Recovery through the Lens of Cultural Diversity 2010

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Executive Summary

Many provincial mental health system reform bodies in Ontario have endorsed the concept of recovery, as have the Kirby Commission, the Mental Health Commission of Canada, and a number of Toronto-area Local Health Integration Networks. Increasingly, community mental health organizations in Toronto are seeking to align their policies and practices with a recovery vision and principles.

Much early recovery research was focused on developing models that could be used to provide guidance for the design and delivery of recovery-oriented services. These first generation models emphasized what is common across individuals. They described general processes, but did not particularize these processes to specific groups or communities, nor did they go very far in integrating broader knowledge about the social determinants of mental health and mental illness. Community Resource Connections of Toronto (CRCT) has worked closely with community partners and other stakeholders to improve access to recovery oriented services for individuals and communities that have traditionally been excluded from the mental health system. As part of that strategy, CRCT has held several recovery trainings for both service providers and consumer/survivors. Service providers who work with clients from diverse communities overwhelmingly gave feedback that some of the strategies presented in these trainings were not culturally appropriate. Clearly, there is a need for a more sophisticated second generation model of recovery that accounts for culture and can be used to inform services and policy.

The overall aims of this project were to examine recovery through a cultural diversity lens in order to develop a model of recovery that, when implemented, will improve the ability of mental health organizations to design and deliver recovery-oriented services that are relevant and responsive to culturally diverse Toronto. The project had three main objectives:

- To nurture a recovery and cultural diversity "community of practice" in the city of Toronto.
- To use a community-based participatory research approach to critique and adapt an existing model of recovery.
- To begin to plan for how the adapted model might be applied to the design and delivery of community mental health programs and services in Toronto.

As suggested by these specific aims, the project engaged in three major activities that were undertaken in three overlapping phases. In the first phase, mental health providers and other organizations serving diverse populations in Toronto (e.g., immigrant and refugee-serving agencies) with a stake in developing culturally appropriate model of recovery were invited to join an interdisciplinary and culturally diverse group of service providers in a community of practice devoted to exploration and action related to recovery and cultural diversity. In the second phase, the group's focus turned to the community-based participatory research component of the project, conducting six focus groups with service user and family members in the Caribbean, Somali, and Tamil communities. In the third phase of the project, members of the community of practice used the findings from the focus groups, as well as material developed through their own discussions, to develop a culturally-responsive model of recovery. At the community forum, held in December 2009, the project and the model were presented to an enthusiastic and engaged audience of some 80-90 service providers, consumer/survivors, family members, and others. There was a wide-ranging facilitated discussion about issues pertaining to recovery and cultural diversity, out of which came feedback on the model, recommendations for policy and practice, and several suggested next steps for the community of practice.

Several points are key to the culturally-responsive model of recovery developed by the community of practice. First, it recognizes that individuals exist in a web of relations constituted by the family, community, and larger socio-political units, such as cities, provinces, and countries. Second, it places culture, systems of oppression and privilege, the social determinants of health, and history in the foreground, positing that these factors are central to recovery. Third, it sees recovery as a collection of processes that occur within the web of relations, contextualized by culture, oppression and privilege, the social determinants of health, and history and conceptualizes the mental health system as potentially supportive of recovery, but not necessarily central to it. Fourth, it notes that the mental health system itself has a culture and history. And fifth, it puts the frontline provider into the model explicitly, thus recognizing that role as critical to bridging the mental health system and the arenas in which recovery takes place.

Recommendations

Based on the work described in this report, the Toronto Recovery and Cultural Diversity Community of Practice makes the following recommendations aimed at promoting recovery for members of cultural diverse communities who are experiencing mental health problems:

- The social determinants of health are of central importance in promoting resilience and reducing vulnerability in cultural-linguistic communities. Cross-sectoral collaboration—between government and civic society, among government sectors such as health, education, social welfare, and economic development—is required to address these social determinants.
- One such area of collaboration lies in the relationship between the mental health and immigration sectors. There is a need to look at ways in which mental health and immigration/resettlement services can be better integrated. For example, the mental health impact of immigration policies should be evaluated. Resettlement workers should receive training that will allow them to identify mental health issues and refer appropriately. Information about mental health services should be included in the orientation curriculum provided to newcomers to Canada.
- Cultural-linguistic communities should also be partners in this collaborative approach. Mental health promotion and illness prevention might best be served by using a community development approach within cultural-linguistic communities. Communities should be supported to take the lead in developing their own priorities. Existing social networks should be identified and strengthened. In addition, communities should be enlisted in the work of devising culturally appropriate strategies for promoting awareness of mental health issues and recovery.
- Inside the mental health system, there should be more focus on the root causes of mental ill health for cultural-linguistic communities and on holistic—not solely biomedical—solutions. The system should be encouraged to have a broader perspective about who it is serving; at times it will be individual clients, but it may also be families or communities. This broader perspective must be reflected in structure and policy, and it is essential that providers working within the system be equipped with the skills, knowledge, and competencies they need to work using this framework.
- Training and education on recovery and mental health should include content
 and reflection on: culture of health care including mental health care and cultural
 competence particularly issues around immigration & settlement processes,
 oppression and privilege, understanding individualism and collectivism,
 understanding of mental health and mental illness across cultures and cross
 cultural communication.

- Local Health Integration Networks should review their policies and practices for compatibility with recovery. For example, they should conduct an evaluation of the central intake model's consistency with recovery principles.
- The Community of Practice may be a useful entity for helping to plan, co-ordinate, or implement many of these recommendations.

Project Background

It is now more than fifteen years since William Anthony first called for recovery to become the guiding vision of mental health systems. Anthony defined recovery as "a deeply personal, unique process of changing one's attitudes, values, feelings, goals, skills and/or roles...a way of living a satisfying, hopeful, and contributing life even with limitations caused by illness." His call prompted a worldwide flurry of research and policy development. Attention to recovery in Canada has grown steadily since the early years of the new millennium. Many provincial mental health system reform bodies in Ontario endorsed the concept, as have the Kirby Commission, the Mental Health Commission of Canada, and a number of Toronto-area Local Health Integration Networks. Increasingly, community mental health organizations in Toronto are seeking to align their policies and practices with a recovery vision and principles.

