

World Hearing Voices Day Conference: 14 September 2007

Accepting and Working with Voices

Louise Pembroke and Sara Stanton

We both hear voices, and are survivors of the psychiatric system and mental health activists who have been involved with Mad Politics over a number of years. Our interest in hearing voices work motivated the need for a national conference in celebration of World Hearing Voices Day, and this article contains our reflections on this year's conference held on September 14 2007.

World Hearing Voices Day (WHVD) was instigated by Louise in 2006. She shared the idea with INTERVOICE (The International Network for Training, Education and Research into Hearing Voices) that voice hearers should have their own day once a year.

WHVD is about challenging the incorrect assumption that hearing voices is always a sign of illness. Hearing voices can take the form of auditory or visual sensations inside or outside the body, and may be

a positive or negative experience. It is one which is frequently not understood or accepted by society. The reactions of others to the experience of hearing voices can be even more isolating than the actual voices. Being diagnosed with a mental illness can lead to even more distress because of the stigma and discrimination associated with receiving a psychiatric label. WHVD then is about raising awareness of the issues facing the estimated 4% of women, men and children who hear voices across the world. It is also about celebrating the diversity of experiences that we have as human beings.

The global Hearing Voices Movement is currently a formidable one. The work of Professor Marius Romme and Sandra Escher (whose first book together was *Accepting Voices*) triggered the biggest seismic shift in the understanding of voice hearing. Romme and Escher's research showed that in 70 to 80% of people, the onset of hearing voices occurred in relation to difficult social circumstances, traumatic experiences, or abuse as an adult or child. The experiences of voice hearers were also found to be similar among those with a formal psychiatric diagnosis and people who had never been diagnosed.

Romme and Escher put the powerful case for accepting and validating people's own interpretations of their voices, and showed how such interpretations often enabled people to live with them far more effectively than biomedical approaches. Their pioneering studies have placed voice hearers at the centre of their work as experts by experience to learn from and with. They see that hearing voices is related to a person's life history, not separate from it.

In launching World Hearing Voices Day, Professor Romme said: 'We are finding more holistic solutions to voices that cause mental distress than those offered by psychiatry. It is very important to stress that in our view voices are an aspect of human differentness, rather than a mental health problem. As with homosexuality, which was also regarded by psychiatry in recent times as an illness, the main issue we have to confront is the denial of human rights to people who hear voices, and our main task is to change the way society perceives the experience. Only if we can do this, do we believe psychiatry will change its mind about voices. That is why holding a World Hearing Voices Day is so important.'

Louise met Marius Romme and Sandra Escher in 1990. She was galvanized. She contributed to *Accepting Voices* and then spoke at the first international congress on hearing voices in Maastricht in 1995. In 2006, we both delivered a workshop in celebration of WHVD which was hosted by Barnet, Enfield and Haringey Mental Health Trust. It was well attended by over 60 staff and service users. This year, we were hosted by Together: Working for Wellbeing (a national mental health charity). From a very small acorn of an idea within the organisation's Service User Involvement Directorate and the Learning and Development Department, a full-blown national conference grew within a matter of weeks. The conference was sold out early in the summer: 140 places were booked with another 85 people on the waiting list. Places were hotly prized, and we can only imagine that this was because of the very diverse and innovative programme of speakers and workshops we had brought together.

The conference addressed areas such as developing coping strategies from outside of traditional psychiatric practice (coping strategies that

really work!), demystifying hearing voices and self-harm, and alternative explanations for the causes of voice hearing. For example as part of the main programme, Dirk Corstens, a psychiatrist and psychotherapist working in Maastricht, talked about voice dialogue. This is a method that enables people who hear voices to explore the voices' motives and discover different ways of relating to them. Psychologist Dr Tamasin Knight spoke about her research into unusual beliefs. Her work is the next phase in HV approaches. It builds on that of Romme and Escher, and involves working within people's belief systems. This approach challenges biological orthodoxy and cognitive behavioural therapy. We both agree that hearing voices cannot be reduced to some (unproven) biochemical imbalance.

