Building a Culture of Recovery: A project in system development and education

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The mainstream interpretation of mental illness comprises a spectrum of disorders and conditions that effect mood, thinking and behaviour. This interpretation is illness-based and speaks to various levels of disability requiring "care" and corrective treatment by professional service providers. Typical mainstream interventions to treat mental illness include medications as well as a variety of verbal and activity-oriented interventions, led by professional clinicians in either individual or group contexts. These interventions, by definition, place the "patient" in a subordinate and excluded position with respect to the services they wish, they require and they deserve. Adopting a *Culture of Recovery* shifts and transforms the balance of power to establish an interdependent framework for relationships.

A transformed set of relationships in mental health service must deviate from the accepted concept of *care* or *helping*, which implies an imbalance of power and self-determination. Recovery rebuilds the knowledge base as a platform of equity, empowerment and interdependence, to realize a commitment to wellness and recovery. Transformation, particularly the radical, operational shift in knowledge and power required to establish a *Culture of Recovery* requires a framework of safe debate and participatory engagement. Fulsome debate is required to reveal and challenge the intersections of power embedded in the language and intention of: illness versus wellness and helper or carer versus partner. This debate must expose the scope and impact of the power structures and relationships, including the need for inclusion and voice. Knowledge is required to develop, support and successfully embed the philosophy of recovery and empowerment and to disarm and dismantle existing relations of intentional and unintentional domination and resistance.

Engaging people in recovery[1] with efforts to shift the matrix of knowledge and power requires substantial sensitivity. Wholesale and honest participation by people in recovery, regarding services that may not have met expectations from people who may be future *caregivers,* may be perceived as too dangerous. Not only does skill and comfort restrict the willingness of people in recovery to shake the tree of traditional power, but as Everett (2000) suggests: to challenge both the "rational scientific truth" and "higher authority of doing good" is obviously daunting. The observation by Nabokov from his novel Bending Sinister, and resurrected by Nafisi in Reading Lolita in Tehran (2004) is particularly apt for people in recovery who challenge authority: "curiosity is insubordination in its simplest form".

[1] Language is also a factor that can either leverage or sustain power and affect engagement. For instance, the medical model, and especially hospital-based services, refer to the people they "care for" as "patients". Community based services often refer to the same people as "clients". The term "consumer" has been adopted in an effort to shift the label and the term "survivor" has been used to indicate the reality of having literally survived the experience of both the experience of mental health problem or diagnosis, and its treatment. For the purposes of this paper, both as a strategy to further shift the attitude and to promote a hopeful and wellness oriented perspective, the term "person or people in recovery" has been used. This term challenges the existing usage and therefore is consistent with the critical perspective inherent in Recovery as a lifestyle model.

Transforming systems of power is not an easy process; it cannot be implemented by simply applying a set of prescribed objectives or activities. Transformation requires critical engagement to review and challenge accepted and established beliefs, practices and structures. Critical theory challenges the basic structure of society, especially the structures which generate and sustain the factors that marginalize people (Hinchey, 2001; McLaren & Giarelli, 1995) – in this case people who have experienced mental illness are seeking to transform the matrix of power and knowledge in the mental health service system. The development of critical thinking requires reflection, challenging of the status quo and a tolerance to the ambiguity and uncertainty of analysis and argument (Brookfield, 1987). The following questions focus the critique of power: who stands to gain from maintaining the status quo; who drives the process; and who is included and heard. Power must be understood in order to propose change. What knowledge and experience do people with mental illness need to infiltrate, influence and transform decision-making?

Re-balancing power from the people who hold professional and positional power to people in recovery is not a simple exercise of correcting the hierarchy. The problematic (Smith, 1984) that underlies this proposal assumes that power is a commodity that can be easily transferred from those <u>with</u> it to those <u>without</u> it; that the powerful generously *empower* the powerless. The preferred concept, embedded in Recovery philosophy, is that of *empowerment* which transforms and improvises power from within the experience of people in recovery by addressing and acquiring power, through education, as it intersects with knowledge and skill (Foucault, 1980; hooks, 1994; Jacobson, 2004).

Education supports the journey of transition, awareness and empowerment, using the matrix of knowledge and power as both the restrictive element that sustains docility and obedience of *patients* in their traditional role as well as a tool to transform and challenge the structures and relationships that sustain this perception. Two interrelated strategies to critically engage and educate people about recovery, empowerment and service partnership are described below.

1. *Like Minds: Peer Support Education* is a comprehensive recovery education program designed and delivered by people in recovery. The curriculum creates a space for learning that promotes curiosity, critique, discussion and debate. Peer educators, in their legitimate role facilitating knowledge exchange, assign the hope essential in a culture of recovery. Embedded in the program is a strong Aboriginal orientation and specific First Nations teachings. Seven peer educators were financed through a Trillium Grant to develop the curriculum and plan their delivery strategies. Grant funding also permitted free access to the program for participants as well as offsetting expenses related to travel to the program.

