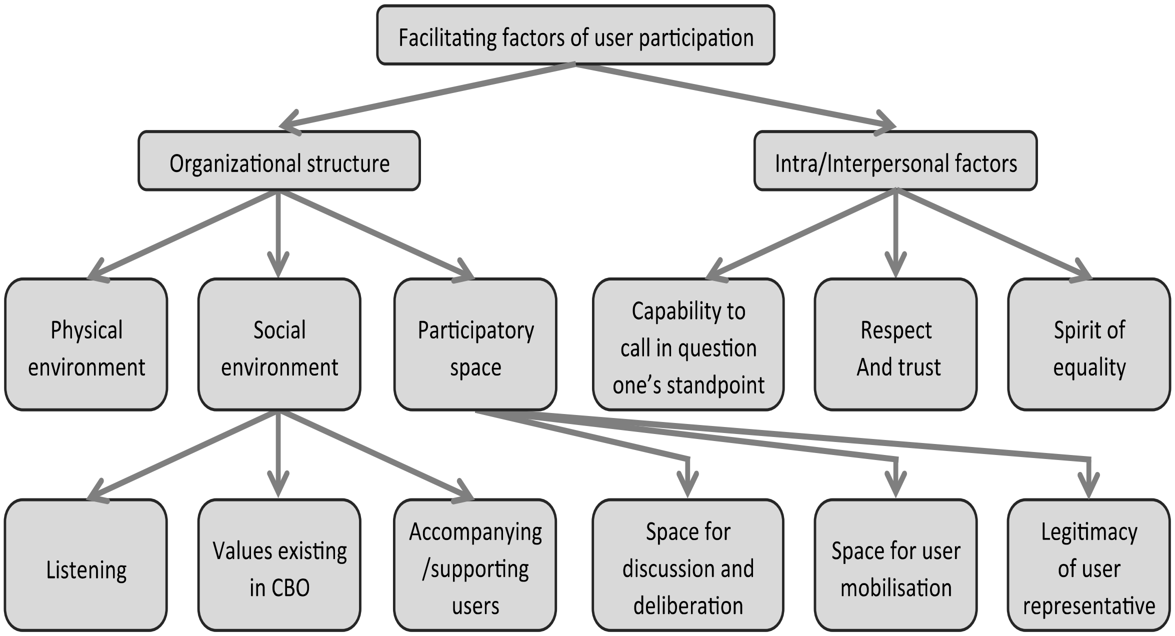
The second theme, Facilitating factors for user participation, is defined as the CBOs' organizational and intra/interpersonal elements that promote user participation. The second theme is composed of two subthemes: (1) organizational structure and (2) intra/interpersonal factors (e.g., interaction between users, directors, and staff).

The first subtheme, "organizational structure", comprises three elements: (1.a) physical environment, (1.b) social environment and (1c) user participatory space. Further, the social environment (1.b) element is further broken down into three sub-elements: listening, CBO values, and accompanying/supporting users. The participatory space (1.c) element also comprises three sub-elements: space for discussion, space for user mobilisation and the legitimacy of user representation.

The second factor "intra/interpersonal" subtheme comprises three elements: (2.a) capability to call in question one's standpoint, (2.b.) respect and trust and (2.c) the spirit of equality among CBO adminsitrators and staff and users.

This second theme details UP facilitators at the organizational level; no facilitating factors at the social and political levels were identified by the three groups of informants. On one hand, the informants described, in depth, the utility of CBO structural spaces in which service users could collectively voice their opinions, sharing their perspectives on the organization of services. On the other hand, the characteristics of interpersonal interactions (e.g., trust and respect, spirit of equality between staff and service users) between the service users and the CBO staff were found to be the bedrock on which service users were energized to engage in the organisation of CBO services.

Diagram 4: Facilitating factors for user participation

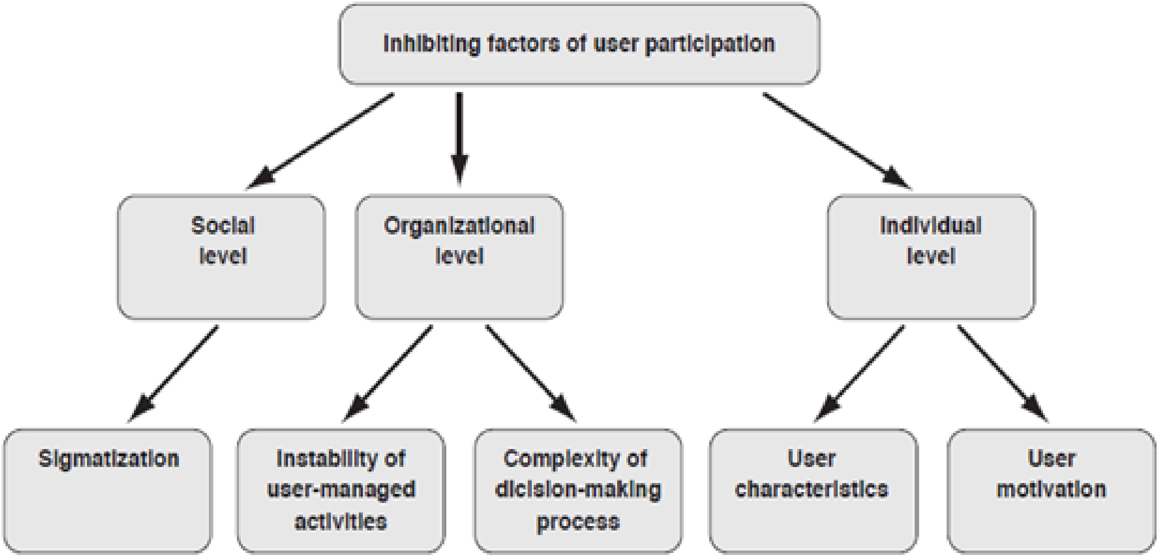


Theme three: The inhibiting factors for user participation.

The inhibiting factors for user participation, as represented in Diagram 5, is viewed as elements that hinder user participation at three distinct levels, hence three subthemes: (1) organizational, (2) individual and (3) social. The factors related to the service users are classified at the individual level. Meanwhile, factors related to the organization of services are grouped into the organizational level. The social level for themes 3 and 4 regroups other influential factors for user participation related to the social context within which the CBO is situated.

The organizational (1) subtheme comprises two elements: (1.a) the instability of user-managed activities and (1.b) the complexity of decision-making processes. The individual (2) subtheme comprises two elements: (2.a) user motivation and (2.b) users' characteristics associated with their mental health problems. The social subtheme (3) includes one element: (3.a) stigmatization. In contrast to UP facilitators, UP inhibitors were not associated with the interrelationships between service users, staff and the administrative team but appeared to be linked to the intrapersonal factors of service users (e.g., service users' characteristics and motivation). For example, the disequilibrium created by a service user's mental health condition is one of the contributing factors to the instability of user-managed activities. Some staff and members of the administrative teams also contended that service users are perplexed at the complexity of BOD decision-making processes.

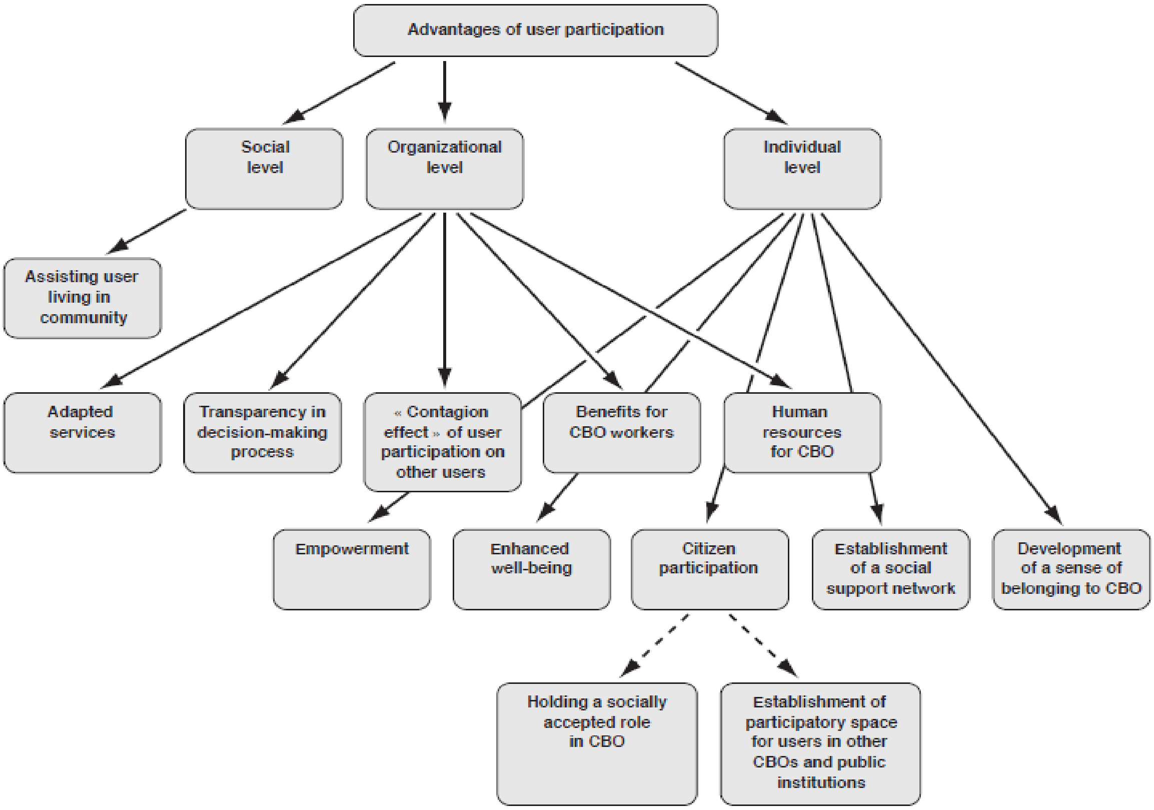
Diagram 5: Inhibiting factors for user participation



Theme four: The advantages for user participation.

The fourth theme (4), the Advantages for user participation, illustrated in Diagram 6, encompasses the beneficial features of user participation under three subthemes: (1) individual level (user advantages), (2) organizational level (CBO benefits) and (3) social benefits (CBO benefits). The first subtheme (1), individual level, comprises five elements: (1.a) empowerment, (1.b) enhanced wellbeing, (1.c) citizen participation, (1.d) establishment of social support network and (1.e) the development of a sense of belonging to the CBO. The element (1.c) citizen participation, is further divided into 2 sub-elements: holding a socially accepted role in the CBO and the establishment of social spaces for user participation in other CBOs and public institutions. Subtheme (2) organizational level, comprises 5 elements: (2.a) the development of adapted services, (2.b) transparency in organizational decision-making processes, (2.c) effect of "contagion" on other users (i.e., users incite other users to participate more in the CBO), (2.d) benefits for the CBO staff and (2.e) additional manpower for CBOs. Subtheme (3), social level, has one element: (3.a) assisting users to live in their communities. As depicted in Diagram 6, the advantages of UP were extensively recounted and acclaimed by all three groups of informants; moreover, they concurred that UP is beneficial not only for service users but also for the CBOs. Thus, it could be surmised that UP represents a therapeutic avenue for service users to both maintain their recovery process as well as lead a satisfactory life in the community. Simultaneously, UP can be perceived as a mechanism through which CBOs can synchronize services according to service users' needs (Finn et al., 2009).

Diagram 6: Advantages of user participation



4.2.3 CBO F: Presentation of data from the high scoring CBO.

Within this section, each theme will be depicted using various excerpts from the three different groups of informants (i.e., administrative team represented by the initials A1, A2; CBO staff (CBO workers) represented by the initialsW1, W2; and users represented by the initials U1, U2).

a) Process of user participation (UP).

This section presents: 1) the description of subthemes with the corresponding *verbatim* comments that go into the construction of this theme and 2) the interpretation of the data. Table VII delineates the four subthemes in theme one, Process of user participation (UP). As indicated by the quotes in Table VII, CBO F service users have availed themselves of opportunities within the CBO to propose new activities to the CBO staff and director. These opportunities included informal discussions with the CBO director, soliciting other users to request new activities and seeking CBO staff's opinions about the feasibility of a given activity. CBO F also has an additional physical and social space, a users' assembly, in which users propose new activities directly to the CBO membership.

In general, as indicated by the responses, users were involved in the CBO decision-making process, leading to the implementation or rejection of newly proposed activities. User participation in the decision-making process was either through dialogue with other users or the CBO staff. In other instances, user participation in the decision-making process necessitated face-to-face discussions between users and the CBO director. CBO F users were also actively involved in the delivery of some CBO activities, such as the sorting and preparation of food baskets for themselves and other users and assisting CBO staff to understand their experiences of living with the side effects of psychotropic medications.

Furthermore, a summer committee made up of CBO users was formed to enable users to plan and implement activities together (e.g., outings or summer camps). According to the director, establishing this committee has become part of the CBO annual activities. Given the autonomy of users in the planning and delivery of summer activities, they also assume responsibility for evaluating these activities and reporting the findings to the BOD. CBO F users are involved, through oral or written processes, in evaluating workshops given by the CBO staff. A recently formed committee of users was also mandated to undertake a more global evaluation of all CBO F activities.

Table VII: UP process as perceived by three groups of informants in CBO-F

1. Users' proposal of CBO activities	«…il y a deux semaines il y a eu par exemple des débats proposés et organisés avec les membres. D'autres membres ont proposé d'aménager un espace pour des livres de développement personnel pour les autres membres.» **W1**[1] « Puis nous-autres [les usagers] on voulait faire payer un peu plus cher les membres qui participent et s'ils réservent leur place pour participer, ce n'est pas remboursable. » **U1** « Pis il y a certaines fêtes comme l'Halloween ou la St-Valentin ce sont les usagers qui proposent et organisent tout de A à Z. **» U2** « S'ils veulent des activités, ils le signifient. Alors s'ils sont plusieurs, ils savent qu'ils ont plus de chances que l'activité va se donner.» **A1**
2. Users' involvement in decision-making process	«…les usagers qui voulaient que la présence aux assemblées d'usagers soit obligatoire pour tous les usagers. Mais il y en avait dans l'équipe de travailleurs qui étaient en accord avec les usagers et autres travailleurs comme moi, j'étais contre l'idée. Il y a eu un vote lors de l'assemblée des usagers sur la question de la présence obligatoire des membres. » **W 2** **« …** comment je pourrais dire ça? Il y a des membres qui sont en train d'essayer l'implication des membres à toutes sortes de niveaux comme dans l'organisation des activités du centre ou formuler des changements des règlements internes du centre. » **U2** « Par exemple : pendant une semaine de relâche de congé pour les travailleurs; je [c'est-à-dire la directrice] consultais des intervenants et par après les membres qui m'ont demandé de garder le centre ouvert. Puis, on a décidé, on a fait ce qu'ils [les usagers] ont voulu.» **A 1**
3. Users' involvement in service delivery	« Donc, j'ai aucune idée sur qu'est-ce que c'est diminuer une médication. J'ai même aucune idée dans les faits sur qu'est-ce que c'est de prendre une médication psychiatrique, d'avoir de la misère à me lever le matin, de sentir mes émotions. J'ai aucune idée de qu'est-ce que c'est. Donc la personne vient apporter cet éclairage-là.» **W2** «Il y a une des membres qui avait plus encore cette préoccupation [l'isolement et la procrastination] chez les membres parce qu'elle-même le vivait aussi, qui du coup a pris en charge le groupe d'entraide.» **W1** « Comme je suis professeur d'éducation physique, j'ai demandé à la directrice d'animer un groupe de marche et j'ai dit "Ça prend pas grand-chose pis on n'est pas obligé d'aller loin ", ça a fonctionné pour 3, 4 sessions. » **U1.** « Et ça, le programme P.M. (dépannage alimentaire) est une des premières activités qui a été mises en place par les membres.» **A1**

Table VII (cont.): UP process as perceived by three groups of informants in CBO-F

4. Users' involvement in the CBO's service evaluation	« …ça fait maintenant plusieurs années, on avait un feedback qui était:« On n'a pas aimé pas » ou « Telle affaire devrait être faite autrement » on a tenu compte de cette évaluation ; par après j'ai dit « l'été prochaine on va former un comité puis vous viendrez dire ce que vous voulez et comment les faire et on va faire ce qui sera possible en tenant compte du budget.»**A1** « À la fin de chaque année, on a organisé une journée ou une demi-journée où on rendait aux membres le travail qu'on avait fait. On, préparait tout un travail. On faisait des petits sketches, on faisait aussi euh... on a écrit des choses qu'on a données aux personnes, chacun de nous avait écrit quelque chose.» **U2** «Ben les, gens doivent remplir un questionnaire pour dire qu'est-ce qu'ils ont aimé, qu'est-ce qu'ils n'ont pas aimé ça c'est,… quelque chose. Pis là la direction se propose de... faire un comité avec quatre personnes pour évaluer tous les services.» **U2** « …les usagers font des évaluations verbales: les gens disent: "ah, moi j'ai aimé ça aujourd'hui.» **W1**

[1] The initial U represents "users", the initial W represents " workers" and the initial A represents "the CBO Administrators". The number represents the first and second users, administrators and workers from CBO F.

Interpretation of results.

Based on the perspectives of the three groups of informants (Table VII), the process of user participation can be viewed as users' actual action in proposing, implementing and evaluating new services or modifying existing services. Within the first subtheme, users' proposal of CBO activities, the following patterns are elucidated: 1) a large number of users united their voices either in meetings with the CBO staff or in meetings among themselves to propose some change in the organization of CBO service; 2) there existed some sense of solidarity among the users that preceded their participatory activities in service design, as is illustrated by the following *verbatim* comment from U2:

> c'est nous qui se sont mobilisés pour dire... qu'on a trouvé toutes sortes de façons que les gens pouvaient s'impliquer. On est allés voir la direction pis là on a dit: 'Ça pourrait être ça,' on a proposé plein de choses, ça s'est mis en branle.

Within the second subtheme, users' involvement in decision-making process, the *verbatim* comments illustrated in Table VII indicate that CBO F user participation takes the form of user partnering at the highest level of decision-making of the CBO – the annual CBO's general assembly. However, according to the CBO director and the president of the BOD, the users' participation in the organization of service is conditional upon the following facts: a large number of users requesting new services or changes in existing services, sufficient CBO funding and the support or agreement of the CBO staff. The role of CBO staff as intermediaries or coaches for service users in their participatory activities within the CBO organizational structure is also noteworthy.

Within the third subtheme, another pattern of user participation in service delivery was noticed; professionals valued users' experiential knowledge because of its distinctness from their academic training. Moreover, CBO staff were able to put aside their academic knowledge and emphasize the relevance of experiential knowledge in service delivery. Consequently, service users were able to put in place their own proposal of activities that highlighted their personal skills (e.g., U 2 had been a teacher) for the benefit of other users.

Within the fourth subtheme, data analysis gave rise to the finding that user participation in service evaluation is active in this CBO. However, the director and the staff play a more dominant role in their decisions about the type of format within which user participation of service evaluation can take place (e.g., verbal evaluation asked by staff, director's decision in forming a committee composed of users and staff to evaluate and design new services).

b)Facilitating factors for user participation.

This section presents 1) *verbatim* comments from informants as evidence for the subthemes and elements that constitute the theme Facilitating factors for user participation and 2) the interpretation of these findings.

Description of findings.

Quotes from the CBO F study informants relevant to factors facilitating user participation are summarised in Table VIII. In terms of the intra/interpersonal subtheme, both the staff and the director discussed how a positive attitude towards user participation required continual self-reflection on their part about their interactions with the service users and the subsequent impact of these actions on themselves, the service users and the organizational structure of the CBO.

Although the users noticed the favourable attitude of the directors and staff towards user participation, they also discerned some discord among staff about the impact of user participation on service user interventions. All informants agreed that CBO F service users and staff demonstrated mutual feelings of respect and trust. Generally, there was agreement between the administrative team (i.e., director and the president of the BOD) and staff on the following finding: trust and respect are essential interpersonal ingredients for the optimization of user participation in the CBO. It is noteworthy that while the director and the staff highlighted the spirit of equality between staff and service users, the service users themselves only spoke about this in a unidirectional sense. In other words, the users perceived that staff recognition of their strengths and social skills did not necessarily mean that staff considered service users as their peers, as illustrated by this *verbatim* comment from U2: “des fois ils [le personnel de l’organisme F] ont comme une vision de ce que les gens: ‘ah non, ils [les usagers] peuvent pas faire … ”

Within the organizational structure subtheme, the president of the BOD emphazised various characteristics of CBO F’s physical infrastructure (e.g., colourful walls, dim lighting, comfortable chairs, adequate room for group sessions), while the director, staff and users were more focused on the social environment. Within the social environment, all CBO F informants conversed about their adherence to the CBO’s values (e.g., democracy, service user empowerment); and the staff emphatically described their non-directive and supportive interactions towards service users (i.e., listening and accompanying). Service users’ perspectives mirrored those of staff regarding the nature of their mutual interactions.

The informants were also in agreement about the participatory space element. In this regard, they underscored the commitment of the director and staff and the active engagement of service users in debating and deliberating activity suggestions from service users. This subtheme also views the user participation role as “activist” – service users who rally or motivate other service users to become more involved in the CBO’s organizational structure. The last sub-element in the participatory space subtheme, the legitimacy of service user representation, is demonstrated by the fact that user representatives on the

BOD and their substitutes are elected as part of a service user assembly separate from the CBO annual general assembly.

Table VIII: Facilitating factors for UP as perceived by three groups of informants in CBO-F

Intra/inter-personal factors	Capability to call in question one's standpoint	«J'aurais peur de laisser toutes les décisions de cette ressource dans la main d'un conseil d'administration composé entièrement d'usagers…j'ai des craintes à tort ou à raison de laisser toute la place aux usagers.» **A1** «…ça demande de la part de l'équipe une ouverture et de se remettre en question, qu'on n'ait pas peur aussi que les gens s'impliquent. » **W1** « Il y a eu un questionnement sur l'implication des usagers à travers l'équipe des intervenants parce qu'il y en a qui sont pour, y'en a qui étaient contre; car certains pensent ce sera leur rôle d'appliquer le principe d'implication obligatoire » **U2**
	Respect and trust	«Comme moi j'en fais partie depuis 20 ans au conseil d'administration, on a beaucoup développé aussi un grand respect des usagers.» **A2** «Il y avait un monsieur ici qui chantait vraiment faux, mais son rêve est d'être chanteur, on a respecté son rêve et il a finalement réalisé son rêve.» **W1** « …disons dans cet organisme les gens qui sont très respectueux.» **U2**
	Spirit of equality	«Les usagers sont très bien accueillis par les intervenants, tout le monde est de façon égale là-dedans.» **A2** «Je laissais les usagers de venir me voir. Quand ils venaient je, j'étais là vraiment comme une collègue en fait.» **W1**

Table VIII (cont.): Facilitating factors for UP as perceived by three groups of informants in CBO-F

Orgnizational structure	**Physical environment**	«Le conseil d'administration a obtenu un local qui est encourageant et qui est valorisant pour les gens.» **A2**
	Social environment	**CBO values** «Les valeurs de la démocratie, le partage, la place des usagers, le leadership, l'appropriation du pouvoir, ça vient beaucoup d'ici au Québec, notre mouvement alternatif dans notre organisme.» **A1** «Cet organisme F est un organisme, alternatif. Donc ici, c'est beaucoup le pouvoir citoyen, fait que si on était dans cet organisme je ne crois pas qu'on aurait de difficulté à s'impliquer.» **U2** **Listening** «Je trouve qu'il est très enrichissant pour moi d'écouter les usagers surtout parce qu'ils connaissent les deux côtés [c'est-à-dire: l'expérience de vivre avec les problèmes de santé et de recevoir des services communautaires et publiques en santé mentale].» **A2** «Donc c'est avec eux qu'on interagit pour répond le mieux; à quelque part; mieux savoir, mieux saisir leur réalité.» **W2** «Ils…les intervenants) nous ont entendu tout ça et nous ont soutenu.» **U2** **Accompanying/ supporting users** « Bon, il ne suffit pas de dire aux gens: "Oui, vous avez la place, faites-le." Il faut être avec eux pour les habiliter à faire cette implication .Je me sentais plutôt comme une accompagnatrice.» **W1** « …développer le rapport plus égalitaire; je suis à côté de toi, je suis le copilote, mais c'est toi qui es le pilote.»**W2** «Il y avait une ouverture. Ils nous soutiennent quand même beaucoup.» **U2**
	Participatory space	**Space for discussion and deliberation** «Mais si les usagers veulent une activité, pis ils sont dix qui sont prêts à la prendre, on n'aura pas le choix que d'en tenir compte.»**A1** « Ça a mis en branle comme un genre de période où on va essayer des choses, on va voir les résultats, que ce soit positif ou pas.» **U2** « C'est assez démocratique au CA on ne va nécessairement pas tous être d'accord. Mais ici, on peut vraiment débattre nos idées.» **W1** **Space for user mobilisation** «Les usagers ont pris en charge d'organiser les fêtes. Ça créé un mouvement.»**A1** «C'est nous qui se sont mobilisés pour dire: " Les gens devraient s'impliquer plus." …on a trouvé toutes sortes de façons pour que les gens pouvaient s'impliquer.» **U2** **Legitimacy of user representation** «Les usagers ont des réunions de groupe, ils font le choix des représentants qui vont être au C.A.» **A2** «Tous les usagers au CA sont là comme délégués des usagers, on les sent valorisés avec cette responsabilité.»**W1** «J'étais élu par les membres comme déléguée substitut si jamais un des trois déléguées tombe malade. » **U2**

Interpretation of findings.

