

**Psychiatric System Survivor/Consumer Advocacy  
A Critical Literature Review**

**Final Report**

**Prepared for the Black Creek Community Health Centre  
Advocacy for Change: Community Mental Health Project**

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## Psychiatric System Survivor/Consumer Advocacy A Critical Literature Review

WE strongly feel that PATIENT POWER could be mobilized effectively against the psychiatrist and the mental hospital, agent and agency of the ruling class, through a politically organized MENTAL PATIENTS' UNION.

Irwin et. al., 1974, original emphasis

### 1. Introduction

In North America and Western Europe collective psychiatric survivor<sup>1</sup> advocacy have a long history dating back to the Alleged Lunatics' Friend Society, which was established in England in 1845 (Hervey 1986). Without doubt however, the psychiatric consumer/survivor/ex-patient (c/s/x) movement that gained momentum during the 1960's dynamic civil rights activism era held a more radical and political stance, and secured a widespread membership than it had ever achieved before. Hence Mel Starkman aptly wrote in his 1981 article published in Canadian anti-psychiatry magazine *Phoenix Rising* that "an important new movement is sweeping through the western world" (A2).

Advocacy, choice, peer support, self-help, self-definition and self-determination, in particular claiming "voice" and talking from the standpoint of marginalized experience have been the guiding principles of the c/s/x movement since its inception in the second half of the 20<sup>th</sup> century. Rooted in broader struggles for social justice these principles have been successfully used by people who are labeled with mental illness to speak their truth, share their stories, voice their opinions, and challenge the authority of the psychiatric system and its knowledge. Collectively people have organized to expose systemic discrimination and abuse they face within the psychiatric system and the larger society, disputed the bio-medical understanding of "mental illness," and created self-help alternatives to coercive psychiatric treatments.

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<sup>1</sup> Psychiatric survivor refers to people, who have been, or were in the past, in direct contact with the psychiatric institutions or mental health system as a patient, client or consumer. Different people identify with different terms such as, mental health services consumer, person with a psychiatric disability, service user/client, Mad, etc. Many people chose not to identify with any of these labels, even though they may be in contact with the mental health system at some point in their lives. The choice of the terminology in this report, psychiatric (system) survivor/consumer, partly reflects this diversity. It also indicates collective, systemic, and political orientation of advocacy efforts that take place in a neo-liberal policy context. For a more detailed discussion on terminology see page 8.

While the psychiatric establishment and government agencies initially dismissed the voices of the psychiatric system survivors, a crucial shift took place in the late 20<sup>th</sup> century. The notions of advocacy, self-help, peer support, and lived experience, which were long standing driving forces of the c/s/x movement, began to appear in popular public discourse as well as in governmental policy reports, and in the mandates and mission statements of mental health organizations. In 2003 the World Health Organization (WHO) produced a detailed report on “mental health” advocacy and claimed its significance for the “promot[ion] of the human rights of persons with mental disorders” (2). Certainly this was partly due to the successes of the organized c/s/x movement. Yet, as many critical scholars, activists, and psychiatric system survivors have noted, these notions have also been systematically manipulated and co-opted by mainstream mental health organizations, as well as government agencies for their own agenda (Morrison 2005, 88; Hurter 124 - 129; Costa et.all 2012)

In this report I review academic and grassroots movement literature with particular focus on the “best and promising” survivor/consumer advocacy practices on local, national, and international levels. In addition, I survey several survivor/consumer organization websites, and incorporate the experiences and insights of the two well-known local community organizers who were interviewed for this report. The contemporary c/s/x movement includes numerous local advocacy groups around the globe, with their particular concerns, goals, and strategies based on their unique socio-political and cultural contexts. However, it is beyond the scope of this report to examine all of these groups and their advocacy practices. Thus this is by no means a comprehensive review. Rather it focuses primarily on three countries, Canada, USA, and England where most of the literature in English language is produced.

In order to build meaningful, transformative advocacy efforts it is critical to look at how these practices, concepts, and fundamental principles were originated and employed within the c/s/x movement during the 1970s. It is also vital to understand how and why these concepts became mainstream at the turn of the 21<sup>st</sup> century. Accordingly, the first part of this literature review looks at the brief history of the psychiatric patient liberation movement— now known as the c/s/x, or more commonly consumer/survivor movement. It highlights the key principles of the movement, and examines the disputed

topics and the political nature of terminology. In this section I also briefly examine the changing nature of mental health policy and advocacy since the 1990s, particularly in Ontario. The main part of the review focuses on the organizing and advocacy efforts taking place in this contemporary context and investigates various ways in which survivor/consumer groups come together, structure themselves, identify their advocacy activities and core principles, and financially sustain themselves. The last section raises important questions on potential problems, tensions, and limitations of the survivor/consumer advocacy that takes place within a neo-liberal economic system particularly when funding for advocacy is attached to state agencies and service organizations.

## **2. C/S/X Movement in the Second Half of the 20th Century: Historical, Cultural, and Political Context, Key Principles & Concepts**

A number of interrelated socio-political and cultural developments account for the rise of the c/s/x activism during the 1960s in North America. Biological psychiatry's failure to fulfill its great promise to "cure" mental illness by the mid 20th century resulted in widespread societal disillusionment. This discontent and mistrust with psychiatry brought psychiatric institutions and practices under greater scrutiny, which eventually led to the diminution of its absolute power. While structural reorganizations and policy reforms that took place within the mental health system followed a different trajectory between the USA and Canada (Simmons 1990, 87- 89), demands for mental health reforms intensified in both countries during this period (125-135).

The rise of the deinstitutionalization movement can be considered as another contributing factor. Whether it was due to economic pressures, responds to increasing criticisms made towards large psychiatric institutions, or the invention of psychotropic medications that made the "care" of the so-called mentally ill outside the confines of hospitals possible, deinstitutionalization efforts in Ontario took momentum in the mid 1960s (Simmons 1990, 160). Consequently, the rapid discharge of large numbers of psychiatric patients without adequate aftercare policies and resources perpetuated the challenges faced by already stigmatized ex-psychiatric patients and resulted in their increasing resentment. Arguably deinstitutionalization also created a space that enabled

more and more ex-psychiatric patients to speak out and share their experiences within the psychiatric institutions (Reaume 2002, 415).

The social and political context of 1960's North America was also shaped by the growth of several social and political movements. The Black Power, second wave feminism, gay liberation, disability rights, labor, and anti-psychiatry movements achieved varying degrees of collective mobilization. These groups were striving for civil rights, individual liberty, social justice, and independent living, which facilitated the rise of several protest and advocacy groups, including c/s/x activism. The strong criticisms directed towards capitalist state ideologies, totalizing institutional control mechanisms, and "expert" authority by these groups verified and enhanced the c/s/x movements' efforts to expose the atrocities of psychiatric practices that were disguised under the rubric of medical treatment. Among these movements, anti-psychiatry had doubtlessly played a particularly significant role in the development of the c/s/x activism, at least in its initial stages (Morrison 2005, 67). The influential critiques of the dissident psychiatrists railing against institutional psychiatry (see Laing 1960; Szasz 1961, 1971; Cooper 1967), as well as a number of academic studies that examined the role of total institutions in the maintenance of the status quo (see Goffman 1961; Foucault 1965) underpinned the theoretical base of the c/s/x movement. Still, this collaborative approach between dissident psychiatrists and ex-patient activists did not last long, as the ex-patients themselves recognized that the voices of psychiatrized people were subordinated under professionals who were speaking from the position of authority and power (Irwin et al. 1974; Starkman 1981, 5A; Morrison 2005, 76 – 78; Chamberlin 1994).

The 1970s was a crucial decade in the growth of c/s/x activism<sup>2</sup> (Burstow and Weitz 1988, 20; Chamberlin 1990; Reaume 2002; Morrison 2005). One of the first known psychiatric inpatient run groups, "We are not alone" (WANA) was formed in 1948 in New York. It took nearly two decades when the next influential, albeit short-lived, ex-patient group, the "Insane Liberation Front," was established in Portland, Oregon, in 1970. That same year, the Vancouver, Canada-based Mental Patients Association (MPA) was the first patient controlled and operated self-help group for ex-

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<sup>2</sup> For a more detailed account of the history of the North American c/s/x movement see Starkman 1981, 2A-15A; Chamberlin 1990; Shimrat 1997; Reaume 2002; Morrison 2005, 57-98.

psychiatric patients<sup>3</sup>. In Ontario cooperation with other self-help and disability rights groups, such as the Ontario Coalition on Human Rights for the Handicapped and Blind Organization of Ontario with Self-Help Tactics (BOOST), was instrumental in the progression of the c/s/x movement (Starkman 1981, 4A). The Ontario Mental Patients Association, which later became On Our Own, was founded in 1977 and became the second ex-patient run and controlled self-help group in Canada. In addition to self-help groups, ex-patients opened drop-in centers; organized conferences<sup>4</sup>; published newsletters and magazines<sup>5</sup>; organized rallies against major professional psychiatric associations<sup>6</sup> as well as against state institutions such as welfare, justice, and prison system to oppose their unjust and discriminatory policies; wrote books, memoirs, and manifestos that critically analyzed the psychiatric system and discussed patient run alternatives<sup>7</sup>; created position papers, engaged in public speaking, initiated legal challenges and obtained full intervenor status in courts<sup>8</sup>, and lobbied for public policy and legal reforms. All these efforts facilitated the growth of the movement and expanded its outreach to other North American cities. These also influenced the cultural, political, academic landscape; challenged stereotypical images and notions of people with mental illness diagnosis in larger society; and exerted some control, albeit limited, over psychiatric system and government agencies.

