Mad activism enters its fifth decade

A few words about one word in particular

Every ten years or so, I get invited to speak at the CMHA national conference. I spoke in Ottawa in 1986 and in Regina in 1997. And here I am again this morning. It's 13 years but who's counting? And I didn't actually get invited: I begged. I begged because I wanted at least one speaker to say the words "mad activism".

Madness, you know, goes back to the beginning of recorded history; there's lots of madness, for instance, in the Old Testament. You won't find "mental illness" mentioned, though. We might never have become familiar with "mental illness" had the battle for who was going to be in charge of madness turned out differently. In my lifetime, the neurologists and the psychoanalysts and the psychiatrists were hotly contesting the field; when psychiatry won, we began talking about "mental illness."

Once we begin talking about mental illness instead of madness, we start talking about mental patients instead of madmen or madwomen or mad people. Do I want to be called a mental patient? Not so much. I prefer psychiatric survivor. More recently, it's been fun to call myself a mad professor.

I am a member, perhaps even a founding member, of the consumer/survivor/ex-patient movement. I am also a student of that movement. I am very interested in the words that members of the movement use to describe themselves. In fact, in two of the courses I teach at Ryerson University, I devote whole lectures to words and the politics of language.

There's a young scholar finishing up a PhD at the University of Toronto. Her name is Shaindl Diamond. She theorizes that there are really three overlapping movements: the anti-psychiatry movement, the psychiatric survivor movement and the mad movement. The anti-psychiatry movement is today mostly an historic artefact; the psychiatric survivor movement seems to be stalled; it's the mad movement that's growing. I know lots of young people who describe themselves as mad or as mad-identified.

So, more and more, I have been thinking in terms of the mad movement and the members of the mad movement as mad activists.

From time to time, you'll hear the term "psychiatric survivor"; that's how I've been self-describing since about 1990. There are a couple of references to "survivor knowledge" by which I mean that knowledge that comes with the lived experience of the social and economic effects of being labelled mentally ill and

being treated for mental illness. If I use other "in house" or idiosyncratic terms, I'll explain them when we get there. If I don't, please don't hesitate to ask me what I mean.

Inspired by a photograph

This talk was inspired by a photograph.

This one: [madness in the street]

10 people going to or coming from somewhere. We note the gender imbalance: 6 women, 3 men, 1 gender queer. The people seem to be happy, with their gender and everything else.

Did they win the lottery?

No, something much better. What these people have is a powerful connection and that connection is madness. On this spring evening, they're on their way to the Dream Team dinner in Toronto. It's April 29, 2010. It's just gone 6 o'clock.

The Dream Team, by the way, is "a group of psychiatric consumer/survivors who advocate for more supportive housing in Ontario for people with mental health issues. By telling [their] personal stories, by conducting and presenting research, and by standing up for human rights, [they]demonstrate and promote the life-altering benefits of supportive housing."[1]

The Dream Team treated us to some theatre earlier this morning.[2]

Back to the photo. You can see that there's quite an age range. Two of us are in our 60s, one of us is in her 20s, there are a few 30-somethings, a couple are in their forties, one in her fifties. You can't see this but 60% of us work or study at the three Toronto Universities and two of us at George Brown College. Two of them are working part-time at the Mental Health Commission.

You can't see this, either: 8 of the 10 people in the photograph identify as mad, a ratio somewhat higher than in the general population, I'm given to understand. I will tell you who the two sane people are later. You'll have to pay attention. There is, however, no exam.

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[1] www.thedreamteam.ca

[2] Exploring the participation of PLES in the development of mental health policy

One of us is wearing a hat. That would have to be Pat Capponi, wouldn't it. Perhaps you caught her session yesterday; it was about leadership development in a supportive housing agency.

Pat is one of my connections to CMHA.

I met her for the first time when she was receiving a CMHA award for outstanding public service. It must have been 1981. I bet the plaque was signed by Steve Lurie. You know, the drummer for the Deloraines. I imagine he has a day job of some kind.

Kathryn Church (2nd from the right) is my other connection to CMHA. In 1985, John Trainor and Kathryn recruited me to be a member of the National Mental Health Services Committee which was just starting its work on a model of community support for people with mental health issues. It was called the Framework for Support[3] and, for my money, twenty five years later it is still the best community mental health idea around. Kathryn and I today work in the School for Disability Studies at Ryerson University, though Kathryn is an associate professor and I am but a humble (ya right) part-time instructor.

People with Lived Experience (PWLEs or PLEs)

The most recent entry in the language business is People with Lived Experience. I leave it to you to imagine what People without Lived Experience are like. You should know, though, that CMHA was a pioneer in foregrounding PLEs though, then, it was called "consumer participation".