Much early recovery research was focused on developing models that could be used to provide guidance for the design and delivery of recovery-oriented services. These first generation models emphasized what is common across individuals. They described general processes, but did not particularize these processes to specific groups or communities, nor did they go very far in integrating broader knowledge about the social determinants of mental health and mental illness. For example, Jacobson and Greenley's² conceptual model of recovery views recovery as a phenomenon made up of conditions both internal and external to the individual who is recovering. Internally, recovery is characterized by processes of hope, healing, empowerment, and connection. Externally, these processes are facilitated by human rights, "a positive culture of healing" in service provision organizations, and recovery-oriented services. In this model, as in other models of recovery, individuals' personal experiences are understood to be important to recovery. These experiences are affected by the contexts in which individuals live, including their cultures, but the first generation models of recovery pay little attention to cultural diversity. The Jacobson and Greenley's conceptual model of recovery was one of the earliest recovery models and one of the very few to include social context.

Community Resource Connections of Toronto (CRCT) has worked closely with community partners and other stakeholders to improve access to recovery oriented services for individuals and communities that have traditionally been excluded from the mental health system. As part of that strategy, CRCT has held several recovery trainings for both service providers and consumer/survivors. Service providers who work with clients from diverse communities overwhelmingly gave feedback that most of the strategies presented in these trainings were not culturally appropriate.

^{1.} Anthony, W.A. (1993). "Recovery from Mental Illness: The Guiding Vision of the Mental Health System in the 1990s" *Psychosocial Rehabilitation Journal* 16 (4): 11-23.

^{2.} Jacobson, N. and Greenley, D. (2001). "What is Recovery? A Conceptual Model and Explication" Psychiatric Services 52 (4): 482-485.

Clearly, there is a need for a more sophisticated second generation model of recovery that accounts for culture and can be used to inform services and policy.

The overall aims of this project were to examine recovery through a cultural diversity lens in order to develop a model of recovery that, when implemented, will improve the ability of mental health organizations to design and deliver recovery-oriented services that are relevant and responsive to culturally diverse Toronto. The project had three main objectives:

- To nurture a recovery and cultural diversity "community of practice" in the city of Toronto.
- To use a community-based participatory research approach to critique and adapt the Jacobson and Greenley model of recovery.
- To begin to plan for how the adapted model might be applied to the design and delivery of community mental health programs and services in Toronto.

Project Activities

As suggested by these specific aims, the project engaged in three major activities that were undertaken in three overlapping phases. In the first phase, mental health providers and other organizations serving diverse populations in Toronto (e.g., immigrant and refugee-serving agencies) with a stake in developing culturally appropriate model of recovery were invited to join an interdisciplinary and culturally diverse group of service providers in a community of practice devoted to exploration and action related to recovery and cultural diversity.3 Members of the community of practice met in a series of eight meetings held over the course of eight months (March-November 2009). The first two meetings focused on developing terms of reference and a statement of working principles and values for the community of practice (included in this report as Appendix A), on debating the definition of culture that would guide the project, and on a general discussion of members' knowledge of and experiences with recovery. At the third meeting, the group engaged in a structured critique of the Jacobson and Greenley model of recovery, an exercise aimed at determining how recovery could better address issues of cultural diversity. The Jacobson and Greenley Model was used as a springboard to a broader discussion of how recovery is being conceptualized and implemented. At the fourth meeting, members of the community of practice reviewed the key learnings derived from the critique and then sought to synthesize their ongoing discussions about culture and recovery. (The substance of these discussions is summarized in the Project Findings section of this report.)

In the second phase, the group's focus turned to the community-based participatory research component of the project. At its fourth meeting, the community of practice began to design a series of focus groups in which service users and family members from diverse communities would be invited talk about their own experiences of mental health promotion and recovery from mental illness. In planning this data gathering activity, members of the community of practice first discussed the main aims of doing the focus groups, then made decisions about which cultural-linguistic communities should be invited to participate. After these initial decisions were made, a smaller group of community of practice members with a particular interest in research met to draft a protocol that included specifics about data collection, focus group conduct, recruitment methods, and strategies for adhering to rules governing the ethical conduct of research. The protocol (included in this report as Appendix B) formed the basis of the REB application that was submitted to the CAMH REB and approved in August 2009.

^{3.} Communities of practice are groups of people who have common interests and commitments and come together in order to engage "in collaborative learning and knowledge sharing activities, group projects, and networking events that meet individual, group, and organizational goals while creating an increasing cycle of participation and contribution." (Source: *Community of Practice Design Guide* 2004, produced by iCohere, Inc.)

The community of practice decided that the focus groups' main objectives would be to collect data about the following topics: the meaning of good mental health; the meaning of poor mental health; strategies for mental health promotion; needed changes in mental health services; and participants' ideas about what the mainstream could learn from their cultures about mental health. In order to ensure that these topics would be salient to focus group participants, the community of practice decided to recruit two groups: adult individuals with lived experience of mental health problems and mental health service use and family members with loved ones who had experienced mental health problems. Based on considerations of size of population in Toronto, diverse experience, and contacts available to the members of the community of practice, a decision was made to recruit from three cultural-linguistic communities: Caribbean, Somali, and Tamil. Thus, the plan was to conduct six focus groups, one each with service users and family members, in each of the three languages. Community of practice members felt strongly that the project also needed to hear the voices of youth from these cultural-linguistic communities, so a decision was made to conduct a single additional focus group, in English, for younger members of these communities.

Although the original plan (as described in the project's application to the Wellesley Institute) was to have members of the community of practice conduct the focus group, issues of time and equity led to a decision to hire and train cultural-linguistic community members from outside of the community of practice to act as focus group facilitators, who would also translate and transcribe. (CRCT generously contributed extra funds to the project to support these individuals.) Thus, in early September of 2009, the project recruited and hired five facilitators who came from the cultural-linguistic communities that would be participating in the research. A one-day training for facilitators, joined by two community of practice members, (one of them (Judy Gabriel) volunteered to act as a facilitator, was held on September 24, 2009. (The agenda for the training is included in this report as Appendix C.)

