

*25<sup>th</sup> Anniversary*

Intervoice & World Hearing  
Voices Congress

Report

Cardiff, Wales 19-21 September 2012

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## Introduction to the Report

This report combines accounts by a small team of people from Mind in Camden who attended the Conference and made notes on the keynote speeches and workshops. However, we were not able to cover every workshop, so programme notes were used to fill in the gaps. The notes are a summary of what was said and we have done our best to write an accurate portrayal. I apologise for any errors.

The Conference was attended by almost 300 people from many countries. It was hosted by the Hearing Voices Network, Cymru and organised by Working to Recovery and Asylum Associates. It marked the 25<sup>th</sup> anniversary of Intervoice. As well as celebrating the achievements of the past, there was much shared about current developments and, finally, looked to the future with the launch of the “One of a Million” campaign.

It was a privilege to attend such an exciting and stimulating event and I hope this report will give a flavour of that for those who were not able to be there.

Rowena Dean  
November 2012

# Celebrating 25 years Intervoice Meeting 19 September 2012

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## Meeting each other, exchanging experiences

### Welcome and Introduction: Sandra Escher

The Hearing Voices movement began in 1987 in the living room of Sandra Escher and Marius Romme. Sandra and Marius invited ten to twelve people to meet regularly in their home including Ron Coleman, Paul Baker and others. The group developed a strong mutual interest with some horses that were living in the garden.

Interest continued to grow and two people from each country were invited to join until the group became too big to accommodate and the meetings ended in 2007. Instead, annual international meetings began, initially alternating between the Netherlands and England.

The acceptance that voice hearing is not an illness became more common, and people were able to talk about it without the risk of them being subject to more psychiatry and more medication. Then the movement developed and “hope to cope” strategies were formed. Gradually, many more people became part of the movement.

The challenge for the future is for the movement to become broader, and as a movement, learn lessons from parallels with the gay movement: more voice hearers hopefully will start to come into the open. There is also a need to develop a group of young enthusiastic supporters.

### News from the Board

The Intervoice Board met yesterday and elected four new members:

Kellie Comans (Australia)

Will Hall (USA)

John Jenkins (UK)

Eleanor Longden (UK)

The other members of the Board are:

Dirk Corstens (Chair) (The Netherlands)

Ron Coleman (UK)

Jorn Erikson (Denmark)

Sandra Escher (The Netherlands)

Intervoice has also become a registered charity.

## Intervoice Meeting: Keynote Speeches

### Hearing Voices and Spirituality – progress or heresy? Hywel Davies

Hywel said the purpose of his talk was to raise awareness and it “may be wrong or it may be right.”

Spirituality is about belief in the Divine; worship; a sense of presence; of prayer and “whatever is holy” (William Blake). Hywel quoted George Clooney, “the difference between religion and spirituality is that religion is for those who wish to avoid going to hell and spirituality is for those who have been there.”

Is it progress **or** heresy to include spirituality in the care of mental health care? In Wales, people have a legal right to request spiritual care as part of their mental health package. Psychiatrists have to take into account the spirituality of a patient. I have been involved in mental health campaigning for 25 years and one of my proudest achievements is that with others we have seen spirituality included in mental health care. It is interesting to note that the motto of the the Welsh Psychiatric Society is “the best kind of doctor is a doctor of the soul.”

Helpful books include “Children’s Past Lives” by an American psychiatrist Professor Ian Stephenson, where he states that reincarnation is a reality. In the book “The Divided Self” by RD Laing he tells of someone ( a “schizophrenic”) who believed he was a reincarnation of Napoleon. Similarly, Marius Romme and Sandra Escher’s book “Accepting Voices”, tells of someone who thought he had been Mussolini. Reincarnation is a living reality, it can be proved.

Hywel described his own story including his reincarnation experiences and read out one of his poems “Good Afternoon, Dear Doctor.” He was, he said, speaking about the unspeakable in that the subject is painful touching on trauma and of his previous lives as Judas Iscariot and a Cathar, a 13<sup>th</sup> Century French (heretic) and James VI of Scotland/James I of England. You can see they are all in someway connected to Jesus and the belief in the divine. James VI for instance believed in the divine of right of kings; the Cathars believed in reincarnation. The common themes here are Christianity, divinity and progress and are part of who I am now.

Madness may be the birth pangs of a higher consciousness. Plato saw insanity as a divine gift and the chief source of blessings to men. What is defined as mental health has varied considerably over the last two hundred years and is likely to change again in the next two hundred years. There are numerous examples of categories of people deemed to be mentally ill when they are clearly not, some examples are single mothers, gay and lesbian people, homeless people, epileptics, Russian dissidents and certain black slaves. Slaves who ran away from their “masters” were given the diagnosis “drapetonania”, whilst impertinent slaves were labelled as having “Dythaesia Aethiopica.” We in the hearing voices movement have a role to play in the process of challenging this labelling of common and positive human characteristics and to progress the debate as follows:.

- Is it progress or heresy to accept Plato’s analysis of madness as a divine gift?
- Is it progress or heresy to regard a person who has mental health issues as a saint, a prophet, a shaman, a guru and/or a genius?
- Is it progress or heresy to have a vision of Jesus?
- Is it progress or heresy to see Jesus as a product of rape? There is a second century Jewish account that says that Mary was raped by a Roman soldier.
- Is it progress or heresy to say that Mary Magdalene was sexually abused as a child?
- Is it progress or heresy to see the statues on Easter Island as past “psychotic” spiritual leaders?
- Is it progress or heresy to believe in astrology?

## *Discussion*

There was a discussion about the word “heresy” interpreted as non-orthodoxy both in the religious and psychiatric context. Someone talked about their own experience of realising that they were a special person and this led to their recovery. He said there was a need to have a more simple and meek approach and to accept that there are things that we can’t explain when it might be easier to say that it doesn’t exist. He described voice hearers as “pathfinders to new ways of seeing and believing.”

Hywel recommended two books:

“Blue Sky God” by Revd Don Macgregor.

“Godhead – the Brain’s Big Bang” by Joe Griffin and Ivan Tyrell.

Someone else recommended “Anger your Spiritual Ally” by Andrew D. Lester.

Another contributor recommended the website [www.mhspirituality.org.uk](http://www.mhspirituality.org.uk) which is a forum for discussion funded by the Department of Health.

## **CBT and Making Sense of Voices: Alison Brabban**

Cognitive behavioural therapy (CBT) and the Hearing Voices movement have a relationship. Most cognitive therapists would endorse the hearing voices movement, but Alison senses that this is not reciprocated. She feels that it is essential that there is a dialogue, recognising that there are similarities and differences, but both have the same aims and they need to work together.

### *The Stress-Vulnerability Model*

Anyone could start to hear voices at any stage in their lives, depending upon how vulnerable they are to that experience. The stress-vulnerability model is that of a bucket which can be large or small depending upon several factors, a small part being genetics, but the major contributor is life experiences. There is a long list of these: abuse, neglect, bullying, losing a parent at a young age, being bullied, or isolated or separated. Water pouring into the bucket represents stress which at some point may overflow. However, there are holes in the bottom of the bucket and these represent coping strategies. Examples are: talking, sleeping, tai chi, meditation –these are different for different people. The holes sometimes become blocked e.g. by drugs, not sleeping well etc.

CBT is about talking to people and making sense of their vulnerability factors. It is not an event that creates a problem, but the way we think about it. For example, if we arranged to meet someone for a date and they didn’t turn up we might think that they have changed their mind and we have been stood up or we might think they are stuck in traffic – these different thoughts would lead to different behaviour, feelings and reactions.

In relation to hearing voices we may believe that we are going mad, are schizophrenic, that others will be frightened of us, we will lose our job or find ourselves locked up on a psychiatric ward. It is not surprising that we feel frightened, or a sense of hopelessness and despair. This is where cognitive therapy and the hearing voices movement come together. It is not about changing the voice but about changing beliefs about that voice.

### **Techniques**

- Talking about the Stress-Vulnerability model
- Talk about how common the experience is – 15% of the general population
- Hear about others’ experience – stories of hope and recovery

- Meet other people who hear voices
- Read about voice hearing

So, stories about recovery are key to the CBT text. Hearing voices is not a catastrophe but a reaction to unbearable stress.

### **Thoughts about the voices**

Stemming from the Romme & Escher research, there are key differences between those who hear voices and get on with life and those who find themselves in the psychiatric system. People who are able to get on in life may have different belief systems and positive life experiences that enable them to set limits with their voices or the voices may be less bossy. The other group may believe they are weaker than their voices and are frightened of them; their life experiences have been negative and they have tried to escape by distraction techniques.