Unlike the larger and highly organized labor movement of the time, the c/s/x movement was, and to a great extent still continues to be, fragmented, independent, locally organized (Starkman; Reville and Church, 1992; Diamond). Local groups were formed with little or no funding by a small number of people who organically came together out of “a shared anger and a sense that through organization they can bring about change” (Chamberlin 1990, “Historical development”). While there was some racial diversity depending on the specific geographical region, particularly in the USA,

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<sup>3</sup> See a recent documentary produced by York University professor Megan Davies, *The inmates are running the asylum: Stories from MPA* (2013). Available to watch at: <http://historyofmadness.ca/the-inmates-are-running-the-asylum/view-movie/>

<sup>4</sup> Such as the annual international conference on Human Rights and Psychiatric Oppression (1973 - 1985)

<sup>5</sup> Such as *Madness Network News* (1972 - 1986) in San Francisco, *In a Nutshell* (1972 - ongoing) in Vancouver, *Phoenix Rising* (1980 - 1990) in Toronto.

<sup>6</sup> Such as the American Psychiatric Association (APA).

<sup>7</sup> See Irwin et. all 1974; Chamberlin 1978.

<sup>8</sup> See Shimrat 120-21; Costa 2013.

movement leaders and most of its membership were all white<sup>9</sup> (Morrison 2005, 78). They were loosely linked to other c/s/x groups through conferences, newsletters, protests, and other movement activities. Consequently each group had their own set of goals, values, organizational structures, and definition of terminology that changed and evolved through time and according to membership. However, all the groups that associated themselves with the c/s/x movement shared certain key principles that informed their overarching objectives and activities. These principles continue to form the basis of the contemporary survivor/consumer activism and advocacy efforts. Thus, it is important to look at them in more detail.

Self-determination, self-definition, and freedom of choice have been the guiding principles of the c/s/x movement (Chamberlin 1978, 1990; Shimrat 1997; Bassman 2001; Morrison 2005, 2006; Costa et. all 2012). Self-determination and self-definition signify individuals' ability to speak for themselves and name their experiences. This is in sharp contrast to most people's encounters in the psychiatric system where they are not listened to, taken seriously, considered experts of their own experiences, or given opportunity to determine their choice of action. As Bassman wrote, "[w]e are refusing to allow others to speak for us and are reclaiming ownership of our experiences" (23), summing up the common sentiments underlying these principles. Freedom of choice indicates complete access to available, alternative understandings of mental distress/illness, treatment, healing, and recovery, and to have power to make an informed choice among these alternatives. It includes the right to refuse any given treatment and the right to control one's mind and body (Chamberlin 1990 "Advocacy")

Advocacy, consciousness raising, and self-help have been the most effective tools used to achieve self determination and reclamation of voice. Connection with the broader social justice struggles, in particular socio-economic class analysis was strong in the early mobilization efforts. Thus, advocacy was defined as working for structural and political change. It went beyond individual and aimed at addressing and transforming systemic, structural injustices and inequalities, such as capitalism, racism, sexism, heterosexism,

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<sup>9</sup> This does not mean that racialized people did not engage in critiquing psychiatric system or advocating for themselves. For an important discussion on the omission of the contributions of racialized people in general and Black people in particular from the "official" history of the North American c/s/x movement see Jackson 2002, available at: <http://www.power2u.org/downloads/InOurOwnVoiceVanessaJackson.pdf>



and colonialism, within which peoples' lives took shape. Similarly self-help included peer support, information & resource sharing, alternatives to psychiatric/medical treatments as well as raising consciousness through telling and examining personal experiences. According to renowned movement leader Judith Chamberlin as a result of this sharing and critical analysis "it became clear that distinct patterns of oppression existed and that our problems and difficulties were not solely internal and personal, as we had been told they were" (1990, "Consciousness Raising"). Indeed Pat Capponi, a Canadian psychiatric survivor and advocate, claims, "the first thing about advocacy is that you get really angry" (2013). For Capponi, the anger about injustice, violence, and discrimination faced by people who are diagnosed with mental illness, and the productive use of this anger is essential to take action and work towards change. This connection to broader issues of social justice is the continuing basis of the contemporary psychiatric survivor advocacy that "disrupts the traditional focus on the psychiatrized as 'mentally ill' patients in need of a cure. It orients away from medical intervention and towards a broader impetus for respecting, responding, and incorporating difference into the social milieu" (Costa et. all, 87).

The choice of terminology reflected the critical and radicalized nature of the early movement years<sup>10</sup>. Up until the 1980s the most dominant terms used by the North American c/s/x groups to define themselves made analogy to the prison system where they called themselves "inmates and ex-inmates." "Mental patients or ex-patients," "psychiatrized people," and "psychiatric survivors" were also among the frequently used terms while in the UK "service users" was preferred. With the rise of the "consumer rights" movement in the larger society and the mainstreaming of advocacy efforts after the 1980s "mental health system consumers," or shortly "consumers," have become widespread. Similarly, the identity movements of the late 20th and early 21<sup>st</sup> centuries generated new expressions that reclaim offensive words such as "lunatic," "crazy," and "mad." Among these, Mad has recently become an umbrella term that embraces diverse identifications and wide range of discourses about mental illness/distress and psychiatric oppression (Diamond 65-6). Naturally, each of these terms comes with their

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<sup>10</sup> For an excellent review of historical development of terminology and debates surrounding it see Reaume 2002.

shortcomings and critiques<sup>11</sup>. Language is always contested and political. Thus, terminology indicates the political location of the consumer/survivor groups and their advocacy efforts along a continuum. However language is also fluid and contextual, continuously evolving, and changing depending on particular context within which it is used. In this review the main focus is on groups that identify as psychiatric system survivor/consumer in order to capture the diversity of identifications while emphasizing the collective and structural elements of the advocacy efforts taking place within the neo-liberal policy context.

Along with the terminology, group membership and funding were the most disputed topics. Groups varied in their inclusion of progressive medical professionals, service providers, and family members into their membership. However, in general the exclusion of “non-patients” was encouraged due to the inherent power imbalance and practical reasons. According to Chamberlin:

those groups that did not exclude non-patients from membership almost always quickly dropped their liberation aspects and became reformist. In addition, such groups rapidly moved away from ex-patient control, with the tiny minority of non-patient members taking on leadership roles and setting future goals and directions.

1990, “Guiding principles”

Others proposed that while the “outside help” would be welcomed, non-patients could only be associate members with no voting rights (Irwin et. all 1974). This was to maintain patient control, and prevent potential problems Chamberlin stated above. Likewise, the issue of obtaining or accepting funding, particularly from government or service agencies was controversial. On the one hand, scarce financial resources obtained through subscription fees of publications, membership donations, or small grants restricted the scope and success of advocacy activities taken on. On the other hand access to bigger funding, while enabling the undertaking of bigger concerns such as housing and employment, almost always came with several strings attached that limited the type and level of the advocacy they could engage in (Shimrat).

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<sup>11</sup> Among these terms “consumer” has been supported by governments and medical professionals alike, and enjoyed a widespread recognition. However it has also faced criticisms and is rejected by more politically oriented activists due to its connotations with consumerism of the market economy, misleading suggestion of choice, and affinity with reformist programs (Reaume 2002 418, 421; Morrison 2005, 80; Diamond 68).

These issues, questions, and debates are ongoing in the 21<sup>st</sup> century with the same urgency due to intensifying conservative neo-liberal political economy and the changing nature of the mental health policy context both in the provincial and federal levels. Particularly since the early 2000s the mental health policy in Ontario has a renewed focus on traditional bio-medical models of mental illness and conventional treatment methods while simultaneously cutting back on both funding and support for meaningful, independent advocacy work<sup>12</sup>. This is coupled with the rise of both philanthropist and governmental monetary investment in brain research and drug therapies, whilst social welfare supports and disability benefits, as well as funding for anti-poverty, legal aid, women's and immigrants centres face the most severe budget cuts (Wilton; Morrow). In addition, co-optation and appropriation of the movement's language and strategies by the neo-liberal agenda of the mental health system create more challenges for the survivor/consumer advocacy. While the notions of advocacy, consumer participation, lived experience, empowerment, and peer support gain widespread recognition, they no longer signify systemic and structural change centered on a social justice agenda (Hurter, see particularly Chapter 5; Morrison 2005, 82 - 86; Costa et. all; Morrow). Rather the focus has shifted from alternatives to psychiatry to medical illness model<sup>13</sup>; from the structural to the individual, emphasizing personal empowerment, self-management, and recovery<sup>14</sup>, devoid from a critical analysis of power dynamics, structural inequality and oppression that shape the lives of survivor/consumers. It is within this larger neo-liberal political economy and mental health policy context that the themes, issues, and practices reviewed in the next section should be considered.

