

Mental Health “Recovery”: Users and Refusers

What do psychiatric survivors in Toronto think
about Mental Health “Recovery”?

Mental Health “Recovery” Study Working Group

January 2009

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Executive Summary

Mental Health “Recovery”: Users and Refusers is the final report of a study that asked the question: what do psychiatric survivors in Toronto think about mental health “recovery”? This research recognizes the emergence of “recovery” as the new “talk” of community mental health services not just here but in the United States, the United Kingdom, and New Zealand. It addresses the fact that amidst a surge of “recovery” related research there are few critical voices especially from the people “recovery” promises to “heal” and “help.” Thus, our primary concern has been to make psychiatric survivors central in both directing this study and acting as participants. Some members of our advisory committee were located in community organizations; some were in the university; most spanned both. Some members identified as psychiatric survivors; some did not. Both of our staff/consultants were consumers of mental health services. Their status as “peers” was fundamental to the conversations that we opened up with study participants around the meaning/s of mental health recovery. We generated our data through focus group conversations held in seven community organizations that are on the “front-line” of service delivery. We analyzed our data through an iterative process of reading, talking together and writing about what participants said as recorded by our note-taker. In this way, we moved from a list of key themes/ quotes prevalent across groups to three lines of argument that constitutes a distinctive “take” on “recovery” in Toronto. The first situates “recovery” as a personal journey. Through their own efforts and achievements, individuals link personal care with self-esteem and positive thinking to achieve hope. The second argument situates “recovery” as a social process in which people address the need for tangible resources such as jobs, income, housing, safety and education. Giving and receiving peer support is fundamental to this view. The third argument takes “recovery” as critique – and targets a range of institutions: medicine/psychiatry, health care, medication/drugs, and the police. It opens terrain for recovering “recovery” from its increasing professionalization within community mental health. Clearly, even though “recovery” is increasingly powerful in organizing the operation of the service system, it has no single meaning – and no unified constituency.

Introduction

In March of 2005, Kathryn Church and Ken Moffatt at Ryerson University received funding from the Ryerson International Research Fund to support qualitative inquiry into policy changes affecting community mental health service delivery in Toronto, Scotland and New Zealand. The project was intended to develop the funding base for an international project that would map the spread of the policy known as “mental health recovery” in these three sites. ² Already engaged in these issues through her doctoral research (2007), Jennifer Poole acted as the staff resource for the project. In this role, she wrote the proposal for a study titled “*Nothing about us without us: What do Toronto psychiatric survivors think about mental health recovery?*” (Charlton, 1998) ³ Lucy Costa volunteered the Empowerment Council ⁴ as a partner for the Ryerson School of Disability Studies in this effort. In June 2006, the joint project was funded by the Urban Health Research Program of the Wellesley Institute.

In probing the emergence of “recovery” as the new “talk” of community mental health services, a primary concern for us was to ensure that the missing voices of psychiatric survivors were central to our inquiry. More than that, we wanted psychiatric survivors to direct and carry out the work. ⁵ The main vehicle for this process was an advisory committee constituted of survivor leaders who were drawn together by Jen and Kathryn from their combined knowledge of existing networks. This group’s organizational base included the Empowerment Council, the Ontario Peer Development Initiative (OPDI), the Friendly Spike Theatre, and Ryerson University through two departments: the School of Disability Studies and the School of Social Work. Over the next two years, this advisory committee selected the project staff, designed the study, collected data, participated in collective analysis and guided the writing of this report. In the process, we evolved a different title for the project, one that reflects a critical engagement with our topic. Thus, this document is titled *Mental Health “Recovery:” Users and Refusers*.

2 The original project was titled “Recovery: Troubling the Talk, Informing the Walk.” Although it gave rise to our good work here, this international project was never itself funded.

3 James Charlton writes: “I first heard the expression ‘Nothing about us without us’ in South Africa in 1993. Michael Masutha and William Rowland, two leaders of Disabled People South Africa, separately invoked the slogan, which they had heard used by someone from Eastern Europe at an international disability rights conference. The slogan’s power derives from its location of the source of many types of (disability) oppression and its simultaneous opposition to such oppression in the context of control and voice” (1998: 3).

4 The Empowerment Council, A Voice for the Clients of the Centre for Addictions and Mental Health (CAMH).

5 We use this term knowing that language is a site of ongoing struggle for people with mental health histories. Not all identify with the term psychiatric survivor, or “consumer/survivor.” Indeed, some may prefer consumer, refuser, lunatic, patient, ex-inmate or simply, ‘mad.’ As we see in the report, this issue of naming and identity continues to be contested.

The research that underpins this document was done in the community-based participatory tradition. The literature on this approach is thick with process suggestions for how participants should work collectively to shape the question, collect, analyze and act upon the data. It is less than forthcoming, however, on the question of writing up the findings – specifically, on how to produce a participatory final report. Often, the participatory nature of research breaks down at the point of writing. Can that process truly be done by “many pens?” Or is writing, by definition, a solitary act?

Our answer to both questions is “yes.” Everyone on the committee had a hand in writing the text that follows. Deb Wise Harris laid the groundwork by doing a systematic and thorough “reading” of her notes from the seven focus groups. She moved the study from raw data to a 30-page first draft organized around a series of titles and illustrative quotations.⁶ Jen and Kathryn then worked this material back and forth between them, as did Kathryn and David, in a series of drafts that the committee read and commented upon for both overall direction and more subtle nuances. Thus, the document was written in many layers, slowly and somewhat painstakingly. The final draft is a negotiated text that blends many contributions into one, confronting but also bobbing in and out of the debates we had along the way. A key turning point was our decision to insert commentaries from committee members throughout the document. In that way, we recognized the ongoing tension between our analysis as a group and our separate “takes” on what participants said. Sometimes puzzled about how to reconcile the “me” with the “we,” we have used writing itself as an analytic tool.

What is Mental Health Recovery?

Recovery refers to the lived or real life experience of people as they accept and overcome the challenge of the disability...they experience themselves as recovering a new sense of self and of purpose within and beyond the limits of the disability.
(Deegan, 1988)

Until relatively recently, it was assumed that most individuals with severe mental illness would never be “well” again (Kruger, 2000). However, longitudinal research by Harding et al. (1986a, 1986b) and the experience of “recovered” patients in the United States (Deegan, 1988) suggested that with peer support, self-care and medication, recovery was not only possible but probable (Mead and Copeland, 2000). Proponents of the related “recovery vision” for mental health reason that dollars are better spent if channelled towards such “recovery”-oriented

⁶ In choosing a “thematic analysis” of data, the advisory committee privileged commonalities of experience across sites over the particular histories and knowledges of each site. What this means, however, is that unique features and contributions of individual sites tend to disappear in a more homogenized presentation of results. This is a limitation of the study as we have presented it in this version. “Next time....”

services as peer support programs, exercise classes, assertive community treatment teams and drug treatments (Mead and Copeland 2000). They claim these services are more cost-effective. They also contend that these services create hope for those who had always expected a painful and progressive deterioration in their condition (Carpenter 2002, Jimenez 1988).

Sounding so good, this vision has been talked up and taken on by a number of American states in an attempt to improve mental health care and outcomes (Jacobson and Curtis 2000), its acceptance cemented when the Bush administration incorporated principles of the “recovery vision” into its platform for mental health in 2003. New Zealand has also adopted “recovery” principles for all mental health service delivery, as has Scotland and other areas of the United Kingdom. Beginning in 2002, “recovery” conferences, committees and organizations began to appear in Ontario. Does this signify that something similar is happening here? Or might we be different?

A surge of research on “recovery” has accompanied this new vision for mental health. Harding (1986) tracked the outcomes of discharged patients over a 25 year period, providing the first “proof” that recovery might indeed be possible. Psychosocial rehabilitation researcher William Anthony outlined how to put it into practice (e.g. 1993). A cluster of consumer-writer-researchers including Pat Deegan have written extensively on its “lived experience.” Nora Jacobson (2004) has explored how it became policy in Wisconsin during the late 1990’s, and Repper and Perkins (2003) have made clear that it is the only “model of practice” to speak to issues of social inclusion in mental health.

However, to date, there has been little Canadian research and very little critique. Some family groups in the United States have questioned “recovery’s” false expectations and “sugar coated” talk, some consumers have expressed concern around the lack of real supports and some psychiatrists have wondered if the vision creates “recovery” possibilities only for those without severe mental illness (Poole, 2007). Fewer still are asking questions around “recovery” in this country- questions that speak to why this vision has appeared now, who ‘owns’ the vision and what effects it is really having on psychiatric survivors, family members, front-line staff, clinicians and policy makers. Is it really making things better?

Research Design

For this research project, we followed the tenets of community-based participatory research (CBPR). Born of action research and participatory traditions founded by Paolo Freire, this approach builds on strengths and resources within the community, promotes co-learning, emphasizes the local relevance of health problems and is always iterative in its process (Israel, 1998). Our choice of CBPR was based in its history of anti-oppressive practice, its focus

on the development of critical consciousness and its aim of breaking down the lines between researchers and researched (Gaventa 1993). Facilitating factors include interdisciplinary research teams (i.e. disability studies, social work, critical public health) and the provision of financial and other incentives (such as publishing and conference participation) to member-researchers for their work (Israel, Shulz et al. 1998).

Not a prescriptive set of methods per se, CBPR is more of an approach to research that highlights collaboration, community participation and what Flicker names as “emancipatory social justice agendas over positivist notions of objectivity” (2005: 2). In line with the research philosophies of both the School of Disability Studies and the School of Social Work at Ryerson,

Community based participatory research in health is a collaborative research approach that is designed to ensure and establish structures for participation by communities affected by the issues being studied, representatives of organizations and researchers in all aspects of the research process to improve health and well-being through taking action, including social change. (Viswanathan et al. 2004)

Community members drive the problem formulation, envision the goal, carry out the research and bring their analyses to the table. Allied researchers do what they can to support the process, and in a direct departure from traditional research methods, only if and when they are asked.

Early Discussions

The early meetings of the advisory committee were large and lively as potential members considered our topic, the people we had assembled, and whether the project was sufficiently important to become a priority in agendas that were already too full. In these wide-ranging discussions, people contributed their observations of the emergence (or not) and spread of “recovery,” how it might be affecting psychiatric survivors and their initiatives, whether and how research might address what was happening. It was here that they first raised the issues that became the core of our project. These included: a lack of attention to the social determinants of health in the recovery literature (such as housing and social exclusion), a lack of discussion around social class, a lack of local/ Canadian research, the absence of critique generally and most importantly, a lack of psychiatric survivor voices in the research literature on “recovery.”

Psychiatric survivor members of the committee noted how “recovery” “was being defined and practiced by those who are not psychiatric survivors with little attention being paid to all the home-grown work being done here in Ontario. They made clear that “we have to look at who recovery serves.” They asked, “Is it just a middle class thing?” Similarly, they discussed the various “recovery” practices of Health Management Organizations in the United States and

wondered, is “recovery a type of downloading onto the individual and community?” Another felt the only way to sustain recovery “is through resources like housing.”

For a variety of reasons – personal and political – some of the people who took part in these initial discussions decided not to continue as members of the advisory committee. However, the legacy of their participation is embedded within the goals of the research: to “take recovery to the ground,” to “reclaim and reshape recovery,” and to tie “recovery to the social determinants of mental health” (Project Minutes, 2006).⁷ From that point onwards, our study was oriented towards stories, questions and themes that spoke back to class, social determinants and what local psychiatric survivors thought of this vision for mental health.

Commentary: We’re a committee that doesn’t travel light-- David Reville

It was during one of the early meetings of the advisory committee⁸ that I was suddenly struck by how much history was in the room.

