IN MY LIFE
PEER REVIEWED SUBMISSION

Ethics in Peer Support Work

Kate Story, Tanya Shute, Ann Thompson

Kate Storey is experienced in direct service, education and administration in both hospital and community settings. She is a family member; she was diagnosed with depression in 1980 and is "in recovery". She is a doctoral student in the Faculty of Education at the University of Western Ontario with research interests in recovery education and empowerment.

Tanya Shute is Executive Director of the Krasman Centre: a Consumer Survivor Initiative, which embraces a wellness and recovery focus. She is a social activist who identifies as having personal experience with mental health challenges and substance abuse. Her undergraduate degree from York University is in Public Policy and Administration; she is completing her MSW in social policy at Laurentian University.

Ann Thompson is a "survivor/ provider" trained in critical social work at York University, who is exploring the application of recovery principles in programs/organizations supporting consumer/survivors and family members. Ann is a certified Wellness Recovery Action Plan (WRAP) Facilitator and has adapted the WRAP framework to a family setting. She developed the Critical Perspectives in Mental Health curriculum in the Masters Social Work program at York University.

Our society's self congratulatory belief that we are free thinking, compassionate and fair people, who hold all citizens equal and worthy, must be challenged. This is especially so regarding our attitudes toward people who have experienced mental health or substance abuse problems. Our society in general, and our clinical systems in particular, consider people with mental health problems or substance abuse as diseased, disordered and disabled – despite that these labels are social constructions that perpetuate pessimism, segregation and discrimination. Being identified as defective, by one's own self as well as by others, and the inherent discrimination associated with "mental illness" or "addiction" blocks recovery for people and affects engagement with services that could support wellness.

Our social systems, primarily conventional clinical services, are intended to support improvements for people in their care; they are intended to reduce symptoms and change quality of life, yet many people still resist engaging with services and many people also describe dissatisfaction with the level of autonomy and support they experience. Similarly, discrimination, in its many forms, including erosion of identity and extinguished hope, as well as compromised access to housing, employment and education, blocks engagement with services and not only frustrates recovery but blinds people to the possibility of recovery (Sky, 2007).

Advocacy by people dissatisfied with their experience in conventional services (Deegan, 1996; Everett, 2000; Storey, 2007; Tosh, Ralph & Campbell, 2000; Valentine, 1989) and awareness regarding the effects of discrimination experienced by people affected by mental health and substance abuse issues has increased the interest in understanding lived experience more fully, and to advance an agenda of recovery. Transforming a system to a recovery orientation requires willingness to critique and reform the availability, appropriateness and effectiveness of existing services… and this willingness is emerging! However, despite a willingness to explore and propose strategies to re-orient clinical services (Social Care Institute for Excellence, 2007), philosophic tensions remain between people living with mental health and substance abuse problems and researchers, clinicians and policy makers.

People living with mental health and substance abuse problems, and people in recovery[1], want social inclusion. They want environmental necessities and comforts. And they want to transform their own journey to wellness, and to ease the journeys of their peers. Researchers, clinicians and policy makers live a different experience. They require definitive and measurable criteria for recovery outcomes, and they strive to identify and utilize *best* practices to guide their practice. Again, professional, clinical services try to support improvements for people in their care and they hope to reduce symptoms and change quality of life – yet a categorical focus on clinical performance sustains a power base that a recovery philosophy hopes to up-end.

Although mental health services have reformed over time and are more inclusive, the power to restrict liberty and negatively affect identity and esteem remains, and casts a shadow that obscures trust and engagement for people who want to, or who are forced to receive services (Sky, 2007). More recently, peer support services, provided by people with personal experience, are recognized as a critical component for recovery, recognizing the equity and mutuality of partnership relationships, and supporting a recovery agenda; but full commitment to recovery is elusive.