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<sup>12</sup> One of the major attempts to curb independent advocacy efforts happened on June 29 2011, when the Ontario Ministry of Health and Long-Term Care announced it would be transferring the services of the Psychiatric Patient Advocacy Office (PPAO) to the Canadian Mental Health Association (CMHA) in Ontario. On July 29th Minister Deb Matthews halted the divestment to CMHA as a result of protests organized by the psychiatric survivors, and promised more engagement in order to foster "the best way to achieve our shared goals of increased independence for the PPAO." This has yet to occur. For more information see: <http://cippao.com/>

<sup>13</sup> For instance, Canadian Mental Health Association (CMHA) states, "self-help and peer support are key elements of *recovery* for many people *with mental illness*... Self-help groups can help people *cope with* mental illnesses like depression, bipolar disorder, anxiety disorders and schizophrenia" ("Self advocacy," my emphasis).

<sup>14</sup> For a detailed study of various (and critical) meanings of "recovery" articulated by survivors/consumers see Mental Health "Recovery" Study Working Group. Also see Marina Morrow's succinct critique of the resurgence of recovery paradigm within the current neoliberal policy context.

### **3. Contemporary Survivor/Consumer Advocacy: Themes, Issues, and “Best Practices”**

The Ontario Ministry of Health answered calls for more consumer survivor participation in mental health policy by encouraging them to set up "patient councils." ...In 1991, both the Kingston and Queen Street provincial psychiatric hospitals started patient council steering committees. The process was at first guided by mental health professionals, but consumer survivors soon reclaimed it, and the new Queen Street Patients Council was born in 1992 with one full-time equivalent staff.

Queen Street Patients Council, “Our Background”

The efforts of the early grassroots c/s/x movement began to pay off during the last decades of the 20<sup>th</sup> century. In 1988 the Liberal government of Ontario published one of the key mental health policy documents, which was arguably the first time that the government seriously considered the demands of the survivor/consumers (Wilton 374). As a result, patient councils formed, and were run by inpatients, in order to engage in systemic and individual advocacy. Similarly the shift from large institutions to community mental health services was accompanied by survivor/consumer representation in their boards, steering committees, and other decision-making bodies. Survivor/consumers were even employed by the very agencies to do peer support and advocacy work (Everett 1998, 2000; Reville and Church; Fabris).

Since the last decade of the 20th century the advocacy efforts of the survivor/consumers can be said to fall into roughly two separate, but at times overlapping, categories (Coney 2004). While the most transformative advocacy work is still carried out by independent grassroots groups, some survivors/consumers now choose to work “inside the system,” through participating in community mental health organizations or in partnership with other stakeholders. While the latter is becoming increasingly popular, there is a growing literature—both professional/academic and activist—that critically investigates the effectiveness of the survivor/consumer “participation” or service-provider/user “partnership” models in relation to advocacy (Beresford and Wallcraft 1997; Everett 1998, 2000, 64 - 78 & 163 - 184; Medernach; Nelson, Lord, and Ochocka; Chamberlin 2005; Morrison 2005, 80 - 97). It becomes evident in this critical body of work that cost-cutting efforts of governments, paternalistic attitudes and power differentials inherent between government agencies, service

providers and survivor/consumers, as well as the frequent ignorance of this power imbalance, hinder the efficacy of the advocacy efforts. As Barbara Everett's study suggests "it is only a certain type of consumer or survivor who receives an invitation to participate" (2000, 166). For instance, one self-identified consumer advocate states:

in order to establish credibility as advocates, we... must be willing to frame our advocacy efforts in terms of the mandate of the organization. While passion may be commented on favorably, it is often only tolerated. We are frequently pressured into conforming to professional models of behavior, to speak softly and not become angry or upset because we must not make others uncomfortable... Our contributions are most highly valued when given free of charge and limited to saying what people want to hear.

Medernach, 225

Accordingly, substantial focus of this section is on independent survivor/consumer led and run advocacy groups and on the ones that maintain their "arms-length" relationship with the mental health system. In the following subsections I examine various ways in which survivor/consumer groups come together, structure themselves, identify their core principles and advocacy practices, and financially sustain themselves.

### **3.1. Beginnings: Membership, Recruitment, and Basic Principles**

Will wrote to David initially about his idea for the Freedom Centre. David Oaks wrote back telling him that he should meet up with Oryx Cohen, another psychiatric abuse survivor who had been diagnosed as bipolar and who was living in Will's area.... Though [Oryx] had initially some doubts about the meeting he now points out "we just got along great and we both had a similar vision for what needed to happen." ...The two of them applied for a grant through the Department of Mental Health... under 'Consumer-Run programs' and they got the grant for \$500...

Hurter, 19

The first UK hearing Voices group was formed in 1988 in Manchester. It was inspired by the pioneering work of Professor Marius Romme and Sondra Escher from Maastricht University, and a Dutch self-help group, Foundation Resonance. Following a national conference held in London in 1990, the Independent on Sunday newspaper published a prominent article on the topic which generated a lot of correspondence. As a result we decided to establish a network of voice hearers and individuals who were interested in the experience of hearing voices.

Hearing Voices Network, "about"

The Ontario Psychiatric Survivors' Alliance (OPSA) was founded on January 27, 1990, by the Ontario participants of the Our Turn conference... Pat [Black] [an executive director of a mental health agency] and another staff member who wasn't officially crazy—and a couple of other people who were the spouses of crazies—founded OPSA,

along with the rest of us, who were crazies. We had a very contentious debate at the first meeting that ended with the decision that only psychiatric survivors would be allowed to vote, although others who supported our principles could participate in meetings and influence discussion.

(Shimrat 89, 90)

The Freedom Centre, Hearing Voices Network, and (now defunct) OPSA are all survivor/consumer run support and advocacy organizations established in the USA, UK, and Canada respectively. The “origin” story of each organization is typical of several other grassroots and not-for-profit, community based psychiatric survivor groups. While some begin their journey with a small, informal gathering of a few like-minded people who share similar experiences and visions, others come together as a result of a call published in a community newsletter, national magazine, or after a conference or a workshop organized on a related theme. In each case the most immediate issues include developing criteria for membership, identification of core principles, as well as decisions about organizational/group structure and funding. A couple of established survivor/consumer organizations that publish practical guidelines on starting a local advocacy and support groups also emphasize membership criteria and basic goals & principles as the most urgent questions that need to be answered<sup>15</sup>.

Some advocacy groups are composed of and limit their membership to survivor/consumers who belong to specific demographic group such as, post-secondary students (i.e. Mad Students Society<sup>16</sup>) or racialized people (i.e. The MAAT Probe in the UK organized by and for African Caribbean men<sup>17</sup>), who have specific experiences (i.e. Hearing Voices Network<sup>18</sup>), or who reside in a specific geographical area (i.e. The Mental Health Rights Coalition of Hamilton<sup>19</sup>). Others are more inclusive, have international or global focus, and form coalitions with wide range of survivor/consumer

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<sup>15</sup> See for instance UK based Hearing Voices Network and NSUN Network for Mental Health guidelines on how to start groups <http://www.hearing-voices.org/hearing-voices-groups/setting-up-a-hearing-voices-group/> and <http://www.nsun.org.uk/assets/downloadableFiles/getting-a-group-started-resource-22.pdf>

<sup>16</sup> <http://www.madstudentsociety.com>

<sup>17</sup> [http://www.thecolourofhealth.com/index.php?option=com\\_content&task=view&id=182&Itemid=27](http://www.thecolourofhealth.com/index.php?option=com_content&task=view&id=182&Itemid=27)

<sup>18</sup> <http://www.hearing-voices.org/>

<sup>19</sup> <http://www.mentalhealthrights.ca/>

groups such as, Mind Freedom International<sup>20</sup> and World Network of Users and Survivors of Psychiatry.<sup>21</sup>

Some groups welcome “allies” who do not self-identify as survivor/consumer, but share the concerns, aims, and principles of the group. For instance, the Freedom Centre<sup>22</sup> states “allies and supporters willing to share their personal experiences are also welcome (mental staff allies are welcome but should contact us first; please no ‘observers’).” Others restrict membership to exclusively survivor/consumers, such as the Toronto based Mad Students Society (MSS), Psychiatric Survivors of Ottawa,<sup>23</sup> and World Network of Users and Survivors of Psychiatry (WNUSP).<sup>24</sup> When allies are allowed however, in general certain restrictions put on their level of participation in order to maintain the survivor/consumer control over the decision making process. For instance the Mental Health Rights Coalition of Hamilton states, “the family members and service providers are also free to join, but only those who have self-identified as consumer/survivors have voting privileges, can stand for election to the Board of Directors, or can be hired to work at MHRC” (“Welcome”). In some cases groups mandate that survivor/consumers represent the majority of seats (51% or higher) in their board of directors and other major decision-making bodies.<sup>25</sup>

