

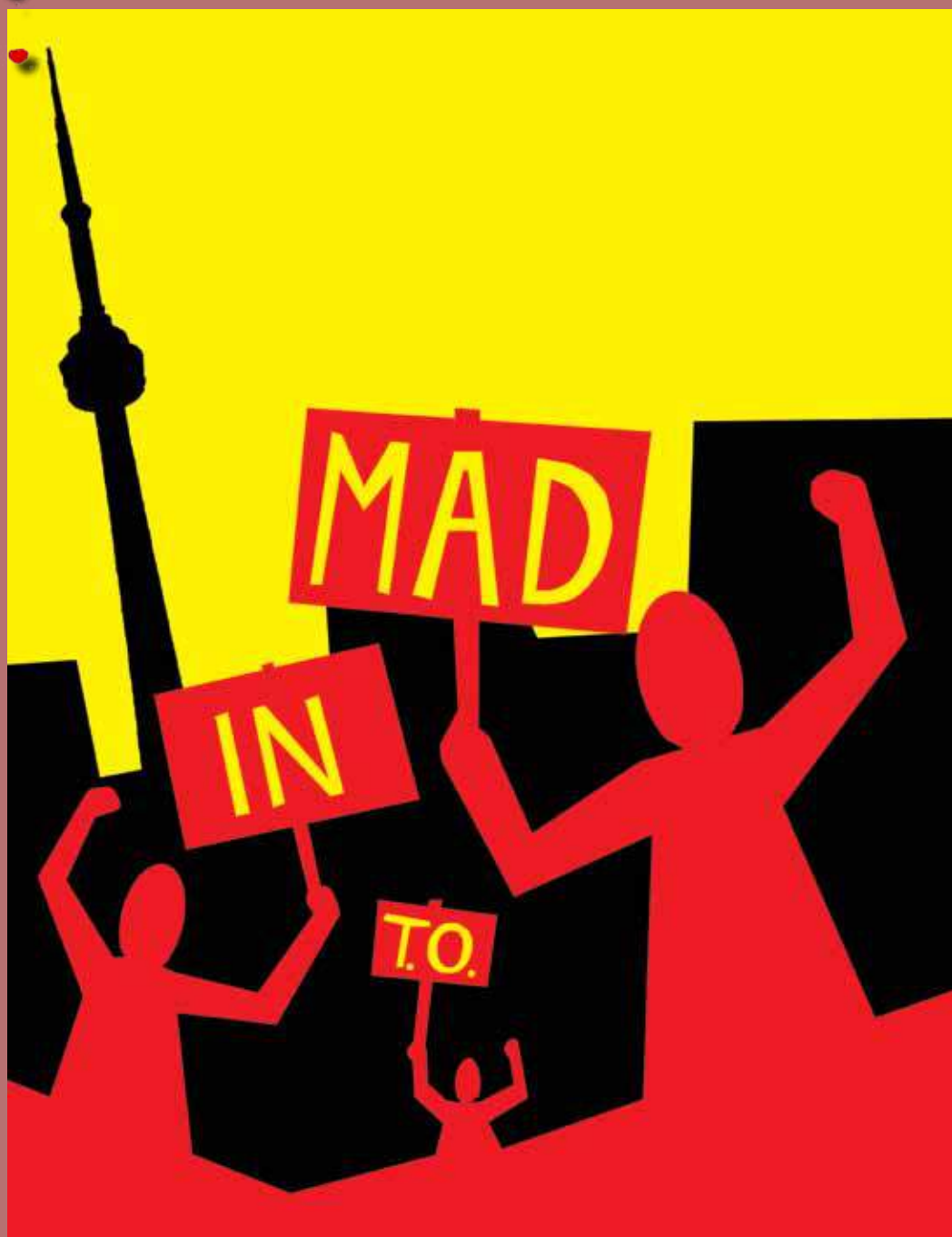
Asylum

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the magazine for democratic psychiatry

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TORONTO: HOW DO WE WIN?

Asylum

the magazine for democratic psychiatry
Volume 20, Number 4, Winter 2013

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and community development

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Associates on behalf of contributors

Toronto issue guest editors: **danielle landry, Jenna Reid, Jijian Voronka, becky mcfarlane, kathryn Church, david Reville and anonymous. Special thanks to the peer reviewers.**

Executive Editor:
Phil Virden: tigerpapers@btinternet.com
general Editors:
Prof Alec Jenner and Lin Bigwood
business manager:
Peter Bullimore

members of Asylum Collective:

Jim Campbell	David Harper
Tamasin Knight	China Mills
William Park	Ian Parker
Dina Poursanidou	Arri Seifipour
Sonia Soans	Helen Spandler
Phil Thomas	Pauline Whelan

design:

Old Dog Graphics

Administration & distribution:

PCCS Books

Unit 2 Cropper Row, Alton Rd, Ross-on-Wye, HR9 5LA

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Back: 'Losing' by Sarařin

Sarařin is a Toronto area cartoonist, illustrator, painter, and Mad Person. You can read her webcomic, *Asylum Squad*, at www.asylumsquad.com and the archived strips at www.thepsychosidaries.com

button images:

Alisa and Elizabeth (two crazy ladies)

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asylum magazine is a forum for free debate, open to anyone with an interest in psychiatry or mental health. We especially welcome contributions from service users or ex-users (or survivors), carers, and frontline psychiatric or mental health workers (anonymously, if you wish). The magazine is not-for-profit and run by a collective of unpaid volunteers. Asylum Collective is open to anyone who wants to help produce and develop the magazine, working in a spirit of equality. Please contact us if you want to help.

The views expressed in the magazine are those of the individual contributors and not necessarily those of the Collective. Articles are accepted in good faith and every effort is made to ensure fairness and veracity.

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EDITORIAL

in the likeness of a group of naïve and idiotic professionals – doctors, nurses, health practitioners, policy makers – who are at the same time well-intentioned and unknowing? And when did we decide that a seat at their table or a moment of their time would make even a bit of difference? What led us to believe that there was power in disclosing our stories, our experiences and our secrets? When did we start deluding ourselves that we mattered that much – or at all, in truth? It would be laughable if it weren't so pervasive. And dangerous.

Inviolable.

There is no institution, big or small, that can protect us from the violence and discrimination that we experience living in this world. No government, no justice system, no asylum. We need to stop looking to them for protection. We do that for each other. We do that for ourselves. We do that in spite of them. In families. In communities. On our own terms.

Tell me I am being idealistic, unrealistic. I don't care. I would rather live my whole life plotting to bring down the asylum than another moment propping it up. And I am not the only one – in Toronto or around the world. Here in these pages, reading these pages.

Call us traitors.

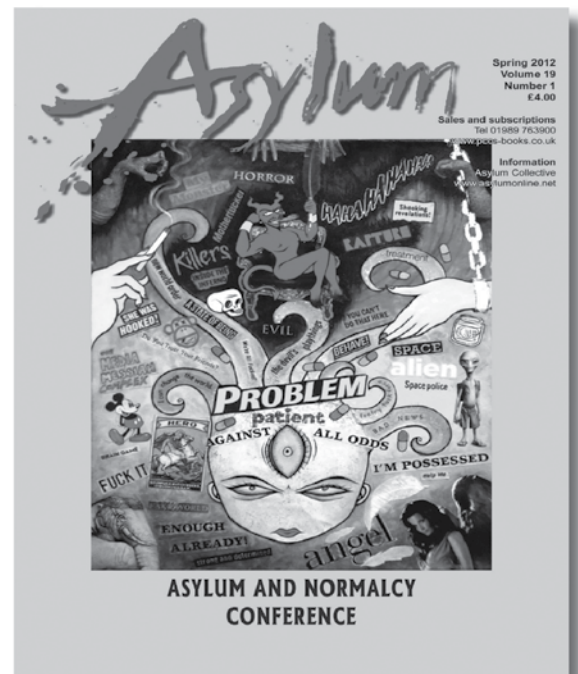
We are tired of losing and angry enough to believe we can win.

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BRINGING MAD POSITIVE HOME SOME LESSONS FROM TORONTO

Helen Spandler (*Asylum* magazine and COMENSUS), Mick McKeown (UNISON and COMENSUS), Lou Rawcliffe (Lancaster Hearing Voices Group and COMENSUS), Keith Holt (COMENSUS), Kirsten Maclean (Oor Mad History and CAPS Advocacy)

In April 2011 the mad-identified activist, David Reville, and the mad-positive academic, Kathryn Church, visited Edinburgh and Preston from Toronto. They spoke about Mad Activism in the Academy to a packed-out hall in Preston. A year later, in May 2012, a small group of survivors, academics and allies travelled to an international event called Mad Positive in the Academy, at the School of Disability Studies, at Ryerson University, Toronto. The group included people from Oor Mad History in Scotland, the COMENSUS project (at the University of Central Lancashire), UNISON (the public sector trade union), a local Hearing Voices group, and *Asylum* magazine.

As readers of *Asylum* frequently tell us, it is not enough just to criticise – we also need to develop practical strategies of resistance and alternatives. We met lots of inspiring individuals, groups and organisations who were doing this in Toronto. This led to the idea of putting together a special issue of *Asylum*, so as to bring some of this home to our readers. Here we share some lessons and personal experiences from this exchange.

Recovering our stories

Our visit came hot on the heels of a successful event in Toronto and the culmination of a wonderful project called Recovering Our Stories. This was about survivors reclaiming their own stories from the dominant 'recovery' agenda. We were greeted with posters proclaiming 'Hands Off Our Stories!'

Academics can be all too eager to co-opt people's individual stories into their own preferred theories and agendas, so this was a sobering lesson for the academics among us. It also speaks to similar issues we have covered recently on the pages of *Asylum*, e.g., Jasna Russo's 'Give me the stories

and I will take care of the rest' (*Asylum* 19:4). The Recovering Our Stories collective developed some practical advice and tips for would-be storytellers to help prevent their stories being used as commodities or 'patient porn'.

Tips for Storytellers,
from *Recovering Our
Stories*

Our stories have the potential to change the world. Sometimes our stories are stolen, appropriated or taken out of context by organizations and institutions acting in their own self interest.

Always remember:

1. Participation is voluntary. You can always say no.
2. Ask yourself, who profits from you telling your story?
3. What purpose does telling your story serve?
4. How do large organizations use your stories to make material change?
5. Sometimes story telling is work. Are you getting paid?
6. 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).

www.recoveringourstories.ca
recoveringourstories@gmail.com
f Recovering our Stories

'Mad identified' and 'mad positive'

While some people defined themselves as 'mad identified', others said that even if they couldn't claim to be mad identified, they were 'mad positive'. Of course, it is possible to be both (or indeed neither!). Being mad positive means challenging the prevailing and assumed negativity around madness: i.e., that it is always necessarily something bad, to be prevented and treated – but without romanticising the potential distress involved. We might have called this 'being allies or friends of the survivor movement'. This made us think more about the need to develop an explicitly 'mad positive' culture in universities, as well as in the wider society.

mad Students Society

We were especially impressed with the young women we met from the Mad Students Society (www.madstudentsociety.com). What is distinctive about this group is that, if it means accepting a psychiatric diagnosis and treatment, they refuse to play by the rules governing 'reasonable adjustment' for mental health difficulties. They campaign for alternative forms of support and provide mutual aid and solidarity for each other. We wondered why we didn't, as far as we know, have similar groups in the UK.

Anti-anti-stigma campaigns

We realised that we aren't the only people fed up with all the mental health 'anti-stigma' campaigns. These campaigns are becoming globalised. They tend to reinforce certain established ideas about mental illness being 'an illness like any other', and the need for medical treatment. In other words, these campaigns are far from being 'mad positive'. Instead of a relentless focus on 'stigma' it might be better to focus on discrimination, human rights and alternatives. Some of us decided that we needed an anti-anti-stigma campaign. In light of the success of 'Hands Off Our Stories!', we thought of calling it 'Hands Off Our Stigma!'

high knowledge crazies

We were reminded of the importance of cultivating what David Reville called 'high knowledge crazies'. For example, 'mad identified' scholars doing higher level degrees, so that they (or we) are not just 'user researchers' or 'research assistants' but valued academic intellectuals in their own right. This is not to devalue the experiential contributions of people without academic qualifications, but it does open up the possibility of different challenges to the discrediting or stigmatisation of 'mad' people. It could also raise interesting opportunities for contesting the separation of university space from local communities, and the previous exclusion of marginalised groups, thus supporting wider efforts to widen access to higher education.

Reciprocal relations

We recognised the value of developing reciprocal relations and alliances with trade unions and the queer and disability communities. The Canadian Auto Workers Union provided some funding for the event, and there is a well-developed Ontario Health Coalition which brings together unions and community groups. We met Becky McFarlane, a longstanding activist in both communities and in the labour movement. She previously helped to organise hotel workers in Toronto, is one of the mainstays of Working for Change and is also active in the Occupy movement. Becky is convinced that there are key challenges facing alliances between unions and survivor groups, not least previous failing of the progressive left to properly understand the politics of mental health. She visited the UK in Fall 2013.

unsettling relations

Inevitably we kept coming back to the recognition that being mad positive and developing reciprocal relations will be difficult at times, and often 'unsettling' – for all parties involved. But perhaps that is one of the reasons we need to do it. As Kathryn Church wryly noted: "No one ever said this was going to be easy!"