The focus groups were held in various locations in Toronto, mostly public libraries, in October and November of 2009. Figure 1 shows the number of participants in each group.

	Service users	Family members
Caribbean	7	2
Somali	14 (two events) ⁴	12
Tamil	10	12
Total	31	26

^{4.} After confusion about location caused a very low turn-out for the Somali service users' group, a second group was held.

Despite efforts to recruit youth, no one showed up at the designated location on the day of the focus group. Feedback received during the recruitment process suggested that youth were likely to be uncomfortable discussing mental health issues in a group setting. The community of practice discussed other possibilities for soliciting youth participation (e.g., a "virtual" focus group held using a social networking site), but pursuing these ideas was not possible given the project's financial and time constraints. (Findings from the focus groups, and demographic information describing the participants, are provided in the Project Findings section of this report.)

In the third phase of the project, members of the community of practice spent their sixth, seventh, and eighth meetings discussing the conduct and findings of the focus groups and how to use the findings, in conjunction with the group's own critique, to modify the Jacobson and Greenley model of recovery. (The result of these discussions, the revised model, is presented in the section of this report titled "A Culturally-Responsive Model of Recovery.") In addition, the group used these meetings to plan a community forum at which the new model could be presented and the possibilities for its wider implementation discussed.

At the community forum, which was held on December 9, 2009 at Hart House on the campus of the University of Toronto,⁵ an audience of 80–90 service providers, consumer/survivors, family members, and others (hardy souls who braved the first snowstorm of the season!) listened to reports from facilitators about the findings of the focus groups in the Caribbean, Somali, and Tamil communities and a description of the new model of recovery. A panel of service providers from the community of practice talked about the implications of the model for their work with clients, families, and communities. Finally, there was a wide-ranging facilitated discussion about issues pertaining to recovery and cultural diversity. (The substance of this discussion is described in the Project Findings section of this report.)

^{5.} The community forum was scheduled to coincide with another recovery-focused public event, one organized by the Toronto's Leadership Project in order to host a dialogue about the role of recovery in the province's new mental health and addictions strategy.

Project Findings

The Community of Practice

The community of practice began its work by discussing how it should define culture, an important debate to have in a project focused on the notion of cultural diversity. After several iterations, the group settled on the following definition:

Culture describes the integrated patterns of human behaviours that include thoughts, communications, actions, customs, beliefs, values, and institutions of racial, ethnic, religious, or social groups.

- Culture is not static but dynamic and one ethnic or social group will go through different levels of acculturation (e.g., first and second generation immigrants).
- "Social groups" includes groups with common identities based on shared experience.
- Cultural *identity* is partially a matter of *self-identification*; cultural *worldview* is often unconsciously shaped by one's social location, upbringing, and everyday experience.
- Culture has both positive and negative aspects. For example, members of cultural groups may experience some of the "integrated patterns" described in the above definition as oppressive.

This definition is broad in its scope, encompassing not just the language and customs of particular ethnic or religious groups, but the wider array of "integrated patterns of human behaviour" that adhere to other social groups. It emphasizes the fluid nature of culture, and also recognizes that culture is in part a matter of self-identification. It is robust because it recognizes the role of power, privilege and social location in shaping our cultural identity and worldview in addition to ethnic and social identity.

The community of practice kept this definition in mind when it embarked on its critique of the Jacobson and Greenley model of recovery and, by extension, a larger critique of the notion of recovery and the ways in which it currently is being used in mental health policy and services. The critique was structured by questions about the group's overall reaction to the model, the gaps in the model, and the conceptual role that culture might play in recovery. The major points to emerge from the group's critique were these:

- The experience of recovery is defined by individuals who are embedded in families, communities, and broader social systems.
- Promoting recovery requires that we address individuals, families, communities, and social systems.

- The domains of the recovery experience (i.e., the internal and external conditions identified in the Jacobson and Greenley model) may be common across individuals, families and communities, but the specific elements of these are shaped by social location.
- Experiences of racism and marginalization, histories of colonization, and other systems of oppression and privilege, as well as inequitable access to resources affect how recovery is understood and experienced by individuals, families, and communities.
- Social determinants of health are critical to recovery and must be emphasized in any recovery promotion strategy.
- As a movement, recovery should focus more on addressing social inequities and changing systems of mental health services and supports and less on changing the individuals who use these services and supports.
- The terminology of recovery is not universally meaningful. We may need a new language.
- Recovery may be explored using narratives, manifestos, or art in addition to models.

In its final discussion during this phase of the project, the community of practice sought to bring together their explorations of culture and recovery. The group talked about the ways in which the mental health system has its own culture—one largely formed by the values and assumptions of mainstream Canadian culture—and how individuals who interact with the system often experience conflicts between their own cultures and this culture. For the members of the community of the community of practice, many of whom are frontline providers, it was particularly important to note that frontline providers often find themselves having to negotiate the intersection of these cultures. For example, members noted that their work with individual clients cannot be separated from their work with clients' families, but that the structures and policies of the mental health system, such as its reporting requirements, are built upon a model of service delivery to individuals. For those providers who are also members of the culturallinguistic communities they serve, there are frequent expectations that they take on "extra" tasks, such as interpreting for their clients in service provision settings. Providers of services to culturally diverse communities thus find much of what they do is officially unrecognized, which places them at a disadvantage when it comes to the system's ingrained categories of work, including its notions of time and progress. This lack of fit hinders frontline providers' ability to support recovery for their clients.

The Focus Groups

Demographic details for the focus group participants are shown below.

