

Judith Ball
Compeer Program
St Vincent de Paul

NGOs and Holistic Care: Reconceptualising Psychological Problems as Social Problems

What I want to do today is propose that the medical model that dominates our mental health system is far too narrow and far too individualistic. I propose that we need to radically re-think the way that we conceptualise mental illness, and the way that we provide care.

I will argue that mental illness is a profoundly SOCIAL problem, in three key ways. Firstly, mental illness is socially defined – we as a society define what is “crazy” and what is normal. Secondly, psychological distress occurs in a social context – people become unable to cope not because they are ‘weak’ or ‘flawed’ individuals, but largely because of the circumstances they find themselves in, and it’s social conditions such as unemployment, and social values such as materialism that have a large part to play in this. Thirdly, we are social animals. I would like to propose that the quality of our mental health is largely dependent on the quality of our day-to-day social interactions.

This paper is more about questions than about answers. I certainly don’t have a clear idea at a practical level of exactly what an alternative mental health system would look like. But what I aim to do today is to present a few ideas that resonate with me and with my relatively brief experience of working in mental health. Many of you have had much more experience and have a much more in depth understanding of the practical workings of the mental health system in NSW, so I will be very interested to hear whether the ideas I am throwing around today ring true with you. I hope that in the last part of this session we will be able to discuss together what these ideas might mean in practical terms. What are the implications for the organisation of the mental health system and the relationship between statutory and NGO services?

The Medical Model: Psychological distress as “illness”

In the western world, the medical model that treats psychological distress as an “illness” is extremely dominant. According to a recent pamphlet released by the National Alliance for the Mentally Ill in the States, for example:

“Mental illnesses are disorders of the brain that disrupt a person’s thinking, feeling, moods and ability to relate to others. Just as diabetes is a disorder of the pancreas, mental illnesses are brain disorders”

This idea, that mental illness is just like physical illness, has certain advantages:

It is certainly preferable to view people as sick rather than criminal or possessed by the devil. Medicalisation of mental disturbance helps to destigmatise sufferers, and may reduce the shame attached to mental illness. I think that it is for this reason that some consumers are strong supporters of the medical approach and find it empowering. The medical model at least gives some kind of framework for making sense of distressing subjective experiences, and gives hope of a solution in the form of medical treatment

On the negative side though:

The “treatment” offered within the medical model, though arguably necessary, is generally not sufficient for recovery. Medical treatment relies heavily on drugs and ignores interpersonal issues, the spiritual dimension of the person and their need for meaning, identity and a sense of self-worth. Medical treatment too often focuses solely on keeping people alive and manageable.

A dramatic illustration of this is the treatment of suicidal in-patients who are stripped of any implements they might use to harm themselves, put on antidepressants and then simply looked in on every 15 minutes to ensure that they have not hurt themselves. Heaven forbid anyone might actually TALK to them or try to understand how they came to this desperate state! Can this be called treatment?? It might keep someone alive bodily, but falls far short of anything that can be called mental health care.

It is a sad indictment on our mental health system that treatment is often more traumatic for consumers than the psychiatric problem itself. We *must* question the assumptions behind a model that all too often leaves people feeling powerless, humiliated and less than a valued worthwhile human being.

The current National Mental Health Plan acknowledges that:

“Specialised mental health services can only meet some of the needs of people with mental illness. Consumers have the same needs as other people for...recreation, employment, education and friendship” (2nd National Mental Health plan, p 16)

But although the importance of these needs is acknowledged on paper, services whose aim it is to meet these needs are almost universally underfunded and undervalued. The medical system is extremely hierarchical and status and funding are concentrated at the high-tech end of the system – brain research, genetic research, drug treatment, evidenced-based everything: the more hard-nosed and medical the better. Acute care gets the bulk of mental health funding, and the result is a system that keeps people in a cycle of bare subsistence alternating with breakdown.

