Notes
Hearing Voices Movement

[http://www.independent.co.uk/life-style/health-and-families/health-news/the-mad-doctor-the-extraordinary-story-of-dr-rufus-may-the-former-psychiatric-patient-440381.html]

The mad doctor: The extraordinary story of Dr Rufus May, the former psychiatric patient

At the age of 18, Rufus May was diagnosed as an incurable schizophrenic and locked up in a psychiatric hospital. Now, he is a respected psychologist and a passionate campaigner on mental health issues. He is also the guest editor of this special issue. Here, he tells his extraordinary tale

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When I was aged 18, I witnessed first hand how society's approach to mental health wasn't working. I was admitted to Hackney hospital - a psychiatric hospital - and told that I could not leave. On the verge of adulthood, and feeling lost after my girlfriend had left me, 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 outcast. When my parents were told my condition 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 I'd be back. It was true: I was readmitted twice before I managed to escape the role of mentally ill regular customer. But I was luckier than most: as well as my parents 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 was 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 for me. It was a Caribbean funeral and hundreds of people turned up for it. 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 needed no delusions to support it. Like Celine, I had gone through the strange process of being talked to as if I was not there, of professionals trying to suppress my odd and disturbing behaviour with drugs without trying to understand why I was acting as I was. No one seemed willing to think what was it like to walk in my shoes.

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 a psychiatric patient strictly under-cover.

When a junior psychologist informally questioned my diagnosis of schizophrenia, suggesting I had had 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 attempting this journey.

My first job, straight out of psychiatric hospital, was working as a night security guard in north London's Highgate Cemetery. I now think that patrolling the heavily wooded grounds in the dark was a deeply therapeutic activity. With no time to daydream, 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 outdoor 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 right-on community centre refused to support me and a group of amateur drama students putting on a play about a nervous breakdown. Nevertheless, from drama classes I learnt 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 10 years of carework and psychology training, where I chose to keep quiet about my previous role as a psychiatric patient, to avoid the possibility of discrimination.

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.

My training as a psychologist in the early 1990s, coincided with a time when psychology as a profession was beginning to interest itself in trying to understand and work with madness, an area which was usually associated with the more medical, drug-prescribing profession of psychiatry. For the past 10 years I have been working as a psychologist covering a broad range of mental-health problems. 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.

In Bradford we have self-help groups where people are encouraged to help others as well as themselves. We also create spaces where for example art, spirituality and physical relaxation can be explored in a number of different ways. We have Tai Chi classes, dance classes and African art classes, as well as political and cultural discussion groups. If people hear troubling voices, I want to understand these beings that haunt them. I will sometimes communicate directly with the voices and try to facilitate a peace process between the voices and the person hearing them.

I must be living proof that people can resist so-called command hallucinations, because initially many voices feel threatened by me and tell the voice hearer to attack me. I am still unscathed, which is a strong testimony to the fact that people who hear voices can learn to resist the most bullying and aggressive of them. So instead of encouraging people to suppress their experiences, which I think generally makes them worse, I try to assist people to face their demons in their own time.

Is society any madder than 20 years ago when I was in hospital? It seems to me that some things are getting worse and some things are getting better. People are getting bolder in talking about their experiences of distress and madness. This is refreshing; the status quo, in which well-meaning professionals and charity heads are the only experts, is starting to be challenged. Britain is a leading light in this consciousness raising, where people are coming out more and more about their experiences of emotional distress. Consequently, a broader range of ideas and approaches to what helps us heal
troubled minds is being listened to.

At the same time, the might of the pharmaceutical industry is stronger than ever before; drug companies are ruthlessly promoting the simplistic and misleading "chemical imbalance" theory of mental distress, while marketing our discontent as diagnosable medical illnesses. In the US, they have been very successful, with roughly 10 per cent of women taking anti-depressants and an astonishing 10 per cent of children being treated for ADHD with the amphetamine derivative Ritalin. Each year in this country, prescription rates rise for psychiatric medication.

While I am not against all use of mind-altering drugs, this trend is worrying. I think that when drugs appear to work, the main effect is that of masking a patient's problems, but as soon as you remove them the problems bounce back, often with a little more oomph due to the fact they have been artificially suppressed. You also need more and more of the drug to achieve the same effect, because our brains build up a resistance to all mood-altering substances. We are then likely to experience the more negative effects of the medication and develop a dependence.

