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REFLECTIONS ON POWER, KNOWLEDGE AND CHANGE

Mary O’Hagan; based on a conversation with Peter Beresford

Introducing myself

From the age of 18 to about the age of 27 I was very involved in using mental health services, with countless admissions to hospital. It was the major feature of my life over those years. Like many people I found the services pretty bad. I thought they didn’t understand my experience or respect what I was going through. They saw me as a bundle of deficits and held out little or no hope for my future.

When I came out of that experience, I felt very strongly that the people who run these services needed the help of people like us to make them better and more responsive. And in various guises I have been working on that project ever since to radically transform how people think about distress and deliver responses for people who are experiencing it.

I started as an advocate and began a peer-led organisation in Auckland called Psychiatric Survivors in the late 1980s – that’s when the movement got going in New Zealand. In 1990 I started up a national network. And in 1991 I was elected the first Chairperson of the World Network of Users and Survivors of Psychiatry. I worked in London for a year as a user consultant, helping services change from an institutional to a more community base. Between 2000 and 2007 was a commissioner at New Zealand’s Mental Health Commission, which was set up to monitor and help improve service delivery. When I left the Commission, I started up a social enterprise called PeerZone where we developed resources and peer support for people in one-to-one and group settings.1 Over the last two years I have been working in the wellbeing promotion end of the spectrum at the Health Promotion Agency of New Zealand. All this time, alongside allies and others with lived experience, my big project has been to radically transform how services and society respond to people.

How much have we been able to achieve?

I sometimes think if I’d joined the gay rights movement as a young woman I might have felt a happier than I do today because so much has changed for lesbian and gay people in countries like ours. I’m not very happy about the progress we have made in the ‘mad’ movement and I’ve experienced a lot of sadness and anger about it. If I talked to a young person today who wants...
to change the mental health system, I'd probably warn them that they might end up at my stage of life wondering what difference they made.

Why haven't we made that much difference? There's a number of things. One is the continuing dominance of psychiatry in health systems and the way psychiatry really still dominates the discourse, the knowledge base, the evidence and the resources. They run the show. It has become increasingly clear to me over the years that while we have a health-led system, that is dominated by clinical people, and uses most of the resources for pills and pillows services, we are doomed in terms of creating a system that really works for people.

**The problem of psychiatry**

Psychiatry doesn't have many tools – they are drugs, the Mental Health Act and hospitals. The trouble is they use these tools for everything. It's like only having a hammer when sometimes you need a screwdriver or a wrench. But it's not just that they don't have many tools – the tools themselves can be intrinsically harmful to people. I think compulsory treatment does more harm than good. I would love to see a world where people don't have compulsory legislation. I also think hospital-based services do far more harm than good. I have been advocating for years for community and home-based crisis support and the drastic downsizing of hospital beds. And of course, the medication is a double-edged sword. Some people feel helped by it and some feel harmed and a lot of people feel a bit ambivalent about it.

Psychiatry does routine harm, not just through the ethical lapses or the incompetence of a few, but because of standard practice and the whole paradigm that operates within.

Psychiatry needs to move away from the hub of the system and be just one of the spokes. Until that happens we won't see any big change.

**Our survivor knowledge**

We have done a lot as survivors over the last 50 years of the movement. But have we made much difference to the lives of people who are currently aged 14, 18, 20 or 25 who walk into a mental health service or who experience extreme distress? It may be that they have a better chance of getting a better deal today but there still are a lot of people getting a terrible deal. It's not just because services are under-resources – it's also where those resources sit and how they are used.

What are the indicators we have made a difference? The way services respond would be an indicator. But it's not just about the deal people get in services. We need to see a positive difference to people's life chances – their employment and housing prospects, and their prospects for having partners, children and friends.

Against a backdrop of psychiatric dominance, lived experience knowledge is very side-lined. It should be central to the whole thing. Our knowledge is optional clip-on whereby sometimes people think, 'Oh yes, we should have a lived experience perspective on this'.

We have a very interesting but tragic situation with the indigenous people in New Zealand. It's tragic that Maori were colonised by the Europeans who stole their land and suppressed their culture and language. There are many parallels because psychiatry has the same features of a colonising force on people with lived experience.