The survival of collectivism

Given the context of rampant individualism here in the UK, we were pleased to see that the spirit of collective provision and welfare responsibility was alive and kicking in Toronto. We were impressed with our visit to a number of radical projects such as Working for Change, Voices from the Street, Women Speak Out and Sound Times (pictured below).



Women Speak Out is located in Parkdale, a rundown but cosmopolitan district of Toronto, near the large psychiatric hospital (CAMH). This consciousness-raising group supports women who find themselves at the margins of communities by virtue of migrant status, mental health or victimisation. Graduates of the programme gain valuable knowledge and skills relevant to community activism.

Sound Times (www.soundtimes.com) provides a much-needed non-medical, freely accessibly sanctuary for people in distress. Community organisations like Sound Times now face hard times since funding sources are squeezed, and an insistence on targets and outcomes sits uneasily with their commitment to flexibility, creativity and meeting the needs of people not usually reached by mainstream services. These conditions will be familiar to organisations here in the UK.

Despite this, projects like Sound Times have found positive and creative ways to survive and thrive. They are a lesson to us all.

personal Journeys

Iou Rawcliffe

I was lucky enough to have the opportunity to visit Toronto and take part in the Mad Positive in the Academy event. Even though I was bringing valuable experience of my own, I was nervous to start with. I experienced huge social anxiety prior to departure as it would be the first time I had travelled abroad in seven years, and more than a decade since I travelled abroad unaccompanied by my partner and 'enabler' Fiona.

The first hurdle of the journey was going through customs with 10 days' worth of Clozaril, despite the fact I had got a letter from my psychiatrist confirming the medication was prescribed. Having got on the plane in one piece I enjoyed the chance to talk with my travelling companions about mental health and feminism, which was where my political journey began in the early 1980s.

On our first evening in Toronto we went out for a meal with Kathryn, who works in the Department of Disability Studies and was one of the organisers of the Mad Positive event. The meal was relaxed, and friends back in Preston and Lancaster were remembered.

Over the course of the next few days I found myself challenged but also really inspired and politicised. Four years ago I was involved in setting up the Hearing Voices Group in Lancaster. Before the launch of the first meeting one of my colleagues asked me if I was looking forward to it. The greatest challenge for me was the possible 'eruption' of voices and social anxiety leading to a struggle to communicate in group situations. This represents a significant problem for me, with inappropriate voices disrupting my participation – particularly in terms of my ability to concentrate for much more than an hour. Inevitably, I was concerned about my ability to cope with this during the Toronto conference.

However, visits to some grassroots projects were truly inspirational. We went to Sound Times, a service-user led 'drop-in' facility which had a relaxed and laid-back atmosphere. There were lovely outdoor spaces with picnic tables and benches surrounded by plants and bushes. 'Peer support' was alive and kicking in this place.

One of the most powerful and radical groups we met was Women Speak Out, an initiative run by women for women. Issues such as empowerment, equality, diversity and self-esteem were discussed, alongside recognition and celebration of the personal narratives of the participating women. The facilitator of the group, Becky McFarlane, defines herself as a revolutionary. This was refreshing to hear, coming from the UK, where a climate of individualism seems to hold sway. A lot of the women in this group were migrants, and listening to their stories about how they had come to Canada was interesting and intensely moving.

As a result of the discussions over the weekend, I felt inspired, challenged, overwhelmed, and at times very emotional. Within the whole scope of mental health is the thorny debate about medication. For me, this is dominated by fear – fear of a recurrence of the absolute terror and

persecution not only of an exacerbation of abusive voices but, more debilitating, the impact of off-the-scale paranoia and mental torture. I am plagued with memories of the experiences of my last psychotic crisis, six years ago, and to this day do not know how I came out of it alive. My 'choice' – if you can call it that – is to continue with meds but hopefully to reduce the dosage whilst developing other psychological tactics to deal with my personal experiences of psychosis.

So, with a lived sense of fear of another crisis, and also ongoing experiences of side effects – sedation, weight gain and apathy – I found myself in conflict between my 'lived experience' and the anti-medication stance I had held for many years. This is a continuing debate I have with myself, and I found it being played out in my head during the event.

Also with us was a wonderful group of people from Edinburgh who had been working on a project they called 'Oor Mad History'. This is a historical study of mental health service-user narratives in Scotland, particularly in long-stay institutions. Throughout Britain there is a huge resource and collective history of people's lived experiences of the old asylums and long-stay institutions. The marvellous work of the Edinburgh team made me consider the narratives that have been overlooked or unheard from the old Lancaster Moor Hospital which now stands derelict, up the road from where I live.

Much of the discussions over the few days focused on the importance of personal narratives. This was framed by the concept of 'mad-activism' in academia. Positively, a focus on lived experience has opened up discussions about power and mental health, psycho-social work, theory and practice. At times I felt the conflict between real lived experience and the articulation of theory and practice in academic settings. Clearly the work we do at home in user- and carer-involvement projects, such as COMENSUS (at the University of Central Lancashire), helps to bridge this gap.

Once again I found myself in conflict about where I stand politically, emotionally and ideologically, and concerning the lived experience of my everyday life, in which I have to deal with challenging voices that are abusive, not only to me, but also at times about other people. I continue to feel shame and embarrassment, even though I have no control over the content or context of my voices.

I spoke about the Lancaster Hearing Voices Group. I also gave the Canadian organisers a small photograph album with postcard scenes from Lancaster and messages of goodwill from our group members to everyone involved with the 'Mad Positive' initiative. We also enclosed a few photographs from COMENSUS meetings and social events. This album was passed on to David, one of the organisers of the conference who had ended up missing the event due to ill health. In terms of grassroots activism and the link between 'our' groups at home and this initiative in Canada, this seemed appropriate.

It was really great to get to know my travelling companions – Keith, Helen and Mick – a bit better, and to engage with the mad positive ideas which they voiced during the event. Having spent time chatting to Helen, I now subscribe to *Asylum* magazine. Keith 'came to my rescue' on more than one occasion, and I really enjoyed the free time we had together exploring downtown Toronto, and then Niagara. Mick's commitment and passion for unionism left me with

a sense of nostalgia about my own involvement in COHSE when I was a young student nurse, many life-cycles ago, in Manchester in the early 1980s. Thought-provoking questions arise from this, including how unions relate to volunteers and voluntary work, such as we do at COMENSUS.

I returned to the North West of Lancashire with lots and lots to think about and work through. From time to time you have conversations that last a lifetime. I had one with a woman called Tessa, about speaking up in group discussions. We talked about this being 'a risk', but also acknowledged the importance of expressing your voice. As someone who has issues about 'being liked', this was a really enlightening conversation. As the conversation progressed she added that 'you have to take the flack', though, when people disagree with your viewpoint. This conversation is etched on my memory.

keith holt

Where do I start? The whole experience brought to mind other struggles we have had in mental health, such as my own over the years, linking gay rights with mental health politics at MIND meetings. The radical view of universities that might see them as much more connected to communities and open to the involvement of ordinary people is well worth striving for. So is the way in which academic staff have helped support fantastic community groups and developments as an alternative to psychiatric services. I love the passion and the politics. The word 'mad' still carries a lot of negative feelings for me – like 'queer' – so I am not so convinced that trying to reclaim these terms always works. But I am open to persuasion!



INTERGALACTIC SPIRITUALITY, HIP HOP & PSYCHIATRY

directing a documentary on Khari 'Conspiracy' Stewart

Jonathan Balazs

It's July 2007 in my hometown of Edmonton, Alberta, and I'm interviewing Khari 'Conspiracy' Stewart for the independent music magazine Ugsmag.com. A few months prior, in Toronto, I had interviewed his identical twin brother Addi 'Mindbender' Stewart for the same magazine. These brothers rap together in a group called Supreme Being Unit (SBU).

Though it had been a year since I last saw Khari, little had changed in his appearance or demeanor. This was the first time I'd been in his home. The basement dwelling is as I expected: overflowing ashtrays, stacks of magazines and newspapers, rap posters adorn the walls. I'm looking at his Canadian rap collection.

This is where I first discovered Khari's curse. I learned that, in his mind, he was the victim of a demonic consciousness from space. Many rumors swirled around the Edmonton rap scene as to why Khari was the way he was: too many drugs, mental illness, etc.

Our interview was popular (if not controversial to some people close to Khari) and it inspired me to pitch Khari's story for my film production class that September. By Christmas I had shot the first iteration of *Mars Project* on Super 8 film. This gave me a glimpse into the life of this decidedly unique individual.

Conspiracy the Rapper had a dubious reputation (many referred to him as 'a crack-head') selling bootleg quality versions of his work on burnt CDs, and generally overcharging for those albums. I think many of us who supported Conspiracy the Rapper, were investing in his virtues as 'an alien artist' rather than in the product itself. I recognized Conspiracy as unique and I knew that his following was esoteric, but I was still honored to be speaking to a Canadian rap legend.

A kind of pride washed over me as I thought about how great it was to be 'normal', not one of those 'crazy people hearing voices'. I think Khari's otherwise candid attitude about his issues compounded by his innate humor and optimism helped to set me apart from him. Still, I was intrigued, even if I knew nothing of Holy Tabernacle Ministries, schizophrenia, mental health or psychiatry.



Director Jonathan Balazs and star Khari 'Conspiracy' Stewart on set during the filming of *Mars Project*, August 2012

In my final semester, completing my BFA, I had heard positive things about a 'History of Madness' class offered by Ryerson University's Dept of Disability Studies. At the time, the class was split between two white-moustached instructors, David Reville and Jim Ward (who could be brothers). Jim Ward challenges my perceptions with his thoughts on what he referred to as 'careerism' in our society (sort of like: workaholics). At the time, I thought this was preposterous.

One evening, during Reville's share of the load, discussion turns to a group called Gravediggaz, and their album *6 Feet Deep* – in particular their single 'Diary of a Madman' (this made no. 82 on the Billboard Hot 100 in July 1994). Reville finds the material distasteful, a preoccupation with morbid topics and devilish violence.

My own affinity for rap music and innovators like Prince Paul and RZA (the producers of *6 Feet Deep*) meant we were going to disagree on this issue. In my opinion, the group was deliberately exploring an aesthetic and not actually condoning ... whatever it was that Reville thought they were condoning. Another student mentioned satire, and that if it were a rock group perhaps we wouldn't be having this discussion. I like that guy. Mr. Reville seems unconvinced, but I'm adamant that few people view Gravediggaz as anything other than gallows showmanship.

In any case, it never occurred to me that Mad folk or consumer-survivors even existed before I enrolled on the Reville and Ward class, and I admit that I was ignorant about the very concept of madness (but still very curious, even if I blindly subscribed to the medical model). I sort of assumed

that 'the insane' should be institutionalized and drugged, since doctors had all the answers. My own anxieties seemed like a silly game when compared to someone like Khari, living with, and effectively subscribing to, a diagnosis of schizophrenia – probably the most mysterious and stigmatized of all the psychiatric disabilities. It's remarkable that a rapper living with a schizophrenia diagnosis over his head, and with no real interest in the politics of the Mad movement, has inspired me to pursue these matters on my own. To say nothing about the social and ideological influence of psychiatric disorders is not just to remain idle, but it's sloppy methodology.



Poster for the film *Mars Project* (2012)

I suppose coercion is a powerful force, especially behind the walls of a psychiatric institution or while under a CTO (Community Treatment Order; though I've heard these referred to as 'an Outpatient Commitment').

From what I can see, patient advocacy suffers because the attitude is that anyone with a psychiatric diagnosis lacks the mental fortitude to make reasonable decisions. There is a great, unenviable position that the Mad community is up against, and it's not just in the courts. Throughout North America, the police and the medical establishments – indeed a gamut of the general population – harbor what could be called superstitions such as: most 'psychotic' people possess super-human strength, or those diagnosed with schizophrenia (I fight not to use the term 'schizophrenic' because it's probably offensive) are inherently violent. Quite the opposite, I would add.

When I decided to produce the feature-length documentary *Mars Project*, due to the very nature of the spiritual narrative, I sought a highly dramatic look and intent. We scripted and shot short dramatic sequences, where a mysterious shamanic-wizard character (played by Khari) appears in a forest searching for something. He discovers a glowing trunk after which a 'third eye' opens on his forehead. Not unlike Khari's own journey of managing his psychological crisis through a spiritual process which he calls 'illumination', the wizard is a kind of thematic device, suggesting Khari's mysterious and often symbolic influence. Perhaps this serves as a metaphor for alternative treatments. And in my memory, Khari lives as a shamanic character: the dark figure at the back of the club, a kind of supernatural 'rap wizard' persona.