CBT is interested in beliefs about the power and identity of voices e.g. those seen as devils, and also whether the intent of the voices is to help or harm. So, how are these beliefs explored? To show people that they could be reactions to stress and to test out their beliefs about the voices, for example, to find out if they believe they have no control over the voices. The aim of CBT is not to remove the voices but to accept and live with them.

### **The way forward for CBT and the Hearing Voices Movement**

The next step is to say that neither approach has it right. CBT needs to have a greater focus on emotion – “Compassion-focused Therapy” is a recent development and in this context, compassion would be towards one’s self and towards the voices. There is also the mindfulness approach.

The Hearing Voices Movement needs to develop its evidence base otherwise the mainstream services and the Department of Health will never take it seriously. It is sad that service providers have not taken this approach on board more as it is not rocket science.

Both CBT and the Hearing Voices Movement have the same goals, but there is no “one size fits all” solution; people need a choice of interventions. The two approaches need to learn from each other and build on their strengths and experiences.

### *Discussion:*

A summary of the main questions and answers:

- How does the practice of CBT takes into account the sensitivity of the person arriving in the bar. Isn't just a question of attitude, but of understanding and communicating with a person who lives in a different environment to someone else? How do therapists relate to people who are experiencing the world in a different way (e.g. psychic ability)? *This is a difficult question to answer. All therapies depend upon the individual therapist. Perhaps more training is needed so that is is not just a set of techniques.*
- One of the difficulties with CBT and the Hearing Voices movement is the stress-vulnerability model which is used in psychiatry. It doesn't go into life stories and the focus is then on the biogenetic model and medication. *My understanding is that it is not primarily biological, it's about lived experience. Cognitive therapists spent a lot of time exploring people's lives. Experiences that made them feel resilient and those that made them feel vulnerable.*
- Another problem is that CBT has colonised self-help: it has taken techniques that have been used for years and professionalised them and then we are told they are not safe for us to use. It is extremely disempowering. *I agree with a lot of that. There is a parallel with what happened with the Quaker movement. That is why an evidence base is needed which is what*



*NICE are pushing for. CBT has managed to become part of the system by conforming but at least it is in the system. The system is evidence driven.*

- It's a good thing therapy is available. Beliefs are very important - about yourself, if you believe you can learn how to live with it. The voices used to be the problem, but now the beliefs are the problem. *Beliefs are only a problem when they cause distress.*
- I'm interested in trying to build bridges, trying to find common ground. It is important to talk about the differences. I'd like CBT therapist to be more curious about the experience. Stress vulnerability can be used usefully but it fails to honour the voice hearing experience. It's a different way of organising consciousness, a creative way. But generally I find a reticence about learning from hearing Voices groups. It's not a treatment; it's a civil rights movement. The evidence is people's testimony. You're a great ally; we don't want to alienate you. CBT therapists are not trained in looking after their own emotions - more trained in controlling emotions rather than work with them. I get a lot of defensiveness from some CBT therapists. Where CBT therapists flourish, hearing voices groups are often absent. There needs to be more lived experience and equal status in CBT conferences. *I have learnt more about hearing voices through the HVN and talking with service users. It needs to move ahead. We also need to learn from HVN about the function of the voices, we don't do that very well. I don't think you can do it without voices hearers. Should be integral - I'm pushing for this in all professionals.*
- I'm a professor of statistics in the USA. We're not driven by the evidence base but we are driven by politics and funding and the media.
- I am from Uganda. You in Britain isolate yourselves a lot. You need to learn from Africa.

## Intervoice Meeting: Open Space Group Discussions

	Topic	Summary of main points
1.	Human Rights	Awareness raising; political pharmacy; what rocks the boat; civil discourse & civil disobedience; links; vigils; bed pushing etc
2.	Expressing your voices in a creative way	Helps coping with voices and emotions e.g. pain; something you can become proud of
3.	Education	DVD about a hearing voices group in an all male independent hospital in North Wales and how it has changed the lives of group members
4.	Media Event: Flash Mob	Tackling stigma; broadcasting positive messages about hearing voices – poll taken between 1) hearing voices is a normal experience and 2) it doesn't mean madness
5.	Video & Media - HVN	Media use: tackling the system; fundraising strategies for using media; social and new media especially for reaching young people. Getting our own voices production company
6.	Funding issues: enabling more people to attend events	The problem of cost of conferences and events; following all avenues to get funding; the Finland lottery which sponsored people to come here
7.	Neuroscientists need voice hearers' experienced based expertise	Data; classifying people's experiences; validating experiences and having some words to gain control
8.	How can we include voices more in the movement through Facebook and in Hearing Voices Groups?	More groups in different languages; including voices more in families – not a taboo subject
9.	Children and Hearing Voices misdiagnosis	Starting conversations much earlier; staff awareness raising; using play
10.	Paranoia	Paranoia peer support: fixed/inflexible; ego centrism; fear of collusion
11.	The psyche and how it relates to voices	Multifaceted; difficult voices can be internal or external; want to take the discussion further
12.	How I got my life back: what worked and what didn't	How services let me down; nothing helped except hearing voices group – but 10 years too late! How my wife got me through and taught me how to live
13.	Peer support: compassion; love for each other as a tool for recovery	Different things work for different people; ground rules; hotline, warmline – different telephone lines
14.	Metaphors – social context of the voices seeking a common language through poetry	Voice hearing is a metaphor – make connections; symbols describe different ways e.g. seashell (feeling safe), feeling like a fox (hunted); need a dictionary of metaphors to help people express themselves
15.	Conversations that change the system	Dialogue between experts by experience an

		experts by professional training; integrating experts by experience into the system e.g. university; recovery (support) for workers; changing the power hierarchies; the need to be respectful when we express anger, grief, loss
16.	Setting up a support centre	Netherlands experience – how can experts by experience find jobs e.g. in mental health care
17.	How mental health affects kids	How professionals don't look for change; always looking at the past negatively; heredity; "your fault"
18.	Peer support in an area which will make an emphasis on CBT	Voluntary run flagship peer support system in County Clare (Ireland) in an area where there are 20 beds for 85,000 people
19.	Ways to focus on cultural change & can we change the world without the system?	Reclaim human language; Consciousness raise – society, human rights; finding the fire to campaign – from anger at injustice or compassion
20.	Language and discourse	International debate; need to move from stigmatising language; the DSM useful or hindrance? Campaign to try to change
21.	Strengthening the user movement internationally	Intervoice to have a document of approval; helping people to step outside the system; supporting countries having these difficulties e.g. Italy or Spain where there is no powerful user movement; economic support
22.	Martial Arts	Control – keep voices happy; play with them; express emotions; use your body as well as your brain

## Intervoice Meeting: Conclusion

### Closing Remarks: Ron Coleman

25 years ago 19 people attended the first Intervoice Meeting; today there are 178 present. Traditionally, each country represented was invited to report on their activities but we are now too big to do that. Instead we use the newsletter to share what we are doing. However, we can still acknowledge where we are from – there followed a roll call of countries.

### *Campaign News*

This week we have begun our “One of a million” campaign to recruit a mass membership; we’re going to go viral!

### *Other News*

Sadly, Professor Mark Rapley died this year. He was someone who dared to say what others wouldn’t and taught against the norm. The Board would like to restart a Roll of Honour for those who have worked tirelessly for the movement. It will be posted on the website.

[The Chair of the Intervoice Meeting, Sandra Escher, closed the day.](#)

# Congress Day One

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## Introduction and Welcome

The Congress was jointly opened by Hywel Davies, Chair of Hearing Voices Network Cymru, and Paul Roberts, Chief Executive of the Abertawe Bro Morgannwg University Board of Health, who welcomed everyone.

Hywel welcomed everybody to Cardiff, the capital city of Wales and to the 4<sup>th</sup> World Congress, he expressed his happiness and pride that Wales had been chosen as the host nation for this years congress. He welcomed delegates in Welsh, English and other languages. Hywel reminded the meeting that 2.9 million people live in Wales and during the last 5,000 years people from Wales have made/or do make a significant contribution to the human race. Wales has time and time again punched above its weight in the fields of religion, music, drama, cinema, sport, philanthropy, science and politics and other significant areas of human activity. Hywel also reminded the Congress of the Welsh nation's special contribution to poetry and concluded his welcome by quoting the final verse from Dylan Thomas' poem "And Death shall have no Dominion" and Waldo Williams' "Child of the Earth" (Plentyn Yddaeear).