“Auxiliary services” like living skills programs, self-help groups, social programs, supported housing and so on, that target “non-health” needs, have the potential to break this cycle and actually help people achieve meaningful, productive and enjoyable lives. And yet these services, usually run by NGOs, are low-priority & low-status. There seems to be an unstated perception that statutory health services are the qualified professionals providing essential care, while NGO staff are well meaning but non-professional providers of “extras”. In my opinion this status-differential between statutory & NGO services has a lot more to do with maintaining the power of the medical hierarchy than it has to do with providing the best care possible for clients. In fact, the undervaluing of NGO services is an enormous barrier to holistic, seamless care.

I’d like to talk about Compeer for a moment as an example of a highly successful non-clinical program. Compeer is a program that matches volunteers from the community in one-to-one friendship relationships with people who have become socially isolated through mental illness. It is a team approach with the consumer, volunteer & referring health professional collaborating to meet the consumer’s stated needs, whatever they are. For almost all participants, the simple experience of a trusting two-way non-clinical relationship is enormously beneficial in building self-esteem & enjoyment in life. It may be the only interpersonal contact that a client has where they are primarily a person, rather than a patient.

There are masses of evidence showing that social isolation is a major risk factor for relapse, and that strong social networks are a protective factor against mental illness. And the outcomes for Compeer program participants support these findings. Of participants surveyed after 12 months in the program, 90% said that their Compeer volunteer was understanding and supportive & 90% felt that participation in the program was helpful or very helpful. 88% reported feeling less alone & better about themselves, and the majority improved their social skills, tried new things and were more active in the community as a result of their compeer relationship.

Health professionals are also very positive about Compeer. In our survey of health professionals last year *no-one* noted a decline on *any* outcome measure for their client– and the majority showed substantial improvement. Notably, 16% of clients showed an improved pattern of hospitalisation & 19% became more compliant with their treatment plan. This is really pretty impressive given that a) for many clients, neither of these were a problem to start with so no improvement was expected, and b) Compeer is all about meeting social and emotional needs – these kind of measurable clinical outcomes are really just a ‘side-effect’. (By the way, the Winter 2001 edition of the Psychiatric Rehabilitation Journal contains findings of a randomised-controlled study of a Compeer program that also has the same positive findings).

What is incredibly frustrating is that although we know that Compeer works, and there is a huge demand for this service, we only have the resources to match about half of the people who are referred to us each year.

Compeer is very clearly having a direct positive impact on the mental health of our participants (not to mention saving the Health system money), but we have had enormous trouble getting funding. I am happy to report, though, that about a fortnight ago, Compeer Sydney DID receive confirmation of our first ever Health Department funding – so the continued growth of the program in Sydney can be accommodated, at least for another year. But the future of Compeer Illawarra & Compeer Griffith remain in doubt – they are funded entirely by Vinnies & private donations.

I think the problem here is precisely in the definition of psychological problems as HEALTH problems. Why *should* the Health Department fund services that address needs other than strictly health needs? It is difficult to argue that meeting up with a volunteer friend for an hour a week is a ‘health need’, for example, and yet Compeer shows that such a service can & does have dramatically positive mental health outcomes. Clearly ‘mental health’ needs are much broader than the medical model allows for. So perhaps we need to think about alternative models for the provision of psychiatric care.

Psychological distress is a SOCIAL problem

So next I would like to suggest that rather than looking at psychological distress as an individual medical problem, we could conceptualise it as primarily a SOCIAL problem. There are three strands to this argument:

1) ‘Mental illness’ is socially defined

The medical model presents itself as strictly value-neutral and objective, but what gets labelled ‘abnormal’ or ‘mad’ is intimately bound up with our social and cultural values. Who gets to decide what counts as ‘mental illness’? It is largely white, male middle-class, heterosexuals who have this power to define, and therefore any

behaviour that falls outside the socially acceptable norms for this group is at risk of being labelled “mad”.

To give an example, it was only in 1980 that homosexuality ceased to be a diagnosable mental illness. What only a few years ago was seen as mental illness, is now understood as an acceptable variation in normal humanity. As values change, so do our psychiatric diagnoses.