The word *recovery* itself is problematic. It is used in medicine to describe a *cure* or the absence of symptoms related to a diagnosis. A person has recovered when he or she reaches the endpoint along the illness continuum, and they are no longer ill. For instance, when my gall bladder is removed, and my body adapts to the changes in diet, I have recovered from my gall bladder disorder or illness. Recovery, from the medical/clinical perspective is defined as the *progression* from illness to cure or when a person responds to treatment with positive outcomes (Jacobson, 2004). The science of "problem – treatment – effect" underpins the conventional

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clinical model of service. In this model, recovery is the outcome of effort invested by clinicians toward their patients, or clients, to advance their progression along the illness or disability continuum. Notwithstanding that this approach is preferred for acute physical distress, such as my defective gall bladder, it pales in the face of the complex issues and conditions that frame a psychiatric diagnosis.

From the conventional clinical perspective, the fundamental assumption for entry into formal mental health services is that the person has a *problem* and the problem requires intervention to effect positive outcome. Problems are classified using a system of diagnoses that emerge through comprehensive psychiatric or psychological assessment that identifies and categorizes symptoms and deficits demonstrated by the person. A problem-orientation is not damning in and of itself; we all have problems we hope to resolve.

The critique of a problem-orientation rests not only in the singular logic of its design, "problem – treatment – effect", but in its intended or unintended personal attribution of responsibility toward the person with the problem – for instance, the experiences of trauma and poverty affect mental health but the diagnostic logic of the problem orientation shifts responsibility (frequently read as blame) to the person affected. When the problem is long-standing, it is enshrined as a disability and optimism that the person will progress to the far end of the continuum is extinguished. With this belief, conventional service providers are haunted by *guarded hope*.

On the other hand, a new understanding of recovery is emerging that appreciates the perspective of people with lived experience, especially the experience of "consuming" services. For people advocating from this perspective, the word recovery explains the longitudinal process of transformation to wellness. Recovery by its nature resists classification as either outcome or evidence based (Deegan, 1996). In this perspective, recovery apprehends the complex and multidimensional realities and violations inherent in the social and personal conditions that lead to the challenges to mental health. People in recovery are re-claiming the word "recovery" to properly articulate how they wish to engage with services and supports – or not.

Perceiving recovery as a process or a journey, rather than an outcome, is a significant deviation in the appreciation of the meanings ascribed by people *in recovery* compared to people providing clinical services. In her book, *In Recovery*, Nora Jacobson chronicles the design and development of a recovery-oriented system of service in that began in Wisconsin about ten years ago. Her narrative profiles the tensions related to disparities in understanding and appreciating the perceptions of recovery between people in recovery and people who had to re-orient their services to be consistent with the values and principles of recovery (Jacobson, 2004).

Without reiterating this excellent review, it is fair to summarize that although recovery as a framework for *respectful care* has positively influenced plans and designs of mental health systems, it was, and remains, a contested field. Mental health and addiction services are social services. As social structures, services reflect or parallel culture (Stark, 1971; Foucault, 1980; Foucault, 1988). So, to change both service perspective and practice requires the introduction and commitment to an alternative discourse regarding cultural identification, engagement, relationships and outcomes. Changing perspective and practice requires a culture shift: building a *Culture of Recovery*.

The *Building a Culture of Recovery Project (www.cultureofrecovery.org)* is a comprehensive education strategy implemented to advance a transformative recovery agenda for the mental health and addiction system in the main, and to support transformation for people in recovery. It articulates a new set of values and principles consistent with a recovery perspective: autonomy and empowerment; building hope; and learning to live from a perspective of wellness, rather than illness. The attempt to address the tension between the interests of professionals and clinicians, and people in recovery emerged from the impact evaluation of *Like Minds: Peer Support Education*, a recovery education program designed and delivered by people in recovery (Storey, 2007).

Like Minds created a space for learning that promoted curiosity, critique, discussion and debate. Using a framework of critique by Foucault (1980, 1988), peer educators engaged in collaborative questioning and critique where they were not only free of reprisal, but where their observations were welcomed and embraced. Although the primary aim of the program was to prepare people in recovery for the role of peer supporter, the process proved to effectively reduce the risk for people in recovery to be *subordinate*, and it fostered curiosity, questioning, and the assumption of leadership roles that led to recommendations for change in the operation of the service system.

