

# 7<sup>th</sup> WORLD HEARING VOICES CONGRESS

6<sup>th</sup> – 7<sup>th</sup> November 2015

Alcala de Henares, Madrid

[www.entrevoces.org](http://www.entrevoces.org)

## PRE-CONFERENCE INTERVOICE MEETING, 5<sup>th</sup> November

Chaired by Dirk Corstens

1. Intervoice Safety Agreement (Kellie Comans)
2. Updates from different countries
3. Lived experience testimonies
4. Human Rights (Olga Runciman & Martin Tellez)
5. Small groups discussion
6. New online forum (Marius Romme)
7. *Hearing the Voice* (Victoria Patten)

### 1. INTERVOICE SAFETY AGREEMENT

An 'Intervoice Safety Agreement' has been created (by the Board) to act as a guide for Intervoice events and meetings. In August, eleven people met to discuss formalising a Hearing Voices Network across Australia. And the Safety Agreement was accepted as expressing the Australian network's founding principles.

#### **Text of Intervoice Safety Agreement:**

*As members of the Hearing Voices Movement, we are inspired by the way Hearing Voices Groups offer a safe space for people to share their experiences, beliefs and ideas in an atmosphere of mutual respect and understanding. These groups can, at their best, be special spaces where members accept a diversity of experiences, being curious about difference rather than defending a particular standpoint. The issues discussed at Intervoice do not exist in a bubble, separate from the world. They have deep personal, social, ethical and political significance and, as such, often involve passion and emotion. Many of us, whether we have experienced voices/visions or not, came to this movement because of a desire for change. Equally, many of us have experience of being unheard, excluded, belittled, invalidated, victimised, hurt and oppressed. The passion that drives this movement is amazing, but we also recognise the need for us to continually work together as a movement to ensure we create safe spaces that enable us to explore the issues that matter to us in a way that is respectful and validating. After reflecting on the values that underpin the movement, **the Intervoice board** are keen to encourage a similar atmosphere within any event or meeting that is held in our name. We feel it is important that the values we all hold so close to our heart are carried with us into all of our activities.*

*To support this, we ask that people attending events hosted or supported by Intervoice (online or in person) ...*

- *Keep warmth, compassion and empathy at the heart of our discussions.*
- *Ask questions, challenge ideas and remember that you have a voice as an individual within this movement. We are stronger because we are diverse.*
- *Listen to one another and respect the beliefs and experiences of us all*
- *Be curious about differences of opinion, rather than defending our own perspective.*

*We encourage people to take responsibility and ownership for their actions and reactions, creating a safe and welcoming space for all.*

*If at any time, someone doesn't feel safe within our events, it is our collective responsibility to address any issues that contribute to this.*

## 2.UPDATES FROM DIFFERENT COUNTRIES

### **Greece**

A (voice-hearing?) psychiatrist from Greece spoke briefly, about how voices are an expression of our feelings, and the predominant feeling in Greece at the moment is *fear*. One part of the reason for this is the financial crisis. He described the hearing voices movement in Greece as a core resistance of 30 people. There was a separate brief presentation later in the day, about the Syria/Afghanistan refugee crisis. Stats were quoted. One-third of people dying during the crossings to Greece from Turkey are children. The term **concentration camps** was used by the speaker to describe the special camps set up for dealing with the refugees, and the descriptor **disgusting** for the arbitrary distinctions being made between “refugee” and “migrant”. The speaker called for an INTERVOICE declaration to affirm that Europe needs the ‘voices’ of the Syrian refugees. The government is to re-open (for refugees) the notorious psychiatric institution on the island of Leros, closed in 1999 after a scandal about the conditions in which its inmates were held. The symbolism of this step is impossible to miss.

### **Australia**

<http://hvna.net.au> & <http://ozvoices.org>

The movement in Australia began with Ron & Karen Coleman visiting in 2005. The work was carried forward by Lyn Mahboub & Joe Calleja . At present the national movement is mainly a website, and state networks are proving easier to organise than a national one. Dirk joked that the Australians are ‘the best organisers in the world’. There are signs that the Australian universities are coming on board. Efforts are being made towards making the movement in Australia more voice-hearer-led.

