30

TAKING MAD STUDIES BACK OUT INTO THE COMMUNITY

David Reville

Introduction

This chapter takes as its starting point an earlier chapter I wrote for Mad Matters – A Critical Reader in Canadian Mad Studies (LeFrançois et al, 2013), which was about the Mad Studies courses taught at Ryerson University in Canada. The Ryerson Mad Studies courses began in 2002, when Mad People’s History was taught for the first time by Geoffrey Reaume, though the term ‘Mad Studies’ was not in use at that point. An outline for a second course, A History of Madness, was also written by Geoffrey Reaume but this wasn’t offered until 2004, when I was hired to teach both courses – Mad People’s History, and A History of Madness. The chapter I wrote for Mad Matters (Reville, 2013) talked about my experience of developing and delivering these courses at Ryerson and concluded with ‘a recipe’ for developing Mad Studies in the academy:

1. Find a way into the academy.
2. Once you’re in, you have to find your way around.
3. That includes making alliances with like-minded people and making nice with the bureaucrats who make things happen.
4. You have to bring Mad students and teachers in, too.
5. Then you have to find your way back out into the community again (2013: 179).

The last stage of the recipe included a section headed Taking Madness Back Out into the Community, which argued that Mad people’s history shouldn’t be cloistered in the university. It also listed the Mad people’s history talks I’d given, some of which were to the Mad community – organisations of mental health service users, or people who have survived psychiatry. Other talks were to mental health organisations or community groups. I also suggested using the internet as a way of getting Mad Studies out of the university. For example, Ryerson’s School of Continuing Education uploaded three videos to YouTube in 2010 and 2011; these discuss Mad people’s history, the consumer/survivor/ex-patient movement and self-labelling and identity. By 2018, these videos have had more than 45,000 views between them.¹

In 2018, Kathy Boxall (who’s based in Australia) got in touch asking if we could talk about what I’d written in Mad Matters. In November 2018, Kathy and I met via Skype for a
Inquiring into the future for Mad Studies

conversation about taking Madness back out into the community; the remaining pages of this chapter document that conversation.

**Kathy** I wanted to ask you about what you say in your Mad Matters chapter (Reville, 2013: 178) about taking Madness back out into the community.

**David** What I meant was to take Mad Studies back. I see Mad Studies as, not just an academic activity, but an activist activity. Given that Mad Studies is founded in the stories of Mad people, it’s wrong to sequester those stories. Those stories need to be shared broadly – but primarily with Mad people. It worries me that Mad people don’t know their own history of resistance and struggle and I think it’s important that they do know that. I also think that dialogue between the community and the university is critical because a good part of that knowledge is going to come from the Mad community.

**Kathy** But I was interested that you talked about taking Madness back out to the community.

So, is there a difference between taking Mad Studies back out and taking Madness back out? I suppose what I’m asking is do we need Mad Studies, or could we do the Madness stuff, the Mad people’s history stuff, without the academy?

**David** I don’t know. I don’t know. Certainly, some of that work has indeed been done by the Mad community, without reference to the academy and I’m thinking of the work that Louise Pembroke (1996) did on self-harm, for instance. That wasn’t an academic project, that was a grassroots knowledge creation exercise. And I’m thinking that some of Judi Chamberlin’s historical stuff was the movement recording its history, although she did get connected with the Center for Psychiatric Rehabilitation at Boston University at some point.

Did you ever read a book called *Women look at psychiatry*? One of the editors was Dorothy Smith, the sociologist – Judi wrote a couple of chapters in that book (Chamberlin, 1975a, 1975b). It was in 1975 and Judi takes after feminists for speaking on behalf of Mad women. After reading that, I remember thinking, Wow was she ever astute – a very clever woman. She wrote her own book too – *On Our Own* (Chamberlin, 1988).

**Kathy** A book I remember reading was Mary O’Hagan’s (1993), *Stopovers On My Way Home from Mars*, where she compares extracts from her psychiatric records with what was going on for her at that time.