While droves of people moved to 'Occupy' everything, Reville, Khari and the rest of our cadre spent 2011 and most of 2012 in making the *Mars Project* feature-film a reality. We funded the project from our own coffers, from an online fundraising campaign and with a grant from the Liaison of Independent Filmmakers, Toronto. Imbuing the

spirit of independent filmmaking in Canada, we had to make some compromises but remained focused on the end-goal. Portraying these issues through the language of cinema can be strongly suggestive, yet allowing for a measure of interpretation sometimes missing in discourse about mental health issues. If we can inspire someone to re-think their assumptions concerning psychiatric categories, or simply to feel and empathize with Khari's experience – that's significant.

Undertaking this film has made a significant mark on me for many reasons, but I have to remind myself that this is Khari's life, these are his experiences and that he's living with all sorts of stigmas. The human in me finds some of Khari's experiences absolutely terrifying. So are some of the conclusions I've come to, namely, the shaky science behind the ideas of biological brain disposition and genetic basis to human behavior – though I'm adamant that these fields will yield new disciplines and discoveries. After half a decade actively gathering material for the *Mars Project*, I can't adequately describe how much this has broadened my views on mental health, diagnostic practice and psychiatry.

Producing this film has been a passionate project that sought to encourage dialogue about mental health issues, with the potential to shine a light on these topics internationally and in a contemporary context. These are issues that are beginning to manifest themselves in the mainstream culture, and hopefully *Mars Project* will benefit from this awakening.

More about the film *Mars Project*, including the trailer and other information, is available at www.marsprojectmovie.com

Jonathan Balazs was born and raised on the prairies of western Canada. He has grown into a multi-disciplinary artist, writer, photographer and filmmaker whose work often addresses issues of mental health and more sinister aspects of the human psyche. In 2010 he graduated from Ryerson University's Image Arts Film program. He lives and works in Toronto, Canada.

PERFORMING MAD PRIDE IN TORONTO

ruth ruth stackhouse

In 1993, celebrations of Psychiatric Survivor and Mad Pride began in Toronto. The Friendly Spike Theatre Band, a local community theatre of psychiatric survivors and others, has participated in the (nearly) yearly event by performing in the festival. From 2003 to 2010, we helped plan the celebrations by joining the organizing committee.

One of the things that organizing psychiatric survivor/Mad Pride events does is help to generate theatricality. It provides a stage for actors to transform their rage, frustration and love into culture, art and social action. In 2007, Friendly Spike worked with organizers to present the first annual Bed

Push Parade. During a 'recovery' conference in 2006, Rufus May, a survivor from the UK, challenged Toronto to stage a Bed Push, as he had done in 2005. Rufus had helped produce the Great Escape Bed Push from Brighton to Bedlam in an effort to raise awareness of the lack of choice in psychiatric institutions.

Organizers in Toronto's Mad Pride organizing committee were enthusiastic about taking up the challenge. Being a theatre company, Friendly Spike could not resist the opportunity to parade, and in 2007 we worked hard with other organizers to launch the spectacle. Toronto's Bed Push Parade returns each year as a reminder of our brilliant struggle, as we push from institution towards community.

This year marked twenty years of organizing Psychiatric Survivor/Mad Pride celebrations



Ruth Ruth Stackhouse celebrates Mad Pride in Toronto

mad Archives in Canada, Eh?

Members and volunteers of PSAT,
the Psychiatric Survivor Archive in Toronto,
describe what it's like to archive
the mad movement.



VOICE OF ANGER — A woman who gave her name as Ruth protests with about 40 others outside the Queen Street Mental Health Centre yesterday against what they called brutality by staff committed in the name of treatment.

(MARK ROZITIS: The Globe and Mail)

Photograph courtesy of the Psychiatric Survivor Archives of Toronto (PSAT) www.psychiatricurvivorarchives.com

Kevin Jackson: The Psychiatric Survivor Archives of Toronto has recognized the need to preserve our rich and diverse survivor heritage, which for too long has been ignored and trivialized by mainstream historians, researchers and medical professionals.

Don Weitz: PSAT is a unique, community-based resource organized and run by several mad and antipsychiatry activists. PSAT preserves and makes publicly accessible

in Toronto. The annual Bed Push paraded down Queen Street West on July 14th, World Mad Pride Day.

Performers abound. Join us next year!

ruth ruth stackhouse is a founder and director of the Friendly Spike Theatre Band, and a Critical Disability Studies student at York University where she is writing the history of her theatre company in the Mad Pride Movement. She is the 2011 recipient of the City of Toronto Access Award, and her work in mad people's community theatre was honored in 2012 by a Queen's Diamond Jubilee medal.



The Mad Pride 'Bed Push' parades down Queen Street, July 14, 2007



our own stories and achievements for our brothers and sisters, supporters, researchers, and the community. Our history empowers and inspires, and we're very proud of it.

Ruth Ruth: By participating as a board member of PSAT I have been able to learn about Mad people's history while helping others to do so. It is exciting to me as a member of the modern Mad people's community that our social ancestors shared in the same feisty spirit as we do! It makes me feel grounded and part of something great.

Geoff Reaume: Mad people's history as public history has been one of the most important goals of the archives since 2001, such as with the preservation, interpretation and memorialization of the 19th century Toronto Asylum boundary walls built by unpaid inmate labourers. This is history anyone can access and use to challenge past and present prejudices in our community about mad people, while also publicly acknowledging the previously ignored abilities of people who were literally hidden behind walls they themselves constructed.

Christina Foisy: I came to PSAT without any direct expertise in the field other than an interest in psychiatric survivor narratives – partly fueled by my family's experience with electroshock therapy. I wanted to know that I was not alone, and to hear stories of people who have been silenced by institutional frameworks of history-making and knowledge-production within psychiatry. I wanted to hear voices, overlapping and contradictory, repeating and retracing a history of solidarity. Archival records have a life of their own, and the role of every archivist is to listen to what they are trying to say without imposing any definitive interpretation onto them. Such an approach mirrors the struggle that many psychiatric survivors faced when dealing with medical labels and discourses that framed their identities and limited their potential to speak 'out of order'.

Mel Starkman: Through the years, in cooperation and in the spirit of community, PSAT has grown to be an integral part of the Toronto survivor/activist scene. It still continues to be a beacon to those who are faced with budgetary shortfalls in this bleak era of austerity and cutbacks, putting many more prosperous groups to the wall of diminishing returns. Starting on a shoestring, we have done remarkable work to preserve the memory, history and development of the survivor movement at home and far beyond in the international community. This unique work we leave to future historians and survivors.

Erick Fabris: The Psychiatric Survivor Archive continues to build from the work of people who have contributed with writing, art, research and publishing. As we continue to identify and restore existing collections, we wish to extend our invitation to all *Asylum* readers: Help us add to the archive to preserve our collective knowledge. Look us up online at psychiatricurvivorarchives.com – and get in touch.

MAD PEOPLE'S HISTORY COMES TO SCOTLAND!

Nyla Mehdi

Imagine a course which aims to explore issues relating to mental health where the perspectives of people deemed to be 'mad', 'insane' or 'mentally ill' are not only at the forefront of the curriculum but are presented as valid forms of knowledge in their own right. I must be crazy to think that such a course exists, right? Wrong. This is the essence of Mad People's History, a course pioneered in Canada by Geoffrey Reaume and now taught by David Reville and others at Ryerson University, Toronto. Along with a small group of other students, I have had the opportunity to study the Ryerson course here in Scotland via distance learning, through 'Oor Mad History', a community history project based at CAPS Independent Advocacy in Edinburgh.

Our study group consisted entirely of individuals with lived experience of a mental health problem. Regularly, over a five-month period, we met up to follow the course online. We covered topics such as 'Madness & Work', 'Great & Desperate Cures' and 'Intersections between Madness & Gender, Sexuality, Race and Class'.

I found the content of the course utterly fascinating, at times evoking strong feelings within myself as I learnt about the ways in which people with mental health problems have been treated not only by society but by those whose job it is to help such individuals, as recounted by those who have experienced this first hand. This was both an eye-opening and enlightening experience for me. Whilst I have been taught to be critical of the mental health system and issues relating to mental health and wellbeing during my time as an undergraduate psychology student, this has predominantly been from the perspective of mental health professionals themselves – as opposed to the views of those with lived experience of a mental health problem. As a fellow student on the course put it, "It's just so important that we are able to tell our story, our history, from our perspective".

Students in the group felt that the course highlighted issues relating to the level of power that psychiatrists have within our society, particularly in relation to the (sometimes forcible) use of medication. We were also interested to hear about what is happening in Canada and how it compares to here, with one student noting that survivor-run businesses have received government funding in Canada, unlike in Scotland where no such funding is available.

Another student writes that

... the main thing I will take away from the course is the strength of courage and determination on the part of activists we have heard about. With all the parallels that can be drawn from other civil rights movements, I can only say that these people will be remembered in the future as the individuals and groups that forced a change of thinking on the idea of mental illness. If experts in neuroscience and cognition can't even agree where the seat of our consciousness lies, or indeed some would say that it doesn't exist at all, then how can the medical community truly stand up and definitively say they know how to treat mental illness? I would certainly not say that they should not try, but the medical model needs to change to one where those seeking or needing treatment are included in the process as equal partners. We will get there in the end, and it is down to people like David Reville and the other activists that that journey is already well under way.

By studying Mad People's History, I've had the opportunity not only to learn from the course content but also from my fellow students, some of whom have been involved in various forms of mental health activism. Learning about the activism of others has inspired me to take a more active interest in the challenges that people face locally when they use the mental health services. It has also helped me to realise that I have the right to have my voice heard too, and that the knowledge that I have gained from my experiences is just as valid as professional perspectives. This has enabled me to feel confident enough to take more of an active role concerning my own treatment.

Thanks to funding from NHS Lothian's Mental Health and Wellbeing Team, we are currently developing our very own Mad People's History module, in collaboration with Ryerson University, CAPS Independent Advocacy and Edinburgh's Queen Margaret University (where the module will be taught). As with the Ryerson-based course, our module will place lived experience at the core of the curriculum. Students will be encouraged to think critically about mental health and the mental health system, enabling them to situate their own lived



Members of the Mad People's History group enjoy a Mad Hatter's tea party



Kirsten Maclean, Nyla Mehdi and Elaine Ballantyne at the conference in Finland

experience within the wider socio-cultural and historical contexts of local, national and international activism, and to identify themselves as ‘experts by experience’. To the best of my knowledge, no course like this currently exists in the UK. Needless to say, everyone involved is excited at the prospect of one becoming available in a university setting!

‘Mad People’s History and Identity’ will be taught as an access-level undergraduate degree module by visiting lecturers with lived experience of mental health issues. The module is set to receive its first cohort of students in 2014. It is unique in that it does not require students to have any formal qualifications or prior educational experience in order to enrol on the course. Instead, the only prerequisite to attaining a place is that the student must have lived experience of a mental health problem. It is envisioned that in future years, the module will be open not only to those with lived experience of a mental health problem, but to anyone who has an interest in the topics covered by the course. In particular, a number of mental health professionals have expressed an interest in attending – which I find to be very encouraging! Our module has recently been approved by the Academic Board at Queen Margaret University. So watch this space!

Nyla Mehdi is a recent graduate in psychology, and a mental health service user. She works as an assistant psychologist and support worker and is also a volunteer with the Oor Mad History project based at CAPS Independent Advocacy, where she is part of the module team developing a Mad People’s History course at Queen Margaret University in Edinburgh, Scotland.

MADNESS: A BEGINNER’S GUIDE

annu saini

Madness, for me, is like having sex in a stairwell: it can be difficult, but it yields its own special brand of pleasure and to people watching – and people DO watch – it’s both beautiful and awkward. The echoing noises are vaguely musical but strange and grotesque at the same time.

I couldn’t tell you when I first ‘went mad’ anymore that I can tell you when I first ‘became queer’. Maybe it was when I was ten and I made imaginary friends with Adam West (as Batman). I spoke to him incessantly under my breath which inspired both annoyance and worry in my parents. On second thought, that was probably considered ‘normal’. Lots of children have imaginary friends. I think I was just lonely.

Maybe I ‘went mad’ when I became overwhelmed with the pain of growing up in an abusive home. I began to etch bloody words into the skin of my forearms with a compass from my school math set. The scars healed and in watching them, I was reminded of my own strength. The process healed my wounds and my heart. So I guess that actually made a certain amount of sense too.

Later in my life, when most would call me an adult, things got worse. I got really paranoid. I felt like people were

after me. I didn’t feel like I could trust anyone, and I felt like people were robots. (This last thought frightened me the most.) Because of family violence, the police came to my house several times a day for about a week. So that explains feeling like people were after me. They were after me. They were the police and they wouldn’t leave me alone! When the feelings came on really strong, I had just been sexually assaulted the last of several times in my life. I had also been beaten-up the last of countless times in my life. I felt like people couldn’t be people. They had to be robots, or else how could they have treated me so badly? It seemed so clear to me that the people beating me up and sexually assaulting me needed help, but instead, people pathologized me by keeping on calling me the sick one. People called me crazy. This was so confusing to me.