In fact, so well-regarded was CMHA in this area, that I was invited to speak about it at the University of Sussex in England in 1988. The conference was called Common Concerns and it brought together consumers from all over the world. I showed up at the conference with a paper Kathryn Church had written for me; it was called "User Involvement in Mental Health Services in Canada: a work in progress."[4]

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[3] http://www.cmha.ca/bins/content_page.asp?cid=7-13-981

[4] Church, K. & Reville, D. (1989). User involvement in the mental health field in Canada. *Canada's Mental Health*, 37 (2), 22-25

Pat Capponi recognized very early that if "consumers" were going to be involved in the mental health system as something other than passive recipients of service, they were going to have to learn a whole bunch of stuff that they hadn't learned on the ward. I wonder if that recognition was related to her involvement as a member of the Mayor's Action Task Force on Discharged Psychiatric Patients. It was 1982. Toronto City Council was being lambasted from all sides because of the sudden influx of "discharged psychiatric patients" into the Parkdale neighbourhood in the west end of the city. The good guys were outraged that people had been abandoned in filthy rooming houses; the bad guys were outraged that somebody - they didn't know who - was dumping what they described as "garbage" into their neighbourhood. The mayor did what politicians do: he set up a task force and he got himself a heavy hitter to head it up - Dr. Reva Gerstein. As luck would have it, I was a member of Toronto City Council. And when the mayor asked me what I thought of his plan, I told him that I wouldn't support a task force about discharged psych patients unless there were discharged psych patients on it. And that was how I came to introduce Pat Capponi to Reva Gerstein. [pic of Pat and Reva?] They looked each other up and down and set about becoming one of the most dynamic duos in mental health history.

To help her folks deal with invitations to participate, Pat developed a leadership training program called "Looks Like Up". She got endorsements from every big shot in the province . But it didn't happen. She didn't give up, though and eventually, in the late 80s, the Ministry of Health ponied up and Pat began developing leaders at the Gerstein Centre[5], the very Gerstein Centre that came out of the Mayor's Action Task Force on Discharged Psychiatric Patients.

Lucy and Jo are following in Pat's footsteps. Lucy is wearing the beautiful scarf and Jo is peeking over her left shoulder. You can see Lucy in a YouTube video of mine; it's called "Self-Labelling and Identity"[6]. Jo teaches at the Redirection through Education program at George Brown College in Toronto; Jo does not identify as mad but she is working like crazy on helping people who do become full citizens. Lucy works for the Empowerment Council at the Centre for Addiction and Mental Health. She's just submitted her final paper for her independent studies

[5] www.gersteincentre.org
[6] http://www.youtube.com/watch?v=pxbw7dDMX60

course at York University. It's called "The Rise of Mental Health Rights in Ontario 1960s - present." If you are a CAMH client, you can go to university right in the hospital. That's because Lucy has designed a course about mental health rights; you have to be a CAMH client to enroll. I'm hoping she'll ask me to come and speak again this year.

Lucy and Jeremiah and Jenna are members of the Mad Students Society, a self-help group established by Lucy in April, 2005.

(MSS) is a group organized for and run by students who have experienced the psychiatric system (known as psychiatric survivors and/or consumers). Mad Students Society works to create a community to empower, support and mobilize students who are currently or may in the future experience the psychiatric system. As a group we support each other, share similar experiences, learn about our history as a community, build from each other's strengths, identify barriers in the education system and address systemic discrimination. We also aim to create a space that is an alternative to bio-medical perspectives on emotional crisis. Our goal is to create an effective foundation for self-advocacy that has its roots in the history of the psychiatric survivor movement and is reflective of the socio-economic factors that impact our experiences.[7]

This spring Jenna graduated with a Masters of Social Work from Ryerson; her master's thesis is about the experience of mad students in a program that describes itself as anti-oppressive. By the way, you don't want to mess with Jenna. She's a highland dancer; she's got a sword. Jeremiah has worked at Sound Times, a survivor-run initiative in Toronto and now is working with PLEs at the MHCC. He also works as a peer support worker at CAMH.

When I arrived at Ryerson in 2004, I met a young research assistant named Jiji Voronka. She told me that she was mad-identified – a new one on me – and that she'd done her MA thesis on carceral spaces which I learned were mental hospitals. Jiji developed a performance piece about her brother Michael who was a patient at the Whitby Psych. Later he lived in a Parkdale boarding and lodging house. Having no faint clue about how to go about being a university professor, I hired her as my TA and I paid careful attention to her good advice. Today Jiji is completing her PhD at U of T and working part-time for the Mental Health Commission of Canada. [I am not going to mention her new lover.]

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[7] www.madstudentsociety.com

Ah! my old friend Deb. In 1994, Deb was diagnosed as having bipolar affective disorder; her life for past 16 years has been a rollercoaster. Despite that, she has completed a M.Ed. at the Ontario Institute for Studies in Education and has worked as one of the associates at David Reville & Associates. People in the mental health field in Ontario will know of her work; she was the lead author of "On Becoming New Best Friends", a review of the opportunities for efficiencies in the front and back offices of community mental health and addictions programs.[8] This Deb did while being so depressed that she was seriously suicidal. Deb doesn't call herself a psychiatric survivor. Instead, she sometimes calls herself a "psychiatric tourist" and other times a "lunachick", proving that different people describe themselves differently and have an absolute right to do that. Right now Deb has three gigs: she's a consultant on a film being made at the Toronto General Hospital; she's finishing up a study of the peer support worker toolkit for the Ontario Peer Development Initiative and she's a researcher for the Toronto "At Home" project funded by the Mental Health Commission of Canada. Deb also advises me on my own mood levels; she does that for free.