**David** Yeah, I met Mary O’Hagan, she did some work in Canada.

**Kathy** For me it was amazing when I read Louise Pembroke and Mary O’Hagan’s books. I found out about them when I joined Survivors Speak Out. Before that, I had no idea that anything like that had been written. I was trying to make sense of my own experiences of psychiatry, with nothing from anyone else who’d had similar experiences, and it was an absolute revelation to read those books. But they didn’t come from Mad studies, or from the academy – so the question I was asking before was: Do we need the academy, or can we do those things without the academy?

**David** I think we can.

**Kathy** So, what can the academy add to that fantastic work that was being done before? And you will know (because you will have been involved far earlier than me) all about the early Mad movement and what was done then. What does the academy add to that?
David  

It creates a location from which all sorts of things can happen. For instance, I used to teach Mad People’s history informally with survivor groups. One of the things I benefited from was the presence of survivor groups to which I could go – they had their own structure and membership, which created an opportunity. If you don’t have those groups, then the university can be the place that creates that opportunity. And maybe they can complement one another – the survivor groups and the university.

I think the other thing is the ability to run research projects. We’ve been able to bring in members of the Mad community as part of the research team, which is another way in which the academy can be beneficial for the Mad community. In 2009, we put together a group of Mad people and academics (some Mad, some not) to ask users what they thought about “recovery” (Mental Health “Recovery” Study Working Group, 2009). And in 2012, we put on an event called “Recovering our stories: a small act of resistance” (Costa et al, 2012).

One of the difficulties I spent time trying to figure out how to overcome was that many people in the Mad community don’t go to university. They can’t go to university, so how do you get them into the university, so I developed this workshop idea, but then I had to spend time finding sponsors for each of the students because they didn’t have any money, and the academy doesn’t do stuff for free. But I keep thinking that if you had tenured professors, they’d be in a position to do some of that stuff in a way that contract staff can’t.

Kathy  

But even if you’ve got tenured professors, you’ve still got the problem of students needing to pay fees to do the course.

David  

Yes, that’s right.

We’re taking one small step to solve the fee problem. Working for Change is an organisation which provides employment and education opportunities for people disadvantaged by systemic barriers.² The David Reville/Working for Change bursary in Mad People’s History pays the fees for a member of the Working for Change community to take Mad People’s History. We did the work earlier this year to make this an endowed award which means that it can go on in perpetuity (Ryerson Today, 2018).

Kathy  

I’m playing devil’s advocate here, but it sounds like what you’re saying is: bring the Mad people into the academy, so we can take Madness or Mad Studies back out to the community, and I’m wondering about that. Why do we need to bring everyone in, so we can take everything out again?

David  

Alright, because the other way to do that is for the academy to go to the community, as I used to do often. There’s a wonderful survivor run organisation in Toronto called Sound Times³ so I spent an afternoon at Sound Times, and spoke about Mad People’s History. It was like a workshop and it was their space and I took a colleague with me, a Mad-identified student so that she could get a bit of practice in doing this kind of stuff, and I think that’s a great thing for the academy to be doing. I think I said in my Mad Matters chapter that I did 20 or more speaking engagements in a year. I would always be talking about something to do with the Mad movement and, of course, that was to a wide range of audiences.
And I want to tell you about this new thing that I’m going to do. I discovered that there’s something called The Life Institute, it’s an organisation that provides educational opportunities for people over the age of 50. There’s a partnership between Life Institute and Ryerson University and I’m taking a course there right now. The course is called The Rock and Roll Era! I got to thinking that maybe I should teach a course at the Life Institute, so in January, I’m going to teach a version of A History of Madness to these students aged 50 plus – that will be a new venture for me. We will see if that takes Madness out to the community, or not!

Kathy Another thing I wanted to ask was, when I read your Mad Matters chapter again yesterday, you talked about the numbers of students doing Mad People’s History and mostly they weren’t Mad-identified students. In a way, isn’t that taking Madness back out into the community? Aren’t those students who are not Mad-identified going to take their learning out with them when they finish university, to whatever they’re going to do in life.