Take Ruth Ruth Stackhouse. A community theatre director with a long history of activism in the psychiatric survivor community, Ruth Ruth took my Mad People’s History course in the winter of 2008. She was fascinated by Geoff Reaume’s (2000) stories of patient labour at the Toronto Hospital for the Insane. She studied the reformers Pinel and Tuke, the fathers of “moral treatment”. Describing the York Retreat, Tuke’s grandson Samuel wrote that “the Retreat had then abandoned ‘medical’ for ‘moral’ means of kindness, mildness, reason and humanity, all within a family atmosphere—and with excellent results” (Porter, 2002). Part of that family atmosphere was work. The patients at the York Retreat did light but meaningful work. However, by the time moral treatment arrived at the Toronto Hospital for the Insane, the light work had become much heavier.

Kathryn Church’s interest has been in more recent history – the consumer/ survivor/ex-patient movement which began in the late 60s. She has described the movement as having three phases – anti-psychiatry, consumerist and entrepreneurial (Church, 2004). The anti-psychiatry phase was influenced by Szasz, Foucault, Laing and Goffman and sought to create alternatives to the mental health system and to expose the social construction of madness. The consumerist phase began in the 80s with “consumer participation” i.e. the notion that the users of a service should have a role in the planning, delivery and evaluation of that service. The entrepreneurial phase was about ex-patients coming together to develop a strategy to deal with their economic

⁷ We wish to acknowledge the contributions of Becky McFarlane (Ontario Council of Alternative Businesses), Lana Frado (Sound Times) and Heather McKee (Canadian Mental Health Association, Ontario Division) in these early formulations.

⁸ Lana Frado, Becky McFarlane and Heather McKee attended early meetings of the advisory committee.

isolation; they started businesses (Church, 2001; 2000; 1997a; 1997b, Church, Shragge et al, 2008).

Inspired and challenged by Dr. Church’s formulation, I developed a metaphor so that I could talk about the movement in six chapters: setting the table, turning (over) the tables, getting a seat at the table, getting tables of our own, making tables and selling them and tabling our critique.

As executive director of Sound Times, Lana certainly has turned the tables; Sound Times is the only self-help group in Ontario that has become a community mental health service provider.

All of the survivors on the committee have or have had seats at the table: “consumer participation” or “user involvement” (Church & Reville, 1989).

Raymond, for instance, is on the board of trustees for the Centre for Addiction and Mental Health, the largest facility of its kind in Canada. Sohrab has worked for a service provider that assists recovering addicts.

Lana was a member of the Toronto/Peel Mental Health Implementation Task Force.⁹ Heather has been a policy analyst for both the national and Ontario offices of the Canadian Mental Health Association. Kathryn’s “Forbidden Narratives: Critical Autobiography as Social Science” (1995) is about what happens when psychiatric survivors get seats on a committee looking into community mental health legislation.

Becky, Lana, Lucy, Raymond and Ruth Ruth have tables of their own. They all are or have been involved in self-help groups, the Ontario Council of Alternative Businesses (Becky), Sound Times Support Services (Lana), the Empowerment Council and the Mad Students Society (Lucy), the Ontario Peer Development Initiative and the Chinese and South East Asian Consumer/Survivors (Raymond) and the Friendly Spike Theatre Band (Ruth Ruth).

Becky makes tables and sells them. She is co-executive director of the Ontario Council of Alternative Businesses. “Founded in 1993, OCAB is an umbrella organization for six to eight economic initiatives that operate at any given time in various parts of the province. Its intent is to provide hands-on assistance with business development and community organizing including producing resource materials, identifying and supporting leaders and influencing legislation and policy” (Church, 2006: 170).

I tabled my first critique of the mental health system in 1967¹⁰ when I published an article in the Queens Graduate Student quarterly “Gavel”; Ruth Ruth tabled one at the “Madness, Citizenship

⁹ The task forces (2000-2003) were part of the last government-sponsored try at mental health reform; it could be said that “recovery” is the most recent entry in the reform field.

¹⁰ I belong to the “setting the table” phase; Howie the Harp, commonly viewed as the founder of the c/s/x movement, did not found the Insane Liberation Front until 1970.

and Social Justice” conference in Vancouver;¹¹ her Mad People’s History play titled, “Tied Together,” was presented in June 2008. At the same conference, Lucy presented a paper titled, “Psychiatric Patient Rights and the Politics of ‘Progress.’”

We’re a committee that doesn’t travel light. We’re carrying a lot of history.

Selecting the Sites

In situating this project as CBPR, we shifted our attention away from individuals – the dominant “subject” of most qualitative research – and “populations” – the dominant preoccupation of positivist science. By deliberate decision, our participants do not constitute a statistical “sample” by age, gender, diagnosis or other personal characteristics. Instead, we focused our attention on group discussion within a range of sites. The advisory committee had several in-depth discussions about which sites would be appropriate and the best way to approach them, how to invite participants, whether and how the research committee would be involved, the questions that should be asked of the groups, and how to handle the research “formalities” so that participants would be comfortable. Our discussions reflected an enormous amount of local knowledge and political sensitivity on the part of advisory committee members.

Amongst a larger “pool” of sites that we weighed as possibilities, we decided to ask the following organizations if we could conduct focus group discussions with their members:

- Parkdale Activity and Recreation Centre (PARC)
- Houselink
- Brighter Days Committee (at Habitat Services)
- Sistering
- Across Boundaries
- A-Way Couriers
- New Outlook (at Central Toronto Youth Services)

We considered all of these organizations to be “downtown” and “front-line,” but we also selected them for diversity. So, for example, by selecting Across Boundaries, we were able to tap participants’ knowledge of the cultural, linguistic and immigration issues specific to their situations as psychiatric survivors. In addition to gender, race/ethnicity, youth/age and sexualities, our site selection sought out people who are “on the street,” in supportive housing, and in private sector boarding and lodging homes. We included one psychiatric survivor-directed initiative.

Anticipating time constraints and the weight of formal negotiation, we did not seek to enter these organizations through formal board approval of our study. Instead, acknowledging the pre-existing connections of our advisory committee members, we entered through established

¹¹ June 12-15/08, Conference on Madness and Citizenship, Simon Fraser University, British Columbia.

relationships. Thus, our process respected the practical “insider” knowledge of the committee, its members’ skills in transacting group formation, the strength of participants in deciding whether or not to take part, and, generally, “the way things actually work” in community organizations. The process went smoothly in each instance.

Site Descriptions

The descriptions that follow are taken directly from the web-sites of these organizations – in their own words. ¹²

The Parkdale Activity — Recreation Centre <http://www.pcic.ca/services.php>

PARC began with a group of community volunteers who understood that a large number of adults were living in rooming houses & boarding homes in the Parkdale area after the local mental health centres began to de-institutionalize psychiatric patients. Most of these adults had little income, few family contacts and no place to go during the day and so PARC was born on March 17, 1980. Over the years PARC has hired from the membership, created employment initiatives, developed new services, shed light on the desperate need for housing for psychiatric survivors, demanded that people with mental health histories be treated with dignity and respect, advocated for increases to basic needs allowances and worked for the improvement of the quality of life of all psychiatric survivors and marginalized persons. The PARC drop-in provides friendship, social opportunities, group and individual creative expression opportunities. Members can have a shower, receive clothing from our clothing bank, emergency food support, a daily meal, a warm place to sit, people to talk to, internet access, computer assistance and training from other members, volunteer support, transportation assistance, art supply subsidies, emergency housing/shelter referral and assistance, emergency warming supplies, outings to local cinema, and many other activities.

Houselink <http://www.houselink.on.ca/>

Houselink’s mission is to improve the quality of life of psychiatric consumers/ survivors including those who are homeless or otherwise marginalized, through the provision of permanent affordable supportive housing and programs. Houselink is committed to the belief that housing is a fundamental right; people have the right to be responsible for themselves and their own destiny; and people have a right to a positive culture for healing and recovery. Houselink is member driven, and offers a community of mutual support and respect where Human Rights Code violations are not tolerated. While Houselink’s main focus is supportive housing, its programs offer opportunities for members to participate in activities that support leadership, wellness and recovery.

¹² These descriptions were approved by staff in these sites prior to publication.

Sistering <http://www.sistering.org/>

Sistering has been supporting homeless, under-housed and low-income women in the Toronto community since 1981. Sistering is a multi-service women's centre that offers practical and emotional supports through drop-ins and other programs which enables women to take greater control over their lives. Services include showers and laundry facilities, clothing, some transportation, referrals, advocacy and housing support, and pre-employment supports.

Across Boundaries <http://www.acrossboundaries.ca/>

Across Boundaries is an ethno-racial community mental health centre and is a registered charitable organization funded by the Ministry of Health and Long-Term Care. Across Boundaries provides a range of supports and services to people of colour including immigrants and refugees who are experiencing mental health problems and/or addictions. The centre provides a holistic approach to dealing with mental health problems and operates within an anti-racism/anti-oppression framework, recognizing the interdependence of the spiritual, emotional, mental, physical, social, cultural, linguistic, economic and broader environmental aspects of health that affect the well being of people of colour. Along with mental health problems, clients are challenged with a unique set of issues that are culturally, politically and socially specific to the country of their origin. In the traditional Western medical field, these issues are not factored in with diagnosis and treatment.

A-Way Couriers <http://www.awaycourier.ca/>

A-Way is a successful courier business with a social purpose. In addition to providing low-cost, dependable courier services, in an environmentally friendly manner, we provide jobs for psychiatric consumer-survivors. The drive to find dignified, meaningful employment grew out of the movement to de-institutionalize psychiatric patients. Historically, it has been nearly impossible for survivors to find meaningful work because they are often labelled “unemployable”. As a result, many spent their days bored and directionless, and some spent many days back in hospital. No employer would hire them because of the strong stigma of mental illness and many people feared those who were labelled “mentally ill”. We set out to prove we could get and keep meaningful work and gain a little respect. We could and we did! With the help of our customers, our friends, and ourselves, we can now celebrate over 20 years of success!

New Outlook <http://www.ctys.org/>

New Outlook is one of four overarching programs at Central Toronto Youth Services (CTYS), which is a community-based, accredited Children’s Mental Health Centre with locations on Wellesley Street, Adelaide Street and in York Region. Since 1973, CTYS has been on the forefront of serving at-risk youth. We give youth a chance to recreate their lives in an environment where they are engaged, then challenged and nurtured to take control of their own destiny. CTYS was one of the first centers of its kind in Ontario, focusing specifically on the psycho-social needs of children and youth. In addition to New Outlook, the other three programs are Youth Justice, Research & Program Development, and the Community Counselling Programs (which includes Pride & Prejudice).

Brighter Days <http://www.habitatservices.org/>

The Brighter Days committee was created with the goal of increasing tenant/consumer involvement in Habitat Services. The group’s mandate is to be a forum for tenants, to act as an advisory body to Habitat staff, board, and owner/operators, to improve tenant welfare and quality of life, and to increase tenant involvement in Habitat activities and decision-making. Twenty years ago, Habitat Services was established as a non-profit, charitable organization to address serious community concerns about the physical living conditions and personal care standards of consumer/survivors housed in Toronto boarding homes. The ground-breaking concept of using a commercial contract to standardize such services and to improve housing standards in boarding homes (the Habitat Model) came about as a result. The details were worked out by consulting with consumer/survivors, advocates, representatives of the provincial and municipal governments, mental health workers and boarding home operators. Habitat has grown in two decades, and now is funded to provide homes to 931 adults in more than forty locations across the city. Habitat Services contributes to the quality of life of individuals with serious mental health issues by improving housing standards and providing supports to tenants.