Paul Roberts explained that the National Health Service in Wales is devolved from the English NHS and is run by the Welsh government. It has a different ethos and embraces traditional values. This includes working with Third Sector organisations. Paul is Chair of one of the seven Welsh Health Boards in an area to the west of Cardiff covering Swansea and Port Talbot. The Boards were set up less than three years ago.

Paul congratulated Intervoice on its 25<sup>th</sup> anniversary and said it was encouraging to see how the message had spread all over the world. He is very impressed by the model of full and equal participation of experts by experience and experts by professional training. He likes the idea of full participation in civil society, but is aware of the on-going battle against stigma. Although many parts of the Health Service in Wales aspire to provide services in partnership, it rarely happens in reality.

Paul said that he had moved to Wales to take up the post about a year ago and has found it to be a very friendly and welcoming place and there is much to admire in the statutory sector there. He also acknowledged that there is much to learn and likes the new ways of working with the Third Sector. He particularly likes the term "experts by experience" rather than the "service user" ethos. He is interested in different models beyond the traditional medical model although there is a long way to go. He was interested to learn that there are 15 hearing voices groups in Wales.

He concluded by wishing everyone a very successful Congress and extended a very warm welcome to Cardiff.

## Congress Day One: Keynote speeches

### Beginning a Movement: Paul Baker & Ron Coleman

Paul began his talk by taking the traditional Intervoice photo of the audience, but this year with everyone making a “V for Victory” sign.

He said that participation was the key term rooted in the beginnings of the movement and one which must be protected. It has developed principally as a network of networks, like a spider’s web and, unlike other organisations, hasn’t developed into a hierarchy. Marius Romme is key to establishing this approach from his own rigorous commitment to social action.

Paul first met Marius in Trieste in 1988 at a World Health Organisation event which he was attending with a voice hearer. Paul was there as a mental health activist. Inspired by what he heard, he set up the first network outside of the Netherlands in Manchester. Very soon, Ron Coleman became involved and Paul said that within a year, both their lives were transformed. The recovery journey is for all - professionals, activists and voice hearers.

The next step is to tackle civil society and change perceptions about voice hearing. Paul said he is looking for stories of hope and recovery.

Ron told his story: in 1990 he was in a Manchester hospital diagnosed with schizophrenia. Life: miserable. He got a new support worker, Lindsay Cooke, who was ginger, had freckles, was always smiling and bounced rather than walked. The first day she lasted half an hour, but she was stubborn and persisted. Ron said, “She was the first person to believe in my capacity to recover.” She started popping in and one day told him of a new group in Manchester. Unwilling, at first Ron was reluctant to go and it was only the suggestion of a beer afterwards that persuaded him. There he met Anne Walton at the group. For the first time, the reality of his experience was acknowledged. Until then, he had always been told to ignore/distract/play scrabble (at which he became an expert). He never made it to the pub but instead sat in the car with Lindsay discussing what had happened.

Ron realised that responsibility had moved to him. He could no longer sit and wait for a “cure.” He continued to attend the group and learned techniques for negotiating with the voices which is a natural way of working. It is a simple, not complicated, intervention. Voice hearers can use this as a strength. Later, other people helped him including Mike Grierson who invited him to go to the pub every Friday. Unbeknownst to Ron, this was “reintegration.”

Ron said that he has had the pleasure of sacking Paul Baker twice. He saw that voice hearers had to take over the running of their own group which eventually developed into a network. There has since been massive growth. However, this was not without cost as the group were not all convinced this was the right way forward and some left. The lesson to learn from this is to find a way forward which will lose no-one. We need to embrace the diversity of experience and opinion and to respect other people’s own truth. This is the reality of a person centred approach.

We need to walk into the future with confidence. No matter what people say, we are proud of who we are. There is no shame in being a voice hearer or in being given labels by others. The movement is the emancipation of voice hearers. We should have the freedom to be citizens and treated with dignity and respect and we need to go forward together.

“Recovery is a human right.” (quoting Hywel Davies)

## The first 25 years: Professor Marius Romme & Dr Sandra Escher

Marius thanked Hywel Davies for his warm welcome and for the Welsh network's hospitality.

Sandra and Marius were both involved from the start of the hearing voices movement. Sandra said that they had different approaches: she was a journalist and liked to get to know a person; which was very different from Marius' approach to interviews as a professional psychiatrist.

Sandra and Marius both described how things used to be. Hearing voices was seen as hallucination or as schizophrenia. People were told they had a life-long condition from which they would not recover and they needed to adapt to the idea that they would never have a career or a steady love story. They could also look forward to a life of medication. There was no hope. Voice hearers could not trust their brains.

However, Marius and Sandra were able to prove that hearing voices was a sign of reaction to problems and it was not an illness. Sandra said that being emotional was not the same as being chaotic. People can learn to develop themselves.

Reality is the background to voice hearing and voice hearers have to accept that they have to do a lot themselves to recover. They must take back the power; change the relationship and live their own lives. Voice hearers can build up their own self-esteem. They need courage to overcome shame, guilt and be willing to talk through problems. There can be trauma and spiritual conflict at the roots of experience and acknowledging that emotions are involved is important. People can learn to make sense of their voices and understand that they have a meaning. They can learn to cope better with their emotions. They can learn to tell their own stories comprehensively. Many people become proud of their voice hearing. It is important for emancipation and you can only emancipate yourself.

Coming from the past to the present, there is a very long list of people who have helped to create the movement and continue to be active. One piece of luck was breaking through the language barrier which enabled the message to spread. Now there are many people offering training.

### **The Future**

Now, the hearing voices movement is becoming a worldwide movement and there is a campaign to sign up a million members. There is an A-Z of coping with voices which is a simple and clear way to communicate. The problem is that there are many voice hearers that don't know about it. There needs to be more creativity to get the message on to the street and to come out of isolation.

We need to involve more families and friends and offer them a better possibility. Parents need alternative ways of relating to their child, understanding and respecting and then the child can become normal again.

It is time to get rid of the label of schizophrenia.

Intervoice could set up a task group with the aim of every country setting up a centre to help people come off medication. Will Hall already has developed a guide and there is also a Canadian group.

Intervoice could also look at developing more advocacy and peer support, for example, buddies and finding a way to support more training.

We are aiming to grow into *a voice hearing society*; we hope that more people will come forward as voice hearers and we need to become politically involved. It will be impossible to change health services without political influences. We are aiming for an inspirational future.

Marius referred to Stella and Phil Thomas who, in 1994, stayed for a weekend and it proved to be a very important moment. There remains a beacon of hope. Marius said, "It gave us psychiatrists' permission to go beyond peddling pills and a different way of working. It was a key moment in psychiatry."

## 100 Years of schizophrenia – is this enough? Professor Robin Murray

Robin is Chair of a panel appointed to review the care of people with psychosis in the UK. The panel comprises 12 people, two with experience of psychosis and the others drawn from a variety of backgrounds including a nurse, an economist, a psychiatrist, a journalist, a social worker and someone from a mental health charity. The review has involved a questionnaire and visits to facilities. There were 2,000 replies to the questionnaire that revealed some heart wrenching stories.

The findings are not yet complete but Robin described his initial impressions:

- There are some wonderful, caring people in the health service
- Some of the inpatient units, particularly in large city hospitals, are so horrendous that people are frightened to approach them and have to be compelled
- The system grinds down staff as well as patients, idealism and kindness disappears after years in the system
- It is surprising how little psychiatrists know about the medicines they prescribe
- Treatments such as CBT are not sufficiently available – they are provided theoretically, but in practice resources are so stretched that people may have to wait two years for CBT
- In Great Britain, people have no choice in psychiatry unlike physical health. If someone wanted to have a different psychiatrist, they would have to be referred by their current psychiatrist (who would then lose some of their budget). There are also stories of lack of continuity – one extreme case was of someone who saw 23 psychiatrists over the course of three years
- Patients/clients are not involved enough

"Schizophrenia" was a term coined by Bleuler 100 years ago, but its use has become a big problem. People diagnosed as schizophrenic feel condemned, stigmatised and it carries an implication of deterioration. Tabloid headlines have altered its meaning. As a term, schizophrenia has no validity: there is no test to prove it exists. What can be used instead? Robin hasn't used "schizophrenia" in his clinical practice for over a decade. He uses "psychosis" which is not a great alternative but at least it doesn't carry the implication of deterioration.

