SEMANTICS, ETHICS and the DISTRIBUTION of RESOURCES

Who Gets What Services: Clinical and Funding Perspectives in Mental Health

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Whenever we speak or write we are in fact translating or interpreting the world we live in and our relationships to that world. Even as we construct our meanings through language we ourselves are constructed as social beings by language. Too often we fail to acknowledge, or even to recognise, that meanings are relative and do not dwell in the words themselves but in the social, cultural and historical contexts in which words are used.

The ways that words are used do have significant material effects on the lives of human beings: for example, in perpetuating powerful myths, stereotypes, and dominant social perceptions. Reinforcement of negative attitudes towards those who are already marginalised and alienated by their experiences of mental and emotional pain is a common, albeit unforeseen, consequence of many attempts to address and alleviate that pain. That is, in trying to 'make things better' we may be making things worse. A possible explanation for this paradoxical effect is that in our very human need to create meaning and impose order amidst the chaos we all insist on believing that some language at least is value neutral: for example, the languages of justice, science, economics, or perhaps just 'our own languages'. In fact, all languages, including the language of 'best intentions', are not only value laden but value dependent.

The ideological justification of resource rationing policies

One of the many challenges facing consumers, carers, and providers of mental health services as we approach the turn of the century is that of funding relevant and effective services and preventative strategies. Currently, the laudable aims of the National Mental Health Strategy are being pursued in a socio-political context of economic rationalism and emphasis on increased productivity. The urge towards greater productivity within the mental health sector is often expressed in terms of achieving better outcomes from the available resources rather than by increasing expenditure. Here, the language of the market place has colonised the territory of social justice--the notion of 'good service provision' is constructed in terms of economic efficiency rather than in terms of human experience. This model of understanding defines the arena in which negotiations regarding funding are carried out but, in addition, the model disseminates its unacknowledged value base into the wider community.

A common attempt to solve the problem of resource distribution is grounded in reductive polarisation of meanings. We all tend to recognise or identify others in terms of the familiar and the unfamiliar; the right and the left; the normal and the abnormal; the well and the sick; the good and the bad. This is not to say that we are always aware of the way we are constructing meaning in terms of opposition but rather that when we use a word such as 'good' the implication is already present that some thing that is 'not good' also exists. This kind of polarised thinking and its material consequences become particularly evident in struggles between different interest groups--especially when those groups are vying for the same prize.

Within the mental health sector, there are a number of ways in which those seeking funding may use language that is inadvertently damaging to large numbers of consumers. The most common categorisations used in pursuit of greater resources for particular services and initiatives can be summarised as follows:

resources should go towards treatment and prevention of

1) Serious illness (which implies that some users of services have conditions that are not serious); or towards

2) treatable conditions (which instantly raises the idea that some conditions are untreatable-- treatment resistant); or towards

3) meeting the genuine needs of the sick (which implies that some service users do not have genuine needs--they are the so-called 'worried well')

Each of these categories of 'greatest need' carries with it an unspoken moral judgement about an often unnamed group against which that need is measured; each assumes the existence of two separate groups of mental health consumers within the community, divided according to whether they deserve to receive services or not. A consequence of this value-laden approach to funding distribution is that those in powerful positions rationalise decisions about resources by employing a language of division and discrimination. Within the whole mental health sector there is an almost casual or unthinking acceptance of this kind of language when it comes to the provision of services. The rhetorical gymnastics that characterise justification of funding decisions become substantial, acquiring a burden of moral significance, as they are conveyed through the system as 'truths'.

If every consumer found her/himself on the 'right' side of one or another of these moral equations there might be a little less cause for concern. However, one of the most damaging consequences of this kind of semantic sleight of hand is that some people find themselves consistently on the 'wrong' side[1]--on the side that being unnamed is invisible and silenced. For these individuals services may be difficult or even impossible to access. Perhaps even more significantly, these people are subjected to a particularly insidious negative discrimination within services and are made to feel that their distress is somehow illegitimate, bogus, or unimportant. Since one of the most common effects of mental and emotional distress is profound loss of self esteem, it is clear that this kind of approach is in human terms cruel, insensitive, and harmful.

Perhaps the ideas flowing on from the categorisation of human suffering require a little more teasing out. For example, if funding decisions are based on a discourse around 'sick' and 'well' the dominant medical paradigm operates, at the level of service provision, to marginalise people whose distress does not fit neatly into a framework of biological causation and treatment. Then again, psychological, social or spiritual approaches to the alleviation of mental/emotional distress invalidate the pain of those whose needs are not met within those models. The currently fashionable--and somewhat unwieldy--term, 'biopsychosocial' has been coined in an attempt to avoid reductive responses to the legitimate needs of consumers. However, like other words, the term is meaningless unless it has currency and context. In the real world, the carefully cultivated and protected insularity of (or even enmity between) many adherents and practitioners of different 'therapeutic' approaches works against co-operative and holistic understandings. Accompanied as it is by sensationalised media reporting, the war of words between different groups of professionals defending their territories tends, at the level of popular understanding, to translate much human distress into failure to cope with life's challenges: weakness, lack of moral fibre, malingering and so on.