	_	sex Age (range) M F			Marital Car		Education	Employment status	Income level	Living situation
Caribbean family	n 2	60 1 Missing data	M 1	1 1	1 Single 1 Widow	(range) 39–40	Grade 11 University	2 Retired	1 Middle 1 Missing data	2 Alone
Caribbean service user	7	27–50	1	6	4 Single 1 Separated 1 Divorced 1 Married	2.5–49	1 Some college 1 Grade 12 3 Completed college 1 Post-secondary correspondence 1 Graduate degree	3 Not working 4 Employed	2 Middle 5 Low	2 With others 2 Alone 1 With child 2 With family
Somali family	12	43–71	2	10	1 Single 4 Widowed 3 Married 4 Missing data	2–15	1 University 4 No formal education 3 Some grade school 4 Missing data	4 Not working 5 Employed 3 Missing data	1 High 7 Low 4 Missing data	1 With others 7 With family 4 Missing data
Somali service user ⁶	14	33–60	5	9	8 Single 1 Widow 5 Married	10–20	1 Grad degree 6 High school 2 Grade 8 3 University 1 College 2 Missing data	11 Not working 3 Employed	3 Middle 9 Low 2 Missing data	5 Alone 5 With family 1 With others 3 Missing data
Tamil family	12	22–56	4	8	2 Single 1 Widow 9 Married	5–19	1 Grade 11 1 Grade 10 4 High school 2 University 1 College 1 Some college 1 Grade 8 1 Missing data	6 Not working 2 Employed 4 Missing data	3 Low 3 Middle 1 High 4 Missing data	11 With family 1 With others
Tamil service user	10	28–53	1	9	2 Single 7 Married 1 Missing data	8–24	2 High school 2 Grade 10 1 Grade 9 3 Grade 12 1 College 1 Some college	9 Not working 1 Employed	9 Low 1 Middle	8 With family 1 With others 1 With child

The focus group transcripts were used to answer three questions: What does it mean to have good mental health? What are people recovering from? What helps people to recover?

For a few participants, the definition of good mental health was nothing more than the absence of mental illness: being "normal" as demonstrated by a lack of symptoms. For most, however, good mental health was a more affirmative concept, understood to encompass both state of mind and level of functioning. As one Tamil service user stated, good mental health means "being happy and doing things that we want to do." Mentally healthy people have balance and coherence in their thoughts, perceptions, and behaviours. They are not overwhelmed by problems or worries. A Caribbean family member said, "you are not being really upset or

^{6.} Demographic data for the Somali family and service user groups are unreliable because of literacy difficulties and administrative error.

unhappy about events that occur in your life." Rather, mentally healthy people have perspective and are able to cope and overcome when things go wrong. Participants talked about the ways in which having good mental health means having the ability to function as part of a family and a community. For example, one Somali service user noted that a mentally healthy person "is able to carry out his responsibilities." A Caribbean family member brought up the notion of "productivity," noting that good mental health allows people to "perform" in the arenas of education and work. In the Caribbean service user group, participants emphasized that good mental health improves the quality of relationships with others, while participants in the Tamil and Caribbean family groups talked about "sociability" and having close family and good friends as important markers of good mental health. In each group, participants spoke about good mental health as a source of ease and opportunity. A Caribbean service user said that good mental health means "just being comfortable in your own skin" and a Somali service user noted, with good mental health "you have a future and life has a purpose."

Participants held a wide variety of beliefs about the causes and triggers of mental health problems, and thus spoke of a wide range of things that people need to recover from in order to enjoy good mental health. For some, the cause was a "chemical imbalance," likely linked to the genes. Others identified temperament as the source of the problem, suggesting that some individuals lack confidence and are thus overly sensitive to stress and prone to rumination. For example, a Tamil family member talked about "a lack of braveness in the heart" and a Caribbean service user described "feeling small all the time." Most of the discussion in each of the groups, however, revolved around the individual and collective experience of external events and conditions. These included interpersonal problems, like marital difficulties or strain between parents and children. More broadly, they also included social problems like poverty, unemployment, resettlement stress, racism and other forms of discrimination, media "negativity," violence, war and political repression. Singly or together, participants explained, these problems lead individuals, families, and communities to become disengaged and isolated, resulting in corrosive feelings of loss, sadness, hopelessness, and anger. In every focus group, participants were particularly concerned about youth mental health and the impact on young people of these social problems, especially as they are manifested in the city's schools.

Participants identified a number of correctives to these sources of poor mental health. What helps individuals recover, they suggested, ranges from healthy habits to medication and counseling to prayer to "cultural healing practices" like herbal preparations to positive thinking to "try[ing] to get [people] out [and involved] in the community," with interpersonal support from family, friends, or professionals—what one Somali family member described as "support, love, and patience"—playing a large role in all of these interventions. But participants also spoke about the need to address the social problems they saw weakening families and communities. Specifically, they emphasized the need for communities and government to develop programs

that restore dignity and social connection to individuals, families, and communities. They identified education, employment, housing, and income as particularly important to preventing mental health problems and promoting good mental health.

Formal mental health services were perceived as problematic by most of the focus group participants. Except for a few very savvy family members, people appeared to have little knowledge or information about what services or treatments were available or how they could access them. The downtown Toronto location of many services was perceived as inconvenient, largely out of reach for residents of the east or west ends of the city. Participants who had used services, or knew people who had, spoke of the ways in which they were misunderstood or rejected by service providers who lacked knowledge of their cultures and could not speak to them in their own languages. In one of the Somali groups, participants expressed a belief that mainstream services were "only for white people." Similarly, a Caribbean family member described how one had to see oneself "as a Canadian" in order to figure out how to use the mental health system. To overcome these barriers, participants wanted to see services developed and controlled by their own cultural-linguistic communities.

Participants described mental health/mental illness as something they started hearing about only after arriving in Canada. (There was some implication that mental illness was something both constructed by Canadian ways of thinking and created by the living conditions experienced by immigrants to Canada.) At home, they explained, everyone knew of people who were "crazy" or "mad," but people didn't talk about it. Unfortunately, most participants reported that in Canada, too, attitudes in their cultural-linguistic communities toward people experiencing mental health problems were marked by both silence and stigma. Mental illness was described as a taboo subject. Participants who had experienced mental health problems, or had family members who did, felt that their communities cared little about them and offered them little acknowledgment or support. Several parents talked about being urged by family and friends to abandon their children when it seemed that their mental health problems might be intractable.

The findings from the focus group and the discussions among the members of the community of practice are mutually reinforcing. Together, they point to a need for a "recovery-oriented" mental health system to attend to a collective and holistic definition of mental health, to the social determinants of mental health, and to matters of access.