The UK 2000 National Survey of Psychiatric Morbidity showed that 10-15% of the population have experience of hearing voices and may have once been diagnosed as psychotic. Many voice hearers don't need to see psychiatrists. There are many whose voices say nice things, but those whose voices say horrendous things need to seek help.

Psychosis can be seen as part of a continuum of a distribution curve – just as height, weight, blood pressure can and there is not a cut off point where one suddenly becomes psychotic, but there is a time when it becomes helpful to intervene. We need to focus on the underlying factors both positive and negative.

Acute psychosis is associated usually with increased salience. Stress can excite releases of dopamine so that salience is attached to ideas and objects, for example, colours become brighter. This is



sometimes described as “delusion”. Anti-psychotics can reduce the underlying dopamine drive but they cannot resolve someone’s earlier beliefs and experiences. Intense experiences cannot be treated by medication; these need cognitive input and it takes a long time to unlearn.

AESOP: an epidemiological study of first episode psychosis in three English cities. This survey showed that population density seems to have an effect on people experiencing paranoid ideas – research has shown that is far more common in South London than less densely populated areas. Psychosis was three times more common in South London than in the other two cities, Nottingham and Bristol. The best predictor was the proportion of people who voted in the General Election. Psychosis is much more common in areas where there are more disenfranchised people, for example, migrants and other disadvantaged groups. Psychosis is increased where there are high levels of abuse and bullying or other victimisation events. Drug use, for example, amphetamines, can increase the risk of psychosis, as can cannabis particularly as, over the years, it has become available in much stronger forms, but not everyone who uses cannabis develops psychosis. Environmental factors and individual susceptibility may also help to explain why some people develop psychosis and others don’t.

### **Conclusion**

The care of people with psychosis is very far from satisfactory, but there are areas of agreement with orthodox psychiatry and the Hearing Voices Movement.

## **Constructs and Formulations: could this be the future? Dr Lucy Johnston**

Lucy described the controversy surrounding the forthcoming publication of DSM-5, due to be published in May 2013. The disagreement focuses largely on its proposed revisions, for example, there are new categories which are bizarre: Disruptive Mood Dysregulation Disorder (temper tantrums); an expanded Attenuated Psychosis Syndrome (this has been dropped) and low reliability of the new categories. There are also significant concerns about its close links with drug companies.

There was a forthright response from the Division of Clinical Psychology which triggered a world-wide protest. The Society for Humanistic Psychology set up an online petition ([www.ipetitions.com/petition/dsm5](http://www.ipetitions.com/petition/dsm5)). The Chair of the DSM4 taskforce, Professor Allen Frances, also objected, “DSM-5 will radically and recklessly expand the boundaries of psychiatry.”

Although the protests are not about the idea of diagnosis, the question is whether psychiatric diagnosis is on the way out? Is there an alternative for psychiatry given that diagnosis is the foundation of the psychiatric approach? From a service user perspective, diagnosis is the first crucial step in the career of any psychiatric patient. People with problems are turned into people with illnesses.

The Hearing Voices Movement alternative to diagnosis is construct: how can we make sense of your voices? Romme & Escher (2000) look at the effect of historical relationships, psychodynamic expression and metaphorical relationship. A construct has a lot in common with the concept of formulation that is used in clinical psychology.

The British Psychological Society has created good practice guidelines on the use of psychological formulation. Formulation is a key skill in clinical psychology in approaching mental distress. Its main points are:

- A summary of core problems
- How difficulties relate to one another
- Why difficulties have arisen at this time
- What interventions are there?

- It is never finished

Formulation is different from diagnosis because it is a “best guess” or hypothesis. If adopted, it would need to replace the entire diagnostic system and so would be a radical act. The differences between diagnosis and formulation are:

- Formulation gives hope, it is empowering and restores meaning. Diagnosis silences people
- Formulation would not say to people “You have schizophrenia.”
- Formulation looks at a person’s strengths as well, rather than diagnosis which asks “What is wrong with you?”
- Formulation looks for resolution, not just treatment

Formulation and construct could work together with construct bringing the peer support principles and emphasis on self-help. They are both based on personal meaning, drawn up collaboratively with the service user, but there are differences:

- Formulation is seen as a high level clinical skill requiring professional input whereas constructs can involve input from families, friends and self-help groups.
- Formulation is based in mainstream psychological theory and evidence whereas constructs accept all frameworks and beliefs.

Psychiatrists are becoming more interested in formulation, but the danger is that they may continue to use diagnosis as well.

Lucy said that she had used formulations within her own work and initial research findings have been very positive. It looks at resolution not just treatment. The evaluation from the local team who were introduced to formulation showed that 100% of participants found it a helpful approach.

#### **Future direction**

More research is needed into whether formulation and constructs can be an alternative to diagnosis:

- Is it helpful to service users?
- Do professionals find it useful?
- Does it help recovery?
- Does it reduce hospital admissions/use of medication and thus save money?

Eventually, we need to replace the whole diagnostic system. Formulation is a radical act; it gives people hope and restores meaning. Diagnosis silences people.

“Helping to create meaning out of despair should be the core function of every mental health professional.”

### **Living Mindfully with Voices: Rufus May**

Rufus welcomed everyone and their voices to the conference. He talked about mindfulness yoga as a way of helping us to be in the here and now. We are often caught up in thinking about plans, worrying about the past. Mindfulness yoga helps to calm the mind and increase awareness. If practised regularly it can reduce stress levels, reduce fear and distract the mind from habitual distractions and create a safe place to go. “Welcome your unwelcome thoughts”. Can we welcome and acknowledge our voices rather than shooting the messenger?

Mindful activity is doing one thing at a time and focusing fully on it. When you become distracted, bring your mind back and keep repeating this step as often as necessary – even if it is a few hundred thousand times! If you keep getting distracted, pay some attention, it may be trying to tell you something; start to have a non-judgmental conversation.

Extreme mindfulness is when someone is experiencing terrifying emotions. Don't try to get rid of them; acknowledge them "Hello, anger my old friend". We need to learn empathy, to calm down and be kind to our self and to others.

# Congress Day Two

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## Introduction and welcome

John Jenkins, a Director of Intervoice, welcomed everyone to the final day of the Congress.

## Congress Day Two: Keynote Speeches

### Voices at Work in Australia: Joe Calleja

Joe is CEO of Richmond Fellowship Western Australia. He began by saying that the work of Romme and Escher was a decisive moment in the lives of many people in Australia. One of the challenges of Australia is that it is such a large country and the population is scattered around the coast.

Joe briefly described the history of the Hearing Voices movement there, beginning with Michael White's Narrative Therapy in the 1970s; he mentioned the importance of John Watkins book in the 1990s and also in the 1990-2000 training courses run by Ron Coleman, Pat Deegan and Arana Pearson. In 2005, the Prahran Mission in Victoria United Church started a group and a clinic in the hospital. In July that year, the Richmond Fellowship in Western Australia was visited by Ron and Karen. In October, Lynn Mahoub started Network Australia in Perth. A Trust gave a grant for £26k for training and further funding and the Commonwealth provided the money to train 30 people in Perth. In 2006 the New Zealand Hearing Voices network was set up.

2008 was an important year when the Intervoice meeting was held in Perth. It was the first non-European Intervoice meeting and was attended by 300 people from all over the world. In 2013 the Victoria network will host the Intervoice meeting and International Congress which promises to be a spectacular event.

The Richmond Fellowship in Australia is currently a loose federation, but it will soon become a legal entity. Its origins were in the UK and there are over 40 branches worldwide. It was established in Australia in 1975. RFWA has a visionary Board and is undergoing a major change process. The Board have seen the need to change their image and their message about mental health. The logo has been changed



and the strapline changed from "Rebuilding Lives" to "Recovery First."

The organisation has faced many challenges, for example, as recently as 2005 NGOs were not considered to be doing "real" work – a perception that has now changed. But the image, language and culture of RFWA needed to change and some of the ideas took staff out of their comfort zone. It is important that people with lived experience drive the change. Training has been a very important part of the change process and a lot of reflection has been done. There was also the task of

managing stakeholder relationships. Some parts of the medical system accused them of being anti-psychiatry and anti-medication, so there is now a statement on the website addressing this.

The challenges facing them included:

- How fast to go – do we walk alongside or crash? There was a lot of inertia in the system and it was challenging to try to manage the tension between progress and change
- There was a gap to bridge between internal and external consumers and training was critical
- Inter-agency partnerships was one area that could have been managed more effectively

However, a recent conference with 700 delegates from all over the world enabled a debate with mainstream services about diagnosis, medication and the use of the peer support model for voice hearers.