Supportive Procedures

The advisory committee hired two people to help us implement our study: one to facilitate group conversation and one to record it. Using word-of-mouth contacts in the psychiatric survivor community, we hired Allan Strong of New Hamburg as the facilitator, and Deb Wise Harris of Toronto as the focus group organizer and notetaker. Deb’s duties later expanded to include

producing a thematic description of what she recorded in her notes in order to further the advisory committee’s analysis of the data.

In terms of recruitment, the advisory committee developed a small poster for each site that invited people to participate in a focus group. We produced a short summary handout about the study that was given to participants. It included contact information for any questions or follow-up discussion that participants might wish to have.¹³ All participants received a copy of the “Study Consent Form” that they had signed.¹⁴ Each person also signed their name to a list that acknowledged their receipt of \$20 for participation. The project paid for refreshments for each session; we also distributed TTC tokens.

In all of our study materials, we used “psychiatric survivor” as an identifier. It was the common denominator of our discussions – although not the only word at play in our talk. “Mad” was a close competitor. In our judgment, the term psychiatric survivor is sufficiently elastic in its current usage that it would not preclude responses to our call from people who identify differently. More than that, we were actively seeking out people who embraced the notion of surviving in order to bring its implicit system critique to bear on this new topic.

At the start of each focus group, the facilitators and committee representatives who identify as psychiatric survivors spoke to the participants about their own experiences and/or critiques of the mental health system. So, for example:

My name is Ruth Ruth Stackhouse

I am a community theatre director with a troupe of players comprised of psychiatric survivors and people with disabilities; I am a person with a disability; I am a student in Ryerson’s Disability Studies program. Before I joined the advisory committee for this study, I had heard about recovery from a number of people in the psychiatric survivor community. Many of them were encouraged by its promise. Also, I had facilitated a theatre workshop at a recovery conference; we called the play we created “Recovery Park.” I believed then, and I believe now, that the recovery vision is, at its best, a vision of hope. It promises wellness if its path is followed; this resonates with many psychiatric survivors.

My strongest impressions of the focus groups were how vulnerable and poor the study participants were. I hope that the promoters of the recovery vision will be mindful of that and will focus on personal empowerment and community building.

Recovery is just a word. Hope, though, springs eternal.

¹³ Copies of these forms are included in the appendices.

¹⁴ Signed forms are on file at Ryerson.

While important, this practice suggests an agreement on language and identity that was not uniformly present. Al and Deb occupied different subject positions within the group discussions and in the study. Al identified as a psychiatric survivor and has a long history of working with/for psychiatric survivor initiatives – including some jobs that now use “recovery” in the title. Deb is a consumer of mental health services who does not identify as a “psychiatric survivor.” Her contract work includes extensive contact with psychiatric survivor groups, but her work history is not completely embedded in this sector. Thus, our two staff members assumed different identities in relation to the advisory committee (each of whom also have their own various workings-through of these issues), the study and the community. These differences were actively debated throughout the study.

The Issue of Identity – Deb Wise Harris

When the issues surrounding psychiatric survivor-facilitators were discussed at the advisory committee, I voiced trouble about the ways in which “we” (Al Strong and I) were being constructed. I had difficulty expressing my concerns at the time, and wound up speaking of “value added.” I find myself still bothered and searching for a more thoughtful way to articulate myself.

What I was trying to get at with “value-added” is that it is not simply a matter of affirmative action -- wanting to see “our own” in paid positions. I am a strong believer in taking affirmative measures on the road to equity in employment. That is not my quarrel. Rather that our very experience in and of the mental health system, in addition to our professional skills, make us uniquely qualified to sponsor a safe, supportive and sensitive research space. The researcher/researched power relationship is unsettled by what I perceive to be the creation of community – which I believe we have been able to foster in each focus group.

The fact that facilitators could introduce themselves as peers had the effect of sponsoring questions and discussion about identity and the significance of having peer-led discussions set/strengthened the ‘tenor’ and ‘safety’ of the discussions. We heard; “I’d rather trust you than the officials.” And “[The facilitators are] a good example of recovery!”

My experience is a tangible asset. Ever vulnerable. Ever at risk. Ever damaged. Ever spoiled. The social world speaks volumes to me about “recovery.” What might my life be, what would the world be, I wonder, if I could be valued as more than an “overcoming narrative?”¹⁵

¹⁵ The source here is email correspondence between Deb and Kathryn over several occasions surrounding the negotiations with the Ethics Review Committee.

In further actions to create a safe space for participants, we requested that staff from the host organizations not attend the focus groups.¹⁶ Our aim was to ensure that all participants (including the facilitators) identified as psychiatric survivors, or at least, as people who use/had used psychiatric services. Even so, a staff member in one site did ask permission to attend. We made an exception in this case because the request hinged on the staff person’s desire to assist new clients with translation and encouraging participants who might feel intimidated to speak up. The issue of the staff person’s attendance was raised with the group (it was not an ideal situation as the would-be translator -- was present and translating) and the participants agreed to have the staff person present. The facilitators discouraged the staff person from actively involving herself in the discussion, except as a translator.

And finally, given how sensitive people in these sites are to being “researched,” the advisory committee decided not to audio-tape the focus group discussions for transcription. Instead, a member of the advisory committee attended each focus group (different members for different groups). This person kept flip-chart notes as the discussion progressed and provided a further reference point for the process. The one exception was the women-only space at Sistering where Deb facilitated discussion, Lucy took notes and Jen recorded the conversation on flip chart paper.

Focus Group Questions

The advisory committee’s discussions about what to ask in the focus groups swung between taking up the notion of “recovery” as a specific discourse currently in use in the mental health system, and notions of “recovery” that might be more generic or intuitive to the study participants.¹⁷ In the end, we mapped out a series of relatively simple questions tapping both meanings.¹⁸ Roughly stated, they included:

The Vision

- Have you heard about “the recovery vision” for mental health?
- Where are you hearing about it?
- What do you think about it? What would it take for you to participate in this vision?

¹⁶ In fact, we “deselected” one organization from our list of possible sites because the executive director refused this condition.

¹⁷ We have hesitated here over whether to use the term “discourse” or “vision” – keeping the latter primarily because it is more generally understood, whereas “discourse” requires some theoretical discussion (and perhaps debate). That said, we do not view, “the recovery vision for mental health” as a vague guiding principle. Rather, we understand it to be a rhetorical mechanism for shaping organization (participation), activity and the distribution of resources within a system.

¹⁸ Participants were also given the opportunity to raise questions and make comments before the “official” questions were posed.

The Lived Reality

- What does “recovery” mean to you? If I say “recovery” what would you say?
- Do you think people can “recover?”
- What would it take for you to “recover?” What would you need?

We added questions at the May 2007 committee meeting in anticipation that some participants in the focus groups might not be familiar with “recovery” as a model or a vision for mental health. Fashioned as a sort of research back-up plan, these additional questions were meant to elicit responses about the idea of “recovery” — in the colloquial sense that it represents “getting well” or “getting better” from an experience or illness — rather than necessarily understanding it as a model for mental health service provision or a vision for mental health.

1. Have you heard about “the recovery vision” for mental health?

What does “recovery” mean to you?

2. Where are you hearing about “mental health recovery”?

3. What do you think about “mental health recovery”?

What would it take for you to “recover?”

What would you need to make “recovery” real for you?

4. What would it take for you to participate in “the recovery vision” for mental health here in Toronto?

Our worry about whether participants would find these questions mysterious turned out to be needless. As Deb reported in an email to Kathryn, “We have met with nearly 50 open and generous people who have a lot to say about what “recovery” does – and does not – mean for them. The groups have been hugely successful, from the perspectives of being a positive experience (for the researchers, and the participants) and yielding fascinating and abundant material for reflection.”

Ethics Review

The work of the advisory committee included the task of securing ethics approval from the Ethics Review Board (REB) at Ryerson University. Translating a community-based design into formal, positivist categories and forms that currently define university-based ethics protocols was a challenging and troublesome task. The increasingly rule-bound direction of ethics review procedures and their role in restricting open inquiry is presently a source of heated debate amongst social scientists, particularly those in the interpretivist (qualitative) stream (see for

example Van Den Hoonaard, 2002; Hoeyer et al, 2005; Kidd & Finlayson, 2006; Tolich & Fitzgerald, 2006; Ellis, 2007; Fisher, 2007; Holland, 2007).¹⁹

Jennifer Poole wrote our Ethics Protocol using a “template” that Kathryn Church has developed, study by study, with colleagues in the School of Disability Studies. She made some initial modifications in discussion with Kathryn and with Ken Moffatt. We submitted the protocol electronically, as is now standard practice.

The REB’s feedback was primarily in the area of refinements to draft forms, or further clarification of process. These changes were easily made. However, there was one substantive issue under “Consent Process.” The board asked us to clarify the role of the psychiatric survivor staff. Were they research “subjects” who should complete consent forms? If not, given that they might know participants outside the research process, how were we addressing issues of privacy and confidentiality?

In our response, the committee wanted to respect the politics of the community in which this study takes place without creating unnecessary difficulties with the REB.

*Hiring people from the psychiatric survivor community is fundamental to the politics of our research. It recognizes that we understand this community’s needs for voice, recognition of expertise, and resources. At the same time, we want to ensure that we do not “re-pathologize” the people who take these contracts by taking up their identity as “vulnerable” in every instance, and by giving it primacy over their work skills and tasks. In this study, we want to draw a clear line between the psychiatric survivors who are paid consultants for the project, and the psychiatric survivors who are key informants. We do not view the facilitator and notetaker as participants in the study in the sense of being “research subjects.” Their consent to participate is signified by their formal application for the two positions that we are making available. We are, of course, sensitive to the issues of privacy and confidentiality that the REB raised but our preference would be to handle this matter through letters of employment that speak to labour standards rather than through research procedures that are specific to university activities.*²⁰

(Kathryn’s response to the REB posted electronically)

¹⁹ This section draws on a lecture titled “Ethics Review Protocols: In whose interests?” given annually by Kathryn to DST 88A/B Research Methods in Disability Studies.

²⁰ In the end, Kathryn created a “Consultant Confidentiality Agreement” for each of our staff to sign. It responds to the privacy concerns of the Ethics Board but maintains our staff as consultant labour rather than subjects of research simply as a consequence of their mental health histories.

To summarize, hiring staff with experience in and of the mental health system as well as professional skills was fundamental to our research methodology. Their lived experience “uniquely qualifies them to sponsor a safe, supportive and sensitive research space” (Wise Harris). But this qualification is compromised if, by claiming it, the staff person is plunged into the same discourse of “vulnerability” or “risk” that research participants are subject to through the Ethics Protocol. In our view, psychiatric survivors performing paid work should be treated as skilled workers whose practices are guided by contractual agreements and employment standards. This position was accepted, our protocol was approved, and we were off and running.

Results: What did People say?

When we asked participants about “recovery,” we evoked a range of responses: from meanings in general use to meanings specifically linked to the language of the mental health service system, i.e. “the recovery model” or “a recovery vision.” What this told us, in part, is that “recovery” does not (yet) reach everywhere in the system. Beyond this, participant responses are not easily categorized: any generalization threatens the richness of particular comments. Accepting that risk, we have organized our “take” on the data along three lines of argument.²¹

1. “Recovery” as a personal journey
2. “Recovery” as a collective journey
3. “Recovery” as (yet another) site of struggle

However, in order to have the conversation at all, study participants often had to begin by asking themselves “recovery from what?” For some, medicine -- specifically psychiatric diagnosis -- provided the definitive concepts and language to understand their lives: “schizophrenia”, “bi-polar manic depression”, and/or “psychosis,” for example. Within this knowledge system, illness is the root difficulty (inextricably linked to “health” as its opposite). The problem is a “chemical imbalance of the brain” which can be controlled by medication. “Living with” this situation through “coping” and “acceptance” is a more realistic goal than “recovery from” in the sense of effecting a cure. For these participants, the psychiatric system is an important resource. Medication – taking and staying on medication – is fundamental.

