

Reclaiming Mad Experience: Hearing Voices Groups, Unusual Belief Groups and Evolving Minds Public meetings

I will describe my journey into working with self help groups and then outline how we have established various self help groups and public meetings that aim to empower people to reclaim their lives from dependence on traditional psychiatry.

Introduction

When I was eighteen I witnessed first hand how society's approach to mental health wasn't working. I had been admitted to Hackney hospital a psychiatric hospital and told I could not leave. Feeling lost after my girlfriend had left me and on the verge of adulthood I had invested in a spiritual search for guidance. The messages I picked up from the Bible convinced me I had a mission. Seeking to discover what my mission was I slowly deduced that I was quite possibly an apprentice spy for the British Secret service. I was eventually admitted to hospital when I became convinced that I had a gadget in my chest that was being used to control my actions. Psychiatric hospital was like another world entirely. Queues for the medication trolley punctuated the boredom and general sense of hopelessness. Any resistance to the regime was quashed by forcible restraints and powerful injections. Many friends felt too scared to visit me. That experience coupled with being given a diagnosis of schizophrenia made me feel like a social outcaste. When my parents were told it was probably genetically inherited the die seemed irrevocably cast. Ward rounds felt like elaborate religious rituals conducted by the consultant psychiatrist, with an audience of medical students and student nurses observing, while my insanity was confirmed and long term drug treatment prophesied. I found the medication made me feel empty and soulless I could not think past considering my basic needs. The drugs made me physically weaker and affected my hormones so I became impotent. I was concerned about this. However, to the outside world because of the mind-numbing effects of the drugs I was less focussed on my spy and spiritual beliefs. The doctors pronounced that I was responding well to the medication. I was determined to stop taking the tablets and injections as soon as I could find other ways of staying calm and centred.

The majority of fellow patients were revolving door patients. I myself was told you'll be back. It was true I was readmitted twice before I managed to escape the role of mentally ill regular customer. Luckier than most, as well as my parent visiting me daily a close friend came back from selling pots and pans to US servicemen in Germany and began visiting me daily too. I started to pick up on her belief that this breakdown or whatever it was I was having was something I could get over. When I had been 12 years old I had witnessed my mother make a strong recovery from a disabling brain haemorrhage so instinctively I knew that I could turn my life around with the right support. So I decided not to believe in the Doctor's wisdom and planned to get a job as soon as I left hospital. While I was still in hospital I started going to churches and community centres offering to

do voluntary work. Although I must have seemed a bit odd I found many kind people who were willing to give me tasks to do and slowly I started to rebuild some social skills.

When a friend and fellow patient Celine took her own life after being heavily over-medicated it became a turning point in my life. It was a Caribbean funeral and 100s of people turned up for it. For me it contrasted strongly with the absence of support she had had when she had been alive and hearing abusive voices from her past. I realised then that I had found a cause that I could invest my energy into. We as a society were making people madder and maybe I could do something about changing that. What if I could make a different kind of come-back to the psychiatric ward as a mental health professional? Then perhaps in Trojan horse style, I could help dismantle the myths of the psychiatric hierarchy. The more I thought about this the more I realised I would have to keep my former identity as psychiatric patient strictly under-cover. When a junior psychologist informally questioned my diagnosis of schizophrenia, suggesting a temporary psychotic episode instead, it made me think maybe psychology was a way of doing things differently. So my mission was becoming clearer I would train as a psychologist. I knew I needed to sort myself out to some extent before endeavouring this journey. My first job straight out of psychiatric hospital was working as a night security guard in Highgate Cemetery. I now think that patrolling the heavily wooded grounds in the dark was a deeply therapeutic activity. With no time to day dream I had to stay aware and face my fears of the dark and the unknown. I also think just walking in close proximity to nature was a very healing process. It was during this time that I successfully came off my psychiatric medication against Doctors advice. I then spent several years doing a range of jobs and learning creative ways to express myself using dance and drama. I shifted my focus from thinking about myself to trying to help others while making sure I looked after my mind and body. I used the out door gym on Parliament Hill, sport and breathing exercises as natural ways to manage my moods. I was careful to avoid unreliable or abusive friends and stick with people who had stuck by me. Studying Sociology helped me understand the wider structures of society, demystifying such things as the class system and power relations between men and women.