So drugs are limited in their usefulness and are perhaps best used as a last resort and for short periods of time. This is not going to be popular in the board rooms of Big Pharma, the Big Brother of mental health. But if we are going to make progress in our quest for healthier communities, we are going to have to limit the pharmaceutical industry's influence on how we understand our minds and approach the recovery process.

[http://en.wikipedia.org/wiki/Hearing_Voices_Movement]

Hearing Voices Movement

Hearing Voices Movement is a philosophical trend in how people who hear voices are viewed. It was begun by Marius Romme, a professor of social psychiatry at the University of Limburg in Maastricht, the Netherlands; and Sandra Escher, a science journalist, who began this work after being challenged by a voice hearer as to why they could not accept the reality of her voice hearing experience. Followers of the Hearing Voices Movement advocate the use of techniques employed by those who have successfully coped with their voices. This can include acceptance and negotiation with the voices.

The movement

The Hearing Voices Movement can be said to have been established in 1987, by Romme and Escher, both from the Netherlands, with the formation of Stichting Weerklank (Foundation Resonance), an organization for voice hearers and others interested in this phenomenon. In 1988, an organization The Hearing Voices Network was established in England, with the active support of Romme.... In following years, further networks have been established in other countries including Italy, Finland (1995), Wales, Scotland, Switzerland, Sweden, Austria, Germany (1998), Norway, Denmark, Japan (1996), Israel, New Zealand, Australia and the USA (2006).

In 1997 a meeting of voice hearers and mental health workers was held in Maastricht to discuss developing the further promotion and research into the issue of voice hearing. The meeting decided to create a formal organizational structure to provide administrative and coordinating support to the wide variety of initiatives in the different involved countries. The new network was called INTERVOICE (The International Network for Training, Education and Research into Hearing Voices). INTERVOICE holds annual steering group meetings, encourages and supports exchanges and visits between member countries and the translation and publication of books and other literature on the subject of hearing voices. INTERVOICE was incorporated in 2007 as a not for profit company under UK law. Its president is Marius Romme.

INTERVOICE is supported by people who hear voices, relatives and friends and mental health professionals including nurses, psychiatrists and psychologists. INTERVOICE members assert that the most important factor in the success of their approach is the importance placed on the personal engagement of the people involved, meaning that all participants are considered an expert of their own experience. They see each other first as people, secondly as equal partners, and thirdly as all having different but mutually valuable expertise to offer. This can either be through direct experience of hearing voices or having worked with voice hearers (and/or a desire to be involved).

INTERVOICE is critical of psychiatry in relation to the way the profession generally understands and treats people who hear voices and holds that their research has led them to the position that schizophrenia is an unscientific and unhelpful hypothesis which should be abandoned....

The Hearing Voices Movement regards itself as being a post-psychiatric organisation,[3] positioning itself outside of the mental health world in recognition that voices, in their view, are an aspect of human differentness, rather than a mental health problem and that, as with homosexuality (also regarded by psychiatry in historical times as an illness), one of the main issues is about human rights. As with homosexuality, members of the movement intend to change the way society perceives the experience, and psychiatry's attitude will follow.

The Hearing Voices Movement is also seeking more holistic health solutions to problematic and overwhelming voices that cause mental distress than what it regards as the generally reductionist, disease based model offered by mainstream psychiatry. Based on their research,[citation needed] they hold the opinion that many people successfully live with their voices and that in themselves voices are not the problem. For this reason they are prepared to accept a range of explanations offered by people who hear voices, including spiritual ones and assert that recovery (see recovery model) from overwhelming voices can be achieved by seeking to understand the meaning of the voices to the voice hearer.

A detailed and neutral account of the significance of the Hearing Voice Movement entitled "Can You Live With the Voices in Your Head?" was published in New York Times Magazine in 2007. Its author Daniel B. Smith writes that the movement's

> brief against psychiatry can be boiled down to two core positions. The first is that many more people hear voices, and hear many more kinds of voices, than is usually assumed. The second is that auditory hallucination — or “voice-hearing,” H.V.N.’s more neutral preference — should be thought of not as a pathological phenomenon in need of eradication but as a meaningful, interpretable experience, intimately linked to a hearer’s life story and, more commonly than not, to unresolved personal traumas.

Position

The position of the hearing voices movement can be summarised as follows:

- Hearing voices is not in itself a sign of mental illness.

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- Hearing voices is experienced by many people who do not have symptoms that would lead to diagnosis of mental illness.
- Hearing voices is often related to problems in life history.
- If hearing voices causes distress, the person who hears the voices can learn strategies to cope with the experience. This is often achieved by confronting the past problems that lie behind the experience.