For other participants, psychology provided an alternative and more amenable way of understanding their lives. These people had replaced the concept of “illness” with one of “trauma.” As one person put it, “Trauma is not a disease like schizophrenia; it is a disorder that

²¹ We perceive other possible formulations. In fact, in a separate, four-page popular publication, we have characterized our findings as “Ten Things We Learned.” Copies available from the authors.

comes as a result of abuse.” This formation makes possible a range of personal responses that go beyond “taking your meds” and receiving ongoing care in the psychiatric system. Participants who understand their difficulties as a reaction to trauma can envision “recovery” as “stopping your meds,” exiting “the system” and “returning to society.” For these participants, “recovery as cure” is “still on the table.”

For still other participants, both conceptions were active and relevant. Some accepted the notion of “mental illness”; some rejected it. In either case, they conveyed a critique of psychiatric treatment, the pharmaceutical industry and/or the community mental health service system in which “trauma” was a factor. However, the trauma that they were most concerned with stemmed not from difficult life situations (e.g. abusive relationships) but from mistreatment and/or abuse within a system that creates oppression under the guise of “help.” As one participant explained, “If you force someone, you are infringing on someone’s rights.”

These positions sparked much debate among advisory committee members. However, our task is not to judge their truth or falsehood. Rather, we want to recognize that part of the ongoing work of “clienthood” – whatever the setting -- is to develop, revisit and refine some kind of explanation for “what is wrong with me” using the discourses that are available. How people position themselves in these discussions influences whether their notion of recovery is primarily personal, collective and/or political.

1. “Recovery” as a Personal Journey

Echoing much of the recovery literature and practice in the United States, United Kingdom and New Zealand, participants spoke of recovery not only in terms of “cure” and of “feeling better” but also in terms of an individual *journey* of well-being. We heard that “[In recovery] you are on your way to better things”. It is a “continuing process”, and one that “that never ends”. “For it is a methodology you have to practice everyday. [There is] no cease point”. Indeed, for one participant, “I can’t really say I’ve recovered. I am still recovering, still battling the inner voices that say I’ve thrown away my life.”

When talking about this process, participants often used the expression, “**road to recovery**”. A common metaphor in recovery “talk”, we heard; “I don’t want to think of just being in ‘recovery mode’, but on the road to recovery.” It means “being in a group like this one” as well as “working with Houselink doing landscaping one day a week”, being on committees and “venturing into the community”. Yet the road is not an easy one to walk;

[It is] an ongoing battle...it doesn’t stop...

I’ve turned left and right, gone through lights,

I’m on Yonge Street; I’m halfway there and I’m proud.

The journey is also a very **individual** one in the sense that every person's recovery is his/her own. We heard; “recovery is an individual thing; it’s about what one needs; how recovery fits them; not about what everybody else needs.” As it depends on each individual, there is “no general broad brush stroke”, “no format”. It is about meeting individual needs and taking control, saying, “I’m not giving you the keys to fuck with my head”. Bringing it down to a grassroots level, it’s about “teaching me skills that I didn’t know I didn’t have instead of taking my power away from me”.

Some participants maintained that that true recovery was not possible without individual work and “**personal achievement**.” We heard; “you’re doing the basic things: taking your meds, going to the drop in”, because “the person has to help themselves too not just only the doctor or medicine”. “[You have to] stand on your [own] feet”, but “if I’m doing so much better, I want the credit (not because the social worker is doing something better); ...it is me who gets better.”

Similarly, we heard a good deal about the role of **nutrition, personal care** and **exercise** in the recovery journey. The way to “recovery is stay on your medicine, eat well, [get] something good to eat/wholesome food; sleep good, drink a lot of water; stay away from drugs and alcohol”. Additionally, the way to recovery is through exercise as it “improves your mental condition a lot because it changes the chemistry of your blood”. Although people “have poor diets” because of poverty, isolation or mental illness, in recovery, “cooking for yourself” becomes important as does “having a bath everyday”. Both practices display a “willingness, a personal willingness” to recover.

According to participants, **self-esteem** and self-respect also play a role in the journey. As recovery means “to get back into feeling good about oneself”, we “need to respect ourselves”, to not “hide” depression and to “not be ashamed”. One participant said, “that’s a big thing for me. We are people and we do count”. Another added that “I found that I had three good friends: me, myself and I. I learned to love myself.” In short, recovery is “how I feel about myself, my self-esteem.”

Linked to feelings of self-esteem and self-respect was **positive thinking**. Positive thinking was deemed “very important” as people “can’t give up”. It was linked to a new “outlook”, to motivation and, above all, to **hope**, another common theme in much “recovery” writing. For one participant, “I battle with hopelessness all the time; to survive I’ve got to have hope that I will get better sometime in the future... Not to feel hopeless all the time; life feels like a prison sentence and the thing that keeps me going is that one day I’ll break out. There would be no point if I didn’t have any hope.”

Given talk of hope, it came as no surprise that a number of participants credit **religion, spirituality** and meditative practices with providing help in one's "recovery journey". This too has been discussed elsewhere in the literature, but for the research team, it was new to the

Toronto mental health scene. Yes, we had heard of the “journey” and the “road” and the individualism at the heart of “recovery” but suddenly it was spiritual.

On this theme, participants noted that “what helped me” was a “reconnection with the Church”, adherence to the Ten Commandments and “treating others how you wish to be treated”; “through faith and belief”; God “really helps you; you should attend church; and thank God”. Some were studying “religion daily; get[ting] a lot of satisfaction from that” and seeing that “thinking turns positive”. Others were “trying to get back to God”, equating “recovery” with “being delivered”.

Turning to more informal spirituality, we heard, one “needs to have purpose in life” and “meditation and taking a more active role in my spirituality would help me recover”. We also heard that for some “mental illness is a sickness of the spirit... My spirituality has come to be accepted by me as a real thing – it has taken away my night terrors, for instance, because I have a place in the universe, if not in this society here...if you have a spiritual underpinning, you can make decisions.”

In short, some understand “recovery” as a deeply individual journey to wellness that relies on willingness, activity, good nutrition, self-care, self-esteem, positive thinking and spirituality.

The View From Here – A Personal Commentary from Raymond Cheng

This research project was a provocative opportunity to hear directly from the people around which the concept of “recovery” has been invoked. Such empowering language that was documented through the voices of the majority of consumer/survivors in these discussions was gratifying to a certain extent. It does, however, possibly raise more questions than answers:

- *It appears that the open-ended nature of researchers’ questions have resulted in participants tacitly acknowledging through their responses that the onus of “getting better” has fundamentally shifted – off the shoulders of service providers in the mental health system – and onto themselves. When did this happen? Does everybody know about it?*

- *Why do participants in this study feel that it is so important that they are individually responsible? Where is the sense that consumer/survivors, as a community, working with each other through peer support, are indeed collectively capable of action? Should not systemic change through public policy change have a meaningful role to play as well? How do recovery-oriented organizations offer opportunities for clients to effect systemic changes, such as those that affect social determinants of health?*

- *If this were indeed the case, would the discussion not have taken a stronger tone of “do-it-yourself” and put into play the consideration of “the elephant in the room” question – the question of resource re-allocation? Should not organizations that profess to be active in encouraging clients’ recovery go further and download some of those resources and tools of self-service delivery into clients’ hands and wallets – such as meaningful employment? Does the talk match the walk?*
- *Does this dialogue about recovery truly extend further beyond the limited space of consumer/survivors and the mental health system? Where are these talking points making themselves heard in a civil society? If the principles of recovery are indeed broad-based, why are we still hearing about poverty as a “special-interest issue”? Has Not-In-My-Backyard (NIMBY) ebbed when it comes to discussing new social housing? Are we in an environment where discrimination and stigma around mental health issues are given their thoughtful due?*

2. “Recovery” as a Collective Journey

Turning now to the second main understanding in the data, we take up “recovery” as a more social process, one embedded in community and supports. Indeed many participants argued for a reclaiming of the social determinants of health that spell “real recovery” from mental illness and the stigma of diagnostic identities. They named safety, housing, money and education. They also echoed the social model of disability arguing that “society is sick”, “has plenty of symptoms” and “needs to recover as much as me”.

Exploring those “symptoms”, participants made clear that individuals with mental illness are “living way below the **poverty** line”, becoming what one participant called “human waste”. We heard; “[There is a] definite tie between mental illness and poverty”, “as middle class [psychiatric survivors] function fine.” We also heard that “if there was no such thing as mental illness, something else would take its place”, for “there have always been the poor, the middle and the rich”.

Similarly, there has always been **social pressure** to improve one’s situation. Although one participant maintained that “if you don’t like it that I’m not productive, then screw you”, another explained, “[I don’t have] the two car garage, the picket fence, two jobs, two children. In some ways I’ve recovered. But in some [other] ways, ‘no’, as there is always this focus on productivity, on making it and becoming a recovered ‘middle class’ person.” Similarly, a participant admitted that “my psychiatrist is trying to get me to have middle-class objectives of wanting nice things”. Another said that people always ask “what do you do for a living?” For one participant, the pressure came from her mother “who tells me to do this, do that...[she is] always comparing me to other people’s kids; wants me to be like other people”, to “be normal”.

Work and **activity** figured very prominently in focus group discussions on this theme. Participants suggested that "being active" will support a person's "recovery of well-being." "Being active" is more than a personal achievement, however. It requires the creation of opportunities for, rather than simply by, people "in recovery." Participants identified the need for (and the lack of) employment opportunities. We heard that “work has saved me” and that many take “pride in work,” in being “independent”. But we also heard that it’s “hard in the workforce. A lot of jobs are part time and don’t cover our medications; we can’t get benefits from employers; if you have a bad day, you can’t do it [go into work.]”

Then there were those who argued that being well could include "not having to have a job". We heard, “we don’t have to feel bad that we don’t have a job; we don’t have to have a job in order to be well”, for ‘work’ was “not necessarily an occupation”, but “[something that] occupies the mind” or **activity**. Such occupations could include “being active in the community”, “a daily routine” and accessing agencies such as Across Boundaries, “Monday to Friday for art, English and computer **classes**”. They could also involve the development of new skills as one participant explained; “I now do a lot of speaking, facilitating townhalls, and I’ve reached a good level.” Finally, another way of being active was through **volunteering**. “My doc said: “get out and do something...instead of doing nothing. Even if it’s just volunteering. It’s good to get out.” Another participant noted, “I knew I was getting better when I started to volunteer”.

Along with work and activity, participants identified stable, decent **housing** as vital to recovery. Indeed it was so important, they argued, that people with mental health problems should have priority for subsidized housing in Toronto. We heard; “...people don’t have adequate housing; waiting lists are long”, but you “can’t live without” your “own space; your own privacy to get yourself together; you can’t recover in boarding homes when your roommate snores. You have to be in a room by yourself”. That “home” needs to be **safe** and it needs to be “a decent place, not a fleabag, because that makes you feel better.” Not surprisingly, however, we also heard that many “have been applying for subsidized housing for years” ending up on decade-long waiting lists with no decent housing in sight.