### **Malta**

[www.hearingvoicesmalta.com](http://www.hearingvoicesmalta.com)

The movement is extremely recent in Malta (August 2015) and is still at the stage where it feels very controversial, in an atmosphere where the medical model dominates. It began from an interest within the university, where Paulann Grech lectures in mental health. Her talks on HV have been well received. There is currently more interest from professionals than from voice-hearers, and still trying to recruit voice-hearer co-facilitators. Dirk pointed out both models work (professional facilitators and/or voice-hearer facilitators).

### **Spain**

There was a meeting in 2013 with Dirk Corstens and Olga Runciman. Out of this start, some groups have resulted. [*Language barrier made further notes difficult*].

### **England**

<http://www.hearing-voices.org/>

The Hearing Voices Network in England dates from 1987. The board of HVN have been re-thinking their approach, coming to the conclusion that they themselves are very unimportant. The really important work is done on the ground by the groups themselves. There all kinds of different groups running — within psychiatric services; independent of psychiatric services; in prisons; hospitals; and for young people. Another outcome of the board’s deliberations was a decision not to fundraise, but instead to try to help people connect, by fostering links with other organisations. For the future, we are looking beyond voices, to apply the same ethos to other forms of distress that have been pathologised.

## Western Balkans Hearing Voices Network

<http://nasglas.org>

Including Bosnia, Serbia, Slovenia & Croatia. Because of their recent history, they're in a stage which can be described as post-traumatic, and needing alternatives to the medicalisation of trauma. The network's beginnings were in 2012, with Will Hall delivering workshops on Voices & Trauma, followed by Rai Waddingham from Mind in Camden in 2013, & Hywel Davies and Dirk Corstens. Rai helped set up their website, *Our Voice*. They also used the resource from Icarus Project: [Friends Make the Best Medicine](#).....and Paul Baker's book *The Voice Inside* which has been translated **by voice hearers** into local languages. Dirk commented on the tension between personal and social processing, quoting Jacqui Dillon: "The personal is political".

### Poland

Trevor Eyles read out a letter from a psychiatrist (Renic?) in Poland. The first seed of interest was sown by a chance meeting between Trevor and Renic at the Congress in Thessaloniki in 2014 – and continued via an ISPS conference in New York earlier this year – culminating in a Hearing Voices Conference in Poland itself on 15th June 2015, at the University of Social Sciences and Humanities in Katowice. A further workshop was held last month (October). They have 2 more workshops planned, an interview with Trevor published on social media, a Polish version of the Maastricht Interview, and a Facebook group. There are active plans for a Hearing Voices Group, to be facilitated by voice-hearers.

### Canada

Brigitte Soucy from Quebec spoke. There has been a Hearing Voices Group in Quebec since 2002, and a national Canadian Hearing Voices Network since 2005. There are now 22 groups in the network. Thanks were expressed to Ron Coleman, Paul Baker, Sandra Escher and Marius Romme for their help in the French translation of the book *Living With Voices: 50 Stories of Recovery*.

### USA

[www.hearingvoicesusa.org](http://www.hearingvoicesusa.org)

Lisa Forrester spoke, describing the USA as a late arrival to the Hearing Voices community. There's been a working group since 2010, making organised efforts (in collaboration with Jacqui Dillon) to bring Hearing Voices to the USA. They've achieved a total so far of 72 groups. They've also benefited recently from a \$350,000 donation to the [Hearing Voices Fund held by the Foundation for Mental Health Excellence](#). The fund is administered by Jacqui Dillon and Gayle Hornstein and concentrates at present on providing training, but later phases will include research and evaluation. Lisa echoed Rai's words from England about trying very hard to be small and insignificant because it's not about the power of the organisation but about the power of the voice-hearers themselves. Lisa and her colleagues/peers hope to host the Congress in the USA in 2017.

### Netherlands

Dutch website: [Schizophrenia Doesn't Exist](#).