The Future:

- Intervoice Congress 2013
- A new definition of mental health services
- Research directors
- National systems e.g. links with employment services
- Engaging with key decision makers
- VoicesVic' excellent media coverage
- Educating politicians
- Excitement about Marius and Sandra's forthcoming visit

## **Working in Group Psychotherapy with People with Psychosis: Professor Manuel Gonzalez de Chavez**

(Translator of "Making Sense of Voices" into Spanish)

Manuel traced the origins of group networks back 200 years to Glasgow. In the 20<sup>th</sup> century group work formed part of social psychology. In 1931 groups were introduced into a Washington USA hospital and, during the Second World War, they were introduced more widely into the UK. Very few books were written on the subject.

In 1996 Kanas reviewed the effectiveness of group psychotherapy and found that it resulted in more enthusiasm and better compliance. There were great therapeutic benefits.

A lot of research has been dedicated to mirroring and some think it is the basis of everything. Group mirroring gives us a more realistic image of ourselves. Each patient is a mirror. Cognitive decentring is an important element. A group provides support factors, self-revelation factors and learning factors from other group members.

Manuel has published a number of papers on this topic.

## **Recovery and Human Rights: Professor Michaela Amering**

"Recovery is a human right."

Recovery is the guiding principle of mental health policy in the English speaking world, but it is different in other parts of the world. Recently, there has been an amazing response in Germany, Switzerland and some parts of Austria where practices are beginning to change. It is "the end of incurability."

What is recovery? In a medical context – service based; in a social context – user based. It is:

- Personal not clinical
- Recovery rather than recovered from
- External factors rather than internal
- Individual rather than person in conflict
- User survivor perspective versus scientific
- It is a civil rights movement or a tool to change the mental health system or both.

What evidence is being questioned? The example of the human right of self-determination was given as an example. The UN Committee on the rights of people with disabilities (CRPD) is important. Why? Because users say so, and because lawyers say so. Disability is an evolving concept, for example, “psychosocial disability” rather than “mental impairment”. The CRPD is a formal convention which has the force of international law when it is ratified and most UN countries have done so.

Article 5 of the convention sets out the principles. One complicated area of debate is the notion of coercion which contravenes the right to non-discrimination; an example of this being implemented in Austria is that there will be no special schools – everyone will have the right to be accommodated in schools.

Michaela referred to the work of Peter Bartlett on this subject.

## **Young people who hear voices – our future looks bright: Kellie Comans**

Kellie presented a Young People’s project in Australia which had won Volunteer Service of the year award mainly illustrated by Youtube clips It was accompanied by very lively Youtube clips. Kellie stressed the need for young people’s groups.

## **Snapshots of the future – where is the hearing voices movement going? Eleanor Longdon, Indigo Daya, Peter Bullimore, Ron Coleman**

Eleanor talked about the stories of so many people who have lived with pain and suffering but for whom there is also hope. She said that the medicalisation of distress has been one of the biggest medical abuses. We need a new language of practice and hope and we can work towards permanent transformation of society. Our movement will provoke resistance but social change cannot be reversed. We can effect change by combating negative media; with early intervention systems; provide training on an international scale; challenge dehumanising language – words such as schizophrenia. We can work towards voice hearing as a normal human variation. We need a clear rationale and we can harness the power of the individual and the power of belief.

Indigo talked about the 123 conference in February and a film that has been made about it – see [www.voicesvic.org.au](http://www.voicesvic.org.au)

Peter said he was proud to be a voice hearer. He said that we need to reach beyond diagnosis to find the person and we need to work with, not for, the person. We need to keep our autonomy as a movement. Over the last 15 years the UK National Hearing Voices Network has stagnated. When it gained charitable status it changed from being a movement into being an organisation. It has become frightened of the Charity Commission. Look at the contrast with the vibrant movement in

Australia. We have gone from being a lion to a mouse. This is the last great civil rights movement. We can start to change history.

Ron said he agreed with Peter. The other side of the world brings great hope. We need to renew and refresh. The mental health profession needs to stop practising from fear. We must walk in freedom. We need one million people. Our future is to be a mass organisation. We need conferences in every country every year. We need to move from our current base to Asia, India, Africa, and South America. This weekend we are launching a campaign. Join the campaign on the website.

### **Congress closes**

Dirk Corstens, Chair of the Intervice Board, closed the meeting, thanking Hywel Davies and Hearing Voices Cymru for hosting such an excellent conference and everyone who had been involved in making it such a success.

# Congress Workshops

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## Workshops Day One

### Workshop 1: “Living with or without voices” Anders Schakow

“I would like to have a debate on different challenges that can occur due to not hearing voices anymore: loneliness, emotional expression and living without their guidance.”

Anders was a small child when he began hearing voices. He played with them and it was only when he was older that they began to turn negative, and he began to try to ignore them. He was 17 when he planned his own suicide, owing to a belief that people were going to have him kidnapped, tortured and killed. He believed the house was bugged and had hidden cameras. He spent a year in hospital and then three years in sheltered accommodation. He couldn't walk anywhere alone, or take a bus, or even go to the basement to wash his own clothes.

Things began to change when he met Trevor Eyles (a psychiatric nurse and specialist in hearing voices). Anders joined a hearing voices group and, after some initial resistance, began trying to communicate with his negative voices. This took a whole year, but he began to make deals with the voices in order to find some peace. He learned the Voice Dialogue method from Dirk Corstens. The voices gradually began to disappear and 4 years ago they disappeared entirely and have not returned. Anders is interested in exploring whether life is better with them or without them. A year ago he started missing his voices because he'd broken up with his girlfriend and felt his voices would have provided some welcome company in the situation of being alone.

Anders now understands his voices as 'sub-personalities' (a concept he got from Dirk Corstens). Anders believes he can notice many different personalities of his own that he sometimes goes through being, in the space of just 5 minutes. A simple example would be the differences in voice, tone and manner which we adopt according to whether we happen to be talking to a child or an adult. Anders and his friend Elisabeth acted out some role play to demonstrate how both of them go through the different sub-personalities which each can trigger in the other.

### Workshop 2: “Working creatively to communicate with voices” Rachel Waddingham

“This presentation shares some of the creative strategies I have used to communicate with, and relate to, the different voices I hear.”

When Rachel first heard of the hearing voices approach, she thought it was crazy. She was, after all ill (schizophrenic) and had been told that the voices were meaningless products of the disease. Terrified by her voices, her only coping strategy was high doses of medication. However, she began to attend a hearing voices group and lots of workshops and discovered that this didn't have to be the end of the story. It was such a sensible approach and Rachel realised that recovery was possible, even though it was difficult to believe at first. Even though she became a group facilitator and helped many people to communicate with their voices, she was still unwilling to listen to her own voices but has found creative strategies that have transformed her relationship with her voices.

The workshop gave opportunities for people to also share their own experiences.



### **Workshop 3: “Lessons learned from the peer support movement in the USA” Oryx Cohen & Will Hall**

Oryx and Will described the work of the Freedom Centre in Western Massachusetts which was established by them 12 years ago. Peer support has a long history in the US. Alcoholics Anonymous started there and was at first treated with great suspicion (as is the Hearing Voices movement now). However, it can take years of advocacy and grass roots pressure to make progress.

They stressed that isolation is the key to psychosis and peer support is the only way to reach many people. They called for advocacy and activism to lead to peer-run organizations. What was learned from the Western Massachusetts Recovery Learning Project was that many peer workers don't avoid just joining the system so there needs to be clear values or ethos underpinning all work. They talked about the difficulty of workers not being co-opted by the system.

**Berta Britz** also talked about her experience of setting up groups in Pennsylvania, where there are now many trained peer specialists.

The workshop participants practised the principles of peer support.

### **Workshop 4: “Older people and hearing voices. A Cumbrian NHS service which has responded to voice hearers both with and without dementia.” David Storm**

This workshop described the work of an Older Persons mental health service in North West England that took a different approach to working with older people who hear voices. Often, this is regarded as a symptom of a mental illness or of dementia. The team works closely with the person and their families to try to understand the origins of their voices and to find ways of helping to support them. They hope that this approach will develop so that services will become more positive and person-centred.