We see that there are now many hearing voices groups emerging all over the country. The British Hearing Voices Network was formed in 1988 to support people to learn and grow from their experiences in their own way, and has developed a diverse range of approaches.

Worldwide in Ireland, the USA and New Zealand there are newly formed and very active HV networks.

The Hearing Voices movement is a more credible force to be reckoned with than an 'antipsychiatry' movement, because it does not claim that all of psychiatry is irrelevant. Its message is: 'OK, you can survive, find ways to live with voices, and you may find medication helpful, but there are numerous other things you might want try first!' So the HV movement is about people defining themselves and helping themselves on their own terms. That's much more powerful than simply critiquing the medical model. The global Hearing Voices movement provides a place where voice hearers can discover their own ways to live, where the explanation of the individual is accepted. If this makes psychiatry obsolete for people well, we see no harm in that because it means that people are finding their own paths, and hopefully professionals can recover a more human way of relating to people who hear voices.

We believe mental health services should offer a range of support. For people who commission, design and deliver services, this should mean thinking and working outside the box. Support could include working with shamans, different faiths, mediums, natural healers, homeopaths, spirituality and arts such as visual media, poetry, dance, drama and music. We need to move beyond the doctrine of drugs and cognitive behavioural therapy. It was really important for us to have clairvoyant-mediums run a workshop at the conference. It was a first; no one has done this before. We asked them because although we know that some people think New Age therapies involve crystal-waving namby-pamby nonsense, we believe they offer some very practical techniques, such as learning how to close off the chakras so that you are less open to spirit intrusion. There is a place for this way of working within mental health services. Even the Royal College of Psychiatry has a 'spirituality special interest group' which explores 'spirit release' work. In New Zealand groups have had shamans involved in their HV days. We feel strongly that WHVD is about getting people involved who can offer a different dimension or understanding to the medical one.

Art as a form of testimony and activism is also something we passionately believe in. This leads to another very important point. The arts are being promoted as a recovery aid, but recovery is a contentious word. Recovery has become commoditized, branded and politically hijacked, as in 'recovery equals paid work'. We hesitate around the use of the word 'recovery'. It is bandied about as the 'catch all' that services so many different agendas: for example, getting people off benefits, getting people into work, and helping people to take their medication by gaining 'insight' into their illness. The concept of recovery is also tied up in social inclusion's inability to tackle the discrimination and stigma associated with being diagnosed, and the loss of social status and difficulties people face in accessing services like education, health care and financial services. It also drives the closure of services in order to prevent people becoming 'dependent' on a building when the alternatives are not clear, and the decisions professionals make about how long services should last. For example, determining that someone is entitled to only six weeks of therapy immediately places parameters on how long recovery 'should'

take rather than the recipient being given the choice. People are set up to fail if they don't recover quickly enough. We both agree that within such confused agendas, recovery has become a very over-used and abused word. In fact we won't ever use it, preferring to think of it as 'discovery'.

An overriding message of the conference was how important it is for all voice hearers to seek out their own truths and determine the meaning of their experiences. This is about more than just identifying triggers and finding ways to cope, it's about making sense of our voices so that we do not have to live in the shadow of them. It's about professionals having the courage to put aside their beliefs and work within the ones that the voice hearer owns. This requires acceptance of the experience, which does not necessarily always lead to agreement but is the most useful thing a professional can do.

When people refer to a 'good' doctor or nurse, they are not referring to clinical interventions, but to someone's human qualities and being valued. Someone bothering to seek and work with another's truths.

WHVD is an opportunity to celebrate our lives, acknowledge our

struggles and share our unique approaches in living. Within that voice hearers need to be proud of who they are.