As illustrated by Table VIII, the facilitors for user participation are multi-faceted. The three groups of informants all had to play a crucial role in the optimization of user participation within CBO F. Without their mutual respect underpinning their interactions, user participation would not be possible. Their respective roles are delicately interwoven: (1) the director in her role of manager to implement the CBO values of democracy and user participation by means of structuring and making accessible the participatory space for users within the daily operation of CBO services and in organizational instances of decision-making, (2) the staff in their role in listening attentively to users' lived experiences of mental health existence and in accompanying users in their participation in the organization of services and (3) the service users' active role in maximizing their participatory activities within the participatory space.

c) Inhibiting factors for user participation.

This section presents 1) *verbatim* comments from informants as evidence for the subthemes and elements that constitute the theme Inhibiting factors for user participation and 2) the interpretations of these findings

Inhibiting factors for user participation.

Table IX regroups various quotes from CBO F study informants regarding inhibiting factors for user participation, more specifically in service delivery. At the individual level, staff quotes underscored two elements that are perceived as obstacles to user particpation: (1) service users' characteristics, and (2) lack of motivation on the part of some users.

At the organizational level, data from the three groups of informants converge on two elements as barriers for user participation: (1) user-managed activities are difficult to sustain, and (2) the decision-making process on important organizational issues (which

were debated on the BOD) has to be adapted and understood by all those involved. It should be stressed that these identified inhibitors are preceded by actual user participation in service delivery. The sustainability of user-run activities is dependent upon the motivation and health of the users who offer and benefit from these services.

There was consensus among the three groups of informants regarding one element of the social subtheme- social stigmatization: mental health service users and their opinions are seen to be discredited because of their mental health problem. The existence of social distancing between the BOD user representatives and the other BOD members (staff-member, director, president) was cited and attributed by one informant (U2) to the negative social status of individuals living with mental health problems.

Table IX: Inhibiting factors for UP as perceived by 3 groups of informants in CBO-F

Individual level	Users' characteristics	« Mais quand on est fragile, je pense qu'on a davantage besoin de se centrer sur soi et on a besoin des autres pour nous-mêmes.» **W 1** « Il y a des gens qui vont me dire: "Ben moi j'attends d'avoir confiance en moi avant de m'impliquer un peu plus. » **W2**
	Users' motivation	« Il peut y avoir des périodes où les gens peuvent ne pas avoir envie de s'impliquer.» **W1** « Ce sont certains usagers qui auraient jamais voulu participer à des conseils d'administration. Ils prennent pour acquis que leur vie est décidée par d'autres.» **A2**
Organizational level	Instability of user- managed activities	« Il y avait quand même beaucoup de monde. Petit à petit le groupe était moins important. Après, c'est tombé parce qu'une usagère devait se faire opérer du genou.» **W1** « Mais c'est comme partout d'ailleurs, tu commences avec 20 personnes, tu finis 10-12.» **U2**
	Complexity of decision-making process	« Quand on parle d'implication d'usagers, c'est une belle philosophie, ce sont des beaux principes. Mais dans les faits c'est vrai que ce n'est pas toujours facile c'est plus long, ça demande plus de patience, ça demande d'adapter les conseils d'administration, d'adapter le rythme aussi en fonction des gens qui sont là. » **W 2** « Au C.A. ils connaissent bien la directrice, tout ce qu'elle va proposer ça va toujours, passer. Sauf que des fois, des usagers peuvent avoir des petites réserves mais... Fait que ce n'est pas si facile que ça de contredire, de dire: "Ah ben nous on n'est pas d'accord".» **U2**

Table IX (cont.): Inhibiting factors for UP as perceived by 3 groups of informants in CBO-F

Social level	Stigmatization	«Moi, je ne parle pas du tout de mes problèmes de santé mentale en dehors de l'organisme F ; il existe toujours des préjugés.» **U1** «Les usagers ressentent le malaise d'avoir été en santé mentale et d'avoir été malade… » **A 2** «Ah, peut-être que si on aborde les gens sur leurs problèmes de procrastination, ils vont se sentir identifiés comme ayant des problèmes de santé mentale.**» W 1** «Parce que la représentante des employés, elle fait partie du personnel; tu fais de belles choses au CA…tu restes quand même dans une catégorie à part. Parce que les gens au CA, ils te voient quand même comme un client avec des problèmes de santé mentale.»**U2**

Interpretation of findings.

Although the identified inhibitors for user participation are categorized into different levels (individual, organizational and social), the emphasis falls on the central role of service users in user participation. At the individual level, the staff group of informants indicated clearly that certain personal characteristics of service users have to be in place so that they can participate in the service delivery. In other words, the stability of mental health status within the service users is the first and foremost ingredient crucial for user participation.

The group of user informants was silent on this issue since one informant (U1) stated that her mood swings did not prevent her from participating actively in service delivery: "Parce que ça prend pas grand chose pour se faire basculer. Faut toujours être sur les gardes mais, moi dans l'implication là … je suis bonne." (U1). Furthermore, they argued strongly for the complexity of the decision-making process (an inhibitor at the organizational level) that hindered their participation on the BOD as illustrated by this *verbatim* comment from U2: "Fait que c'est comme si quand on sent que tous les membres de CA (autre que les usagers) sont ensemble, sont d'accord d'avance et sur tout, c'est difficile de s'affirmer" (U2). In other words, according to users' perspective, UP is deterred more by the functioning of the BOD than the complexity of decision-making processes.

At the social level, data collected from the three groups of informants concurred that stigma is a major inhibitor for user participation. However, there are different perceptions of social stigmatization from the three different groups of informants. The administrative team informants sympathized with users, indicating that less user participation on the BOD due to their mental health problems is comprehensible. In doing so they put a heavy burden on users for their participatory activities and potentially less emphasis on the adaptation of the organizational structure in order to optimize user participation. Meanwhile the CBO staff are more sensitized to the implicit stigmatization of users when they identify users' problematic coping strategies (e.g., procrastination) in association with their mental health problems. The user informants subjected to social stigmatization appeared to accept this social labelling as part of the identity of a mental health service user.

d) Advantages of user participation.

This section presents 1*) verbatim* comments from informants as evidence for the subthemes, elements and sub-elements that constitute the theme "Advantages of user participation," and 2) the interpretation of these findings

Advantages of user participation.

Table X presents informants' quotes on the advantages of user participation across three levels: individual, organizational and social.

At the individual level, user participation contributes to service users' personal self-development through empowerment (i.e., service users feel they have choices and power in decision-making processes). User participation also enhances users' wellbeing. Moreover, user participation is seen as a strategy for service users to establish and sustain their own social support networks. Most importantly, user participation is seen as a form of citizen participation in that user participation serves as a strategy for users to achieve a more visible status (e.g., as a BOD member) within this CBO. User participation also is a crucial means to attain to other social roles in other CBOs or public institutions. Finally, user participation contributes to the development of a sense of belonging to the CBO.

At the organizational level, staff and the administrative team perceived that one advantage of user participation is transparency in the organizational decision-making process, whereby final decisions are taken by the three following procedures: (1) consensus among service users, staff and the director; (2) voting mechanism during BOD meetings and (3) debates and voting mechanism during the annual CBO general assembly. The second organizational advantage of user participation (be it oral or written, in groups or person-to person with staff or director) is that the CBO's thematic activities are more attuned to service users' needs and interests. The third organizational advantage of user participation is to engage other service users' to implement collectively concrete actions (e.g., gifting a coffee-maker in recognition of CBO staff's work) for the benefits of the CBO and its staff. The fourth advantage of user participation is additional human resources through user volunteers to carry out CBO activities. Finally, the fifth advantage of user participation was noted by user informants as the ripple effect whereby a service user is motivated to become more actively involved in the CBO after witnessing another service user's participatory activities. The BOD president mentioned that one of the advantages of user participation is that by involving themselves in the CBO service organization, service users are less likely to need hospitalisation. It is possible that society (or the social level) may benefit from user participation within mental health CBOs because of service users' continuing to reside in the communnity.

Table X: Advantages of UP as perceived by three groups of informants in CBO-F

Individual level	**Empowerment**	«Donc de trouver des lieux, des espaces d'application où ils ont des possibilités de faire des choix, d'avoir du pouvoir.» **W1** «Je suis contente de pouvoir affirmer mes opinions et en plus de voir que les autres usagers aussi veulent affirmer leurs opinions qui sont différentes de celles de la directrice. » **U1** «Cheminer ou retrouver leur pouvoir personnel…les usagers plus conscients de ce que ça veut dire la réappropriation du pouvoir. » **A1** « Moi je trouve que c'est extrêmement important. De voir à ce que les gens soient respectueux, soient respectés comme des êtres humains pis que leurs idées soient acceptées. »**A2**
	Enhanced well-being	«Normalement ils s'améliorent [sur le plan de leur santé] un peu avec leur participation.» **A2** «…ils [les usagers] ont dit que leur implication a un impact sur leur qualité de vie, leur bien-être» **W1** «C'est l'implication…Ca m'a révélé en tant que personne, être humain.» **U2** «Nous, les membres étaient bien heureuses que nous avons pu organiser la fête pour donner en retour aux intervenants.» **U2**
	Citizen participation 1.*Holding a socially respected role in CBO* 2.*Establishment of social spaces for UP in other public institutions*	«Aller défendre tes droits en tant que citoyen au CA, etc…c'est une mobilisation qui peut partir vraiment de l'organisme pis s'étendre à toutes les sphères de la vie de la personne …» **U2** «Donc, elle a …quitté le comité rétablissement puis elle s'est occupée du groupe d'entraide sur la procrastination.» **W1** «J'ai une cliente ici qui était au conseil d'administration [du CBO- F] et qui a décidé de s'impliquer au conseil d'administration du regroupement provincial.»**A1** «L'implication ça aussi dans ta vie à l'extérieur, c'est comme …aller défendre tes droits en tant que citoyen.» **U2**
	Establishing a social support network	« Il y a beaucoup d'entraide, il y a beaucoup de solidarité, il y a beaucoup de choses qui se passent les usagers qui est bon.» **W1** « Depuis l'été passé, on est 4-5 filles, on s'appelle de temps en temps, on va danser de temps en temps le vendredi soir.» **U1**
	Development of sense of belonging to CBO	«Tu sais, mais c'est sûr là-bas c'est comme ma deuxième maison là. » **U1** «Je trouve que l'implication des membres donne un sentiment d'appartenance à l'organisme. » **U2**

Table X (cont.): Advantages of UP as perceived by three groups of informants in CBO-F

Organizational level	**Activities adapted**	« C'est avec les usagers qu'on peut répondre le mieux à quelque part. Et mieux savoir, mieux saisir leur réalité pour pouvoir donner du service en fonction de ce qu'ils souhaitent.» **W2** «Alors pour les usagers, ce qui était clair, c’est que le centre reste ouvert. Ils pourraient venir quand ils voulaient dans la semaine [la semaine de relâche des employés].» **A1**
	Transparence	« On arrive avec une suggestion. Mais souvent la suggestion… est modifiée, est améliorée parce qu’il y a des interventions des usagers justement.» **A2** «En fonction de ce que les usagers disent, en fonction de ce que nous [les travailleurs] dit, en fonction de ce que la direction va dire, le conseil d'administration va prendre une décision la plus juste possible….au pire on va aller au vote.» **W2**
	Contagion effect of UP on other users	«Il y a des usagers qui se sont mobilisés et... ça, a soulevé un intérêt et du désir de s'impliquer des membres. » **W1** « …pour moi comme usagère, je te dirais que les usagers ont fait beaucoup pour que l'implication existe parce qu'il n’y en avait presque pas avant. » **U2**
	Benefits for CBO workers	« Au moment de la St-Valentin, le comité rétablissement des usagers a décidé de prendre en charge la fête de la St-Valentin et de souligner par exemple le travail des intervenants. Ce qui était une grande surprise pour nous.» **W1**
	Human resources	«Maintenant des usagers sont impliqués dans la programmation d’été. » **A1** «Comme l’usagère, j’"étais dans le comité pour organiser les sorties d’été. »**U1**
Social level	**Support for users living in the community**	«Si l’organisme avait un peu plus de sous, on pourrait prendre plus de monde, on pourrait impliquer plus de monde; ils demanderaient moins de services à l’hôpital et resteraient dans la communauté.» **A2**

Interpretation of findings.

The three groups of CBO F informants concur on the advantages of user participation mainly for the service users. As discussed in the section *Interpretation of findings* on theme Inhibitors for user participation, the stability of service users’ mental health status is a fundamental condition needed for the occurrence of user participation.

Subsequently, within this theme, Advantages of user participation*,* service users and the administrative and CBO staff alike confirm that the consequence of user participation is that service users' wellbeing is further enhanced, hence service users' recovery processus can be said sustained.

At the organizational level, user participation is valued not only in the adaptation of services according to the expressed needs of service users, but it also has added value for the CBO since service users provide services for others without the need for additonal funding. In addition to the five organizational advantages of user participation, user participation serves as an organizational means of communication between service users, staff and the adminstrative team about the organization of service design and delivery.

The following quote from A1 depicts not only the channel of communication but also the fact that the mechanism of user participation is ingrained in the organizational culture:

> Par exemple dans une semaine de relâche, nous-autres on a une semaine de congé. Et là on se demandait: Est-ce qu'on maintient le service? Moi je cherchais avec les intervenants pour qu'ils me donnent le pouls des usagers. Mais là on n'était pas sûrs. On a décidé de leur demander ce qu'ils voulaient. Finalement, on a décidé avec eux de maintenir de service. A1

In other words, user participation is embedded in this CBO organizational culture to the extent that the director and the staff almost automatically activate the user participation process, and user participation takes the form of user partnering in final decision-making process.

4.2.4 CBO G: Presentation of data from a low scoring CBO.

The following section presents the four study themes (i.e., the process of user participation, the facilitating factors for UP, the inhibiting factors for UP and the advantages of UP) in relation to CBO G (low score) .

a) *Process of user participation.*

This section presents 1) *verbatim* comments from informants as evidence for the subthemes that constitute this theme, and 2) the interpretation of these findings across 3 groups of informants in this CBO.

Process of user participation.

Table XI regroups quotes from CBO G informants regarding the first theme, Process of user participation. Within CBO G, service users' proposals have to go through different channels (directly from service user to staff) and in accordance with the organization's centralized hierarchical structure (user to staff then staff to manager). Further, service users' proposals are mainly about the types of activities offered and rarely about changes in the way services are offered (the organization of activities). Only one example regarding user participation in a decision-making process was found. User participation in the decision-making process comprises (1) the user representative voicing his opinions regarding certain issues (e.g., abolition of certain CBO activities due to funding cuts), (2) an ensuing discussion among BOD members on the issues raised by the user-representative and (3) a final decision by the BOD taking into consideration the user representative's perspective in this one instance. User participation in service delivery is present in CBO G in situations in which staff are unavailable (staff on sick leave or vacation). User participation in service evaluations is mainly in the form of service users' satisfaction or dissatisfaction regarding CBO activities and is expressed orally. Exceptionally, certain types of service users' complaints must first be dealt with by the manager and then by the director.

Table XI: The process of UP as perceived by three groups in CBO-G

1. Users' proposal of CBO activities	«Souvent les gens vont demander à ce qu'on ait un atelier, un certain atelier qu'ils aiment. Ils vont le demander. Donc ça peut nous influencer quand on va planifier la prochaine session» **W3** «…l'année dernière nous, les usagers demandent une augmentation de paie pour notre travail; cette année, on demande des privilèges qu'on n'a pas, on parle de ce qu'on veut faire, ce qu'on veut améliorer.» **U4**
2. Users' involvement in decision-making process	«Nous avons négocié avec le directeur pour pouvoir travailler plus d'heures et d'être payé plus. On a obtenu ce qu'on voulait.» **U4** **«**Sur le CA, nous avons écouté les opinions de l'usager sur sa proposition des activités nécessaires à maintenir selon les besoins des usagers et nous avons décidé en tenant compte de ses opinions » **A4**
3.Users' involvement in service delivery	«C. a utilisé le service de l'organisme; elle est une usagère ... maintenant, elle travaille au centre…mais comme aide-animatrice.»**W3** « L'usager connaissait déjà la guitare, il connaissait ça déjà quand il s'est inscrit au cours. C'est lui qui donne le cours de guitare finalement.» **A3**
4.Users' involvement in the CBO's service evaluation	«Au début de chaque rencontre, il y a eu toujours l'évaluation entre les membres.» **W3** **«…**quand les clients font des critiques sur des choses, les intervenants, les animateurs les entendent et vont le rapporter à la coordonnatrice et ils vont essayer de modifier des affaires s'il y a lieu de les modifier.» **A3**

Interpretation of findings.

The CBO G director and the secretary of the BOD concurred about some users' participatory activities on the BOD. Staff and service user informant groups agree that user participation in CBO G consists mainly of user attendance at CBO activities and some remunerative activities related to service delivery. User participation in service design appeared to be limited because users have no access to the CBO manager to propose directly changes in service. Service design and service delivery remain almost exclusively in the hands of CBO staff and the manager. Additionally, despite lengthy transcripts of service users' interviews with the student-researcher, there is little evidence of user participation in the organization of services. Therefore, it is difficult to discern the process of user participation in this CBO (low score).

b) Facilitating factors for user participation.

This section presents 1) *verbatim* comments from informants as evidence for the subthemes and elements that constitute the theme Facilitators for user participation and 2) the interpretation of these findings across the three groups of informants in this CBO.

Facilitating factors for user participation.

Table XII presents quotes from CBO G informants describing the two subthemes intra/interpersonal factors and organizational structure. Under the subtheme intra/interpersonal factors, one informant from the adminstrative team discussed his perception of user participation and the principle of recovery in dealing with mental health problems. He described in detail how the CBO manager mobilized CBO staff to facilitate more active user participation. Another facilitating factor, mentioned by another informant, was the staff's insightful perspectives vis-à-vis user-staff interactions so that interpersonal exchanges offer increasingly opportunities to involve service users in the planning of activities.

Under the subtheme organizational structure, all informants of the three groups from CBO G agreed that the physical environment (i.e., new equipment, disco lighting, and spacious rooms) contribute to user participation and regular attendance in several activities. Conversely, the subtheme social environment and its element CBO values were discussed mainly by the administrative team and one staff member rather than by the service users.

The CBO G staff verbalized the value of user participation in the organization of services but had yet to effectively internalize it, that is, they had taken few actions to facilitate user participation. The element -accompanying/supporting users- was discussed in detail by the director, but the other two informant groups were not as clear on this. As cited in Table XII, one user informant (U4) indicated that when a staff member gave him a certain assignment the associated responsibility engendered positive emotions that subsequently led to his becoming more actively involved in other areas of service delivery.

Under the participatory space element, the quotes from the three groups of informants indicate that the administrative team understands the value of user participation and has attempted to implement certain strategies such as in-house education for the staff in order to promote user participation. They discussed certain participatory events/activities in which user participation is influential to specific and non-recurrent service delivery. Nonetheless, no data was collected from the group of service users regarding their active participation in the organization of CBO service, which apparently indicates that participation was often limited to assisting staff in CBO activities.

Table XII: Facilitating factors for user participation in CBO-G

Intra /interper-sonal factors	Capability to call in question one's standpoint	«Il faut avoir aussi l'ouverture d'esprit de dire: "Voici, on se pose des questions sur telle chose et on s'attarde sur ce que les usagers désirent » **A3** «Ça va prendre du temps pour que le centre de jour intègre la philosophie de la participation, du rétablissement des usagers… la coordonnatrice du centre de jour a une rencontre chaque semaine pour insérer ça [c'est-à-dire la participation des usagers] au niveau des activités au centre.» **A3** «C'est nous-autres qui gère toute l'organisation du centre. Les usagers participent aux activités. Mais il y a peut-être une place pour une participation beaucoup plus active justement.» **W3**
	Respect and trust	«Dans toute l'organisation au niveau des clients, écouter, entendre ce qu'ils ont à dire; on essaie toujours de le faire. La relation qu'on a avec les clients est une relation de très grand respect.» **A3** **«**On a le respect pour la clientèle.» **W3** «La confiance m'inspire…La façon que le monde m'inspire. Ça aide à continuer.» **U4**
	Spirit of equality	No quote from informants
Organiza-tional structure	Physical environment	«Regardez autour de vous, on a vraiment un très grand local, bien aménagé avec de beaux instruments de musique pour toutes sortes d'activités comme la danse sociale.» **W 3** «Les usagers ont accès à des plateaux d'activités comme les quilles, le gymnase, la piscine, des terrains de baseball, des gymnases pour le hockey… l'organisme a une diversité aussi d'activités, nous avons des ateliers d'ordinateur, de la musique, du multiculturel, du social, du sportif. » **W 4**
	Social environment	• **Listening** Quote from secretary of BOD about the importance of listening to users. **A4** [This informant refused to record the interview]. • **CBO value** «Ça fait partie de la philosophie qu'on a maintenant que les gens soient plus impliqués, de l'empowerment..» **A3** «L'écoute des membres fait partie de la philosophie de l'organisme»**A4** «Ce processus du rétablissement, c'est depuis longtemps c'était pratiqué ici, cette ouverture et respect pour la clientèle.» **W3** • **Accompanying/ supporting users** **«**On ne me coupe pas l'herbe sous le pied mais on comprend mes émotions et par après on me demande de faire des trucs (par exemple : réserver des places pour les usagers pendant des sorties. » **U4** **«**Il faut le [l'usager] structurer s'il en a besoin. Il faut essayer de savoir qu'est-ce qu'il veut également, le supporter dans la direction qu'il veut prendre. » **A3**

Table XII (cont.): Facilitating factors for user participation in CBO-G

Organiza-tional space	Participatory space	• **Space for discussion and deliberation** «… deux clients ont dit: «Nous, on est capable de faire la peinture; l'intervenante a dit: Oui, ils sont capables de faire de la peinture ». Donc c'est eux-autres qui vont faire la peinture.» **A3** • **Space for user mobilisation** No quotation found that illustrates this element • **Legitimacy of user representation** «Il n'y a eu élection des représentants des usagers au CA à cause du manque des candidats.» **A4**

Interpretation of findings.

Consistent with the findings from the theme Process of user participation, data show a lack of convergence between the group of user informants and the staff and the administrative team about the facilitators for user participation. While the adminstrative team and the staff emphazise their respect for the service users, the service users do not perceive the staff's respect in their mutual interactions, as illustrated by this quote from U3: "… J'ai donné mon nom et il [staff] m'a dit carrément que j'avais pas les qualités requises pour animer le groupe…." This finding is consistent with the absence of quotes from the staff and administrative team about the strategy of active listening (element within the subtheme social environment) in their interactions with the service users. As previously mentioned, within the element participatory space for user participation (CBO G), the data evidenced the limited number of participatory activities of users in the organizational space, such as BOD representation to influence the organization of CBO services. These findings may be associated with the fact that CBO G service users are high-school drop-outs, live in supervised housing facilities and have been struggling with mental health problems for more than two decades. Another hypothesis could be postulated about the association between the users' limited participatory activities and the more limited staff's supportive strategies for user participation in the organization of CBO services (in comparison with CBO F).

Although the informants in the CBO G administrative group agreed with staff and service users on the facilitators for user participation, their perspectives put much more emphasis on their efforts to develop better organizational structures (i.e., staff meetings putting more emphasis on recovery-oriented interactions with service users) to facilitate greater user participation in the future. On the other hand, the administrative informants attribute few user participatory activities in the participatory space to the users' personal characteristics rather than the absence of an organizational structure that would facilitate user participation.

c) Inhibiting factors for user participation.