The evaluation also confirmed that participants appreciated the opportunity to discuss, consider and reflect about the philosophy of peer support, as well as their experience of discrimination. Participants identified the need for radical change to the service infrastructure, including a commitment to have peer support and peer leadership valued with fair remuneration. They recommended that peers provide recovery education to clinical and system powerbrokers to demonstrate the value, credibility, and legitimacy of peer support as an equal but distinct partner in service. *Like Minds: Peer Support Education* was experienced as an effective educational strategy that raised awareness, and provided a framework to debate and advocate rebalancing of power from those who typically hold it, to those who have typically been perceived as less capable and therefore less engaged.

Armed with the strength of these enlightened recommendations by emerging recovery advocates, further peer support education was supported with funding 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. An early dilemma was, "Should developing peer support education and employment be a priority in the absence of the capacity within the mental health system to accept and sustain it?" Given this question, the vision for the project expanded beyond developing and implementing a structure of peer support service and training, to the broader goal of transforming the system to embrace a *Culture of Recovery*!

Implementation of the project hinged on a primary commitment to education for people in recovery and service providers to ensure a shared understanding that recovery is not something *done* to or for people, but is rather the creation of an environment of hope, op-

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portunity and support. Recovery, by its nature, requires that people be 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 (Copeland, 1997; Copeland and Mead, 2003) and Pathways to Recovery (Ridgway, 2002)] would be embedded in the project, and delivered by peers using a "train-the-trainer" methodology.

Participants were provided with two opportunities to learn personal recovery support strategies during *Orientation to WRAP* followed by an opportunity for certification as a WRAP facilitator. The evaluation of this educational experience included retrospective self-reflection. Results of the preliminary evaluation of this WRAP education indicates that participants report noticeable transformation toward recovery, especially in terms of understanding "recovery" as a concept and the fostering of hope (www.cultureofrecovery.org). To further support efforts to increase awareness, advance recovery, and decrease discrimination, the project supported the development of a full length documentary produced by Sky Works Charitable Foundation, called "Extra Ordinary People" – a collection of personal portraits that reveal the effects of discrimination and celebrates hope and wellness. This film premiered as the final event at the "Rendezvous with Madness" film festival (November 2007) and is now available with an educational tool kit to support discussion (*www.cultureofrecovery.org*).

Adopting a *Culture of Recovery* first acknowledges and then transforms the balance of power to establish an interdependent framework for relationships. The transformed relationships must deviate from the accepted concept of *care* or *helping*, which implies an imbalance of power. 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 shift in knowledge and power required to establish a *Culture of Recovery*, requires safe and participatory engagement. Fulsome debate will 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 and dismantle existing relations of intentional and unintentional domination and resistance. Knowledge is required to develop, support and successfully embed inclusion and voice.

Engaging people in recovery with efforts to shift the matrix of knowledge and power requires substantial sensitivity. Wholesale and honest participation by people in recovery in discussion with people who may be future caregivers, regarding services that may not meet expectations, 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".

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 assess 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 are seeking to transform the matrix of power and knowledge in the mental health service system. The development of critical thinking requires reflection, challenging the status quo, and tolerance for ambiguity and uncertainty of analysis and argument (Brookfield, 1987). The following questions focus a power critique: "Who stands to gain from maintaining the status quo? Who drives the process? 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 *with it* to those *without* 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, and, using the matrix of knowledge and power, the traction required to sustain reform is strengthened. Knowledge about alternatives positions people to consider and risk change. Equalized power is a tool that transforms the restrictive element that sustains docility and obedience of *patients* in their traditional role, to autonomous challengers of the structures and relationships that sustain perceptions of authority.

Building a Culture of Recovery is a comprehensive recovery education strategy which operates an engaged pedagogy (Hooks, 1994) and that opens 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. The project sparks and supports generative dialogue and alternative discourse to reframe and decentre current and accepted power structures – and re-claim recovery, with all its autonomy, empowerment, hopefulness and wellness! Participants describe their experiences as empowering; they identify increased knowledge, skill, awareness and comfort with respect to their relationship with the mental health system as a distinct agent of recovery. Recovery is about hope; we are hopeful that we can support a culture of recovery – for everyone!

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Footnotes

[1] *Language is an artifact that leverages or sustains power and affects 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 problems 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.*

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Address for Correspondence: *e-mail: kstorey2@uwo.ca*

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