The initial recruitment of members can be accomplished in several ways including but not limited to existing contacts; flyers in local mail boxes; posters in neighborhood shops, community centres, schools, libraries, community health and recreation centres, or other related advocacy and social justice group locations; announcements on community newsletters, local newspapers, radio and TV stations, and social media; organizing a town hall meeting or a small awareness raising event to stimulate interest, etc. The most important point in creating publicity and recruiting potential members is determining *who* you are planning to attract and giving them a reason or incentive to participate. Incentives to participate need to take into consideration everyday realities of people and go beyond providing accessible space, transportation

<sup>20</sup> <http://www.mindfreedom.org/>

<sup>21</sup> <http://www.wnusp.net/>

<sup>22</sup> <http://freedom-center.org/welcome>

<sup>23</sup> <http://www.psychiatricsurvivors.org/about-us.html>

<sup>24</sup> <http://www.wnusp.net/index.php/membership-information.html>

<sup>25</sup> See for instance Law Project for Psychiatric Rights, “By-Laws, Article III, Governing Body, Qualifications” <http://psychrights.org/>

costs, food, child care, etc. The group has to be relevant to their lives, be clear and transparent in its aims, and be mindful of the potential benefits and risks of participation. Two Toronto based academic/activists David Reville and Kathryn Church argue “the necessity to claim membership in the face of stigma and discrimination, to name that membership against the grain of conventional discourse, and to alter its meaning in the eyes of others” is “a basic tenant of survivor organizing” (190). However this approach to survivor/consumer organizing does not consider the risks inherent in claiming membership (as a psychiatric survivor/consumer), particularly for racialized, immigrant, and working class people whose livelihood, legal status, and relative safety may depend on their disidentification from such membership/identity (Gorman).

At this point it is imperative to take note from the insights of a long-term local community organizer Becky McFarlane. First and foremost a clear articulation of “who is at the table and what voices you want to hear” is crucial (2014). According to McFarlane the core members of any social justice and advocacy group need to be able to articulate principles of social justice, have a basic analysis of power, and understand the structural inequalities that shape our experiences. As core members become the ones who greatly influence the goals and direction of a group it is vital that they have a good grasp of these issues (Ibid.). Furthermore, the ability to connect personal experiences to collective community experiences is important. McFarlane believes that building strong, lasting relationships with the community is essential, and critical analysis coupled with connection and engagement with local community is the crux of successful advocacy. (Ibid.). Pat Capponi, a long-term Canadian psychiatric survivor/consumer activist, adds that:

A good advocate speaks for his or her whole community, not just what would make life better for him, not just for a treatment or solution that he wants, or agrees with. He has a demonstrable understanding and respect for the wishes and yearnings of his base... respects his community, does not put them down to advance his own sense of prestige.

Leadership Files

Capponi employs these insights in the *Voices from the Street* initiative, which was initially started as advocacy training for psychiatric survivor/consumers<sup>26</sup>. Capponi

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<sup>26</sup> For more information see <http://www.ocab.ca/voices.htm> and [http://workingforchange.ca/?page\\_id=14](http://workingforchange.ca/?page_id=14)



believes that bringing many people with marginalized experience, such as single mothers, racialized people, immigrants, people with addiction issues, etc., to the table proves to be more effective (2013, 2014). People with mental illness labels, regardless of their survivor/consumer/mad identification, recognize that the struggles they face is not necessarily because of their diagnosis or so-called “illness,” but “maybe there is something else going on here” (2014). The focus shifts to critical understanding grounded in personal experience but one that goes beyond individual and focuses on structural issues such as racism, poverty, unemployment, discrimination, inadequate social and economic support and safety networks, etc. This approach to recruitment indicates that connecting with the existing social justice and advocacy groups in the community and bringing their attention to the unique issues psychiatric system survivors/consumers face can be one of the valuable ways in which to recruit group members. This would also address the problems with explicit survivor/consumer identification that may discourage certain people to participate in organizing and advocacy efforts<sup>27</sup>.

In sum, while survivor/consumer advocacy groups vary in their criteria for membership and inclusion of friends, family members, or allies as members, the most influential ones stipulate and uphold the fundamental principles of social justice and basic understanding of unequal power relationships. In addition, as discussed in the history of the c/s/x movement, engaging with the local community and connecting with the broader social justice issues and struggles are essential for the success of any transformative advocacy efforts. Our experiences and struggles are not one dimensional, nor are the resistance and advocacy strategies we formulate. To quote Capponi once more:

Whatever gets you to your first meeting is powerful and motivating, but you will do better as an advocate if you start to understand and feel how things interconnect, how people are forced to endure many of the same negative attitudes and consequences such as isolation, rejection, marginalization, and invisibility no matter what Ministry they come under or what label they carry. We are divided and sub-divided into diagnostic categories for the convenience of funders and

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<sup>27</sup> In addition, as Shaindl Diamond states, “it cannot simply be assumed that people outside this political community [of survivors, Mad identified people and anti-psychiatry activists] do not have a critique of psychiatry and other sanist organizations. To the contrary, people in various communities across Toronto are organizing in different ways against psychiatric oppression, albeit not always in collaboration with established... groups, and not always using the same language as psychiatric survivor...” (67). Diamond cites Toronto Women of Color Collective and THRIVE, the Multicultural Women’s Coalition Against Violence and Oppression, as two of these organizing efforts that include psychiatric oppression in their violence against women work.

agencies. Although this may have made sense once upon a time, it now serves to obscure systemic issues that plague the majority of those who require government assistance or depend on agencies for care.

Leadership Files

These points are supported by a comprehensive literature review of existing theoretical frameworks on social inequities and mental health/distress relationship (Ingram et. all). The authors of the review conclude that:

The definitions that best capture the links between mental health and social inequities are those that emphasize the structural nature of inequities and thus place a clear focus on societal power arrangements. For this, intersectional frameworks are best, as they elaborate on the complexity of the intersecting social categories like, class, gender, ethnicity, disability, and geography and locate inequities in systems of power.

6, 43

Furthermore, they emphasize the damaging impact of individual and systemic level discrimination against people diagnosed with mental illness, and diagnostic labeling process shaped by the dominant understanding of “normalcy” and biomedical models of mental illness (44). In here the historical and ongoing use of mental illness diagnosis to construct and maintain racial categories and to discipline racialized bodies should also be mentioned<sup>28</sup> (Kanani 2011; Tam 2012).

In accordance with these points, self-determination, informed choice, claiming voice and consciousness raising, challenging dominant medical paradigms and practices, and developing alternatives to them, establishing linkages with the history and culture of the survivor/consumer activism, and engagement in systemic advocacy constitute the underlying principles of the prominent survivor/consumer advocacy organizations. Below are excerpts from the common values, goals, visions, and terms of references of some of these organizations that reflect their basic principles.

The Empowerment Council will:

- Advocate on a systemic level (e.g. to C.A.M.H., government) on behalf of addiction and mental health clients.
- Ensure client access to information, and educate clients in regard to choices, self-advocacy, critical thinking, leadership development, and political awareness.

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<sup>28</sup> For instance, in the UK African Caribbean men are three times more likely than white men to be 'sectioned' under the Mental Health Act (The Color of Health). For an extensive literature review on complex intersections and mutual construction of race and madness see Kanani.

- Ensure the representation of the client perspective at C.A.M.H. through participation on relevant committees, work groups, etc.
- Increase client involvement in decision-making and accountability structures.  
Empowerment Council, “Terms of Reference”

Common Values:

- Mental health and addiction services should be directed by and accountable to the people they are intended to serve.
- CSIs must be self-determining and autonomous, representing their members with integrity. CSIs by definition require independent governance and funding/accountability agreements.
- Enhancing capacity for our community to participate in decision-making bodies requires consciousness raising within our community, and for those “bodies” to learn to relate to our community with respect and equality.
- Equity in relation to social determinants of health. Decent housing, income and employment are necessary for health to be possible.
- Our definition of our experience, community and culture extends beyond the medical model and this needs to be reflected in decisions about directing resources.
- Various experiences of oppression interplay with each other and all have an effect on health.
- We do not define force and coercion as help

Consumer/Survivor Initiative Network, Toronto Central LHIN

We, as survivors and consumers of the mental health system, engage in mutual support, empowerment, and information sharing. We, affirming the dignity and worth of the individual, advocate for alternatives and improvements to the established health care system, services and issues which affect our well-being.