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[1] That is if we assume that services are useful and non-hurtful. This is a challenged contention amongst consumers.

Two examples

In pursuing our interests we often create language which are later ridiculed as 'jargon'. However, in the process of creation something interesting happens. We find a way to make something visible that had previously been invisible; to say something that previously, perhaps, could not have been said. I am particularly interested in looking at the way that we invent language which will enhance our capacity to argue or explain our politics. Two examples of invented language that have emerged from debates taking place in the mental health sector during the last few years are the terms 'met-un-need' and 'serious-not-mental-illness'.

1) *Met un-need*

The term 'met-un-need' was coined by clinicians in relation to the debate about resource allocation. My understanding is that it arose from what appeared (statistically) to be an irregular distribution of resources. My interest here, however, is in the term as one which throws the onus of responsibility onto the person seeking to have their 'un-need' met. This has interesting implications about how those who created the term understand the power relations operating between clinicians and 'patients'. I am also interested in how this phrase is 'heard' by consumers, particularly given the all too common scenario in which people with certain characteristics (depression and/or female gender for example) are very likely to believe that their needs are not legitimate, are fraudulent, are not as important as everybody else's, are selfish and un-need-like.

2) *Serious not-mental-illness*

The second term is similar in its use of a negating prefix. In contrast to 'un-need' this term has come from the consumer movement. We have started to talk about 'serious not-mental-illness' due to a realisation that within the legitimate sphere of mental health interest and activity some of us face life conditions which we might not want to name as illness. In trying to demonstrate the issues around 'not-mental-illness' I sometimes use the analogy of a public hospital casualty department and the ways in which such a facility deals with physical pain and trauma. There is a triage process but this process has two different 'doors' through which people with 'needs' might be ushered. Through the first door might go a person with 'serious illness' but another person with serious (traumatic) injuries also has a legitimate and resourced place to go. In this physical health context there is no denial of 'seriousness' that is blatant; there is no doubting of the 'seriousness' of many forms of not-illness. However, when we come to discussing 'seriousness' or legitimacy in mental health we seem to have only one door, one path, one way in. Trauma is often rendered invisible and, even when it is acknowledged, it is frequently dismissed as being outside the province of mental health services.

Although the casualty department analogy has been helpful in trying to explain what we mean by 'serious not-mental-illness' it is not adequate. Firstly, it overlooks the fact that the triage process in acute services is often fraught and challenged. Secondly, it often produces conceptual confusion between people with trauma induced brain-damage and the people to whom I am referring here with life-experience related mental distress. Thirdly, it runs the risk of delegitimising yet another group of people--those who can't identify adequate life trauma to understand their pain.

'Serious not-mental-illness' was a term we introduced to try to point out the absurdity of identifying some manifestly serious problems as not serious. The most glaring instances of this absurdity came in the first few years of the First National Mental Health strategy when policy directives were being reinterpreted and framed into service level triage arrangements. For me, one of the most telling examples was when a co-committee member spoke to me (off the record) during the lunch break of a national policy meeting in Canberra. He commented that some people were 'just too

fucked' and 'a waste of public mental health resources'. His reference was to people with so-called 'personality disorders' who also happened to be women caught between forensic services, drug and alcohol services and the mental health system. It made me even more angry when, during the afternoon session, it was claimed that the same women did not fulfil the criteria defining the category of 'serious mental illness'--with the implication that what was happening in their lives was not serious. It seemed preposterous that an individual could have problems that were both too serious to be of interest to the mental health system and not serious enough to claim a legitimate place there.

Social justice/ consumer politics and distribution of resources

When I was thinking about this paper I was working around a sub-title which would go something like this: 'Strange bedfellows--consumers and the private psychiatry industry' or perhaps; 'Why do I have to fight with the people I want to agree with?' In the end I wasn't able to put the words together well enough to get what I wanted to say right. Still, I would like to draw attention to a deceptive and reductive linguistic shorthand that is muddying the waters of some debates regarding mental health resource allocation.

The problem concerns two issues which often become entangled and which, we believe, need to be very carefully separated.

* The first of these relates to the role of subsidised private psychiatry in Australia and the capacity of relatively wealthy people to access a disproportionately large share of that publicly subsidised service;

* The second issue is about definitions of 'seriousness', of 'priority setting in policy'; of 'who gets what?'

Often I hear people talking in ways that confuse these two issues. For example, psychotic illness is not necessarily related to material disadvantage. There are, of course, many people who have been labelled as having psychotic illness who are on pensions and who experience the oppression of poverty. However this is not (and why would it be) a definitive coupling. In the same way, I have heard dismissive terms, like 'the worried well', 'only neurotic', 'just personality disorders without the label', used by public health practitioners to describe the clients of private psychiatrists: usually in an effort to attract greater financial support for public provision. This kind of generalisation is equally nonsensical. Poverty, oppression, and disadvantage are extremely important issues but it is mistaken to blame those seeking services, but whose distress and circumstances attract the 'wrong' diagnostic label, for the chronic mal-distribution of resources.