Looking at other historical periods and other cultures gives further evidence of how social values feed into definitions of psychiatric illness. In certain non-western cultures, for example, people who hear voices and see visions are understood to be spiritually gifted and are revered in their communities, and in others that have a Shamanistic tradition, what we would call ‘psychosis’ is a necessary stage that a person must go through in order to become a shaman. Incidentally a study by Littlewood (1998) showed that people experiencing what we would call schizophrenia have a much better prognosis in developing nations than in the West.

So how we define mental illness, and the meanings we attach to “abnormality” are clearly SOCIAL, and depend on the time and culture we are in. Mental illnesses are not objective entities that simply exist IN THE PERSON, they are social judgements. The way we conceptualise the problem has huge implications for the way we organise the provision of care, and on the outcomes for people experiencing distress. My point is that there is nothing fixed or inevitable about the way we conceptualise psychological problems. The medical model doesn’t *have* to dominate. It is possible to re-think “mental illness” and develop a more holistic understanding that is more empowering for people who are trying to recover.

2) Psychological distress happens in a social context

Not only does the medical model give insufficient attention to the emotional and spiritual needs of the person, but it also ignores the social context in which psychological distress occurs. Mental illness does not happen in a vacuum. Oppression, economic disadvantage and social marginalisation are both a cause and a result of mental illness.

Aboriginal mental health issues provide a clear example here. The people of this land have lost their land, sovereignty, way of life, and their dignity, and face appalling racism, discrimination and disrespect on a daily basis. Unsurprisingly this has had a devastating effect on the mental health of many Aboriginal people.

We cannot address mental health issues without addressing issues of social justice, but the medical perspective conveniently allows us to ignore this. We focus on “fixing” the individual, when perhaps the problem is in society – in racism, sexism, intolerance & a culture that values material productivity above all else.

3) People are social animals

Since Descartes, the western world has understood people to be separate, individual beings, with both a body and a mind. The mind is thought to be a ‘thing’ that, like the body, may malfunction or break down from time to time. It is a very individualistic model, that likens human beings to machines. We may interact with each other and the world, but fundamentally, according to this view, we operate as bounded individuals who are driven and controlled by internal forces that are private and personal. I think it’s fair to say that this conceptualisation is so dominant that it seems to be obvious and self-evident.

But Cartesian individualism has come increasingly under attack from thinkers such as George Herbert Mead, Lev Vygotsky, Michel Foucault, Kenneth Gergen and others who see subjectivity, or personhood as a fundamentally social and interpersonal achievement. I don't want to go into a long philosophical discussion here but the basic idea these theorists propose is that the person you understand yourself to be is not pre-given at birth and internal, but is inferred over time from our experiences with others and the taking up of socially defined identities.

Mead: "No hard and fast line can be drawn between our own selves and the selves of others..."

Swann: "One cannot separate self-views from the interpersonal contexts that sustain them"

The point I really want to argue is that human beings are fundamentally SOCIAL creatures. Interpersonal contact is not just something we do for fun, but makes us who we are and is a prerequisite to our survival as healthy human beings.

Think of the Romanian orphans a few years back. Even when they had clothing, shelter and food, they remained sickly and failed to grow because they weren't getting the love and affection that are basic needs of human beings.

This phenomenon has also been noted in animal studies and in zoo situations – when animals don't receive caring attention, or when they are put in unfamiliar surroundings, they get sick, go crazy or die. Is it so strange to think that humans might be the same?

Solitary confinement is another example. [Dorothy Rowe]

"As torturers all over the world know, the one torture which will eventually destroy the strongest person is complete isolation. We all need other people just as we need air food and water. Without other people our body aches and then ceases to function properly and becomes vulnerable to illness, while our mind, without the encounter of other minds, loses its capacity to distinguish its own contents from the contents of the world around it"

In short, solitary confinement drives people mad. And right now we have thousands of people effectively living in solitary confinement in our suburbs. No job, no family, no friends...