It wasn’t long after I started to feel this way that I was incarcerated at the Centre for Addiction and Mental Health. People say that it is one of the best places for people with ‘mental illnesses’. There I was, strapped down to a gurney in a small empty room with cement walls painted eggshell white. I was drugged against my will and denied access to a phone to talk to my lawyer or my loved ones. The next day, when I came out of my drug-induced coma, I ended up

acting as 'normal' as I could and asking them to let me leave so I could go to a fabricated job interview. I got permission to leave, I left, and never returned.

It was several months after I got my first official diagnosis that I figured out that madness, like queerness, is less about who you are and what you do than about who the people in power are and what they do. Take Dick Cheney and Patrick Daniel. They are two people in power. What do they do? They make tons of money off of foreign oil, with the companies Haliburton and Enbridge. Who's sane? The tens of thousands of people who sign up for the military to kill mostly brown bodies. Who's insane? The same people who return deeply disturbed and traumatized by what they've witnessed. Madness is about who has power and what they do.

So, while I felt like I had put part of the puzzle together in figuring out that madness, like race, is socially constructed – that is, it is made up by people in power – this wasn't only part of the puzzle for me. I was definitely going through something real, though I didn't think it was 'a mental illness', like the doctors said.

In fact, I'm not alone in questioning the whole concept of mental illness. The entire concept of illness rests on the notion that people who are 'ill' have symptoms that people who are 'well' don't have. So for example, if you have a kidney infection, you have a higher than normal level of bacteria in your kidney which causes a fever and pain which you wouldn't have if you were 'well'. But people with 'mental illnesses' don't experience any symptoms that their 'well' or 'sane' counterparts don't experience. Everyone feels sad, makes things up, and even hears voices in their head from time to time.

When I was incarcerated with other mad people again, this time for longer than one night, I began to realize that most, if not all of the people that I was incarcerated with, like me, had a broken heart. Some of them had been broken like mine, by getting beaten up or sexually assaulted one or more times. Some had been broken by people hating on them for being different (something that I was no stranger to either), the way that people sometimes hate on you for dancing around in a convenience store. I noticed that although our hearts had been broken, they were also still

beating, because that's what hearts do. After all, we are just people like everyone else.

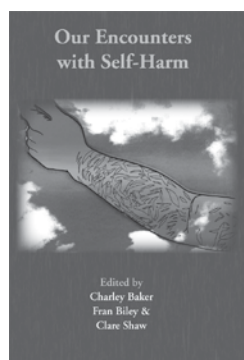
As a writer, I'm obsessed with words. There are some words that I'm constantly trying to figure out how to use. One of them is 'misnomer'. This is a funny word. It refers to something that is named in a way that doesn't really reflect what it is. It's when the word for something is just wrong. Everything I went through with doctors, hospitals and 'mental health professionals' has taught me that 'the mental health system' is a misnomer. Although the name suggests that the system makes your health better, this is not the case. When you're in the mental health system you try your best not to die. It is something that, if you are strong and lucky, you survive. That's why people call themselves 'psychiatric survivors'.

When I went to the hospital and told them I was suicidal the doctor gave me a prescription for very toxic drugs that would help me sleep. It seemed to me that they had heard that I wanted to die and they were providing me with effective tools to kill myself. In fact, that's exactly what they did, and many people do die that way: they suicide using psychiatric medications.

I managed to resist the urge. Instead I swallowed the prescribed dose. I slept deeply for the first time in several weeks, maybe even months. I woke up groggy and disoriented. After some time had passed, I picked up the book I had been reading on my bedside table. As hard as I tried, I couldn't read it. I couldn't focus on the characters or make sense of the words. I began to cry, and like a child reborn and given the responsibility to parent itself, I gathered my emotions and began slowly to recall and teach myself how to read.

This is how my time is spent since then until now. I teach myself things I once knew how to do: read, love, be. I have begun to love my own strength and embark on an amateur, flawed repair job of my bruised and broken heart.

annu saini is a poet, writer and activist. You can find her work in *make/shift* magazine or the upcoming book *Dear Sister: Letters from Survivors of Sexual Violence*. Every third Saturday of the month, she also co-hosts the show *Frequency Feminisms* on radioregent.com and www.frequencyfeminisms.wordpress.com



Our Encounters with Self-harm

Edited by Charley Baker, Clare Shaw & Fran Biley

ISBN 978-1-906254-63-6

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This volume brings together a range of voices on the theme of self-harm – from those who have experienced self-harm directly, alongside the friends, family and staff who live and work with self-harm. Too often, our understanding of the unique and complex experiences of people who self-harm is limited to concepts of mental illness, disorder and disease. Yet these stories demonstrate the strength, survival and recovery of people with rich and diverse lives.

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series collects together unmediated, unsanitised narratives by mental health service users, past service users, carers and professionals.



our encounters with madness

Alec Grant, Fran Biley & Hannah Walker (eds), 2011

our encounters with suicide

Alec Grant, Judith Haire, Fran Biley & Brendan Stone (eds), 2013

NOT A REAL ACTIVIST:

Finding the Mad activism that works for you

PhebeAnn
Wolframe

Initially, I was reluctant to submit something to this issue of *Asylum* because I often feel like an impostor or a fraud in the Mad community. There are a couple of reasons for this. First, I do not live in Toronto, or anywhere near an established group of Mad activists; as such, I feel estranged from explicitly politicized Mad communities. Second, even when I recently lived in the Greater Toronto Area, I'm not sure that I was really an activist. I signed petitions, I wrote to politicians once in a while, occasionally I went to a demonstration, I briefly sat on a couple of boards, and sometimes I even attempted to organize things. However, I was nowhere near as active and dedicated as many of the people I know and admire in the Toronto Mad community.

Thinking through my feeling of being an impostor in the Mad community, however, has led me to ask myself a couple of questions that I think are worth posing. These are: Who gets access to Mad community? To what extent is Mad community geographically restricted? What constitutes Mad community? And, if Mad community is about activism, what counts as activism?

These questions came out of my own experiences in the Toronto Mad community. But if they are not already asking them, I think they are questions that people should be asking in other Mad communities as well.

When I broke away from the psych system, I did not know that there was a Mad movement, and though I'd met plenty of people who had complaints about their psychiatrists, it didn't occur to me that this was something people might organize around, or that the problems I experienced in the mental health system might be, well, systemic. I stopped taking my cocktail of meds – cold turkey since I didn't know any better – because I had decided that, since they were not fixing my life, I should probably try a different approach.

That different approach (a story for another time) worked well enough that I made my way through an undergraduate degree and into a graduate program in English Literature and Cultural Studies at McMaster University in Hamilton, Ontario. It was there, while doing unrelated research, that I first stumbled across a reference to the psychiatric survivor movement. Following this discovery, I read all I could about the history of psychiatric resistance. A year later, I had finally worked up the courage to meet some people in the Mad community.

My first step in doing this was, as a visiting student, to take Geoffrey Reaume's Mad People's History course in the Department of Disability Studies at York University in Toronto. My department let me do this because, by this point, I had decided and had told them, that my PhD project was going to be about Mad women in literature. I know lots of Mad people who are critical of academia, and I share many of their criticisms. However, I, for one, would have probably never discovered Mad community without my academic experience.

When I first became involved in the Mad community, I had to commute one hour by bus to Toronto to do it.

There was not much of a Mad community in Hamilton, where I lived until six months ago. While I wanted very much to be involved in the Mad community, I found it time-consuming, exhausting, and expensive to get to, and then to navigate, a crowded and unfamiliar city. Although I found support in the Mad community in Toronto, I also found it stressful at times to participate in Mad organizations where, as in any organization, conflict is inevitable. To have to face an extensive commute after a stressful meeting was so unpleasant that sometimes I would just sit at the bus depot for a time, reading a book so as to avoid the commute home and my turbulent thoughts about my involvement with the Mad community.

Especially since I did not live in Toronto, where most of the Mad people I knew lived, it was difficult for me to socialize with them regularly. As such, my relationship to the Mad community often felt quite business-like, when secretly, I think, I was hoping for more of a chosen family, for the closeness I had read about in books on the Mad movement. I tried to establish Mad connections in Hamilton, so that I would not have to go so far afield to find a community, but I was not particularly successful at that, either. Maybe I'm not charismatic enough; maybe I was too busy (almost) going nuts (again) over grad school – an exceedingly stressful occupation, as I think anyone who has been there knows. In fact, in the third year of my PhD program, at the height of my involvement (albeit minimal, compared to some) in Mad organizing, I was burning out, overwhelmed and considering dropping out of school entirely. Instead, I moved back to my home town, Thunder Bay, in Northern Ontario, where I hoped to gain some perspective on my life.

Like Dorothy in *The Wizard of Oz*, one of the things I have come to realize since I moved home is that part of what I was looking for in the Mad community in Toronto was right here in my own back yard in Thunder Bay, long before I'd even heard of the psychiatric survivor movement. When reconnecting with some of my old friends here, I realized that the people I befriended as a 'mentally ill' teenager were other crazy people. We didn't call ourselves 'psych survivors' or 'Mad community', and none of us were activists in or against the mental health system, but one thing we all had in common is that we had all been psychiatrized and were critical of that experience. If one of the goals of the Mad movement is to connect Mad people together and to build alternatives, then we were, in fact, a Mad community. We were each other's main support system and provided each other with a sense of community that kept us, for the most part, un-institutionalized.

Realizing that I did, in fact, have Mad community as a young person, even if I did not have a political language to accompany it, has made me reconsider what counts as Mad community.

In major urban centres, where Mad activism has a long and continuing history, I think that Mad community sometimes becomes a bit insular. People who are part of an established group can, I think, pretty easily forget how hard it is to get established. Mad people



in established urban communities may sometimes overlook the fact that for people in smaller centres, Mad community and activism may look quite different than it does in Toronto, Vancouver or Portland – or in London, UK.

Some people in the Mad community in Toronto have told me that academic work on madness, for example, is not Mad activist work. Activist work, they claim, involves direct action, and tackles issues that immediately affect the lives of Mad people. While I think that direct action approaches are important, I argue that writing and speaking about alternate perspectives on madness and Mad issues – in both academic and non-academic contexts – is also essential, especially in places where there is no existing grassroots or institutional infrastructure upon which to build one's Mad organizing.

Here in Thunder Bay, I am learning to develop my own sense of Mad community and activism. I have connected with people who, while they may not participate in c/s/x/m¹ political action, have experienced psychiatrization, and know, from their own lived experiences what I am talking about when I criticize psychiatry. I talk to the people I spend time with – artists, students, social workers, family members, old friends of the family, former professors, fellow feminists and queer folk, and yes, psychiatrized people, too – about alternate perspectives on 'mental health'. I continue to write about Mad history, Mad politics, Mad activisms and Mad literature in my thesis, in academic publications, in short stories and poems, in letters to the editor, and in facebook posts and tweets which others discuss and share. Next fall, I am going to be teaching a course on Mad women in literature through the Women's

1. c/s/x/m: consumer/survivor/ex-patient/mad

THE CONSUMER/SURVIVOR TIMEBANK

Madness Meets Marxism

Andrea White

Longing to eschew the endless debates about identity and oppression and the what and the why of madness, never mind the medication debate, I wrote a brief grant proposal to fund an alternative currency program.

Thankfully, the Reva Gerstein Legacy Fund found my idea to be one worthy of support. So we are currently working on pulling together folks to share their skills and talents, and to find alternative ways of support without having to deal with the drudgery of the mental patient career – i.e., seeking social services upon an ever-shifting and increasingly austere social service terrain. Do you live in a priority neighbourhood? Complex mental health needs? Medication compliant?

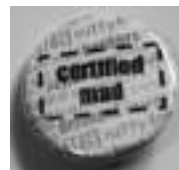
We don't care about any of that stuff: whom you vote for, or if you've read your Foucault at bedtime. We just want folks to be willing to contribute, and to have an interest in doing things differently. We deal in time, and all work is of equal value. Membership is free. You earn timedollars by helping someone out, teaching a class or sharing a skill. You spend timedollars by 'purchasing' a service. You cat-sit for me, I help someone with a doctor's appointment, she mows

Studies department at Lakehead University, where I did my undergraduate work. I have maintained, and in some cases furthered, some of the fledgling friendships and associations I developed in the Mad community in Toronto via facebook, twitter, listservs, and correspondence by both email and good ol' fashioned letters sent by post.

Despite my initial claim that I am not an activist, what I want to suggest is that all of these forms of communication, sharing and community-building are activism. All of these things are worthy things for Mad people to do, things that should 'count' just as much as doing direct advocacy as part of an established group, sitting on a board or committee, or marching in the Mad Pride Bed Push. Not all of us are going to do activism in the narrowly defined sense of direct action. Not all of us can do that kind of activism, for various reasons: these include the nature of our madness, disAbility or disAbilities, mental and/or physical difference(s), and our histories of psychiatrization and/or criminalization. But that does not mean that we are not part of Mad community or that we are not activists.

