7th WORLD HEARING VOICES CONGRESS

6th – 7th November 2015

Alcala de Henares, Madrid www.entrevoces.org

DAY ONE

Keynote speakers:

- 1. FERNANDO ALONSO Denigrating voices, social context and the art of disobedience
- 2. MARTIN TELLEZ & SASCHA ALTMAN Navigating the space between brilliance and madness: stories and lessons from the North American Mad Movement
- 3. WILL HALL Austerity, corruption and mental health
- 4. ROBERT WHITAKER Anatomy of an epidemic: history, science and the long-term effects of psychiatric drugs

OPENING REMARKS

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 or Paul Baker 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

Olga Runciman spoke about the **butterfly** as a symbol of transformation. Also symbolised soul to the early Christians. The pupa stage involves dissolution to liquid, and this 'dissolved' state can be seen as symbolic of psychosis — or crisis — with its as-yet-unrealised potential for transformation. The butterfly itself displays many vivid colours and travels the world (like members of the hearing voices movement).

1. FERNANDO ALONSO

Denigrating voices, social context and the art of disobedience

The thrust of this presentation was to establish a polarity between materialism on the one hand and human relationships on the other. FA has been hearing voices all his life since age 19. Instead of tracing the voices to a single traumatic event, or to the family environment, FA looked at the impact of social environment on psychological life. One third of Spain is at risk of social exclusion. All paradigms recognise the link between social and psychological issues — yet without attempting to address social change. This is an unsustainable situation which is nevertheless sustained — until it collapses. Psychological suffering is just that collapse. Denigratory voices express the hollow values whereby "happiness" is defined as having an ever greater accumulation of possessions/goods. RESISTANCE IS FERTILE, RESIGNATION IS STERILE. The denigratory voices can be disobeyed. No-one is a 'shit' or a 'bastard' because they have been evicted from their home or fired from their job. I AM A PERSON NOT A NUMBER. We can organise ourselves and set limits, creating safe spaces (hearing voices groups) and setting a threshold between what is and is not dignity.

2. SASCHA ALTMAN

Navigating the space between brilliance and madness: stories and lessons from the North American Mad Movement Books plugged (available as free downloads from the Icarus Project website):

- Friends Make the Best Medicine
- Harm Reduction Guide to Coming Off Psychiatric Drugs
- Navigating the Space Between Brilliance & Madness

SA at the age of 26 found himself locked up for a month in Los Angeles County Jail, one of the 3 biggest psychiatric hospitals in the USA. He was injected with Haloperidol, kept in solitary, and coped by talking to the fluroscent light and believing in his own extreme importance. He was diagnosed with a brain disease *bipolar disorder*. A year later he wrote an article describing his story and saying how lonely he felt. Some of the thousands who read it got in touch and ICARUS PROJECT was born, starting as a <u>website forum</u>. Key founding members were Madigan Shive and Will Hall. Icarus is named after the son of Daedalus who flew too near the sun (with wings designed by his father out of wax) and fell and perished. We see ourselves (in the Icarus Project) not as diseased, disordered and dysfunctional but as possessing dangerous gifts. If we *are* sick, the sickness can be both beneficial and useful. What does it mean to be crazy in a world that's obviously insane? What is the world that we're trying to be healthy in? Some of the influences that helped shape the Icarus Project were:

- New York riots around 1990
- the anti-capitalist movement in Mexico
- farms and permaculture, as a metaphor with which to talk about our lives

SA has moved from an initial attitude of FUCK YOU, WE'RE NOT DISABLED towards embracing the notion of disability, as being defined by the fact that society doesn't have the spaces where we can be, and we must create them. He spoke of intersectionality — the idea that you can't separate out the many different aspects of the struggle for social justice. For example, Icarus Project is affiliated with INCITE whose book *The Revolution Starts At Home* tackles the power dynamics of race and gender. And Fountain House (The International Clubhouse Movement) provided Icarus with an office for 2 years. SA spoke of the growing movement to create spaces to keep people out of hospital, e.g. Soteria and Parachute

NYC which is going to be piloted in the UK. Ending with a quote from Martin Luther King: Human salvation lies in the hands of the creatively maladjusted.