The Community Forum

In the facilitated discussion at the community forum attendees were asked to respond to three broad questions: What are your comments or suggestions about the project and/or the model? What recommendations should come from this work? What should be the next steps for the community of practice?

In general, participants were enthusiastic about the project and thought that the model was useful. They drew upon their own experiences to point out ways in which the project work might be extended and the model improved. For example, people talked about the need to gather data from more cultural-linguistic communities and to conduct more analysis about the different issues facing men and women and about the issues facing elders in these communities. There was some discussion of the need to look at cultural-linguistic communities living in rural areas and a suggestion to do a finer grained analysis of similarities and differences between cultural-linguistic community members from different generations. One person made a very specific suggestion about the visual representation of the model, which has been integrated into this report. Finally, another participant suggested that the model be taken back to the cultural-linguistic communities for their feedback.

Several attendees raised challenges to parts of the model that they found problematic. One person asked how the notion of collaborative team work around individuals as it is currently being practiced could be reconciled with idea of collaborative team work around collectives that is embedded in the model. A number of people questioned how broadly or narrowly community should be conceptualized. Another attendee noted that the model's focus on community was somewhat at odds with the empirical finding that many individuals and families who are experiencing mental health problems feel isolated and alienated from their communities. In a written comment, a participant asked how improving the accessibility of services would help when cultural-linguistic community members are often reluctant to use formal services because of the stigma. One audience member expressed concern that the model still required people to be labeled (as mentally ill) in order to receive needed services.

There was some discussion about the idea of recovery in general. One participant endorsed the importance of hope to the process of recovery, but noted the ways in which ODSP and medication use stand as barriers to people feeling hopeful. Another argued that mental health services should not be seen as central to recovery, and that the language should be changed (from "recovery-oriented" to "recovery-supporting") to reflect that fact. A third spoke to the importance of including consumer/survivor expertise in all policy and practice initiatives.

The audience's suggested recommendations similarly reflected the diversity of their own positions and standpoints. There was a recommendation to take stock of what is already working in the mental health system (and, by extension, in cultural-linguistic communities), in order to build from success and make the prospect of change less overwhelming. There was discussion of the need to recruit and train more providers from within cultural-linguistic communities, and of ways in which mainstream providers should get more education and training to equip them to work in culturally competent ways. One attendee raised the issue of technology and how it might be marshaled to improve services—for example, improve access to interpretation through the use of videoconferencing. Partnerships—with families and community groups were seen as key. Several participants noted that such partnerships could help to "create space" for recovery outside of clinical environments for example in neighbourhood centres and spiritual and religious centres. There was a suggestion that the mental health system develop partnerships with other sectors that are experiencing similar issues—work that could be supported by financial incentives from government. Audience members also pointed out ways in which the current climate of reform at both the federal and provincial levels was creating both opportunities and threats. Finally, participants talked about how communities—and community strengths and needs—should be placed at the centre of any effort to promote recovery in cultural-linguistic communities.

Many possible next steps for the community of practice may be inferred from this summary of the discussion. First, the community of practice should consider engaging in more research. Second, it should look at finding concrete ways to promote system responsiveness and community resilience and capacity. Specific strategies might include educational initiatives or partnership-building activities. It was also clear from the community forum that the Toronto Recovery and Cultural Diversity community of practice has contributions to make to the current discussions about mental health system reform at the provincial and federal levels. The community of practice should consider how these contributions can be made most effectively.

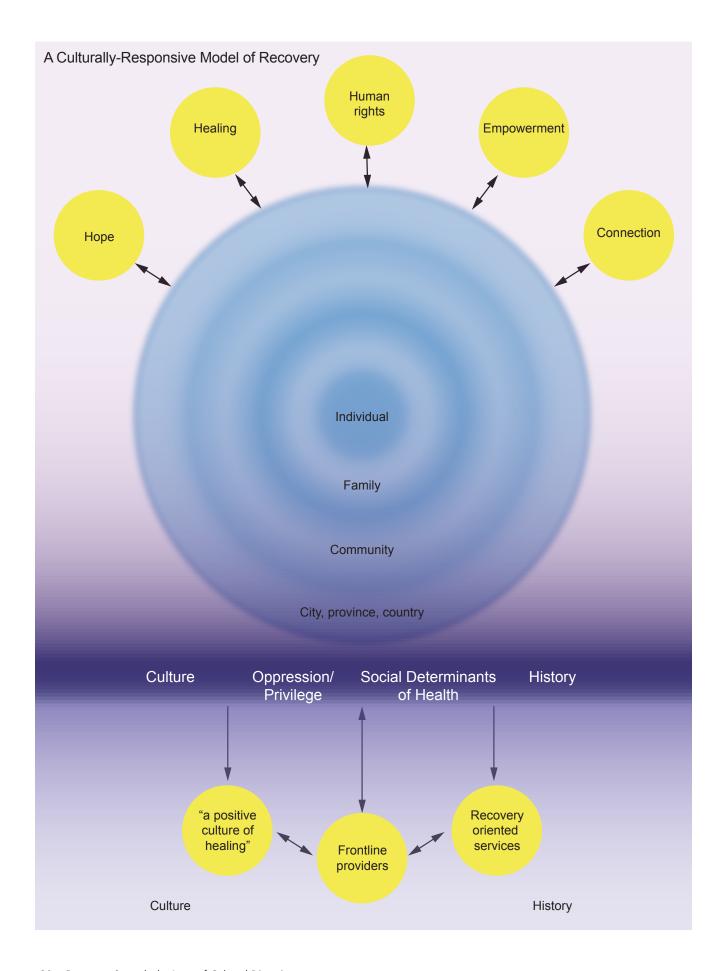
The community forum appears to have been successful in making the work of the community of practice visible to a wider audience. Attendees were engaged, and their suggestions for the project/model and the future work of the community of practice were very valuable. A number of individuals left their contact information, indicating that they wanted copies of the materials presented at the forum, or that they wished to be informed of future workshops, or that they themselves wanted to join the community of practice.

