

## **Recovering our Stories: A Small Act of Resistance**

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*ABSTRACT This paper describes a community event organized in response to the appropriation and overreliance on the psychiatric patient “personal story.” The sharing of experiences through stories by individuals who self-identify as having “lived experience” has been central to the history of organizing for change in and outside of the psychiatric system. However, in the last decade, personal stories have increasingly been used by the psychiatric system to bolster research, education, and fundraising interests. We explore how personal stories from consumer/survivors have been harnessed by mental health organizations to further their interests and in so doing have shifted these narrations from “agents of change” towards one of “disability tourism” or “patient porn.” We mark the ethical dilemmas of narrative cooptation and consumption and query how stories of resistance can be reclaimed not as personal recovery narratives but rather as a tool for socio-political change.*

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We all have stories. Many of our stories are deeply personal. Some of our stories are painful, traumatic, hilarious, heroic, bold, banal. Our stories connect us—they reflect who we are and how we relate to one another. Stories are extremely powerful and have the potential to bring us together, to shed light on the injustice committed against us and they lead us to understand that not one of us is alone in this world. But our stories are also a commodity—they help others sell their products, their programs, their services—and sometimes they mine our stories for the details that serve their interests best—and in doing so present us as less than whole. - Becky McFarlane, Recovering Our Stories event, June 2011

## **Introduction**

Sharing experiences through stories or “testimonies” by people who self-identify as having psychiatric disabilities has been central to the history of organizing resistance and change in and outside the psychiatric system (Church, 1995; Cresswell, 2005; Morrison, 2005; *On our Own*, 1980-1990). In the last decade, however, mental health organizations have begun to use and rely on personal stories from users of mental health services—people who are often homeless or struggling to survive below the poverty line. It is now commonplace for mental health organizations to solicit personal stories from clients—typically, about their fall into and subsequent recovery from mental illness. These stories function to garner support from authority figures such as politicians and philanthropists, to build the organizational “brand” regardless of program quality, and to raise operating funds during times of economic constraint.

This paper discusses an event called “Recovering Our Stories” which was held in Toronto, Canada in June 2011 (from this point forward, we refer to event organizers as “the Collective”). It was intended to interrupt the proliferation of this popular type of storytelling within the mental health sector—judging it to be not just problematic but “pornographic.” By pornographic we mean that, while some people reveal their most intimate personal details, others achieve relief through passive watching, while still others profit from the collaboration of those on the front lines in compromised positions. Today storytelling is far from being an unstoppable juggernaut: rather, it is in our hands how stories can be used and abused as sought after commodities. “Writing up” the June event is our call for further action and reflection from other psychiatric survivors/consumers about how to reclaim personal stories and efforts at mobilization.

“People with lived experience” has become the catch-phrase to designate those who speak directly to “living” lives affected by mental illness. But lives are shaped and constructed by social, political, economic, and cultural realities that necessitate an analysis of inequity. Our “small act of resistance” was an imperative: resistance to the hegemonic influence of biomedical determinism that occurs by way of a most personal avenue—self disclosure. We offered people an opportunity to focus discussion on the ability of the mentally ill to

organize and work towards change using a social justice agenda (Crossley, 2006; Fraser, 1987). Just as feminist, anti-colonial, im/migrant, migrant, racialized, disabled, and Aboriginal (First Nations, Metis, and Inuit) activist groups in Canada have worked towards reclaiming subjectivities that are of value, so too has the consumer/survivor movement fought for its worth and dignity.

Our social justice agenda transcends the goals that are commonly assumed to bind mental health mandates and mission statements—locally and nationally. It calls for more than simply working towards improving access to services, increasing peer involvement, bettering client care, and other concerns related to the mental health system. Like the authors of *Mad Pride-Mad Culture*, our agenda “asserts the rights of ‘mad’ people without pleading for minor concessions, but instead changes the world into a fit place for us to live” (Curtis, Dellar, Leslie, & Watson, 2000, p. 8). Grounded in the recognition that there are many ways to “be” and “understand,” our “politics of resistance” fundamentally calls into question the ways in which mental health mandates are normalized and assumed as “truth.”