Movement history

In an overview of the challenging new research and practise initiatives developing across Europe,[4] Baker charts the progress made from a view of voice hearing as bizarre and dangerous[5] towards a recognition of voices as real, meaningful, and related to people's lives. This recognises that the experience can be overwhelming and deeply distressing, but also, that the attempt to understand their meaning can be part of a solution.

Leudar and Thomas

In a recent book, Leudar and Thomas (2000): *Voices of Reason, Voices of Insanity*, review almost 3,000 years of voice-hearing history, including that of Socrates, Schreber, and Janet's patient 'Marcelle', amongst others, to show how we have moved the experience from a socially valued context to a pathologised and denigrated one. Foucault has argued that this process can generally arise when a minority perspective is at variance with dominant social norms and beliefs.

Romme and Escher

The work of Romme and Escher... provides a theoretical framework for these new initiatives, and provides much of the impetus for the self-help movement in recent years. They demonstrate:

1. Not everyone who hears voices becomes a patient. Over a third of 400 voice hearers in Holland had not had any contact with psychiatric services. These people either described themselves as being able to cope with their voices and/or described their voices as life enhancing.
2. Romme cites demographic research.... indicating that hearing voices in itself is not a symptom of an illness, but is apparent in 2–4% of the population (some research gives higher estimates); and even more (about 8%) have peculiar personal convictions, also known as delusions, and do so without being ill. His own research has provided further verification of this...
3. Comparisons between people. People who cope well with their voices and those who did not show clear differences in terms of the nature of the relationship they had with their voices..
4. People who cope better also differed in terms of the kinds of strategies they adopted to manage their voices and its personal impact.
5. 70% of voice hearers reported that their voices had begun after a severe traumatic or intensely emotional event, such as an accident, divorce or bereavement, sexual or physical abuse, love affairs, or pregnancy. Romme et al. (1998) found that the onset of voice hearing amongst a 'patient' group was preceded by either a traumatic event or an event that activated the memory of an earlier trauma. There was a high association with abuse. These findings are being substantiated further in an on-going study with voice hearing amongst children....
6. Some people who hear voices, regardless of being able to cope with this or not, may have a burning need to construct a personal understanding for their experiences and to talk to others about it without being designated as mad.
7. A long-term developmental process of psychological adjustment was identified by surveying the considerable range of experience and the negotiation methods that people reported. Romme.... has developed this approach with several studies showing that hearing voices can be associated with memories of emotionally 'undigested' events, usually connected with key relationships.

Romme et al. (1999) finds that these important connections can be addressed using cognitive behaviour therapy (CBT) and self-help methods.

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Romme describes a three phase model of recovery.

- Startling. Initial confusion; emotional chaos, fear, helplessness and psychological turmoil.
- Organization. The need to find meaning, arrive at some understanding and acceptance. The development of ways of coping and accommodating voices in everyday living. This task may take months or years and is marked by the attempt to enter into active negotiation with the voice(s).
- Stabilisation. The establishment of equilibrium, and accommodation, with the voice(s), and the consequent re-empowerment of the person.

Alternative to medical model

The Hearing Voices Movement reflects significant disenchantment with the medical model and the practises of mental health services through much of the Western World.

Brown et al. (1998) finds that 23% of people diagnosed with a psychotic illness experience positive symptoms that are resistant to medication. It has been reported that only a minority (roughly 35%) obtain significant benefits from antipsychotic drug treatment..... Further, there is a range of secondary problems and withdrawal effects associated with both traditional and atypical antipsychotic drugs....

The movement also focuses on the complexity of the experience of hearing voices. In addition, emotional problems (such as depression and anxiety) are found in 25–40% of those diagnosed with psychosis,.... and the risk of suicide is increasingly recognised....

Apart from the issue of medical effectiveness, 'getting better' must be as much a personal process, to do with the nature of the experience, as a medical one..... Many service users have reported negative experiences of mental health services because they are discouraged from talking about their voices as these are seen solely as symptoms of psychiatric illness....

Slade and Bentall (1988) conclude that the failure to attend to hallucinatory experiences and/or have the opportunity for dialogue about them is likely to have the effect of helping to maintain them.

Romme (1991) describes several case stories to show how the acceptance or non-acceptance of voice hearing is socially and culturally determined, which can influence the outcome of treatment with people diagnosed with schizophrenia. Baker (1995) suggests that the extent to which nurses accept the experience of people they believe to have psychotic disorders has an effect on the extent to which they can discuss it with them. Martin (2000) describes the creation of an environment conducive to discussing the experience. Such strategies do not demand textbook answers, but emerge from service users living, in a supported way, with the experience of voice hearing.