I am inviting you to think of the Mad community as bigger than the boundaries of your Mad community, bigger even, than what is visible in any given book, listserv, google search or archive. Mad community happens in small places, and there are small, everyday ways to do Mad activism. C/s/x/m community can be quite dispersed – it can happen in moments, not just in movements. I think that finding those moments, in itself, is a form of activism.

phebeann w olframe is a psychiatric survivor and a PhD student living in Thunder Bay, Ontario.



the lawn for someone, and on and on. We are also hoping to hold a monthly community meeting to check in with folks and share some food and maybe talk activism.

We hope that involvement raises self-confidence, reduces the need for services, and generally makes people's lives better and more bearable in a big city. We remain in the shadow of an institution (Centre for Addiction and Mental Health) that is ever re-fashioning itself, and never quite abandoning its dark history of oppression and coercion.

We are looking for folks primarily in the Toronto area, but if there is national and international interest in forming a network where we exchange info and expertise, we will gladly initiate that.

We are out of the asylum and in the neighbourhood. We may as well be nice to each other, share our talents, and try to get along.

If you would like more information on the Consumer/Survivor Timebank, please contact us at c.s.timebanking@gmail.com.

Andrea White has an MA in social anthropology and lives in Toronto. She has been involved with the Psychiatric Survivor Archives of Toronto, and hopes one day to find a paying gig.



What I've learned about organizing from activists in Toronto's mad movement



Over the past couple of years, I've been fortunate to get to organize with and learn from a number of Toronto's mad activists. They've taught me a few things about organizing that I think are worth sharing.

- Don't be afraid to move. To move on, to move forward, to move beyond. Remember: they're called social 'move'ments for a reason. Get together. Move together. Organize!
- Get pissed off. Channel that anger and let it motivate you.
- Recognize there's something wrong here. Bring trusted people together to talk about and identify the problem. Figure out what's going on, who the enemy is and the best ways to respond.
- Community care is self-care. Engaging in collective struggle gives us purpose. Personally, it gives me a reason to get out of bed in the morning. Fighting alone is hard. Fighting in solidarity with others makes us stronger. Recognize how our struggles are shared and work with others to tackle them together.
- Find the right people to work with.
- Get useful information from those in the know. Use that information strategically. Find key people within organizations who can help make change happen.
- Use your resources wisely. Use the tools you have in innovative ways. Use social media. Use whatever you've got to get the word out high and low.
- Don't be afraid to ruffle feathers.
- Wear your message! On buttons, on t-shirts, on hats, on wheelchairs. Be creative and get that message out wherever your wardrobe allows.
- Engage people you know in conversations that matter: in person, on the phone, online. Let them know why they should be concerned, why we should all be concerned.
- Connect with other social movements. Many issues such as poverty, discrimination and violence affect a number of our communities. We'll need to work together in order to form a resistance that can take on these issues.
- Plan ahead: ensure events and communications are fully accessible.
- Get the turnout. Make sure you've got the right people in the room and you've packed the house.
- If you threaten to do something, be sure you're ready to back it up.
- Serious activism can still be fun. This is something I've heard from other activists like UK-based fat activist Charlotte Cooper, and I've experienced first-hand from working with local advocacy groups.
- Laugh. Laugh together and laugh out loud. As the author Thomas King said in a recent radio interview (Q on CBC Radio, November 14, 2012) use humor, satire and sarcasm to communicate how an issue will affect people. You can't just tell people what to think, but if you tell them a story and get them to pause and consider your position, you might just change their minds.
- Celebrate the small victories. Seeing that change is possible, even in small ways, is energizing.
- Don't burn your bridges. It's a small community and we need each other.
- Mentoring matters: we need to continue passing on knowledge to the next generation of mad activists.
- Do it with love; fight from the heart.
- Dare to imagine other possible futures, ones where we actually win.

danielle landry is a mad student and activist living in Toronto.

REMEMBERING MAD ACTIVISM IN TORONTO

David Reville

Introduction

In the winter of 1965, three of us were on a day-pass from the Toronto Psychiatric Hospital and we were shooting the breeze in a bar across the street from the hospital. One of my companions was a crazy psychiatrist and the other was a crazy mathematician. Me, I was just a crazy former law student. In a few weeks they would go back to psychiatry and mathematics. I had no clue where I was going, nor how long it was going to take me to get there.

Skip ahead almost fifty years. I am an adjunct-professor in the School of Disability Studies at Ryerson University. This is a very urban university, and that's good because I'm a very urban guy. At Ryerson, I teach Mad People's History. Much

of what I teach I remember; what I forget I can often find out because I know a lot of people to ask. What follows comes mostly from my memory. If I've got it wrong, I expect there are people who will correct me.

Setting the table¹ (wherein stuff happens to set up the mad movement)

Scroll back to 1967. I'm disguised as a hippie, a nice change from my previous disguise: chronic mental patient. I know I was a chronic mental patient because I'd just spent more than a year in that part of the mental hospital where they

1. For Mad People's History, I developed a metaphor to describe the mad movement. You can watch it on Youtube: <http://www.youtube.com/watch?v=9uTbEBPkAAk>

store chronic mental patients. I've just published an article in the Queen's University Graduate Quarterly, *Gavel*. The article is critical of the mental health system – criticism that the mental health system has ignored for lo! these many years. So much for The Mightiness of the Pen.

By 1972, the counter-culture has gone mainstream: everybody's a hippie. My new partner, Cathy Jones, who wears embroidered jeans and a long braid, runs a co-operative nursery school. She's plugged into many activisms. She hooks me up with Barry Morris, a United Church street minister who introduces me to R Allan McChesney and Don Weitz. Allan wants to set up a storefront law office and Don wants to bring down psychiatry. The storefront is established within months and continues to operate to this day. Bringing down psychiatry is going to take a bit longer.

Turning (over) the tables, wherein mad people sometimes turn the tables, turn over the tables or both

The first 'action' I remember was paying a visit to the Leader of the Opposition. We thought mental patients should be able to vote in elections. There was no legal barrier to mental patients voting. Rather, it was a bureaucratic problem: people in mental hospitals weren't enumerated and therefore they weren't on the Voters' List.

The second 'action' was more of a pronouncement. Don had been to visit the Mental Patients Association in Vancouver. On his return to Toronto, he pronounced: "I'm going to set up an Ontario Mental Patients Association". He did, four years later, in 1977. The founding meeting was at All Saints Church, at the gritty corner of Dundas and Sherbourne, just east of the downtown. Originally named the Ontario Mental Patients Association, it was renamed On Our Own in tribute to Judi Chamberlin's seminal book *On Our Own: Patient-Controlled Alternatives to the Mental Health System*.

On Our Own would survive twenty years, lurching from crisis to crisis (as seems appropriate). It operated a drop-in centre, a store (The Mad Market), and published an anti-psychiatry magazine called *Phoenix Rising: The Voice of the Psychiatrized*.²

Getting a seat at the table (wherein mad people sit down with their tormentors)

It's 1982, and the mayor of Toronto is feeling the heat. The failed de-institutionalization policy of the Ontario government has dumped 2,000 former mental patients into a west end neighbourhood called Parkdale. Everybody is up in arms: the good guys because the housing is so crappy, the bad guys because they see former mental patients as 'garbage'. No fool he, the mayor sets up the Gerstein Task Force, so named because a well-connected psychologist named Reva Gerstein will be leading it. However, before he does so, he requests input from the crazy city councillors. Councillor Reville tells

2. Thanks to the Psychiatric Survivors Archives of Toronto (PSAT) all of the *Phoenix* issues are available at www.psychiatricurvivorarchives.com



the mayor that he won't support the Task Force unless there are former mental patients on it.

Enter Pat Capponi. Pat had been sent from a psych hospital to live in a crappy Parkdale boarding and lodging house.³ Within a couple of years she was showing the people of Toronto just how crappy they were. Reluctantly, she agreed to serve on the Gerstein Task Force and, because of her presence there, the Task Force Report made recommendations of real benefit to mad people, not just in Toronto but nationally.

The appointment of Pat to the Task Force was an early example of what the mental health system called 'consumer participation'. (In the UK: 'user involvement'.) By 1990, the principle of consumer participation was well enough established that the provincial government offered Pat a seat on a legislative subcommittee that was considering community mental health legislation. Fed up with being the token crazy, Pat agreed on condition that two other mad people got appointed as well.⁴

Getting tables of our own (wherein mad people establish self-help groups and (some of them) get government funding)

On Our Own was the first group of mad people which had a table of its own. And for a long time it remained the only group. But Away Express opened for business in 1987, and two years later came Fresh Start Cleaning and Maintenance.

In Ontario, it wasn't until 1992 that mad people got serious money. That year the government of Ontario brought in a number of anti-recession measures, one of which was the establishment of the Consumer Survivor Development Initiative. This funded thirty-six groups across Ontario.

And so On Our Own, A-Way Express (www.awaycourier.ca), and Fresh Start Cleaning and Maintenance (www.freshstartclean.com) began to receive funding. There was also funding for several new groups in the city: Toronto Psychiatric Survivors, Consumer/Survivor Information Resource Centre (www.csinfo.ca), Job Quest, Breakaway Survivors and Friends and Advocates. Two provincial groups were also funded: the Ontario Psychiatric Survivors Alliance (OPSA) and the Consumer Survivor Business Council (now known as Working for Change). OPSA didn't last long but it organized groups all over Ontario. On the other hand, Working for Change seems to go from strength to strength.

A kind of survivor training school was also funded: the Leadership Facilitation Program. Its leader was Pat Capponi, and its headquarters was the Gerstein Centre, the non-medical crisis centre recommended by the Gerstein Task Force.

Other groups also emerged, which neither applied for nor received government funding. One important unfunded group was West End Survivors which, in 1993, organized the very first Psychiatric Survivor Pride Day.⁵

3. See *Upstairs in the Crazy House: The life of a psychiatric survivor*. (1992) Toronto: Penguin.

4. To learn more about user involvement in Canada, see Church, K. (1996) *Forbidden Narratives: Critical autobiography as social science*. Routledge.

5. For more on Mad Pride, see: www.madprideto.com



Making tables and selling them (wherein mad people start businesses and pay themselves salaries and commissions)

From the get-go, mad people saw the need for economic development: so many mad people lived on social assistance, and it was tough for mad people to get jobs. So, as early as 1980, On Our Own was running the Mad Market. A-Way Express Couriers began offering courier services in 1987; this was founded by two service providers who were responding to the recommendations of the Gerstein Task Force. Fresh Start Cleaning and Maintenance opened its doors in 1989, and the Consumer Survivor Business Council (later the Ontario Council of Alternative Businesses, and now Working for Change) was founded in 1992. The Mad Market has been closed for a decade but A-Way Express, Fresh Start Cleaning and Maintenance and Working for Change all soldier on, at 26, 24 and 21 years old, respectively. It is, if I may say, a stunning act of resistance by mad people.

Tabling our critique (wherein mad people tell the world what's what – and what isn't)

Mad people are, by their very self-styling, a critique of psychiatry and the way society views madness and mad people. Mad people have been at pains to table their critiques in many ways.

So, Pat Capponi, not merely a facilitator, has published

seven books. Don Weitz, with colleague Bonnie Burstow, edited Canada's first collection of survivor tales. Working for Change (then the Ontario Council of Alternative Businesses) worked with filmmakers to create the documentary *Working Like Crazy* (NFB, 1999). More recently, the collective Recovering Our Stories called the mental health system on its mass production of 'patient porn'.⁶ The Mad Students Society⁷ began in Toronto and has grown to provide peer support to students all over North America; it maintains an ongoing critique of the post-secondary school system, as well as of mad stereotyping. And the Coalition for an Independent Psychiatric Patient Advocacy Office⁸ is critical of the government's dilution of advocacy services for mad people.

Conclusion

I've run 'the tables' rather more quickly than usual. In my online course, this story fills 6 (count'em) modules. My project here, though, is to provide some grounding to this issue of *Asylum*, which I recommend you read, comment on and share.

David Reville has been a mad activist since 1967.

6. Costa, Voronka, Landry, Reid, McFarlane, Reville & Church (2012) Recovering Our Stories: A small act of resistance. *Studies in Social Justice* 6:1.

7. www.madstudentsociety.com

8. www.cippao.com

Purple Is The Colour

Michael Voronka

Purple is the colour
Of my first love's dress
The colour of my head
When my head is a mess
Purple is the colour
Of Utopia
When the world is an inch
From heaven
Or less.
Purple is pleasure
And little white pills
The colour of flowers
That cover valleys and hills.
Purple is the colour
That sucks and that kills
The colour of candy
And wine when it spills.
Purple can last for hours
In messy attics and towers
But can never last for years ...
Unlike sorrow and sadness and tears.

(April 10, 1973 – April 12, 1994)

Heated Arid Earth

Matilda Ramacieri

Heated arid earth
felt cold rain.

I had given up,
was just
going through the motions,
in silent despair,

When you came into
my life.

Hurt turned slowly
into hope,

Because you loved me,
Because I know
you'll always love me,

no matter what
we may disagree about.

I remember
when I felt

alone

though my world
was filled,
with people,
wanting
to talk to me.

I feel safe and secure
in a way
I never have
before.

