

To Live is to Fight: Human Rights in Mental Health – Dax Centre, August 9th

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I was on a plane the other day and the woman next to me turned to me and asked me what I did for a living. I took a breath – as I often do, wondering how to explain what I do – and settled for my generic “I work in mental health.” She smiled at me and said “gee, your heart is in the right place!”

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I’ll come back to this idea of good intentions later – in my PhD research I describe a phenomenon that I call “benevolent othering”. But I’m going to start this talk in my body. Because the body matters, bodies matter and my body tells me what matters. Sometimes these messages are hard to understand, but I’m learning to listen really carefully. I know we all have these bodily clues that tell us what’s ok, and what doesn’t feel ok. And what she said sat uneasily with me.

When we speak of human rights in mental health, we can’t ignore the body:

- the fact that the life expectancy for people with so called ‘serious mental illness’ is 10 years younger than the rest of the population (except indigenous people);
- the fact that there are laws that allow the State to violate your bodily integrity when you are already distressed, and we don’t even call it violation – we don’t bear witness to this *as violation* – we call it “involuntary treatment” and expect you to be grateful;
- the fact that many of us take psychotropic medications that effect our bodies in ways that aren’t completely understood or acknowledged. Many of us are chronically dazed and foggy, or we’re legally forced to endure excruciatingly painful injections in our bum every month, our livers or teeth are worn out, our metabolism slowed so much that we balloon from a size 14 to a size 24, or we dribble or shake. Or we get Parkinsonian symptoms, like one of the most brilliant thinkers I know, Shery Mead, and we tremor, or we take meds to stop the tremors and these deaden our capacity to think.

This all matters.

But I want to speak of something else – something more subtle. I want to speak of the feeling in my own body when I know I don’t matter, or when I know that what I think or feel or know has been socially delegitimised.

For example, when I wait for an appointment at my local area mental health service and am kept waiting for nearly half an hour with no apology, and the waiting room is lined with patronising posters suggesting I should eat well, give up smoking and have a positive attitude. When I finally get my appointment, I am bombarded with a stream of questions that have so little to do with my experiences and my deep understanding of my experiences, and are obviously about slotting me into a pre-existing system. In my body, I know that I don’t *really* matter.

Or when I speak of harms caused by the mental health system and my society doesn’t want to hear them, *really hear them*. We seem to be so deeply committed to believing that the mental health system is basically good, it’s progressing, it’s full of good people with good intentions. I mean, there might be a few rotten apples, but it’s basically good. Right?

Or when I speak alongside a Professor, a barrister and a CEO, I am socially positioned as knowing less. I don’t mean this as an individual, I mean as someone speaking from lived experience. There isn’t even really a word for my speaking position. We often use “consumer”

or “person with lived experience of mental illness” but these have such negligible cultural legitimacy.

And yet the knowledge gained from lived experience of mental distress, from using the mental health system and surviving with my spirit more or less intact, well, more or less, and from living amongst a community who have been diagnosed as crazy and lacking in insight and whose bodies have been violated by the State, this has given me the deepest insight, into suffering, structural violence, power and the complex meanings of madness. I’m currently finishing my PhD, and I have to say that the insights coming from my mad community are deeper than most of what I find in “the literature,” in “the published evidence base”, and I don’t mean this in a patronising way, I mean true intellectual rigour. There are some damn fine minds in the mad community, but their thinking is systemically marginalised.

At this point, I’d like to acknowledge some intellectual debts I owe – to Merinda Epstein, who I now have the privilege of working alongside, and whose writings quite possibly saved my life, or at the very least made sense of it in a way that the psych literature from “The Experts” doesn’t; Cath Roper, who is Victoria’s only mad academic, or at least the only one who is “out” as such, and employed to teach and research from that positionality, and whose subtly and depth of thinking constantly pushes my own; Dr David Webb, who completed the world’s first PhD on suicide by a suicide survivor and who calls a spade a spade while theorising the phenomenology of “the crisis of self” at the heart of suicidality, in the face of so much research that is utterly beside the point. ... Internationally and locally there are many more people I could name whose thinking is just extraordinary. If these names are unfamiliar to you, may I suggest this is the result of the structural disrespect for those of us with lived experience. If we lived in a different world, these people would be called “professor” or be elders – they are my elders – but instead they, like me, are daily dismissed and ignored. And we all feel it, in our bodies, knowing that what we have to say is not taken as seriously – at a systemic level – as what is said by Professor so-and-so or Dr. whoever.

And I’m talking about this because I believe this dynamic is at the heart of human rights abuses in mental health. For example, someone coming under the Mental Health Act, being taken into a psychiatric hospital against their will and being “treated” against their will – or knowing if they don’t comply, they will come under the Act – there is a profound disrespect, a sense that Dr. Whoever knows better than the crazy person. And in the context of mental health policy and vision, we still believe that those with expertise-by-training know better than those of us with expertise-by-experience. Yes, we are allowed to “participate” or be “consulted” or even have some lowly paid positions in psych services. But the system isn’t *ours*, and I say it bloody well should be. And in the context of mental health discourse in our communities, in the academy, in public policy, in law, we still believe, for example, that Professor Patrick McGorry is God, I mean he’s a snowy haired psychiatrist with a very earnest face, and is obviously The Expert in all things mental health.