Recent studies revealed that about 50% of two community samples of people diagnosed with schizophrenia reported that they had no friends or relationships outside their families.

Is it any wonder that chronic psychological distress is a major problem in this country when we look at mental illness as a medical problem located in the brain of an individual and fail to address that person's emotional, spiritual and interpersonal needs, or their place in society?

Maslow's hierarchy of needs has been extremely influential, and it seems that our mental health system is based on this model. [Diagram: Need for physical survival, need for safety, need for love and belonging, need for esteem, need for self-actualisation]. Maslow's theory is that we have different levels of needs, and the needs of a higher level only emerge when the needs of the lower level are satisfied.

I guess there is a certain common sense to this: if we found someone shivering and homeless on the streets, our first reaction would probably be to get them clothed, fed and housed as a first priority rather than sitting down there and then offering friendship in an attempt to fulfil their social needs.

But I would like to propose a different version of Maslow's model that makes our fundamental emotional needs primary: the need to feel cared for, to feel a sense of belonging, and the need to feel worthwhile or competent. After all, if you don't have a basic sense of self-worth, then why would you struggle to have your bodily needs met? If you feel completely unloved and worthless, life is not worth living – our suicide statistics attest to this.

To suggest that someone who is hungry or homeless does not experience a need for belonging or a need for self-esteem is crazy – and yet this seems to be how our mental health services are organised.

Coming back to the example of outreach work with the homeless, Bill Davies of Sydney's ICLA City Street Outreach Service who spoke this morning described how the first task of the outreach workers is always to establish rapport and trust with each new client that they seek out on the streets, under bridges, in culverts or wherever they happen to be living. Sometimes this can take months of almost daily visits. Not until that trust is established, can any of the practical issues like housing be broached.

To quote Bill:

"[The service] is based on a recognition that a trusting and empowering direct relationship between the worker and the client is essential to expedite the client's use of services...For many clients, having simple basic contact with someone concerned for their well being is a positive outcome"

So even in situations of desperate need for food, clothing and shelter, it is the human connection – one human being reaching out to another – that opens up a space where change becomes possible.

Compeer, again, is another example where the simple expression of friendly concern and an ongoing trusting relationship can work miracles in the life of someone whose sense of self-worth has hit rock bottom. I am reminded of Jeffrey Mason's saying "What we need are more kindly friends and fewer professionals" (Against Therapy, 1988)

Focusing on the Future

Don't get me wrong – I'm not arguing that medical treatment is bad or unnecessary, or that programs like Compeer could *replace* clinical services. What I am saying is that medicine can only provide *part* of the answer to the problem of mental illness. In order to provide effective care that promotes recovery rather than the revolving door syndrome, we need to fundamentally re-think what mental illness is, and what sufferer's basic needs are. We need to look at mental health problems in their social context, and treat people as people – with social, emotional and spiritual needs. And we need to work together – no single program or perspective has all the answers.

Post-script: Notes and ideas for progressive change:

- A first and obvious step forward is to listen to services users – people who are living with or recovering from psychological problems. What is it like to experience psychosis? How does it feel to be involuntarily hospitalised? What aids recovery? What un-met needs need to be addressed? We need consumer perspectives in training programs. Genuinely client-centred approaches. Fit the treatment to the client and not vice-versa.
- Because NGOs tend to be established in response to expressed needs and are closer to the community, and possibly less hung-up about needing to be ‘experts’, I think they play special role to here.
- Mutual respect and co-operation between NGOs and statutory services is vital if we are to realise seamless holistic care. Forums for ideas sharing such as this conference are really necessary. We need to work on ways of further developing communication & cooperation, and boosting the status, recognition and funding of NGO services – no more begging for crumbs that fall from the table of the medical “experts”.
- If the medical model is too narrow and mental health needs are much broader than what would normally come under “Health”, then maybe we need a whole new structure for the care of people with psychological problems. How about bringing psychological care out from under Health and creating a Department of Psychosocial Services.