Resisting the diagnostic gaze

"We cannot abandon the injured or the maimed, thinking to ensure our own safety and sanity. We must reclaim them, as they are part of ourselves." Brian Keenan

Despite being promoted by the World Health Organisation and most Western institutions the psychiatric diagnostic system misrepresents people's emotional problems. The Diagnostic process converts someones's distress from a psychosocial problem into an individual problem. It takes the person's experience out of their social and historical context and tries to categorise the evolving mental state into a fixed category. This suits the interests of the pharmaceutical industry who need to associate specific drugs to diagnostic categories but it does not serve the interests of the person on the receiving end. It has been well documented that diagnostic categories do not stand up to scientific scrutiny (see Boyle, 1987 Bentall, 2004). However despite this awareness, in practice psychiatric diagnosis continues to be seen as useful and important in understanding and treating mental health problems. The impact of diagnosis is huge on people's lives. The diagnostic process has a similar psychological effect to assigning someone to a low social caste, having a significant influence on how the person sees themselves. For example if a person is given a diagnosis of schizophrenia they and the people around them can often acquire a learned hopelessness; similarly a young person given a diagnosis of bipolar disorder can resign themselves lifelong episodes of mania and depression; a spiritual experience can feel written off if it is described by clinicians as a delusion. The powerful effect of the diagnostic process is described as a 'clinical gaze' in Foucauldian philosophy which suggests a form of psychological imprisonment takes place (Roberts, 2005).

I first became aware of this process when aged 18 I was given a diagnosis of schizophrenia. Clinicians focussed on my behaviour and did not try to understand my subjective experience. I did not find the term schizophrenia a helpful description and I chose to ignore it and focus on a holistic recovery process. Later I decided to train as a psychologist in order to develop more positive ways of describing and addressing distressing and confusing experiences.

In my current work as a psychologist I do a lot of work trying to undo the smothering impact of diagnosis and clinical language in general (eg. illness, symptoms, relapse etc). Just recently a consultant psychiatrist told a young man who has been in and out of hospital for the last 5 years; that he definitely had Schizophrenia and it was 'engrained' so he should not expect much improvement and he would need to take medication for the rest of his life. In fact the young man was not told directly, his parents were told this in front of him as if he was not there. With diagnosis the person becomes invisible. The young man later told his mother he was devastated what the consultant psychiatrist had said. Eleanor Longden (2005, page 35) eloquently brings this alienation process to life: *"You feel as if you've passed from romance to realism in one wretched step. You feel at the mercy of events; even though you know events have no mercy in them. I can't ever explain; the way despair feels is only an approximation…I stopped being Eleanor then and instead became "that schizo" From fear of darkness came fear of light…Friends ceased to be friends, because they wanted me as they remembered, which was solid, capable and sane".*

In my work helping people in distress and confusion I have adopted a community development approach (Orford,J, 1993 Scileppi, J. 2000). I place considerable emphasis on self help group-work, and community meetings but also work individually with people using a range of psychotherapeutic approaches.
Within this I aim to integrate the wisdom gleaned from the user movement, the recovery literature and organisations like the Hearing Voices Network (Downs, 2000, Rose, 2001, Repper and Perkins, 2003 Wallcraft et al. 2003).

Resisting the Pathologisation process

While experiences and behaviours need to be described, I find pathologisation rarely appropriate. I find it more useful to focus on exploring frameworks that enable meaning to be made of their experiences and actions that will help reduce distress and increase psychological and social functioning. In place of clinical/ medical approaches, I will work with the family or supporting social network and the individual to reinstall hope of a better future and to help the person make sense of their experiences and situation in relation to social and psychological events (see May, 2004). I try to create an atmosphere of acceptance, understanding and optimism. Helping people describe their own experiences on their own terms (e.g. feelings of dread, hearing voices, dissociation, panic, despair) and coping strategies (e.g. pacing, self harm, avoidance, and withdrawal) is both more respectful and more practical than trying to fit these into pathological categories (Newnes et al. 2001). As people look back at these experiences, and seek to explain them, helping them record these reflections can give them a broader perspective. Some people will find this helpful, but I would suggest also that this making sense process is an ongoing one so the writing down of experiences or explanations should not be seen as 'the last word'. Also it is likely that at any one time period, we may hold more than one explanation according to the context or role we find ourselves within. For example a person may simultaneously hold an emotional explanation of their situation and a spiritual explanation.

Conceptual work

I will work creatively to help someone learn that there are many different ways of seeing their situation and their potential for growth. I will explore literature and ideas that introduce these different perspectives. One person in a hearing voices group proclaimed "I believe we're not mad we're gifted". Another voice hearer responded "yes it's a gift but badly wrapped". Can the perception of alternative realities or the experience of extreme pain have a silver lining - a meaning or a purpose in our lives? These are important questions to consider in breaking from the shackles of psychiatric definitions. There is much literature and resources to do this, such as the understandings of Mad Pride, R.D Laing, spiritual writings and shamanism (e.g. Dellar, 2000, Mullan 1995, Mindell, 1993).

Adopting a community development approach I have helped create a series of public meetings in West Yorkshire called Evolving Minds to explore different understandings and approaches to mental health. In various ways the meetings have questioned the logic of society's parameters around sanity and insanity. For example,

in contrast to western definitions of mental health problems, in Buddhism it is believed everyone is 'mentally ill'- that everyone's perception of reality is influenced by delusions they hold. 'Mental illness', in this frame of reference, becomes no longer an exclusive and alienating affliction but something we are all struggling. Reversing the diagnostic lens by diagnosing the officially sane, can also shed new light on how we see health. In this vein the spiritual teacher Krishnamurti is attributed as stating: "It's no measure of health to be well adjusted to a profoundly sick society". Together in one Evolving Minds public meeting we discussed; "how do we survive in a sick society?" Among the suggested strategies were creativity, meditation, mutual support systems and being part of green/peace movements.