[MARTIN TELLEZ presentation missed — JW.]

3. WILL HALL

Austerity, corruption and mental health

WH described this conference as a ray of hope for a future world that will welcome different states of consciousness. He delivered a list of assertions which he said characterise the disability movement:

- my voices/guides are normal
- paranoia is normal
- suicide is normal
- quietness is normal
- to be sensitive is normal
- autism is normal
- depression is normal

Disability is not within the person but within society. Just as trauma can be individual or collective, so can therapy. WH called for a strategy to attract more people from black and ethnic minorities to the 8th Hearing Voices Congress in 2016. 20-30 years ago to be gay was to be diseased. The psychiatrists generalised that because higher levels of suicide, anxiety and addiction were to be found among the gay population, this was symptomatic of the disease of being gay. We now

know that the suffering was real but it was located at the point of interaction between gays and society. Similarly we can ask in Darwinian terms, *In what sense are psychosis and madness an advantage to the species?* Answer: they contribute complexity. This makes the Hearing Voices Movement a GREEN movement. We're also a movement in the tradition of the civil rights and gay liberation movements: so why have we failed? Answer: corruption at an institutional level. "Pharma" has more influence even than the oil industry. The reason we can't make change is FEAR. A study to find out if writers were scared of their web-browsing being caught by surveillance, discovered 26% of writers have this fear — this remains constant, regardless which country (and political system) is examined. So how to put a stop to fear? Fear is corruption within ourselves and the answer to fear is love.

4. ROBERT WHITAKER

Anatomy of an epidemic: history, science and the long-term effects of psychiatric drugs

RW began as a science journalist. While working for the Boston Globe newspaper in 1998 he came across Mind Freedom [then named Support Coalition International] and discovered a different narrative from the one he had always accepted where mental illness was a brain disease. The people actually being prescribed anti-psychotics didn't like them. He wanted to know how it could be, that this entire alternative narrative was being suppressed. The project of his first book Mad in America was to go back through history tracing the parallel existence of these two narratives — discovering for example as far back as the 1800's the following quote: "They called me mad, and I called them mad, and damn them, they outvoted me" [in fact attributed to Nathaniel Lee c.1690 - JW]. RW's 2nd book Anatomy of an Epidemic examined the narrative created and exported by the USA, from the point of view of scientific documentation, revealing that little or none of the scientific documentation supports that narrative. For example recovery (ie. hospital discharge) rates were actually significantly better before 1955 (when the first 'anti-psychotic' Largactyl arrived) than they have been ever since. Also the burden of numbers of people receiving treatment has increased hugely from 350,000 in the USA in 1955 to currently 5 million. One in five adults in the USA are taking a psychiatric drug on a daily basis. Yet as early as the 1970's, scientific efforts to observe, e.g., low seratonin in people with depression were already failing and it was announced by one medical textbook in 1998 that the 'chemical imbalance' theory would have to be abandoned. Conclusion: we have organised ourselves around a false story. We are all losers when we silence the narrative of a significant section of our own population — as happens when those who resist the orthodox narrative are labelled 'lacking insight'.