Psychiatric Survivors of Ottawa, “Mission Statement”

NARPA’s mission is to promote policies and pursue strategies that result in individuals with psychiatric diagnoses making their own choices regarding treatment. We educate and mentor those individuals to enable them to exercise their legal and human rights with a goal of abolition of all forced treatment.

National Association for Rights Protection and Advocacy (NARPA)

Mind Freedom goals are to win human rights campaigns in mental health; challenge abuse by the psychiatric drug industry; support the self-determination of psychiatric survivors and mental health consumers; promote safe, humane and effective options in mental health.

Mind Freedom International

We call for compassion, human rights, self-determination, and holistic options. We create alternatives to the mental health system's widespread despair, abuse, fraudulent science and dangerous treatments. We are based in pro-choice harm reduction philosophy regarding medical treatments, and include people taking or not taking medications.

Freedom Center

Our Vision is a community of empowered and mobilized Mad Students who are aware of the history of the psychiatric survivor movement and practice alternatives to medical perspectives on madness by supporting each other. We need post-secondary environments that are free of systemic discrimination and celebrate and support differences of all kinds so that people can achieve their learning goals.

Mad Students Society (MSS)

### **3.2. Group Structure & Process**

Barbara Everett argues that effective movements need to develop an organizational structure for their operation in order to “renew feelings of mutuality and translate the resulting energy into activity,” to consolidate “group’s emotional and intellectual commitment to the cause,” and to map its priorities and future directions (2000, 54). Not every social and political movement organization would concur with this argument. According to Toronto based psychiatric survivor and archivist Mel Starkman in its early years the Mental Patients’ Liberation movement practiced “total democracy in an effort to avoid the kind of hierarchy of power that they had experienced as inmates. There was an almost total lack of structure, and emphasis on collective decision-making and action” (5A). However, Starkman also recognizes that total democracy and lack of structure created several challenges particularly when the groups became larger, obtained funding, and struggled with political/ideological factions transpired among members and the leadership. For instance, one of the influential names of the Canadian c/s/x movement, Randy Pritchard, reflects back on the shortcomings of the OPSA that eventually led to its demise, and argues that “things would have gone very differently if we’d built up our structure to the point where the board, rather than us [individual leadership figures], had developed policy, and we had implemented it” (cited in Shimrat 105).

While over planning, and rigid, hierarchical structure inhibit group development, certain decisions, from execution of mundane activities to long-term action plans, need to be made. These include, but are not limited to the degree of formal organizing (board, steering committee, advisory committee, creating a constitution/charter/by-laws), decision-making process (consensus based or majority vote), ways to resolve conflict and conflict of interest (a procedure to follow, formal policy, rules, and regulations, or informal means), division of responsibility and tasks (subcommittees, paid-staff, coordinators, volunteers), formal documentation (annual reports, board meeting minutes, terms of reference).

Most, if not all, advocacy groups create formal statements of their mission, vision, goals, and terms of reference. Some make their organizational structures, charters/constitutions, regulations, conflict of interest policies, and by-laws publicly available for transparency and accountability purposes<sup>29</sup>. In most jurisdictions the law also requires formal documentation and structure if groups incorporate or are registered as charity. Typically a formal board, elected by the general membership, is formed and becomes responsible for major decision-making and overseeing the general activities of the group. Certainly establishing a certain level of structure and basic rules are needed. However Capponi cautions us that:

New groups tend to surround themselves, stifle themselves, with rules. It is unnecessary and counter-productive. We need to have some faith in each other. The one over-arching rule is respect, respect for each other's time, respect for the co-facilitators, and respect for process. At this point, what is most important is learning about one another...

Notes for participating in a successful meeting

While an advisory committee consists of experienced survivor/consumer advocates or movement leaders would likely be a valuable resource, both Capponi and McFarlane highlight the importance of role models and leadership figures within local

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<sup>29</sup> See for instance archival web site of Queen Street Patients Council "By-laws and policy" <http://www.qsos.cc/qspc/policy.html>, Mind Freedom "Who we are" <http://www.mindfreedom.org/who-we-are>, Hearing Voices Network "Charter" <http://www.hearing-voices.org/hearing-voices-groups/charter/>, NSUN network for mental health "Governance" <http://www.nsun.org.uk/about-us/our-governance/>, World Network of Users and Survivors of Psychiatry "Statutes," <http://www.wnusp.net/index.php/wnusp-statutes.html> and "Board members" <http://www.wnusp.net/index.php/wnusp-contact-information.html>, House Link "Board minutes" <http://www.houselink.on.ca/board-minutes/>, Empowerment Council "mission statement, statement of purpose, organization, and agenda" <http://www.empowermentcouncil.ca/index.html>

communities. In other words, they reason that local leaders who are familiar with the particular context/dynamics of a community, and who have critical analysis and commitment to social justice would be better equipped to provide guidance on advocacy. They would be more effective than a group of well-established survivor/consumer advocates who may be knowledgeable about certain survivor issues, but lack the crucial knowledge/experience to grasp the complex everyday realities of survivor/consumers residing in the community.

In recent years several groups have developed websites to publicize their work, as well as to expand their outreach and advocacy activities. As the availability of free and public Internet services become available, these groups set up Internet discussion forums and email lists. The full impact of this shift towards virtual space and electronic communication techniques on organizational structures, group dynamics, and mobilization efforts remains to be seen. Yet, the Internet and virtual discussion forums carry enormous potential for instant access to vital information, establishing links with various survivor/consumer groups, and for keeping the advocacy momentum alive<sup>30</sup> (Morrison 2005, 88-9).

Despite the increasing popularity of Internet forums and discussion groups that cut across time zones and geographical locations, local, in-person meetings are still a significant component of advocacy groups and thus require some consideration. Capponi emphasizes the practical issues such as: making sure meeting spaces are accessible, food, childcare, and TTC tokens or other forms of transportation fees are provided, and survivor/consumers' knowledge/expertise and time are properly compensated (mostly in the form of honorariums). For Capponi these are essential elements that would ensure ongoing participation and engagement of survivor/consumers in advocacy work. However, the question of honorarium is a thorny one, as it can quickly turn into a silencing mechanism. As McFarlane points out that:

[w]e rarely talk about who is included and who is excluded from collecting that payment – about how the exchange of money has allowed the system to put conditions on how we participate, when, and to what extent, with little worry that we will push back... It is hard to not conclude, at some point, that the honorarium

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<sup>30</sup> However it should be noted that access to such support and discussion forums and resources require not only publicly available computers & free internet services but also computer, internet, and electronic communication literacy. Thus they would benefit only certain group of survivor/consumers.

has become more of a tool to silence than one that honors our contributions – particularly when there is little or no analysis that acknowledges how we are being used.

2013, 31

For McFarlane advocacy is a distinct type of work, and it needs to be volunteer-based in order to evade conflict of interest and cooptation (2014). But she adds, if we are to accept money “we should do so with our eyes wide open and with a commitment to resist the system whether we get paid or not” (2013, 31) if we are really working towards transformational change.

### **3.3. Advocacy Activities**

Advocacy, both on individual and structural levels, is one of the mainstays of the c/s/x movement since its beginnings. The type and extent of advocacy efforts vary according to particular size, human and financial resources, composition of membership, geographical and political/economic context, and goals of the survivor/consumer groups. However, sharing information, providing mutual support, and creating political awareness for self-determination, informed choice, and successful negotiation & navigation of the mental health system are the most basic activities taken up by all the groups (Chamber 1990; Morrison 2005). Some organizations engage in exclusively system-level advocacy such as the CAMH Empowerment Council in Toronto, to use collective issues as an impetus for systemic change. According to Psychiatric Patient Advocacy Office (PPAO) systemic advocacy requires “study, analysis, research, administrative changes, or legislative remedies aimed at reducing or preventing barriers and ensuring equitable access and treatment of a group of people” (Simpson, 44). Thus the common advocacy activities include “writing letters to the editor; writing academic articles; responding to media inquiries; being on hospital and community based committees... preparing position papers; and appearing before legislative committees at both the provincial and federal levels” (Ibid.) among several others. Even the organizations that solely focus on systemic change, however, provide tools for self-advocacy by sharing information and resources, and by offering educational workshops and training such as on legal and human rights of survivor/consumers.

According to Canadian psychiatric survivor and a former member of the Ontario provincial parliament David Reville, fighting for good quality subsidized housing, and

against the use of Electroshock (ECT) and forced treatments were the major advocacy issues in the early years of the Canadian c/s/x movement (192). He recounts that:

In Toronto, fighting for better housing meant dealing with building codes and zoning by-laws, as well as finding money to build alternatives... While on city council, I was also a member of the Ontario Coalition of the Stop Electroshock. I used my public role to hold hearings in the council chamber on the use of electroshock... When the government introduced Community Treatment Orders, I organized the Care Not Cuffs Coalition which, together with the No Force Coalition... made deputations to the parliamentary assistant sent out to consult with the stakeholders about the legislation...