Working in the person's reality

I have learned from the hearing voices movement the power of creating spaces where different beliefs about the nature of reality are respected (see Romme and Escher 1993, Knight, 2005). In the Hospital based Recovery self help group I facilitate, the first ground rule is that we respect different belief systems- as long as we also respect each other as equals (ground rule number 2.). If someone believes they are a twenty-first century prophet, their beliefs are respected, if someone believes they are not biologically ill but reacting to experiences of oppression we will respect that view too. Group members may suggest their own accounts of the world to others but it is not acceptable to attempt to impose worldviews on others. In diagnostic ways of working, unusual beliefs are often seen as delusions which are part of people's 'illness', justifying belief modification techniques. However in working with people, conscious of the importance of self determination, beliefs are not pathologised. The premise is that the belief is not the problem in itself; the challenge is how do we negotiate our beliefs in the wider social world we live in. By finding a safe space to share a distressing belief or experience, the process of being listened to compassionately can bring a great deal of relief. We can then look at different ways to reduce the associated distress together.

If someone sees their problems in spiritual terms I will help them connect with people who can help them spiritually. Our Bradford hearing voices group recently supported a woman who believed she was possessed for the last twenty years to visit a Catholic priest who carries out exorcisms. She found the assessment of the priest, (for example that the possession was not her fault but related to ancestors) and suggested prayers very helpful and validating. There is a growing interesting the associations between experiences seen as psychotic and spiritual experiences (e.g. Clarke, 2002 and Jackson, 2001)

Working inside and outside psychology

I have found that there are a huge range of resources that people find useful in dealing with distressing experiences and developing their potential, many of them outside the traditional psychology literature.

Whatever their diagnosis, a major problem for people receiving help from mental health services is their isolation. Introducing people to others who have some commonalities in their social situation or experiences can be more helpful than any psychological intervention in many cases. Self help groups are good places for this to occur. They are democratically run spaces for people to exchange support, relate experiences and be role models for each other. As well as the self help groups I support, I also have a mobile Library of self help books from different traditions

including various psychology schools, Daoism, mindfulness, yoga charts (and recordings) and spiritual books from different traditions. Again these offer people a broad range of ways of seeing themselves and identifying with others. I am happy to help people access a range of holistic approaches to wellbeing (e.g. meditation classes, Tai Chi, acupuncture, reiki etc). The evidence base for these approaches comes from the group members, if they find an approach useful they are supported to pursue it, if not the approach is discarded. Finally I have found it is important to create space for people to express their anger or hurt feelings about discrimination they have experienced in relation to diagnostic thinking. Where possible I will support people to find ways to speak out about these experiences, contributing to the growing pressure for political change in society's approach to distress and confusion.

In summary to assist people in resisting the diagnostic gaze I invest in creating democratic spaces where people can explore alternatives to clinical and diagnostic ways of thinking about mental health. This seems to be popular with both individuals and the various self help groups and community forums I am involved in. I see these groups as part of global resistance movement that offers people real choices in how they can define their experiences and find solutions to their difficulties.

R. Bentall (2004) *Madness Explained: psychosis and human nature*, Penguin.

Boyle, M. (1989) *Schizophrenia - a Scientific Delusion?* Routledge: London.

Clarke, I (Ed.) (2002) *Psychosis and Spirituality: Exploring the New Frontier.* London: Whurr.

Dellar, R. (2000) *Mad Pride, a celebration of mad culture*. Chipmunka publishing.
Knight, T. (2005) You'd better believe it, accepting and working in the client's own reality. Clinical Psychology Forum November Issue.

Downs, J. (2000) *How to Set up and Support Hearing Voices Groups* Hearing Voices Network publications.

Jackson, M (1997) *A Study of the Relationship between Psychotisis and Spiritual Experience.* Unpublished Thesis. Oxford University: Oxford.

Longden, E. (2006) The *Dance of the Lepers*, Asylum magazine V15 pp 34 -36.

May R. (2004) Making sense of psychotic experiences and working towards recovery (pp245-260) in *Psychological Interventions in Early Psychosis* Ed. by Gleeson, J. and McGorry, P. Wiley.

Mindell, A. (1993) *The Shaman's Body: A New Shamanism for Transforming Health* Harper San Fracisco.

Mullan, B. (1995) *Mad to be Normal: Conversations with R.D. Laing*. London: Free Association Books.

Newnes, C. Guy Holmes, Dunn, C. (2001) This is Madness Too, PCCS Books.
Orford,J. (1993) *Community psychology: theory and practice*, Wiley.

Scileppi, J., Lee, E., Torres, R. (2000) *Community Psychology: A Common Sense Approach to Mental Health*, Prentice Hall.

Repper, J. & Perkins, R. (2003) *Social Inclusion and Recovery: a Model for Mental Health Practice,* Bailliere Tindall

Roberts, M. (2005) *The production of the psychiatric subject: power, knowledge and Michel Foucault* Nursing Philosophy Vol 6, 1.

Romme, M. & Escher, S. (1993) *Accepting Voices.* London: Mind.

Rose, D (2001) *Users' Voices: The perspectives of mental health service users on community and hospital care*. London: The Sainsbury Centre for Mental Health.

Wallcraft, J., Read, J. & Sweeney, A. (2003) *On Our Own Terms: Users and survivors of mental health services working together for support and change*. London: The Sainsbury Centre for Mental Health.

Rufus May works as a clinical psychologist in adult mental health for Bradford District Care Trust. He is an honorary research fellow at The Centre for Citizenship and Community Mental Health, Bradford University. He has some articles available at:
http://www.brad.ac.uk/acad/health/research/cccmh/index.php