Along with a lack of housing, many participants experience extreme **personal rejection** as a result of the stigma of being a psychiatric survivor. “When you’re suffering depression, people snub you” –including friends, family, husbands, wives and prospective romantic partners. “As soon as a woman hears ‘mental illness,’ they’re out the door”, said one participant. Another noted that many people made him feel like a “leper”. This constant rejection was described as a type of “continuous psychological punishment” making recovery almost impossible for many. In short, “as soon as you say ‘mental illness’ people’s attitudes change...the walls come up”.

Similarly, participants identified a lack of dignity and respect in their **relationships with professionals** as a major barrier to recovery. Although some people credited agencies such as PARC and Sistering with creating/restoring their “well being”, we heard others say, “I was not

treated as a person [in the mental health system].” Instead, “[I was] patronized and coerced by social workers”, psychiatrists and others who did nothing except “get money off of me.”

What participants did want more of for recovery was **community**. That meant a “sense of belonging”, “a niche where you are safe from attack”, a place to “check in with one another” because recovery means “wanting to wake up in the morning, having a social network, friends...”. Indeed, many argued “recovery” is only possible in the presence of “**kindership**”: when other human beings — friends, family, and health-care providers — care about you. They said, to “recover,” you need “a phone number and a name, someone who will help you”, “good friends” and people who treat each other like family. “Recovery” benchmarks are things like “acceptance, relationships, a partner, not being isolated and alone.” In short, you need “people with a smile on their face” to give you hope.

Many were more specific, naming the **receiving of peer support** as vital to recovery. Even though there are not enough peer supporters around, not enough “survivors in the system” who can act as “mentors”, we heard that “it is easier to be with people with similar experience”. They help us through our “transitional periods” in “recovery,” for they are “teachers” and “philosophers”.

Others described the **giving of peer support** as equally, if not more important to “recovery.” Some wanted to share their time, “to provide hope”, to “make sure people know they are not alone in this fight”. With “one hand on [the ladder] and the other hand reaching down to give someone a hand up”, others said;

Pick a friend, pick a brother; try to help someone you know not to get involved in certain things...you can stop things before bad things happen...we helped troubled teens in high school; I took on a brother; who is still my friend...I was the only guy who cared.

I participate by being a leader; I help people to participate in programs (at Across Boundaries). I lead discussions about what is going on in the community, and the world; making people feel welcome and comfortable.

Along with peer support, participants identified **access to education** as paramount. Some argued that “the road to recovery involves education” including “funding for transitional education” that would help survivors qualify for or return to ‘school’. It could also be about starting small by “going to the library, getting books”. Some were using their education again like the individual who noted “I graduated as an artist so I was teaching one year at CMHA...it brought together people from different cultures, and we learned from one another.” Others were seeking “workers who can teach us, in a different environment (not a school) to be equally recognized in what we can achieve”. Echoing similar arguments by “recovery” scholar Patricia

Deegan, the idea of “recovery as education” was put forth as just as important as “recovery as a journey”.

In the end, many aspects of a more social model of “recovery” came down to money. The “mental health system is dumping people into the community where there are no resources”, but those resources, especially financial resources, are key to that community. If “recovery” meant a journey to some, to others it meant “money”, “support” and “disposable income”. With income, one participant “bought musical instruments; [I got] a home, clothing, a computer. I went back to school and [now I am] not socially isolated”. With money, “you feel independent”. Without it, you “have to fight all the time to get your basic needs met”, and that meant dealing with ODSP which some felt was a punishment for being diagnosed. On that topic we heard, “there is not enough money”, we need more “justice” and “they’re keeping me poor on ODSP because I have the thing called mental illness.”

For this second understanding of “recovery,” an understanding rooted in access to the social determinants of mental health such as education, housing and safety, money was the common thread, and lack of it a common threat to recovering from mental illness.

Commentary: “Déjà vu all over again”²² -- Kathryn Church

*Baby, I’ve been here before
I know this room
I’ve walked this floor....
(Leonard Cohen)²³*

My initial role with this project was administrative: managing the budget, providing meeting space, and being a liaison with the funder. Dry tasks and a bit standoffish -- reflecting the ambivalence I felt about my involvement. For fifteen years, I made my living doing participatory research with psychiatric survivors: first, on their involvement in making mental health policy and later on their approach to local economic development. I was passionate about the work but stopped in 1999, troubled on a number of fronts: by the struggle to “fit” in a context defined by identity politics, by my desire for intellectual autonomy and variety, by the system’s devaluation of qualitative research, and the related realization that what I/we so laboriously produced through “CBPR” had an uncertain or fleeting impact on policy. The appearance of a model of system reform imported -- yet again -- from the United States seemed only to confirm my decision to stay out. “Recovery” looked like the antithesis of all that we had worked for during a

²² Saying attributed to baseball player, Yogi Berra.

²³ I borrowed this snippet from Leonard Cohen’s “Hallelujah.” On June 6/08, in his Toronto concert, he sang this as “Darling, I’ve been here before...” a rewording that recognizes, perhaps, rethinking the politics of “baby” in his lyrics.

time when asking questions about power/ empowerment was central to policy formation. Why bother with it?

It was the advisory committee that warmed me to the project. I knew all of the people we assembled but, with a couple of exceptions, had never worked with them directly. Even so, as I sat through our early meetings, I was flooded with familiarities. The disturbing edge was to realize that a person could return to the scene after a ten year hiatus and find the situation within a particular community remarkably unchanged. How is it that the dynamics of the mental health field continuously reproduce the status quo? The joyous edge was to feel the resurgence of my affinity with the people who sat around the table. All of them struggle to make change, to work against the grain of things by creating spaces in which reconnection, redefinition and contestation become possible. They do so from psychiatric survivor-run sites in which clinical services are not the dominant response to complex human needs: a thin layer of organizations that represent a victory for earlier waves of mental health activism. They occupy jobs that were previously unimaginable, and that position them perfectly to know what life is like for psychiatric survivors “on the ground.” Our project enabled a convergence of first-hand observations into dialogue. The sharp bite of “survivor-speak” recalled for me the capacity of this community not just for opinion but for gritty, uncompromising critique. Re-engaging with the ongoing movement of “mad” knowledge became one of the high points of the project. Unexpectedly, it felt like coming home.

During the summer of 2007, Deb was frequently in and out of my office at Ryerson: receiving cash for honoraria and food, delivering signed Participant Agreements and chatting about how the focus groups were proceeding. She radiated enthusiasm for the discussions that were taking place – as did other advisory committee members through email and in meetings. I envied them! Trapped in other projects, I was the one person on the advisory committee who did not attend a focus group and, consequently, could not feel the process. That disconnection made me particularly eager for Deb’s thematic analysis – hoping that it would bring me closer to the “recovery” problematic that the committee had been discussing for months.

I have to say that it delivered a punch – that internal document – but in ways that surprised me. If I expected something new – and I suppose I did – it was there in the extent to which study participants voiced such a tremendous sense of personal responsibility for their “journey” through “illness” towards “healing.” This metaphor was not dominant in progressive mental health policy even a decade ago. Along with my fellow commentators, particularly Raymond and Ken, I am disturbed by its prominence. Although I agree that it is not the only way to read the data, I view the “talk” on self-care as evidence of how neo-liberalism works to shape the ways that people narrate their lives. We live in an era in which selective corporate “social

responsibility” is replacing broad-based state support in the public sphere. ²⁴ Part of what enables that narrowing is that we “forget” the workings of systemic disadvantage, the lessons and gains made by collective action from the margins -- such as David recounts – and the availability of individual protections -- Lucy’s primary concern.

It was reassuring, then, to find a more systemic line of argument in our data, one in which participants articulated the fundamental importance of “a job, a home, and a friend” – and, by the way, they added, what about education and truly supportive community services?

Reassuring, yes, but disturbing in a different way.

In the late 1980’s, David and I were involved in a national policy development exercise that argued the necessity for strong “consumer participation” in building multi-sectoral “frameworks of support” that would enable people with mental health histories to live well in local communities. The documents from that initiative were instrumental in shifting mental health policy across the country – at least temporarily – in a more inclusive direction. ²⁵ Among them was a report on the first-ever Canadian research to seek out a “consumer perspective...upon some of the most critical issues today in community mental health” (Hutchison, et al, 1985). ²⁶ According to the participants in that qualitative study, the issues that really mattered included the stigmatizing effects of psychiatric labels, the demoralizing effects of hospitalization, rampant unemployment, poor income supports and a lack of meaningful activity, inadequate housing, and debilitating social isolation. Almost twenty-five years later, the participants in our study pinpointed precisely these same issues.

So, what year is it anyway? How do we have the gall to speak of “recovery” under these conditions? What kind of a game is this?

I do not intend these as rhetorical questions but I have to leave them as such. Obviously, a major effect of this project has been to evaporate the distance I set up between me and it, and to notice the return of an all too familiar rage – one that I had trouble living with the first time around (Church, 1995).

²⁴ Neo-liberalism refers to a set of policies, including free trade, that enable the roll-back of government regulation to free capital investment across national borders: it signals the power of corporations and cut-backs in state welfare provisions.

²⁵ Building a Framework for Support was a project of the Canadian Mental Health Association (National). I was its first coordinator; David was the first “out” psychiatric survivor member of the national committee that guided its work.

²⁶ I refer to the period of time during which the Canadian Mental Health Association made a shift from the clinical language of “patients” and “severe mental disabilities” to the language of service “consumerism.” The word “consumer” in our documentation represented a first stage victory in the battle over definitions (categories), words (labels) and meanings as part of a larger attempt to depathologize the language of mental health. As our participants demonstrated, while other changes have occurred, the battle still rages.

Grasping for objective ground, my final comment is about methodology. In every way possible, the advisory committee addressed the critique of research that has been made by marginalized communities – disability activists among them (see Oliver, 1992; Stone & Priestly, 1996; Barnes & Mercer, 1997; Barnes, 2003; Tregaskis & Goodley, 2005). Here we have a study that is highly participatory, consciously reflexive in terms of power and voice, grounded and sensitive in its implementation, and rich in its articulation of people’s experience. And yet, when I consider the profound overlap between what researchers heard from listening to psychiatric survivors in 1985 and what we heard in this study, I remember why I gravitated to other research traditions.

It is not sufficient to produce research in which the only objective is to give people voice (see also Mykhalovskiy & McCoy, 2002). The world does not change simply because we produce more information about people’s “troubles” -- or their speculations about how things came to be. We need to know this experiential layer but we cannot know just this. Without losing our grasp on the power relations of producing knowledge, we want research that discovers how things are put together organizationally to produce the experiences we repeatedly discover (Smith 2002; 1999; 1990; 1987) -- research that tells us where and how to intervene in order to make a difference. In that sense, research itself is a site of struggle

3. “Recovery” as (yet another) Site of Struggle

Turning now to the third main understanding in the results, we found something different, something unique to this research. Although many have argued that “recovery” is individual (Deegan 1996, Anthony 1993) and some have countered that it is a more social process (O’Hagan, 2004), critical voices are rare in the literature -- especially from the people that “recovery” promises to “heal” and “help.” However, in this section, “recovery” becomes critique, a process that must happen if psychiatric survivors are to reclaim both the “walk” and the “talk” of “real” recovery.

Not surprisingly, “recovery” as critique started with questions around **medicine**; many participants pointed to the inadequacy of medical mental health care as a central obstacle to recovery. Not only is it “hard to get a psychiatrist”, but “some doctors will medicate you and send you on your way”. These doctors were called “lazy”, “hopeless”, interested only in “factory housing” survivors in hospital. In the words of one individual’ “I want to tell them to fuck off”.

