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THE INTERNATIONAL SOCIETY FOR PSYCHOLOGICAL AND SOCIAL APPROACHES TO PSYCHOSIS UNITED STATES CHAPTER



## How to Start a Hearing Voices Café

# (Or at least, the story of how we started in Toronto)

By Kevin Healey

We've had a lot of interest in our Hearing Voices Café in Toronto since we started just over a year ago.

The Café, for me, has two key inspirations: 1) an article by Rufus May and 2) Dora Garcia's exhibition "SEE WORDS I HEAR VOICES"

The following article will illustrate the inspiration behind the Hearing Voices

Café as well as what makes our Cafe work so well.

#### **Blurring the Lines**

The first thing that inspired the Hearing Voices Café was a 2014 article by Rufus May in *Occupied Times* "*Time to End The Asylum Mentality*," in which he talked of how there are not those of us who have experiences that get called "mental illness" and then the rest of us who don't; of how we need to blur the lines between community and asylum, and blur the lines between those we cast into those roles "mad" and "not mad"; how we need to bring the community into asylum and bring the asylum out into the community. After a year of working in one such place I was ready to experiment with ways that broke the mold, to resist the clinical gaze and resist the narrative that says we need confine human experiences to special conversations, held in special language and in special places. I'd been looking for opportunity to do something just like this.

Each of us is susceptible to experiences that get called "psychosis" yet it is such a taboo subject in conversations. We have made so many aspects of human experience into something we cannot talk about. Yet doing so means that it is more – not less – likely that when we too have these experiences, we will become isolated, powerless, and maybe we will become "ill" too.

The second inspiration, and also the impetus, was Dora Garcia and being invited to collaborate with her on her exhibition I SEE WORDS I HEAR VOICES, which ran at Toronto's The Powerplant Contemporary Art **President's Column** 

By Jessica Arenella



ISPS-US has purchased the licensing rights to screen three documentaries portraying psychosocial and alternative approaches to understanding experiences labeled psychotic: <u>CrazyWise</u>, <u>Healing Voices</u>, and <u>They Heard</u> <u>Voices</u>. All three films have been screened in NYC at least once and have led to fruitful discussions about how we understand and address experiences commonly referred to as psychotic.

Showing a film is a great way to introduce alternative approaches to psychosis to people with lived experience, family members, mental health professionals, members of the media and the community. The films also offer messages of hope and empowerment to people who are working to recover from extreme, unusual or traumatic experiences. It is our hope that screening attendees will become more curious and consider joining ISPS-US. If you would like to

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#### How to Start a Hearing Voices Café

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Gallery, Canada's "premier contemporary art space," from September 2015 to January 2016.

#### Seeing Words, Hearing Voices

This exhibition included five pieces exploring themes of *Exile*, *ESP*, and James Joyce's *Finnegan's Wake*. If you're not familiar with this kind of work – and I was only a little – it's the kind of art in which the viewer, the person entering the gallery, plays an important role as actor or performer: how we respond is a key part of it.

For example, *Finnegan's Wake*, James Joyce's novel, was featured with a table, laid out with annotated copies of the work from shared readings held by the Joycean Society in Trieste. Also in a screen showing Garcia's documentary film: *The Joycean Society*. Then on opening weekend there was also a live, shared reading of the book itself: about thirty-five people gathered round the table reading a couple of pages together, making sense of the text and sharing possible meanings, interpretations, guessing at Joyce's intentions, just as the members of Joycean Society do at their meetings.

Something that struck me from this experience was just how much like voices Joyce's writing is. Joyce, amongst many things, played with language; he famously counted a good day as having written two sentences. Like many others, I struggled, and still struggle, with reading Joyce alone. Enacting reading as a shared activity, or listening along with others, brought the text on the page to life, just like Finnegan himself was brought again to life by a splash of spilled whiskey at his wake. I came away thinking it was as if Joyce intentionally crafted language – words and sentences – so that they could be interpreted in as many different ways as possible. I was profoundly struck by how voices, at least the ones I hear, do much the same: the meaning I take away is always mine to choose.