192-3

Similarly, Judith Chamberlin states that the early North American c/s/x movement's "advocacy has focused on the right of the individual *not* to be a patient" (1990 "Advocacy," my emphasis), as ending involuntary treatment has been one of the primary goals of the patients' liberation movement. In the mean time however "movement activists work to improve conditions of people subjected to forced treatment, and to see that their existing rights are respected, keeping in mind that these are interim steps within a basically unjust system" (Ibid.). While adequate housing and forced treatment continue to be the major concerns, current survivor/consumer groups undertake a diverse approach to advocacy work. Below I will focus on four interrelated key advocacy activities that consumer/survivor groups engage, including legal & human rights advocacy and education; consciousness raising and developing alternatives to mental health system; public education, strategic action, and influencing public policy; community development & cultural production.

### 1. Legal & Human Rights Advocacy and Education

Advocacy on legal and human rights of survivor/consumers take several forms including developing a Bill of Rights, such as the one created by the Empowerment Council. According to its web page the *CAMH Bill of Client Rights* is the highest standard of hospital based mental health rights in Canada to date. The clients who are using the services of the CAMH, their families, and the Empowerment Council staff developed the *Bill* collaboratively. Everyone working at the CAMH, including volunteers, is expected to respect and uphold the *Bill*. Some of the rights specified



include the Right to be Treated with Respect; the Right to Freedom from Harm; the Right to Make an Informed Choice and Give Informed Consent to Treatment; and the Right to Complain<sup>31</sup>.

Educating the survivor/consumers, as well as the general public and service providers on the legal rights of the people within the mental health system, is a crucial form of advocacy. For Lucy Costa, the outreach coordinator of the Empowerment Council, “knowing what your rights are is pretty important when you have your freedom taken away” (cited in Himmelsbach 2014). Costa initiated a ten-week educational series called “Mad about Rights” for psychiatric survivor/consumers in October 2008. This short course is offered through the Empowerment Council and covers mental health law, the Charter of Rights and Freedoms, important activists in the psychiatric survivor/consumer community, prejudices in the law and media, and the creation of patient rights documents in an accessible language (Costa 2009). Similarly, several other advocacy organizations provide workshops, legal clinics, online articles and detailed resource lists specifically on survivor/consumer rights in related laws, basic legal principles in relation to forced treatment, case law summaries, and constitutional challenges,<sup>32</sup> as well as create position statements and make submissions to local, national, and international human rights committees and other judicial bodies.<sup>33</sup>

In addition to developing the Bill of Rights, position statements, and rights education, some survivor/consumer groups have more direct engagement with the law such as through obtaining intervenor status in “lower and higher courts, inquests, and, more recently, in processes of court diversion” (Costa 2013, 201). According to Costa, the 1999 Supreme Court of Canada case *Winko vs. British Columbia* was the first time where a Canadian c/s/x organization applied and obtained intervenor status to challenge the constitutionality of the mental health laws, which signified new avenues for survivor/consumer advocacy work in litigation (200-1). Since this date,

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<sup>31</sup> Available at [http://www.empowermentcouncil.ca/PDF/client\\_bill\\_rights.pdf](http://www.empowermentcouncil.ca/PDF/client_bill_rights.pdf)

<sup>32</sup> For instance see The Law Project for Psychiatric Rights <http://psychrights.org/>, National Association for Rights Protection and Advocacy <http://www.narpa.org/>, Queen Street Outreach Society review of the Mental Health Laws in Ontario in plain language <http://www.qsos.cc/legal.html>

<sup>33</sup> For instance see World Network of Users and Survivors of Psychiatry, Human Rights Issues <http://www.wnusp.net/index.php/human-rights-issues.html> and International Advocacy <http://www.wnusp.net/index.php/international-advocacy.html>, as well as the Empowerment Council Accomplishments of the Last 10 Years Report <http://www.empowermentcouncil.ca/index.html>

survivor/consumer groups have participated in several inquests and court challenges<sup>34</sup>, while others have taken strategic direct legal action against forced treatments and rights violations through individual legal representation, such as the Alaska based Law Project for Psychiatric Rights.

## 2. Consciousness Raising and Developing Alternatives to Mental Health System

Raising consciousness and political awareness through information and resource sharing, including telling, sharing, and examining personal experiences with other survivor/consumers, have been the earliest and most effective tools for advocacy. Critically examining personal experiences and connecting them to broader issues of social justice through peer support, self-help and discussion groups, and other learning activities is the continuing basis of the contemporary advocacy and community building efforts (Canning; Crossley & Crossley). Indeed according to a survey conducted on user/survivor groups in England, 79% of local survivor groups consider self-help and mutual support as their core activity. (Wallcraft, Read, and Sweeney, 15). This also facilitates the development of alternatives to conventional mental health services, treatments, and discourses, as illustrated in the below quote:

By 2003, the organization [Freedom Centre] met for both a support group and had an organizing meeting once a week, as well as a bi-weekly film series, a weekly yoga class, a weekly writing group, and a weekly meditation group.

...All of these activities, with the exception of film series... have been initiated by people diagnosed with mental illnesses; they are initiated either in an effort to reveal truth about the psychiatric industry or to provide alternatives to this establishment.

Hurter, 20, 22

For this purpose several consumer/survivor organizations establish drop-in centres where members may access resource libraries, community information boards, computers and Internet, as well as create newsletters, participate in educational or recreational programs, get involved in creative projects, and participate in formal or informal peer support group meetings, socials, and online discussion forums. Some groups find creative ways to stimulate interest. For instance, Photovoice is one of the past projects of the Mental

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<sup>34</sup> For more information see Costa 2013.

Health Rights Coalition of Hamilton that combines photography and social action by providing cameras to survivor/consumers “so that they can record images that will help them tell their stories. It helps people record and reflect on the community's strengths and weaknesses... identifies important issues through group discussion... [and] gets the attention of politicians and other policy makers” (“previous projects”). In addition, the coalition facilitates four community educational forums each year pertaining to issues that affect survivor/consumers. The Empowerment Council’s most recent project, Tortoise and Rabbit Reading Society, is another example of creative attempts for consciousness raising. The reading society, which meets weekly, is described as a relaxed, thoughtful reading and discussion group for consumer/survivors who want to read articles written by the consumer/survivor community to support each other through learning.<sup>35</sup>

Other groups maintain comprehensive information and resource centers,<sup>36</sup> such as the Toronto area Consumer/Survivor Information Resource Centre<sup>37</sup> that provides assistance and referral to consumer/survivors in the Greater Toronto Area through telephone, email, mail, and in person meetings. The centre also offers a broad range of literature and information catalogues that are available for take away; hold workshops of interest<sup>38</sup>; and publishes a newsletter twice a month, “which contains information of relevance to consumer/survivors such as articles, drug warnings, newsbytes, workshops and conferences, job postings and free, low cost things to do in the Toronto area” (“Home”). Similarly, Psychiatric Survivor Archives of Toronto (PSAT)<sup>39</sup> holds a comprehensive collection of historical documents and works produced by survivor/consumers with emphasis on “critical perspectives including anti-psychiatry that is primarily produced by psychiatric survivors whether institutionalized or in the community,” in order to ensure “that the rich history of people who have experienced the

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<sup>35</sup> See [http://www.csinfo.ca/bulletin/Bulletin\\_503.pdf](http://www.csinfo.ca/bulletin/Bulletin_503.pdf) page 8.

<sup>36</sup> See for instance Freedom Centre Resource link <http://freedom-center.org/section/resources>, Mind Freedom alternatives to the traditional mental health system <http://www.mindfreedom.org/kb/mental-health-alternatives>

<sup>37</sup> <http://www.csinfo.ca/>

<sup>38</sup> Some of the topics they have covered are: housing rights, ODSP, retiring on a low income, becoming a Peer Support Worker, the Disability Tax Credit, and debt and financial management. For more information see <http://www.csinfo.ca/services.php>

<sup>39</sup> <http://www.psychiatricsurvivorarchives.com/index.html>

psychiatric system is preserved for our community and the wider community as a resource from which everyone can share and learn<sup>40</sup>, (“mission statement”). In addition, many survivor/consumer groups publish newsletters, develop list-serves, discussion & support forums where members discuss their experiences, share resources, information, and relevant news, provide support, debate about important issues, and create alternatives to traditional mental health paradigms, services, and treatments<sup>41</sup>.

### 3. Public Education, Strategic Action, and Influencing Policy

Creating public awareness, taking strategic action, and shaping policy decisions on crucial issues that affect survivor/consumers are accomplished in many ways, including building political and educational campaigns<sup>42</sup>, engaging in public speaking, organizing protests, writing letters, creating online petitions<sup>43</sup>, preparing press releases, position statements<sup>44</sup> and conference presentations<sup>45</sup>, utilizing social media<sup>46</sup>, networking and forming coalitions, engaging in knowledge production through grassroots, community-based, survivor/consumer run research, sitting in and representing survivor perspectives in boards and committees, providing training to police service, mental health professionals, legal and clinical students, family members, etc.

