

Human rights and the madness of “dual diagnosis”.

David Webb, December 2007

When we use the language of “dual diagnosis”, and all the other medical terminology that comes with it such as “comorbidity”, we are participating in the medicalisation of everyday life. Some people are calling this “selling sickness” (Moynihan & Cassels 2005) or “disease mongering” (PLoS 2006). I think it is best described as the medical colonisation of the human spirit. Whatever we call it, we must beware of and resist the excessive medicalising of what it is to be human.

Although almost every aspect of life is being colonised by medicine, it is perhaps nowhere more advanced, and more harmful, than in the mental health industry. In most western societies, the marketing of distressing human experiences as medical conditions is almost complete, with broad community acceptance of the myth that our psychological wellbeing is determined by the biology of our brains. The notion of “mental illness” has become so pervasive that this metaphor is now being taken as a literal truth. The narrow and shallow medical reductionism of modern biological psychiatry is not only causing great harm to individuals caught up in the mental health industry. Its blindness to essential aspects of our being diminishes all of us – our communities, our social fabric, our culture. Mainstream psychiatry today sees only biology so that it not only fails to see that our psyche includes psychology, consciousness and spirituality, it forbids them.

If this sounds exaggerated or alarmist, then consider the current status quo in the mental health industry. If you experience extreme emotional distress that triggers, for instance, suicidal feelings, and you come to the attention of the medical profession then you will almost certainly find yourself with a psychiatric diagnosis – i.e. a medical judgement that you have a mental illness. We’ll analyse this a little more closely later, but once this judgment has been made and you have a psychiatric label, your mental illness will almost certainly be treated with psychopharmacological medications. Furthermore, if the doctors also judge that you are incompetent because

of your madness then you will quite likely be forced to take these medications whether you consent to them or not.

There are three issues we need to look at here – diagnosis, treatment, and human rights. But to put this into the context of this book we need to recognise that this medical way of thinking that has already colonised mental health is now advancing on the drug and alcohol sector under the guise of dual diagnosis. My plea to readers is to resist this colonisation. Indeed, my wish is for the reverse to happen so that some of the knowledge, expertise and wisdom of the drug and alcohol sector can find its way into desperately needed reforms of the mental health industry.

I should perhaps give my “credentials” to be writing this chapter. My PhD research into suicide, completed in 2006, is relevant to the topic of this book but my primary “qualification” is that I have experienced both madness and addiction. I was therefore asked to write a “consumer perspective” on dual diagnosis so I need to tell a little of my story here. I dread this, however, because it may relegate this chapter – as so often happens with the consumer perspective – to the novelty of the “human interest” angle that the so-called experts then comment upon. Like many of my colleagues, I assert the expertise of the direct, lived experience and reject the tokenistic, “human interest” role in the discourse around mental health.

Before proceeding, an aside on language is necessary. First, many people around the world, are now (re-)claiming, as I do here, the language of madness in preference to the sterile and stigmatising medical language of mental illness. We do not seek to impose this language on anyone who is not comfortable with it but, equally, we do not accept the medical language being imposed on us. Similarly, many of us also reject the label of “consumer” for similar reasons and prefer to identify as users or ex-users (of psychiatric services) or sometimes as psychiatric survivors. This again is a matter of personal choice and not to be imposed on anyone by anyone, with my own preference being psychiatric survivor, though I’ll use the term “consumer-survivor” in the rest of this chapter. Now, it’s story time ...

While in England in 1979, at the age of 24, I spent a few months in a hospital burns unit after an accidental fire following a deliberate overdose. As the years passed, I began to regard it as simply some sort of youthful aberration. It was with some surprise then, to say the least, that I found myself suicidal again in 1995. For the next four years I struggled with persistent suicidal thoughts, made a couple of serious attempts, and several half-hearted, clumsy suicidal “gestures”. For much of the time, whenever I could, I self-medicated my *psychache*¹ with heroin.

During the more recent episode, the drug and alcohol services I turned to for help included several short-term (10 days or less) residential “detox” centres, a couple of longer-term (5 weeks to 6 months) residential “rehab” centres, and various self-help programs, most notably Alcoholics and Narcotics Anonymous (AA and NA). All of these you could probably call ‘psychosocial’ (i.e. non-medical/clinical) services. I also did a couple of medicated detoxes in hospital, and the other major medical “treatment” I received was nearly a year on Methadone. The psychiatric services that I received during this time included two voluntary inpatient admissions to a hospital psychiatric ward (one of less than a week, the other for three weeks), and one involuntary admission of only three days. I also saw six different psychiatrists over this period, some I saw only once or twice, others for longer (one weekly for about 12 weeks, another for monthly appointments over nearly a year).