Perhaps we resort to reductive argument because it is politically unsafe to place the blame publicly where it belongs: that is, on a stratified social structure that systematically advantages those with material resources and disadvantages those without. Within the mental health arena this disparity is aided and abetted by the monopoly of psychiatrists and their social power. Of course, the reality is much more complex than either under theorised generalisation or deterministic structural analysis can comprehend. For example, I know of several psychiatrists who bulk bill particular groups of consumers who have been totally rejected by the public mental health system (often because they are 'too difficult' or 'socially undesirable'). Given the simplistic nature of the swings and punches of the discourse, these people could easily be rhetorically located (or locate themselves) within the debate, under the derogatory labels of 'the worried well', 'only neurotic' or 'just a personality disorder'.

Careless language which discriminates

Some time ago two other consumers and I attended a meeting of a public mental health service in Melbourne. We were presented with a copy of the latest flier advertising the area's community and acute services. We found that our attention was drawn to the second page of the document where the area was attempting to define its clientele. I will quote from the section:

> *These services are offered by a clinician (social workers, occupational therapists, nurses, psychologists and medical staff) to individuals aged between 16 yrs and 64 yrs who have a serious mental illness and/or associated psychiatric disability. This includes people suffering from:*
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> - *psychosis*
> - *severe mood and eating disorders*
> - *severe anxiety disorders*
> - *as well as individuals with severe personality disorder in a situational crisis who are at risk of self harm.*

This is indeed an interesting reflection of the culture with which we are dealing. It would appear that people with so-called 'personality disorders' don't actually 'suffer'. We need to question any service ideology that insists on defining and distinguishing between those who suffer and those who do not on the basis of the label that has been assigned to them. This sort of language use (abuse) is abhorrent.

Suffering and disability

I had an opportunity to sit on the committee overseeing the evaluation of the first National Mental Health Strategy. Towards the end of what was a quite long and sometimes difficult process it became obvious that we would have to try and say something about the use of the term, 'serious mental illness'. We discussed whether the problem was about the folly of trying to define a priority population? or was it that the use of a term without sufficient definition left too much room for 'mis-definition' ? As a consumer what interested me most was the problem of positivist science. There was a push to solve all semantic, and even profound ethical and social problems, by resorting to definitions which would supposedly lend themselves to measurement. That is, if we chose to continue to use a term like 'serious mental illness' we would have to bite the bullet and define it. If we were going to bite the bullet and attempt to define it we would need to have measurable criteria for 'seriousness'.

From a consumer perspective, this approach perpetuates the problems of pain. Pain and suffering can not be measured. Disability can perhaps (and arguably) be ascertained but disability is not mental distress necessarily or absolutely. It took me some considerable time and a couple drafts to get the word 'suffering' back into the evaluation report.

Fear of Inundation

As I have become increasingly aware of the political debates taking place at a national level I have started to better understand the links between public mental health policy and politics. It is very clear to me that the nature of so-called 'personality disorders', for example, renders them risky in a pragmatic political sense. There seems to be a widespread belief that if people with so-called 'personality disorders' were defined less brutally (and perhaps even treated respectfully, kindly, genuinely and supportively by public services) then others would seek this 'good treatment' and the

system would be flooded--there would be no resources left for people with 'real' illnesses. This position is very rarely expressed so explicitly. The fear of inundation, though unstated, is nonetheless influential in relation to service provision.

The struggle for theoretical ascendancy

There is a popular anti-psychiatry movement emanating, in part, from 'survivors' interested in the role of psychiatry as a mechanism of social control. I remain sympathetic to some of their arguments and this sympathy is reinforced as I spend time with people whose pain has been significantly intensified by iatrogenic practice. Within this set of social theories there is a particular critique of what the DSM IV calls Axis II diagnoses. The critics argue that these 'conditions' are not in fact 'individual' but rather a reflection or expression of the condition of society, and that it is erroneous and dangerous to pathologise the individual. Some would argue that the fewer people who get entangled with psychiatry the better and that psychiatry has absolutely no place in the lives of people who are not demonstrably sick.

In terms of attracting resources, however, this debate divides many of us who would otherwise be allies.

As politically active consumers interested in the relationship between suffering and resources we need to get the social theorists to the table to talk with us. Although there might be disagreement about what sort of services are available (and the models used by those who provide them) there is surely agreement that people's efforts to reclaim their mental health should be encouraged and resourced.

Stigma: and its role in the management of mental health resources

Finally, I would like to make one small comment about stigma. The Community Awareness Program played a central role in the First National mental Health Strategy. An essential part of this program was a public relations assault on stigma. In a paper I presented to 1997 THEMHS Conference in Sydney I spoke about stigma--more accurately about 'stigmas'--arguing that there is not one stigma but in fact many and that these sometimes pull in opposite directions to one other. One kind of stigma tells people that getting 'help' for mental pain is weak, feeble and dependent. The message becomes very clear when we hear terms like 'the worried well' bandied around by Health Ministers even while they are running ads on the television to address the problem of stigma. The point I am making here is that stigma serves a social purpose. It discourages people from seeking services. It is a frontline weapon in the defence against 'inundation'. We must ask ourselves whether we really want to banish stigma or do we rather wish to manipulate its effects in order to fashion politically and economically 'appropriate' service demand?