Using a framework of critique presented by Foucault (1980, 1988), collaborative questioning and challenges to process that are not only free of reprisal, but are welcomed and embraced, form a deeper approach to participation. The intent is to effectively reduce the risk for people in recovery to be curious and insubordinate, to question, to assume leadership roles and therefore to contribute to actively evaluating and managing the mental health system. The curriculum is intended to increase theoretical knowledge regarding process and structure as well as building and improving skills related to reflective awareness, assertiveness and

productive argumentation to support the transfer of legitimacy from an external authority to oneself.

Facilitated dialogue addresses the legitimacy of expertise related to personal and lived experience rather than expertise related to professional credential. The curriculum articulates the often subtle but significant differences between peer support and mainstream mental health and addiction services, and how these two areas of services can become interdependent. Keeping in mind the important relationship Foucault proposes between knowledge and power, each module of Like Minds: Peer Support Education is intended to provide background knowledge and build understanding about the role and value of peers in recovery and leadership.

The program includes the following content: orientation to, and education about, the philosophy and background of recovery and peer support; issues related to role adjustment and transition; as well as relationship skills such as communication; conflict management, facilitation; motivation and crisis intervention. Education regarding personal skills included: self care; boundaries; and organization and time management. One module of the curriculum is designed to increase knowledge of the technical language and treatment perspective of mainstream partners.

Like Minds: Peer Support Education was delivered to 44 people in recovery; one consolidated follow up session was held. A comprehensive evaluation indicated that participants attended because they were interested in becoming peer supporters or to enhance their current skills and knowledge and to feel more comfortable in their current job. Participants represented many kinds of peer support; nearly half (45%) of the participants worked in mainstream teams. Membership on boards of directors was another way peers supported peers: 23% of participants identified that they were members of mainstream boards of directors or committees and 15% were members of a consumer-run boards of directors or committees. Slightly fewer participants worked in initiatives operated by people with mental illness, or peer run programs. This diversity supported our philosophy of inclusion and broad scope of the curriculum.

The follow up session was attended by 16 participants, 81% of whom were currently providing peer support, with half of those participants employed in paid positions. The evaluation of program effectiveness and utility indicated that the content met or exceeded expectations, it was well delivered, and participants learned new knowledge and skills. Based on the feedback results, which indicated that participants found the program overwhelming and intense, adjustments were made to separate the modules by a few days in order for participants to absorb the volume and complexity of the information.

More importantly, the impact evaluation confirmed the theoretical perspectives described above regarding both the existing premise of power and subordination as well as confirming the effectiveness of transformative strategies achieved through education. The results indicated that 100% of participants reported a better understanding of peer support and 85% of participants currently providing peer support reported feeling more confident in their role after attending the program. Sixty-two per cent of the participants reported that they have a

better understanding of how peer support integrates with mainstream services and 69% of participant's currently providing peer support reported that they place higher value on their role after attending the program. In terms of developing knowledge and skills, 77% of participants currently providing peer support reported they now have more knowledge to do their work and 69% of participants currently providing peer support reported they have more skills now to do their work.

The impact evaluation confirmed that participants appreciated the opportunity to discuss, consider and reflect about the philosophy of peer support, as well as their experience of discrimination and stigma. Participants identified the need for radical change to the mental health and addiction infrastructure and system, including a commitment to have peer support and peer leadership valued with fair remuneration. Participants expressed frustration with the mainstream perspective and recommended that peers provide recovery education to clinical and system power-brokers to demonstrate the value, credibility, and legitimacy of peer support as an equal but distinct partner in service. Participants agreed to the importance of establishing peer support as its own distinct approach to service

Participants also identified changes in their personal awareness and growth during the reflective process; they report that the program raised awareness related to empowerment. The evaluation concludes that recovery education leads to increased interest in and capacity to address imbalances in power and supports personal empowerment. Like Minds: Peer Support Education was experienced by all its participants as an effective educational strategy that raised awareness, and provided a framework to debate and advocate a shift to the balance of power from those who typically hold power to those who have typically been perceived as less capable and therefore less engaged.

2. *Building a Culture of Recovery* is a system development and education project that builds on the recommendations resulting from *Like Minds: Peer Support Education* as well as from the growing recognition of peer support as an emerging best practice in mental health. "Peer support role development and network building" was identified as a priority for the Central East Mental Health Working Group and unspent Mental Health Implementation Task Force funds from the Whitby and Penetanguishene task forces were re-allocated to this project. The geographical area to be served by the project is the Central East Region – which includes: Simcoe County, York Region and Haliburton, Kawartha, Pine Ridge.

The *Peer Support Role Development and Network Building* project, as it was originally named, had two key outcomes: 1) to define and establish the role of peer support, and implement education to develop a peer support service; and 2) to develop a network of "consumer" and family leaders which will initially inform the development of the role of peer support as well as to support and sustain relationships and capacity building for consumers. Ann Thompson, a survivor and recovery educator was engaged as a consultant to this project and a representative steering committee was established comprising leaders of Consumer Survivor Initiatives (CSI), Family Mental Health Initiatives and Ontario Peer Development Initiative. Included also were the co-leads of a parallel public education strategy that is also recovery-based.