DAY TWO

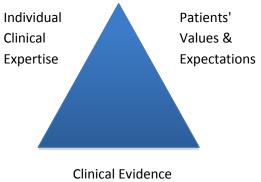
Keynote speakers:

- 1. ANGEL MARTINEZ HERNAEZ Don Quixote in the era of neurodiversity: from neuro-self to collective construction
- 2. ASSUMPCIO PIE New ways of social participation: the pro-communization of the body and health
- 3. BHARGAVI DAVAR Voice hearing experience, embodiment and culture
- 4. UTE MARIA KRAEMER Riding psych disorder through history's abyss: lost generation's comeback from the maze of psychological irrelevance to transgenerational justice
- 5. CARINA HAKANSSON The extended therapy room

1. ANGEL MARTINEZ HERNAEZ

Don Quixote in the era of neurodiversity: from neuro-self to collective construction

AMH described himself as an anthropologist, and sees Don Quixote in terms of 'somebody trying to attain the unattainable'. He made reference to The Ship of Fools in the work of Michel Foucault, and asked whether we want dialogue with madness or a monologue which denies madness a place. He claimed that madness has 'the power of deconstruction' and warned against the false dialogue, and the distrust, which results when professionals try to impose the language of common sense. Although individual professionals humanize what they do, the medical model sets aside the evidence of narratives based on lived suffering. He critiqued the theoretical model expressed in the diagram below, saying that the reality is all too often a lack of horizontal dialogue between individual clinical expertise and patients' values and expectations.



2. ASSUMPCIO PIE

New ways of social participation: the pro-communization of the body and health

The right to suffer is the right to live. Suffering is a right for its own sake. Because suffering is shameful, it results in a split between private and public, where professionals in particular are not entitled to have feelings. This leads to dissociation so that we end up being forced to understand life in fragments. To engage with a politics of suffering means: (1) to tell ourselves about our suffering, (2), to make suffering visible, and (3), to be clear what makes people suffer. The politics of suffering cannot be approached from the point of view of hierarchy. We have an entitlement to show ourselves to others in a new light, nothing to do with consumerism, goods and possessions. Sun, river and oceans belong to no-one (cf. Antonio Lafuente) — and, just as these are under threat from market forces, so are our pain, our body and our suffering. Denial of suffering means the denial of our humanity. Our suffering may be a positive building element for our subjectivity — but it goes both ways and our suffering also has an impact on others. To be alienated from pain can have a severe impact on our ability to communicate. The medical model imposes silence on pain, and this amplifies the pain. What can happen when we stop denying suffering and start sharing our feelings? We must establish a new dialogue — testing, analysing, researching, sharing feedback — in order to watch and listen to our bodies and not to be colonised by medical approaches.

3. BHARGAVI DAVAR

Voice hearing experience, embodiment and culture

BD 'came out' as a non-voice-hearer. However she has learned (through her family background of colourful, spiritual, traditional spiritual culture) to open her body and mind to unusual belief systems. Her mother was institutionalised and given ECT without anaesthesia, and it has taken her 40 years to process these family experiences. BD works in India for a charity called <u>BAPU Trust</u>, part of the *TransAsian Alliance for Transforming Communities for Inclusion* (TCI Asia). She

quoted Article 19 of the UN Disability Convention about creating opportunities for people with disabilities to live in the community with self-determination and dignity. BAPU achieves this through human rights advocacy and by designing community programmes. BD highlighted the very different experience of identity for people in the vast rural tracts of India, where there simply aren't the mental health services we are used to. The people she works with are unlikely to identify as 'voice-hearer' or 'psychiatric survivor' — there is no response of victimhood because there are no psychiatric services, in fact there is a demand for services because they are seen as a better alternative to traditional practices like cageing people up who are suffering mentally. Also, rural India has not bought into the myth of the 'self' as a single. linear, rational, cognitive and language-based phenomenon. For them, selfing is a process. Rural India doesn't use the word schizophrenia at all. Many women are possessed by spirits, and djinn, and goddesses: even possession by evil spirits is tolerated, where the person is visibly distressed. There's a tradition of spontaneous public dance performances where women are able to express themselves and their sufferings freely, in a way denied them within the normal limits of society. For this, they won't be stigmatised or judged or institutionalised. However there is change afoot and an increasing tendency towards systematic psychiatric screening — a change radiating outwards from the relatively narrow confines of the urban centres. BAPU Trust also works in those urban centres — e.g. Pune, a city with a population of 10 million. They use arts-based therapies with lots of dance, drumming & breathing practices. Their typical clients are those termed 'bad-bads', characterised by self-neglect, talking to themselves, substance misuse, and (increasingly) those who have been mistreated by psychiatry with overmedication and seclusion. BAPU's ideas and findings are in direct opposition to those of the burgeoning psychiatric industry.