This section presents: 1) *verbatim* comments from informants as evidence for the subthemes, elements and sub-elements that constitute the theme Inhibitors for user participation and 2) the interpretation of these findings.

Table XIII provides quotes from CBO G informants on inhibiting factors across three levels: individual, organizational and social. At the individual level, staff and service users' comments suggest that a large proportion of the CBO G users are unable to undertake initiatives that are not within their routine activities at the CBO. Further, service users' personal characteristics associated with their mental health (i.e., their need to reside in supervised housing facilities, being hospitalised for long periods) do not facilitate service users' involvement. They also acknowledge the stress of involvement in service delivery, as noted by U3.

Meanwhile, the staff group mentioned several staff endeavours to implement some participatory space for service users in the CBO's arts and culture programmes but not in the organization of CBO services. Concurrently, they also asserted that service users' characteristics (i.e., low level of social functioning) are an inhibitor to user participation.

The two user informants appeared not to be very informed about the accessibility of participatory space for them. While one service user cited only a concrete example in which he participated in a decision-making process regarding his working conditions, the other service user informant seemed unable to ascertain the means to participate in the organization of CBO activities.The administrator group perceives user participation in the organization of CBO activities as a complex process necessitating the implementation of preparatory and formative sessions for service users and several modifications in the BOD’s functioning. Negative perceptions of service users with mental health problems are a social issue. Even the user informants admitted to distancing themselves from other service users whose behaviour disturbed others during group activities.

Table XIII: Inhibiting factors of UP as perceived by three groups of informants in CBO-G

Individual level	• **Users’ characteristics** «J'étais bloquée à plein de sujets, J'étais comme malade un peu ; il y a des intervenants qui me talonnent, ils me checkent, je suis fâchée et je reste dans mon appart; je ne voulais plus faire le bénevolat. » **U3** «On a au moins 200 personnes qui sont moins autonomes;pour eux, ils fonctionnent bien dans une routine, c’est rassurant pour eux d’avoir de faire les mêmes activités d'année en année. » **W4** «On m’a invitée à l’assemblée générale …j’ai écouté ce qu’il [le DG] disait mais ça ne me touche pas. » **U3**
	• **Users’ motivation** «Je ne suis pas fait pour ça, je ne serais pas peut-être bien vu pour arriver au conseil d’administration. ») **U4** «J'ai peur de me tromper, d'être impolie, ça me tente pas de travailler à la réception. » **U3** [l’usagère parlait quant à sa perception de son intérêt du travail bénévolat de réceptionniste]
Organizational level	• **Instability of user- managed activities** No quotation found that illustrates this subtheme
	• **Complexity of decision-making process** «Pour que les usagers s’impliquent dans des décisions sur les activités du centre de jour, il faut les préparer davantage, adapter [le propos] à leur niveau, avoir aussi l’ouverture de l’esprit pour bien les comprendre. » **A3** «Parfois le langage administratif au CA est difficile pour l’usager de bien comprendre. …il est possible que des fois l’usager parle peu dans des réunions de CA à cause de la complexité de certains dossiers. » **A4**
Social level	• **Stigmatization** «Si vous êtes sur l'autobus puis quelqu'un met une étiquette "C'est quelqu'un avec un problème en santé mentale »;… je leur demande d’essayer de ne pas juger, [d’effacer] toutes les choses préconçues; Puis il y en a qui comprend, il y a d'autres évidemment c'est difficile: les vieux patterns de voir les autres ayant des problèmes graves de santé mentale.» **W3** «Ils ne veulent pas participer dans les activités ici parce qu’ils ne veulent pas être étiquetés; je sais qu'il y a des gens qui ne veulent rien savoir ce genre de centre.» **W4** « Il y a des membres, ça a tiré par les cheveux autrement dit, ça veut dire ça n’a pas d'allure, tu sais… j’aime beaucoup ce que je fais à l’organisme E. et je veux garder mes activités comme ça.» **U3**

Interpretation of findings.

Several quotes from the group of user informants confirm the finding that service users in CBO G have personal characteritics which do not lend themselves to participating actively in the service delivery. Indeed no recurrent user run activity was observed in this CBO. The inhibitors for user participation remains at the individual level. Beyond the users'personal characteristics aforementioned, users' lack of self confidence may be hypothesized as a preceding factor in their lack of motivation to participate in the organizational structure of the CBO.

The phenomenon of social stigmatization is quite remarkable in that the service users themselves label negatively other service users within the CBO, as is depicted by the following quote from the group of users: "*C'est sûr qu'il y a du monde [les personnes utilisatrices de services] qui nous dérangent, fait qu'on tient pas à les déranger encore plus là. Fait que... on vit avec ça*" (U4). This negative labelling among service users themselves may also be a potent inhibitor for user participation at the organizational level in CBO G because its service users do not unite to voice their opinions collectively.

d) Advantages of user participation.

This section presents 1) *verbatim* comments from informants illustrating "Advantages of user participation" and 2) the interpretation of these findings.

Advantages of user participation.

Table XIV regroups the quotes from the three groups of informants discussing the advantages of user participation. At the individual level, from the point of view of one service user, her sense of well-being was enhanced by her ability to participate in a self-development workshop and to contribute as a volunteer to activities related to service delivery. The other service user indicated a sense of belonging to the CBO after participating in recreational workshops and working as a CBO employee.

At the organizational level, the advantages of user participation were limited to how the user representative could influence the BOD to make specific non-recurrent decision concerning the organization of one CBO activity. At the social level, the administrative informants stated that user participation presents some advantages because those that attend at least some CBO G activities require fewer hospital services and can live in supervised housing facilities as opposed to institutional settings.

Table XIV: Advantages of UP as perceived by 3 groups of informants in CBO-G

Individual level	Empowerment	«Au CA, l'usager a parlé au sujet de coupure de service au centre de jour, il était écouté et a influencé la décision finale [réorganisation des services au centre de jour].» **A4**
	Enhanced well-being	«Pour les usagers, c'est d'apprendre, de s'écouter, de faire confiance à nos intuitions, des choses comme ça. c'est un cheminement intérieur.» **W3** «En plus, nous on est allé dans un autre domaine qui a donné du succès, c'est un domaine plus intellectuel qui est le journal. Et ça c'est valorisant pour les gens aussi, beaucoup plus que toujours aller faire du ménage.» **A3** «C'est valorisant de participer dans des activités de groupe de croissance. » **U3**
	Citizen participation	
	1.Holding a socially respected role in CBO	**«**La semaine prochaine c'est elle [une usagère] qui va animer le groupe.» **W3** «J'ai fait quelques activités; ils ont eu une bonne perception de moi. Fait qu'ils m'ont demandé de devenir bénévole pour parler pendant les activités. Ensuite j'ai intégré l'entretien ...» **U4**
	2. Establishment of social spaces for UP in other public institutions	No quote from informants
	3.Establishment of a social support network	«Ils se connaissent très bien entre eux. Puis il y en a qui se fréquentent à l'extérieur du centre. Ils font des activités ensemble, ailleurs même.» **W3** «Eux qui sont plus fonctionnels, quand, à la pause ils jouent à un jeu serpent-échelle genre là, très simple avec 2-3 personnes qui sont peut-être moins fonctionnelles.» **W4**
	4.Development of sense of belonging to the CBO	**«**C'est un peu comme une famille il y a beaucoup de monde qui viennent depuis des années.» **W4** «Je leur ai dit que j'aimais mon travail ici. Je n'ai pas besoin de penser à ma famille directement, je peux penser à ces gens ici, c'est comme ma deuxième famille.**»** **U4**

Table XIV (cont.): Advantages of UP as perceived by 3 groups of informants in CBO-G

Organi-zational level	Adapted services	No quote from informants
	Transparency of decision-making process	«Écoute et prise en considération d'une autre perspective, surtout les opinions des usagers et des décisions du conseil en conséquence.» **A4**
	Contagion effect of user participation on other users	No quote from informants for this subtheme
	Benefits for CBO workers	No quote from informants for this subtheme
	Human resources	«Ils [les usagers] sont habitués. Une usagère aime ça couper le céleri. C'est toujours elle qui coupe le céleri; on avait quelqu'un aussi lors du repas qui aidait à servir.» **W3**
Societal level	Support for users living in the community	«Quand ils [les intervenants] les réintègrent dans la société, ils [les intervenants] les dirigent souvent ici.» **W3** «Les activités de loisir ou sport au centre pour les usagers occupent leur temps et il y a moins de chances qu'ils décompensent et se trouvent à l'hôpital.» **A4**

Interpretation of findings.

Consistent with the finding that there have been only a limited number of user participatory activities, the three groups of informants from CBO G perceived few advantages to their involvement. Noteworthy is the fact that at the individual level, the advantages of user participation to service users were discussed more by the staff and administrative groups than by the service users themselves. This finding may be associated with the personal characteristics of the user informants (e.g., lack of self-confidence leading to absence of participatory activities and the ensuing perception of no impact of their participatory activities on their wellbeing).

In contrast, the staff informants' perspective indicated that user participation brings about more advantages both at the individual and organizational levels. According to them, these advantages are users' sense of belonging to the CBO, users' network of social support within the CBO and additional human workforce to help them in their functions. From the administrative informants' viewpoint, the ensuing advantages of user participation are few since the actual user participatory activities are almost completely absent at the service planning and minimal on the BOD.

4.2.5 Comparison of CBO F and CBO G findings.

Differences and similarities between informants for CBO F (with a high score of user participation) and CBO G (with a low score of user participation) are discussed below and are presented in Table XV.

a*) Staff perspectives: Process of user participation.*

Within the first theme, CBO F staff play a major role in not only encouraging the service users to participate but also supporting them in the actual process of user participation (table VII and table XV). According to the group of staff informants of CBO F, users are actively engaged in programming CBO summer activities. In contrast, CBO G users must depend upon staff to represent and defend any new service proposals during the team meetings. Furthermore, service users from CBO F provide certain activities that are distinct from those delivered by the staff. In certain workshops, service users actually plan, recruit participants and implement the activities themselves. Therefore, the group of staff informants conceded that they play a supportive role. Moreover, service users are implicated in the decision-making process not only in the choice of activities, but also through their user-representative on the BOD, the highest governing body of the CBO, allowing them to change CBO rules or policies (e.g., making user attendance compulsory). Conversely, CBO G user participation was limited to that of a helper: called upon to provide occasional services (assistance in an activity) and provisionally in the absence of CBO staff.

From the staff's perspectives in both CBOs, service user evaluations of CBO services consist of indicating their satisfaction or dissatisfaction about a specific activity or service. It is clear that service user evaluations have some impact on high-scoring CBO F's actual programming or activities, while from the CBO G group of staff informants' perspective, user participation in service evaluation has minimal impact upon the programming of activities.

Given the fact that the two groups of staff informants are university educated and have similar years of experience working with individuals affected by serious and persistent mental health problems, the differences in the actual process of user particpation between CBO F and CBO G may be attributed to the degree of chronicity and seriousness of mental health problems of service users, as illustrated by the following *verbatim* comment by W3: "*On a une clientèle lourde*." In other words, according to the staff informants, user participation in CBO F is viewed as the activities of users playing the central role of planning, delivery and evaluating of certain services. In CBO G, the staff informants perceive the process of user participation as one-time participatory activities of service delivery during special circumstances and appear to think that participatory activities of most service users have little impact on service design. Consequently, another interpretation of the study result is that user participation in CBO F takes form in an active role- that of a partner with the administrative team and the staff. Concurrently, although there is some instance in which CBO G service users involve themselves in service delivery, user participation is more of a "reactive-passive" form. Indeed, service users "reacted" to the administrative request to replace staff although in these instances, service users were actively involved in providing service. Thus one plausible hyphothesis is that CBO G user participation appears to be instrumentalized as an incidental adminstrative means in responding to the organizational need of staff replacement rather than as part of a social strategy.

b) Staff perspectives: Facilitating factors for user participation.

In Table XV, under the heading Facilitating factors for user participation, subtheme Intra/interpersonal factor, there are noticeable differences between CBO F and CBO G staff. While the staff at both CBOs believe in the value of user participation, CBO F staff engage actively in critical introspective discussions and appraisals of their interactions with service users. As a result, concrete examples of their respect for and trust in service users' ability to participate in the organization of CBO activities as equals (staff and users as colleagues) were explained to the student-researcher during the interviews. Simultaneously, only one of the two staff informants of CBO G expressed his insights on the issue of promoting user participation. In one instance, a CBO G staff member indicated the possibility of involving service users in the planning of CBO activities and establishing a service user committee in the future. Given that the role of staff (in listening and accompanying users in their participatory activities) is found to be omnipresent in CBO F and rather limited in CBO G, it could be concluded that CBO staff's supportive interactions with users are essential for the optimization of user participation.

Within the subtheme organizational structure, while the CBO F staff emphasized the importance of their accompanying or supporting service users in user participation in CBO activities, CBO G staff conversed very little about their role in this regard. The two CBO F staff members concurred on the CBO values of democracy and service user empowerment. From their perspectives, user participation is actively present within the participatory space of CBO F; meanwhile, according to CBO G staff perceptions, participatory space exists in CBO G but is infrequently utilized by service users. More importantly, the issue of the legimitacy of user representation on the BOD is resolved by the election of user representatives by the majority of service users in CBO F. The issue of user representative legitimacy in CBO G remains unresolved. The current user representative on the BOD of CBO G was elected without any opposant and has been in place for more than five years The reason given by the CBO G staff informants is the lack of motivation and personal characteristics of the majority of service users. CBO G service users' social functioning is not optimal because of the severity of their mental health problems. The absence of formal structure within CBO G (in CBOF there exists an independent structure of regular meettings exclusively for users) may also account for the lack of service users' mobilization towards to elect their representative on the BOD.

c) Staff perspectives: Inhibiting factors for user participation.

Under the theme, Inhibiting factors for user participation, the opinions of staff from both CBOs converged on the social stigmatization of service users, both within the CBOs and in the wider community. Limited social credibility, due to service users' mental health problems, is considered a major inhibiting factor for user participation. Additionally, one CBO G staff member perceived that service users need to be involved in familiar CBO activities, but not the unfamiliar and more stressful processes of organizing activities. CBO F staff also pointed out that periods of instability in the service users' mental equilibrium and the complexity of decision-making processes within the BOD could deter service users from active participation.

Given these facts and, as mentioned earlier, for both CBO F and CBO G, it could be deduced that one of the inhibitors for user participation resides in the service users themselves. In CBO G, the group of staff informants remarked that the severity of mental health problems prevents service users from participating actively in service delivery. Concurrently, the group of staff informants provided a richer source of data that may be interpreted as follows: the stability of the mental health status of users is the facilitator that precedes user participation; once user participation in service delivery occurs, the sustainability of user-run activities is dependent on the organizational structure that supports user providers of services. The adaption of BOD work (in terms of language, the rhythm of meetingand the preparation for meeting) to the level of users'comprehension has to be accomplished before the occurrence of active user participation. Another inhibitor of user participation worthy of mention is the phenomenon of social stigmatization in which mental health service users are often perceived as less credible than others. Another explanation is that CBO staff's means of communication (i.e., rational) in sharp constrast with service users'ways of communication (i.e., emotional and even passionate) leads to staff' implicit discrediting service users' perspectives (M. Barnes, 2008; Carr, 2007; A. Gibson et al., 2012).

d) Staff perspectives: Advantages of user participation.

At the individual level, staff from both CBOs felt that participation in CBO activities enabled service users to enhance their sense of wellbeing, develop a sense of belonging to the CBOs and establish social support networks. In some rare cases in CBO G, in which service users were involved in service delivery (e.g., assistant to staff), service users also gained social status as user-staff within the CBO. Beyond these advantages, staff in CBO F also highlighted the empowerment of service users as a critical advantage.

At the organizational level, staff from both CBOs agreed on the organizational advantages of user participation, specifically access to a volunteer workforce. Other advantages, remarked uniquely by staff from CBO F, included user-adapted activities, benefits for staff, transparency of decision-making processes, and the "contagion" effect of user participation on other service users.

At the social level, CBO G staff drew attention to the advantage of involving service users in CBO activities in order to assist their continued residence in the community. Given the above facts, the two groups of staff informants converge on the advantages of user participation especially on volunteer work from the service users as service providers or assistants. However, the CBO F group of staff informants were quite eloquent in stating that user participation has much more impact on the decision-making process of the CBO and on the mobilisation of other service users towards even more active user participation. One possible hypothesis is that in CBO F, where users' input is valued in the participatory social space, the advantages or output of user participation is accordingly increased. Meanwhile, in CBO G, from the perspectives of staff informants, little input or participation of users within the social participatory space produces little, if any, output or advantages of user participation. Within this theme, it is noteworthy that most of the advantages attributed to service users, in their endeavours to participate in the organization of CBO services, were mentioned by staff.

Table XV: Four themes contrasting the groups of staff from CBO-F and CBO-G

Themes	CBO F (High score of user participation)	CBO G (Lower score of user participation)
Process of user participation		
a. Proposition of new activities within CBO	New activities planned by users **W1**	Worker's consideration of users' opinion **W3**
b. User participation in the decision-making	Users proposed that activity attendance to be compulsory **W 2**	No *verbatim*
c. User participation in service delivery	User's initiative to form a new group of user and to animate this group **W1**	User's acceptance to animate one workshop during the worker's absence **W3**
d. Service evaluation	Users evaluate orally at the end of each session **W1**	Discussion among users about their satisfaction or dissatisfaction at the beginning of each meeting **W3**
Facilitating factors		
a. Intra/interpersonal factors within the interactions between workers and service users		
i. Capability to call in question one's standpoint	Workers' willingness to question themselves and to be open for UP despite their fear of loss of decision-making power **W1**	Worker expresses the possibility to involve users in the planning of CBO activities **W3**
ii. Respect and trust	Workers respect the users' dream (even when it is apparently unrealistic) **W1**	Administrative team talks about the value of respect towards users **A3 and A4**
iii. Spirit of equality	Worker consider users as their colleagues **W1** Worker considers herself as co-pilot and user as pilot .**W2**	No *verbatim*

Table XV (cont.): Four themes contrasting the groups of staff from CBO-F and CBO-G

Facilitating factors		
b. Organizational structure	CBO F	CBO G
i. Physical environment	No *verbatim*	Physical layout of the CBO is welcoming for users **W4**
ii. Social environment		
Listening	Workers recognize the importance of listening to users' lived experiences **W1** and **W 2**	No *verbatim*
Values existing in these two CBOs	Workers adhere to CBO values of democracy and user empowerment **W2**	Worker's value the principles of recovery and respect towards users **W3**
Accompanying/Supporting service users	Worker accompanies user in the process of playing a major role in UP **W1**	No *verbatim*
iii. Social space accessible for user participation		
Space for discussion and deliberation	Users and workers reach most of the times a consensus **W1**	No *verbatim*
Space for user mobilisation	Active incidence of UP serves to mobilize other users **W1**	No *verbatim*
Legitimacy of representation	Election of user representative to BOD **W1**	No *verbatim*

Table XV (cont.): Four themes contrasting the groups of staff from CBO-F and CBO-G

Inhibiting factors		
a. Individual level	CBO F	CBO G
i. User characteristics	Fragility of users' mental health and their need to center only on themselves **W1**	Half of users of this CBO day centre need simple and familiar recreational activities to keep them busy **W4**
ii. Users' motivation	Users may have difficult moments so they are not interested in UP **W1**	No *verbatim*
b. Organizational level		
i. Instability of activities managed by service users	User has some difficulties to maintain the activity initiated by her **W1**	No *verbatim*
ii. Complex decision-making process	Certain functioning of BOD [e.g., BOD documentation] has to be changed to facilitate UP **W2**	No *verbatim*
c. Societal level		
Stigmatization	Workers' fear that in naming certain problems associated with mental health problems, the users may feel labelled negatively **W1**	As users of CBO G , people could be identified by others in the community as having mental health problem **W4**

Table XV (cont.): Four themes contrasting the groups of staff from CBO-F and CBO-G

Advantages of user participation		
a. Individual level	**CBO F**	**CBO G**
i. Empowerment	Workers' belief in empowering users **W1**	No *verbatim*
ii. Enhanced well-being	Users' self-confidence is enhanced by UP **W1**	In participating in creative workshop, users feel better **W3**
iii. Citizen participation		
a)holding a socially respected role in CBO	Users take upon themselves to form new group of mutual aid **W1**	One user will animate the group during worker's absence **W3**
b) establishment of other social spaces for user participation in other public institutions	No *verbatim*	No *verbatim*
iv. Establishment of a social support network	Existence of social support network between users **W1**	Existence of social support network between users **W4**
v. Development of sense of belonging to the CBO	Sense of belonging to the CBO from the users **W2**	Sense of belonging to the CBO from the users **W4**
b.Organizational level	**CBO F**	**CBO G**
i. Activities adapted for service users.	CBO services are adapted to the needs of users **W2**	No *verbatim*
ii. Transparency in decision-making process	Users, workers and directors listen to all different opinions; voting has been used to resolve differences **W2**	No *verbatim*
iii. "Contagion" effect of user participation on other users	Users are motivated by role model of other actively involved users **W1**	No *verbatim*
iv. Benefits for the CBO workers	Workers' efforts are concretely recognized by users **W1**	No *verbatim*
v. Human resources for the CBO	Users volunteer in organization of certain CBO activities **W1**	Users volunteer for simple activities **W4**
c. Societal level	**CBO F**	**CBO G**
Supporting users living in the community	No *verbatim*	Activities for users in the community instead of being hospitalised **W 4**

e) Administrative teams' perspectives.

The following text analyzes the similarities and differences in the perspectives of the administrative teams of both CBOs according to the four key themes. Table XVI depicts the divergent and convergent perceptions from this group of informants

As indicated in Table XVI, within the theme, Process of user participation, the director of CBO F was receptive to service users' proposals for new activities under favourable conditions (e.g., sufficient financial and human resources and number of service user requests). Conversely, the CBO G director, who was also the president of the BOD, did not indicate any instances wherein service users' proposals could be expressed and heard by the administrative team. Both directors indicated some degree of user participation in service delivery; but at CBO F this is an ongoing and recurrent process, while user participation in service delivery at CBO G is not a recurrent process. Within CBO F, user participation in service evaluation has contributed to change in service planning, while user participation in service evaluation was not discussed by the CBO G director. The interpretation about the differences in the process of user participation as perceived by the two CBOs directors may be explained by the fact of the regular interactions between the service users and the director of CBO F, whereas the CBO G director has little contact with the service users. The frequent interactions between the CBO F director and service users may contribute to the receptivity of the CBO F administrative team regarding user participation.

Another possible explanation is that within CBO F's structure for the past two decades a user committee has been in existence that provides a social space exclusively for CBO F service users to unite their voices in the process of user participation within the organization of services; in CBO G, on the other hand, no such user committee exists. Thus a social space contributes to the development of solidarity among service users and the subsequent active user participation.

Within the theme, Facilitating factors for user participation, the CBO F director asserted that a spirit of equality among staff and service users exists. Both CBO directors discussed their respectful attitude towards service users. The CBO values (user empowerment, user participation) were similar in both CBOs. The CBO directors did not discuss the role of staff interventions in accompanying/supporting service users. Having a social space for discussions and deliberation was acknowledged as a facilitating factor by both the CBO F director and the CBO G secretary of the BOD. Given these results, it is possible to argue that both CBO directors have the same convictions about the value of user participation in their organizations. But in the daily operations of both CBOs, the adminstrative teams' values in relation to user participation are not equally followed and applied. In order to facilitate user participation, the CBO F administrative team cited respect and trust their interactions and those of the staff towards the service users (as described in the preceding section on the analysis of staff informants' perspectives) as evidence of their implementation top-down of the principle of user participation in the organization of CBO services.

The major difference between the two CBOs in facilitating user participation on the BOD was the legitimacy of user representatives; these are elected annually in CBO F, while the one user-representative in CBO G has been on the BOD for several years. One possible explanation is that the existence of the user committee and its independence from the influence of the administrative team in CBO F has successfully mobilized most service users to regroup and elect their representatives to the BOD in order to legitimatize service users' participatory activities on the BOD. At CBO G, there is no user committee, and the administrative team appears to give priority to educating the staff in the value of user participation rather than expending its human resources on assisting the users to participate in the organization of services; this is illustrated by the following quote from the CBO G director:

> C'est beau de parler l'implication des usagers, mais c'est pas évident que tout le monde va devenir premier ministre…; il y a eu déjà des sessions de l'information pour le personnel sur le rétablissement chez nos usagers de service et aussi l'importance de leur implication dans notre service **(A3)**

Within the theme, Inhibiting factors for user participation, the CBO G team stressed the need to adjust the functioning of the BOD to meet the needs of the user representative.