In line with one of the key principles of successful advocacy efforts, survivor/consumer groups benefit from collaborating with each other and other social justice organizations to inform the public, take action, and influence policy on issues that

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<sup>40</sup> Furthermore, PSAT preserves this rich history and culture through creation of heritage sites such as the Lakeshore Asylum Cemetery Project <http://www.psychiatric survivor archives.com/cemetery/index.html>, and the patient build wall on the CAMH’s grounds where a memorial plaque has recently been installed on.

<sup>41</sup> See MSS list-serve <http://www.madstudentsociety.com/involved.html>, Hearing Voices Network online forum <http://hvn.forumatic.com/> and support groups <http://www.hearing-voices.org/hearing-voices-groups/>, Nsun Network members forum <http://hvn.forumatic.com/>

<sup>42</sup> See various Mind Freedom campaigns <http://www.mindfreedom.org/campaign>, Freedom Centre campaign on poverty in relations to survivor/consumers <http://freedom-center.org/poverty-is-not-a-crime-local-campaign>

<sup>43</sup> See NARPA’s petition on gun control and mental health issue: [https://www.change.org/petitions/stop-scapegoating-people-with-psychiatric-disabilities-in-gun-control-legislation?utm\\_campaign](https://www.change.org/petitions/stop-scapegoating-people-with-psychiatric-disabilities-in-gun-control-legislation?utm_campaign)

<sup>44</sup> See list of advocacy positions prepared by the Queen Street Patients’ Council <http://www.qsos.cc/qspc/positions.html>, Position Statement on DSM 5 & Psychiatric Diagnosis by the Hearing Voices Network <http://www.hearing-voices.org/about-us/position-statement-on-dsm-5/>

<sup>45</sup> See list of conference presentations done by individual MSS members as well as collective presentations and workshops <http://www.madstudentsociety.com/work.html>

<sup>46</sup> See for instance Recovering our Stories Collective FB group page <https://www.facebook.com/groups/211006928920573/>

directly affect psychiatrized people's lives. For instance, addressing and preventing violence against people with mental illness diagnosis, while simultaneously challenging the pervasive "violent mental patient" stereotype is one of the central issues that survivor/consumer groups mobilize around. In this regard, Queen Street Patient Council's partnership with Urban Alliance on Race Relations resulted in an important conference and the production of a comprehensive report called *Saving Lives – Alternatives to the Use of Lethal Force by Police* (2002). Co-sponsored by several community-based organizations such as the Aboriginal Legal Services, the Black Action Defence Committee, the Chinese Canadian National Council-Toronto Chapter as well as the Toronto Police Service, the conference and the resulting report included 27 extensive recommendations on transparency and accountability on the actions of police force<sup>47</sup> where the patient council "successfully advocated for input into police training and an open and transparent Police Services Board committee on mental health" (Empowerment Council, "Accomplishments"). More recently Toronto Anti-Violence Coalition for People with Psychiatric Disabilities,<sup>48</sup> comprised of "psychiatric survivor/mental health advocates, workers, people living with psychiatric disabilities/consumers/survivors/ex-patients, community members, and researchers" is formed to bring visibility and formulate responses to a broad range of violence encountered by psychiatrized people. Currently the coalition is focusing on four areas of research and public education including past inquests into psychiatric patients' deaths, violence as a disability justice issue, best organizational practices for addressing violence, and racism & systemic violence.<sup>49</sup> In another successful instance of collaboration, numerous psychiatric survivor/consumer groups and community allies mobilized in 2008, expressing their outrage at the Ontario Public Services Union (OPSEU) discriminatory ad campaign that perpetuated the violent mental patient stereotype. As a result of this collaboration, OPSEU was forced to remove its campaign three days after it commenced. Furthermore, it reissued a counter ad that invited public to challenge stereotypes about people with

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<sup>47</sup> For more information see <http://urbanalliance.ca/2013/08/13/uarr-speaking-notes-press-conference/>

<sup>48</sup> <http://torontoantiviolencecoalition.wordpress.com/>

<sup>49</sup> See <http://www.empowermentcouncil.ca/PDF/EC%20Newsletter%20Summer%202013.pdf>

mental illness, which was designed in partnership with the Empowerment Council and other survivor groups<sup>50</sup>.

Representing survivor/consumer voices and perspectives in mental health related committees, boards, task forces, government and service organizations is another significant task undertaken by several survivor groups and their members. This form of advocacy can include “acting as consultants and representatives, taking part in training or recruitment of staff, service monitoring and evaluation, user-led research, and running local user [survivor] consultation forums” (Wallcraft, Read, and Sweeney, 16). For this purpose survivor/consumer organizations offer effective communication, negotiation, and leadership skills training to their members. For instance Mental Health Rights Coalition of Hamilton trains its members, who participate in “Voices of Experience” project, to facilitate the effective representation of survivor voices in the decision-making levels<sup>51</sup>. Similarly “Voices from the Street” is a 12-week leadership training program developed in 2005 by Working For Change<sup>52</sup> (formerly the Ontario Council of Alternative Businesses, an umbrella organization for psychiatric survivor/consumer operated businesses across Ontario.) The program aims at providing in-depth leadership training for people with lived experience of poverty, homelessness and mental health issues in order to:

bring their voices and perspectives to decision-making bodies that shape public policy. Graduates from the program are part of a Speakers Bureau that creates opportunities for members to advocate for societal change... [and they] are available to speak on various topics related to poverty, mental health, addictions, homelessness, domestic violence and newcomer issues.

As part of voicing survivor experiences and perspectives, and shaping public policy efforts some groups also engage in survivor/consumer run and led research projects. According to British scholars Beresford and Wallcraft, undertaking research “has been part of the survivors’ movement’s project of survivors speaking and acting for themselves; improving their lives... changing and equalizing relationships between research and research subjects, and developing survivors’ own knowledge collectively”

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<sup>50</sup> For more information see <http://www.empowermentcouncil.ca/PDF/EC%20Summer%202010%20Report.pdf> and [http://www.csinfo.ca/bulletin/Bulletin\\_383.pdf](http://www.csinfo.ca/bulletin/Bulletin_383.pdf)

<sup>51</sup> See “Ongoing Projects” <http://mentalhealthrights.ca/HTML/projects.html>

<sup>52</sup> [http://workingforchange.ca/?page\\_id=14](http://workingforchange.ca/?page_id=14)

(1997, 10). The research activities can range from conducting small scale surveys and focus groups to determine the needs and wishes of the group membership for future direction<sup>53</sup>, to national level quantitative and qualitative research projects that aim at making policy recommendations to government bodies<sup>54</sup> and contributing to academic knowledge production. The Survivor Researcher Network (SRN)<sup>55</sup>, for instance, is a part of an independent, service-user led charity in England. The network provides a forum for survivor/consumers who are interested in research “for networking, sharing information and supporting each other<sup>56</sup>.” The SRN “specialises in foregrounding the perspectives of mental health service users and survivors in the thinking and innovation around mental health, wellbeing and recovery” with particular emphasis on the views and opinions of service users from Black, racialized, and other marginalized communities. In addition to undertaking research projects, the network members also conduct workshops, project evaluations, and public speaking on issues related to the lives of the mental health service users.

In an effort to raise public awareness some organizations create their own alternative media such as MindFreedom Web Radio<sup>57</sup> that broadcasts a live radio show every second Saturday, and Madness Radio,<sup>58</sup> which is co-sponsored by the US based survivor groups Freedom Center, The Icarus Project, and Portland Hearing Voices. Both radios focus on personal experiences of “madness” from beyond conventional perspectives and mainstream treatments. They feature authors, advocates, and researchers speaking on madness-related topics, including civil rights, policy reform, holistic health, history, and art. Most survivor/consumer groups however engage with the mainstream media as a more effective means of reaching larger audience, particularly in the form of letters to editors, opinion pieces, and press releases. For instance, Queen Street Patients Council lists “increas[ing] public awareness campaigns through Toronto newspapers and

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<sup>53</sup> For instance see “Research/Survey” section in Empowerment Council Activities between May 2012 and June 2013 <http://www.empowermentcouncil.ca/PDF/EC%20Activities%20Report%202012-13%20REV.pdf>

<sup>54</sup> See particularly *On Our Own Terms* study conducted in England <http://www.nsun.org.uk/assets/downloadableFiles/on-our-own-terms.pdf>

<sup>55</sup> See <http://www.survivor-research.com>

<sup>56</sup> <http://www.nsun.org.uk/about-us/what-we-do/survivor-researcher-network>

<sup>57</sup> <http://www.mindfreedom.org/campaign/media/radio>

<sup>58</sup> <http://www.madnessradio.net/about-madness-radio>

weekly's, CBC and other television and radio stations, in documentaries and website linkages” among its key activities<sup>59</sup>.