### **Workshop 5: “Reclaiming lives from hostile voices: Narrative Therapy Approaches.” David Denborough**

There is a long history of narrative therapy being used to assist voice hearers to reclaim their lives from hostile voices. This was a practical workshop that explained a number of narrative therapy practices that can be used in voice hearing groups. It was illustrated by reference to the work of Michael White in Australia in the 1990s which included a song “Power to our Journeys Group.” Stories were also shared from the Dulwich Centre Alternative Community Mental Health Project (London).

## Workshops Day Two

### Workshop 1: “Listening to Ambassadors of Forbidden Truth.” Rufus May, Flo Bellamy and Topdog

“We can change the relationship with terrifying voices if we find ways to listen to the unmet needs they are pointing towards.”

This workshop described how to understand the important messages that hostile voices bring: by setting boundaries, dialoguing with them and learning from them. This work can be emotionally powerful and needs to be handled with sensitivity and care. The workshop considered how to support people to manage very strong emotions arising from relationships in their pasts and also how to move away from survival strategies that are no longer needed.

### Workshop 2: “Is it normal to be different? Presentation of a documentary film about a network of two alternative self-help projects in Kenya.” Caroline Von Taysen & Kanya Waithira

This film “It is Normal to be Different” described the experience of setting up hearing voices groups in Kenya and brought home vividly the challenges that people face in an environment of poverty and in a culture where families will try to hide relatives who are different and where attending such a group can be stigmatizing. It needs a “slowly, slowly” approach. Despite these obstacles, the film was very upbeat and showed a vibrant and creative group of people. The group focuses on healing through artistic expression and mutual support and it offers a platform for people to exhibit their work and generate income from selling it.

### Workshop 3: “Peer Support and self-help.” Marissa Lambert & Karen Machin

This practical workshop focused on addressing the question “who is a peer?”

Marissa and Karen work for a voluntary sector organisation, the *Institute of Mental Health* formed in Nottingham in 2006, as part of a team of nine including peer trainers, academics and admin support workers. They were here to tell us about their *accredited peer support training module* (an 11-day course, delivered over 6 weeks) developed in partnership with the NHS and Nottingham University. Marissa describes the aims of this course as being ‘to explore ways of working with people who’ve had different experiences from ourselves’. This bland-sounding mission turned out to contain a very powerful message, which Marissa presented via a simple graphic:

A man points at a green apple, and says: ‘You’re an orange!’ The apple begins to change its colour until it is orange all over. Then, in an alternative version of the same graphic, the man points at the green apple, says ‘You’re an orange!’ but the apple answers back: ‘No I’m not, I’m an apple!’ This metaphor proved useful in the ensuing conversation. For instance - suppose one member of a peer support group believes s/he has schizophrenia, and another wants to challenge the concept ‘schizophrenia’ – the situation for the peer support worker can be framed as: *How can I help apples find ways of talking with oranges?*

There was extensive discussion of language, particular around the word ‘peer’. Marissa suggested the word ‘peer’ implies a relationship based on:

- mutual experience

- shared experience of emotional/psychological pain
- equality
- the valuing of experiential knowledge

It was acknowledged that some people dislike the word, that it could be ambiguous whether it is shorthand for 'service user', and also that it is always *relational* (you cannot be a peer except in relation to another person). We reviewed a list of different, possibly interchangeable, terms - all similar – and realised in the process what a contentious and confusing situation exists in this area of terminology:

*client, resident, consumer, customer, survivor, mentalist, peer, member, service avoider, service user' patient, ex-patient, ex-service user, mad activist, expert by experience, participant.*

### **Workshop 5:<sup>1</sup> “A quiet revolution.” Matthew Morris & David Williams**

To introduce people to the potential and possibilities for change and influencing new ideas in their services.

Since the 1990s a small group of NHS staff in Suffolk (England) have been working to bring about a quiet revolution in relation to working with voice hearers. This gradual, influential approach is more likely to succeed in effecting change than by stirring up controversy and conflict.

This has been achieved so far by training and conferences. An “Introduction to working with voices,” course has been attended by over 300 staff and 450 people have attended two conferences.

### **Workshop 6: “Give time to your experience with voices. It deserves it!” Marina Lykovouniotti**

(No report available)

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<sup>1</sup> There was no Workshop 4

# Congress Parallel Sessions

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## Parallel Sessions Day One

### Parallel Session 1: Spirituality and different belief systems

**Patrick Le Cardinal & a paper by Sonia Johnson**

*“Where do the phenomena (voices, tastes, visions, smells, physical phenomena in general) actually come from?”*

A paper from **Sonia Johnson** (read out on her behalf) described the approach she promotes France where she had set up the first hearing voices group. She discussed guardian angels and other non-hierarchical deities, lay lines, shakras, natural spirits (energies e.g. when we witness branches moving when there is no wind) and when we find unexpected energies such as being prompted to do housework in the middle of the night. Have we ever thought to ask their names?

**Patrick Le Cardinal** described himself as a psychiatrist and a human being. He talked about the history of voice hearing, starting with earliest times when voice hearing would have been a survival tool. Patrick described different cultures which had developed habits of dealing with spirits and how this knowledge had been lost with the development of civilisation. There are cultures which build houses for gods e.g. temples where the gods devolve power to priests and where voices are not considered abnormal. In the three main monotheistic religions God talks to humans. Priests and Imams are able to exorcise demons. In the Middle Ages, there was a less tolerant approach with women being burnt as witches, but with one later admitted to be a mistake: Joan of Arc.

Patrick explained a new approach in Lille working with voice hearers describing the stories of a young man from Morocco whose Imam had not been able to help with his voices and another account of a woman who had two male voices instructing her to do opposing things – one to avoid men; the other to go out soliciting on the streets. Patrick described a model that includes a protector/controller; an inner child; an inner critic and a pusher.

**Willa Casstevens**

*“Voice hearing interpreted: coping with spirits, demons and/or stress”*

Willa told three stories of people from the United States with different faith backgrounds who had integrated their voice hearing experience into their spiritual beliefs. There was an atheist, a Christian and someone who embraced New Age spiritual beliefs. Willa reflected on the effect of the “person centred environment” such as family support, income, home life. The spiritual beliefs of each person had made a significant contribution to how voices had been welcomed (or not) into their lives. It demonstrates the unique nature of interpretation and experience. Each had a range of coping strategies; however, none of the people viewed their voices as symptoms of illness.

**Wendy Micklewright**

***“Telepathy as old as the hills? If voice hearing is often caused by trauma, could it be telepathy? What do you think? After emailing 900 psychologists with a simple questionnaire their replies were interesting.”***

Recent law cases have also been sad, but may indicate how important it is to perhaps think of the voices as one of the 250 million voice hearers on the planet (Catherine of Cambridge, Luton slavery case, Rochdale case, the Blackpool case, literature from the homeless charity (Centerpoint) or the families of 77 Norwegians)). Words can have strange meanings like the word compromise, insane, pagan, prove, propaganda, rational, forfeit and desensitise.

The voices have also replied kindly to some of my questions on the subject. For example A voice said "are you a human being?" I reply "yes" in the voices then the logic goes we are equal and different as human rights people might think. Some of the voices have said very disturbing things about the idea of control within the voices. Not to mention the idea of talking to the dead within the voices. I have also heard voices in languages I do not understand.

Some of us have hallucinated for 40 years. Reading the testimonies of other voice hearers as well as listening to other voice hearers in a Voice hearing group in Richmond Surrey and attending free voices hearing courses and conferences. Makes you think !

## **Parallel Session 2: Hearing Voices Research**

**Clara Humpston**

***“Schizophrenia is fundamentally a self-disturbance. In this paper I attempt to explain the many facets self-disturbances by disentangling the boundaries between others and self”***

Based on the premise that schizophrenia is fundamentally a “self-disturbance” which has been much debated, this presentation explored concepts such as ‘existential permeability’, ‘disorientation’, ‘disembodiment’. Clara presented psychosis as a self-disturbance/loss of self and brought together philosophical literature, her own research and lived experience. She hopes to raise awareness among health practitioners and service users to help in the path to recovery.

**Amanda Waegeli**

***“Outcomes of the Richmond Fellowship voices@work project”***

Amanda described the Richmond Fellowship Western Australia ‘Voices at work’ programme which supports voice hearers in work and their employers. Their hypothesis was that supporting people with coping with distressing voices would result in better engagement at work. Voice hearers are sometimes thought of as lacking motivation or being unable to engage. Amanda described a project that had successfully engaged with 25 voice hearers working towards employment. She described the work necessary to build relationships, increase trust and give hope to people who have often felt let down.