The effects of this “lazy” care were many. Some drew attention to an often ignored issue, identifying stigma around their mental health issues as a barrier to **physical health care**. They said, “we don’t need just psych care but also physical [health care]”, because “we all live in fear of getting physical illness”. Illustrating this point, we heard; “even if I have a flu, or other medical issue — [the doctors] will treat you with anti-depressants before physical treatment”. Because if “a professional knows you have mental illness...they devalue what [I] say”. Even if “I had a bone sticking out of my leg, [they’d say] here, take this psychiatric drug”.

Others took issue with “**dirty**” medication, or the “cures” that come with toxic and disabling effects. Such medication made participants feel “lazy”, “hear voices” and “see things coming out the television”. Others brought on other illness, for “health professionals have to be honest with us about the side effects of medication. I have diabetes as a result of medication.” With so many iatrogenic effects, some participants had come to the conclusion that “psychiatry and psychology are not hard sciences; it’s a hit and miss approach with clientele”. They had also decided that “recovery is not a serum that comes inside a syringe and makes everyone recover”. In fact, it’s all just a gamble when it comes to the medications supposed to create “recovery”.

Turning now to a second institution, participants had much to say on how problems with **policing** had become a major barrier. Arguing that individuals with mental health issues were at the “mercy of the police”, we heard participants say, “Police have been given more powers under the *Mental Health Act*, if he ‘thinks’ you’re acting in an erratic way, they can take you for assessment; they often abuse you”. In a well known case of this, we heard “Edmund Yu was on the way to becoming a professional engineer, police shot him dead when he had a breakdown on the TTC.” Another participant was “told I didn’t have the right to charge someone because I’m a consumer/survivor”. Equally powerful was the participant who asked of the police, “when you need to ‘form’ me, just take me to the hospital, don’t make a mockery of me”.

In brief, we heard that the police just “don’t know how to deal with mental illness”. The police, like medical practitioners, are often seen as impediments to “recovery”.

And so, “recovery” as critique includes questions around the so called “helpful” institutions of medicine and policing. It also includes what we have called a process of reclaiming “recovery” from a professionalized, “hijacked” model being used to exploit and force mental health care.

During the focus groups, we found that many participants were already familiar with “the recovery vision”. It had been introduced as part of recent conferences, workshops, training sessions, working groups, and committees delivered or organized in the context of mental health service delivery and/or community mental health organizations. Specifically, they were hearing about it at the Recovery Working Group (Houselink), the Social Issues Committee (Houselink), in church basements, “...in the hospitals, in outpatient programs, the Salvation Army” and an injured workers’ group. One participant told us, “Ann Thompson talked about recovery,” and “WRAP was all about recovery.”²⁷ Another said, “We’re having a [recovery] conference in November”, and “We’re having a recovery focus group at PARC”. Others said they had books and training tapes on “recovery”.

Additionally, many participants understood mental health “recovery” as an increasingly **professionalized model** for mental health service delivery. The “Making Gains” conference

²⁷ Ann Thomson is a certified WRAP facilitator; WRAP stands for Wellness Recovery Action Plan.

talked about “recovery” from the perspective of workers who were helping members with their “recovery”, and “workers (at Houselink) had to take “recovery training”. In fact, many organizations, including Houselink and Centre for Addictions and Mental Health, were now in “recovery mode”, even though some staff “went kicking and screaming.” It was this version of “recovery”, this “staff-driven” practice that garnered particular criticism from the focus group participants.

Many felt it was allowing professionals to **force** “recovery” on clients. In the name of something better, participants said they were “being forced on medication which doesn’t help” and being forced to agree to electro-convulsive therapy (ECT). They said, professionals “believe they’re helping us”, but “if you force someone you are infringing on someone’s rights”.

Others saw professionals using “recovery” as an excuse not to do anything. “Some workers have used [recovery] as a crutch, so they don’t have to do their job”, said one participant. Yet another insisted that “recovery” had to be more than **talk**, more than good intentions. Behind the talk, people are “still on the same medications”, still not “getting better”. They “don’t want to just hear the talk about recovery”, they “want to see the actions.”

We also heard “recovery” needs to be more than a **“fashion”**. [Recovery is like] “basic black”, “really in at the moment; very fashionable now”. It may be a “new fad word in the psychiatric world”, but it “does not address quality of life”.

In fact, many argued that the original notion of “recovery” had been **“hijacked” by professionals**. “It’s big in Europe and US and may have started in consumer movements, but it has been hijacked by a whole stratum of professionals”. To some, “recovery did not feel like a consumer/survivor driven idea; it felt like it came with institutions – giving it to us and pretending it was ours”. Another participant added, “It’s being fed to consumer/survivors so they’re starting to pick up on it”, but some of us “don’t want fucking recovery, [we] want a life”. Disappointed, disconnected and still waiting for real action, one individual noted, “I’m not into making recovery movement happen, if the professionals are going to take credit for it”. In short, “We were fine with Mondays being Social Rec but now it’s all about recovery”.

With hijacking came talk of **exploitation**: by the pharmaceutical industry, the medical field, the “abuse in the outreach industry” and even the peer specialists who are “supposed to be the key to a recovery-oriented mental health system”. “Professionalized in Georgia”,²⁸ “peer specialists are making money on broken people who need to be fixed”. They have become part of a “world industry trying to fix us.”

Instead of professional models, hijacking and exploitation, “what is needed are supports that allow us to function without having to be fixed. We might need training wheels, or extra

28 Larry Fricks, founder of the Georgia Certified Peer Specialist Program, was the guest speaker at an event in Toronto on May 24, 2006.

time...but we don't need recovery.” In fact, once again echoing the social model of disability, “society needs to recover from the idea that we need fixing.”

Commentary: Rethinking “recovery”, rethinking citizenship? -- Ken Moffatt

I believe that current transnational forms of organizing social relations are both cultures of compliance and cultures of constraint (Franklin, 1999). This point of view means that I am looking for the way these global forces reconstruct people's identities so that they are given few social options for agency. There is a trend in the “recovery” movement to, at best, a constraining and, at worst, an oppressive set of social discourses and relations. I argue that the language of “recovery” needs to be questioned for its congruency with the type of social actor that is required for the successful spread of the global market economy.

Global relations based on self reflexivity and individualism are well suited to global market relations. This form of social organization is not only related to a person's understanding of her/himself (Alphonse, George & Moffatt, 2007; Giddens, 2004; Poole, 2007) but also to her/his understanding of citizenship in the global era (Beck, 1994; Jubas, 2007). Giddens (2004), a key theorist in the effects of global relations on the perception of the self, has argued that the manner with which we construct our identities is influenced by the demands of the global social and economic orders. The self needs to be a flexible self that can change as the global economy demands. Furthermore, the flexible self needs to be self-reflexive so that persons can reconstitute their demands, needs and voice in manner congruent with technological forces, market economies and global discourses.

Rather than act in a collective manner outside of constraining global relations persons deal personally with a whole array of social contradictions. The act of individualization becomes a compulsive response to the social order even though it is represented as free choice of the citizen. The adjustment occurs among individuals at the personal level. Too often it is assumed by creating our own biographies we can overcome intransigent social relations (Beck, 1994). In the new global era individuals are expected to reflect on their own circumstances and make personal adjustments. The individual person becomes a ‘free chooser’ and a consumer who bears the duty of taking on social risk. The individual is to be flexible, changing her/his lifestyle and tactics in order to adjust to constantly changing circumstances (Bauman, 2005).

In an inequitable world the move to the individuated reflexive self amplifies the pain felt by marginal groups. Persons who are marginalized by forces of globalization come to understand themselves as individuated selves who must adjust to their social circumstances. Persons take personal responsibility for structural forces that are affecting their well being. Structural problems such as poverty and prejudice become the problem of the individual who must problem solve her/his life circumstances. When forces of global social relations insist that well being is achieved by the individual on her/his own without social support, some people despair

to the point that self-destruction and conflict seem to be the only way out of the dilemma (Alphonse, George and Moffatt, 2007).

As an advocate of reflexive self as a form of well-being and informed citizenship this is sobering critique of reflexivity for me. There are some ways out, however, from the conundrum of reflexivity. The first is to imagine the self as social; the self is not known outside its relationship to the other (Miehls and Moffatt, 2000). A conceptual distinction that might help us out of this conundrum of the burdens of the reflexive self is to move from universal concepts of the self and citizenship. That is, we avoid the faulty logic that concepts such as self and citizenship apply universally in a uniform manner. Rather citizenship can be viewed as a dialectic whereby universal notions of citizenship are informed by difference defined by distinct social experience according to social location.

Finally, we might define citizenship according to six factors: rights, responsibilities, resources, recognition, residence and resistance. One might argue that these elements must be in place so that a person experiences citizenship. At the same time one recognizes that these elements of citizenship can challenge as well as support each other (Jubas, 2007).

It is evident in the findings of this study that elements of citizenship are lacking for study participants including the lack of resources and lack of residence. My colleague Deb Wise Harris brings into question the element of recognition in her discussion about identity. In her commentary, Lucy Costa makes a compelling argument about the centrality of rights to best understand well-being yet she argues there is an absence of rights in the discourse of “recovery”. So, in the “recovery” discourse the identity of those who are “recovering” is not supported by the status of citizens, since the model lacks the elements of resources, rights and recognition that are essential to full citizenship. The citizenship of psychiatric survivors is trampled. They are forced to rely on the reflexive self as defined by global forces to adjust as best they can to insecure social relations.

At the same time, consumerism is a central ideology of globalization (Bauman, 2005; Jubas, 2007). The “recovery” movement is dangerous if it stays solely focused on the adjustment of the individual to social forces by “recovering”. It might be argued that it is a form of reflexive individualization that global relations demand. Or it might be a form of consuming a new product (Poole, 2007).

I wish to change my focus, however, to Jubas’ final element of citizenship, that is, resistance. Jubas (2007) argues that consumer discourses have been so successful internationally that resistance has been left out of the discussion of citizenship. Consumerism has replaced a complex understanding of citizenship.

It is my contention that to be just we need to challenge taken for granted social norms and identities. The taken for granted needs to be challenged especially when normalized relationships contribute to the marginalization and exploitation of communities. How do we understand the findings of this study in a manner that challenges international constructions of

the self that are congruent with global capital and the culture of constraint? What is the taken for granted in “recovery”?

“Recovery” reminds me of the metaphors associated with modern international development. While leaving people under-resourced, we promise the panacea of hope. One always is to strive for a future horizon of significance no matter how dismal the current reality. The assumption is that with effort, self-assertion, and commitment to hope we will attain a better future. These relationships are perverse through no fault of the person who hopes but through the social forces that make the satisfaction of hope unattainable. Our desires are never satisfied yet are played with against a vague future hope (Alys, 2007). This unattainable hope with the demand for personal adjustment through self reflection or “recovery” is the taken for granted.

There are many clear voices of resistance within this study about the mistreatment and marginalization of those who have been characterized as in need of “recovery”. Some of the resistance is to the broad social forces of marginalization while other comments seem to be in resistance to the recovery movement itself. There are four of the many resistances in this rich report that I wish to acknowledge: the understanding of structural factors associated with marginalization; the use of the pronoun of we to counter the individualizing forces of the discourses; making concepts of productivity problematic, and, most importantly, the disdain of many participants to the idea of being fixed.

Taken together, we can use such resistance to construct a shared and creative form of “recovery” that stands outside the concept of the individuated reflexive self that needs to take the burden of change onto itself. It is a form of “recovery” that does not stay focused on the actions of those persons categorized as in need of “recovery” but rather understands their well-being in the context of shared relations. This reconceptualization of “recovery” is also a reconceptualization of citizenship. Maybe if we start from the ground and build from these four forms of resistance mentioned in the previous paragraph we will have not only a new way of thinking about “recovery” but also a new form of citizenship that makes resistance to a global culture of constraint a central feature.