Every symbol
of your love,

from tulip stickers
on a paper heart,

to a handmade card,

to the lyrics of a song,

Remind me,
your love is there
always.

And though,
distance divides us,
And we've never
met in person,

I don't feel
alone, anymore.

Heated arid earth
felt cold rain,

And I live.

Matilda Ramacieri has bipolar mood disorder and has found a friend in someone who is in a group which also faces stigma – inmates. For three and a half years we have been writing and offering support and understanding. There is a big age difference, but we understand each other perfectly.

About this supposed healing

Cat Fitzpatrick

What did I understand or learn? I just
Got older, cried and drunk and fucked
Had a good time, bad time, whatever, had
A time and now you hear me say 'recall'.

Recall. Each interaction was a wound.
Each time I went to buy some milk and was
Misread I thought I'd have to die. I have
No words to call the ways I was. And is

It done? I ask, they ask, us healers all,
Hoping to see me all made up
And put together, good face on, as if

I could say anything we want to hear,
As if I could redeem these things instead
Of only screeching 'memory! revenge!'

Cat Fitzpatrick is an unwilling wanderer over the face of the earth. She has lived in London, Manchester and Toronto, and is currently lost somewhere in the New Jersey swamplands, swatting mosquitos, sinking deeper into the mud, and insisting she knows where she's going.

They're Whispering

Erika Hammel

I can hear them quietly talking
But can't make out all the words.
They're whispering about something,
Something unusual and absurd.

The look on their faces is strange –
Raised eyebrows, while frowning,
then nodding.
I wonder what they're talking about,
I can't just go to them, prodding.

They glance in my direction
Every once in a while.
I don't know whether to ignore them
Or just sit here and smile

Are they talking about me?
I wonder, as I sit there.
I'm dressed alright, I think,
As I check the clips in my hair.

I sip some more of my coffee
And try to think of my day.
I have a busy schedule.
Soon I'll be on my way

Gossiping women in coffee shops,
They're still whispering there.
I wish I could ignore them
And pretend I don't care

Must be my paranoia.
Why would they talk about me?
I'm just a stranger to them,
Sitting and having a coffee

Whispers always bother me
No matter where or who.
It's usually idle gossip
And none of it is true

Perhaps they're passing judgment
On how people live and look?
I guess it doesn't matter
As I finish reading my book.

Let them whisper their secrets
As I leave to go on my way.
I have nothing to worry about,
At least not today.

Erika Hammel is a Toronto poet (published in the book: All That is Real, Workman Arts, 2013). She also exhibited her poetry and artwork in the show 'Place' (Toronto, Fall 2013). She is a writer and visual artist who also composes and performs classical guitar music, and is a singer/songwriter of folk songs.

Shock Doctors Who Can't Wait¹

Don Weitz

For Elizabeth Ellis and all other
courageous women shock survivors – my sisters.

Wake up everybody
it's shock day every monday-wednesday-friday
in psychoprison Anoka
where 67-year-old Elizabeth Ellis
waits in silence, refuses to talk to
doctors who can't wait
to label her 'catatonic'
doctors who can't wait
to fire 200 volts
into her fragile aging brain
doctors who can't wait
to perform electrical lobotomies on her sisters
doctors who can't wait
to commit elder abuse
doctors who can't wait
to commit psychiatric rape
doctors who can't wait
to conspire with sons and husbands
to lock up and shock
daughters, mothers, grandmothers, wives
doctors who can't wait
to traumatize, re-traumatize, stigmatize
women labeled
depressed
bipolar
manic
histrionic
schizophrenic
post-partum
premenstrual dysphoric disorder
doctors who can't wait
to erase memories – 'side effects', collateral damage
doctors who can't wait
to damage brains,
doctors who can't wait
to destroy careers and lives

your daughter
your sister
your girlfriend
your mother
your grandmother could be next
doctors who can't wait
to silence voices of 'noncompliant patients', freedom
fighters –
doctors who can't wait
to con health ministers to fund shock mills
like Anoka, CAMH, Riverview, Bellevue, McLean,
Langley-Porter, Rockland State,
doctors who can't wait
to lie to patients, prisoners, families, lawyers, reporters
about 'safe, effective and lifesaving ECT'
to a disinterested disconnected world
ignorant, betrayed, brainwashed by
nazis in white coats who torture
in the name of DSM² and ECT³
who torture/lie/cover-up in the name of mental health
time to rise up, fight back
against psychiatric fascism
MAYDAY! MAYDAY!

1. Originally titled 'MAYDAY – Doctors Who Can't Wait'.
'Mayday' (m' aidez = help!) is the universal distress-emergency
call sent out by pilots in danger of crashing and captains whose
ships are about to sink. Revised and expanded, this poem was
first read at the Mayworks Poetry Marathon on May 1, 2011, and
then at another anti-shock protest, 'Stop Shocking Our Mothers
and Grandmothers', on May 7, 2011 in Toronto. Unpublished.

2. *Diagnostic and Statistical Manual of Mental Disorders*
– psychiatry's bible of unscientific diagnoses – or character
assassinations.

3. Electroconvulsive Therapy: a brain-damaging psychiatric
procedure more commonly and accurately called 'electroshock'.

*Don Weitz is a psychiatric survivor, antipsychiatry and social
justice activist for over 30 years, and author of the e-book
Rise Up/Fight Back. His chapter: 'Electroshock: Torture as
Treatment' appears in the anthology Mad Matters: A Critical
Reader in Canadian Mad Studies (2013). Don is also a member
of the Coalition Against Psychiatric Assault, co-founder of
Psychiatric Survivor Archives Toronto, and member of the
Ontario Coalition Against Poverty.*

CAMPUSES ARE TREATMENT CENTRES – OR ARE THEY?



Jenna Reid

Recently, the issue of mental health on post-secondary campuses has been a major issue in the media. *Macleans* magazine proclaimed “A Mental Health Crisis on Campus” (5 Sept, 2012). Using #brokengeneration, Macleans invited people to join the conversation on Twitter. (For those of you who are unfamiliar with it, Twitter is an online social networking service and microblogging service that enables its users to send and read text-based messages of up to 140 characters.) Actually, there were less than a dozen relevant posts when I looked up the posts on #brokengeneration, and about half were by university administrative bodies. Personally, I was thankful that this idea of linking the notion of ‘a broken generation’ with mad experiences on post-secondary campuses did not catch on in any large-scale way.

We have to ask ourselves the questions:

- What are the implications of focusing on the experiences of mental health as a crisis on campus?
- What are the implications of inciting participation via a hashtag labeled ‘broken generation’?

The term ‘broken generation’ in and of itself positions the problem within the individual, and positions it as one that is focused on notions of deficit and dysfunction. And so it follows that a large amount of our efforts are being focused on solving this ‘crisis on campus’ by working on and investing in the development and improvement of mental health services on campus.

In the report by Focus on Mental Health our attention is brought to the fact that on one university campus:

- Administration is quoted as seeing a 200% increase in students who were ‘homeless, suicidal, really sick’. However, the entire report focuses on services and service delivery and does not take up the issue of poverty and homelessness.

The report also largely focuses on:

- How we can train university staff and faculty to effectively police the development of ‘psychiatric symptoms’: a call to be more proficient at recognizing early signs and symptoms. Why is this? So we can make referrals to services. This has us (the university community) seeing actions of policing others as actions of compassion. The objectives are to identify and manage risks and to provide guidance regarding appropriate responses and referrals.

- Positioning it as ‘a crisis on campus’, the focus on mental health conference emphasizes the need to improve services and the need to encourage those who are in distress or considered to be acting or presenting outside of the norm to seek those services. There is a big focus on ‘pushing’ services onto or into campuses.
- So here we have the development of the character in our story: the university community (staff, faculty and students) are constructing the notion of the student at risk.
- A key phrase found within this story is ‘healthy campuses’. This is largely connecting to, and hiding behind, the rhetoric of stigma. As opposed to being seen as an issue about how mad students are treated or viewed negatively, stigma is viewed as an issue because it is something that inhibits people from seeking services.
- This rhetoric of stigma is conflated with the need to remove barriers to access. But access to what? Because all of the focus is on access to services and none is on access to programs, education or graduating.

We also have to consider that:

- formal support systems, services and treatments are not actually seen as useful or positive for all people.

Efforts to address the ‘crisis’ in mental health on post-secondary campuses have mainly focused on the improvement and development of mental health treatments and services. As a result of this, universities are positioning themselves as the next major mental health treatment facility.

Instead of stopping at a critique of this conundrum of ‘the broken generation’, I strongly urge us to refocus our efforts. We need to separate two conversations that are too easily conflated: that of mental health services, and that of the issue of access to education for mad people. Our mental health strategies need to base themselves in an understanding of madness as it is connected to a marginalized identity. Once we do that we can begin to partner with the mad community and other social movements so as to begin to put into action ways in which we can accommodate mad people in the post-secondary environment.

Jenna Reid first became involved in the mad movement as a response to her experiences as an undergraduate student.

ANTI-ANTI-STIGMA CAMPAIGNS

**"IT'S
ALL
IN YOUR
HEAD."**

OR, AS WE'RE DISCOVERING,
YOUR BRAIN.

Defeat denial.
Help defeat mental illness.



**"IT'S
NOT
ALL
IN YOUR
HEAD."**

POVERTY is REAL
EXCLUSION is REAL
DISCRIMINATION is REAL

NO ONE IS IN DENIAL!!!





If Lance Armstrong had overcome schizophrenia, would you have applauded?

We need your help to change attitudes. To dispel the belief that mental illness is somehow a threat or a weakness. To stop the stigma and stop people from seeking help.

STOP THE STIGMA.



I could “overcome” schizophrenia without pharmaceuticals. Could Lance Armstrong?

We need your help to change attitudes. To dispel the belief that mental illness is somehow a threat or a weakness. To stop the stigma and stop people from seeking help.

SUCK MY STIGMA.



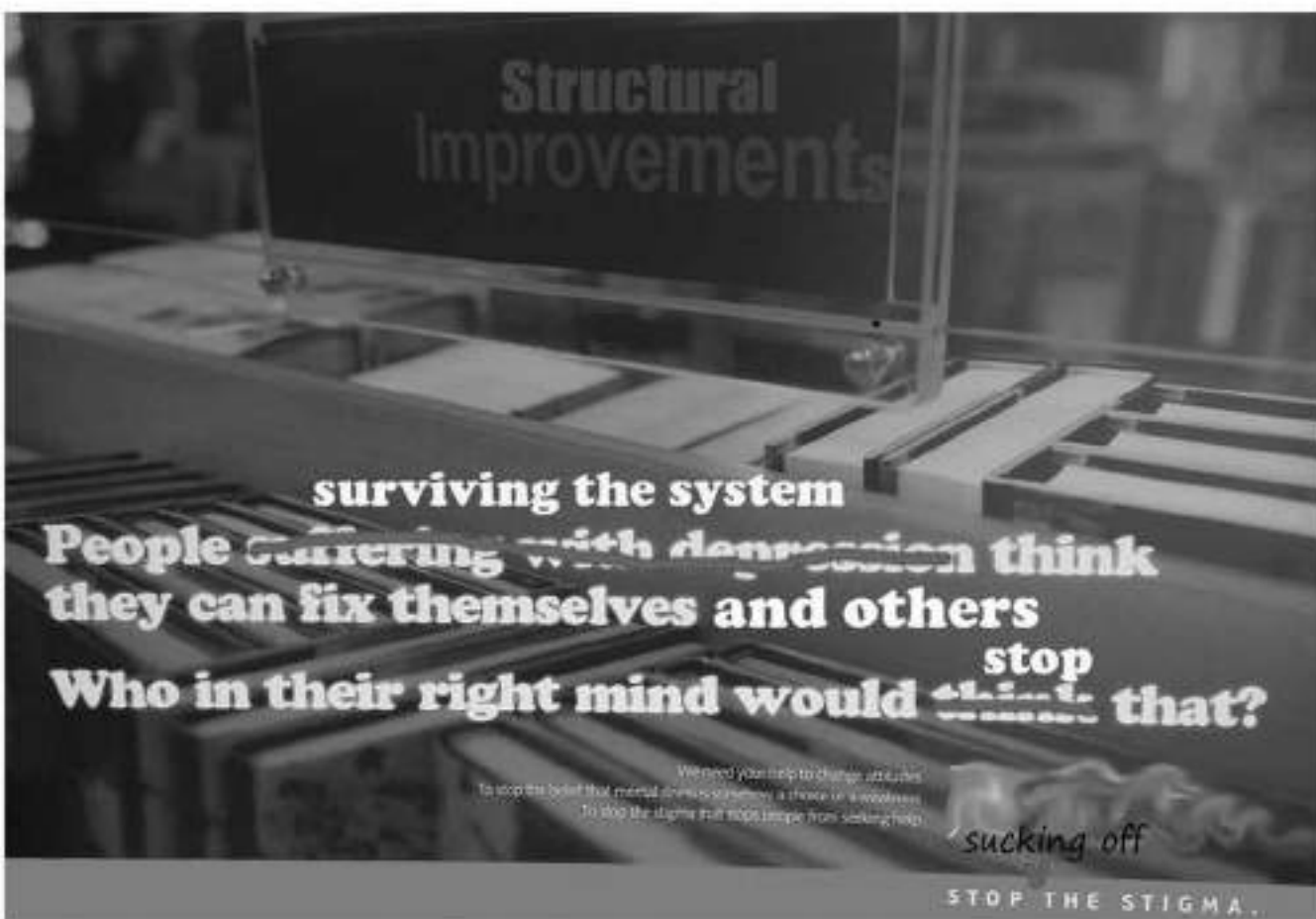
Self-Improvement

**People suffering with depression think
they can fix themselves.**

Who in their right mind would think that?