More pointedly, it questions the ways in which mental health systems have begun to promote their own agendas by co-opting the language of social justice itself. Fraser (1987) has commented that the means of interpretation and communication tied to the cultural imperialism of dominant groups is their ability to express its values, goals and achievements as the norm as well as attaining and sustaining cultural status through these norms. Here, we seek to explore how the resignification of language such as “resilience” and “recovery,” as told through client accounts, is a means by which mental health service systems have been able to absorb resistance accounts, sanitize them, and carry them forward in ways that are useful for them, without disrupting their dominant practices. It is precisely through this recalibration of norms that mental health systems are able to maintain their cultural and economic status which occurs partially through the incorporation of the patient story wherein this incorporation ruptures away from the history of psychiatric survivor storytelling to radicalize, towards one that uses stories to further solidify hegemonic accounts of mental illness.

This disregards the original purpose of storytelling to work towards radical change. The situation is very similar to that of other social action groups, such as non-status migrants, “who are generally denied the right to express themselves as political beings, [however] engage in a political act or an assertion of political subjectivity” (Basok, 2010, p. 99) in order to better organize for change. Psychiatric survivor organizing that attends to broader issues of social justice (discrimination, not stigma; employment; human rights violations) disrupts the traditional focus on the psychiatricized as “mentally ill” patients in need of a cure. It orients away from medical intervention and towards a broader impetus for respecting, responding, and incorporating difference into the social milieu.

## **Stories on Parade and Stagnant Welfare Rates**

How and why did getting the mentally ill to divulge their lives become so pervasive in the last decade? Grappling with that urgent question motivated us to create a forum for larger discussion and exploration. Within the Collective, many were familiar with being asked to speak. Familiar, as well, with being asked quite explicitly for “the story” of diagnosis, treatment and recovery: this by contrast with, for example, being asked to speak of the actual employment/activist work that we do within various settings.

Our initial thoughts on how we might best intervene on this growing practice revolved around the idea of developing a series of workshops for current and future psychiatric survivor/consumer storytellers. We knew that many of the individuals who were active on the storytelling circuit could be quite critical of the broader mental health system and, if given the opportunity, were more than capable of developing a useful critique of this intensifying practice. We thought of venues in which to deliver workshops or educational sessions of this nature. We knew also that there were other psychiatric survivors/consumers who would be interested in engaging in this project, if only because the opportunities for learning within the actual mental health system were few and far between. So, we knew why a set of workshops might be useful and we knew where we wanted to hold them.

The question of content was more challenging. Should the workshops focus on ideological questions, such as, “who profits from your story?” Or should they be practically based and offer “tips,” such as, “how not to say something you will regret later”? Over a number of weeks, our deliberations caused us to shift away from the workshops and towards planning a public event that would include a keynote speaker (American poet and story-teller Eli Clare was our final choice), as well as locally-based individuals who could speak to storytelling within Aboriginal, consumer/survivor, and academic communities. In our view, the three sectors or “circuits” of story solicitation would complement the questions we hoped to raise by the end of the forum.

We favoured a public event over a workshop because we recognized that a workshop directed at consumer/survivors who tell their stories would interrupt only their practice; it would have no impact on those that were soliciting stories (both individuals and institutions). We wanted researchers, service providers, and psychiatric institutions to know that we knew they were using our stories—not in consumer/survivor interest—but for the benefit of professionals. We wanted to make it public so that, at the very least, they might hesitate before they asked us to bare our souls for their gain.

Personal and political storytelling originated with psychiatric survivors who were eager to counter the silence and dehumanization that was core to the experience of being a “mental patient” (Chamberlin, 1978; *On Our Own*, 1980-1990; Reville, 1988; Shimrat, 1997). The consumer/survivor movement fought long and hard to have the voices and narratives of their members understood as politicized accounts, and not just delegitimized rants of people who are routinely dismissed because of diagnosis (Berkenkotter,

2008). In the 1980's and 1990's, psychiatric survivors began to insist that their perspectives represented real knowledge of how the psy-complex worked<sup>1</sup>, and that this knowledge must be taken seriously in public decision-making (for more on the psy-complex see Rose, 1990). Like other social movements, we found venues to speak back to psychiatry (both inter and intra- organizationally) (Crossley, 2006). Over time, these acts of resistance were systematically co-opted as psy industries learned how to manipulate these stories to their own purposes.