Indeed the president of the BOD commented that certain people are predisposed to believing they can do little to change an organization. Although, social stigmatization of service users with mental health problems as an inhibitor to user participation was mentioned by other groups of informants from these two CBOs, it was not elaborated on extensively by the administrative team of CBO G. The interpretation of this finding may be that the adminstrative team from CBO F perceive the inhibitors for user participation to be mainly at the individual level (user motivation), and thus they would have no influence on these inhibitors. This interpretation converges with that regarding CBO F's organizational structure. Because the latter sustains the existence of an independent user committee, it can be hypothezised that administrative support rather than the personal characteristics of service users is crucial for active user participation.

Within the theme, Advantages of user participation, the two administrative teams converged on the social advantage of user participation: namely, the fact that the more users benefit from CBO services (either as users, user volunteers or user providers of services) the less likely it will be that they will require hospitalization. While the CBO F administrative informants elucidated numerous advantages of participation for their users, the CBO G adminstrative team mentioned few advantages for theirs, except for the one instance when the user representative spoke out. The interpretation of this finding is straigthforward. Since user participation exists in CBO F, the adminstrative team were able to observe the consequences or impact of user participation in a positive way. Conversely, as there is little user participation in CBO G, its administrative team observed little impact of user participation for service users and the CBO.

Table XVI: Four themes contrasting the groups of administrative teams from CBO-F and CBO-G

Themes	CBO F (High score of user participation)	CBO G (Lower score of user participation)
Process of user participation		
a. Proposal of new activities within CBO	Acceptance of some users' proposals by the director **A1**	No *verbatim*
b. User participation in the decision-making	Users' involvement in final decisions **A1**	No *verbatim*
c. Service delivery	Presence of UP in service delivery **A1**	UP in service delivery as a replacement for workers **A3**
d. Service evaluation	Director's openness to revise the planning of summer activities based on the users' evaluation **A1**	Complaints from users living supervised apartments **A3** No *verbatim* regarding UP in service evaluation at day center of CBO G. **A3**

Table XVI (cont.): Four themes contrasting the groups of administrative teams from CBO-F and CBO-G

Facilitating factors	CBO F	CBO G
a. Intra/interpersonal factors within the interactions between workers and service users		
i. Capability to call in question one's standpoint	The director's doubt about "the risk" of the BOD composed 100% of users **A1**	The director's affirmation of his affinity to the principle of recovery **A3**
ii. Respect and trust	Affirmation of respect towards user-delegates on the BOD **A2**	Affirmation of respect towards users **A3**
iii. Spirit of equality	User-delegates on the BOD are considered as equal as other members of the BOD **A2**	No *verbatim*

Table XVI (cont.): Four themes contrasting the groups of administrative teams from CBO-F and CBO-G

Facilitating factors		
b. Organizational structure	**CBO F**	**CBO G**
i. Physical environment	Affirmation of the BOD president on the importance of physical environment as conducive to UP **A2**	No *verbatim*
ii. Social environment *Listening*	Affirmation of the BOD president about his action of taking notice of users' opinions **A2**	No *verbatim*
Values existing in these two CBOs	Affirmation from director that "empowerment" and "democracy" are CBO values **A1**	Affirmation of the secretary of BOD about the importance of listening to users **A4**
Accompanying / Supporting service users	No *verbatim*	No *verbatim*
iii. Social space accessible for user participation		
Space for discussion and deliberation	Users discuss their points of view and influence the final decisions **A1**	Users' proposal for service delivery is accepted **A3**.
Space for user mobilisation	Users' enlisting other users' participation in the organization of CBO activities **A1**	No *verbatim*
iv. Legitimacy of representation	The independence of users' assembly to elect their representatives and substitutes to the BOD **A1**	No *verbatim*

Table XVI (cont.): Four themes contrasting the groups of administrative teams from CBO F and CBO G

Inhibiting factors		
a. Individual level	**CBO F**	**CBO G**
i. User characteristics	No *verbatim*	No *verbatim*
ii. Users' motivation	Lack of interest of some users to be involved in the business of BOD **A2**	The language and the functioning have been obstacles for optimal UP at the BOD **A3 and A4**
b. Organizational level		
i. Instability of activities managed by service users	No *verbatim*	No *verbatim*
ii. Complex decision-making process	No *verbatim*	No *verbatim*
c. Societal level		
Stigmatization	Users experience uneasiness when they are identified as having mental health problems in the community **A2**	No *verbatim*

Table XVI (cont.): Four themes contrasting the groups of administrative teams from CBO-F and CBO-G

Advantages of user participation		
a. Individual level	**CBO F**	**CBO G**
i. Empowerment	UP contributes to the empowerment of users **A1** and **A2**	Empowerment of user-representative to influence the BOD decision – making process **A4**
ii. Enhanced well-being	UP contributes to the promotion of well-being of users. **A1 and A2**	UP contributes to the promotion of well-being of users **A3** and **A4**
iii. Citizen participation *a) holding a socially respected role in CBO*	No *verbatim*	No *verbatim*
b) establishment of other social spaces for user participation in other public institutions	UP present on other CBOs and public institutions **A1**	No verbatim
iv**.** Establishment a social support network	No *verbatim*	No *verbatim*
v. Development of sense of belonging to the CBO	No *verbatim*	No *verbatim*
b. Organizational level		
i. Activities adapted for service users.	Existence of these two elements (adapted services and transparency in decision-making) **A1**	No *verbatim*
ii. Transparency in decision-making process	No verbatim	No *verbatim*
iii. “Contagion” effect of user participation on other users	No *verbatim*	No *verbatim*
iv. Benefits for the CBO workers	No *verbatim*	No *verbatim*
v. Human resources for the CBO	UP in delivery of for summer activities **A1**	No *verbatim*
c. Societal level		
Supporting users living in the community	UP in the organization of activities contributes to the lessened need of users’ hospital services **A2**	UP in CBO activities diminishes the chances of users’ hospitalization **A1**

f) Users’ perspectives.

This section analyzes the divergent and convergent perceptions of service users from both CBOs across the four themes. It is noteworthy that, in terms of comparative analysis, CBO F informants U1 and U2 are university educated, live independently and were either an elected user representative or substitute representative (i.e., replaced the user representative in BOD meetings or service user assemblies as needed). Conversely, the two CBO G user informants live in supervised apartments, have not completed their secondary studies and are not user representatives on the BOD. Although the average interview length for this group of user informants was 90 minutes, CBO F user informants expressed in detail their participation in the functioning of the CBO, while the CBO G users did not discuss specific instances of their participatory activities. Table XVII regroups user-informant quotes for both CBOs. The first finding of the analysis of users across the two CBOs is that the educational background of the users seems to be associated with their perspectives on their participatory activities.

Within the theme, Process of user participation, the CBO F user informants (U1 and U2) cited several concrete examples to illustrate the presence of user participation across all of the subthemes: service users’ proposing new activities and involvement in decision-making processes and service delivery and evaluation. However, only one CBO G user informant provided an example in which he had been involved in proposing a new activity for a specific group of users (including him); he was also involved in the decision-making process with the manager. Given this fact, it is quite clear that the process of user participation in CBO F is of a different nature from the process of user participation in CBO G, according to their service users’ perspectives. While CBO F service users play an active role in service design, delivery and evaluation during daily CBO operations and in BOD decision making, the CBO G service users do not participate in the organization of CBO services, except for one incidence. The next step in analysing this study finding and in accordance with the second study objective is to look for the most salient facilitators that precede user participation in CBO F and the most inhibitors that precede user participation in CBO G according to the users’ perspectives.

Within the theme, Facilitating factors of user participation, one CBO F user informant observed that staff often question themselves (i.e., staff's reflectivity) on their own standpoint (i.e., staff's valuation of user participation) during their interations with the staff. The user informants from both CBOs confirmed that they felt respected by the staff during their daily interactions.

Under the subtheme, Social environment as a facilitating factor, user informants from both CBOs acknowledged staff efforts in accompanying/supporting them; however, thestudent- researcher was unable to elicit from the two CBO G user informants about the nature of their interpersonal interactions with the staff (i.e., whether users feel supported by CBO workers to participate more actively in the organization of CBO services). The user informants from CBO F conceded that the CBO's values were consistent with staff and user interactions. But the student-researcher had difficulty to obtain clear answers to her questions addressed to CBO G informants about CBO G's values.

The last subtheme, participatory space as a facilitator of user participation, was well detailed by CBO F user informants; however, CBO G user informants did not see the relevance of their involvement in the organization of service planning or evaluations. Given these findings, the following interpretations can be made. CBO F service users pointed out three salient facilitors for user participation: (1) the respect and trust that they feel in their interactions with the staff, (2) the staff's strategies of listening and accompanying them in participatory activities and (3) their optimal utilisation of the participatory social space within the CBO. From the perspectives of the service users in CBO G, these facilitators for user participation were limited (except for some staff support to one user informant in his work as a volunteer).

Within the theme, Inhibiting factors for user participation, CBO F user informants did not perceive that their mental health problems or their level of motivation were barriers to their participating in the organization of CBO services. CBO G user informants talked about their lack of interest in user participation. Furthermore, the CBO G user informants seemed unaware of inhibiting factors at the organizational level. Meanwhile, CBO F user informants elaborated on certain inhibitors to user participation: the complexity of decision-making processes and the instability of user-managed activities. In terms of social stigmatization as a barrier to user participation, CBO F user informants emphazised the social distance between mental health service users and staff (including the administrative team), while CBO G user informants stressed the social distance between service users, specifically those who are socially less functional. As a result of this negative impression of other service users, CBO G user informants considered their participation within the CBO to be optimal.

Given the described data from both groups of informant users, one conjecture is that service users are insightful as to their capacities to participate in the organization of the CBO services. In contrast to their perceptions of CBO G service users, the more educated service users do not perceive that lack of personal motivation hinders user participation. Given the absence of a user participatory space in CBO G, it is not surprising that the group of CBO G user informants plays a minor role, if any, in participating in service delivery in comparison to the group of CBO F user informants.

Within the theme, Advantages of user participation, user informants from both CBOs confirmed that their sense of wellbeing was enhanced through user participation. While CBO F user informants felt empowered by their participatory activities, no similar statements were identified for CBO G user informants. The element -citizen participation- was considered an advantage by CBO G user informants working as volunteer helpers supporting staff. CBO F user informants expanded their participatory citizenship activities not only through active involvement in the CBO F governing body but also through involvement with other CBOs and public institutions. While CBO G user informants had established a group of friends at the centre, they did not discuss whether this social support network extended beyond the centre. In contrast, CBO F users affirmed that user participation was the cornerstone of their social support networks and contributed to their sense of belonging to CBO F. There was no clear agreement between the two CBO G user informants concerning their sense of belonging to CBO G: one user-informant considered CBO G as his second home, while the other perceived CBO G as a place for recreation free from supervision.

At the organizational level, CBO F user informants discussed as an advantage of user participation how user participation plays a major role in mobilizing other service users to become more involved in the CBO. Further, they recognized that their role in planning, service delivery and evaluations of summer activities was also advantageous for the CBO F. No quotes relevant to organizational advantages (e.g., adapted activities, additional human resources) were detected in the CBO G user informants' transcripts.

At the social level, neither user-informant group discussed CBO user participation as having an impact, positive or negative, on their need for hospitalisation or public mental health interventions.

Table XVII: Four themes contrasting the user groups from CBO-F and CBO-G

Theme		
Process of user participation	**CBO F**	**CBO G**
a. Proposition of new activities within CBO	User's proposal of new activities (ongoing process) **U1** and **U2**	User's proposal of new activities (one-time occurrence) **U4**
b. User participation in the decision-making	Involvement of users at all levels (e.g., on the BOD and during activities) of CBO **U2**	One instance whereby the group of users influence the CBO's director decision **U4**
c. Service delivery	User animation of a group of users **U1**	No *verbatim*
Facilitating factors	**CBO F**	**CBO G**
a. Intra/interpersonal factors within the interactions between workers and service users		
i. Capability to call in question one's standpoint	Some workers' self-questioning about their standpoint on UP **U2**	No *verbatim*
ii. Respect and trust	Workers demonstrate their respect towards users **U2**	Worker' trust in user promotes his participation **U4**
iii. Spirit of equality	No *verbatim*	No *verbatim*
b. Organizational structure	**CBO F**	**CBO G**
i. Physical environment	No *verbatim*	No *verbatim*
ii. Social environment		
Listening	Workers provide attentive listening **U2**	No *verbatim*
Values existing in these two CBOs	Empowerment is one of this CBO value facilitates UP **U2**	Perception of support from workers for users **U4**
Accompanying/Supporting service users	Perception of support from workers for users **U2**	No *verbatim*
iii. Social space accessible for user participation		
Space for discussion and deliberation	User's statement regarding the exercise of debate between users, workers and administrative team **U2**	No *verbatim*
Space for user mobilisation	Users model UP for other users **U2**	No *verbatim*
Legitimacy of representation	Election of user-delegates to BOD **U2**	No *verbatim*

Table XVII (cont.): Four themes contrasting the user groups from CBO-F and CBO-G

Inhibiting factors		
a. Individual level	**CBO F**	**CBO G**
i. User characteristics	No *verbatim*	Instability of user's mental status **U3**
ii. Users' motivation	No *verbatim*	Lack of user'interest in BOD work **U3** Lack of user's self confidence in becoming a user representative on BOD **U4**
b. Organizational level	**CBO F**	**CBO G**
i. Instability of activities managed by service users	Low attendance by other users in user-run activity **U1**	No *verbatim*
ii. Complex decision-making process	Difficulty to change the agenda of BOD **U2**	No *verbatim*
c. Societal level	**CBO F**	**CBO G**
Stigmatization	Social distance between user-representative and other members of BOD **U2**	Presence of users whose behaviours that are disturbing for other users **U3**

Table XVII (cont.): Four themes contrasting the user groups from CBO F and CBO G

Advantages of user participation		
a. Individual level	**CBO F**	**CBO G**
i. Empowerment	Feeling of being empowered in some affirmative actions towards the administrative team **U1**	No *verbatim*
ii. Enhanced well-being	UP brings out positive self-identity for users **U2**	Increased self-esteem **U3**
iii. Citizen participation		
a) holding a socially respected role in CBO	Being elected as user delegate at BOD **U2**	Doing maintenance work for the CBO **U4**
b) establishment other social spaces for user participation in other public institutions	UP at the BOD facilitates other involvement in other social activities outside this CBO **U2**	No *verbatim*
iv. Establishment a social support network	Formation of social group outside CBO **U1**	No *verbatim*
v. Development of sense of belonging to the CBO	Sense of belonging to CBO **U1** and **U2**	CBO as a second home **U4**
b. Organizational level	**CBO F**	**CBO G**
i. Activities adapted for service users.	No *verbatim*	No *verbatim*
ii. Transparency in decision-making process	No *verbatim*	No *verbatim*
iii. “Contagion” effect of user participation on other users	Active users serve as model of UP to other users **U 2**	No *verbatim*
iv. Benefits for the CBO workers	No *verbatim*	No *verbatim*
v. Human resources for the CBO	UP in organization of CBO services **U 2**	No *verbatim*
c. Societal level	**CBO F**	**CBO G**
Supporting users living in the community	No *verbatim*	No *verbatim*

4.3. Emergence of three core themes resulting from the analysis of study results

Beyond the nature of user participation, its determinants (i.e., facilitators and inhibitors) and its advantages, the following section brings together three core themes resulting from the second level of analysis of the study findings. During the second step of analysis (higher level of analysis), the *verbatim* most mentioned by the informants and their commonalities coalesce into three core themes: (1) recovery process of the mental health service users in relation with user participation, (2) the relevance of reflectivity as practiced by the CBO staff and administrative team and (3) the empowerment of service users who participate actively. Reflective practice from CBO staff may in fact ease the way for service users' in terms of assisting them towards active user participation and the ensuing user empowerment.

The recovery process of mental health service users has been documented in the literature as a non-linear, complex back and forth journey that at times are punctuated by phases:1) being diagnosed and being stigmatized as having mental health problems (Michalak et al., 2011) or the equivalent of the descent into "hell" (Noiseux & Ricard, 2008); 2) being disrupted in sense of identity and everyday activities (Bury, 2010) and working through feelings of grief and mourning; and 3) acquiring a sense of self that is associated positively and constructively with their mental health problems (Fullagar & O'Brien, 2012; Provencher, 2002; Quintal et al., 2013; Ridge & Ziebland, 2006). In this study, the form of participation in CBO has been modulated by the recovery process of service users. Service users who participate in the active form (as partner with CBO staff and or as service provider) are within the third phase since they express their feeling of well-being in their everyday activities (e.g., they volunteer at the CBO, participate in CBO recreational activites) and the positive effects of active participation in the CBO organization of services. Thus, it can be deduced that service users need to accomplish certain cognitive work (e.g, overcoming the disruption brought by mental health problems upon their life and gaining a positive sense of self) before they could participate actively in the organization of CBO services. Another possible hypothesis is that service users whose sense of self is yet to be consolidated positively also participate to a lesser degree in the organization of services with intense and sustained support from people within their social network be it family members, friends or their healthcare providers (Elstad & Eide, 2009). Effectively, the transmission of hope as an intervention from CBO staff and health professionals (community mental health nurses included), consisting of instilling, nurturing and diffusing hope to service users within the community settings has been strongly promoted and found to sustain users' recovery process hence has been widely promoted (Bonney & Stickey, 2008; McCubbin et al., 2010). Arguably, the specificity of the interactional communication between nurses distinct from other health professionals resides in their use of everyday speech (unscripted dialogue), the "day-to-day" relationships they develop with service users within a holistic approach (Hurley, 2009; Shanley & Jubb-Shanley, 2007).

The study results indicate that CBOs staff are reflective in their interactions with the service users. Reflective practice has been defined as the ability of health care providers to stand back and question crtitically themselves about their feelings and attitudes (psychic and affective reflectivity) towards mental health service users and their theoretical framework underpinning their interventions/interactions with service users (conceptual reflectivity) with two ultimate objectifs: the development of professional practice more in tune with the service users' health concerns and the promotion of the service users' well-being (Bristow, 2008; Mezirow & Taylor, 2009; Tee et al., 2007). (Bristow, 2008; Mezirow & Taylor, 2009; Tee et al., 2007). Thus, it is feasible that the CBO staff critically appraised the presumptions ingrained within their personal frames of reference or "meaning perspectives" (i.e., how and why they think, feel, and act within the context of their work with mental-health service users) (Mezirow & Taylor, 2009). In doing so, their initial perspective, regarding the value of scientific knowledge (concerning the meaning of living with mental health problems), transforms to a different mind-set leading to a deeper understanding of the service users' social world and their lived experiences (Thompson & Pascal, 2012). This transformation of meaning perspective was evidenced by CBO staff's acknowledgement that the experiential or lived knowledge of service users is more meaningful in the resolution of several issues of importance to users' everyday activities (e.g., users' management of medications, users' coping mechanism of their anxiety) than their own academic background and professional experiences.

Henceforth, it can be conjectured that CBO staff's reflexivity underpins their respectful interactions with service users. In the CBO with the high score on user participation, staff demonstrate reflexivity by providing attentive and non-judgemental listening to service users' voices and taking into consideration their input as experts (by the lived experience of mental health problems and of using mental health care services) (McLaughlin, 2008) not only in the micro-management of CBO daily activities (i.e., user – helper in workshop) but also in the BOD work. Furthermore, the director of the high score CBO demonstrates her psychic reflectivity in her work as the highest-ranking manager in the CBO in conceding to her uneasiness to have most of the CBO activities run by the service users. As such, CBO Fstaff and the director' reflective practice appears to transcend the traditional power dynamics existing between the staff and the service users. Service users empower themselves to take on the social-valued role of user-helper thus the role of partner in relation to the staff on an equal footing (S. McDaid, 2009).

Empowerment represents the process in which service users acquire skills, gain access to decision-making instances within CBOs situated in their community of residence, and thus have some influence and even control over organizational and social issues that matter to them (Linhorst, 2006; Zimmerman, 2000). Within the community mental health domain, empowerment has been associated with user participation more as its ensuing effect than as its antecedent (Linhorst, 2006; Tambuyzer & Van Audenhove, 2013). User participation in the active form (service user as partner with CBO staff) is found to have an enduring empowering effect for service users and the CBO. Indeed power should not be mainly about the control that people have over others but power has significantly more social value as the influence that people have over their actions (Mendel, 1998). Undeniably, in participating actively with CBO staff and the administrative team, service users empower not only themselves but also play a major role in transforming the organizational structure of CBO.

Empowerment has been studied more at the individual and interpersonal levels than at the organizational level (Rogers et al., 2007). However, this study's findings show that the high score CBO has the characteristics of an empowering organization in the way that its administrative team demonstrates leadership in making accessible to service users participatory spaces (e.g., BOD, user assembly), in integrating user participation into its organization structure of service delivery. This study adds to the small but growing body of knowledge that suggests that an empowering organization plays an important role in promoting mental health service users' community participation and integration (Janzen, Nelson, Hausfather, & Ochocka, 2007; C.T. Mowbray, Lewandowski, Holter, & Bybee, 2006; Svanberg, Gumley, & Wilson, 2010).

Chapter 5

Discussion

The following chapter discusses (1) the findings of this study in conjunction with the literature on user participation, (2) recommendations regarding avenues for improving nursing education and practice, (3) recommendations for further research studies contributing to the corpus of knowledge on community mental-health care related specifically to user participation, (4) recommendations for policies and decision-makers to actualize the value of user participation into principles and concrete plans of actions in order to optimize mental-health service user participation in the organization and delivery of CBO activities, and (5) the methodological limits and strengths of this study.

The study's objectives were to document and describe the nature of mental-health service user participation within CBOs and to explore the individual, organizational, social and political factors that facilitate or hinder user participation. Although the corpus of knowledge on user participation within public mental-health institutions has grown substantially (Abelson et al., 2007; Bradshaw, 2008; Kemp, 2010; Lub & Uyterlinde, 2012; Mitton et al., 2009), there remains a dearth of literature on user participation in CBOs within the community mental health domain (Akingbola, 2012; Poirel et al., 2011). While studies on user-run organizations and self-help groups have been on the rise in high income countries across North America (the U.S.A. and Canada) and Europe (Grant, 2010; Hernandez et al., 2010; Hutchison et al., 2007; Pistrang et al., 2008; Radermacher, Sonn, Keys, & Duckett, 2010), actual user participation within the organizational and service-delivery structures of CBOs, particularly those operated by non-service users, remains under-documented (Muir et al., 2010; Panet-Raymond & Lavoie, 2008; Poirel et al., 2011).

The originality of this study stems from its focus on the nature of user participation in mental healthcare CBOs and its socio-political determinants embedded in a French-Canadian urban setting. Based on the literature review, a schema was proposed to guide the study of the nature of user participation and the factors facilitating and inhibiting it at the individual, organizational, social and political levels. The following sections present the study's findings from the first and second phases of the study as compared to other published works.

5.1 Study findings: Phase 1

In the first phase of the project, the Adapted User Involvement Questionnaire survey was administered to 12 CBOs, subsequent to which two CBOs were selected for phase two. Findings based on the first phase of the study are discussed according to the four dimensions of user participation and are contrasted with other empirical studies on user participation in CBOs.

5.1.1 First dimension of user participation: Official roles of users on the BOD.

The presence of two user representatives on a BOD suggests a potential for mutual support among the user representatives in fulfilling their role on the BOD (M. Barnes & Sharlow, 1997; Broqua & Jauffret-Roustide, 2004). Although four of the study's CBO directors affirmed that user representative could hold an official role (i.e., president, vice-president, secretary or treasurer), no user representatives filled these roles in three of these CBOs. One plausible explanation, as advanced in the literature, for the quasi-absence of users in official BOD roles is that these positions are elected from among BOD members; thus, as user representatives are a relative minority, numerically they have a reduced chance of securing an official role on the BOD (Grant, 2007; C.T. Mowbray, Robinson, & Holter, 2002). Another hypothesis holds that service users who are engaged in a process of building a more positive social self-identity may not perceive themselves as being able to fulfil these official roles, hence, do not present themselves for such roles (Tew et al., 2012).