A Culturally-Responsive Model of Recovery

The main points to emerge from the project activities were:

- A robust definition of culture
- A focus on the collective, not the individual
- The importance of the social determinants of health
- An understanding of recovery processes in context
- A recognition that recovery can happen apart from the mental health system
- The obligation of mental health system to be responsive (not directive)
- The key position of the frontline provider

Taking account of these points, the community of practice developed the culturally-responsive model of recovery shown below.



Several points are key to this new model. First, it recognizes that individuals exist in a web of relations constituted by the family, community, and larger socio-political units, such as cities, provinces, and countries. Second, it places culture, systems of oppression and privilege, the social determinants of health, and history in the foreground, positing that these factors are central to recovery. Third, it sees recovery as a collection of processes that occur within the web of relations, contextualized by culture, oppression and privilege, the social determinants of health, and history—the top part of the model—and conceptualizes the mental health system—the bottom part of the model—as potentially supportive of recovery, but not necessarily central to it. Fourth, it notes that the mental health system itself has a culture and history. And fifth, it puts the frontline provider into the model explicitly, thus recognizing that role as critical to bridging the mental health system and the arenas in which recovery takes place.

Individuals, families, and communities exist in complex and interdependent states of vulnerability and resilience. The risk and protective factors that either promote or hinder good mental health may reside at the individual, family, or community levels, or may cut across these levels. Policy commitments made by cities, provinces, or countries serve either to heighten vulnerability or to support resilience. For example, discussions among the focus group participants revealed the ways in which the migration process—the personal and social stresses and strains of leaving home to live in a new and strange place—led to increased levels of distress for individuals, families, and communities. Their experiences suggest that there are ways in which immigration and resettlement policies might be changed to provide more initial support in the areas of income, housing, and employment, thus reducing the vulnerability of immigrant communities and increasing their natural resilience.

Recovery thus refers not just to the processes of hope, healing, empowerment, and connection occurring at the individual level, but to the need for these processes to work at several levels. Hope encompasses not only an individual's belief that a better life is possible for himself, but a broader sense of opportunity for an entire community. Healing means not just that an individual's distress is lessened, but that his extended family is able to move toward better health and functioning. Empowerment speaks both to parents' wish to be able to act so as to create a better life for their children, and also to the need for communities to be active participants in making decisions about the government-run systems with which they interact. The process of connection links individuals, families, communities, and larger socio-political units, promoting a sense of belonging that serves as a corrective to the abandonment, isolation, and loneliness that the focus group participants described so vividly.

The model's foregrounded conditions of culture, oppression and privilege, social determinants of health, and history structure both the problems that individuals, families, and communities are recovering from and the solutions that can help to promote their hope, healing, empowerment,

and connection. For example, in refugee communities and in communities of colour, the daily lives of individuals, families, and communities are often affected by complicated legacies and current experiences of violence, deprivation, and discrimination. Recovery requires that there be a broader societal recognition of these legacies and experiences, with interventions directed at ameliorating the effects of past violations and preventing future violations. The fifth recovery process of human rights is set in motion when state-based entities are accountable for designing and implementing policies and services that reflect such rights-based responses.

In this model, then, the mental health system (as one of a number of state-based entities) should support recovery by conducting its business of prevention, treatment, and rehabilitation in ways that promote hope, healing, empowerment, connection, and human rights. Recoveryoriented services need to address families and communities—not just individuals. "A positive culture of healing" within service provision organizations requires attention to the geographic, cultural, and linguistic accessibility and acceptability of services. The frontline provider plays a key role by bridging the cultures of clients and the culture of the mental health system. It is essential that the individuals placed in these positions be equipped with the knowledge, skills, and competencies—particularly those pertaining to culture, oppression/privilege, the social determinants of health, and history—they need to negotiate both the system and the relational web of individuals, families, and communities, and that the mental health system recognize the boundary-spanning nature of their work and provide the flexibility and resources needed to support it. Although somewhat beyond the scope of this report, it is important to note that working in this model will require that the individuals and organizations that make up the mental health system confront those aspects of the system's culture and history that may stand as barriers to recovery-oriented transformation.

Appendix A—Terms of Reference

What is a Community of Practice?

Communities of practice are groups of people who have common interests and commitments and come together in order to engage "in collaborative learning and knowledge sharing activities, group projects, and networking events that meet individual, group, and organizational goals while creating an increasing cycle of participation and contribution." (Source: *Community of Practice Design Guide* 2004, produced by iCohere, Inc.)

Role of the Community of Practice

- In general, the community of practice will serve as critical informants at all phases of the project, providing input and sharing knowledge, experience, and expertise to assist in developing a firm understanding of the recovery and cultural diversity.
- Meetings will be co-chaired by the Principal Investigators.
- Co-chairs will be responsible for the agenda preparations, room booking, and will attempt ensure that there is representation from all the stakeholders.
- Community of practice members will meet approximately 8 times throughout the yearlong project.

Community of Practice Working Principles and Values

- Safe Space: we will strive to create a climate for open, honest and constructive dialogue that encourages a broad range of input.
- One does not represent the many: we are all coming to this community of practice with varying levels of lived experiences and knowledge. We acknowledge that one member is not expected to articulate the power dynamics, history, culture, and experiences of oppression and current group status of a particular group.
- Invisible social identities: we are aware that some social or group identities are invisible. Religion, sexual orientation, social class, ethnicity, and disability status are some examples of groups that may be represented in our community of practice, but are not visible to the eye.
- The influence of our social identities: we acknowledge that our social identities shape our views and ways of expressing those views. This community of practice strives to value our diversity and acknowledge the impact of power on our views and forms of expression.
- Learning Opportunities: we will view and use difficult situations as an opportunity to learn together.

Principles

- The experience of recovery from mental illness is individually defined;
- Culture impacts individual's understanding of the illness and possible solutions, as well as attitudes toward seeking help from health care providers
- While culture impacts on conceptualization of issues and definition of mental wellness and recovery, the community of practice will operate with the understanding that the systems of oppressions are multi- faceted and each aspect impacts on the recovery of individuals. Each of the socio-political identities will be considered.