From my experience of the two sectors, it’s hard to imagine a more stark contrast between ostensibly similar services. Perhaps the most striking contrast occurs when you first walk in the door. At drug and alcohol services, I was always greeted warmly with a big effort made to try and make me feel as welcome and comfortable as possible. This is especially important the first time you enter a service, which can be intimidating and you probably don’t want to be there at all. Typically this welcome includes one of the “old-timer” residents (i.e. has been there more than a few days) showing you around, introducing you to the others, where to get a cup of tea and have a smoke etc. Sometimes this is formalised into a ‘buddy system’ as part of the

¹ A term coined by Professor Edwin S. Shneidman, often regarded as the founding father of (American) suicidology, that he defines as psychological *pain* to distinguish it from the mythical medical illness of “depression”.

program. It's a scary thing to step into one of these places, but it helps when you're greeted by someone who has done it themselves just a week or so before you. It also helps that they seem to be doing OK, that maybe you could feel OK soon too.

The psych wards were so very different. First, the admission formalities are cold and clinical as you wait for judgement – like in a courtroom or being dragged before the headmaster – on whether you will be admitted or not. Once you're admitted, you'll be shown around, but almost certainly by a nurse or one of the other staff. As you get this tour, you may be introduced to the other residents, but quite likely not. Social interaction among patients is not facilitated or even encouraged, it seems. It feels like we are expected to be incompetent and incapable of just about anything – otherwise we wouldn't be there, right? And psychiatric wards for me were so unbearably dull and boring that on one occasion I felt I had to leave after about three weeks or I'd go mad!

Which is the next big contrast. The drug and alcohol services were mostly active, busy places – even at the detoxes where many of the residents are sick with their withdrawals. Apart from the formal program of classes, other group activities, and homework etc, there were scheduled walks or other exercise, informal 'meetings' among residents were encouraged, and everybody took part in the cooking, cleaning and generally caring for the space we were living in. If anything, the day was too full of activities so that you sometimes felt you needed some time-out space. Psychiatric wards, in contrast, are characterised by passivity, dullness and boredom. The highlights of the day were meals – trays of hospital food that you had not been involved in the preparation of – and then the drug trolley rounds. There were very few other activities and the nursing staff always seemed to be busy elsewhere. Watching TV was the main way people killed time before the next meal or the next dose of drugs. Dull, dull, dull – maddeningly dull!

Another striking difference was the makeup of the staff. The staff in drug and alcohol are mostly non-clinical and many, sometimes all of them, are themselves ex-users. Having ex-users on the staff makes for a very different environment. They know

what we were going through because they've been there themselves. And we knew that. And we knew that they knew, and they knew that we knew. And so on. This not only meant that there was an automatic empathy and respect for the hard work of coming off drugs (or booze). It also meant that they knew most of the games we played, with ourselves and with each other, to rationalise or deny our addiction or to think we were somehow different to others in the struggle to get clean/sober. It made for some tough confrontations at times. But it also made for many lively conversations and plenty of laughs, which is another striking difference with sullen, humourless psychiatric wards.

Next, the approach to “therapy” is very different between the two services, which is highlighted in the language – clinical staff give “treatment” to patients in psychiatric wards, whereas in drug and alcohol clients or residents are working through their “recovery” program. In drug and alcohol, the recovery approach was much more holistic, a whole-of-person approach. Diet, exercise, the busy daily routine of activities, social interactions, conversations both formal and informal, various responsibilities and duties, such as cooking dinner or being a buddy to a newcomer etc were all considered important parts of your recovery program. In the psychiatric wards, treatment revolved around medication. A couple of times a day the drug trolley would come around, staff would be watching for symptoms and/or side-effects, and then the doctors would occasionally fine-tune the mix or dosages of the drugs accordingly. That was it.

The final major difference is rarely mentioned in the literature and conferences on dual diagnosis but it is a critical difference that I wish to highlight in this chapter. Drug and alcohol services are voluntary (unless you're there through a diversion program of the criminal justice system) whereas at the heart of psychiatric services is the threat of force, of involuntary treatment, a threat that is routinely carried out.

This is inevitably a very shortened version of my story that cannot be taken as either comprehensive or typical. There are many other stories that need to be heard and in much greater detail than the occasional focus group “snippet” that might find its way

into the research literature. The failure of researchers and policy-makers to engage meaningfully with the first-person knowledge and expertise of those who know about madness and addiction “from the inside” is the single greatest weakness in our efforts to develop better policies and services. Furthermore, it is clear that this failing will only be corrected when more researchers and policy-makers are themselves consumer-survivors.