The service users' limited social functioning, generally related to the intensity of their persistent mental-health problems (as reported in the CBOs' annual reports), was a commonality among the low-scoring CBOs. Nonetheless, several authors assert that the perceptions of staff, director, in relation to the service users' interpersonal skills or perceived lack thereof, are a contributing factor to low user participation in CBO organizational structures and the delivery of services (Dobransky, 2009; Radermacher et al., 2010; Tee et al., 2007). Indeed, Barnes and Bowl (2001) found that the mental-health service users' sense of self, in regard to their capacities, is profoundly affected by the perspectives of others (particularly non-users or professional healthcare providers). Not unexpectedly, user participation within an organization often conforms to others' expectations vis-à-vis user participation in activities, including their ability to participate. Other scholars conjecture that the service users' self-stigma (i.e., labelling oneself with negative characteristics) not only affects their self-esteem (Camp, Finlay, & Lyons, 2002) but also accounts for their limited participation in community activities (Brohan et al., 2011; Hall & Cheston, 2002).

The election of BOD user representatives by service users at the CBO annual general assembly is seen as the democratic mechanism legitimatizing the role of user representatives. Indeed, the application of an electoral process has been found not only to empower the user representative to express his or her opinions on the BOD but also to enhance the credibility of his or her proposals within the BOD's work (Duval, 2007; Whitney, Harris, & Anglin, 2008). Nonetheless, other studies (F. Brooks, 2008; Gauld, 2010; Martin, 2008) question the legitimacy of using an election process alone as an absolute indicator of user representativeness. However, the legitimacy of user representation by election was not raised as an issue among the study's CBO sample, which may be explained by the fact that most of the CBO directors' expressed view that this was a generally accepted democratic practice.

5.1.2 Second dimension of user participation: Management of CBO staff.

The study's findings indicate that user participation in CBO staff management within the majority of the CBOs is minimal. The literature identifies and underscores the following factors contributing to minimal user participation in staff management: staff resistance and the conflict between different sources of knowledge (i.e., academic vs.

experiential knowledge). Several authors (Bennetts et al., 2011; Diamond et al., 2003; Gordon, 2005; Rummery, 2009) attest to a resistance among mental healthcare providers (e.g., psychiatrists, nurses, social workers) in public institutions and some CBO staff to the inclusion of service user participation in staff recruitments and in-service trainings. Hansen and colleagues (2004) conjecture that the low credibility of service users' experientially-based opinions in comparison to those of academically-accredited professionals, the resistance to the redefinition of roles from 'user-as-helpee' to that of 'user-as-helper', and the historically-ingrained paternalistic approach to individuals with serious mental-health problems may explain limited user participation in staff management issues. These points have also been raised by Whitney and collaborators (2008).

5.1.3 Third dimension of user participation: Planning, delivery and evaluation of CBO services.

As discussed in Chapter IV, all of the CBO user-informants in this study indicated that they informally evaluated CBO services during their interactions with staff. The CBO staff or administrative teams also conduct weekly meetings in which user feedback is discussed. In some of the CBOs, formal written evaluations are also used. According to some studies (Sibitz et al., 2008; Wynaden et al., 2012), user evaluations, in terms of service users' satisfaction or dissatisfaction vis-à-vis the proffered services, are the most prevalent form of user participation in CBOs and mental health public institutions. Some even present guidelines for family and user participation in CBO service evaluations (Finsterwald & Spiel, 2012; Repper & Perkins, 2006). Beal (2007) describes the process by which the service users' input changed the Canadian Standards for the practice of psychiatric mental-health nursing. Additionally, Weinstein (2006) asserts that user auditing of the service-care provided by a public mental-health centre results in tangible improvements in services. Nevertheless, there remains a paucity of literature on the following dimension of user participation in CBOs: user evaluations of the organization, appropriateness and quality of services.

Within 7 of the CBOs (out of 11 CBOs, one was eliminated from the original 12 due to its unique mandate), service users are involved in some forms of CBO service delivery. This fact is consistent with numerous studies on service user volunteerism within CBOs (Muir et al., 2010; Raponi & Kirsh, 2004) and the subsequent social, organizational and individual benefits. However, service users in the high-scoring CBOs, relative to this dimension, did not have employee status despite their active participation in service planning and service delivery. Some CBO directors were nonetheless receptive to the possibility of employing users as service providers in the future. The study's finding also coincide with the recent Quebec evaluative study on the integration of service users as regular paid staff in some CBOs and public health institutions (Provencher, Gagné, & Legris, 2011). This relatively recent phenomenon (user-provider employment) aligns with the growth in research literature pertaining to the implementation of peer-provider services and the merits of these services (Kidd et al., 2007; Moll, Holmes, Geronimo, & Sherman, 2009; Sells, Davidson, Jewell, Falzer, & Rowe, 2006).

Additionally, active participation in their recovery, as a global social movement (M. Barnes & Coelho, 2009; Van Til, Hegyeshi, & Eschweiler, 2007) and as an individualized journey for service users, is crucial for users in reclaiming, collectively and individually, their social identity. As a result, as part of the recovery movement, users are being called upon to become more actively involved not only in their mental healthcare but also in the organization of that care, and this despite the severity of their mental health problems (Piat et al., 2009; Stotland, Mattson, & Bergenson, 2008)

Consequently, the recovery approach has been transformed, by researchers and clinicians, into guiding principles that should, ideally, shape mental healthcare institutions and their services (Piat, Sabetti, & Bloom, 2010; Tsai et al., 2011). Within the spirit of a recovery-oriented mental healthcare system, the introduction of the new peer- or user-provider role (i.e., the user is employed and has a status equivalent to non-user staff) in CBOs and public health institutions has gained in social recognition as a viable alternative or complement to traditional professional treatment teams (Wakefield et al., 2011). In this regard, Lewis (2009) found that the volunteer sector is, in fact, leading the way in implementing government-directed policies for user participation in daily operations.

5.1.4 Fourth dimension of user participation: Networking with other institutions.

This dimension of user participation was an adjunct to the original survey conceptualized by Diamond (Diamond et al., 2003) in light of the literature pertaining to CBOs in Quebec (Burlone et al., 2008; Jette, 2008; Panet-Raymond & Lavoie, 2008). Half of the CBOs in the study sample did not involve service users in networking with other CBOs and public mental-health institutions. A plausible hypothesis for this might be found in the spontaneous answers of three CBO directors. They perceived their specific executive and official functions to include representing their organization during instances of networking with other CBOs or public institutions. Therefore, it can be conjectured that for some participating CBO directors, their role as the CBO's official representative in networking with other CBOs and public health organizations is highly valued by them. As a consequence, these directors would not delegate this function to service users. Besides, certain scholars have suggested that the alliance between service users and CBO administrators, built upon a positive interpersonal relationship, is a major factor leading to the delegation of networking responsibilities (Beresford, Harrison, & Wilson, 2002; Starnes, 2001).

5.2. Study findings: Phase 2

The following four themes are discussed in this section: (1) the process of user participation, (2) the facilitating factors for user participation, (3) the inhibiting factors for user participation and (4) the advantages of user participation. The first three themes were identified from predetermined codes based on the schema of user participation determinants (Figure 1). The fourth theme was identified from *verbatim* transcripts of the three groups of informants from the two divergent CBOs: one with the higher score for user participation, CBO F, and one with the lower score, CBO G. The remaining three themes are discussed (i.e., facilitators, inhibitors and advantages) according to the different levels: individual, organization and social levels. Noteworthy, the student-researcher was not able to identify any elements that could be classified at the political level.

5.2.1 The process of user participation.

Bracht (1990) defines: “User participation as the social process of voluntarily taking part in formal and informal activities as well as in discussions to bring about changes or improvements in the participants’ lives and access to services” (p.110). This study has enriched this definition by further defining user participation as a social process at two different levels (individual and organizational) and in detailing four constituting elements of user participation. As such, the study’s finding on the definition of user participation is in agreement with Tambuyzer and other colleagues (2011) in their review of more than 45 definitions of user participation/user involvement.

At the individual level, user participation in the studied CBOs consisted of service users submitting proposals as part of regular formal meetings among users and between users and staff and/or administrators in CBO F (high score for user participation). In CBO G (low score), service user proposals are submitted informally to the staff, who then must be relied on to raise these proposals with the administrative team. CBO F demonstrates the characteristics of an organization with a supportive social environment in which a receptive administrative team and staff enable and encourage users to articulate their needs and formulate proposals for changes in services. Organizations with a supportive social environment, as demonstrated in CBO F, have been found by other researchers to have a positive effect on user participation (M. Barnes, Davis, & Rogers, 2006; Hernandez et al., 2010; Maton & Salem, 1995). The intermediary role/function (i.e., on behalf of the users) of CBO staff and healthcare professionals in public institutions, as seen in CBO G, has been documented extensively in the literature (Harrison, Barnes, & Mort, 1997; Kent & Read, 1998; Robson et al., 2003b; Wynaden et al., 2006). Thus, this study, through the two CBO case studies, is illustrative of the two forms of user participation in CBOs and as documented in the literature.

Neither CBO is a user-run organization. User representatives comprise one out of the seven BOD members in CBO G and 3 out the 10 in CBO F, and they also have distinct differences in terms of user participation in the organization and delivery of services (i.e., planning, delivery and evaluation). During daily activities in CBO G (low score), user participation was limited to activities in which users assisted staff and, on occasion, acted as short-term replacements for staff. This phenomenon of limited user participation in the organization of CBO services, as found in CBO G and inasmuch as it pertains to individuals with severe and persistent mental-health problems, is consistent with the literature on user participation in community activities (Granerud & Severinsson, 2006; Horgan, 2007; C. T. Mowbray, Woodward, Holter, MacFarlane, & Bybee, 2009)

At CBO F (high score), user participation is present across all stages of service delivery (activity planning, delivery and evaluation) and is accessible to all regular service users attending CBO F. Even though CBO F is not a user-led organization, the presence of active user participation is consistent with the body of literature describing user-run organizations and the integration of user-providers (i.e., as part of user participation in service delivery) into the mental healthcare system (Beetlestone et al., 2011; Bellamy et al., 2006; Fukui, Davidson, Holter, & Rapp, 2010; Nelson & Lomotey, 2006; Tanenbaum, 2011).

Generally, according to the literature, user participation in service evaluations consists essentially of service users' feedback to staff about their satisfaction or dissatisfaction with an activity or service (Binet et al., 2004; Nelson, Ochocka, & Lord, 1998; Repper & Perkins, 2006). A major finding from this study is that at the organizational level, CBO F service users aspire to user participation status not just as consultants but as volunteers who contribute to the planning and delivery of services to other service users in partnership with the CBO staff and administrative team.

5.2.2 Facilitating factors for user participation.

In comparing and contrasting the two CBOs, two factors contributing to more active user participation in CBO F at the organizational level were identified: (1) the formalization of participatory social spaces for service-user deliberation and mobilisation and (2) a shared belief among users and staff in recovery and the contributory value of user participation. Comparatively, and as a direct result, user participation was more actively pursued in CBO F than in CBO G. CBO F has established formal, structured spaces for users to participate in the organization of services (e.g., users' committee to plan CBO summer activities), whereas, in CBO G, there are no structured spaces (e.g., summer activity-planning is carried out by the CBO staff).

The study's first finding, that official user participatory space within a CBO is an organizational facilitating factor, also concurs with the literature on user participation including community mental-health institutions (Clément & Bolduc, 2009; Saout, 2009) but also in other healthcare services targeting disenfranchised sub-populations (e.g., people with physical handicaps) (Castro-Silva et al., 2008; Milner & Kelly, 2009; Tremblay, 2007). The second finding, that a shared belief in the recovery approach and the value placed on user participation by CBO staff and service users is an organizational facilitating factor, is also corroborated by several researchers examining user participation in consumer-run organizations (Fukui et al., 2010; Grant, 2007). Together, these two findings on organizational facilitators add to the corpus of knowledge on user participation in mental-health CBOs as follows: the implementation of an official user participatory space has to be done simultaneously with the offering of educational sessions for CBO staff and service users on the value of user participation in order for users to involve themselves in the organization of services and for staff to accompany users in their process of participation(Perkins et al., 2007). Conversely, CBO G exemplifies an organization that has only partially implemented this approach: it has initiated a process of staff education on the value of user participation. However, limited user participation was observed in the organizational structure of its services probably due to limited organizational space for user participation.

On the basis of the evidence presented in this comparative study, active user participation in mental health CBOs is sustainable but is conditional on the practice and value of user participation being integrated among users and staff alike and the provision of space within the organization rather than as a directive to staff. This fact is in agreement with Duval (2007), who stresses the importance of CBO staff and users working together to adapt CBO services to be more in tune with service users' needs.

At the individual level, the major facilitating factor for active user participation is the existence of mutual trust and respect between the users, staff and/or administrative team. To a great extent, the organizationally embedded value of user participation, evidenced by an empowerment-based approach (i.e., staff act as co-pilots to users in their participatory projects), optimizes user participation in the organization of services. This finding further substantiates other published works on the role of mental healthcare providers as guides in accompanying users in their recovery (Corrigan et al., 2012; Davidson, O'Connell, Tondora, Styron, & Kangas, 2006). Further, recent studies have shown that active user participation is enhanced by the quality of the interpersonal relationships between users, staff and mental healthcare providers in the community (Tew et al., 2012; Ware, Hopper, Tugenberg, Dickey, & Fisher, 2007).

Undoubtedly, CBO F staff focus on coaching service users towards leading a meaningful and socially fulfilling life (as defined by the service user) as well as towards developing and maintaining social contacts within their communities' of residence. In other words, CBO F staff practice a philosophy of mutual support and empowerment, previously identified as a facilitating factor by other researchers (Brown et al., 2008; Poirel et al., 2011; Robson et al., 2003a) during staff-user interactions.

Finally, all CBO informants in the study placed more emphasis on the facilitating, rather than inhibiting, factors of user participation. This contrasts with the literature, which is more descriptive of challenges and barriers to user participation (e.g., financial constraints, negative staff attitudes, mental health care based on bio-medical care, the asymmetry of power between users and staff) (Bennetts et al., 2011; Tsai et al., 2011).

5.2.3 Inhibiting factors for user participation.

The study identified individual and organizational factors that hinder user participation in the CBOs as (1) service users' personal characteristics associated with their mental-health problems and (2) social stigmatization.

CBO G (low score) staff perceived service users' personal characteristics (i.e., low social-functioning) associated with a life-course of persistent and serious mental-health problems as an inhibitor to actualizing user participation. Conversely, in terms of the UP inhibitors, CBO F (high score) staff perspectives, attributed inhibitors to fluctuations (i.e., non-linearity) in the service-users' recovery process and the fact that the organizational structure appeared to provide insufficient support for user-managed activities and UP on the BOD.

Contrary to the literature, the study found that staff and users in both CBOs did not bring up potential tensions between them due to their different perceptions related to user participation (Norman, 2006; Pigeon & Fortin, 2005). Users in the high-scoring CBO iterated the support they received from the staff to participate in service design, while users in the low-scoring CBO did not perceive themselves as having the capacity to participate actively in service design.

Although, and in contrast to the study's findings, tension between users and staff is well-documented in the literature, particularly in regard to conflicts between health professionals and service users regarding the users' level of contribution to healthcare plans and participation in organizations providing services (Bochel, Bochel, Somerville, & Worley, 2007; Gordon, 2005; McCann et al., 2008; Tee et al., 2007; Wakefield et al., 2011). This contrary finding may be rooted in the fact that CBOs, in general, are perceived as offering a supportive voluntary service, an alternative and complementary service, to the biomedical healthcare treatment offered by public institutions; hence, they are less subject to the same tensions (Corin et al., 2011).

Within the mental-health domain, social stigmatization is defined as the negative labelling or stereotyping of individuals on the basis of differences in appearance and/or behaviours associated with mental health problems (Camp et al., 2002; Depla, de Graaf, van Weeghel, & Heeren, 2005; Pinto-Foltz & Logsdon, 2009). In agreement with other research studies, in this study, social stigmatization, as verbalized and perceived by the user-informants, was identified as being present in the CBOs and seen as limiting users' participatory activities (Battams & Johnson, 2009; C. Berry, Gerry, Hayward, & Chandler, 2010; Pescosolido et al., 2008; Rusch et al., 2006). Certain user-informants perceived both the social distancing (between them and the CBO staff and administrative team) and their service user identity as factors inhibiting their optimal participation. Conversely, the administrative informants attributed the lack of active user participation to service users' lack of self-confidence and limited personal experience, particularly in BOD work.

5.2.4 Advantages of user participation.

In line with previous research, the service users in both CBOs recognized several benefits to user participation (either in their role as volunteers supporting service delivery or as stakeholders in decision-making processes) for the service user: (1) enhanced mental wellbeing, (2) a sense of belonging (Mezzina et al., 2006), and (3) ability to develop a self-identity beyond that of an individual living with mental-health problems (Granerud & Severinsson, 2006; Schön et al., 2009). In fact, in terms of the third benefit, study informants in both CBOs expressed their sense of belonging to the CBO, and this, despite concurrent feelings of being stigmatized and devalued socially because of mental-health problems (Dobransky, 2009).

Within both CBOs, the influence of user participation upon the organizational structure (i.e., the implementation or non-implementation of service users' proposals) was of lesser importance to the service users than their perception regarding the responsiveness or receptiveness of the staff and administrative team toward these proposals. This finding is consistent with the results of other study on user participation in community-based art workshops (Howells & Zelnik, 2009) and community-housing organizations (Browne & Hemsley, 2010). The role of service users as active, daily protagonists of certain micro-changes in the organization of CBO services concurs with the vision of user participants as the everyday makers-of-change described by Bang and Bochel (Bang, 2005; Bochel et al., 2007). Mental health service users perceive their involvement in CBOs as meaningful when they can voice and discuss concerns with the staff and administrative team. Indeed, service users' participatory activities, as indicated in this study, are meaningful because of the service users' perception of being givers (i.e., co-providers/producers of services to other users in partnership with mental health professionals) – a self-identity more positive than that of service users.

The most prevalent body of literature discusses and depicts user participation in the form of user consultants at ad-hoc public consultation forums (M. Barnes & Coelho, 2009; Litva et al., 2009; Mitton et al., 2009). However, meaningful participation has to be perceived fundamentally by service users; it must engender satisfaction in the participatory activities, result in a perceived benefit from the activities, and give the perception that their contribution is genuinely respected, accepted and/or valued (Macdonald & Mullet, 2008). In other words, service users want to connect their participatory activities with actual organizational changes, regardless of the magnitude of those changes. They aspire not for ultimate control of decision-making processes in service delivery and evaluations but to have their experiential knowledge and input validated through concrete changes within the organization providing services (Hutchison et al., 2007). The indicators of meaningful participation from the service users' perspectives include a sense of belonging, a chance to make choices and a perception that their ideas count (Corrigan et al., 2012), as evidenced in CBO F.

5.3 Recommendations

5.3.1 Recommendations for education, practice, and research in community-mental health nursing.

As aforementioned, the ecological approach served as the theoretical lens for the student-researcher in addressing the research questions (i.e., user participation and its determinants) and analysing the study's results. Within the field of health promotion and public health, the ecological approach has gained popularity as a perspective for examining individual and environmental (e.g., individual, interpersonal, organization, political) determinants of human behaviours (e.g., nutrition, physical activity, etc.) (Richard et al., 2011). Nevertheless, in the domain of mental health promotion, specifically at the tertiary level of preventive measures targeting service users, the ecological approach has yet to be widely utilized to study service users' behaviours (e.g., participation in community activities) with a view to sustaining their recovery process (Rossler, 2006). This study's unique contribution to the ecological approach knowledge base resides in the fact that it explores a social process, as experienced by one of the most marginalized subpopulations (i.e., the service users with serious and enduring mental health problems), across multiple determinant levels.

This section consists of recommendations that impinge on education, practice, and research needs in the field of community mental-health nursing.

a) Education for community mental-health nursing.

Given that the study's goal was to explore and document user participation in mental-health CBOs including the facilitators and inhibitors of user participation, its results may contribute to the body of nursing knowledge, specifically, on the practice of mental health nursing in supporting service user in community participation. It provides information on the role of service users in the organizational structures of CBOs and on the specific facilitators and inhibitors over which nurses have some influence. The value of UP, an intrinsic approach towards community integration for service users, and UP as an interventional avenue for sustaining service users' recovery has yet to be ingrained in the role of mental-health nurses working in the community (Bennetts et al., 2011).

Therefore, as part of community mental-health nursing curricula, nurses should become acquainted with the network of mental health CBOs, their services, and the varied organizational approaches from non- to fully-inclusive of the user participation approach. From this study's findings, service user members of CBO governing BODs could be solicited to speak to nursing students about their BOD experience as part of their participatory activities. They could dialogue with nursing students about the potential role of community mental-health nurses in facilitating user participation within CBOs as part of the nursing interventions (e.g., coaching service users in requesting for new CBO services) intended for service users living in the community. The service users as guest-speakers within nursing classrooms or at conferences has also been asserted by Hinshaw and Stier (2008), as an effective means of attenuating social stigmatization towards service users through constructive debates between the service users and groups of citizens (nursing students in this case).

The role of service users as educators contributing to nursing education is one of the promising avenues through which community mental-health nurse interventions can be shifted from interventions based on the traditional bio-psychosocial medical model to a nursing practice that is underpinned by the recovery-oriented and user-centred paradigm of which user participation is a major component (Bennett & Baikie, 2003; Khoo, McVicar, & Brandon, 2004; Schneebeli, O'Brien, Lampshire, & Hamer, 2010). Indeed, it is suggested that nursing education needs to be explicitly focused on the application of recovery-oriented care delivery (Gale & Marshall-Lucette, 2012). As a point of fact, some authors (Holm & Severinsson, 2011; McLoughlin & Fitzpatrick, 2008) affirm that nursing recovery-focused intervention approaches should be explicated to students (e.g., emotional support for users' self-advocacy activities in dealing with social issues, practical support for stress management, coaching service users towards a more active social role in the community). Students and nurse clinicians, need to be more informed about the patient-partner approach, not only in shared decision making regarding medically-related treatment plans (McCloughen, Gillies, & O'Brien, 2011) but also in the evaluation and shaping of mental-healthcare delivery (Litva et al., 2009; Wallcraft, 2012). A consensus exists in the literature that the patient-partner approach should encompass the service-user's self-determination and assumption of responsibility in the choice of healthcare services, based on respectful and trusting relationships as well as collaborative interactions with nurses (Green, 2014; Shanley & Jubb-Shanley, 2007; Thomas et al., 2010)

Furthermore, nurse scholars who are responsible for designing the nursing curriculum would be well-advised to educate nursing students on integrating reflective practices into their work with mental-health service users. Reflective practice in nursing praxis has been underpinned by Watson's Human Caring philosophy (Cara, 2003) in research studies conducted by Dube (2012) on elder care as well as Cara and O'Reilly (2008) on patients needing rehabilitation care. Within mental-health community nursing, among the ten clinical *caritas* (i.e., Greek, meaning to cherish and give special loving attention) processes [core tenets of the Watson Theory of Caring] the seventh resonates with the reflective practice of CBO staff in this study: "Engaging in genuine teaching-learning experience that attends to unity of being and meaning attempting to stay within others' frame of reference" (Cara, 2003). This clinical caritas process lays the foundation for nursing students to interact holistically as teacher–student, on an equal footing with service users, and empathetically, within the service users' frame of reference.

Nurse educators in partnership with service users could offer training workshops on reflectivity not only to nursing students (Cleary, Horsfall, Happell, & Hunt, 2013) but also to community mental-health nurses as part of continuous education programmes (Karpa & Chernomas, 2013).

b) The practice of community mental health nursing.

Results from this study suggest the following recommendations for the practice of community mental-health nursing. Globally, over the past ten years, community mental-health nurses have seen their scope of practice expand (Carlyle et al., 2012; Comité d'experts sur la pratique infirmière en santé mentale et en soins psychiatriques, 2009; Elsom, Happell, & Manias, 2007). On the basis of the three core themes described at the end of Chapter IV (i.e., recovery process, reflective practice as well as individual and organizational empowerment), community mental health nurses are called upon to assess the individualized recovery process as experienced by service users) in order to propose and plan, in collaboration with the service users, the nature of their participation in a CBO activities or its organizational structures supporting service delivery.

Service users living in the community recognize and appreciate the community mental-health nurses' expertise and interpersonal skills in dialoguing with them to identify risk factors for the development of mental-health crises (Crowe et al., 2001). Consequently, community mental health nurses should place greater emphasis on co-constructing with service users, mental-health-care plans that include individualized participative actions in their community (Broer, Nieboer, Strating, Michon, & Bal, 2011). Community mental-health nurses could also benefit from continuing educational sessions to refine their reflective practice skills underpinning their interventions with service users. Beyond teaching service users about the effects of their medications (related to their mental-health problems), nurses could also coach service users in their process of participation in the organization of CBO services as a therapeutic means to increasing their self-confidence.