Stigmaphobia

I want to move now to some conceptual work from my PhD, specifically the concept of stigmaphobia. We often talk of “stigma” in mental health, and much of the time the proposed solution is community education – so we get billboards, like those from Beyond Blue that declare “Depression or Anxiety can affect anyone” or Experts advocate for a need to improve mental health literacy by teaching people “the facts” about mental illness, from the perspective of the medical model.

One of the problems with anti-stigma campaigns is that they tend to rely on what I call a “stigmaphobic” logic. Stigmaphobia is when you de-stigmatise one group by distancing it from another, for example, “people with mental illness are not stupid” or “asylum seekers are not criminals”. This approach leaves the prejudicial structures in place, but removes some people

from a tainted category. And I suggest this is what Beyond Blue have rather successfully done with depression and anxiety – there are even calls for these to no longer be considered “mental illnesses.” But this casts a shadow over the rest of us who are left behind. Likewise, the emphasis on early intervention – one prominent proponent of early intervention has more than once called those of us who are over 30 and still suffering from mental illness “*palliative cases*.” In these ways, while some people’s experiences become more respectable and deserving of cultural legitimacy, resources and attention, some of us are relegated to the shadows, unredeemable.

Benevolent othering

A second concept I wanted to share from my PhD is “benevolent othering,” because the mental health system is in many ways built on this discursive framework, on being understood as “helping professions.” People don’t go into psychiatric nursing, or social work, or psychiatry thinking “gee, I’d really like to control and harm people.” But I daily bear witness to terrible harms experienced within the psychiatric system.

Benevolent othering has several parts, and I can’t do it justice here. But suffice to say it depends on a logic of identifying certain people – “others” – and managing them. This management has a logic of benevolence – of being good for them.

Benevolence is not evil. It is human to want to help. And we all know the experience of being anxious because we don’t know how to be helpful. And we all also know the experience – the infuriating experience – of being “helped” in unwanted ways. If you can’t relate, just think about your parents or partner being “helpful” when their help is not wanted!

The antidote to stigmaphobia and benevolent othering is connection and deep listening, and being able to sit with the discomfort of what comes up.

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Finally, I want to turn back and look more explicitly at human rights in mental health. The European Network of Users and Survivors in Psychiatry are calling for a Truth and Reconciliation process in mental health – a process like they had in South Africa post-apartheid, where the community would publicly bear witness to the harms people have experienced in psychiatry.

And it’s not just critics of psychiatry who are calling for this – a similar argument has been made by Mike Slade, who many of you may have heard of – he’s a prominent UK Clinical Psychologist, and was the keynote speaker at the Inaugural Recovery Forum in Melbourne in June this year [2012], which was hosted by our own Chief Psychiatrist, Ruth Vine. Slade has argued that the first step towards genuine partnership with people with lived experience should be a public apology for the wrongs done in the name of psychiatric treatment.

He writes that ‘real reconciliation and partnership may only be possible once a line has been drawn, through the symbolism of an apology, which explicitly recognises the need for a new trajectory in the future’. (Slade,M. (2009) *Personal Recovery and Mental Illness*, Cambridge, Cambridge University Press)

Slade argues that public apologies are justified when the dominant group has inflicted harm on the subordinate group over a sustained period. He lists some examples where former psychiatric patients have called for public apologies. While a few very specific apologies in psychiatry have been made, there hasn’t been general acknowledgement of wrongful treatment. In fact, I would argue we have a profound, deafening silence around the continuing wrongful treatment.

What are these harms?

Of course, we've had lobotomies – and remember that the creator of lobotomies ([António Egas Moniz](#)) won a Nobel Prize in 1949 – that's in my mother's lifetime! And we've had metrazol shocks, swinging chairs and insulin comas, but also tardive dyskinesia, involuntary Electro Convulsive Therapy, Community Treatment Orders, seclusion, restraint and sexual assaults.

We've also had much more subtle harms – the indignity of knocking on the nurse's station in an acute ward, knowing that no one wants to pay you any attention, that *you don't matter*. Or – and this is the experience of a dear friend of mine – being sexually assaulted by a psych nurse while drugged up in hospital and there being *no consequences*. And, years later, this friend of mine was teaching student clinicians and was asked “but how did you know it really happened? I mean, you were psychotic after all.” With gracious dignity, she replied “because we know.”

We know, we know in our bodies.

We know when we sit in a meeting and are representing consumer perspective, and the rest of the committee don't really respect where we are coming from, and the benevolent psychiatrist nods and fails to hear us, and then speaks and is heard. Or the social worker listens to us, co-opts our ideas and presents them as if she can now speak for us. And is heard.

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And yet, there are glimmers of hope.

- The fact that, here, the Dax Collection, is engaged in an ongoing shift, from Experts interpreting the anonymous creations of “psychiatric patients”, to consumer/survivor artists being intrinsically involved in constructing exhibitions;
- The fact that there are a growing number of healing spaces, groups, projects and training led by people with lived experience – including Our Consumer Place (where I work), Voices Vic, Heal for Life, Brook Red ... and the list goes on. We are creating the alternatives that we need, that we yearn for;
- The fact that I have a network of fellow survivors and consumers with whom I can share thinking and cups of tea and even sometimes get small sums of money to do our own research, so that we can create an “evidence” base,
- And finally, the very fact that I'm here speaking, so thank you for this opportunity and for listening.