Final Commentaries

As we have already demonstrated, advisory committee members had much to say and write about what they heard, saw and felt during this study. We close with two final commentaries: one from Lucy in which she poses questions that went unanswered for her by the study, particularly about the absence of talk about rights; and one from Jennifer who addresses the interconnections of housing, social exclusion, and community-based participatory research.

We don't have RECOVERY if we don't have RIGHTS - Lucy Costa

One of the key questions I had while working with this project was: would the local "recovery" talk include feedback on rights victories or violations? Put another way, could "insanity" and "recovery" co-exist given that "madness" is under the purview of psychiatry, and psychiatry is essentially married to law?

As this study got underway, results were coming in from another study. I work in (but not for) a psychiatric hospital, the Centre for Addiction and Mental Health (CAMH). When CAMH announced that it wanted to develop a recovery policy, my employer, the Empowerment Council²⁹ felt it was absolutely necessary to check in with clients.³⁰ The Council wanted to know what recovery would look like to them.

We surveyed clients from the four main sites³¹ and conducted two focus groups, one of which included forensic clients. We spoke to approximately sixty clients in total. Our questions were meant to generate discussion about what clients knew or didn't know about "recovery". The focus groups' feedback essentially broke down into three areas: the meaning of "recovery," the things that help and hinder recovery and the things that are helpful and unhelpful at CAMH.

*The key findings were that every one has his/her own vision of "recovery" and that "recovery" means having choices. Other points included the need to come together with peers and being treated as an expert about one's own life. "Recovery" was also action oriented; accomplishing things as opposed to being told what to do, being forced or not getting what is needed. The goal of our feedback collection is to push the mental health system to **implement** the suggestions of its clients.*

What is most interesting and paradoxical about the growth of the "recovery" movement in and outside of hospitals, is that it coincides with the implementation of community treatment order (CTO) legislation (2000) and with an increase in the number of people being pushed through the mental health and criminal justice systems. It is another example of the system shrewdly appropriating psychiatric survivor knowledge without giving up any of its power. The magnetism of recovery talk, the "hope talk" is picked up while the contentious bits regarding citizenship and advocacy are left behind.

²⁹ The Empowerment Council is a nonprofit corporation, responsible to its own members and board. The Empowerment Council's membership, board and staff are all current or ex-clients of mental health or addiction services. The Empowerment Council advocates on a systemic level on behalf of CAMH clients.

³⁰ CAMH has adopted the term "client" to refer to people receiving its services.

³¹ The College Street site (the former Clarke Institute for Psychiatry), the Russell Street site (the former Addiction Research Foundation), the Brentcliffe site (the former Donwood Institute) and the Queen Street site (the former Queen Street Mental Health Centre.)

Long before "recovery" became a household name, psychiatric survivors were already actively demanding their rights through 'zines like "Phoenix Rising" (1980) and "The Cuckoos Nest" (1984) and books like "Mental Health Law in Canada" co-authored by psychiatric survivor Carla McKague (Savage and McKague, 1987). Advocacy groups like the Ontario Psychiatric Survivors Alliance (1989-1992) pushed the envelope on rights abuses. The Advocacy Act of Ontario (1992) was an attempt to address the gaps between what was written in law and what happened on the ground. More recently, from 1999 to 2002, activist Graeme Bacque issued 18 Human Rights Alerts.³²

In 2002 former Queen Street Patients Council (QSPC) held what was probably the first official "recovery" conference; it brought together local psychiatric survivors and consumers and "recovery" specialists from the United States such as Judi Chamberlin, Loren Mosher and Courtenay Harding. The 120 delegates were eager to hear the wisdom of our neighbours to the south who had been doing "recovery" for a number of years through organizations such as the National Empowerment Centre and the Center for Psychiatric Rehabilitation at Boston University. The conference reached a wide range of psychiatric survivors. In many ways, it signalled the desire for successor vision to that of the 80s and 90s.

The conference was the result of the grassroots work of the QSPC. It recognized that psychiatric survivors/consumers were frequently unaware of their rights and that some knowledge is "privileged" and seldom shared with the actual recipients of services. The QSPC believed that psychiatric survivors/consumers need more than information about hopeful literature; they needed to understand their rights and to learn how to be agents in the services they received.³³ Often, psychiatric survivors/consumers would talk about having been deceived because they had not been offered a full scope of perspectives on "mental illness". The naming and identifying of this censorship of information allowed survivors and consumers to decide for themselves what agency they could or should have in a system that is adverse to admitting and acknowledging its mistakes.

When people learned that there were more perspectives than just clinical ones and that laws exist to govern what happens in hospitals and with treatments, jaws would drop in disbelief. This was particularly true with issues of informed consent, an epidemic problem for psychiatric survivors and consumers. Do conversations of "recovery" today include an increase in informed consent conversations or better access to representation in legal situations?

³² <http://bacque.graeme.tripod.com/HRA/>

³³ With minimal budgets for sharing the information, we would have to devise creative ways to share "data". For example, I recall doing one session at Chinese & S.E. Asian Consumers/Survivors Self-Help Centre of Metro Toronto (C-SACC) with the help of a translator. I would share one paragraph at a time with the translator so she could share with the group. This was also done at Across Boundaries to facilitate discussion and Q&A.

Today new initiatives and institutional practices carry the language and torch of "recovery". We see an industry that has provided us with peer recovery workers, alternate milieus for "recovery", resource rooms aimed at assisting with wellness and "recovery", family centred recovery, "recovery" facilitators, conferences, guides and courses on "recovery" and of course, new technology which will assist us with managing all things "recovery". We have rolled out the red carpet for "recovery".

From my location inside an institution, all this fervour looks like a "mosquito bite gone malaria".³⁴ As someone who is often consulted for feedback on "recovery" projects, I notice that what is usually lacking is a solid position on advocacy for the community in many "recovery" initiatives. For instance, job descriptions for "peer recovery workers" do not require candidates to be aware of advocacy and rights issues. Teaching psychiatric survivors how to use "recovery" tools for crisis management or symptom awareness is but one aspect of what psychiatric survivors and consumers need in order to become empowered. If staff and peers are not teaching each other about mad history and culture then what exactly are they doing other than replicating a new version of cure?

Professionals trained in "recovery" are not always equipped with a rights framework even though rights are supposedly valued as important. How can institutions and agencies promote "recovery" when individual options continue to be so limited? What kind of "recovery" is it when a client cannot get access to fresh air daily? Should not "recovery" include informed consent? How does "recovery" fare given the tensions that exist in unionized work environments? Should not "recovery" include the ability to hire your own service providers and purchase your own supports?

One hot summer, a few years ago, I talked with a group of social workers, nurses and therapists who were baffled and stuck on how to address the lack of air conditioners for their clients living in inadequate housing with dubious landlords. Does not "recovery" require service providers to mobilize politically to change the conditions their clients find themselves in? More than that, should not "recovery" require workers to include their clients in work that is about making political change?

*"Recovery" became the bombastic rainbow of hope filtering its ways through our windows and into meetings about strategic planning, implementation tools, programs, and technology in early 2002. But has "recovery" been here all along? Psychiatric survivors were still doing what they have always done, which is to **show** "recovery" through the fight for employment opportunities such as the Ontario Council of Alternative Businesses (OCAB) demonstrates or through the*

³⁴ I owe this nifty metaphor to Erick Fabris.

historical demonstrations and protests on topics of coercion and abuses³⁵ or through the insistence that stigma does not quite capture the actual discrimination that survivors experience. Where is the abuser in stigma? Because of the advocacy efforts of survivor activists, we are finally hearing "stigma" coupled with "discrimination".

Those of us situated in position of privilege can learn a lot from survivors who, amidst and despite all the fads that have come and gone within the psychiatric system, find creative and innovative ways to survive against all odds, in an imperfect world that blows hot and cold, a world where food banks grow and social services shrink.

Social Exclusion, Housing and CBPR -- Jennifer Poole

Reflecting on the findings, my fellow research team members have commented on rights, the social determinants of health, citizenship and identity-- to name just a few issues. They have made clear what they read in the results, what has been left out and what the next steps and questions need to be to reclaim, rework and even ‘recover’ what is now known as mental health recovery. In this short piece, I want to take us back to the initial proposal we developed for the Wellesley Institute, and reflect on doing this research as well as its findings, take up the issues of housing and, in particular, social exclusion.

Informed by the World Health Organization, we began our process of CBPR by arguing that social exclusion has always been a factor of poverty and relative deprivation. It results from racism, discrimination, stigmatization, hostility and unemployment- issues regularly faced by psychiatric survivors in Toronto. “These processes prevent people from participating in education or training, and gaining access to services and citizenship activities. They are socially and psychologically damaging, materially costly, and harmful to health. People who live in, or have left, institutions, such as prisons, children’s homes and psychiatric hospitals are particularly vulnerable” (Wilkinson & Marmot, 2003, p. 17).

We also argued that housing is a key social determinant of mental health for psychiatric survivors. Jack Layton has argued that between 30 and 50% of homeless individuals suffer from ‘mental illness’ (2000, p.99) and the wait for affordable and assisted housing is more than 18 years long. Compounded by deinstitutionalization and the lack of ‘community’ investment, the situation is only getting worse (Capponi, 2003).

Imported from the United States in 2002, the ‘recovery vision’ or ‘mental health recovery’ is supposed to dramatically improve the lives of all individuals with mental illness, increasing independence, restoring hope and reducing social exclusion. As we explain in our report, it has been defined as a “highly individualized, strengths-based approach to symptom management”

35 Phoenix Rising 1980-1990 provides excellent textual journey of the work and resistance by psychiatric survivors as does the Psychiatric Survivors Archives of Toronto with its collection of archival evidence.

emphasizing “hope”, “self-directed therapy, fitness, nutrition, peer support and spirituality” (Ontario Recovers Campaign, 2005). It also relies heavily on access to medication and participation in programs such as the six-step ‘wellness recovery action plan’ (WRAP). Yet, this “highly individualized” approach has been criticized for excluding the severely mentally ill (Peyser, 2001) as well as widening the gap between those who can afford to pay for therapy, medication and good nutrition and those who cannot. In addition, there had always been a suspicious lack of critique in the formal and informal literature on recovery as well as a dearth of Canadian and survivor voices. In fact, despite modeling itself as a more progressive ‘patient-driven’ response to a marginalizing medical mental health system, the recovery field tended to exclude those it professed to ‘help’, with well-housed consultants, researchers and middle class educators cornering the ever growing local recovery ‘market’.

Faced with this particular form of social exclusion, our process of doing CBPR on recovery became especially paramount. As outlined in the report, our research practice was very local, very much a ‘survivor’-driven team approach. Survivors outweighed non-survivors, research and focus group questions were dreamed up collaboratively as was how we were going to write this final report. Individuals with personal experience of mental health were hired and paid to collect the data and craft the initial report, and as with any good participatory process, it all took more time than we planned. And yet, we have produced the first participatory, survivor driven Canadian research on mental health recovery, and in these commentaries, in our findings and learnings, survivor voices come through loud and clear. Finally, we have a Canadian response to the deeply American notion of mental health recovery. Finally, we have a response crafted by those recovery has always proclaimed to help.

Turning to that response, it would appear that there are three quite distinct understandings of recovery circulating through Toronto’s psychiatric survivor communities. After seven local focus groups, two years and countless analyses of the data, we now know that like our neighbours to the south, some survivors see it as a very individual and at times, deeply spiritual process. Others understand it as a social process, only possible with supports such as housing, and some talk about recovery as a set of resistance practices to stigmatizing institutions such as psychiatry and policing.