In partnership with service users, nurses should coordinate liaison services among different CBOs and public healthcare institutions. Moreover, based on a shared value in recovery–oriented practices, nurses and CBO staff are called upon to acknowledge their professional interdependence in order to optimize their inter-professional and inter-organization collaborations. In partnership with service users, both groups of professionals work in synergy to implement or sustain UP facilitators (e.g., accessibility of participatory space for service users) at the organizational level and to diminish negative effects of UP inhibitors (e.g., stigmatization) so that service users can actively participate in CBO services (Bee et al., 2008; G. Cunningham & Slevin, 2005).

Beyond empowering users and supporting user participation in the community, community mental-health nurses can take inspiration from the values and practice of user participation that exists in certain CBOs (particularly those such as CBO F). Based on ‘emancipatory knowing’, as outlined by Chinn and Kramer (2008), nurses could give collective voice to embedded social issues (e.g., the root cause and pervasiveness of stigmatization) and take leadership roles in implementing incremental user participation in service delivery in their workplace (Chinman et al., 2008) to transform, gradually, the negative social image of mental-health service users into that of active societal members in the exercise of their civic citizenship (Pelletier et al., 2009).

Furthermore, community mental-health nurses can play an increasingly major role, through close collaboration with other health professionals and CBO staff, in creating service user participatory spaces not only in public institutions but in CBOs as well (Rise et al., 2011). In line with their work in the community, nurses should be mobilized to be more actively involved in the organization of services within CBOs such as becoming an elected representative of the public at the BOD of mental health CBO

c) Recommendation for nursing and community mental-health research.

Further quantitative studies in different settings (e.g., rural settings) are needed to elucidate the empirical links among organizational facilitators (e.g., participatory spaces), inhibitors at the individual level (e.g., users' characteristics associated with their mental-health problems) and the influence of user participation at the individual (i.e., as perceived by service users), organizational and social levels.

Service users are increasingly assuming the role of experts in multiple forms: consultants in research projects, providers, and advocates. Therefore, further qualitative and quantitative research studies are needed to elucidate and evaluate the process and outcomes of service users working as "experiential experts" in CBOs and in public health institutions (Moll et al., 2009; Provencher et al., 2011; Rivera, Sullivan, & Valenti, 2007). More specifically, the core themes of this study (e.g., the intricate links between recovery process, user participation, and empowerment) indicate the relevance of future qualitative studies, such as a phenomenological study of the lived experience of service users' involvement in CBO or a "grounded theory" study exploring the process of user participation. Admittedly, in order to optimize nursing care for service users, in-depth knowledge of human experience and meaning, as lived and narrated by service users, is needed (Daggenvoorde, Goossens, & Gamel, 2013; Poirel et al., 2011).

Research qualitative studies are also needed to enrich the knowledge on how government policies can be translated into actual implementation, specifically in relation to mental-health service user participation at the local level (CBOs and public institutions) (H. Brooks, Pilgrim, & Rogers, 2011).

5.3.2 Recommendations for policies and decision-makers.

A number of authors (Bowl, 1996; Bradshaw, 2008; A. Brooks, Malfait, Brooke, Gallagher, & Penn, 2007; Goodwin & Happell, 2006; Muir et al., 2010; Piat et al., 2010; Zubritsky et al., 2006) offer guidelines for service users, staff and managers in public health institutions and CBOs on how best to implement government policies on user participation in mental-health-care systems. The actualization of user participation through the employment of user-consultants or user-advocates within public health institutions is also well documented (Bennetts et al., 2011; Kidd et al., 2007).

Increasingly, knowledge is accumulating on the effectiveness of user-operated organizations and self-help groups (Curtis et al., 2010; Fukui et al., 2010; Latimer et al., 2011) vis-à-vis shared decision-making in care planning and in developing a sense of community belonging among service users (Folgheraiter & Pasini, 2009). In accordance with the study findings from CBO F, service users can serve as mentors for other service users, thus encouraging more active participation in the CBOs and public health institutions that serve them. They can also be called upon to play a more active role on user committees within these institutions. Furthermore, closer collaboration is needed between policy makers and administrators of both CBOs and public health institutions in order to optimize user participation in service delivery within these organizations through the implementation of sustainable participatory spaces for users. Additionally, given that user participation in the organization of services is considered to be of value, it is recommended that administrative teams and staff in CBOs with high user participation should engage with their colleagues in CBOs with low user participation through forums that bring together all the stakeholders (service users, CBO staff and administrative teams) with the goal of exchanging ideas on strategies at organizational and individual levels to enhance user participation. Finally, some scholars (Clément, Rodriguez del Barrio, Gagne, Lévesque, & Vallée, 2012; Mack, 2010) argue strongly for more clarity in governmental policies regarding the role of service users, the objective of UP, the distribution of additional financial and human resources allocated exclusively to support UP, and accountability for these.

5.4 Limits and strengths

As an exploratory study, this study is meaningful within the context of French-Canadian urban settings. Therefore, the transferability of the study results may be applicable within populations with the following characteristics: a similar rate of utilization of mental healthcare services and the presence of CBOs within the service users' community of residence.

The combination of different data sources, such as interview transcripts from the three groups of informants in the two CBOs with differential scores on user participation, and archival data analysis contributed to the trustworthiness of the study's findings (Patton, 2002). Detailed records of the data collection process, data analytical operations (e.g., categorizing, constant comparison, iteration) and methodological and inferential memos were kept in order to enhance the scientific rigour of the study. Furthermore, a journal of all observational data relating to the physical settings of each CBO (during the first study phase), the social interactions between CBO staff and users, and reflective notes (e.g., notes commenting on the student-researcher's impression of CBO staff and their interactions) were kept by the student-researcher.

The findings of this study were derived from the inputs of the directors, BOD executive members, staff and service users of two CBOs. The possibility that study participants provided answers they perceived to be socially desirable is, plausibly, a limiting factor. Moreover, the self-selection of study informants based on their experiential knowledge of user participation and their motivation to discuss their perspectives may be influenced by their desire for positive social self–representation. Another possible militating factor is the service users' educational level: service users from CBO F are university educated, while CBO G users had not finished secondary studies. This differential educational background may have influenced how the service users perceived their capability for participatory activities. Furthermore, the small number of study informants (n=12) should also be considered as a limiting factor of this study.

Another potential limiting factor is researcher bias (Miles & Huberman, 1994). The research inquiry could have been limited by the outsider status of the student-researcher. However, a student-researcher's personal and professional experiences can serve to minimise this bias (Strauss & Corbin, 1998). In this regard, the student-researcher has been working as a community health nurse for more than two decades; and, for the past three years, she has been volunteering at a mental-health CBO. Within her work, she collaborates regularly with the CBO staff and director. The student-researcher's reflective journal and the audit trail also serve to minimise researcher bias (Bradbury-Jones, 2007)

Conclusion

The study's first objective was to describe and document the nature of user participation in mental health CBOs. Based on a literature review of user participation in public institutions and CBOs offering health care and, more specifically, community mental-health services, a schema of user participation and its influencing factors, based on the ecological approach (Richard et al., 2011), was developed for data collection in this study.

A second study objective was to explore the facilitators and inhibitors for user participation. The study findings suggest complex and intricate linkages between facilitators and inhibitors across individual, organizational, and social levels. As identified by this study, and supported by other published research, the influencing factors for user participation are: (1) the accessibility of user participatory spaces, (2) the CBO staff supporting users to participate in the organization of CBO services, and (3) the service users' capacity (in relation to their recovery process) to participate (Hopper, 2007; Racine, 2010).

The comments, made by the three groups of informants, concretely delineate the complexity of user participation (i.e., its four themes: process of user participation, inhibitors, facilitators, and advantages) and provide empirical data on their constituting components. Moreover, the following three core themes emerged from the second level of data analysis: (1) individualized recovery process influences the form of user participation, (2) reflective practice is a crucial determinant of user participation, and (3) user participation results in user empowerment.

Increased user participation is desirable, both as part of the recovery process and in terms of supporting service users to become more actively involved, not only in the mental-health services offered in their communities but in the organization of these services as well. Facilitators and inhibitors for user participation, as identified in this study, should be considered by community mental-health nurses —who, due to their proximity to service users and their role as service coordinators, are major social actors —in working towards optimization of service users' integration within their communities of residence. Globally, the current social climate coupled with governmental policies (D. McDaid, 2008; Piat & Sabetti, 2012) in mental health in the higher-income nations tends to embrace recovery-oriented and user-centred approaches in the organization of mental-healthcare system and in mental-health care. Undoubtedly, user participation is a critical component of the recovery approach (Wallcraft, 2012); however, the practice of user participation in mental-healthcare system has yet to reach its full potential (Hernandez et al., 2010). Moving forward, qualitative nursing studies on the experience of user participation as lived by service users, nurses and other stakeholders (e.g., managers, decision-makers) are needed to identify and elucidate embedded social issues underpinning UP barriers (Broer et al., 2012). Trans-disciplinary quantitative and longitudinal studies may also help to uncover the specific contextual factors within and between the social, political, organizational, and interpersonal environments that optimize user participation. Just as caring constitutes the holistic core of nursing work (J. Watson, 2006), user participation is a promising avenue through which nurses can engage service users and acknowledge their humanity and dignity during their oft stormy recovery process.

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Appendix 1

Medline data search strategy

(*denotes plural form or other truncation; “ adj2” determines two words separating “service” and “organization”)

1. community mental health /or* mental health/ or community health care service/or *community health planning
2. nursing/or community nurse*/ or community mental health nursing/ psychiatric nursing
3. community network*/voluntary organization*/or *community-based organization*/or consumer run organization*
4. Organization*/or service(*adj2 organization)/* mental health service organization
5. *consumer/ or user / or * service user / or public/ or citizen
6. *participation/ or *consumer participation/ or *user involvement/or * mental health service user participation
7. 1, or 2, 3 or 4 or 5 or 6
8. 6 and 7

Appendix 2 :

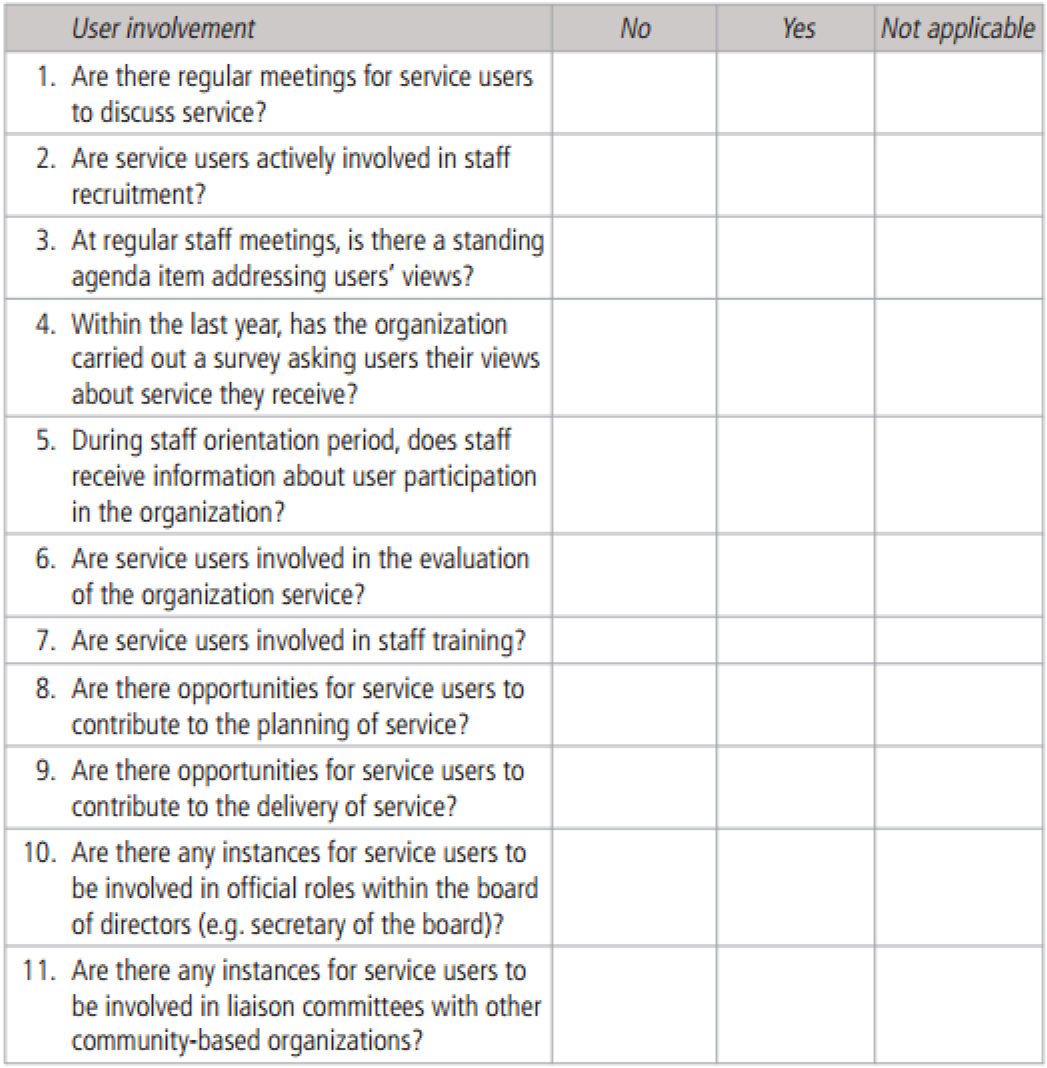
Assessment questions

1. What is the type of article ? Theoretical articles? Empirical articles?
2. What is the country in which the study was carried out?
3. What is the nature of the organization? Public or community- based organization?
4. Context of user participation (local, regional, national, supranational)
5. Who are the study participants? The staff? The service users? The health professionals? The managers?
6. What is the role of the users in their participatory actions?
7. Is the participation process explicit?
8. At which level of organizational structure (i.e., service planning, delivery and evaluation of service) is user participation situated?
9. What are the facilitating factors (if any) related to user participation?
10. What are the inhibiting factors (if any) related to user participation?
11. What was the authors' conclusion (if any) about the nature of user participation within the study context?
12. What was the authors' conclusion if any about the relation between user participation, the recovery process and community integration ?

Appendix 3 (a)

Adapted User Involvement Questionnaire (English version)

(Diamond, Parkin, Morris, Bettinis & Bettesworth, 2003, p.618)

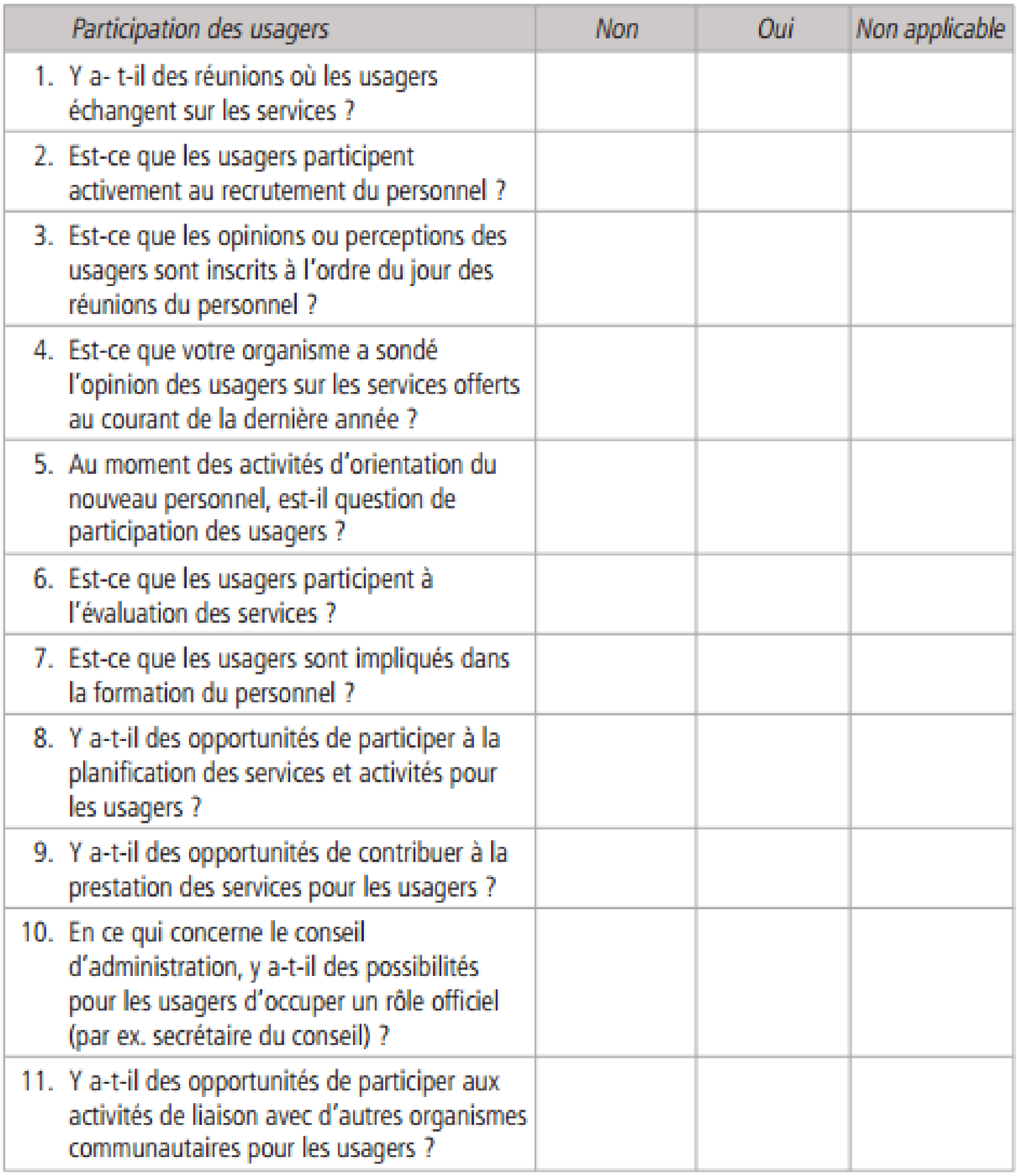


User involvement	*No*	*Yes*	*Not applicable*
1. Are there regular meetings for service users to discuss service?			
2. Are service users actively involved in staff recruitment?			
3. At regular staff meetings, is there a standing agenda item addressing users' views?			
4. Within the last year, has the organization carried out a survey asking users their views about service they receive?			
5. During staff orientation period, does staff receive information about user participation in the organization?			
6. Are service users involved in the evaluation of the organization service?			
7. Are service users involved in staff training?			
8. Are there opportunities for service users to contribute to the planning of service?			
9. Are there opportunities for service users to contribute to the delivery of service?			
10. Are there any instances for service users to be involved in official roles within the board of directors (e.g. secretary of the board)?			
11. Are there any instances for service users to be involved in liaison committees with other community-based organizations?			

Appendix 3 (b)

Questionnaire sur la participation des personnes utilisatrices de services

(Version française)



Participation des usagers	*Non*	*Oui*	*Non applicable*
1. Y a- t-il des réunions où les usagers échangent sur les services ?			
2. Est-ce que les usagers participent activement au recrutement du personnel ?			
3. Est-ce que les opinions ou perceptions des usagers sont inscrits à l'ordre du jour des réunions du personnel ?			
4. Est-ce que votre organisme a sondé l'opinion des usagers sur les services offerts au courant de la dernière année ?			
5. Au moment des activités d'orientation du nouveau personnel, est-il question de participation des usagers ?			
6. Est-ce que les usagers participent à l'évaluation des services ?			
7. Est-ce que les usagers sont impliqués dans la formation du personnel ?			
8. Y a-t-il des opportunités de participer à la planification des services et activités pour les usagers ?			
9. Y a-t-il des opportunités de contribuer à la prestation des services pour les usagers ?			
10. En ce qui concerne le conseil d'administration, y a-t-il des possibilités pour les usagers d'occuper un rôle officiel (par ex. secrétaire du conseil) ?			
11. Y a-t-il des opportunités de participer aux activités de liaison avec d'autres organismes communautaires pour les usagers ?			

Appendix 4 (a)

Lettre d’introduction aux directeurs des organismes communautaires

(Volet 1)

(Note : le terme «directeur » est utilisé à seule fin d’alléger le texte et désigne autant le directeur que la directrice).

Date:
[Directeur/trice]
[Organisme]
[Adresse]
[Ville], [Province]
[Code postal]

Objet : Étude sur la participation des usagers et usagères au sein des organismes communautaires oeuvrant dans le domaine de la santé mentale

[Monsieur, Madame],

Je suis une infirmière qui travaille depuis plusieurs années dans un CLSC à Montréal. Présentement, dans le cadre de mes études de doctorat à l’Université de Montréal, je mène une étude visant à décrire la participation des usagers au sein des organismes communautaires oeuvrant dans le domaine de la santé mentale. Tous les organismes communautaires oeuvrant dans le domaine de la santé mentale sur le territoire de l’hôpital Louis H. Lafontaine seront invités à participer à l’étude. Comme il est décrit en détail dans le Formulaire d’informations et de consentement, cette étude implique d’abord la conduite d’une entrevue d’environ d’une heure avec le directeur de l’organisme communautaire ou son représentant. Les questions porteront sur la contribution des usagers au sein de l’organisme. Suite aux résultats obtenus lors de ce premier volet de la recherche, deux organizations participantes seront sélectionnées afin de conduire une série d’entrevues plus approfondies sur ces thèmes. Les personnes que nous souhaiterions interviewer à ce moment sont le directeur, des employés, le président du conseil d'administration et des usagers.

Dans le contexte actuel de transformation des services en santé mentale, les résultats de cette étude permettront d'alimenter les décideurs et les intervenants dans leurs réflexions en vue de favoriser l'intégration sociale des usagers. De plus, les résultats de cette étude permettront aux organismes communautaires d'approfondir leur connaissance sur l'étendue de la participation des usagers et les facteurs qui la facilitent ou l'entravent.

Le Formulaire d'informations et de consentement présente une information détaillée sur l'étude et sur la nature de la contribution attendue de votre organization. J'espère sincèrement que vous répondrez favorablement à mon invitation.

Afin de me signifier votre intérêt, je vous saurais gré de compléter le formulaire de consentement ci-joint et de me le retourner par la poste dans l'enveloppe pré -adressée fournie. J'effectuerai un suivi téléphonique dans les prochaines semaines. Votre participation est importante pour assurer le succès de cette étude et sera certainement appréciée. N'hésitez pas à communiquer avec moi si d'autres renseignements étaient nécessaires.

Je vous remercie pour votre attention et vous prie d'agréer, [Monsieur, Madame] l'expression de mes sentiments les meilleurs.

____

Signature de l'étudiante-chercheuse

Appendix 4 (b)

Formulaire d’informations et de consentement

(Volet 1/ Directeur ou son délégué)

(Note : Afin de faciliter la lecture du texte, le genre masculin inclut le genre féminin)

.

I. Introduction

Nous vous demandons de participer à ce projet de recherche parce que vous êtes le directeur général de l’organisme (___________________________). Avant d’accepter de participer, veuillez prendre le temps de comprendre et de considérer attentivement les renseignements suivants.
Ce formulaire d’informations et de consentement vous explique le but de l’étude, les procédures, les avantages, les risques et les inconvénients, et vous fournit le nom des personnes avec qui communiquer, s’il y a lieu.

Le présent formulaire peut contenir des mots que vous ne comprenez pas. Nous vous invitons à poser toutes les questions que vous jugerez utiles à l’étudiante-chercheure et aux autres membres du personnel impliqué dans ce projet de recherche et à demander des explications sur tout mot ou renseignement qui n’est pas clair.

À partir du moment où vous êtes en possession de ce formulaire, vous disposez d’une période de réflexion de deux semaines pour donner votre accord, signer le formulaire et nous le retourner si vous acceptez de participer au projet de recherche.

II. Description de l'étude

1. Titre : Ce projet s'intitule : « La participation des usagers et usagères au sein des organismes communautaires oeuvrant dans le domaine de la santé mentale ».

2. Étudiante-chercheure : Truc Huynh, Faculté des sciences infirmières. Université de Montréal.

3. Directrice de recherche : Lucie Richard (professeure titulaire, Faculté des sciences infirmières. Université de Montréal.

4. Co-directrice de recherche : Caroline Larue (professeure agrégée), Faculté des sciences infirmières. Université de Montréal.

5. Introduction, buts et objectifs : La contribution des organismes communautaires à la promotion d'une plus grande intégration des usagers est largement reconnue. À cet égard, une des interventions valorisées est de promouvoir et soutenir la participation des usagers dans les activités offertes par les organismes communautaires en santé mentale. Pourtant, on en sait encore très peu quant à la participation des usagers au sein des organismes. La présente étude vise à combler cette lacune en examinant la participation des usagers au sein des organismes communautaires ainsi que les facteurs qui l'influencent.