I was reminded of the prejudice against the subject of mental illness when a politically correct community centre refused to support myself and a group of amateur drama students putting on a play about a nervous breakdown. Nevertheless through drama classes I learned the art of re-inventing oneself through improvisation. I will always remember how one of my drama teachers impressed upon us all the message that 'this life is not a rehearsal'. My confidence in acting was to become useful over the next ten years of care-work and psychology training where I chose to keep quiet about my former role as psychiatric patient, to avoid the possibility of discrimination. I had to act sane , always have been guvnor!

For me the dividing line between the mentally ill and the sane was more a question of social boundaries than actuality. I had found some very mad people in hospital very helpful and some of the so-called well nurses quite bullying and hostile, it suggested to me that to some extent madness was in eyes of the beholder. I also knew that my own

madness had been meaningful; for example, my fantasies about being a spy had given my life meaning and my search for a spying mission was a metaphoric search for a meaningful quest in my life. As I trained as a psychologist in the early nineties it coincided with psychology as a profession beginning to get interested in trying to understand and work with madness, whereas previously it had been the domain of the more medical drug prescribing profession of psychiatry. For the last ten years I have been working as a psychologist with a broad range of mental health problems (see May, 2004). I know that to really help someone who is deeply suffering or confused we need to be very creative and offer a wide range of resources. Over the last 8 years I have shifted my focus from therapy to self help. This is because self help networks appeared to offer a genuinely more respectful and empowering environment for people to get on with their lives. I have also found holistic therapies and approaches to wellbeing very useful both for myself and others, including mindfulness and bodywork (e.g. Yoga and Tai Chi).

The Hearing Voices Movement

One of the most exciting developments in the United Kingdom in the last 15 years in the mental health arena has been the development of hearing voices self help groups (See Romme and Escher, 2003). There are now nearly 200 groups in England and Scotland. Hearing Voices groups have three important principles

- 1) They do not presume that voice hearing is a mental illness;
- 2) They see each voice hearer as holding expertise and wisdom about their experiences;
- 3) They hold the view that there is no one best way to understand and approach voice hearing. Rather, Hearing Voices groups welcome different approaches to living with the experience of hearing voices (e.g. spiritual, psychological paranormal and even biological approaches!).

The ground-breaking value of the hearing voices movement is *acceptance*; unlike bio-medical psychiatry hearing voices is not seen as a problem, the problem (if there is one) is in the relationship between the voices and the voice hearer. The hearing voices movement seeks to create spaces where people can gain the confidence to change the way they relate to their voices. For example in our hearing voices group in Bradford people learn a lot from each other and the strategies that have been helpful in dealing with the voices. Group members have been keen to learn Zen meditation techniques which can help them stay grounded and stable when difficult voices or visions appear. We have also raised funds for free Tai Chi classes which if regularly practiced enable people to learn was to develop emotional calm, as we have found that difficult voices appear to feed off trapped emotions. Where it appears helpful people are also supported to dialogue with their voices to negotiate better relationships with them. There is a way using chairs where a facilitator can interview someone's voice using chairs and help the voice hearer and voice come to better understandings about each other. I and group facilitator Eleanor Longden are developing a manual with the Dutch psychiatrist Dirk Coerstens that will show people how to use this voice dialogue technique.

The emphasis of activity in the hearing voices movement is on *community development*

rather than therapy; developing more supportive and democratic communities for people who hear voices with an emphasis on education and mutual support. Education is also focused on the wider communities people live in. Thus the emphasis is as much on changing the environment around the person as much as on the individual changing (see Downs 2001). There is also a value placed on making connections between people who hear voices who have never used psychiatric services with people who have received psychiatric services

The impact of hearing voices self help groups is that many people have reclaimed their lives from being dependent on psychiatric services. They have become empowered to face their experiences of hearing voices learn to live fulfilling lives whether the voices are there or not. By having a supportive space to face their voice hearing experiences, voice hearers have been able to gain greater understanding about their purpose in their lives. Simultaneously efforts have been leveled at the media to educate the public that voice hearing is an experience we all should accept and respect, rather than shun and fear. For example in 2006, survivor activist Louise Pembroke proposed that September the 14th be world hearing voices day. This was organized in conjunction with Intervoice the international hearing voices organization and media events were organized on an international basis.