[Apologies, JW missed this update]

## **3. LIVED EXPERIENCE TESTIMONIES**

We heard from two different Spanish voice-hearers. The **first lived experience testimony** felt there was scope for a very broad interpretation of what we actually mean by 'voices'. A dominant theme was his isolation during 15 years of medical treatment – treatment which he describes as *an obstacle not a help*. He spoke of his rising interest and

passionate reading around the areas of philosophy and psychology, and his growing political awareness and spirit of independence. Parallel to this process, his voices starting becoming much more positive, and then disappeared altogether, as the 'voices' of his friends and family began to take their place. The **second lived experience testimony** included: her father's diagnosis of schizophrenia; how she experienced visions from when she was very young; how she lost her only daughter; coming out of that dark time by making contact with the Hearing Voices Movement; using painting, poetry and creativity for healing herself; and how the ideas of Carl Jung resonate for her, strongly.

#### **4.HUMAN RIGHTS**

Olga Runciman & Martin Tellez

Olga spoke about how psychiatry is deluded but has power – which it exercises unconstrained by the [European Convention of Human Rights](#). It diagnoses voice-hearers with schizophrenia – and then medication, restraints and seclusion can follow. When a system defines you, you lose your voice. Olga searched thousands of academic studies looking for people's own accounts of how medication had helped them. She found fourteen. 70% of people taking medication, when given a choice, will stop. Abuse-survivors experience forced medication as re-traumatising. When 'anti-psychotic' medication first came in, in the 1950's it was described (by scientists themselves) in these terms:

- Is a 'chemical lobotomy'
- Does not prevent people hearing voices
- Makes people 'manageable and passive'
- Makes people 'able to describe their life but without connection to it'

Martin asked what do we do to respect human rights? Very little it seems. Among the mass of printed literature and leaflets routinely provided by mental health services, there's a marked absence of any explaining how to take your case to court under Human Rights legislation. The **World Health Organisation** has [guidelines around Mental Health & Human Rights](#), but these are rarely implemented. Martin sees the task as being one of 'generating common knowledge'. He also challenged the usefulness of the term "recovery".

#### **5.SMALL GROUPS**

1. Politics & Spirituality
2. Human Rights
3. The Maastricht Interview

##### *1.Politics & Spirituality*

'Pticasus' is the name of an activist closely involved with Icarus Project in France. He opened the workshop by describing how distrustful and uninterested anarchists tend to be, in anything to do with spirituality or self-help or alternative healing methods. Conversely, his friends among the latter group had no interest in political activism. For him, recovery means discovering connections and relationships – between political action, self-healing, and spiritual awakening. Within the Icarus Project, the image of the dandelion is used. Viewed as a pest in orthodox horticulture, it is medicinal and has deep roots which symbolise the power of underground networking. Pticasus commented on Olga's assertion that psychiatry is a delusion. He said the way forward is **for all the delusions (i.e. realities) to have a voice**. Across psychiatry, politics and science in general, there tends to be the dominant voice of a single paradigm. *Welcome to diversity*, as he put it. Lisa Forrester spoke eloquently of how the spiritual communities themselves don't welcome

diversity. She was denied the opportunity to participate in a Buddhist meditation workshop on the grounds that she was too 'vulnerable' with her psychiatric diagnosis.

## 2. Human Rights

There were several points:

1. Circulate accounts of successful legal cases (e.g. the Eli Lilly case)
2. Make available standard letters (with translations available) to help people assert their Human Rights
3. The importance of connecting (e.g. with refugees)
4. Intervoice, with a presence in 27 countries, has the power to be a global co-ordinator
5. Anti-stigma campaigns can be stigmatising, by teaching us that we are ill.
6. Mental health issues are political.

## 3. Maastricht Interview

Many of those participating in the workshop had received and/or delivered the interview. The Interview itself has always been a collaborative effort from the very start (between Patsy, Marius and Sandra). It gave us our voice as voicehearers. It recognised that voices can have many meanings. But it can be less helpful when it is used as a way for the professional to say: *I am the professional, you are the voice hearer, and I will impose my meanings on you*. In England, sometimes the Interview is being prescribed by statutory services – usually in a clinical setting where there is no encouragement to be able to say no. This was reported extensively by many of the workshop participants. The Maastricht Interview is being used (or abused) as a means of imposing power – instead of being used as a way for voices hearers to find out, rather than being told, what their voices mean. The interview can be a good experience when it comes from true curiosity, taking the cue from the voice hearer, and allowing scope and flexibility for roaming through other subjects. Process and curiosity are more important than structure. Finding the right questions to ask people from other cultures can be difficult, and one solution is simply to ask: *What questions do you want me to ask?* Clinical language is a felt hindrance – so words such *tool* and *intervention* are less helpful than words like *discovery*, *exploration* and *opportunity*. The Maastricht Interview has shaped and founded our movement. It's our responsibility to care for it for the next 25 years – maybe even to extend it and find new, creative ways of incorporating what lies beyond language.