6. Méthodologie et modalités de participation : Il s'agit d'une étude en deux volets. Le volet 1 portera sur une enquête réalisée auprès des directeurs des organismes communautaires oeuvrant sur le territoire desservi par l'hôpital Louis H.-Lafontaine. Le volet 2 sera consacré à une étude détaillée de la participation des

usagers dans deux organismes communautaires choisis en fonction des résultats obtenus lors du premier volet. Les modalités de participation pour chacun des volets sont les suivantes :

Volet 1 : Il s'agira de faire passer un questionnaire aux directeurs ou leur représentant portant sur l'étendue de la participation des usagers au sein de chaque organisme communautaire. Cette entrevue durera environ d'une heure.

Volet 2 : Il s'agira de recueillir une description détaillée des activités de participation des usagers au sein des différentes instances des organismes communautaires. Les répondants invités incluront le personnel des organismes communautaires, le président du conseil d'administration et des usagers. L'entrevue, d'une durée d'environ une heure, abordera également divers facteurs susceptibles d'influencer la participation des usagers. Une deuxième entrevue avec les directeurs, le personnel, les présidents du conseil d'administration et les usagers d'une durée de 30 minutes serait sollicité dans l'éventualité que des données recueillies devraient être clarifiées avec les participants.

III. Nature de la contribution du participant

En tant que directeur ou représentant du directeur, vous serez appelé à participer à l'entrevue au volet 1. Dans l'éventualité où votre organization serait choisie pour le second volet de l'étude, vous seriez invité à réaliser une seconde entrevue et à nous aider à identifier des participants pour réaliser notre seconde série d'entrevues. L'entrevue sera enregistrée avec votre consentement.

IV. Risques et inconfort

La participation à cette étude ne présente pas d'autres inconvénients que le temps à consacrer aux entrevues.

V. Avantages à participer

Vous ne retirerez aucun bénéfice personnel de votre participation à cette étude. Toutefois, les résultats obtenus pourraient contribuer à l'avancement des connaissances dans ce domaine. En effet, les résultats permettront de mieux connaître la participation des usagers dans les organismes communautaires et de fournir des pistes d'action concrètes afin de favoriser l'intégration sociale des usagers.

VI. Participation volontaire et possibilité de retrait

Votre participation à ce projet de recherche est tout à fait volontaire. Vous êtes donc libre de refuser d'y participer. Vous pouvez également vous retirer de ce projet à n'importe quel moment, sans avoir à donner raison. Vous avez simplement à aviser l'étudiante- chercheuse.

L'étudiante- chercheure peut aussi mettre fin à votre participation si vous ne respectez pas les consignes du projet de recherche ou si cela n'est plus dans votre intérêt.

Par ailleurs, le Comité d'éthique de la recherche des sciences de la santé (CÉRSS) de l'Université de Montréal peut également mettre fin au projet, notamment pour des raisons de sécurité ou de faisabilité.

En cas de retrait ou d'exclusion, les renseignements contenant dans les bandes audio et toutes les autres données associées qui auront été recueillis au moment de votre retrait seront détruits avec l'aide de la déchiffreuse

De plus, vous serez avisé de toute nouvelle information susceptible de vous faire reconsidérer votre participation à l'étude.

VII. Confidentialité

Durant votre participation à ce projet, l'étudiante-chercheure recueillera dans un dossier de recherche les renseignements vous concernant, nécessaires pour répondre aux objectifs scientifiques.

Tous les renseignements recueillis demeureront strictement confidentiels. Votre nom de même que celui de votre organisme demeureront confidentiels. Vous ne serez identifié que par un numéro de code attribué aux participants. Votre organisme sera également identifié par un numéro de code d'établissement. Les bandes audio portant des codes identifiant des participants seront conservées sous clé par l'étudiant dans son bureau situé à la faculté des sciences infirmières de l'Université de Montréal. Seules l'étudiante et ses directrices auront accès aux codes identifiant des participants et des organismes. La clé des codes, reliant votre nom et l'organisme à votre dossier de recherche, sera conservée par l'étudiante. Les données de recherche seront conservées pendant sept ans après la fin de l'étude et seront détruites par la suite.

Vous avez le droit de consulter votre dossier de recherche pour vérifier les renseignements recueillis et les faire rectifier au besoin, et ce, aussi longtemps que l'étudiante-chercheure ou l'établissement détient ces informations. Cependant, afin de préserver l'intégrité scientifique du projet, vous pourriez n'avoir accès à certaines de ces informations qu'une fois votre participation terminée.

Pour des raisons de surveillance et de contrôle de la recherche, votre dossier pourra être consulté par le Comité d'éthique de la recherche des sciences de la santé (CÉRSS) de l'Université de Montréal. Toutes ces personnes respecteront la politique de confidentialité.

Les données pourront être publiées dans des revues scientifiques, mais il ne sera pas possible de vous identifier.

VIII. Compensation et indemnisation

Vous ne recevrez pas d'argent pour votre participation à ce projet de recherche. Cette participation pourrait vous occasionner des dépenses (stationnement, essence, repas, taxi) qui ne vous seront pas remboursées.

En signant le présent formulaire d'informations et de consentement, vous ne renoncez à aucun de vos droits ni ne libérez l'étudiante-chercheure et ses directrices de recherche de leurs responsabilités civile et professionnelle.

Si vous deviez subir un préjudice ou quelque lésion que ce soit du à votre participation à ce projet (i.e résultant des traitements et/ou des *procédures)*, vous recevrez tous les soins et services requis par votre état de votre santé, sans frais de votre part.

IX. Communication des résultats

Vous pourrez communiquer avec l'étudiante-chercheure afin d'obtenir de l'information sur l'avancement des travaux ou les résultats de cette étude. Les faits saillants de l'étude vous seront acheminés à la fin de l'étude.

X. Personnes-ressources

Si vous avez des questions au sujet de cette étude, vous pouvez communiquer (avant, pendant et après l'étude) avec l'une des personnes suivantes : *Truc Huynh (étudiante-chercheure)* et Lucie Richard (directrice de recherche

Pour toute question relative à l'éthique sur les conditions dans lesquelles se déroule votre participation à ce projet, vous pouvez en discuter avec le responsable du projet, expliquer vos préoccupations à la présidente du Comité d'éthique de la recherche des Sciences de la santé.

Si vous avez des questions concernant vos droits en tant que participant ou si vous avez des plaintes ou des commentaires à formuler, vous pouvez communiquer avec l'ombudsman de l'Université.

Surveillance des aspects éthiques du projet de recherche

Le Comité d'éthique de la recherche des sciences de la santé a approuvé ce projet de recherche et en assure le suivi. De plus, toute révision ou modification apportée au formulaire d'information et de consentement et au protocole de recherche doit au préalable être approuvée par le comité d'éthique de la recherche.

XI. Consentement

J'ai pris connaissance du formulaire d'information et de consentement. Je reconnais qu'on m'a expliqué le projet, qu'on a répondu à mes questions à ma satisfaction et qu'on m'a laissé le temps voulu pour prendre une décision. Je consens à participer à ce projet de recherche aux conditions qui y sont énoncées. Une copie signée et datée du présent formulaire d'information et de consentement me sera remise.

____

Nom et Signature du participant

Date : ________________________________

Engagement et signature de l'étudiante- chercheur

Je certifie qu'on a expliqué au participant les termes du présent formulaire d'information et de consentement, que l'on a répondu aux questions que le participant avait à cet égard et qu'on lui a clairement indiqué qu'il demeure libre de mettre un terme à sa participation, et ce, sans aucune conséquence négative.

Je m'engage à respecter ce qui a été convenu au formulaire d'information et de consentement et à en remettre une copie signée au participant.

____

Nom et signature de l'étudiante-chercheure

Date : ____

____

Nom et signature de la directrice de recherche

Date : _____________________________________

Appendix 5

Analytic grid of archival data

Name of community-based organizations	***Type of document*** **(e.g. promotional video, information handout, web site)**	***Reference to users' participatory actions***	***Organizational factors that influence users' participation*** **(e.g. presence of user committee)**

Appendix 6

Grille d'entrevue avec le directeur des organismes communautaires

(Volet 1)

A. Prise de contact

Bonjour, mon nom est Truc Huynh. Je suis étudiante au doctorat en sciences infirmières à l'Université de Montréal. Je réalise actuellement une étude sur la participation des usagers au sein des organismes communautaires oeuvrant dans le domaine des services en santé mentale. Je vous ai fait parvenir une lettre et des documents expliquant mon projet de recherche en détail.

Q. Avez-vous reçu cet envoi?

[oui] Avez-vous des questions?

[non] Je vais vous faxer à nouveau les documents et vous rappeler pour prendre un rendez-vous.

Q. Pourriez-vous fixer une date pour une entrevue face à face?

B. Réalisation de l'entrevue

Avant de commencer, j'aimerais savoir si vous avez des objections à ce que j'utilise un magnétophone afin de conserver les propos de notre entretien. Le magnétophone faciliterait la prise de notes et le retour sur ce qui a été dit. Toutes les données seront présentées de façon anonyme. Votre nom ne sera mentionné nul part.

C. Déroulement de l'entrevue

Je vous remercie pour votre intérêt et votre participation à ce projet. Voici les questions que j'aimerais vous poser. Les questions abordent les activités auxquelles les usagers participent dans votre organisme. Par exemple : la première question vise à savoir si les usagers ont des occasions d'échanger sur les services offerts par votre organisme. Les dix questions suivantes vont dans le même sens, à savoir si les usagers ont des occasions de parler avec le nouveau personnel, de contribuer à la planification et à l'évaluation des services.

Avez-vous des questions supplémentaires sur ce projet? Avez-vous des commentaires à ajouter? Merci de votre aide.

Appendix 7 (a)

Lettre d'introduction au directeur des organismes communautaires

(volet 2)

Date:

[Prénom et nom de la personne]
[Fonction]
[Organisme]
[Adresse]
[Ville], [Province]
[Code postal]

Objet : Étude sur la participation des usagers (ère)s au sein des organismes communautaires œuvrant dans le domaine de la santé mentale

[Monsieur, Madame],

La présente fait suite à votre participation à l'étude mentionnée en rubrique. Après l'étude des résultats obtenus lors du premier volet de cette étude, nous avons sélectionné deux organismes pour lesquels nous aimerions procéder à une étude plus approfondie. Votre organisme a ainsi été retenu. Ce second volet de l'étude visera à approfondir les thèmes abordés lors du premier volet et à explorer l'influence de facteurs probables sur la participation.

À titre de directeur vous serez invité à réaliser une entrevue et à nous désigner les autres répondants qu'il nous serait utile de rencontrer. À cet égard, nous souhaiterions interviewer des membres du personnel, le président du Conseil d'administration et quelques usagers de cet organisme. Au cours des prochains jours, je communiquerai avec vous afin de vérifier si vous êtes toujours intéressé (e) à participer à cette étude et, le cas échéant, fixer le meilleur moment pour l'entrevue. .

Dans le contexte actuel de transformation des services en santé mentale, les résultats de cette étude devraient permettre d'alimenter les réflexions des décideurs et des intervenants en vue de favoriser l'intégration sociale des usagers. En plus, les résultats de cette étude permettront aux organismes communautaires d'approfondir leur connaissance sur l'étendue de la participation des usagers et les facteurs qui facilitent ou entravent cette participation.

Le Formulaire d'informations et de consentement, présente une information détaillée sur l'étude et sur la nature de la contribution attendue de votre organisme.

Je vous remercie pour votre attention et vous prie d'agréer, [Monsieur, Madame] l'expression de mes sentiments les meilleurs.

Signature de l'étudiante-chercheure

Appendix 7(b)

Formulaire d’informations et de consentement

(Volet 2 – Directeur et le personnel de l’organismecommunautaire)

I. Introduction

Nous vous demandons de participer à ce projet de recherche parce que vous êtes le directeur général de l’organisme (____________________________). Avant d’accepter de participer, veuillez prendre le temps de comprendre et de considérer attentivement les renseignements suivants.

Le Formulaire d’informations et de consentement vous explique le but de l’étude, les procédures, les avantages, les risques et les inconvénients, et vous fournit le nom des personnes avec qui communiquer, s’il y a lieu.

Le présent formulaire peut contenir des mots que vous ne comprenez pas. Nous vous invitons à poser toutes les questions que vous jugerez utiles au chercheur et aux autres membres du personnel impliqué dans ce projet de recherche et à demander des explications sur tout mot ou renseignement qui n’est pas clair.

À partir du moment où vous êtes en possession de ce formulaire, vous disposez d’une période de réflexion de deux semaines pour donner votre accord, signer le formulaire et nous le retourner si vous acceptez de participer au projet de recherche.

II. Description de l'étude

1. Titre : Ce projet s'intitule : « La participation des usagers et usagères au sein des organismes communautaires œuvrant dans le domaine de la santé mentale ».

2. Étudiante-chercheure : Truc Huynh, Faculté des sciences infirmières. Université de Montréal.

3. Directrice de recherche : Lucie Richard (professeure titulaire, Faculté des sciences infirmières. Université de Montréal.

4. Co-directrice de recherche : Caroline Larue (professeure agrégée), Faculté des sciences infirmières. Université de Montréal.

5. Introduction, buts et objectifs : La contribution des organismes communautaires à la promotion d'une plus grande intégration des usagers est largement reconnue. À cet égard, une des interventions valorisées est de promouvoir et soutenir la participation des usagers dans les activités offertes par les organismes communautaires en santé mentale. Pourtant, on en sait encore très peu quant à la participation des usagers au sein des organismes. La présente étude vise à combler cette lacune en examinant la participation des usagers au sein des organismes communautaires ainsi que les facteurs qui l'influencent.

6. Méthodologie et modalités de participation: Il s'agit d'une étude en deux volets. Le volet 1, maintenant terminé, portait sur une enquête réalisée auprès de l'ensemble des organismes communautaires oeuvrant dans le domaine de la santé mentale sur le territoire desservi par l'hôpital Louis H.-Lafontaine. Le volet 2 sera maintenant

consacré à l'étude détaillée de la participation des usagers dans deux organismes communautaires choisis en fonction des résultats obtenus lors du premier volet.

Pour ce second volet, il s'agit de procéder à des entrevues avec des informateurs-clés des organismes afin de recueillir une description détaillée des activités de participation des usagers au sein des différentes instances des organismes communautaires et d'explorer les facteurs qui pourraient influencer cette participation. Ces entrevues, menées avec le directeur, le président du conseil d'administration, le personnel et des usagers dureront environ 60 minutes. Afin de clarifier des ambiguïtés qui pourraient survenir lors des entretiens avec les directeurs, les présidents du conseil d'administration, le personnel et les usagers, une deuxième entrevue d'une de 30 minutes avec ces personnes serait sollicitée.

III. Nature de la contribution du participant

Vous serez appelé à participer à une ou deux entrevues dans le cadre du volet 2. L'entrevue sera enregistrée si vous y consentez. Selon votre préférence, ces entrevues auront lieu dans les locaux de l'organisme________________, ou dans un autre lieu à votre choix.

IV. Risques et inconfort

La participation à cette étude ne présente pas d'autres inconvénients que le temps à consacrer aux entrevues.

V. Avantages à participer

Vous ne retirerez aucun bénéfice personnel de votre participation à cette étude. Toutefois, les résultats obtenus pourraient contribuer à l'avancement des connaissances dans ce domaine. En effet, les résultats permettront de mieux connaître la participation des usagers dans les organismes communautaires et de fournir des pistes d'action concrètes afin de favoriser l'intégration sociale des usagers.

VI. Participation volontaire et possibilité de retrait

Votre participation à ce projet de recherche est tout à fait volontaire. Vous êtes donc libre de refuser d'y participer. Vous pouvez également vous retirer de ce projet à n'importe quel moment, sans avoir à donner raison. Vous avez simplement à aviser l'étudiante- chercheuse.

L'étudiante- chercheure peut aussi mettre fin à votre participation si vous ne respectez pas les consignes du projet de recherche ou si cela n'est plus dans votre intérêt.

Par ailleurs, le Comité d'éthique de la recherche des sciences de la santé (CÉRSS) de l'Université de Montréal peut également mettre fin au projet, notamment pour des raisons de sécurité ou de faisabilité.

En cas de retrait ou d'exclusion, les renseignements contenant dans les bandes audio et toutes les autres données associées qui auront été recueillis au moment de votre retrait seront détruits au moyen d'une déchiqueteuse.

De plus, vous serez avisé de toute nouvelle information susceptible de vous faire reconsidérer votre participation à l'étude.

VII. Confidentialité

Durant votre participation à ce projet, l'étudiante-chercheure recueillera dans un dossier de recherche les renseignements vous concernant, nécessaires pour répondre aux objectifs scientifiques.

Tous les renseignements recueillis demeureront strictement confidentiels. Vous ne serez identifié que par un numéro de code attribué aux participants. Votre organisme sera aussi identifié par un numéro de code d'établissement. Les bandes audio portant des codes identifiant des participants seront conservées sous clé par l'étudiant dans son bureau situé à la faculté des sciences infirmières de l'Université de Montréal. Seules l'étudiante et ses directrices auront accès aux codes identifiant des participants et des organismes. La clé des codes, reliant votre nom et l'organisme à votre dossier de recherche, sera conservée par l'étudiante

Vous avez le droit de consulter votre dossier de recherche pour vérifier les renseignements recueillis et les faire rectifier au besoin, et ce, aussi longtemps que l'étudiante-chercheure ou l'établissement détient ces informations. Cependant, afin de préserver l'intégrité scientifique du projet, vous pourriez n'avoir accès à certaines de ces informations qu'une fois votre participation terminée.

Pour des raisons de surveillance et de contrôle de la recherche, votre dossier pourra être consulté par le Comité d'éthique de la recherche des sciences de la santé (CÉRSS) de l'Université de Montréal. Toutes ces personnes respecteront la politique de confidentialité.

Les données pourront être publiées dans des revues scientifiques, mais il ne sera pas possible de vous identifier.

VIII. Compensation et indemnisation

Vous ne recevrez pas d'argent pour votre participation à ce projet de recherche. Cette participation pourrait vous occasionner des dépenses (stationnement, essence, repas, taxi) qui ne vous seront pas remboursées.

En signant le présent formulaire d'informations et de consentement, vous ne renoncez à aucun de vos droits ni ne libérez l'étudiante-chercheure et ses directrices de recherche de leurs responsabilités civile et professionnelle.

Si vous deviez subir un préjudice ou quelque lésion que ce soit du à votre participation à ce projet (i.e résultant des traitements et/ou des *procédures)*, vous recevrez tous les soins et services requis par votre état de votre santé, sans frais de votre part.

IX. Communication des résultats

Vous pourrez communiquer avec l'étudiante-chercheure afin d'obtenir de l'information sur l'avancement des travaux ou les résultats de cette étude. Les faits saillants de l'étude vous seront acheminés à la fin de l'étude.

X. Personnes-ressources

Si vous avez des questions au sujet de cette étude, vous pouvez communiquer (avant, pendant et après l'étude) avec l'une des personnes suivantes : *Truc Huynh (étudiante-chercheure)* et Lucie Richard (directrice de recherche):

Pour toute question relative à l'éthique sur les conditions dans lesquelles se déroule votre participation à ce projet, vous pouvez en discuter avec le responsable du projet, expliquer vos préoccupations à la présidente du Comité d'éthique de la recherche des Sciences de la santé.

Si vous avez des questions concernant vos droits en tant que participant ou si vous avez des plaintes ou des commentaires à formuler, vous pouvez communiquer avec l'ombudsman de l'Université.

Surveillance des aspects éthiques du projet de recherche

Le Comité d'éthique de la recherche des sciences de la santé a approuvé ce projet de recherche et en assure le suivi. De plus, toute révision ou modification apportée au formulaire d’information et de consentement et au protocole de recherche doit au préalable être approuvée par le comité d’éthique de la recherche.

XI. Consentement

J’ai pris connaissance du formulaire d’information et de consentement. Je reconnais qu’on m’a expliqué le projet, qu’on a répondu à mes questions à ma satisfaction et qu’on m’a laissé le temps voulu pour prendre une décision. Je consens à participer à ce projet de recherche aux conditions qui y sont énoncées. Une copie signée et datée du présent formulaire d'information et de consentement me sera remise.

____

Nom et Signature du participant

Date : __________________________________

Engagement et signature de l’étudiante- chercheure

Je certifie qu’on a expliqué au participant les termes du présent formulaire d’information et de consentement, que l’on a répondu aux questions que le participant avait à cet égard et qu’on lui a clairement indiqué qu’il demeure libre de mettre un terme à sa participation, et ce, sans aucune conséquence négative.

Je m’engage à respecter ce qui a été convenu au formulaire d’information et de consentement et à en remettre une copie signée au participant.

____

Nom et signature de l’étudiante- chercheure

Date : ____

____

Nom et signature de la directrice de recherche

Date : ____

Appendix 8

Formulaire d’informations et de consentement

(Volet 2 : Président de conseil d’administration ou son représentant)

I. Introduction

Nous vous demandons de participer à ce projet de recherche parce que vous êtes le président du conseil d’administration de l’organisme (-------------------------------------). Avant d’accepter de participer, veuillez prendre le temps de lire attentivement les renseignements qui suivent. Le formulaire de consentement vous explique le but de l’étude, les procédures, les avantages, les risques et les inconvénients, et vous fournit le nom des personnes avec qui communiquer, s’il y a lieu.

Le Formulaire d’informations et de consentement peut contenir des mots que vous ne comprenez pas. Nous vous invitons à poser toutes les questions que vous jugerez utiles au chercheur et aux autres membres du personnel impliqué dans ce projet de recherche et à demander des explications sur tout mot ou renseignement qui n’est pas clair.

À partir du moment où vous êtes en possession de ce formulaire, vous disposez d’une période de réflexion de deux semaines pour donner votre accord, signer le formulaire et nous le retourner si vous acceptez de participer au projet de recherche.

II. Description de l'étude

1.Titre : Ce projet s'intitule : « La participation des usagers et usagères au sein des organismes communautaires œuvrant dans le domaine de la santé mentale ».

2.Étudiante-chercheure : Truc Huynh, Faculté des sciences infirmières. Université de Montréal

3. Directrice de recherche : Lucie Richard (professeure titulaire, Faculté des sciences infirmières. Université de Montréal.

4. Co- directrice de recherche : Caroline Larue (professeure agrégée), Faculté des sciences infirmières. Université de Montréal.

5. Introduction, buts et objectifs : La contribution des organismes communautaires à la promotion d'une plus grande intégration des usagers est largement reconnue. À cet égard, une des interventions valorisées est de promouvoir et soutenir la participation des usagers dans les activités offertes par les organismes communautaires en santé mentale. Pourtant, on en sait encore très peu quant à la participation des usagers au sein des organismes. La présente étude vise à combler cette lacune en examinant la participation des usagers au sein des organismes communautaires ainsi que les facteurs qui l'influencent.

6. Méthodologie et modalités de participation:

Il s'agit d'une étude en deux volets. Le volet 1, maintenant terminé, portait sur une enquête réalisée auprès de l'ensemble des organismes communautaires œuvrant dans le domaine de la santé mentale sur le territoire desservi par l'hôpital Louis H.-Lafontaine. Le volet 2 sera maintenant consacré à l'étude détaillée de la participation des usagers dans deux organismes communautaires choisis en fonction des résultats obtenus lors du premier volet.

Pour ce second volet, il s'agit de procéder à des entrevues avec des informateurs-clés des organismes afin de recueillir une description détaillée des activités de participation des usagers au sein des différentes instances des organismes communautaires et d'explorer les facteurs qui pourraient influencer cette participation. Ces entrevues, menées avec les directeurs, le président du conseil d'administration, le personnel et des usagers dureront environ 60 minutes. Afin de clarifier des ambiguïtés qui pourraient survenir lors des entretiens avec les directeurs, les présidents du conseil d'administration, le personnel et les usagers, une deuxième entrevue d'une durée de 30 minutes avec ces personnes serait sollicitée.

III. Nature de la contribution du participant

Vous serez appelé à participer à une ou deux entrevues dans le cadre du volet 2. L'entrevue sera enregistrée si vous y consentez. Ces entrevues auront lieu soit dans le bureau de l'organisme____, soit dans un autre lieu à votre choix.

IV. Risques et inconfort

La participation à cette étude ne présente pas d'autres inconvénients que le temps à consacrer aux entrevues.