We need your help to change attitudes:
To stop the belief that mental illness is weakness, a choice or a weakness.
To stop the stigma that stops people from seeking help.

STOP THE STIGMA.



Structural Improvements

surviving the system

**People suffering with depression think
they can fix themselves and others**

Who in their right mind would ~~think~~ that?

We need your help to change attitudes:
To stop the belief that mental illness is weakness, a choice or a weakness.
To stop the stigma that stops people from seeking help.

stop

sucking off

STOP THE STIGMA.



In July, 2012 a group of c/s/mad identified people of colour got together at Mad Pride Toronto and, using our collective knowledge, constructed an alternative tree-shaped history of Mad Pride. Using sticky notes we posted our thoughts on the tree form in three different categories: the roots, the trunk and the branches and leaves.

The Trunk: Our Expressions of Mad Pride

- Finding ways to talk about suicidal ideation and craziness in POC spaces
- I am "out" about how I think and feel
- WOC writing about abuse, decolonization, trauma
- Being OK being myself, listening to voices, talking to imaginary companions, people and animals
- NEW TO MAD PRIDE... on the road to discovery
- Talking about spaces of madness and how they really feel
- Working with disability justice movement
- Fashion!
- Self-identifying as mad (sometimes) – advocating for others
- Reframing dominant conceptions
- Building QTPOC branch of Itanus project
- In Being Me
- I express my mad pride by sharing alternate histories of psychiatry with folks who assume that you are either sane or mentally ill and mention that different identities exist and that psy practices can be/are violent and implicated in colonial projects.

The Roots: Our Experiences of Mad Pride

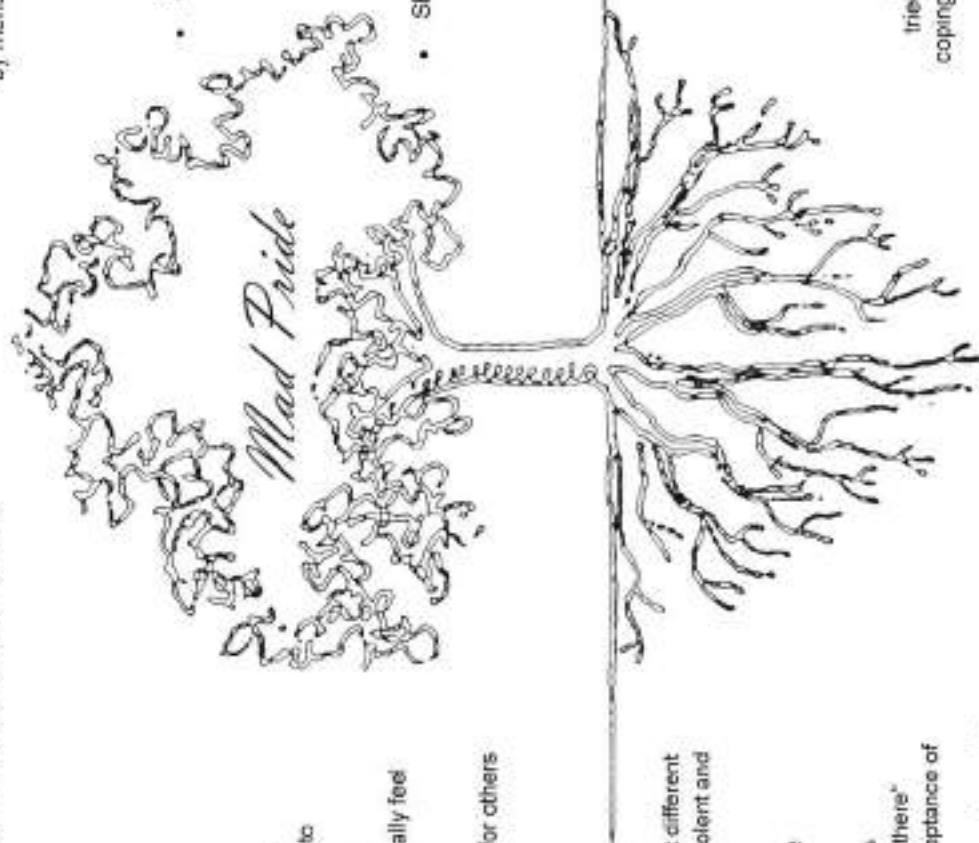
- Crazy people in Brown families
- Empowerment by angry mad anti-racist activists
- Mad Pride love - free, great class analysis, "out there"
- Mad Pride hurt - anger, judgment, pride vs. acceptance of shame process
- Mad Pride Grow: nuanced discussions, openness to new ideas
- Mad Pride: included + friendliness, fluidity
- Finally feeling included with POC only writing and discussion
- Lilith Finkler (queer Arab 0+) is main organizer of psych survivor pride in the late 80s
- Tons of White people survivors being defensive
- Feeling excluded, rarely found space at Mad Pride
- Learning to be proud of how I think and feel makes me strong
- It's hard to know how you fit in at Mad Pride
- I love meeting the new people
- Informal QTPOC crazy friends network

The Branches and Leaves : Our Goals For Mad Pride

- Have spaces/programs developed for mad people of colour to meet and organize and receive alternative health services that are not run by social workers or funded by mental health institutions and are free of White Buddhist yoga mamas
 - More POC events : We Are The Majority
- More Brown food (cooked vegetarian food) at Mad Pride
 - Decolonizing healthcare and well being
- Transforming non-crazy identified POC spaces to be less fucked up about madness
- Cross identity/intersectional organizing a prioritizing anti-ableism
 - Caring more for myself and not putting pressure on myself for always doing creative projects
 - Centrel/ re-centre indigenous and/or POC in organizing in framing madness/mad history
- ASSERTIVE EXPRESSIVE SELF-EMPOWERMENT
 - Taking back culturally appropriated spirituality and calling out white people on it
- SELF-RELIANCE and simultaneously MUTUAL AID INTERBEING
 - Breaking through inhibitions and feeling self-consciousness
 - I want a Mad Pride that centres indigenous peoples' and people of colour's experience
 - More reflection – have not thought about my identity as a mad person enough
- Finding and sharing decolonial healing tools
 - No more bullshit, fake shamanism
 - Community a more MAD P.O.C

The Roots (continued)

- Feeling excluded by the "mad" umbrella term and English
 - I love having a POC space
- Limits of reflection, meditation and anti-racist spirituality
- The amazing people I've met through Mad Pride have never tried to control or police my behavior and haven't judged my ways of coping or living. I haven't felt like I've been at risk of being reported even when I've felt like or have self-harmed
- When calling out how the Mindfreedom "Boycott Normal/Occupy Normal" campaign was colonialist in its use of occupy I was told by a White mad activist that I was being sanist which denied accountability and hurt me
- Have been to Mad Pride and tried to talk about POC experience... but its taken 6 years to develop a critical mass of mad POC
 - Confusion v. clarity
- Basic ideas are at Mad Pride, but don't centralize POC/Indigenous etc.
 - When I spoke others felt silent and ears appeared open
- 1 POC hurt me because I was the 1 Black woman in a room of 60 people
 - Time constraints, other people pulling me away



By Annu Saini, Louise Tam, Onar Usar,
Rachel Gorman, Leah Lakshmi Piepzna-Samarasinha and others.

MAD PEOPLE OF COLOR – A MANIFESTO

Rachel Gorman, annu saini, Louise Tam,
Onyinyechukwu Udegbe & Onar Usar

We are a group of queer, mad people of color who experience the ‘psy complex’ in different ways – sometimes as survivors, patients, ex-patients, or inmates of the racist, sexist, and oppressive psychiatric system, and sometimes through racist, sexist, and oppressive interventions by doctors, teachers, social workers, community members, or police.

We write this manifesto because we know that racism, sexism and oppression circulating in the system are also circulating in the mad movement.

Over the years we, and other mad people of color, have been in mad movement spaces – sometimes as organizers, and sometimes as participants. We have been present, vocal, and visible – bringing forward our concerns about racism, about our precarious legal status, about the experiences of working class immigrants, and about the violent and subtle ways that people of color are psychiatrized.

Yet each time we speak or write these truths, our perspectives are dismissed or deflected by people who want the mad movement to be white and middle-class.

We have been accused of attacking white people when we express our views. We have been called ‘sanist’ for talking about racism in the mad movement. How can it be that we are sanist when we criticize white people for being racist, but white people are not sanist when they call us angry and irrational? Tell us, is sanism something that only happens to white people?

We don’t believe in an oppression that only white people experience.

Audre Lorde taught us that when white people don’t confront their own racism, they blame people of color for ‘being angry’. We know why we are angry. Racism, sexism, and class oppression make us angry. We know why people attack us for being angry. Guilt, entitlement, and a refusal to work with us fuel your attacks.

White mad activists tell us that we are responsible for our own inclusion. We don’t want to be ‘included’ in a white movement: we want you to take responsibility for keeping your movement white. The mad movement presents a mad identity based on white people’s experiences and white people’s theories. Tell us, is madness something that only white people experience?

We know that:

We are the experts of our own stories and experiences. We talk to each other. We read African theorists and theorists of color. We listen to each other’s experiences of being trans-national. We talk about surviving in more than one cultural context.

We cannot separate our experiences of racialization, madness, and other oppressions.

White people’s experiences of psychiatry are not ‘like colonialism’. Colonialism is like colonialism.

Race and disability have suddenly become an academic fad for white people.

We Demand:

- Stop asking us to educate you about racism, and then ignoring or contradicting us when we do.
- Stop basing your ideas about a collective mad identity on the dominant culture.
- Stop presenting the white mad movement as a culture to be celebrated as part of Canada’s multiculturalism.
- Stop saying things like “even people in prisons have it better than we do”. Some of us experience both.
- Make anti-racism and anti-oppression training a priority, especially for consumer/survivor organizations. If you want us to educate you, pay us.
- Acknowledge your racism and take action to end it.
- Ask yourself whether your goal as a mad activist is to regain the white middle-class privilege you lost when you were psychiatrized.
- Ask sincere questions, and then listen to the answers. If you are wondering if psychiatry is like colonization, ask someone who has experienced both! If you want to know if the hospital is worse than prison, ask someone who has experienced both!
- Stop pretending you’ve never heard these criticisms before. Stop pretending our work doesn’t matter. Stop pretending you’ve never heard of us. Stop pretending we don’t exist.
- Stop appropriating anti-racist struggles.¹

1. Most recently, this happened in New York City, when mad activists used Martin Luther King Day, and his writing on creative maladjustment, to protest mental health profiling. They did this without connecting his critique of psychology to ongoing struggles against anti-black racism.

IN WHOSE INTERESTS? COMPLICATING NARRATIVE RESEARCH

Kathryn Church

School of Disability Studies, Ryerson University

A couple of years ago, some activists in Toronto organized an event called *Recovering Our Stories*. They were concerned that a rash of story-snatching by traditional mental health organizations was robbing the psychiatric survivor community of the ways people use stories to organize collective resistance and social create change. As one of several panelists, they asked me to speak to the use of stories in research.

Over the past several decades, following the paradigm-cracking 'narrative turn' in the social and health sciences, working with stories emerged as a highly promising approach to inquiry and sharing research findings. An apt expression of the interpretive tradition, this approach is used in a range of disciplines as a holistic way of investigating complex questions. I have deep investments in narrative methodologies, and particularly in critical autobiography as a practice of feminist sociology. I did not come to life as a researcher until I started to work with stories – including my own. Stories are where I feel most at home and most effective in fighting the bureaucratic management of human life. So, to confront the perils of using stories in research was to examine and to deconstruct my own professional comfort, competence ... and hope.

In the research world, qualitative researchers – perhaps especially narrative researchers – tend to think well of ourselves. After all, we are not trading in large-scale surveys and cold, hard statistics to make our living. We are the humanizers – all about purpose and meaning. We take time to cultivate trust with participants. We are sensitive to their position; we are empathic, even emotional ... as we elicit their pain and articulate their dilemmas. The challenge of *Recovering Our Stories* was to face the possibility that – precisely because of these qualities – we may be the more potent enemy: the ones who by our very self-reflexivity have

figured out how to be *really* effective at stealing stories.

Research is about power – in the dramatic but also the mundane practices of our trade.