The Maori people have a very different worldview to the European derived culture in New Zealand. The Maori world view gets dropped and side-lined by the dominant white culture. People are so marinated in the dominant culture, that they can't even see that their goldfish bowl is one of many.
I think the same happens in psychiatry and the mental health system. People in the system are so indoctrinated into a particular world view that they have to make a huge effort to understand and absorb other world views, in this case the world view built up by people who experience distress.

The prospects for change?

Over my life, the power has stayed with psychiatry and increasingly with biological psychiatry. I read somewhere recently that 45 times as many research dollars are spent on biological research as on psycho-social research into what they call ‘schizophrenia’. That tells you everything.

Despite my sadness I hold out hope for change. In New Zealand, we talk about the three baskets of knowledge – clinical, cultural and lived experience. We need to give each of these baskets an equal weighting. I don’t necessarily subscribe to that, because I don’t know if the clinical world view is that helpful, but some people say they have benefited from it.

In our country, we’ve got used to the challenge from Maori people saying, ‘We’ve got a different way of knowing things’. So there’s a parallel challenge to the one that we give as people with lived experience. I think it’s quite helpful for people with lived experience, even though white people with lived experience can side-line the Maori world view as much as any other white people can. But in some ways Maori and lived experience world views have some things in common. The clinical European-derived scientific world view is about separating all the parts and examining them all in isolation from each other, splitting things off so your knowledge isn’t contaminated with confounding variables. Whereas from a Maori world view that seems absurd because they have a very holistic, multi-dimensional view of life. Lived experience world views also favour the holistic and the subjective.

There is an increasing involvement of Maori in lived experience activities. There was some in the early days but it dropped off. Now they are a growing force with their own national network. This is important because Maori more often face intergenerational trauma and are much higher users of services. They are also subjected more to compulsory interventions.

Mad Studies

I’m all in favour of Mad Studies. I haven’t gone down an academic route in my life although I guess I could have. I have quite high hopes for Mad Studies, but there’s a network working in New Zealand and Australia, that calls themselves Service User Academia. Every time I go to one of their conferences I tell them, why don’t you change your name because you’re not in the role of service user when you are being academics. I can’t understand why they don’t change their name. They might think ‘Mad Studies’ is a bit provocative but other names have been suggested such as ‘First Person Studies’.

What worries me is that quite often these lived experience academics are tagging on to other people’s research, they are not setting the research agenda. We’ve got women’s studies departments and disability studies departments. I don’t know if there’s a Mad Studies department anywhere in the world, though I think Ryerson University in Toronto is heading in that direction. I would like to see Mad Studies as a full discipline and not have lived experience academics hanging off the coat-tails of clinically trained academics. That worries me.

Psychiatry as a discipline has the service arena, but it also has academic arena and similar dynamics apply. Having said that, there are some very good psychiatrist and nurse academics who have really supported the development of academics with lived experience. They have
cleared the way for lived experience academics to work in a self-determining way on their own projects.

I see hope with Mad Studies but I would like it to have been more developed by now. I’m getting to the point where a lot of the changes I would like to see may not happen in my lifetime.

**Challenges to our movement**

It’s really interesting to see what’s happened to our movement over the years. I think it’s lost a lot of its edge. Movements start off with a hiss and a roar and they get under the establishment’s skin. But what happened in New Zealand was the system said, ‘Why don’t you come and work for us?’ Initially we had a lot of independent survivor-led organisations which were weakened by the fact that a lot of the people in them ended up with jobs in the system. And now most of our contribution is not so much based on human rights or restoring our place in the world, it’s about providing services within the service system.

It’s good we have a place in the system, even if it is not a powerful place. But I do think there is a place for that more edgy, independent advocacy that in many countries it has receded. There is still an awful lot of advocacy needed for people who have ended up in the mental health system.

I don’t have an answer to how you revive an independent movement. If we revived it today, it would be different. A social movement is a bit like spontaneous combustion. You can’t plan or control a social movement.

**Note**

1 See more at https://www.peerzone.info/