David Many of them say that they will do that, particularly the ones in the helping professions, who say that the course was transformational, and that they will be approaching their clients or patients differently because they took that course. I think one of the things that’s amazing is that Ryerson has two courses – one is A History of Madness and the other is Mad People’s History. The people who take the History of Madness are from all five faculties – so we have Engineers taking A History of Madness, as well as Social Workers, and people from Performing Arts – and it really has turned out to be an interesting opportunity to present an alternative to the medical model.

Kathy I think there’s no doubt that that kind of work has an impact on students, but I wonder about what happens when they get back out there into the mental health organisations, or even the ordinary social work or social welfare organisations where the medical model is so dominant. Can we teach enough students to be able to make a difference in those kinds of organisations, where the power’s held by the people at the top, who’ve been around for the longest and haven’t done Mad People’s History at Ryerson University?

David And they should be made to do it [Laughs]. I agree with you that we send these young people out with a new way of looking at things and they step into a space where that new way of looking at things is not welcomed, and what do they do about that? I think some of them manage to do their best with that. And some, not so much.

Kathy That’s no criticism of them really, given how powerful all these ideas are in those sorts of organisations, how powerful dominant medical model and individual deficit views are.

David Yes, and I wonder the same thing often. I go to the Convocation and see the students from Disability Studies graduating, with a whole new way of looking at disability, and then they go back to work. And I think, ‘Oh my God, we have made things so hard for these people?’ And particularly in disability studies the students are primarily women, many of them are what we call ‘visible minorities’, many of them are mothers, some of them are single mothers. And they are all amazing, really amazing.
Taking Mad Studies back out into the community

Kathy And they have to earn an income when they finish their studies, and sometimes in order to do that they have to work in organisations where those medical model views dominate. I think it can be really hard for people to resist that, to work in those organisations and resist the medical model.

David We have some managers now, the School has been around long enough now that some of our graduates are now managers, so they would be able to resist some of that pressure, I would think. One of our graduates, who comes to the summer awards that we have each year, runs an agency for people with developmental challenges, and she’s the boss, so I think that would be a very different organisation.

Kathy That’s the work I did when I got out of the psychiatric hospital, working with people with developmental disabilities. I think it’s easier in that arena than in the so called ‘mental illness’ arena, because people think we’re mad and bad; but people with developmental disabilities are seen as deserving in a way that we’re not.

David Yes, yes.

Kathy David, I like what you did in your Mad Matters chapter, at the end where you talk about a ‘recipe’ for Mad Studies, for getting Mad Studies into the academy. And I’m wondering if we could have a recipe for taking Madness, or Mad Studies back out to the community?

David [Laughs] What do you think?

Kathy Well I’m thinking, bring them in – bring Mad people into the academy – to start with, at the beginning of the recipe.

David Certainly, bringing the Mad people in is part of the recipe. What I talked about in my Mad Matters chapter was how do you make sure that Mad knowledge is coming into the academy? And you do that by bringing in Mad teachers as well as Mad learners. But I think the really critical thing is to keep Mad Studies from becoming elitist, and one way you can do that is to make sure that you’re in strong communication with the Mad community. The way I’ve seen that working is when those of us who are in the university have really strong connections with the Mad community and with people that aren’t in the university. That’s the trick I think, if the connections are strong between the university and the Mad community. Of course, it’s easier if the Mad community is well organised and that certainly won’t be everywhere.

I came into the university after a lifetime of community activism. That isn’t the case for the high-knowledge crazies coming up. However, scholars like Jijian Voronka, Lucy Costa, Jenna Reid and Danielle Landry are active in the Mad community. What a resource these four women are! Jenna and Danielle are teaching A History of Madness and Mad People’s History at Ryerson these days. Lucky Ryerson. Me, I continue to be on the board of Working for Change.

This brings me to another important topic: mentoring. I’ve been glad to be a mentor to others; and Danielle Landry and Kathryn Church write about mentoring in Searching for a Rose Garden: Challenging Psychiatry (Landry and Church, 2016).
**Kathy** You talked about the Mad community being well organised, or not so well organised, can I ask about the inclusion of Indigenous people and other minorities in the Mad movement in Canada? In Australia, where I am now, there are university preparation courses, scholarships and support schemes for Aboriginal or Indigenous students – not for Mad Studies courses, but for courses generally – and it looks like you have similar schemes in Canada; for example, Indigenous Services Canada’s programs to support First Nations and Inuit students.