Appendix B—Research Protocol

It is now some fifteen years since William Anthony first called for recovery to become the guiding vision of mental health systems. Anthony defined recovery as "a deeply personal, unique process of changing one's attitudes, values, feelings, goals, skills and/or roles...a way of living a satisfying, hopeful, and contributing life even with limitations caused by illness." His call prompted a worldwide flurry of research and policy development. Attention to recovery in Canada has grown steadily since the early years of the new millennium. Many provincial mental health system reform bodies in Ontario endorsed the concept, as have the Kirby Commission, the Mental Health Commission of Canada, and a number of Toronto-area Local Health Integration Networks. Increasingly, community mental health organizations in Toronto are seeking to align their policies and practices with a recovery vision and principles.

Much extant research on recovery has been focused on developing models that can be used to provide guidance for the design and delivery of recovery-oriented services. These first generation models emphasize what is common across individuals. They describe general processes, but have not sought to particularize these processes to specific groups or communities, nor have they gone very far in integrating broader knowledge about the social determinants of mental health and mental illness.

It is generally accepted that the individual's personal experience (or worldview) and how the person negotiates his or her own experience of illness is likely to affect his or her progress towards recovery. Therefore, any comprehensive recovery model has to integrate cultural attitudes, as well as the context of the social situations people find themselves in. The delivery of high-quality mental health care that is accessible, effective, and recovery oriented requires providers to have a deeper understanding of the socio-cultural background of consumer/survivors and the environments in which they live. There are two basic assumptions that this project will operate from: 1) the experience of recovery from mental illness is individually defined; and 2) that culture impacts an individual's understanding of the illness and possible solutions, as well as attitudes toward seeking help from health care providers. Clearly there is an increasing need for researchers to develop more sophisticated service delivery models which reflect this broader definition of recovery.

^{1.} Anthony, W.A. (1993). "Recovery from Mental Illness: The Guiding Vision of the Mental Health System in the 1990s" *Psychosocial Rehabilitation Journal* 16 (4): 11-23.

Community Resource Connections of Toronto (CRCT) has been working closely with our partners and other stakeholders to improve access to recovery oriented services for those traditionally excluded. As part of that strategy, CRCT recently held several trainings in the area of recovery for both service providers and consumer/survivors. The service providers that work with diverse clients and consumer/survivors from diverse communities overwhelmingly gave feedback that some of the strategies were not culturally appropriate. It is clear that there is an identified need to incorporate socio-cultural diversity into recovery oriented strategies. We believe that this project will address that need.

Aims and Objectives

The overall aims of this project, a collaboration between CRCT and the Health Systems Research and Consulting Unit at the Centre for Addiction and Mental Health (CAMH), will be to examine recovery through a cultural diversity lens in order to develop a second generation model of recovery that, when implemented, will improve the ability of community mental health organizations to design and deliver recovery-oriented services that are relevant and responsive to culturally diverse Toronto. The project will have three main objectives:

- To nurture a recovery and cultural diversity "community of practice" in the city of Toronto.
- To use a community-based participatory research approach to critique and adapt an existing model of recovery.
- To begin to plan for how the adapted model might be applied to the design and delivery of community mental health programs and services in Toronto.

Project Design

Overview

The project will have three phases. In the first, CRCT will invite mental health providers and other organizations serving diverse populations in Toronto (e.g., immigrant and refugee-serving agencies) with a stake in developing culturally appropriate recovery model of services to attend a series of meetings. The hope is to engage an interdisciplinary and culturally diverse group of service providers, numbering 12-20 people, in a community of practice devoted to exploration and action related to recovery and cultural diversity. This community of practice will serve as critical informants at all phases of the project. At the first meeting, participants will have a general discussion of recovery and recovery-based services. At the second meeting, participants

^{2.} Communities of practice are groups of people who have common interests and commitments and come together in order to engage "in collaborative learning and knowledge sharing activities, group projects, and networking events that meet individual, group, and organizational goals while creating an increasing cycle of participation and contribution." (Source: Community of Practice Design Guide 2004, produced by iCohere, Inc.)

will engage in a structured critique of an existing model of recovery—the conceptual model developed by Jacobson and Greenley.³ The exercise will lead the group to identify the strengths and weaknesses of the model for use in culturally diverse communities. In the second phase, the focus will turn to community-based participatory research. Beginning at its third meeting, the nascent community of practice will be invited to design a series of focus groups in which service users and family members from diverse communities can talk about their own experiences of mental health promotion and recovery from mental illness. After the focus groups have been completed, transcribed, and translated, the community of practice will contribute to the analysis of data resulting from the focus groups. The goal will be to use the data (and the results of their own critique) to modify the conceptual model of recovery in order to make it more relevant and responsive to the needs and contexts of culturally diverse communities in Toronto. In the third phase, members of the community of practice will discuss how to incorporate the enhanced model into their current work and how it might be used to develop new programming at the partner agencies. At the conclusion of the project, the community of practice will invite a large group of stakeholders to a community forum at which the model will be presented and the possibilities for its wider implementation discussed.

Data Collection

As indicated, this study will gather data using focus groups with service users and family members of service users. There will be 7 focus groups: One each with service users and family members from the Somali community—conducted in Somali. One each with service users and family members from the Tamil community—conducted in Tamil. One each with service users and family members from the Caribbean community—conducted in English. The seventh group will be composed of youth (age 18-25) from all three communities; it will be conducted in English. These communities were selected by the Community of Practice for several reasons: They represent cultural-linguistic groups with populations of significant size in Toronto. They have varying histories and experiences of immigration and have been in Canada for varying amounts of time. They have varying degrees of access to community mental health services. Finally, members of the Community of Practice have contacts with organizations that provide services to these communities, which will facilitate recruitment.

Each focus group will have 6-12 participants and will last approximately 90 minutes. This size and length are typical for focus groups and are believed to yield maximum information. Groups will be held in places convenient for participants and accessible by public transit. Specific locations will be determined after ethical approval is obtained, but likely prospects include community centres,

^{3.} Jacobson, N. and Greenley, D. (2001) "What Is Recovery? A Conceptual Model and Explication" *Psychiatric Services* 52 (4), 482-485. In the model, recovery refers to both internal conditions experienced by persons who describe themselves as being in recovery—hope, healing, empowerment, and connection—and external conditions that facilitate recovery—implementation of human rights principles, a "positive culture of healing" in service provision organizations, and recovery-oriented services.

community health centres, or the CRCT downtown offices. Participants will receive an honorarium of \$30 in acknowledgment of their time and will also be given TTC tokens to cover their travel.