In the last decade, as capitalist societies have emphasized the substantial losses in productivity associated with mental illness<sup>2</sup> and the potential profit inherent particularly in pharmacology (Whitaker, 2010), personal stories have entered the marketplace (Jamison, 1997; Steele & Berman, 2001). Campaigns to normalize mental illness feature well-known “talking heads” who use their status and public profile to propagate the message that “it can happen to you.” In Canada, they include broadcasters Shelagh Rogers and Valerie Pringle, singer Steven Page, and Margaret Trudeau.

To popularize the message that mental illness affects us all<sup>3</sup> social service agencies have recently cornered the market on personal storytelling. For a twenty dollar honorarium and a couple of transit tokens, select psychiatric survivors are recruited and paraded in front of institution staff, patients, Boards of Directors, and local politicians in an effort to prove that the golden road to recovery will reveal itself—but only if you take your medication and listen to your mental health care providers. Issues of systemic poverty and discrimination, an appalling lack of choice in services, and mistreatment are conveniently left out of the story. Favoured stories feature the uplifting message that with a little hard work and perseverance, you too can be cured. Common themes include: How this or that service saved my life; how this or that medication saved my life; and how this or that pursuit of a normal existence saved my life. The ubiquitous message is that mental illness is a biological problem and treatment (i.e. pharmaceuticals) the solution. Funding to do critical work that challenges the way the mental health system conducts itself is difficult to find. Quantitative data and statistics take precedence and most philanthropy is dedicated towards research that explores brain functioning or chemistry.<sup>4</sup> Given the dominance of this bio-medical storytelling, rarely are organizational funds directed towards autonomous and critical narratives.

The Recovering our Stories Collective was not sponsored by an organization or institution; all of its activities and products were created by volunteers and through donations in kind. In Ontario, the struggle to be included as full participants in civic engagement began on a shoestring. It came about with the support of volunteers and other allies who were doing social movement organizing in the 1990s (Church & Reville, 1989; Church, 1995; Nelson et al, 2006; Reaume, 2002). The 90s also saw the rise of psychiatric survivor/consumer-run support groups and organizations that stressed the importance of inclusion and consumer/survivor voice within mainstream mental health agencies. Zines, books, and reports were produced by mad people themselves,

independent of mental health institutions (Campbell, 2011). A number of these consumers/survivor organizations have since been defunded and/or absorbed into larger mental health organizations, but the legacy of their practice has made it increasingly difficult to exclude persons with psychiatric disabilities from the formal governance of mental health organizations and institutions (Reville & Church, 2012).

By the late 1990s, practices of “client-centered care” and the involvement of people with “lived experience” became requirements if an organization was to represent itself as a community based or community involved service provider (Bhui, Aubin, & Strathdee, 1998, Crawford, 2001; Department of Health, 1989). At the same time, the methods by which organizations sought participation remained rooted in conservative and paternalistic values. Psychiatric survivors and the more radically marginalized were not recruited; instead, those who called themselves “consumers” and those more or less appeased by the mental health services they had received were the first to be chosen to sit, speak, and represent on various boards, in consultations, and on panels.

While the Collective was well aware that lived experience was important, we were concerned that some lived experiences were not being relayed. Sanitized stories were preferred—but they do little to change the way that agencies function or to address broader issues such as poverty, unemployment and discrimination. These conditions persist despite the work of social service providers, police, government and other powerful institutions capable of implementing systemic change.<sup>5</sup> A pressing item on our agenda was to equip those who were being paid, cajoled, and/or manipulated into storytelling with some basic tools that would enable them to question and/or resist the practice. To acknowledge that, for decades—even centuries—the very institutions that had deliberately and systemically erased the experiences of psychiatric survivors in their charge were suddenly scrambling to squeeze every salacious and gory detail out of their journey to recovery was an exercise in consciousness-raising.

A further complication in the evolution of storytelling lies in the paradoxical gains levered out of research that champions consumer/survivor participation and harnesses discourses of inclusion. As literature and more importantly “evidence” is being constructed as to the importance of inclusion so too are these discourses being co-opted into the flexible agendas of liberalism for its own gains (Cooke & Kothari, 2011; McRuer, 2006). The very research that is supposedly conducted to empower those with psychiatric disabilities (and more generally, across-disability communities) becomes the research which is enveloped into the “talk” of managing the disabled.