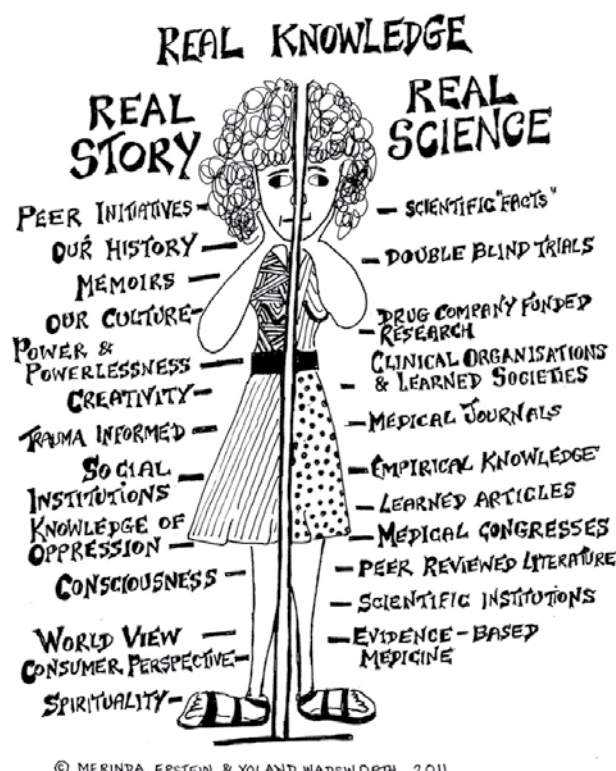
Regardless of the tradition we follow or the specific methods we use, research is about selecting certain words, ideas, characters, activities and events from where they occur naturally, lifting and transferring them into strikingly different circumstances – ones that are much more familiar and important to us than they are to study participants.

As researchers, we claim the power of translation – of interpretation. As we peek, peer, probe and poke, we are never neutral. Whether we want to or not, we carry the baggage of our profession and our organizational contexts.

Recovering our Stories got me thinking about the fact that long before we ever interview a research participant or host a focus group we have already written and 'sold' a couple of big stories. One of them is the Research Proposal, and the other is the Ethics Protocol. These 'tellings' are directed to players who

are hugely influential, even as they remain invisible. They are written for professional audiences, articulated through peer review to conventional definitions of (and debates over) science. They may be sophisticated and progressive – invoking whatever savvy we have about the way in which academic and other funding bodies work. They may specify essential accountabilities. Regardless, these documents establish the conceptual and institutional context for all of our more intimate (even authentic) encounters; for how those local conversations will be understood.

There is no innocent place to stand in this situation – no perfect procedure for getting it right. All we have is the struggle to be as clear and open as possible about the actualities



of our knowledge production, so that people can judge for themselves the legitimacy of what we offer.

So, what can politically alert researchers actually do?

We need to situate our studies to engage the fight against marginalization that communities face in the current political and economic climate. And that means dropping our objectivity and our notions of bias. The biggest struggle I have had working with members of the mad movement is to continuously unravel my professional distance so that the rage I feel in the face of outrageous acts is not muted or obliterated in my social science.

We need to conceptualize our studies outside of the dominant narratives that govern people's lives – as a prime example, the psychiatric narrative. Much of what I read in the community mental health literature fails to question bio-medical disease formulations. 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 – by 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 the difficulties of working across difference.

We need to be as aware and as up-front as possible about who we are as researchers. When I first started to practice, I took this suggestion quite literally ... writing from "I" and experimenting with autobiography as a form of critical social analysis. I still believe that 'first person political' is an important voice for researchers. But over the years, I have shifted away from the psychic self in order to engage more directly with my shifting social self, with how I wield it to form and implement research: my institutional locations and instrumentalities in creating results, my investments in particular kinds of outcomes and products.

Narrative methodology is not just about telling stories; it is about listening to them, too. A couple of things strike me here. In our research, we will miss many other vital storylines if we listen only for 'the lived experience' of individuals, and only for processes of illness and recovery. 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. And finally, in listening to what sound initially like individual stories, we must learn to perceive and reveal the bones of the large social institutions that shape the flesh-and-blood experience characteristic of personal stories. Once we've pushed into that terrain, voyeurism is fair game.

Advice for Study Participants

- You can say no. You can find people, groups, organizations who will help you say no.
- If you decide to say yes, you can tell your story the way you want to tell it. You can ignore the questions you are asked. Disclose as much or as little of your history as you want. And take the money anyway.
- Pick your spots. Ask a lot of questions about the project, the researcher, and the organization/site from which the study is being organized. Don't say yes right away. Take your time.
- If you decide to participate in a study, try to remember that your story is unlikely to appear in full form, or precisely in the way you gave it. There will be a translation, and you may or may not recognize your contribution.
- Ask for a copy of the final report. Read it. Circulate it to others. Ask them what they think.

kathryn church is Associate Professor and Director of the School of Disability Studies at Ryerson University, Toronto. She has been allied with the mad movement for 25 years.

merinda epstein has been working as an activist in mental health for almost 30 years. She has become increasingly committed to working outside 'the system', particularly writing and cartooning. She works for an Australian-based organisation called Our Consumer Place which is a resource centre for all people diagnosed with 'mental illness' and anyone else who is interested in what we think. In 2004 she won The Australian Human Rights Award in the community category.



DEAR MAD PRIDE, WITH GRATITUDE

On the affinities between mad and trans politics

Catherine Fitzpatrick



Are trans people mad? This can be an unfriendly question. A lot of psychiatrists have answered it with 'Yes'. The new *DSM-5* diagnosis is 'Gender Dysphoria'. In another sense, however, there might be a 'yes' I would be happy to give, and which I hope mad-identified people might be happy to accept. I think there is a real alliance to be made between people who get defined as 'trans' in one way or another, and those who get defined as mad. I feel that thinking about the notion of 'mad pride' has done a huge amount to help me understand my own position. Maybe this is a 'thank you' note.

Psychiatry is so acquisitive. One key way it captures is through naming. It pre-empts us in our own experiences. Its powers of coercion and compulsion go along with the power to tell us what we want and what to do about it. I had surgery to turn my penis into a vagina. Actually, I'm glad I did. But if I remember the way I got there, the desperate begging to get appointments, the need to win approval in them, the encounters with the surgeons who wanted to be satisfied of my maturity, the nurses who prepared me for surgery and told me how I should make sure to have sex after, it seems like the institutions I encountered took something, many things, I might have desired or wanted and made them part of a process in which my desire had no room to exist. The place it might have taken was already either filled up with their 'knowledge' about me, or worse, prepared for me by the questions they asked, so that I was led to pour my incipient self-understandings out in a way I would not otherwise have chosen, but which I took for my own.

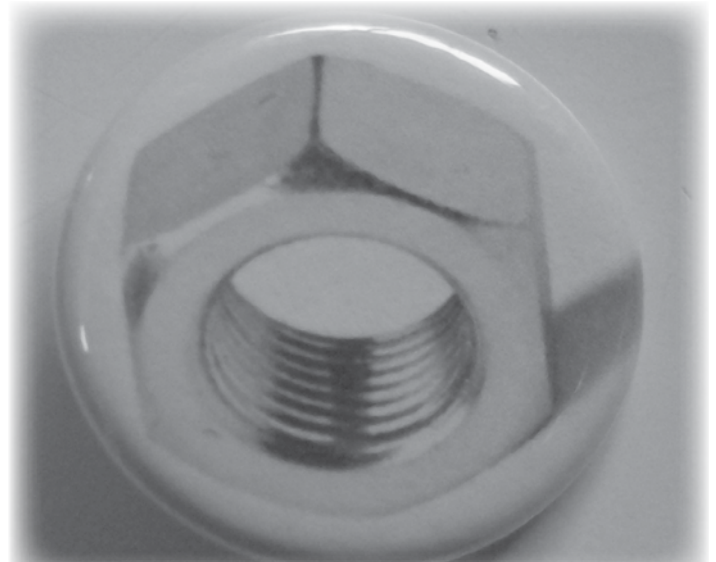
Psychiatry treats individuals it diagnoses 'gender dysphoric' differently from those with most other diagnoses, in that it exerts power over us primarily through what it does or might deny us (surgery, hormones, legal recognition) and only secondarily through things it forces us to do (RLE, therapy, gender conformity). But it also treats us the same way, in that it appropriates our experiences, and only gives them back to us in an alienated form. The words we have to talk about ourselves, the very boundaries of the group we constitute ourselves as part of, are their words, their boundaries. To contest them means re-inventing 'ourselves', and the more completely, the better. It is this understanding that my encounter with the idea of 'mad pride' led me to, and I am grateful for it.

Because of this shared experience of being defined by doctors, trans people and mad people (and perhaps others, including those who get medicalized as 'intersex', 'obese' or 'disabled') can stand together in contesting not only the medical institution's stories about us, but also the medical institution's stories about itself. We should all be interested in disputing the idea that if technologies currently considered medical are to be applied, it must be by people considered doctors. Many trans activists come up against the double bind that we argue against diagnoses that pathologize us, but that we also say we need some kind of diagnosis in order to access those services which we do want. I don't know, but I can imagine mad activists might sometimes encounter similar difficulties, perhaps particularly when doctors act as gatekeepers to non-medical services such as housing. This difficulty, apparently so absolute in practical terms, always seems to me to be built on a fallacy. You only need to accept that you should need a diagnosis to access these services if you accept that these services should be medical in the first place. Doctors may have invented these techniques, or they may not have, but there is no reason they have to belong to them.

Surgery was once performed by barbers, drugs were prescribed by apothecaries. There is nothing natural or inevitable about doctors. In fact, what is remarkable is their ability to keep inserting themselves where they are not wanted, with the claim that they are the ones who really know about other people's lives. Many trans people access both hormones and certain kinds of surgery through their communities, and cut out doctors altogether. Trans activists need to defend these choices (even as we recognize the potential dangers) and oppose their criminalization. We need to start thinking about how we can work with them to create better alternatives to the medical system that claims the right to define our experiences, alternatives that we have ownership over. The movement for 'informed consent' – whereby trans people would not have to pass psychiatric tests, but only to provide 'informed consent' in order to get hormones – is a good start, but it still concedes too much. And the more fundamental the level at which we pitch our opposition, the more, I think, trans people will find they have in common with the psychiatric survivor and mad pride movements.

There has not been enough of this opposition from the trans community. Perhaps that is because we have been so keen not to be pathologized, so keen to be accepted as normal, reasonable people. It is this desire the medical establishment, setting itself up as arbiter and gatekeeper, has consistently used against us. I think we need, as mad pride movements have, to stand by our 'pathology' and our 'unreason', since these are what we have, and to deny the validity of any of the understandings psychiatrists, psychologists or neurologists want to bring to bear on us. In so far as we can, we must start refusing to be 'helped' any more.

Catherine Fitzpatrick has a PhD in English Literature from the University of Sheffield, and will be teaching next year at Rutgers University, Newark. She has been published in Cambridge Quarterly and The May Anthologies, and has a forthcoming article on confessionality.



Button images throughout this issue were created by Alisa and Elizabeth. Alisa and Elizabeth are two.really.crazy.ladies (@gmail.com) working, learning, laughing, loving, hanging out, and going nuts in the Greater Toronto Area (and occasionally Calgary)!

Cover art by SaraFin. SaraFin is a Toronto area cartoonist, illustrator, painter, and Mad Person. You can read her webcomic, *Asylum Squad*, at www.asylumsquad.com and the archived strips at www.thepsychosisdiaries.com

ON GETTING PAID TO 'PARTICIPATE'

Becky McFarlane

It would seem that in the realm of consumer involvement, the expectation of an honorarium in exchange for participation has become the norm. Attending a meeting, engaging in a community consultation, speaking at an event – each comes with the expectation of payment for time and expertise. Of course, this makes sense in an economic system where the exchange of money for labour is what makes the world go round. And of course the social service sector and the professionalization of community means that everyone else is getting paid – so why not the so-called consumer?

Mental health advocates have fought hard for the honorarium. There was a time not so long ago when the idea of paying someone for their 'lived experience' would be absurd. As service users, any effort we put into making the system better was perceived as payment enough and we were thanked by an acknowledgement that we had taken up space that was never ours to occupy in the first place – the space reserved only for those who are deemed credible. Once in the room, we recognized and felt the imbalance and concluded that demanding payment was an equalizer of sorts.

Well-intentioned and entitled, we fought for and won the right to an honorarium – and we have reveled in that victory ever since. Our turnout has improved, people are slightly less poor, and the system has ushered in all sorts of frightening changes under the guise of consultation. Of course, we rarely talk about who is included and who is excluded from collecting that payment – about how the exchange of money has allowed



the system to put conditions on how we participate, when, and to what extent with little worry that we will push back. We are getting paid, after all.

It is hard to not conclude, at some point, that the honorarium has become more of a tool to silence than one that honours our contributions – particularly when there is little or no analysis that acknowledges how we are being used. If we take their money – because we need it – we should do so with our eyes wide open and with a commitment to resist the system whether we get paid or not.

Contributing to conversations that see tinkering with a fundamentally flawed system is just that – contributing to a fundamentally flawed system. Transformational change happens in the street where payment comes in a much different form – the hope that we will one day realize a better world.

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