Each group will be conducted by two facilitators, who will be responsible for recruiting the participants, organizing the group (reserving space, procuring refreshments, etc.), obtaining informed consent, and conducting the group. Facilitators will not be direct service providers. Facilitators will be fluent in both English and the language in which the group is conducted. All groups will be tape recorded. The facilitators will be responsible for producing a transcript of the proceedings in English. All facilitators will receive training from the principal and co-investigator in conducting focus groups. The co-investigator will be available to provide support to the facilitators in recruiting participants and organizing the groups.

The "focus" of the focus groups will be on how participants understand recovery and mental health promotion. The questions that will be posed to the group are:

- What is mental health?
- What does it mean for a person to be mentally healthy?
- How can a person achieve good mental health?
- What supports do people need to become and stay mentally healthy?
- Where do people find these supports?
- What does it mean to have poor mental health?
- What helps a person who is not mentally health to get better?
- What changes would you like to see in mental health services?
- What can your culture teach about mental health? [Prompt: What might service providers or the wider community learn about mental health from your culture?]
- Is there anything we haven't discussed that is important for us to talk about before we finish?

At the conclusion of each focus group, participants will be asked to complete a short demographic questionnaire. This information will be used to describe the total sample. For bookkeeping purposes, participants will also be asked to sign a form acknowledging receipt of the honorarium and the TTC tokens. Participants will also be offered the opportunity to sign up to receive an invitation to the community forum that will be held at the conclusion of the project.

Analysis

All transcripts will be read by the investigator and the co-investigator, who will extract themes and relevant excerpts of the text. The themes and anonymized transcript excerpts will be presented to the Community of Practice for their review and feedback, which the investigators will use to re-view the data. Final themes from the focus groups will be combined with the results of the Community of Practice's structured critique of the Jacobson and Greenley model of recovery to develop an enhanced model of recovery that adequately addresses issues of cultural diversity.

Recruitment

Members of the Community of Practice and the investigators will ask contacts at mental health agencies, organizations serving immigrants and refugees, faith groups, and other organizations to post and to pass on project information flyers to clients who are eligible for the focus groups and might be interested in participating. The flyers will include information about the purpose of the focus groups, the type of participants sought, a description of what will transpire at the focus groups, basic information about voluntariness and confidentiality, information about the date, time, and place where the group will be held, and a phone number to call to RSVP or to get more information. Potential participants will call the telephone number, which will be directed to voicemail at CRCT. A recorded message will repeat the salient information about the study and prompt callers either to RSVP for a specific group or to leave a message if they want to learn more about the study and the groups. Facilitators will return any messages. The flyer will be translated into the relevant languages and the voicemail messages and the returned telephone calls will be in the participants' languages. (Note: separate flyers will be prepared in each language, but all will be translated from the English version, which is included in this package.)

Ethics and Ethical Review

All focus groups will begin with an informed consent procedure and another opportunity for participants to ask questions. Participants will provide written consent using consent forms that have been translated into the relevant languages. Should a participant become upset during the focus group, all facilitators will be provided with a short list of resources that participants can contact for help.

All signed consent forms and honorarium receipts will be stored in a locked filing cabinet in a secure location. Hard copy transcripts will be stored in a locked filing cabinet in a secure location and electronic files (including audio files) will be stored on password protected computers. If data are distributed—for example, if anonymized data are presented to members of the Community of Practice to obtain their feedback on analysis—they will be collected at the conclusion of their use.

External confidentiality will be guarded. Transcripts will be redacted for proper names. No individual names will be used in any reports produced. Focus group participants will be cautioned that although participants will be urged to maintain confidentiality about what they see and hear in the focus group, the investigators cannot control what people choose to say.

Both investigators have completed ethics training. All facilitators (who have not yet been hired) will be trained in ethics procedures for this study, and will complete the TCPS online training module.

Dissemination

The project will make use of multiple modes of dissemination, most of which are built into the very design of its activities. First, a key objective of the project is to build a community of practice devoted to issues of recovery and cultural diversity in Toronto. By their very nature, such communities of practice serve a dissemination function, as their members return to their own organizations and become champions for the sharing and implementation of new knowledge. Second, the project will culminate with a community forum that will bring together stakeholders from across the city of Toronto, including consumer/survivors, family members, service providers, researchers, and LHIN representatives. At this forum, the enhanced model of recovery will be presented and the participants will engage in discussions about how it might be implemented in community mental health programming. Third, the project partners and members of the community of practice will collaborate in developing a conference presentation and an article, both of which will be targeted to venues where they are likely to be seen by a broad audience of practitioners, researchers, and policymakers—for example, at the Canadian Mental Health Association-Ontario's annual conference and in the *Psychiatric Rehabilitation Journal* or the *Canadian Journal of Community Mental Health*.

Appendix C—Agenda: Focus Group Facilitator Training

September 24, 2009

9:00-9:15—Introductions

9:15-10:00

Project Background (Deqa)

- Recovery in Community Mental Health in Ontario
- Project Impetus
- Project Goals
- Project Activities

Recovery Background (Nora)

- Introduction to Jacobson & Greenley model
- Main points from Community of Practice Discussions
- What we hope focus groups will contribute

10:00-11:00—Focus Groups 101 (Nora)

- What
- How
- Troubleshooting
- Ethics

Break

11:15-12:15—Review of Focus Group Question Guide (Nora and Dega)

Lunch

1:15-2:15—Research Procedures (Dega)

- Recruitment
- Day-of procedures
- Roles of facilitator and notetaker
- Paperwork (consent forms, demographic questionnaires, honoraria and receipts)
- Ethics

Break

2:30-3:00—Producing a Transcript (Nora)

3:00-5:00—Online Tri-Council Ethics Training http://ethics.gc.ca/english/tutorial/

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