For critical researchers wanting to do emancipatory work the challenges are daunting. In the qualitative paradigm, narrative researchers in particular tend to think of themselves as “the good guys.” They are not trading in large scale surveys and cold, hard statistics to make their living. Rather, they are interested in purpose and meaning, and draw on methodologies that attempt to counter “the dominant perspectives representing the hegemonic

interests of ruling groups” (O’Shaughnessy & Krogman, 2012). In general, they take the time to cultivate trust with participants. They are sensitive to power, empathic, even emotional when eliciting various dilemmas of social justice. But often unremarked is how it is precisely this type of researcher who may pose the most threat: the ones who, by their very self-reflexivity have discovered how to be really effective at stealing stories for their own academic gain. Ironically, efforts made to deliver genuine involvement in mental health research, while significant, also demonstrates the need for further reflection on methods and practice.

### **Communications and Social Media as Resistance**

As a Collective, our project was to alert the community to the dangers of storytelling. At a time when language, public debate and opposition are censored or overly regulated, not only by authorities but by the professional helpers who “regulate personhood” (Hook, 2007; Rose, 1990;), the Collective engaged various audiences on this highly taboo subject. From intent to implementation, all of our products (posters, info-cards and a public discussion) were created to resist the technologies that encourage people to tell bio-medical stories. Social media allowed an even broader reach and an expanded dialogue.

In designing the event poster, a major consideration was to ensure that all elements of the design conveyed an aesthetic that would have cross-cutting appeal to not just our primary target audience: people in the radical queer/disability studies arena. We recognized the need to be inviting to a highly diverse group: consumer/survivors who are actively engaged in storytelling (as individuals and in groups); service providers and mental health experts who benefit from survivor narratives; individuals in the disability community who were already concerned about the interests that such voicing serves.

We debated the language we should use to describe those who have had psychiatric encounters. Consumers would speak to service providers, an important constituency that the group agreed was crucial to have in attendance. We wanted to ensure that those who solicit “patient porn”<sup>6</sup> for their organizations were present. At best, we wanted to unsettle the taken-for-granted language of their work. Others pointed out that using the term consumer would alienate the psychiatric survivor/mad/ex-patient movement, and not appeal to the politicized. We bantered back and forth on whether to use “consumer,” “consumer/survivor,” or “psychiatric survivor” to describe those that were telling such stories.

We decided against using “service users” (common in the UK lexicon); “mad” (too radical); “ex-patient” (too antiquated?) for the text of the poster. Finally, one member declared herself unwilling to use consumer just to appeal to service providers. To do so would debase our purpose and ensure that the poster had no political weight for the rest of us. In the interest of creating a poster that we would all be proud to hang on our walls, we settled on, “In

Whose Interest? How psychiatric survivors can use our stories to change the world.” Claiming the word *our* signified that the event was organized mostly by psychiatric survivors. The phrase, “use our stories to change the world,” gave the title an uplifting, hopeful twist. It also acknowledged the potential of our narratives, if used collectively, to challenge power.

For the info-postcard, we chose the slogan, “Hands Off Our Stories.” It was derived in part from an experience in which someone grafted their emotional desires/deficiencies onto the personal narrative of one of our members. “Go get your own agony!” they replied. Another option we tossed around was, “Back off, and get your own story,” cheeky words derived from a sandwich commercial.<sup>7</sup> Both slogans connote what audiences do (and do with) when confronted by pain, oppression, and systemic discrimination in which they are unwittingly or unconsciously implicated.

What audiences do when they listen to a story depends on where they are positioned. Audience members who work within psy service systems often pull on stories in ways that work for them. They also hear in ways that protect them from being implicated in systems the storyteller is naming as oppressive, unjust, or discriminatory. Sherene Razack calls this “stealing the pain of others.” The “pleasures of flinching” allows an audience to vicariously and safely descend into degeneracy, reemerging unscathed, without having to confront their implication and collaboration in the storyteller’s narrative (Razack, 2004; 2007). The gleeful “Hands Off Our Stories” was at once a reclamation of our own life histories (ones that had been relegated to case files and whispers), and a declaration that these “tragedies and triumphs” belonged to us. They could not be claimed by systems of intervention that simultaneously took credit for our recoveries and remained distanced from the “unbeautiful” struggles and resistances that have been unexplored in recent storytelling.