Unusual Beliefs Movements

In West Yorkshire we have taken these principles of community development into other areas of mental health as well as hearing voices. We have been inspired by the work of Tamasin Knight who has researched how people cope with unusual beliefs (Knight, 2006). She found many people are able to live with unusual beliefs and get on with their lives. Examples of unusual beliefs that psychiatry might describe as 'delusions' are beliefs about spiritual possession, alien abduction, telepathy, and global conspiracy. Her research suggests that if someone is attached to their belief rather than label and try to remove someone's unusual belief we should be helping people live with their unusual beliefs and get on in the world. Again the consequence of this thinking offers a real challenge to conventional mental health practice. When asked to intervene, psychiatry has tried to medicate away people's unusual thinking and therapies have sought to train people to think more rationally. The alternative approach is to educate society that there are many ways to perceive the world and its *how* people relate to their beliefs and to the world around them that is crucial to their quality of life not the ability to think normally or rationally. Therefore self help groups where different ways of thinking about the world are accepted and people can explore how to live with their beliefs are a crucial part of this approach.

In Exeter there has been a self help group called 'You better believe it!' that has been going for three years. In Bradford we have established a similar group called "Believe it or not!" Our launch meeting was attended by 60 people and included presentations by Tamasin Knight and an African Shaman called Odi Oquosa. Odi talked about his own experience of using spirituality to overcome trauma and spiritual attack and the power of

artistic expression and nature in the healing process. For Odi, madness is an initiation of a healing process; an awakening of the unconscious mind. For this healing to be enabled it is important not to suppress these experiences as western psychiatry has tended to do, rather we need to create artistic spaces where this unconscious state can be expressed symbolically, understood and lessons learned from it by the surrounding community. The believe it or not group has supported someone who believed they were possessed seek spiritual advice and guidance. Another group member who understands his intense experiences of powerful energy as Kundalini has been supported to access a Kundalini yoga class and Kundalini self help literature. Joe was a group member who felt shy and wanted to improve his social confidence and relation-building skills. One meeting Joe presented this poem he had written about an enlightenment experience.

*As I was walking late one night
Out of the blue there came a light
And the light said relax and don't take flight.
Then all of a sudden, I didn't exist as one.
I was the birds, I was the bees,
I was the whistle in the breeze.
I was the stars, I was the sky,
I was the clouds floating by.
I was the rivers I was the sea,
I was the grass, I was the trees.
And I existed as everything but not as me.
But then I felt that this couldn't last
And there I was stood back on the path.
If that's enlightenment, without any shadow of a doubt
Please light shine on me whenever I am out*

As a consequence of Joe's interests we invited a Buddhist guest speaker to the self help group to tell us about Buddhism. When Joe described his experience the Buddhist told Joe he had a special gift. Joe began attending Buddhist meditation classes taking up regular meditation practice. He also got involved in some voluntary work decorating the Buddhists monastery. At the same time Joe kept up going to a Christian church and started going out more to Karaoke bars and night-clubs. With his increased powers of relaxation Joe became more socially confident and out-going. He then joined an on-line dating agency. This is an example of how a self help group has been helpful in developing someone's participation in different communities in Bradford.

We have also established some more general mental health self help groups called Recovery groups that try to observe the same values as the afore mentioned groups. This includes one group that is held in the local psychiatric hospital and is open to all psychiatric in-patients. This Recovery group introduces people to the mutual self help ethos and often people then are enabled to seek alternative support from our groups once they have left hospital.

Evolving Minds public meetings

Evolving Minds public meetings meets in two venues in the West Yorkshire region (Hebden Bridge and the city of Bradford). The aim is to create regular monthly public forums to discuss different approaches to mental health problems. This includes social, spiritual and personal approaches. We recognise that there is no one best way of understanding this subject. The Meeting holds the belief that each person has a wisdom and expertise about their own experiences and what is likely to be real and or helpful for them, and that this wisdom needs to be valued and respected.

The aim of Evolving Minds is therefore to create a public space where different understandings and initiatives can be shared. In this way Evolving Minds hopes to generate an increased level of acceptance and understanding of experiences of distress and confusion (and creative ways to deal with this) in the wider communities we live in. Evolving Minds is also interested in addressing social justice and human rights issues in relation to mental health problems. 'Evolving Minds' the name comes from a film of the same name that looks at different ways of dealing with psychosis (to view see www.undercurrent.org/minds).