Production of videos and documentaries are less frequently utilized but significant tools for public education and awareness raising, as well as means of cultural production. Over the years, several documentaries that portray the challenges and successes of psychiatric system survivor/consumers are produced and widely screened. Among these, *Working Like Crazy* (1999), a National Film Board of Canada documentary, was produced with the participation of the (former) Ontario Council of Alternative Businesses, and screened around the world. The documentary follows the everyday lives of the six psychiatric survivors who were labeled "crazy" and “unemployable,” and as a result who started their own community businesses with successful results. Similarly, *The Inmates are Running the Asylum: Stories from MPA* (2013) is one of the most recent Canadian productions that documents the history of the Vancouver’s MPA (Mental Patients Association). This short documentary is created by the key members of the MPA in collaboration with scholars and filmmakers. It provides important insights into community building, social justice, and early radical survivor/consumer advocacy in Canada, acting as an important historical document and educational tool.

#### 4. Community Development & Cultural Production

Some projects, such as creating business opportunities or putting on a stage performance of one’s experiences in a psychiatric ward, may not immediately appear as advocacy work. However these activities play a significant role in helping psychiatricized people to take charge of their lives, build and develop their communities, and forge new alliances. The positive impact of consumer/survivor initiatives (CSIs),<sup>60</sup> which include a range of organizations from alternative businesses to patient councils, in the lives of survivor/consumers and in their communities is well established by evidence-based research (CAMH Ontario et. all). Among several CSIs across Ontario, alternative business are particularly noteworthy for their potential to offer employment for people with mental health issues. Owned and operated by survivor/consumers, alternative

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<sup>59</sup> Also see “EC in the Media” section in Empowerment Council Activities between May 2012 and June 2013 <http://www.empowermentcouncil.ca/PDF/EC%20Activities%20Report%202012-13%20REV.pdf>

<sup>60</sup> See <http://www.opdi.org/about.php>



businesses “recognize the struggles that consumer/survivors face, particularly in accessing and maintaining employment” (OCAB, “what is different”)<sup>61</sup>. Working for Change is an umbrella organization for alternative businesses operating in Ontario. It was established in 1994 to provide “hands-on assistance to survivor groups wanting to create and operate collective businesses” (Church, end note #2). Since opening their first catering company, the Raging Spoon, in 1997, five additional social enterprises have been added that provide employment to psychiatric survivor/consumers including a grassroots, community based research initiative and a horticultural business among others.<sup>62</sup> In addition to offering employment opportunities and skills building, alternative businesses contribute to community development and consciousness raising by linking the political analysis and basic principles of the c/s/x movement to business practices, such as survivor/consumer control and ownership, self-determination, and peer support (Church).

Similarly, cultural events such as Mad Pride— an arts and culture festival initiated by psychiatric survivor/consumers in the UK— have wide ranging outcomes besides bringing people labeled as mentally ill together in a community celebration. Mad Pride also presents an opportunity to connect with other social justice movements. In Toronto it was set out “partly as a response to the lack of affordable housing and crowded, hazardous living conditions in many boarding homes” (Finkler, 2) in the Parkdale neighborhood where there was a high concentration of psychiatric survivor/consumers. Indeed the original organizers proposed six objectives when they launched the first Toronto “Psychiatric Survivor Pride Day” (renamed in 2001 as Mad Pride) in 1993:

to combat stigma; to celebrate psychiatric survivors ‘as active members of Canadian society;’ to ‘present the history and culture of psychiatric survivors from the perspective of those who lived...this experience;’ to ‘link up with other marginalized groups [including] persons with disabilities, people of colour, first nations,’ in ‘rejecting oppressive cultural stereotypes;’ to connect with ‘other community based groups in Parkdale to ensure visibility and acceptance of persons with psychiatric histories;’ to ‘empower those of us previously excluded, to participate in the creation and preservation of our contribution to Canadian culture.’

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<sup>61</sup> For more information see <http://www.ocab.ca> and <http://workingforchange.ca/>

<sup>62</sup> For more information see [http://workingforchange.ca/?page\\_id=12](http://workingforchange.ca/?page_id=12)

Now preparing for its 21<sup>st</sup> anniversary in July 2014, Mad Pride has flourished around the globe building on its early history; its activities ranging from The Mad Think Tank Series to Mad Love Dance Party, to theatre performances and panel discussions.

#### **4. Advocacy in Neo-Liberal Times and in Institutional Context: Major Issues, Tensions, and Limitations**

Success is a double-edged sword. With no doubt, experienced survivor/consumer groups and advocates are acutely aware of these edges. The early c/s/x movement's hard work has brought their concerns, demands, and claims for voice to the forefront, and attracted government funding as well as institutional and professional interest in survivor/consumer advocacy. However government help, particularly in the form of financial support, and "professionalization" of advocacy (as opposed to grassroots formations) in institutional and neo-liberal policy contexts have also meant ruptures in political solidarity, constriction of systemic advocacy, and cooptation of fundamental principles and means of grassroots survivor/consumer advocacy. This brief section highlights some of the potential problems, tensions, and limitations of the survivor/consumer advocacy that takes place within a neo-liberal economic system, specifically when funding and other resources for advocacy are attached to state agencies and service organizations. It also offers constructive suggestions for meaningful advocacy within these limitations.

Reliance on government or service agency funding generates a number of problems, including constraints put on the type and extent of advocacy actions, increased bureaucratization, loss of control, autonomy, and sense of community. For instance, Irit Shimrat recounts "many OPSA [Ontario Psychiatric Survivors' Alliance] groups found themselves with new troubles as soon as they received government funding" (97). One of Shimrat's informants, interviewed for her book, states "once there are paid stuff... volunteer involvement and dedication drop off. The sense of community involvement slips away" (98). Another one adds, "...we got funded, and there was even more stress, with all the paperwork and criteria to meet... What I am hearing more and more is, 'We

don't care if the government pulls the funding. We did more when we didn't have any money'" (98). Even more alarming, however, is loss of independence and control over the decision-making process, as a recent report on consumer/survivor initiatives in Ontario illustrates:

Over the years several of the CSIs originally funded under the 1991 CSDI Anti-Recession Strategy have **lost their independent board of directors and right to receive transfer funding directly from the Ministry of Health and Long-Term Care**. Some of these groups have remained as consumer/survivor-run programs within a larger mental health agency. Of particular concern are those cases where the consumer/survivor funding envelope has been given directly to service providers with the result that consumer/survivor-run peer support has been lost in those communities.

(CAMH Ontario et. al, 12, original emphasis)

The above examples also reflect the evident disparity between philosophical and operational frameworks of the funding agencies and survivor/consumer groups. In some cases the reporting and documentation requirements of funders or sponsors are incompatible with the principles of the CSIs, while in other cases CSIs are "treated more as a program of the [sponsoring] agency, rather than an autonomous group" (Ibid). In both cases the basic principles of self-determination and freedom of choice are negated.

In addition, existing power imbalances between mental health professionals, service providers, family members, and survivor/consumers, particularly under the prevailing context of involuntary commitment laws, inhibit any meaningful collaborative advocacy efforts. The ability to define what is an illness, or "irrational" behavior and thought, and conversely what is not, is an inherent element of this power imbalance. For Judi Chamberlin, a former education and training director of the US based National Empowerment Center, acknowledging and understanding the implications of this imbalance is essential for an actual partnership (2005). Yet, these are rarely openly addressed by professionals or even by family members. For a meaningful collaboration to materialize Chamberlin urges survivor/consumers and their organizations to take an active role in the "training of mental health professionals; design and operation of mental health service programs; evaluation of services; mental health research; [and] provision of and funding for alternative user-run programs" (2005, 12). Furthermore, contentious

topics such as involuntary commitment and service provider misconduct require careful discussion in a climate of mutual respect. Accordingly, Chamberlin suggests that:

Protocols need to be in place, in advance, that are the subject of joint decision-making, so that in the event that someone is in an emotional state that presents difficulties, there will be a clear idea of how to proceed. One important aspect would be to develop “advance directives” so that each situation is approached in an individualized way. Should an individual temporarily have to withdraw from the activity because of a period in which he or she is experiencing a high level of distress, it should be made clear that he or she can resume the activity once the distress has been alleviated. In this way, difficult emotional states can be seen as natural life events rather than as medical crises.

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For Becky MacFarlane a clear articulation and acknowledgement of the limits of advocacy within an institutional context is the basis of a meaningful collaboration. She states “people deserve to be taken seriously... which demands complete transparency and honesty” about the aims and limits of any collaboration and advocacy project (2014). Creating unrealistic expectations by overlooking organizational, structural, and legislative constraints and power imbalances can be particularly disempowering for survivor/consumers who have always been at the receiving end of paternalistic approaches. In this regard, a project team working with LGBTQ youth with intellectual disabilities reminds us the subtle ways through which systemic oppression operates in everyday life and offers a useful tip sheet on accessible approaches to collaboration within an institutional context. Their recommendations reiterate the significance of transparency, acknowledgment of power differentials, clarity about the meaning of collaboration, and availability of range of options for participants to choose from (Marshall and Vo, 72 - 75) in a successful collaborative advocacy work.

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