A gaze more familiar to the Freak Shows of the past has been finding its way forward into meetings, fundraisers, and research (Clare, 1999; Fausto-Sterling, 1995; Garland-Thomson, 2009; Longmore, 2005; Garland-Thomson, 1996;). It is a modern day voyeurism whereby, in listening to a cast of characters, spectators continue to justify the “otherness” of madness while curbing the watcher’s anxiety. As late as the mid-20<sup>th</sup> century, visiting asylums for voyeuristic entertainment was a common form of amusement. Joseph Workman, former superintendent for what is now called the Centre for Addictions and Mental Health, once criticized such spectators as “empty-headed visitors” who came to “stare and laugh” at patients (Reaume, 2002, p. 182). Somewhat later, Foucault wrote:

Madness here was erected as spectacle above the silence of the asylums, and it became, for the joy of all, a public scandal. Unreason was hidden away discreetly in houses of confinement, but madness was a continued presence of the world stage, more strikingly than ever before. (2009, p. 144)

Thus, mad stories have become a kind of pornography that is produced and

consumed in the interest of the audience itself. Like those inmates paraded out in the past, the storyteller is barely acknowledged, and rarely appropriately compensated.

In addition to the info-postcard, the Collective created buttons to remind our audience of the nature of this consumption and to encourage conversation beyond the event itself. A local artist created the design; a small circle pin displaying the words *patient porn* stroked out by a red diagonal line. This visual exemplified the use of stories as exploitation as well as the refusal to have stories used as patient porn. A humorous memento, the buttons were a small token from us to the audience, transmitting a simple yet provocative message—and encouraging people to fill out an evaluation form. Enticed by the message, audience members were eager to own such a provocative pin. Some found the graphic language too strong but for the Collective, again, it provoked a notion of resistance.

The front of the info-card featured an image of four hands grasping for a microphone alongside the christened slogan “Hands Off Our Stories.” For the Collective, this image symbolized attempts to reclaim the voice which has been a site of contention and co-optation. But the info-card was also meant to inform. On the reverse was a list of suggestions, written from a critical perspective and intended as a reminder of the potential for stories to be stolen and appropriated by organizations and institutions. Six tips cautioned that:

- Participation is voluntary. You can always say no.
- Ask yourself, who profits from you telling your story?
- What purpose does personal story sharing serve?
- How do large organizations use stories to make material change?
- Story telling as an exercise of labour/work. Do you get paid?
- The internet lasts forever. Because of the technology available today, your interview or story will likely be accessible to the public for a very long time. That includes future employers and landlords.

Finally, the info-cards served to connect Torontonians to the Recovering Our Stories website, email address and Facebook page. The group strategically disseminated the postcards throughout the city, targeting community drop-in centers, institutional settings, university mental health centers, and so on. This distribution launched the communication of ideas between the Collective members and the greater Toronto community. In addition to providing practical advice to potential storytellers, the cards were meant to stir interest leading up to the Recovering Our Stories event.

The Collective also created a website ([www.recoveringourstories.ca](http://www.recoveringourstories.ca)), a Facebook page, an electronic e-invite and a gmail account to manage inquiries. We circulated the posters electronically as well as posting them in hotspots. We drew on our varied personal contacts to ensure that researchers, academics, consumer/survivors, service providers, journalists, critical students, politicians and all who intersect across such nexuses were invited and would spread the word.

## **Interlocking Social Justice: Disability, Race and Queer Politics**

June 28, 2011 was the big day. We chose it to coincide with the anniversary of the Stonewall riots, an informal event on the Toronto LGBTQ Pride schedule. With this political reference, we hoped to stress the importance that resistance struggles have played as vehicles for social change, and to acknowledge the interlocking issues that queer and mad communities face. A few days ahead of time, columnist Helen Henderson (2011) covered the event for the Toronto Star. Her piece got the word out. “Grassroots group takes back patients’ stories,” declared the headline:

Some call it “patient porn,” which is not exactly the same as “disability tourism,” but not totally different either. Both are ways in which the world in general does the quickie exploration tour of the world of disability. We might as easily talk about gender tourism or racial tourism or any other expedition into otherness, any trip into what travelers call unchartered territory. They peak, peep, peer, probe, poke their noses in and come away thinking they have gained perspective. This may or may not be true, but either way the risks are huge for those who find themselves the object of such study, no matter how well-intentioned or how scholarly. (Henderson, 2011)

We held the event on the campus of Ryerson University in Toronto’s downtown core—close to the LGBTQ Pride Toronto activities with easy access for most people. On that rainy afternoon, one of our members welcomed the packed house by articulating the purpose that brought us together. We chose to quote these passages in length out of a respectful attempt to leave our members thoughts intact:

Our Collective came together with very specific goals in mind. We were not interested in establishing another organization—all of us belong to a number of organizations and are engaged in a great many examples of resistance. Here, we wanted to:

- a) Produce some tips for psychiatric survivors who have been asked or who might be asked to share their personal stories—which we have done and which is available at the registration table.
- b) Put on an event that brought together people that represented many different interests to think, listen, and learn about the difference between storytelling as an act of community building or as an act of personal resistance—and the solicitation of personal stories that fit the specific agenda of an institution, organization or agency.
- c) Call attention to the importance of solidarity—by hosting an event that looks at storytelling from different perspectives—recognizing that the kind of “patient porn” that has become prevalent within the psychiatric survivor community is a phenomenon that other marginalized communities can relate and respond to.

Another of our members marked the historical transition from oppositional

storytelling to patient porn:

For the longest time, the mental health system wasn't interested in our stories. Our stories, after all, were the stories of mad people and, therefore, not credible. By the mid- 80s, though, some parts of the mental health system began to think that what we had to say might be of interest. So, in 1985, the Canadian Mental Health Association - National published a pamphlet called "Listening to People who Have Directly Experienced the Mental Health System." As the idea of consumer participation became more popular, more and more of us were invited to tell our stories. Telling our stories didn't make us rich. One storyteller, expecting to receive an honorarium for telling his story, instead was presented with a small bag. In it, he found a pack of cigarettes, a pack of chewing gum and a bag of peanuts. We're not speaking for peanuts anymore. Our stories have gone mainstream.

If you have been selected by the mental health system to tell your story, you will be familiar with people coming up to you and telling you how courageous you are, how you must have been misdiagnosed, how you are a hero for getting out of bed in the morning. If you're like me, you will attempt to set people straight—no, it's not courage, you may say, it's my life—and you will wonder why people have such a hard time getting it. If you're like me, you may wonder, too, if you have become part of the "patient porn" industry. You may be looking to create spaces where you can reclaim your story and tell it in solidarity with others who are seeking social justice.

Many people had come to hear Eli Clare, our keynote speaker. White, disabled, and queer, Eli has a book of essays on disability, queerness and liberation (1999, 2009) and a recent collection of poetry (2007). Proudly claiming a penchant for rabble-rousing," he is a huge draw across the disability and queer communities. We believed that Eli could speak to the political nuances of storytelling in ways that would not alienate our audience. We knew that his presence would attract those who otherwise might spend a summer afternoon elsewhere. Others in the audience were consumers/survivors familiar from other events; many were mental health providers, and there was a strong showing of young students.

The concluding panel of commentators included an academic who tries to use consumer/survivor narratives to elucidate systemic oppression. She argued that researchers:

need to conceptualize our studies outside of the dominant narratives that govern people's lives—the psychiatric narrative, as a prime example. Much of what I read in the community mental health literature fails to question biomedical disease formations. Our studies remain encased in diagnostic categories, even when they enact participant involvement that is quite admirable. These categories are not just debatable; they are being actively contested. We need to weigh in against them, openly, wherever we can.

Following the lead of community-based research, we should be as participatory as possible in the enactment of our studies—working closely not just with people or in sites where we are comfortable but with strong leaders

from politicized organizations and communities who will challenge us to push the envelope. As we do this, we need to know that even impeccable participation is no guarantee against difficulty in working across difference. In our research, if we listen only for the “lived experience” of individuals, and only for processes of illness and recovery—we will miss many other vital storylines. We need to complicate what we are listening for: to listen less for stories of healing and recovery and more for stories of resistance and opposition, collective action and social change.