4. UTE MARIA KRAEMER

Riding psych disorder through history's abyss: lost generation's comeback from the maze of psychological irrelevance to transgenerational justice

Picking up on Sascha Altman's description of madness as 'having dangerous gifts', UMK described her presentation as a 'dangerous gift' to the Congress. A middle-class girl living close to the countryside, she was passionate about ponies and horses from the age of 9. At age 17 her world was shattered when her father sold her horse. Her world became a melee of shoutings, judgements and accusations — changing her experience of the world dramatically. A year later she found herself in the woods looking up at the moon asking: God, why have you put a witch inside me? Despite this inner turmoil, she went to Rennes-Mediation University to study cultural and clinical anthropology. Following her degree, her father once more withheld something she wanted, refusing to support her while she did her PhD. She returned home but everything seemed ghostly and unreal. She had 3 years of psychotherapy and managed never to mention her issues with her father during the whole of that time. [UMK's impressive portfolio of artwork was displayed at this point, dominated by the theme of horses, with a strong fantasy element]. In the middle of working on an art project, she collapsed and ended up in psychiatric care with a diagnosis formed on the basis of a 2-minute conversation. UMK shared with some considerable eloquence how she feels about having these 'huge, passionate, wild, haunting experiences which I knew as core ingredients of my identity' pathologised. She described it drily as a 'manipulative enterprise'. The remainder of her talk centred upon her quest to understand her father. He was a dedicated and successful businessman, with friends in high places. Her paternal grandfather before the war had belonged to the Social Democrats — actively involved in opposing the Nazis — and when they came to power the family were evicted and living in poverty throughout the war, during which her father was 7-12 years old. He played among the ruins when Cologne was 94% destroyed by Allied bombing. All this was never spoken of. UMK was clearly moved at the thought of this lost generation of children carrying so much trauma through their adult lives in silence. She says there is a systematic hiding of the experiences of the oppressed (cf. Paolo Freire). By this effort to understand his inner world, she finally grasped the reasons for his decision to sell her horse: from his point of view she was a 'lefty anti-capitalist intellectual' who had failed to grow up.

5. CARINA HAKANSSON

The extended therapy room

In 1987, CH was a social worker in Sweden, who came to realise she couldn't be a social worker. She couldn't accept (and still can't) the way people talked about other people, and the personal-professional distinction. And so she founded the Family Care Foundation. We have been taught there is an 'us' and a 'them' and that we professionals are different — but this difference creates unnecessary trouble. The Family Care Foundation began with 4 family homes and now has 35. It was created out of a pre-existing project of foster homes where therapeutic conversations took place round a table in a domestic situation, not in a clinical room. CH's organisation challenges the received wisdom that professionals should never display strong feelings, such as fury or fear, and never self-reveal. But instead of rejecting feelings, her staff are encouraged to be themselves and scream and cry and react. The feedback from clients indicates that this is appreciated because it fosters a feeling of inclusion and humanity. It's sometimes the first time the client has felt permission to explore their voices or hallucinations or strange experiences. The professionals are encouraged to deal with fear by taking it into themselves. Likewise with self-disclosure, it's important to have permission to self-reveal and to find that it is not dangerous. It is not a technique and not a 'must'. But sometimes for example CH talks about being daughter to a heavily drugged psychiatric patient father who, late in life, finally found someone who asked him to talk about his experiences and encouraged him to come off the drugs. Like so many other people, he had been told he had a chronic disease when there is so much evidence this is not true.