Increasingly, in acknowledgement of the methodological weaknesses, poor prognostic power, symptomatic variability and general weaknesses inherent in the diagnostic validity of the term schizophrenia, the psychological literature has increasingly tended to focus on specific or discrete symptoms or aspects associated with it....

Thus, there has been a rapid growth in research investigating theory and treatment of strange beliefs, attention and concentration deficits, self-esteem, family processes (such as the Expressed Emotion literature), to mention but a few, as well as 'voices'. In addition, recent developments in the theory and treatment of post-traumatic stress disorder and dissociative conditions offer new understandings emphasising the close links between severe trauma in earlier life and voice hearing subsequently along with other potentially very disabling psychological symptoms. Romme et al., for example report that the disability incurred by hearing voices is associated with previous trauma and abuse, in some way (Romme et al., 1998). Similarly, in a follow-up study (Romme et al., 1999) find that these important connections can be effectively addressed clinically using a mixture of psychological therapy and self-help methods.

Romme and Escher (2000) have developed a method they call "Making sense of voices" to explore the problems in the life of the voice hearer that lie at the roots of the hearing voices experience. This approach was adopted as a consequence of the results of the studies they carried out, that they claimed, showed that to hearing voices, in itself, is not a symptom of an illness, but in most people is a reaction to severe traumatic experiences that made the person powerless, and are in effect, a kind of survival strategy.
[edit] Recent work

Recent work has focused on beliefs about voices in addition to the voices themselves. Chadwick, Birchwood and Trower (1996) and Bentall (1994) have proposed a number of psychological theories for understanding the experience of hearing voices and the beliefs associated with them. Chadwick and Birchwood, 1997) reported marked reductions in voice hearing, and associated distress based on their cognitive model.

In an intriguing study, Birchwood et al. (2000) found close parallels between the experience of subordination by voices and the experience of subordination and marginalisation in social relationships generally. This suggests that distress arising from voices may not only be linked to voice characteristics but also social and interpersonal beliefs based on life experience.

A range of other psychological and psychosocial treatment approaches are also reported in the literature. In Slade and Bentall (1988) a number of psychological strategies and the evidence supporting their efficacy are reported in terms of distress and anxiety reduction as well as in the frequency and/or intensity of the voice hearing experience.

The importance of respecting and supporting voice hearers' own capacity to develop their own understandings and personal coping resources has been emerging in recent years (Warnes et al. 1996). In a single case study, Davies (1999) was able to demonstrate the value of a diagological approach, which supported the voice-hearers' own development of a meaningful and helpful personal narrative. McNally and Goldberg (1997), as has Romme and Escher (1994, 1998) emphasised the importance of the individuals own coping resources and beliefs in developing effective intervention strategies. They identified a variety of ways in which 'self-talk' and other naturalistic coping strategies can be actively deployed towards managing voices and related experiences. Warnes (1996, 1999) discusses the value of interventions that maximises and supports the person's own experience of control of their experience.

Researchers are also seeking to discover what are the distinctive features of positive experiences (including pleasurable ones) of auditory hallucinations in people with psychosis who experience both positive and negative voices, and amongst people in the "normal" population.... Beavan's research, for instance, found nearly half the people who heard voices said their hallucinations were mostly friendly or helpful.

***Living with Voices: 50 Stories of Recovery* (2009)**

Living with Voices: 50 Stories of Recovery: Marius Romme, Sandra Escher, Jacqui Dillon, Mervyn Morris, Dirk Corstens (Editors), *Living with Voices: 50 Stories of Recovery* (2009)... United Kingdom....

This is new study is based on 50 stories of voice hearers who claim to have recovered. The accounts are intended to form an evidence base for the effectiveness of hearing voices approach alongside an analysis of the hearing voices experience outside the illness model, resulting in accepting and making sense of voices. This book seeks to demonstrate that it is possible to overcome problems with hearing voices and to take back control of one’s life. The central message of the book is that the path to recovery from overwhelming voices can be achieved by addressing the main problems voice-hearers describe – the threats, the feelings of powerlessness, the anxiety of being mad – and helping them to find their way back to their emotions and spirituality and to realise their dreams. This book also claims to hold true for those who have been given a diagnosis of schizophrenia. At the heart of this book are the stories of fifty people who have recovered from the distress of hearing voices, it documents how they have changed their relationship with their voices in order to reclaim their lives.