Our event only touched the surface of a myriad of questions. We have yet to unpack the ways in which stories within the mental health sector perpetuate racism or homophobia. Another one of our invited panelists spoke to the difficulty of relying on “social determinants of health,” a discourse that at its core is meant to address inequity. However, with a focus on “outcomes” based on clinical indicators and standards, are such priorities authentic or do they further shift racialized stories and voices into more comfortable and digestible narratives? Further, intergenerational trauma talk is now also commonplace with its commitment to “healing,” but can that inadvertently coerce familial relations (healing) when it may not be the desired choice? Who benefits from stories of reparation? What psychiatric abuses have yet to be reconciled? And further, as Gorman (2013 forthcoming) has identified, race is still only being discussed as “stigma” or “trauma” in the psychiatric paradigm.

### **Next Steps? “Honour stories. Respect survivors.”**

The Collective had previously decided that some form of feedback, participation and/or criticism from the audience was an important outcome from the day. It would enable us to gauge peoples’ perceptions and engagement with the questions we had raised at the event and identify whether there were others who had similar concerns and questions. It was also meant to guide us in any next steps we might need to take on as a group.

Following the event, an evaluation form was offered at a table near the exit along with a small reward for its completion—the *no patient porn* pins—and a promise of confidentiality.<sup>8</sup> Of the 200 plus who attended, 63 people took the time to complete the form. Apart from one Likkert scale and a list of identifiers, it was open-ended. Feedback was generally positive. On a scale of one to ten, respondents gave the event an average rating of 8.8. The Collective was interested in knowing whether both of the groups we targeted in our marketing had showed up at the event: those caught up in the politics of storytelling and those implicated in the institutional practice of appropriating stories. We included a series of tick boxes beside various identifiers as a means of collecting data on the diversity of social locations in the crowd. These identifiers included, “Psychiatric survivor/consumer/mad,” “service provider/worker,” “researcher,” “student,” “media,” and “other” (with an

open field). As hoped, all groups were represented. The majority of attendees also selected more than one of the listed identifiers.

The open-ended questions were designed to find out whether the audience had heard our messages. As well, they offered a further opportunity for reflection, inviting respondents to revisit the dilemmas that storytelling presents. Questions included: “What did you learn about storytelling within the psychiatric survivor/consumer/mad peoples’ community?” “What did you learn about the process or ethics of sharing personal stories?” and “What do you think would improve the way people tell their story?” A surprising number of respondents took the time to write lengthy, thoughtful responses. Others kept their comments brief and to the point: “Honour stories. Respect survivors.” A few detractors expressed feeling overwhelmed:

“But too much in 1 session. Overwhelmed, where to go next.” - Anonymous respondent

“2 workshops in terms of content. Break needed. Realize that folks are on board, no need to PUSH.” - Anonymous respondent

The *other comments* section that we included at the end was generally left untouched, apart from a few general responses about the length of time:

“A very good integration of issues for many communities. Excellent use of limited time frame for presentations.” - Anonymous respondent

“I would have liked more time.” - Anonymous respondent

Responses to the open-ended questions ranged from recapping to simply echoing lines from Eli Clare’s talk and those of the other presenters and panelists. However, some respondents reflected on their own use of storytelling practices:

“As a journalist, it really made me think about how I navigate my craft and how my colleagues navigate their storytelling and how I need to reflect on how I will take that into my future endeavours.” - Anonymous respondent

“As a researcher, I need to further problematize my relationship with those who are researched and how our research gets framed (i.e. recovery and not resistance).” - Anonymous respondent

The responses confirmed that the audience was receptive to and engaged with the speakers’ messages. However, the evaluation does not tell us whether attendees who are implicated in the institutional practice of appropriating stories will be compelled to act to change those practices. Indeed, a follow up column by Joe Fiorito from the Toronto Star on the event offered a bizarre and confusing analysis. In his column, “Telling Stories is Part of Being Human,” Fiorito (2011) wrote about being distracted at the event by the workmen

outside while listening to the talk, from which experience he concluded that the only story was the “human story.”