PANEL - ABOUT THE AUTHORS

LOUISE PEMBROKE

Louise Pembroke has been active in local and national service user/survivor groups over the last 20 years. She is a former chair of Survivors Speak Out, and the founder in 1994 of the National Self Harm Network (NSHN), which she also chaired. Louise organised the first national UK conference on self-harm with service users as the keynote speakers in 1989 which inspired her first book *Self-Harm: Perspectives from Personal Experience* (Survivors Speak Out 1994). She is co-author of the *The Hurt Yourself Less Workbook* (NSHN 1998), which was the first self-management workbook by and for people who self-harm. Her DVD *Dedication to the Seven: Hearing Voices in Dance* (available from Mind Publications with an

accompanying booklet) about her experiences of hearing voices has been screened at conferences including those held by Mind and the Royal College of Psychiatrists, and was selected for the 2006 M1 Singapore Fringe festival on art and healing. This year Louise produced a further dance film, *Catatonia*.

Louise says that hearing voices is both an ordinary and an extraordinary experience: 'For me it's normal to hear voices, but it's the responses to it that can be extraordinary . . . I find the psychiatric explanation of voice hearing limiting, because it means being a mere victim of one's biology with faulty brain chemistry and waiting for the drugs to "work".'

For Louise, dancing has opened up another way for her to speak about her voices. 'Movement means that I can give them a physical shape. However, dancing is not "therapy" nor is it "recovery". Activism, peer support and having a passion in my life have been some of the things which have enabled my survival.'

SARA STANTON

Sara Stanton currently works for the Service User Directorate at Together. She has spent many years as a freelance trainer, working in a range of mental health, community and formal education settings. She has also been involved with a number of service user/survivor groups – from the early days of the National Self Harm Network through to supporting the newly established National Self Harm Minimisation Group (hosted by Together) and the London and East of England Service User/Survivor Training Network. She is passionate about education and working in ways which create and improve access to quality learning opportunities for people with mental health support needs.

Sara has always been clear that her voice hearing very much makes up the fabric of her existence. 'I understand my voices as real – if only subjectively – and purposeful in terms of my experience of existence. Existence is about more than life itself and much bigger than historically and culturally specific terms like "schizophrenia".'

Sara's interest has come out of the ever-complicated relationship between her self-harm and her voice hearing. She says: 'I became involved in campaigns around better treatment in A&E, and working for acceptance that self-harm is a valid coping strategy – that people can learn to live with self-harm. Links can be made here with people finding ways to live with their voices; recognising that learning how to deal with voices is a process of engagement, and it is the voice hearer's own understanding that can be utilised to provide appropriate support.'

ON RECOVERY

Speaking at the conference, Louise said: 'For me it means learning to surf the waves of my madness. Sometimes I fall into the water and don't manage daily life well and can barely leave my flat. Then sometimes I have to kneel on the surf board, and then at other times I can stand on the board and ride the big wave. For me it's about how I ride the waves and how I manage it, that's my measure for me. Rather than pinning recovery down to a set list, I would prefer to

see the focus on helping people to live as well as they can, however that is. Reclaiming our lives, in whatever form.'

In her conference presentation, Sara said: 'Getting to where I am now, for me it's always been about looking back on where I've come from rather than setting goals to be achieved and action plans around how to reach them. My life has always been more chaotic . . . and what on earth am I meant to be recovered from? Some other point in my life that I wish to move away from? The voices I heard when I was fifteen, or the ones I heard yesterday? That's never really rocked my boat, as built into it is a sense of failure around what has been lost, could have been.'

Louise and Sara are currently planning their next event for World Hearing Voices Day 2008. To be sent details about this please forward your contact details to sara-stanton@together-uk.org

More information about Together and the Service User Directorate
can be found at: **www.together-uk.org/**

For help with hearing voices in the UK contact:

Hearing Voices Network

www.hearing-voices.org, email: **info@hearing-voices.org**

For information about the National Self Harm Network go to:

www.nshn.co.uk email: **info@nshn.co.uk**

For more information about INTERVOICE go to:

www.intervoiceonline.org

Accepting Voices (1993), edited by Professor Marius Romme and
Sandra Escher, can be purchased from MIND Publications. See:

www.mind.org.uk/osb/itemdetails.cfm/ID/10

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together

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