The project’s outcomes included higher confidence, greater understanding and more coping strategies. It showed how hearing voices support with an employment focus can have a far-reaching impact on recovery with concrete outcomes such as getting a job.

**Joachim Schnackenberg**

***“Experience focused counselling with voice hearers – early feedback from randomised controlled studies”***

Joachim described a randomised controlled pilot study in Experience Focused Counselling (EFC) with voice hearers (using ‘Making Sense of Voices’). The study consisted of interviews and validated questionnaires with scales to see if the intervention had effected any changes. Joachim emphasised the difference between EFC and CBT and explained the set-up of the trial. The audience were impressed by this ambitious trial.

**Wendy Traynor**

***“Is Person-centred Experiential Therapy helpful to adults who hear voices?”***

Wendy described her doctoral research using structured change interviews to find out what was helpful in the therapy process. It comprised three studies, the first with semi-structured qualitative interviews with twenty person-centred practitioners; a systematic mixed method study case using the Hermeneutic Single Case Efficacy Design (HSCED); and data collected from a sample of fifteen participants who had received PCE therapy as clients. Early results show a wide range of outcomes including positive changes in relation to social anxiety. There is a need for empathy, acceptance of client’s reality and a multi-disciplinary approach. Outcomes for some voices could improve without them necessarily being talked about. However, the study had some limitations including its small sample size.

### **Parallel Session 3: Workers changing practice**

**Pino Pini**

***“The importance to link closely the voice hearers groups to user and relative associations and to services. A Tuscany experience”***

Pino’s presentation was a factual survey of the progress of the Hearing Voices movement in Tuscany since the 1980’s, culminating in the establishment of *Parla Con Le Voci* in 2006. There are currently over 20 HV groups listed on the *Parla Con Le Voci* website, across Italy. Historically, Tuscany mental health services have tended to exclude both the voluntary sector and the user groups.

The first hearing voices group in Italy, using the approach of Romme & Escher, started in 1998 when AISMe (Italian Association for Mental Health, founded in Prado in 1993) invited prominent user-survivors from UK to Italy to talk. The mainstream mental health services in Prado refused responsibility for the project. They tended to prefer their own more generalised psychiatric self-help groups which were easier to control. The result was a sense of competition between the old and the new groups. However, the municipality and the GPs were more supportive.

AISMe uses a model of co-operation between users, municipality (e.g. local politicians) and MH services – termed the *Joint Experiences and Mental Health Systems Project*. The term refers to the interface between statutory mental health services and local community, where most of the joint experiences between different service providers and community agencies are located. Joint working between different statutory agencies is no longer enough: the whole system requires re-engineering and re-adaptation from the perspective of service users and carers.

### **Loretto Foster**

#### ***“Leading by Following: the power of the hearing voices approach to transform a mental health team”***

The key concept presented by Loretta was ‘leading by following’. She manages a 17-strong Mental Health Team in Melbourne, four of whom have disclosed lived experience. Her story was all the more inspirational for the fact of coming from a Manager who has no direct involvement in clinical work, and whose understanding of Hearing Voices has all come second-hand through the enthusiasm of her staff. She hesitates to call the change *bottom-upwards* because, for her, it seems more like a movement *outwards*. She used the term *ripple effect*. For the team, it has meant changes not only in how they view service users, but how they view each other, and even how each person views him/herself – and the freedom to relate to one another on a more human level.

Five or six years ago, certain members of her team had their first contact with Ron Coleman and began training in Voice Dialogue. This was followed by visits from Jacqui Dillon and Rufus May. It became clear to Loretta as this way of working took hold of her team, that, with HV being a grass roots movement, it was impossible to know what might happen next and she decided (in her words) simply to ‘hop on and hang on’ instead of following the usual managerial requirement to predict outcomes.

Objections arising both within their own minds, and from colleagues in other teams or in senior management, include: ‘Are we skilled enough?’ and ‘Shouldn’t psychologists be doing this?’. She spoke wryly of having acquired a (false) reputation for encouraging service users to reject drugs and refuse treatment. Her enthusiasm was really infectious, saying: ‘It’s simple truth, not science. It doesn’t look complex enough to be science – it just works!’ Of all the quotes she has reviewed, she is proudest of one from a team member (speaking of how the team is seen by service users): “They know that we want to know”.

### **Susan Ruggari**

#### ***“The MHC experience: transforming a private secure unit to be recovery orientated and embracing the hearing voices approach”***

Susan is a counselling psychologist working for a private healthcare company Mental Health Care in two secure hospitals in Wales: *Plas Coch* (all-female) & *New Hall* (all-male). Her previous careers include high school teaching and couples counselling. She has written a published thesis on *Asperger’s syndrome and humour* and ran a support group for people with Asperger’s. She describes a common thread running through all her jobs as ‘working with individuals to explore the constraints of the systems they are immersed in’.

Susan spoke vividly of her shock and disbelief when starting hospital work, at the discovery of people being provided with medicine and distractions but nothing that actually addresses their problems. And they are simply left there long-term. In 2010, she set up a HV group at *New Hall* which has 10 participants; another at *Plas Coch* has proved less successful because Susan is not directly involved in running it, and in consequence it isn’t taken seriously (by management). Susan identified two of her best tools in the ongoing effort to sustain these groups, as being the supervision process and the peer support groups run by and for the facilitators themselves. Comments she’s received from her team include: “an opportunity to learn about who I am as a person,” and, “the trust he has in me is something you can’t buy in a shop.”

Last year 20 of her colleagues together with a number of ‘patients’, or experts by experience, were trained in the Hearing Voices method (voice profiles, Maastricht Interview, etc) by Ron Coleman and

Eleanor Longden. Susan provided a very colourful and amusing description of how she lost her temper with colleagues during the training because some of them were objecting to sharing the kitchen facilities with those whom they normally thought of as 'patients'.

**Marion B. Goldstein**

***"Working as a voice hearer at a crisis centre"***

Marian is an expert by experience, and voice hearer. Marian first encountered mental health issues at the age of 40, when she saw a choice between suicide or talking with a CBT psychologist. Then she researched other treatments online and was so horrified at what she found, she became a 'radical activist'. She was headhunted in January 2011 for her current job as the only voice hearer on a team of 10 at a recovery-orientated, 'non-biological approach' Acute Crisis Centre in Denmark. Marian used the word 'indoctrinated' to describe people who come to the Crisis Centre believing that their distress is an illness: *The helplessness is huge, enormous.....sometimes I really feel a bit alone and fighting windmills.* She feels frustrated because of the constraints of the service she is part of being short-term only, which means having no choice but to refer people on to mainstream psychiatric services where the treatment will be medical. She is also uncomfortable providing the truth to people taking anti-psychotic medication about how much harm their medication is doing them, since this amounts to recommending they cease taking it, and she is careful to recommend that any withdrawal from these drugs be gradual.

## **Parallel Session 4: People's recovery stories**

Four people from different parts of the world shared their personal histories of voice hearing. They had in common experience of psychiatric systems that left them without hope and yet all were able to make a recovery journey through encounter with the hearing voices movement. One person said "now my future looks very bright."

### **Workshop One: "Setting up and running Hearing Voices networks." Indigo Daya & Paul Baker**

This was an interactive workshop run by two people with extensive experience of setting up networks in Australia and in the UK. The workshop gave participants the opportunity to share their experiences, set goals and address some of the practical problems of developing or creating networks.

### **Workshop Two: "Training on making sense of voices." Peter Bullimore & Chris Tandy**

This workshop focused on a recent training initiative developed by the presenters which aims to raise awareness of voice hearing. It is aimed at people who work in mental health, in the criminal justice system or in third sector agencies and who work alongside people who experience voices. It addresses the need to challenge misconceptions and myths used to challenge psychosis. It also offers practical strategies for people who hear voices or see visions.



## Parallel Sessions: Day Two

### Parallel Session 5: Spirituality and different belief systems

**Carol Dugdale**

*“An introduction to astrology as a tool for self awareness in identifying the contradictory nature within our personalities”*

The idea of this presentation was to teach us some basic astrology, but there were a couple of points where the subject of Hearing Voices was touched upon:

Carol happens to be a spiritualist and a medium. She mentioned how people often come to her with a strong positive wish to have the voice-hearing experience, and wanting to know how they can develop this. Carol is firm and clear about the need for any prospective medium to ask themselves: *Why?* She said there’s a need for ‘brutal’ self-awareness in case the person has any ‘unresolved issues’.