V. Avantages à participer

Vous ne retirerez aucun bénéfice personnel de votre participation à cette étude. Toutefois, les résultats obtenus pourraient contribuer à l'avancement des connaissances dans ce domaine. En effet, les résultats permettront de mieux connaître la participation des usagers dans les organismes communautaires et de fournir des pistes d'action concrètes afin de favoriser l'intégration sociale des usagers.

VI. Participation volontaire et possibilité de retrait

Votre participation à ce projet de recherche est tout à fait volontaire. Vous êtes donc libre de refuser d'y participer. Vous pouvez également vous retirer de ce projet à n'importe quel moment, sans avoir à donner raison. Vous avez simplement à aviser l'étudiante- chercheuse.

L'étudiante- chercheure peut aussi mettre fin à votre participation si vous ne respectez pas les consignes du projet de recherche ou si cela n'est plus dans votre intérêt.

Par ailleurs, le Comité d'éthique de la recherche des sciences de la santé (CÉRSS) de l'Université de Montréal peut également mettre fin au projet, notamment pour des raisons de sécurité ou de faisabilité.

En cas de retrait ou d'exclusion, les renseignements contenant dans les bandes audio et toutes les autres données associées qui auront été recueillis au moment de votre retrait seront détruits avec l'aide de la déchiffreuse.

De plus, vous serez avisé de toute nouvelle information susceptible de vous faire reconsidérer votre participation à l'étude.

VII. Confidentialité

Durant votre participation à ce projet, l'étudiante-chercheure recueillera dans un dossier de recherche les renseignements vous concernant, nécessaires pour répondre aux objectifs scientifiques.

Tous les renseignements recueillis demeureront strictement confidentiels. Vous ne serez identifié que par un numéro de code attribué aux participants. Votre organisme sera aussi identifié par un numéro de code d'établissement. Les bandes audio portant des codes identifiant des participants seront conservées sous clé par l'étudiant dans son bureau situé à la faculté des sciences infirmières de l'Université de Montréal. Seules l'étudiante et ses directrices auront accès aux codes identifiant des participants et des organismes. La clé des codes, reliant votre nom et l'organisme à votre dossier de recherche, sera conservée par l'étudiante
Les données de recherche seront conservées pendant sept ans après la fin de l'étude et seront détruites par la suite.

Vous avez le droit de consulter votre dossier de recherche pour vérifier les renseignements recueillis et les faire rectifier au besoin, et ce, aussi longtemps que l'étudiante-chercheure ou l'établissement détient ces informations. Cependant, afin de préserver l'intégrité scientifique du projet, vous pourriez n'avoir accès à certaines de ces informations qu'une fois votre participation terminée.

Pour des raisons de surveillance et de contrôle de la recherche, votre dossier pourra être consulté par le Comité d'éthique de la recherche des sciences de la santé (CÉRSS) de l'Université de Montréal. Toutes ces personnes respecteront la politique de confidentialité.

Les données pourront être publiées dans des revues scientifiques, mais il ne sera pas possible de vous identifier.

VIII. Compensation et indemnisation

Vous ne recevrez pas d’argent pour votre participation à ce projet de recherche. Cette participation pourrait vous occasionner des dépenses (stationnement, essence, repas, taxi) qui ne vous seront pas remboursées.

En signant le présent formulaire d'informations et de consentement, vous ne renoncez à aucun de vos droits ni ne libérez l’étudiante-chercheure et ses directrices de recherche de leurs responsabilités civile et professionnelle.

Si vous deviez subir un préjudice ou quelque lésion que ce soit du à votre participation à ce projet (i.e résultant des traitements et/ou des *procédures)*, vous recevrez tous les soins et services requis par votre état de votre santé, sans frais de votre part.

IX. Communication des résultats

Vous pourrez communiquer avec l’étudiante-chercheure afin d’obtenir de l’information sur l’avancement des travaux ou les résultats de cette étude. Les faits saillants de l’étude vous seront acheminés à la fin de l’étude.

X. Personnes-ressources

Si vous avez des questions au sujet de cette étude, vous pouvez communiquer (avant, pendant et après l'étude) avec l’une des personnes suivantes : *Truc Huynh (étudiante-chercheure)* et Lucie Richard (directrice de recherche)

Pour toute question relative à l’éthique sur les conditions dans lesquelles se déroule votre participation à ce projet, vous pouvez en discuter avec le responsable du projet, expliquer vos préoccupations à la présidente du Comité d'éthique de la recherche des Sciences de la santé.

Si vous avez des questions concernant vos droits en tant que participant ou si vous avez des plaintes ou des commentaires à formuler, vous pouvez communiquer avec l'ombudsman de l'Université.

Surveillance des aspects éthiques du projet de recherche

Le Comité d’éthique de la recherche des sciences de la santé a approuvé ce projet de recherche et en assure le suivi. De plus, toute révision ou modification apportée au formulaire d’information et de consentement et au protocole de recherche doit au préalable être approuvée par le comité d’éthique de la recherche.

XI. Consentement

J’ai pris connaissance du formulaire d’information et de consentement. Je reconnais qu’on m’a expliqué le projet, qu’on a répondu à mes questions à ma satisfaction et qu’on m’a laissé le temps voulu pour prendre une décision. Je consens à participer à ce projet de recherche aux conditions qui y sont énoncées. Une copie signée et datée du présent formulaire d'information et de consentement me sera remise.

____

Nom et Signature du participant

Date : __________________________________

Engagement et signature de l'étudiante- chercheure

Je certifie qu'on a expliqué au participant les termes du présent formulaired'information et de consentement, que l'on a répondu aux questions que le participant avait à cet égard et qu'on lui a clairement indiqué qu'il demeure libre de mettre un terme à sa participation, et ce, sans aucune conséquence négative.

Je m'engage à respecter ce qui a été convenu au formulaire d'information et de consentement et à en remettre une copie signée au participant.

____

Nom et signature de l'étudiante-chercheure

Date : _____________________________________

____

#Nom et signature de la directrice de recherche

Date : ______________________

Appendix 9

Invitation

Aux	Intervenants/Animateurs des activités de l'organisme communautaire
Objet	**Projet de recherche** : La participation des usager(ère)s au sein des organismes communautaires en santé mentale **Étudiante-chercheure** : Truc Huynh **Directrice** : Lucie Richard **Co-directrice** : Caroline Larue

Le présent projet vise à décrire la participation des l'usager (ère)s au sein des organismes communautaire en santé mentale et à identifier les facteurs qui influencent cette participation. Votre participation à ce projet de recherche nécessite d'une entrevue avec l'étudiante-chercheure portant sur vos activités dans cet organisme communautaire. Si vous me permettez de transmettre votre nom à l'étudiante-chercheure ainsi que votre numéro de téléphone, celle-ci pourra vous expliquer le projet et vous pourrez décider de participer ou non à la recherche.

J'accepte de transmettre mon nom et mon numéro de téléphone à l'étudiante-chercheuse.

Nom du participant: ____
Numéro de téléphone :____

Signature: ______________________ Date _______ / _______ / __________
(Jour) (Mois) (Année)
Nom de l'organisme communautaire : ________________________________

Appendix 10

Formulaire d’informations et de consentement

[Usager(ère)]

I. Introduction

Nous vous demandons de participer à ce projet de recherche parce que vous recevez des services de l’organisme (---------------------------------------). Avant d’accepter de participer à ce projet de recherche, veuillez prendre le temps de lire, de comprendre et de considérer attentivement les renseignements qui suivent.

Ce Formulaire d’informations et de consentement vous explique le but de l’étude, les procédures, les avantages, les risques et les inconvénients, et vous fournit le nom des personnes avec qui communiquer, s’il y a lieu.

Le présent formulaire peut contenir des mots que vous ne comprenez pas. Nous vous invitons à poser toutes les questions que vous jugerez utiles au chercheur et aux autres membres du personnel impliqué dans ce projet de recherche et à demander des explications sur tout mot ou renseignement qui n’est pas clair.

À partir du moment où vous êtes en possession de ce formulaire, vous disposez d’une période de réflexion de deux semaines pour donner votre accord, signer le formulaire et nous le retourner si vous acceptez de participer au projet de recherche.

II. Description de l'étude

1. Titre : Ce projet s'intitule : « La participation des usagers et usagères au sein des organismes communautaires oeuvrant dans le domaine de la santé mentale ».

2. Étudiante- chercheure : Truc Huynh, Faculté des sciences infirmières. Université de Montréal

3. Directrice de recherche : Lucie Richard (professeure titulaire, Faculté des sciences infirmières. Université de Montréal.

4. Co- directrice de recherche : Caroline Larue (professeure agrégée), Faculté des sciences infirmières. Université de Montréal.

5. Introduction, buts et objectifs : La contribution des organismes communautaires à la promotion d'une plus grande intégration des usagers est largement reconnue. À cet égard, une des interventions valorisées est de promouvoir et soutenir la participation des usagers dans les activités offertes par les organismes communautaires en santé mentale. Pourtant, on en sait encore très peu quant à la participation des usagers au sein des organismes. La présente étude vise à combler cette lacune en examinant la participation des usagers au sein des organismes communautaires ainsi que les facteurs qui l'influencent.

6. Méthodologie et modalités de participation:

Il s'agit d'une étude en deux volets. Le volet 1, maintenant terminé, portait sur une enquête réalisée auprès de l'ensemble des organismes communautaires oeuvrant dans le domaine de la santé mentale sur le territoire desservi par l'hôpital Louis H.-Lafontaine. Le volet 2 sera maintenant consacré à l'étude détaillée de la participation des usagers dans deux organismes communautaires choisis en fonction des résultats obtenus lors du premier volet.

Pour ce second volet, il s'agit de procéder à des entrevues avec des informateurs-clés des organismes afin de recueillir une description détaillée des activités de participation des usagers au sein des différentes instances des organismes communautaires et d'explorer les facteurs qui pourraient influencer cette participation. Ces entrevues, menées avec le directeur, le président du conseil d'administration, le personnel et des usagers dureront environ 60 minutes. Afin de clarifier des ambiguïtés qui pourraient survenir lors des entretiens avec les directeurs, les présidents du conseil d'administration, le personnel et les usagers, une deuxième entrevue d'une durée de 30 minutes avec ces personnes serait sollicitée.

III. Nature de la contribution du participant

Vous serez appelé à participer à une ou deux entrevues dans le cadre du volet 2. L'entrevue sera enregistrée si vous y consentez. Ces entrevues auront lieu soit dans le bureau de l'organisme____, soit dans un autre lieu à votre choix.

IV. Conditions de participation

Pour participer à l'étude, il est essentiel que vous répondiez aux conditions suivantes :

- Avoir plus que 18 ans
- Autonomie dans vos activités quotidiennes
- Avoir un état mental stable
- Résider dans la communauté
- Avoir participé dans les activités de l'organisme ___________________depuis 3 mois

V. Risques et inconfort

La participation à cette étude ne présente pas d'autres inconvénients que le temps à consacrer aux entrevues.

VI. Avantages à participer

Vous ne retirerez aucun bénéfice personnel de votre participation à cette étude. Toutefois, les résultats obtenus pourraient contribuer à l'avancement des connaissances dans ce domaine. En effet, les résultats permettront de mieux connaître la participation des usagers dans les organismes communautaires et de fournir des pistes d'action concrètes afin de favoriser l'intégration sociale des usagers.

VII. Participation volontaire et possibilité de retrait

Votre participation à ce projet de recherche est tout à fait volontaire. Vous êtes donc libre de refuser d'y participer. Vous pouvez également vous retirer de ce projet à n'importe quel moment, sans avoir à donner raison. Vous avez simplement à aviser l'étudiante- chercheuse. Le retrait précoce de votre participation n'affectera pas vos relations et les services avec l'organisme ________________________________

L'étudiante- chercheure peut aussi mettre fin à votre participation si vous ne respectez pas les consignes du projet de recherche ou si cela n'est plus dans votre intérêt.

Par ailleurs, le Comité d'éthique de la recherche des sciences de la santé (CÉRSS) de l'Université de Montréal peut également mettre fin au projet, notamment pour des raisons de sécurité ou de faisabilité.

En cas de retrait ou d'exclusion, les renseignements contenant dans les bandes audio et toutes les autres données associées qui auront été recueillis au moment de votre retrait seront détruits avec l'aide de la déchiffreuse.

De plus, vous serez avisé de toute nouvelle information susceptible de vous faire reconsidérer votre participation à l'étude.

VIII. Confidentialité

Durant votre participation à ce projet, l'étudiante-chercheure recueillera dans un dossier de recherche les renseignements vous concernant, nécessaires pour répondre aux objectifs scientifiques.

Tous les renseignements recueillis demeureront strictement confidentiels. Vous ne serez identifié que par un numéro de code attribué aux participants. Votre organisme sera aussi identifié par un numéro de code d'établissement. Les bandes audio portant des codes identifiant des participants seront conservées sous clé par l'étudiant dans son bureau situé à la faculté des sciences infirmières de l'Université de Montréal. Seules l'étudiante et ses directrices auront accès aux codes identifiant des participants et des organismes. La clé des codes, reliant votre nom et l'organisme à votre dossier de recherche, sera conservée par l'étudiante

Les données de recherche seront conservées pendant sept ans après la fin de l'étude et seront détruites par la suite.

Vous avez le droit de consulter votre dossier de recherche pour vérifier les renseignements recueillis et les faire rectifier au besoin, et ce, aussi longtemps que l'étudiante-chercheure ou l'établissement détient ces informations. Cependant, afin de préserver l'intégrité scientifique du projet, vous pourriez n'avoir accès à certaines de ces informations qu'une fois votre participation terminée.

Pour des raisons de surveillance et de contrôle de la recherche, votre dossier pourra être consulté par le Comité d'éthique de la recherche des sciences de la santé (CÉRSS) de l'Université de Montréal. Toutes ces personnes respecteront la politique de confidentialité.

Les données pourront être publiées dans des revues scientifiques, mais il ne sera pas possible de vous identifier.

IX. Compensation et indemnisation

Vous recevrez $25 pour votre participation à ce projet de recherche. Cette participation pourrait vous occasionner des dépenses (stationnement, essence, repas, taxi) qui ne vous seront pas remboursées.

En signant le présent formulaire d'informations et de consentement, vous ne renoncez à aucun de vos droits ni ne libérez l'étudiante-chercheure et ses directrices de recherche de leurs responsabilités civile et professionnelle.

Si vous deviez subir un préjudice ou quelque lésion que ce soit du à votre participation à ce projet (i.e résultant des traitements et/ou des *procédures)*, vous recevrez tous les soins et services requis par votre état de votre santé, sans frais de votre part.

X. Communication des résultats

Vous pourrez communiquer avec l'étudiante-chercheure afin d'obtenir de l'information sur l'avancement des travaux ou les résultats de cette étude. Les faits saillants de l'étude vous seront acheminés à la fin de l'étude.

XI. Personnes-ressources

Si vous avez des questions au sujet de cette étude, vous pouvez communiquer (avant, pendant et après l'étude) avec l'une des personnes suivantes : *Truc Huynh (étudiante-chercheure)* et Lucie Richard (directrice de recherche)

Pour toute question relative à l'éthique sur les conditions dans lesquelles se déroule votre participation à ce projet, vous pouvez en discuter avec le responsable du projet, expliquer vos préoccupations à la présidente du Comité d'éthique de la recherche des Sciences de la santé.

Si vous avez des questions concernant vos droits en tant que participant ou si vous avez des plaintes ou des commentaires à formuler, vous pouvez communiquer avec l'ombudsman de l'Université.

Surveillance des aspects éthiques du projet de recherche

Le Comité d’éthique de la recherche des sciences de la santé a approuvé ce projet de recherche et en assure le suivi. De plus, toute révision ou modification apportée au formulaire d’information et de consentement et au protocole de recherche doit au préalable être approuvée par le comité d’éthique de la recherche.

XII. Consentement

J’ai pris connaissance du formulaire d’information et de consentement. Je reconnais qu’on m’a expliqué le projet, qu’on a répondu à mes questions à ma satisfaction et qu’on m’a laissé le temps voulu pour prendre une décision. Je consens à participer à ce projet de recherche aux conditions qui y sont énoncées. Une copie signée et datée du présent formulaire d'information et de consentement me sera remise.

____

Nom et Signature du participant

Date : ________________________________

Engagement et signature de l'étudiante- chercheure

Je certifie qu'on a expliqué au participant les termes du présent formulaire d'information et de consentement, que l'on a répondu aux questions que le participant avait à cet égard et qu'on lui a clairement indiqué qu'il demeure libre de mettre un terme à sa participation, et ce, sans aucune conséquence négative.

Je m'engage à respecter ce qui a été convenu au formulaire d'information et de consentement et à en remettre une copie signée au participant.

____

Nom et signature de l'étudiante-chercheure

Date : ____

____

Nom et signature de la directrice de recherche

Date :_____________________________

Appendix 11

Grille d’entrevue avec le directeur / le président du conseil d’administration

(Volet 2)

Présentation

Bonjour, mon nom est Truc Huynh. Je suis étudiante au doctorat en sciences infirmières à l’Université de Montréal et je m’intéresse à la participation des usagers au sein des organismes communautaires en santé mentale.

Je vous ai fait parvenir des documents expliquant mon projet de recherche en détail. Avant de commencer l’entrevue, vous pouvez prendre le temps de lire le formulaire de consentement. Votre consentement est nécessaire pour que je puisse effectuer une entrevue avec vous. Il est également nécessaire pour que je puisse enregistrer (si la personne refuse l’enregistrement, je lui demanderai de parler lentement afin que je puisse prendre des notes). Avez-vous des questions au sujet de mon étude?

[Oui] Je vais donc répondre à vos questions.
[Non] Alors, nous pouvons commencer.

L’entrevue ne débute que lorsque le formulaire de consentement est signé. L’enregistrement ne débute que lorsque le formulaire de consentement est signé.

Déroulement de l'entrevue (apporter la grille complétée au volet 1)

1. Pour commencer, j'aimerais que vous me décriviez à nouveau votre organisme.

   Les questions (aide-mémoire) :

   - Quels sont les services offerts par votre organisme?
   - Quelles sont les valeurs ou principes qui guident vos actions dans l'organisme?
   - Parlez-moi de la clientèle.
   - Parlez-moi de la participation des usagers au sein de l'organisme.
   - Quelle est votre appréciation du niveau de participation des usagers?
   - Qui sont les intervenants de votre organisme? Leur formation?

2. Lors de notre première rencontre, vous avez identifié différents lieux où les usagers s'impliquent. Dans votre organisme les usagers sont actifs durant…… (se référer aux réponses de la première entrevue). Décrivez-moi, pour chacune des ces activités, ce que font les usagers.

   Les questions (aide-mémoire):

   - Quelles sont les retombées suite à cette participation au sein de votre organisme? Pour les usagers? Pour votre organisme?
   - Comment évaluez-vous cette participation?

3. J'aimerais avoir votre avis sur les facteurs qui pourraient influencer la participation des usagers au sein de votre organisme.

Les questions (aide-mémoire)

- Quelles sont les caractéristiques des usagers qui influencent leur participation? Si oui, précisez.
- Est-ce que certaines caractéristiques de votre organisme ou la façon dont les choses fonctionnent ici peut faciliter ou empêcher la participation? Si oui, précisez.
- Est-ce qu'il y aurait d'autres influences, venant de l'extérieur de votre organisme comme par exemple au niveau des politiques ? Si oui, précisez.

Vous avez répondu aux questions prévues à l'étude. Y a-t-il des éléments qui n'ont pas été abordés et que vous voudriez souligner? Ou d'autres commentaires?

Je vous remercie d'avoir accepté de participer à cette entrevue.

Appendix 12

Grille d’entrevue avec le personnel des organismes communautaires

Présentation

Bonjour, mon nom est Truc Huynh. Je suis étudiante au doctorat en sciences infirmières à l’Université de Montréal et je m’intéresse à la participation des usagers au sein des organismes communautaires en santé mentale.

Je vous ai fait parvenir des documents expliquant mon projet de recherche en détail. Avant de commencer l’entrevue, vous pouvez prendre le temps de lire le formulaire de consentement. Votre consentement est nécessaire pour que je puisse effectuer une entrevue avec vous. Il est également nécessaire pour que je puisse enregistrer (si la personne refuse l’enregistrement, je lui demanderai de parler lentement afin que je puisse prendre des notes). Avez-vous des questions au sujet de mon étude?

[Oui] Je vais donc répondre à vos questions.
[Non] Alors, nous pouvons commencer.

L’entrevue ne débute que lorsque le formulaire de consentement est signé. L’enregistrement ne débute que lorsque le formulaire de consentement est signé.

Déroulement de l’entrevue

1. Pour commencer, j’aimerais que vous me décriviez votre organisme.

Les questions (aide-mémoire) :

- Quel était votre parcours avant de travailler pour cet organisme?
- Qu’est-ce qui vous a amené à travailler ici?
- Quels sont les services offerts par votre organisme?
- Quelles sont les valeurs ou principes qui guident vos actions dans l’organisme?

- Parlez-moi de votre clientèle.
- Parlez-moi de la participation des usagers au sein de l'organisme.
- Quelle est votre appréciation du niveau de participation des usagers?
- Pouvez-vous identifier les lieux dans lesquels vous êtes en contact avec les usagers? (Conseil d'administration, comité de travail, comités de planification, d'évaluation, réunion, activités destinées aux usagers).

- 2. Pour chacun de ces lieux, pouvez-vous me décrire plus en détail ce que font les usagers?

Les questions (aide-mémoire) :

- Quelles sont les retombées suite à cette participation au sein de votre organisme? Pour les usagers? Pour votre organisme?
- Comment évaluez-vous cette participation?

3. J'aimerais maintenant avoir votre avis sur les facteurs qui pourraient influencer la participation et l'implication des usagers au sein de votre organisme.

Les questions (aide-mémoire)

- Quelles sont les caractéristiques des usagers qui influencent leur participation? Si oui, précisez.
- Est-ce que certaines caractéristiques de votre organisme ou la façon dont les choses fonctionnent ici peut faciliter ou empêcher la participation? Si oui, précisez.
- Est-ce qu'il y aurait d'autres influences, venant de l'extérieur de votre organisme comme par exemple au niveau des politiques ? Si oui, précisez.

Vous avez répondu aux questions prévues à l'étude. Y a-t-il des éléments qui n'ont pas été abordés et que vous voudriez souligner? Ou d'autres commentaires?

Je vous remercie d'avoir accepté de participer à cette entrevue.

Appendix 13

Grille d’entrevue avec l’usager(ère)

Présentation

Bonjour, mon nom est Truc Huynh. Je suis étudiante au doctorat en sciences infirmières à l’Université de Montréal et je m’intéresse à la participation des usagers au sein des organismes communautaires en santé mentale.

Je vous ai fait parvenir des documents expliquant mon projet de recherche en détail. Avant de commencer l’entrevue, vous pouvez prendre le temps de lire le formulaire de consentement. Votre consentement est nécessaire pour que je puisse effectuer une entrevue avec vous. Il est également nécessaire pour que je puisse enregistrer (si la personne refuse l’enregistrement, je lui demanderai de parler lentement afin que je puisse prendre des notes). Avez-vous des questions au sujet de mon étude?

[Oui] Je vais donc répondre à vos questions.
[Non] Alors, nous pouvons commencer.

L’entrevue ne débute que lorsque le formulaire de consentement est signé. L’enregistrement ne débute que lorsque le formulaire de consentement est signé.

Déroulement de l’entrevue

Nous allons aborder les questions suivantes :

1. Qu’est-ce qui vous a amené à recevoir des services de cet organisme? Pouvez-vous me décrire les services que vous recevez/avez reçus de cet organisme?

2. Qu’est-ce qui vous a amené à vous impliquer au sein de cet organisme (dans le fonctionnement, dans l’offre de services, dans l’administration, etc.) ?
3. Parlez-moi un peu de votre contribution au sein du fonctionnement/de l’offre de services/de l’administration de l’organisme? (Votre rôle, depuis quand, le type d’activités, les tâches reliées aux activités).
4. Qu’est-ce qui vous encourage à vous impliquer de cette façon au sein de cet organisme? Est-ce que c’est facile ou difficile pour vous de vous impliquer dans l’organisme?
5. Les raisons qui facilitent ou rendent difficile votre implication (fonctionnement/offre de services/administration) au sein de cet organisme?
6. Pensez-vous que votre implication a une influence sur votre état de santé et votre fonctionnement quotidien ?
7. Voyez-vous des changements dans l’organisme suite à votre implication?

Vous avez répondu aux questions prévues à l’étude. Y a-t-il des éléments qui n’ont pas été abordés et que vous voudriez souligner? Ou d’autres commentaires?

Je vous remercie d’avoir accepté de participer à cette entrevue.