As a journalist, Fiorito is in the business of writing the human story of the tragic and unfortunate, and this “working class” news often includes stories about psychiatric survivors/consumers, living in poverty or dying as a consequence of horrendous living conditions and systemic discriminations. These stories are often told within a “last stop” or “end stop” narrative—when things have gotten dangerously bad or, even better for a salacious story, have resulted in death. However this “end story” too is a narrative form, one that is valuable within journalistic circles often competing for coverage not only with other journalists but with the barrage of stories and testimony that fill our newspapers, books, journal articles, government reports and legal proceedings. And these stories are governed by parameters that fit the page and are accessible to the “average reader.” The fact that these stories are often left unwritten until an end, and that it is difficult or uninteresting to shed light on the history or moments when individuals were treated as objects, as less than human, appear to have been lost on Fiorito. Butler (2004) poignantly has queried, “Who counts as human? Whose lives count as lives? And finally, What makes for a grievable life?” (p. 20). Popular media coverage that waits until an ultimate end story is easy, lewd and indecent media. Is this coverage meant to redress, or rather is it caught up in similar processes that the Collective wishes to expose—stories used as a way to sustain journalistic stakeholder gain on front-page headlines? The Collective hoped for something more, something beyond the regulation of stories that re-create a dualistic tragedy/heroic disability chronology.

## **Conclusion**

The Recovering Our Stories Collective formed as a purposeful group organized with the intent to agitate and unsettle leading assumptions that individual stories can single-handedly change deeply embedded, oppressive and interconnected powerful social structures. We seek to question the use and propagation of personal narratives, and elucidate how our stories are increasingly being used as a way to harness support, funding, or press coverage for the systems that we recognize as being part of the problem. Our discussion is meant to add to the ongoing work that is beginning to call these practices out as suspect and damaging. We hope to further explore a theory of storytelling and practices of storytelling (we have in fact, told a complicated story here) that allows and mobilizes psychiatric service users to have the freedom to create, build and be innovative their own identities and histories, which would simultaneously enable and allow a basis through which psychiatric survivor/consumers can resist unethical exploitation.

Finally, survivor/consumer storytelling is intricately connected to narrative control and history-building. In the past, voices and stories were relegated to case histories and most often been used as evidence to incriminate and abuse.

Reclaiming our stories as political knowledge that elucidates social injustices has, over the last half-century, been a founding movement strategy to connect and collaborate with others. This paper traces how our stories have suddenly been understood as useful by dominant hegemonic orders and incorporated into neoliberalist mental health agendas in order to support and sustain the validity of health service systems. We seek to mark and disrupt this trajectory, asking those who reveal their stories to consider doing so in a way that is politically accountable and focused on social justice change. And through this small act of organizing resistance, we inform those that solicit stories that we are now asking, in whose interest?

## Notes

- <sup>1</sup> Attempts to be inclusive and engaged in participatory initiatives or research bolster the optics for large organizations. There is increasingly more grant funding available for those with the resources to apply for them. However, most committees, advisories, etc. with clients/patients are extremely vague on how they reach their decisions (e.g. consensus, vote) and rarely measure the inclusion of patient voice.
- <sup>2</sup> The Organization for Economic Co-operation and Development found people with mental illness are often off sick from work, and between 30 and 50 per cent of all new disability benefit claims in OECD nations are now due to poor mental health (OECD, 2011).
- <sup>3</sup> For example, *Mental Health Affects Us All* was the title of a human rights seminar presented by the Public Service Alliance of Canada in Dec. 2010.
- <sup>4</sup> For example, in Toronto the Centre for Addiction and Mental Health received a \$30 million donation from the daughters of the late Audrey Campbell and their families. It is the largest private donation ever made to a mental health centre in Canada. It will fund a research institute focused on brain science (CAMH Connexions, 2012).
- <sup>5</sup> In 2010 and 2011 there have been a number of reported shootings by police on individuals identified as having a mental health issue. The Toronto Star commented that police training was inadequate (Tapper, 2011).
- <sup>6</sup> Lucy Costa recalls hearing the phrase patient porn in approximately 2005 from fellow activist Lana Frado. Lana in turn, references Heather McKee as coining the provocative term.
- <sup>7</sup> The “back off, get your own sandwich” commercial produced by Maple Leaf Meats for their product, Lean ‘n’ Lite sandwich meat held a TV spot entitled: “Sandwich Defense” (Circa 2000).
- <sup>8</sup> Names and email addresses were collected upon arrival for possible use in future organizing.

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