There was a strong emphasis, during the astrology lesson, on the idea of opposites. Where two planets stand in opposition (on opposite sides of the zodiac), she pointed out that this always entails a third position in the middle, where the person themselves can experience being torn between the two planetary influences. She compared this to being a person caught between two different ‘voices’.

**Ivan Barry**

*“Oracles, dreams and footprints in the sand. What happens when we pay attention to signs and symbols that manifest in front of us as we travel this life?”*

Ivan’s presentation hardly touched on hearing voices at all. He wanted to challenge us to think about questions such as:

- What are the boundaries between the rational and the irrational? Do they exist at all?
- What happens when we respond to the prompts, signs and symbols that manifest as we travel our lives?
- How much freedom/risk can we give ourselves in co-creating our realities?

These issues were vividly illustrated by the story of what had happened to him in Egypt when he had a powerful dream which turned out to be an authentic depiction of a Sufi festival. Following this dream, he chanced to meet a Jungian analyst in Egypt who took the dream seriously, and pointed him towards the new library of Alexandria (the *Bibliotheca Alexandrina*) where he chanced upon a painting which seemed an exact replica of one of the scenes in his dream.

The analyst had a mysterious intuition Ivan should get a bus into the Sinai desert and climb Mount Sinai, but Ivan missed his bus, twice, and took this as a sign to travel instead to the Siwa oasis on the Libyan border (a community of Berbers with their own distinct history and culture), which he did. Ivan had a wealth of anecdotes and photos from Siwa which were very entertaining.

## Parallel Session 6: Hearing Voices Research

**Summer Schrader**

***“International perspectives on voice hearing research.”***

The biomedical model is more dominant in America than in the UK. In the US, Voices tend not to be considered as important because they are seen as a symptom of schizophrenia, a biological disease that must be treated with medication. In contrast, in the UK treatment such as CBT is gaining more respect and therefore there are more likely to be articles published about voices. There is nothing equivalent to the Wellcome Trust in America. The anti-psychiatry movement is stronger in the UK, as is the Hearing Voices movement and this may have influenced clinicians and researchers. Summer is about to undertake a research project to find out if America really is producing less research on voice hearing than other countries.

**Angela Woods & Charles Fernyhough**

***“Hearing the Voice”***

Angela and Charles are working on a multi-disciplinary project at Durham University (UK) that is funded by the Wellcome Trust. It involves input from academics across the humanities spectrum as well as voice hearers, service users and other experts by experience. One of their objectives is to try to understand what is the underlying difference between distressing voices and happy voices. The project will involve phenomenology, cognitive neuroscience, hermeneutics and therapeutic practice. Sandra Escher, Marius Romme and Gail Hornstein have worked with the team to develop the project. More information can be found at: <http://hearingthevoice.org>

**Eleanor Cross**

***“I must be a beast, an absolute beast, to be on a section: schizophrenia, identity and normality”***

This project takes a critical stance on the current approach to schizophrenia when it involves the removal of personal liberty under the auspices of the 1983 Mental Health Act. How can compulsory detention fit with the principle of liberty enshrined in the 1998 Human Rights Act? There are moral, if not legal, objections. The Mental Health Act assumes a medical model of “mental disorder” and the power of compulsory detention it carries assumes a causal link between mental health and dangerousness. This is itself a dangerous and irrational assumption.

**Marcello Macario & Raffaella Pocobello**

***“The Italian Voice Hearers Movement: networking and research outcomes.”***

The Italian Voice Hearers movement has developed and grown remarkably in the last five years despite the economic recession and the groups are now promoted by community mental health services. The network has also translated into Italian books about voice hearing and hosted the Congress in Savona last year.

The research committee is an inter-disciplinary team of academic scientists, user researchers, professionals and, being Italian, includes a mother! The research is looking to construct a model of the recovery process and it involves two main elements:

- what does recovery mean to voice hearers?
- what does involvement in the hearing voices movement mean for the individual’s recovery process?

One hoped for outcome is that there will be knowledge transfer that will enable the implementation of recovery oriented mental health services and that will teach recovery to the next generation.

**Maria Haarmans & Filippo Varese**

***“Links between trauma, dissociation and voices: evidence from quantitative and qualitative studies of the Liverpool Psychosis Research Team”***

This presentation focused on a synthesis of two investigations looking at the links between trauma, dissociation and voices. Findings show that sex and gender impact on the dynamic of voice hearing. The relationship that people have with their voices often relates to their life history as does power/subordination in their relationships. It is important to make a distinction between sex (biological characteristics) and gender (a social construct where the traits of male/female are learned) and how they interact with other diversity indicators and early adversity or trauma to understand the impact on someone’s voice hearing experience.

## **Parallel Session 7: Young people and hearing voices**

**Claire Chapman**

***“Working with young people throughout their journeys to self defined recovery”***

Claire works in an early intervention service in North eastern England and talked about their arts programme, including a graffiti project in a public underpass, and joint art programmes in schools to help change attitudes to mental health. Young people and their families say they appreciate this approach which “thinks outside the box” and helps to make them feel that they are people rather than symptoms.

Claire stressed the importance of staff being open and taking part, and starting with small things like transport and food to help engage young people.

**Claire Powell & Yan Weaver**

***“Working with young people who hear voices to challenge stigma”***

Voice Collective is a London-based project to support children and young people who hear voices, and their families. Stigma and bullying at school are some of the challenges these young people face and the Voice Collective team has developed a range of strategies to address these issues that include “Get your voice heard” workshops. The team also runs training courses to raise teachers’ awareness. Some of the young people have recently produced a short anti-stigma animation.

**Ros Thomas & Sarah Sewell**

***“Working with voices: reframing, reconnecting, recovering”***

After being trained in the Hearing Voices approach, Ros described how it had been applied in the Young People’s Discovery Programme in Western Australia. There was also a practical demonstration of voice dialogue that was very moving and thought provoking.

## Parallel Session 8: Peer Support and Self help

**Indigo Daya**

***“Individual peer support programme: merging the hearing voices approach with intentional peer support”***

A new, innovative recovery programme for individual voice hearers is about to be launched in Melbourne, Australia. The programme has trained two voice hearers as peer workers and another as a peer researcher. It aims to bring in ideas from Intentional Peer Support with the hope of creating a more participatory recovery dynamic. The project is being run as a single-blind randomised control trial in conjunction with the Monash Alfred Psychiatry Research Centre that hopefully will help to strengthen the profile of voice hearing work.

**Catherine Whitaker, Julie Madden & Sharron Withers**

***“I leave my voices in my cell on Fridays: Hearing Voices Groups in prisons: Hearing Voices Prisons Project, England”***

This presentation shared the journey of a pilot project set up in London prisons and secure mental health units in 2011. It has been exciting and challenging. Initially, prison staff were cynical about people’s potential to engage in peer support within prisons, but several successful groups have been created.

Topics covered the challenge of convincing prison staff; changing the prevailing culture; managing staff anxieties and creating safe groups in unsafe places. The presentation also discussed topics such as working with feelings of anger, hopelessness, loss and guilt.

**Nicky Forsythe**

***“Talk for health: therapy without therapists”***

This programme is a new approach to mental health which focuses on teaching people how to talk and listen in a therapeutic way. The programme was developed by Psychotherapist and researcher, Nicky Forsythe who has been researching the boundaries between therapy, therapeutic talk and everyday chat. It is an extraordinarily effective method that doesn’t rely on professionals or sophisticated techniques.

**Zanell Neethling**

***“Mixing Music and coping with voices”***

Zanell described this as “the best coping strategy I have ever experienced for hearing voices”. He described how mixing music brings huge benefits – you have to concentrate on listening to the music, counting beats and mixing the sounds together to make a smooth ‘set’. The volume can help to drown out the voices, and if it isn’t always successful, you at least will be creating some good music.

## **Workshop one: Coming off psychiatric medications and harm reduction approach. Will Hall**

This workshop looked at a very sensitive topic which is almost taboo, but it was based on eight years experience that resulted in the publication “Harm Reduction Guide to Coming Off Psychiatric Drugs” (published by the Icarus Project and Freedom Centre)

It is best approached by collaborative working. Topics considered were:

- How does medication work?
- What is best use?
- How do we balance risks and benefits?
- What are the basic guidelines for reducing and withdrawing?

## **Workshop two: Working with male survivors of sexual abuse. Jim Campbell and Ron Coleman**

The two presenters have recently published a book “Reclaiming our lives: a workbook for males who have experienced sexual abuse.” The workshop created a space for the presenters and others to share their stories. It also featured techniques that help people to recover.