The following table summarises what I regard as the key features that distinguish the two services. What is apparent from this summary is a massive clash of cultures. This culture clash is already recognised and features in current debates around dual diagnosis, though the emphasis tends to be more on differences to do with institutional infrastructures and the professional status of the workforce rather than the experience of service users. Instead of addressing each individual item in the table, I want to return to the three key issues of diagnosis, treatment and human rights that underpin the medical colonisation that so concerns me.

Table 1

<i>Mental Health</i>	<i>Drug and Alcohol</i>
Medical model	Psychosocial model
Focus on treatment (of illness/symptoms)	Focus on recovery
Biological	More holistic
Pathologises the individual	Considers social context
Emphasises deficits (illness)	Strengths based
Intimidating	Welcoming
Little or no peer support	Strong peer support
Passive participation of patients	Active participation of residents
Mostly clinical staff	Mostly non-clinical staff
Involuntary	Voluntary

First, diagnosis. The best that can be said about the scientific status of the current diagnostic system of modern psychiatry is that it is an hypothesis. Some people go further and say that it has as much scientific credibility as astrology, but as an hypothesis is does have some scientific merit. Beyond that, though, the hypothesis

that psychological distress is due to some biological malfunction of the brain has not yet been demonstrated (Bentall 2004, Kutchins & Kirk 1997). Despite this, the marketing of the mental illness metaphor, and particularly the “chemical imbalance of the brain” myth, has been so successful that it has become generally accepted in the community.

Second, treatment. Given the lack of any solid science behind psychiatry’s diagnostic system, it is hardly surprising then that the treatments psychiatry offers for these questionable illnesses also lack scientific credibility. The most severe expression of this is the claim still made by some that psychopharmacological drugs “fix” the alleged chemical imbalances in the brain. This is not to say that these drugs do not have a role to play, but what they can – and cannot – do needs to be understood (Watkins 2006). Antidepressants, for instance, are best understood as psychological painkillers. The more potent neuroleptic (“anti-psychotic”) medications are powerful tranquilisers that can sometimes suppress some of the symptoms of so-called psychosis. But these drugs don’t “fix” mental illness any more than morphine fixes broken bones, though it is usually a good idea to have some morphine if you break a leg. Another example of the misleading hype of disease mongering is the current re-packaging of some anti-psychotic drugs as “mood stabilisers” for the sole purpose of expanding the market for these drugs (Healy 2006).

Concern about the excessive medicalisation of madness is sometimes heard even within the mainstream of psychiatry. In 2005 the then President of the American Psychiatric Association, Steven S. Sharfstein, observed that, “we must examine the fact that as a profession, we have allowed the biopsychosocial model to become the bio-bio-bio model” (Sharfstein 2005). Despite Sharfstein’s succinct description of it, the medical colonisation of the psyche marches on, led by his profession.

The third major feature of the mental health industry that distinguishes it from the drug and alcohol sector is the use of force, or “involuntary treatment” as it is euphemistically called. In most western countries, the use of force is not permitted in drug and alcohol services, in stark contrast to the mental health industry which has the

threat of force at its very foundations, a threat that is carried out daily on thousands of people. Once again we need to be alert to the misuse of language. One of the slogans of the psychiatric survivor movement is that “If It’s Not Voluntary, It’s Not Treatment”. Psychiatric force is about control, not treatment. It is about subduing people, primarily with drugs, in order to control their behaviour, and invariably for the benefit of others around the person rather than for the persons themselves. Medical treatment without consent is not only a violation of a fundamental human rights principle. It also contradicts, is mutually exclusive with, and ultimately self-defeating for any recovery based service.

There is a clear relationship between medical issues of psychiatric diagnosis and treatment on the one hand and, on the other hand, legal issues of the human rights prohibition against medical treatment without consent. Mental health laws rely on psychiatry to justify depriving a person of the right to refuse treatment. This occurs despite the lack of scientific credibility of psychiatric diagnosis and treatment, which only highlights that psychiatric force is about control, not treatment. There is an urgent need for legal scrutiny of the scientific justification for psychiatric force, but this is a debate for another forum. Meanwhile, these human rights issues will now arise in the drug and alcohol sector as the medical colonisation of the sector proceeds under the guise of “dual diagnosis”.

This can best be illustrated with a brief description of the current dual diagnosis strategy here in the state of Victoria where I live, followed by a human rights question that exposes a serious flaw in the strategy. A centrepiece of the dual diagnosis strategy here is called the “No Wrong Door” policy, where the intention is that regardless of which type of service you go to for help, you will get access to the services you need. Central to the No Wrong Door policy is the need for staff from both sectors to be trained to become what is called “DD aware”. The aim here is not for all staff to also become experts in the other field but to become sufficiently aware to be able to recognise when the other service is necessary and then to make the appropriate referral. The final plank of this policy is to build the relationships between service providers in both sectors so that people are not just given a phone

number and sent on their way, falling through the huge cracks as they currently do. The service of the first door walked through takes responsibility for ensuring the person makes contact with the other service, which may include setting up appointments, personally accompanying them to the other service, whatever is required. So far so good. Lots of good policy ideas here, though still a major challenge to see them implemented in practice.