**David** Yeah, that’s a place where maybe the academy can be especially helpful. Ryerson University is committed to supporting Indigenous students5 – but outside the academy, my experience of the Mad movement is that it’s mostly white. There are better connections with LGBTIQ people than there have been; but for visible minorities, not so much; Indigenous people, not so much. And part of that, I believe, is that being out as a Mad person is more dangerous, way more dangerous than it is for me – it’s not dangerous at all for me, anymore. And the university, at least Ryerson University, is wonderfully multicultural, but there’s still the issue around inclusion of Indigenous people in Mad scholarship. We just started to see some scholarship from visible minorities who are Mad-identified who are looking at those kinds of issues, but I’m not aware of anything like that from the Indigenous community in Canada.

Someone who’s written about Indigenising the Mad movement is Louise Tam, one of the first South East Asians I knew in the Mad community – she has a chapter in *Mad Matters* (Tam, 2016).

**Kathy** OK, so going back to this recipe – the recipe looks like you bring the Mad people into the academy or the university, and the university has a role to play here in bringing in students from diverse groups, and staff from diverse groups. So, what’s the next stage of the recipe.

**David** Well I think the academy has to go out into the community and to be very purposeful about that as well.

**Kathy** So, do we want to offer a list of ways that they could do that?

**David** Well, I think it’s really a question of developing relationships with community leaders and then ways for the academy to assist will come to mind – I know they will – once those relationships have been built.

**Kathy** When you say community leaders, do you mean community leaders in general?

David You don’t just mean the mental health organisations, you mean the local politicians, the people that organise events in the Town Hall – do you mean all of those people?

**David** Well that’s becoming a very tall order to try and have that many relationships. I mean, clearly, you need to start with building relationships with leaders of the Mad community and sometimes that will include service providers, and sometimes not. There’s an organisation in Canada called the Schizophrenia Society,6 which is not a friend to the Mad movement at all. It’s a carer organisation, they want the Mental Health Act amended so it’s really easy to lock people up and force treatment on them! We’ve been at loggerheads with them forever. But that’s certainly not the case with all individual family members and sometimes you can find an organisation which is very progressive.
One organisation is called the Canadian Mental Health Association,\(^7\) which is organised provincially and locally and the local branch provides services. Parts of that organisation are very progressive, but they change from time to time too, so you have to sort of be alert, so for instance the local Canadian Mental Health Organisation sponsored students to come to my workshops and I think they sent a couple of staff as well as participants, so that's great when that can happen.

**Kathy**

I think we're getting there with the recipe. We've got that you bring the Mad people in, as learners, teachers and researchers, and the academy can help because universities have requirements around diversity and lots of diverse students are coming into the university, including Indigenous students. And then you start to take Mad Studies back out again, but we need to do that in a purposeful way, by building relationships and making connections with the community out there. That needs to start with Mad people's organisations, but can also be a range of other organisations. And we've also got the students from diverse backgrounds who come into the university to do the courses and take what they've learnt out to the community as well.

Is there anything else you want to add?

**David**

I can’t think of anything else right now! Maybe it will come to me in the middle of the night!

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**Notes**

1. See [https://www.youtube.com/watch?v=AKBFYi6A6pA](https://www.youtube.com/watch?v=AKBFYi6A6pA)
2. See [http://workingforchange.ca](http://workingforchange.ca)
3. [http://soundtimes.com](http://soundtimes.com)
4. [https://www.thelifelineinstitute.ca](https://www.thelifelineinstitute.ca)
5. [https://www.ryerson.ca/content/aboriginal-news/aboriginal-report-web.pdf](https://www.ryerson.ca/content/aboriginal-news/aboriginal-report-web.pdf)
6. [http://www.schizophrenia.ca](http://www.schizophrenia.ca)
7. [https://cmha.ca](https://cmha.ca)

**References**