What can I say about Kathryn Church? From 1984-1988, she staffed the Framework for Support Project at CMHA National. Then she left to do a PhD at the U of T, leaving psychology for sociology. She then worked for a number of years out of her basement as a independent researcher. Her clients were mainly psychiatric survivor organizations and, for them, she wrote a shelf full of plain language documents. In 2002, she joined the School of Disability Studies to run the Ryerson RBC Research Institute for Disability Studies Research and Education. Kathryn is now an associate professor but there are bigger titles just ahead. Unless I miss my guess, next July, Kathryn will be taking over as Director of the School of Disability Studies. Kathryn's on sabbatical this year; one of the things she's doing is working on a book in which she and I

[8] *www.health.gov.on.ca/english/public/.../reville_report.html*

recall our work on consumer participation.[9] Dr. Church does not identify as a mad person but she is the strongest ally mad people could ever hope to have.

Erick Fabris came to Toronto in 1993 fresh out of the psych hospital in Vancouver. He bumped into Lilith Finkler in Parkdale and joined the West End Psychiatric Survivors. He helped organize the very first Psychiatric Survivor Pride Day. He then went on to work for the Queen St. Patient Council and later the Queen Street Outreach Society. Right now he is writing his PhD dissertation; it is about alternate explanations for psychosis. Watch for his book on Community Treatment Orders which will be out next year. This fall he joined Jim Ward and me at Ryerson where we teach A History of Madness. I am overjoyed.

Crossing Over

There's something neat happening right now. Mad activists are crossing over. So Pat Capponi has made the natural leap to anti-poverty activism. Much of her work these days is with people who identity first as poor and second, if at all, as psychiatric survivors. I'm thinking of her work with a group called Voices from the Street and her work on the social assistance review being undertaken by the government of Ontario. Becky McFarlane, co-director of the Ontario Council of Alternative Businesses, is working with the Hotel Workers Union on a social enterprise project; here's survivor knowledge being sought after by a labour union. [pic of 60 Richmond]

A-WAY Express, a survivor business now in its 24th year, has joined its neighbourhood Business Improvement Association and, for the past two years, has been the sponsor of a jazz festival. [A-Way Autoirickshaw pic]

As I've said, Erick Fabris is now team- teaching A History of Madness at Ryerson; students from all faculties get to benefit from survivor knowledge. At Ryerson, for students working towards a degree in disability studies, I have taught two core courses, one in community organizing and

[9] consumer participation is called "user involvement" in the UK. Kathryn and I just wrote the foreword for a book about a project in which users designed the curriculum for health care and social service works at the University of Central Lancashire.

the other called "Leadership for Social Action". In those courses, I bring learnings from the mad movement as well as bits and bobs I've picked up elsewhere. Most of our students do not work with psych survivors but rather with people who have developmental disabilities and/or physical disabilities.

A new era of mad activism

We are standing on the threshold of a new era in mad activism. That's because there are a number of smart young activists doing post-graduate work. I call them, not entirely tongue-in-cheek, "high knowledge crazies." So, Jenna has started work on a PhD at York, Erick and Jiji are further along on their PhDs at U of T. When they write and speak, they start, of course, with the authority that comes with lived experience. But should you not want to take their word for it, they'll have a certain powerful something that most of us don't have. That's right, they will have the right to be addressed as "doctor". In a credentialist society, "doctor" is something worth having on the front of your name. So, my friend Geoffrey Reaume, Associate Professor at York Univeristy, is not just Geoffrey Reaume, treated at 14 for paranoid schizophrenia. He's **Doctor** Reaume and don't you forget it. [353]

The Challenge

Let me finish up by issuing a challenge to CMHA. Take a look at this:

it's the cover of the final report of the Select Committee on Mental Health and Addictions; it was completed this summer. It's got a nice recovery-oriented title --"Navigating the Journey to Wellness"--it's got four nice-looking people, appropriately diverse in age and gender and ethnicity--and it's got four seasons, though what that has to do with anything I'm not sure. It's got the usual bunch of nice recommendations, too. You have to get all the way to recommendation #21 before the alarm bells go off. I'll read you some it:

The Ministry of Health...should create a task force...to propose changes to Ontario's mental health legislation...pertaining to involuntary admission and treatment. The changes should ensure that involuntary admission...entails treatment.

Yes, you spotted it. Forced treatment. Change the law so that it's easier to drag you off to the mental hospital, like it or not, and force treatment on you. My giddy aunt! They want to dump us back into the bad old days, those nice legislators on the committee. Why? because somebody told them that rights have trumped care, that rights activists have been so successful that people are wandering around without the treatment they need. Apparently, as we navigate our journey to wellness, we're going to have travel at least part of the way in handcuffs and leg irons.

The Toronto media thinks forced treatment is a good thing; after all, those poor crazed souls don't know their own mind.

Mad activists don't think that forced treatment is a good thing. We are going to have to saddle up and ride out to fight for patients rights.

My challenge is:

CMHA, ride with us.

[3164 words]