Elsewhere I have written extensively on the language of recovery (Poole, 2008) and the different discourses on recovery now present in Ontario’s mental health communities (Poole, 2007). I argued that how we talk and understand recovery seems to hinge on where we are positioned in the system, whether we are survivors, professionals, educators or administrators. I found that some are talking ‘recovery story talk’, some ‘marketing talk’ and some the professional language of models and evaluations, and the differences in these ‘languages’ have caused both confusion and conflict when it comes to understanding and ‘doing’ recovery locally.

But this CBPR project has taken those findings further, suggesting that within local survivor communities in particular (and I use the plural to pay heed to those who identity, those who

don't and those who prefer other categories), there is no ONE understanding of the recovery vision or the recovery process. Yes, there are individualizing voices around recovery, those that tie the process to self-esteem, hope and a 'God'. However, there are also those who argue that recovery must be grounded in social inclusion, community and what some participants called 'kindership'. To be 'well', they say, one needs friends, family, love, circles of support and people who care. One also needs good, safe, accessible, affordable housing, not any old housing either, but the kind of room/apartment/house that actually makes you feel better. And in a complete departure from much of the literature and research on recovery, we heard that recovery includes being able to question and critique institutions that hold the power to make or break the 'recovery' process. That questioning, that outing, is part of the process, just as keeping silent about rights abuses, hostility and discrimination is part of the problem.

In a perfect world, the recovery vision would include individual, social and resistance processes. It would mean that being well could involve personal work as well as a building strong community, fighting for social inclusion, a decent income, good housing as well as room to critique and reform rights abuses, policing practices and what our participants called “lazy” psychiatrists. But we do not live in that world. Instead, we live in a world where the individualizing forms of recovery, as Ken Moffatt has made clear, the ‘understanding’ that recovery is not linked to inclusion and housing, are dominant. Indeed, one could argue that this popular, pervasive and personal understanding is itself a form of social exclusion, a process that is “socially and psychologically damaging, materially costly, and harmful to health”. The question becomes what to do with that. Do we name it ‘false consciousness’? Do we work to change the language altogether or is it enough to say there are multiple ways into recovery from mental health issues and it is this multiplicity that creates options and possibilities for people just trying to feel better?

Clearly, the results raise even more questions for those worrying, working for and wanting ‘real’ recovery locally. However, we do have something new to hold on to here. By focusing on what survivors really ‘think’ of recovery in Toronto, we have showcased what it all looks like under the ‘talk’ and hype. By focusing on a psychiatric survivor-driven inquiry, we have reversed some of the social exclusion we have seen in the research literature, and by keeping it local, we have made clear to survivors, researchers, educators and policy makers worldwide that recovery has a particular flavour here. Sure we have the individual ‘brand’, the one tied to American individualism and faith, but we also have the beginnings of something else, something wrapped up in social inclusion, community, critique and resistance. And this is a long-awaited, entirely home-grown alternative to that being marketed by our friends to the south.

Conclusion

A major achievement of this research has been to complicate the discussions about “recovery” that currently abound in the mental health system by seeking out and foregrounding the opinions of psychiatric survivors in Toronto. Doing so was predicated on a thoughtful and persistent engagement with each other – from start to finish – in doing community-based participatory research. Together, we surfaced three lines of argument that constitute the distinctive “take” on “recovery” made by seventy or so study participants. The first line situates “recovery” as a personal journey. Through their own efforts and achievements, individuals link personal care with self-esteem and positive thinking to achieve hope. The second line situates “recovery” as a social process in which people address the need for tangible resources such as jobs, income, housing, safety and education. Giving and receiving peer support is fundamental to this view. The third line takes “recovery” as critique and targets a range of powerful institutions: medicine/psychiatry, health care, the pharmaceutical industry, and the police – for starters. It opens terrain for recovering “recovery” from its increasing professionalization within community mental health. Clearly, even though “recovery” is increasingly powerful in organizing the operation of the service system, it has no single meaning – and no unified constituency.

Making this collective analysis has enhanced our understanding – if only with new questions and avenues of inquiry. At the same time, it has not displaced our longstanding individual views of what “recovery” signifies. As David amply demonstrates, we are a committee with a substantial historical view on the system -- and its refusers. Raymond’s concerns go to poverty and the need for collective action to ensure resource allocation in support of community life. Kathryn reinforces Raymond’s concerns – and the solution he proposes – by drawing forward a 25 year old study and finding it an uncanny mirroring of our own results. Ken ponders the ways that people carry globalization in their bodies, and challenges us on the possible connections between rethinking “recovery” and rethinking citizenship. Speaking to a silence in the data, Lucy keeps her grip on advocacy and rights – victories and violations – by reminding us that “you can’t have “recovery” if you don’t have rights.” Jen brings us full circle by capturing the scope of our journey and savouring the flavour of “recovery” in Toronto – that blend of “inclusion, community, critique and resistance” that we have identified as the “something new” of this particular place and time. Thus, by drawing on the past and the present, on action and reflection, engagement and distance, chorus and solo, we contribute our findings to what we hope will be an ever-expanding debate over mental health “recovery.”

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Appendix A: Sample Poster

Are you psychiatric survivor or consumer? Do you have something to say about mental health recovery?

Ryerson University and the Empowerment Council are looking for survivors 18 years and over who want to voice their opinions about mental health recovery.

WE WANT TO KNOW WHAT YOU THINK

June 5th 2007

1:00PM – 2:00PM

(10 spaces for participants)

The groups are going to be facilitated by survivors for an hour each. Anyone who wants to participate will receive an honorarium for their time as well as tokens to get to the location.

If you would like more information about the study, please call:

Jen: (416) 979-5000 Extension: 6253

Appendix B: Recovery Focus Group Project:

A QUICK SUMMARY FOR ORGANIZATION STAFF

What we’re doing:

- Got a little money from the Wellesley’s urban health grants to ask survivors, consumers, refusers and users in downtown Toronto what they think of mental health recovery
- Project has just been approved by Ryerson’s ethics board to go ahead
- We’re hoping we can hold a one hour long focus group at your organization of between 5 and 10 folks sometime in June.
- We’ll bring snacks, tokens and honorariums (20 dollars) for all the participants. We’ll also put up flyers if you need us to.

What the project is called; ‘Nothing about us, without us’: What Toronto psychiatric survivors (consumers, refusers and users) think of the recovery vision for mental health

Who is running it: Lucy Costa at the Empowerment Council, David Reville, Al Strong, Deb Wise-Harris, Ruth Ruth Stackhouse, Becky McFarlane, Kathryn Church at Ryerson’s Disability Studies plus Ken Moffatt and Jen Poole at Ryerson’s School of Social Work.

Who has funded it: Each year the Wellesley Institute gives out small grants to enable community groups to explore urban health issues. Ours is for about 8000 to hire to survivor facilitators to do the work and give everyone an honorarium for each focus group.

Why we are doing it: There’s a lot of research on recovery these days and all kinds of experts like Pat Deegan coming to show us how to do it, but there is almost nothing on Canadian responses to recovery and even less on what survivors think here. We thought it was time to change that.

What we want to have at the end: The first report on what Canadian survivors think, ideas for research articles, workshops and other ways to make sure survivor opinions are part of the recovery talk.

What about ethics? We will ask all the people in the focus groups to sign consent forms, but we are not taping the groups or writing down anyone’s name on the notes we’ll take at each group. Ryerson has approved our process, but if you need to touch base with your own research committee, we understand and can send you our approved ethics submission or even meet with them if you need us to.



What happens next? What will happen is that if you’re interested, Deb will follow up with you about a time and place for the group. We’ll send you flyers if you need them or you can start a sign up sheet. On the day, we’ll do a short orientation for everyone about the project, consent forms etc. and if they still want to participate, we’ll ask them to stay for the discussion. On the day, Deb and AI will be leading the focus group, but there will also be someone there from the steering committee to sit in, get the coffee, do the orientation and answer any questions.

Need more details?

If you need more, contact Jen at jpoole@ryerson.ca or 416 979-5000 (6253) and she’ll send you what you want. For now, please see the study abstract and flyer attached.

Appendix C: Study Consent Form/Information Sheet

Study Title: Nothing about us, without us: What psychiatric survivors in Toronto think about mental health recovery

Investigators: Dr. Ken Moffatt (Social Work), Dr. Kathryn Church (Disability Studies), Dr. Jennifer Poole (Social Work), Lucy Costa (The Empowerment Council)

Sponsor: The Wellesley Institute

Invitation to Participate

The information on this form outlines the terms and conditions of a survivor driven study on mental health recovery. As a psychiatric survivor with someone thing to say about recovery, you are being invited to participate in this study.

Background & Purpose of Research

This qualitative study is about what psychiatric survivors in downtown Toronto think of mental health recovery. As part of the study, participants will join one of 5 focus groups to be held during the spring of 2007. These groups will meet for 90 minutes. During the focus groups, participants will be asked to discuss certain questions by the trained survivor-facilitator. These questions will relate to mental health recovery.

Participation

- Participation in the study will involve a 30 minute consent process and attending one focus group.
- Each focus group will last 90 minutes and will be conducted at a time most convenient to the participants.
- Notes will be taken during the groups and recorded on flip charts visible to all participants. There will be no audio taping of the group conversations.
- Participants can refuse to answer any particular question or terminate their participation at any time, and if after the interview, participants feel uncomfortable with anything they have said, it can be deleted from the paper notes immediately.
- Participation in the study is completely voluntary, and participants may withdraw from the study at any time with absolutely no consequences. Upon withdrawal, names and all personal identifying information will be deleted from the study files immediately.
- Participation, non-participation or withdrawal will have no effect on relationships with Ryerson University and the Empowerment Council.

Privacy & confidentiality

- The identity of each participant will be known to the principal investigators and the survivor research team.
- While the researchers (and the facilitators) will maintain confidentiality and it will be requested of focus group participants, this cannot be guaranteed.
- In addition, the information provided by participants is confidential within the limits of the law. (I.e. confidentiality will be maintained unless a particular situation arises, such as child abuse, harm to self/others, court subpoena and communicable diseases, that we are bound by law to report.)
- No identifying personal information will be used in any reports, articles or presentations which result from this study. Instead we will use numbers for each participant (i.e. ‘participant #1, #2) to ensure privacy unless a participant asks us to use his/her real name.
- All files including notes and computer disks will be kept in a locked cabinet at Ryerson University accessible only to the principle investigators.

Compensation

- Transportation costs will be paid for each participant to and from the focus group site.
- Upon completion of focus group, participants will be also be given a small honorarium of \$20.00.

Rights

- Participants waive no legal rights by being involved in this study, but if there are any concerns about rights, please contact the principle investigators (see information below).
- Should participants also wish to contact the Research Ethics Board at Ryerson and discuss any concerns about the project, they can call Nancy Walton at (416) 979-5000 (ext. 6300) or Alex Karabanow (416) 979-5000 (7112).

Findings & and Future Research

- If any new findings come to light during the course of this research which may influence a participant’s decision to continue, they will be notified immediately.
- At the end of the study, participants may request a copy of any publications that arise from this research.
- Participants may be contacted in the future with respect to further research on mental health recovery.

Copy of informed consent for participant

Participants should retain this document as a copy of their informed consent.

I agree to participate in this study.

Your signature: _____

Your printed name: _____

Today's date: _____

Contact names for questions

1. Ken Moffatt: (416) 979-5000 (6215)
2. Kathryn Church: (416) 979-5000 (4592)
3. Jennifer Poole: (416) 979-5000 (6253)

Stay in touch

Register with the wellesleyinstitute.com to participate in our blog discussions and receive the latest news and analysis.



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