Sandra Escher replied briefly, saying that there are guidelines for how to use the Maastricht Interview in the book *Making Sense of Voices* – and if they're not being followed, it isn't right.

## **5. NEW ONLINE FORUM**

Marius Romme spoke of Spain having a population of 50m, and since the stats predict 4% of the population hear voices, this means 2 million voice-hearers in Spain. We should not forget them. Multiple copies of a letter were made available, in Spanish and English, inviting people to get in touch with Marius & Sandra [a.romme.escher@gmail.com](mailto:a.romme.escher@gmail.com) or Paul Baker [paul.baker@radishonline.net](mailto:paul.baker@radishonline.net) if they are a voice-hearer who copes well with their voices and would like to participate in a private and moderated online forum, where members can adopt an avatar to protect their identity if they so wish. Among the benefits would be:

- To share stories & experiences
- To get a better understanding of the voice-hearing experience
- To help change social attitudes and promote freedom of minds

## 6. HEARING THE VOICE

Presentation by Victoria Patten

[Hearing the Voice](#) is a large interdisciplinary study at Durham University, aiming to impact the perception and awareness of voice-hearing in the scientific, clinical and public arenas. Comprises a team of 20, drawn from fields as diverse as:

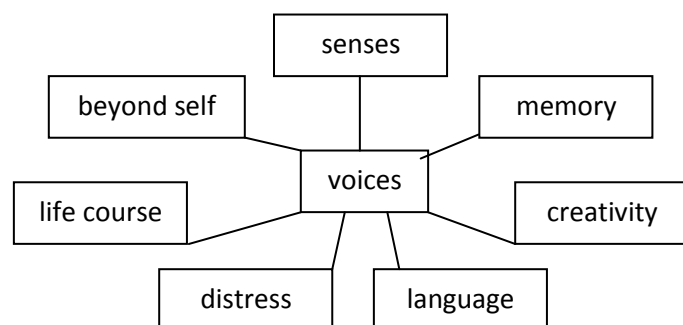
- Cognitive neuroscience
- Cultural studies
- English literature
- Medical humanities
- Philosophy
- Psychiatry
- Psychology
- Theology

The thrust of the research is moving away from a reductionist approach, where voice-hearing is seen as a symptom, and asking instead questions such as: *What is it like? How does it arise? What does it mean?* Also, embracing the cultural, religious and historical context. E.g. by looking for resonance in the lives and works of Charles Dickens, Virginia Woolf, Margery Kemp and Julian of Norwich. The Writers' Inner Voices Study in 2014 looked at the similarities/differences between writers' voices and those of people receiving clinical treatment.

In 2013 there was a collaboration with the [Lived Experience Research Network \(LERN\)](#) which threw up interesting questions such as **Are 'hear' and 'voices' even the right terms?** and confirmed that:

- people with and without diagnosis hear voices
- there is a wide variation in the character of voices
- voices can be both positive and negative
- 10% of voice-hearers report 'thought-like' voices with no auditory characteristics.

The map of **future areas to be studied** looks like this:



- Jo Atkinson at University College London is going to be looking at **voice-like experiences in people who are deaf**
- Another study will look at **voice-hearers in the spiritualist community** (employing both neuro-imaging and phenomenology)
- A **new website** is coming (in partnership with Rethink, the NHS & HVN) to be called ***Integrated Voices***. Victoria put out a request for help and input from Intervoice, in deciding how best to include the perspective of voice-hearers themselves on the new website
- A major exhibition in Durham November 2016 to January 2017, in partnership with Wellcome, provisional title: ***Hearing Voices: Suffering, Inspiration, Everyday***