One of the challenges that the steering committee considered was the dilemma of increasing capacity for both peer support education and peer support employment in the absence of capacity in the mental health system to accept and sustain it. For instance, the evaluation of Like Minds: Peer Support Education highlighted the need to create a better understanding and acceptance regarding the role of peer support and recovery. People already in peer support roles reported that they experienced frustration with the level of understanding about scope and credibility for peer support as a distinct service. They recommended that people in recovery educate partners about the subtle but significant differences between peer support and mainstream support. They also recommended that the hierarchies that exist be addressed using a focus on recovery.

The steering committee suggested that a strong foundation of value, credibility, and legitimacy of peer support as an equal and complementary service needed to be established before peer support training could be implemented. With this in mind, and with the advice and support of Ann Thompson, a vision was agreed upon that would ensure that the project objectives would be met while expanding the scope of the project to achieve more complete and effective outcomes.

The vision for the project expanded beyond developing and implementing a structure of peer support service and training to transforming the system to embrace a *Culture of Recovery*! The implementation begins with general education for people in recovery and service providers about the philosophy of recovery. Specifically, this education would ensure that there was shared understanding that recovery is not something done to or for people but rather the creation of an environment of hope, opportunity and support. A *Culture of Recovery* is inclusive and equitable so, it addresses the hierarchies and power base, as suggested by current peer supporters.

Recovery, by its nature, requires that people are active and engaged; people in recovery are equal partners in service. To support this cornerstone of recovery, it was agreed that two emerging best practices in self-help and peer support group programs: Wellness Recovery Action Planning (WRAP) and Pathways to Recovery would be embedded in the project, and delivered by peers. A plan to offer "train-the-trainer" programs for these programs in each of the Central East geographical areas is being implemented and the early anecdotal results confirm the expectation that people are experiencing personal growth, interdependence and empowerment. To support the knowledge base and to help access tools, a Recovery Clearing House will also be developed by the end of the project.

The second purpose of the project is to establish a network of leaders who are in recovery. Strength in leadership is an essential component to the system change outcome described above. The more pressing need currently identified by leaders is an interest in learning from and supporting each other and activities to address this wish has become the focus of meeting to date, however, this process is not without its own challenges, including the wide geography and budget constraints of consumer programs which limit availability for face to face meetings.

An emerging issue for leaders in recovery is the discrepancy in leadership styles that exists between how they effectively lead their organization or group from a consensus-based style of leadership, and how they function as a representative leader at democratically-oriented mainstream planning tables. Consultation with provincial leaders in recovery, as well as LHIN partners, has recommended strategies such as a leadership summit, or conference, that draws participants for a focused, time-limited agenda.

The scope of the project has been enlarged from its focus on developing and training the role of peer support to a broader objective of embedding peer support in a transformed service culture. General recovery education, WRAP and Pathways to Recovery, Like Minds: Peer Support Education, and a Recovery Clearing House will form the framework for this transformation – and it will support a more effective realization of the project outcomes. A comprehensive evaluation of the project outcome and impact will be undertaken. Specifically, the impact of the recovery education programs will be evaluated to assess changes in capacity and practice to support recovery as well as assessments related to perceptions of autonomy and wellness for people in recovery. It is anticipated that this evaluation will both identify areas that strengthen the approach and outcomes as well as to support ongoing sustainability for the critical work of shifting the culture in terms of bias and power.

Despite what we choose to identify as primarily good intentions, the mental health system has perpetuated a hierarchy of power that places recipients of service in a subordinate position that excludes them from meaningful participation in service planning and delivery. A theoretical perspective of illness and deficit has supported the belief that people "with mental illness" are neither capable of nor willing to engage in critique of the system. More importantly, challenging the hierarchies of power bears risks for people in recovery who may wish to challenge structures and relationships that are too great to safely consider. "Consumerism" (Tosh, Ralph and Campbell, 2000), the advocacy movement that emerged from within the ranks of people with lived experience with mental illness and the mental health system, has worked to counter the prevailing attitude and the next step, which advances a theoretical perspective of recovery insists on increasing participation, awareness, engagement and finally equity and empowerment.

Both *Like Minds: Peer Support Education* and *Building a Culture of Recovery* are recovery-based education programs that operate an engaged pedagogy and that open a safe and nurturing space where knowledge exchange and acquisition can expose the seat of power and unbind the matrix that sustains both the structure and relationships of power as well as spark and support generative dialogue and debate to reframe and decentre current and accepted power structures. Participants describe their experience with both programs as empowering; they identify increased knowledge, skill, awareness and comfort with respect to their interrelationship with the mental health system as a distinct agent of recovery. Recovery is about hope; and we are all hopeful that we can support a culture of recovery – for everyone!

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