This policy comes crashing down on the human rights issue of involuntary treatment. And it crashes so badly that it runs the risk of becoming the No Right Door policy. The question I ask policy-makers and other leaders in the dual diagnosis debate is:

“What happens when word gets out on the street that if you go to a drug service for help and they think you’re mad, they’ll take you up the street to the nuthouse where there’s a very good chance they’ll lock you up?”

So far, I’ve not received any satisfactory answers to this question. To elaborate this scenario just a little more, we know that the biggest and toughest step to take towards recovery, especially for young people, is the very first step of turning to a service for help. Indeed, one of the greatest challenges in both sectors is how to access those in need of help. We also know that drugs users (and not just illegal drug users) do not like being locked up and, furthermore, that they are extremely skilful at avoiding the lockup. So it would only have to happen a few times before word got out on the street that volunteering yourself to a drug and alcohol service ran the risk of finding yourself locked up in a mental health service. This would be a disaster for drug and alcohol services, especially for young people, with many people avoiding services altogether. The No Wrong Door policy becomes the No Right Door.

What can we take from this brief “consumer perspective” to help us respond better to the needs of those struggling with both madness and addiction? There are three issues I would like to highlight.

First of all, I want to encourage the drug and alcohol sector to stick to their guns and resist the medical colonisation of the sector by psychiatry. The current psychosocial model and recovery based approach of the sector is the correct approach, not only for drug and alcohol but for mental health as well. Indeed mental health consumers around the world have been calling for psychosocial, recovery based mental health systems for many years and although some progress has been made in this direction in some countries, the medical model still remains dominant. Medicine has an important role to play – in both sectors – but the catchphrase that sums up what this role needs to become is “doctors on tap, not on top”.

Second, the first-person knowledge and expertise of those who know madness and/or addiction “from the inside” needs to play a much greater role in research, policy and practice – in both sectors. One the most damaging aspects of medical colonisation is its narrow and shallow third-person perspective (masquerading as “objectivity”) that denies the validity of first-person knowledge. Affirmative action initiatives are required to correct this, such as employment policies to promote greater consumer/survivor participation in the workforce of the services sectors and also in public sector bureaucracies, with special emphasis on creating genuine leadership positions. Likewise in our universities and research funding bodies, scholarships are needed to bring more of the first-person understanding of madness and/or addiction into the research that will guide policy and practice.

We can look to the achievements of the disability movement over the last thirty years or so to guide us in how to engage more meaningfully with the first-person voice. Under the banner of ‘Nothing About Us Without Us’, the disability community has asserted the validity and the importance of knowledge grounded in the direct, lived experience of disability. They have also given us the social model of disability, which recognises the social context of disability that is so neglected by the mental health industry and also the drug and alcohol sector, though to a lesser extent. The emergence in recent years of *psychosocial disability* as part of the social change, human rights disability movement will have major impact on the mental health industry, which is to be encouraged and supported.

“A safe space to tell our stories” is the phrase that best captures the most critical need for someone facing a crisis of madness and/or addiction. It also highlights the significance of the first-person voice. All healing begins with a story. It may be a story told to a professional therapist or counsellor. It may be a “sharing” at an AA meeting or some other peer support, self-help group. Or it may simply be confiding in someone close to you. Stories are important. Stories are the primary means for accessing the first-person knowledge of the lived experience, the vital missing “data” of most current research, policy and practice. Stories and story-telling not only bring out this critical knowledge, they can also have great healing power. This applies to both the healer and the healed, and there is an urgent need for the healer to heal thyself, which will also require the first-person voice of workers in the field to be heard.

The phrase “a safe space to tell our stories” also takes us to the third and final issue I wish to highlight. Whatever spaces we create for people to tell their stories it is essential that they be a *safe* space. Force does not work. Human rights principles are important because when they are neglected, harm and suffering inevitably follow. Medical treatment without consent, the cornerstone of the medical colonisation of mental health, automatically creates a very unsafe space. It contradicts and destroys the principles of recovery based services. Psychosocial healing and psychiatric force cannot co-exist. Services for people who experience madness and/or addiction must be motivated by compassion and care rather than the fear and control that motivate most of our mental health systems. We cannot ignore human rights.

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