We encourage everyone who attends to contribute to decision making about both the content of the meeting and the way it is organised. Evolving Minds Meetings began in April 2004. It came about after a public showing of the film Evolving Minds at the Trades club in Hebden Bride in November 2003. The film Evolving Minds directed by Mel Gunasena similarly looked at alternative approaches to dealing with psychosis. Over 70 people turned up to see the film and take part in the discussion, discussants included Mel Gunasena herself and there was a lot of interest in taking the issues the film raised further.

The Evolving Minds meetings have covered a range of topics including - Personal accounts of recovery; Forum theatre as a way of dealing with oppression; Guided Meditation; 'Communicationz Promotin Recovery', a Manchester based grass roots self help and media group; How to survive living in a mad world; Binaural beat Technology (a self help strategy that uses stereophonic sound to change mood); Spiritual healing; Ways of reclaiming language of self; Co-counselling; Discussion of the ideas of R.D. Laing; Creativity and mental health. Meetings have also looked at Self esteem- Eastern and Western perspectives; How to live with Suicidal thoughts; Understanding Paranoia; 5 Rhythms Dance and wellbeing; How does war affect us emotionally; Homeopathy and Herbal Medicine; Tree Spirit Healing. We also hosted a performance theatre piece which charted one person's psycho spiritual journey through madness.

Prior to the meeting there is a half hour creative slot where guest artists variously perform poetry, tell stories and play music. The meeting then usually has both guest speakers and small group discussions. The guest speakers are both from within the meeting's membership and from further a-field. The numbers of people coming to Evolving Minds varies between 25 and 40 people. Whilst there are a small group of regular attenders, in general, the attendance is quite changeable. It is likely many people choose to attend

when the meetings subject matter interest them. This means that the ideas and attitudes promoted by Evolving Minds (hope, respect for different understandings of experience, respect for subjective wisdom) reach a broader group of people. Evolving Minds runs largely on social capital; contributors are not paid. Funding for room hire and mail out comes from personal donations.

The meeting is open to anyone and everyone and encourages public debate and dialogue. The public nature of Evolving Minds means that it has quite a good local profile. Posters highlighting each meeting are put up around the local town helping to raise awareness both of the meeting and the issues it looks at. For example one poster read 'How sane is it to be well-adapted to a sick society?' Such slogans and sound bites help to raise the profile of subjects and perspectives that are generally not given a voice. In addition Evolving Minds has had several positive stories in the local newspapers.

There are a lot of people who have described how coming to Evolving Minds has increased their understanding of unusual experiences and distress and given them confidence to act positively around this subject. A series of drama work-shops have developed alongside the Evolving Minds meetings, using 'Theatre of the Oppressed' Techniques developed by Augustus Boal. The drama work-shops have looked at issues to do with identity and ways to challenge experiences of oppression. The Bradford Evolving Minds organized a Mad Arts festival in Bradford which involved major shops and cafes in Bradford exhibiting Art produced by people affected by mental health services and/or problems. It also featured a Mad Cabaret and several other Arts events.

A Campaigning sub-group of Evolving Minds has also got involved in campaigning against the oppressive use of force in the mental health system. This has included two campaigning bed-pushes where we have symbolically escaped from psychiatric institutions. For example in the most recent bed push, dressed in pyjamas, we pushed a psychiatric bed along the road for 60 miles chased by a carnival sized giant syringe (see www.bedpush.com). We also had a fake Electro Convulsive Treatment machine and we offered free treatments to passers by. These publicity stunts were to support the Kissit campaign against forced treatment in psychiatric hospitals (see www.kissit.org). The bed-pushes have achieved national and international media coverage, raising awareness about the human rights abuses that occur routinely in the psychiatric system and the need for social change regarding this issue.

The networks created by the self help groups in Bradford and Hebden Bridge over the last three years are starting to become an alternative resource to people who want to reduce or avoid dependence on conventional bio-medical psychiatry. People who were seen as quite disabled are recovering more active lives and starting to make valuable contributions into their communities. Also family members, friends and other members of the community who have had contact with our activities are learning to be more accepting, creative and hopeful about distressing and confusing experiences and alternative realities. We are beginning to develop real alternatives to the established psychiatric tendency to medically label and suppress odd or distressing behaviour.

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