Another exhibit featured video interviews with wellknown Latin-American authors including Juan Rulfo, author of *Pedro Páramo*, whose chief character visits a remote village seeking connection with his father and, after only a couple of days, discovers that everyone he has been meeting and talking with is dead – a ghost, spirit, voice, vision – choose your language. The book has become a favorite of mine.

#### **Close Encounters of a Saturday Kind**

For our part, we led with the *Saturday Encounters*. Each Saturday afternoon for a couple of hours we would set up a small circle of seats in the center of this huge space and people would come and sit, talking with and listening with each other, sharing personal experiences of experiences that can be difficult to talk about, and difficult to find language for.

For two hours, we turned this huge post-industrial space into an intimate human encounter that allowed whoever came to share what can be so difficult to share. For two hours, we got to occupy one of Canada's premier art spaces to do our thing and invite others to join us. Many visitors went away having their eyes and minds opened. No doubt we were all challenged by these experiences, for me it was very learningful.

Other groups involved in the Saturday encounters brought different experiences and different language together connecting with another of the exhibits. The *ESP* exhibit presented a table laid out with first-person accounts of "experiences not easily understood by simple understanding of the senses."

The whole exhibition offered opportunity to make different connections with "voices" or "spirits," "experiences," or whatever language you choose – each inviting us to question what we assume, what we think we know, and especially the false certainty with which we like to categories human experiences.

In these conversations, we would also refer to our connection with our own experiences of the other elements, the displays in the room – and the room itself. There were no limits placed on the conversations, in the manner of open space technology; the people who came were the only ones who could come; what we talked about was the only thing we could talk about.

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### **President's Column**

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screen one of these films in your community, or at an organization or institution that you are affiliated with, please contact <u>Karen Stern</u> for additional information.

CrazyWise will also be screened at our Sixteenth Annual Conference in Portland, November 17-19, as one of the subjects of the documentary – Gogo Ekhaya Estima – is giving the Keynote address regarding the spiritual transformation she made through her experiences that had been labelled psychotic. Our Honoree, Narsimha R. Pinninti, MD, will also be discussing the transformation of trauma through mindfulness in the context of the TIMBER model for treatment of psychosis.

I am looking forward to hearing these plenary talks and all of the presentations regarding Psychosis in Context: Exploring Intersections in Diverse Identities and Extreme States. However, I am most looking forward to seeing all of our ISPS-US members from previous years and meeting new members attending the conference for the first time. The annual conference is a time when we can all come together to strengthen our relationships and inspire each other to continue the important work of building more diverse, inclusive, humane and nonstigmatizing methods of assisting others through extreme or unusual experiences.

Speaking of diversity, our Diversity Committee needs members! We are seeking members of multiple identities with regard to race, ethnicity, gender, gender identity and expression, socio-economic status, nationality, citizenship, religion, sexual orientation, ability and age – or anyone who is interested in promoting diversity – to participate in this new committee. Please contact <u>Julie</u> <u>Kipp</u> for more information.

Finally, with a very heavy heart, I must announce that the Moderator, major contributor and driving force behind the ISPS-US Debategraph maps, member Paul Peacock from NYC, has passed away. Paul was a tremendously kind, insightful, gentle, unique, and visionary person who sought to transform the way western society views "mental illness." He was also passionate about environmental issues and always sought to make the world a better place.

If there are any inquiries regarding Debategraph, please contact me at <u>president@isps-us.org</u>. If anyone is interested in donating in Paul's honor, you may do so through the <u>Foundation for Excellence in Mental Health</u> or the <u>Charter for Compassion</u>.

## Letter from the Editor

By Marie C. Hansen

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Welcome to the Summer 2017 newsletter!

One of the things I like most about the current issue of our newsletter is the diversity of viewpoints expressed, each article highlighting the varying perspectives of our members. We kick things off with Kevin Healey from ISPS Toronto writing about how he started a Hearing Voices Café. Healey believes it is the non-stigmatizing and relaxed environment of a local café that makes the meetings so successful. Currently running for about a year, the Toronto Hearing Voice Café has become a fixture in the community, bringing people from all walks of life together to discuss the voice-hearing experience.

Next, we have psychologist Mohiuddin Ahmed discussing his opinions about the current mental health treatment for psychosis, which he views as hyperfocused on people's past experiences. Ahmed sees the present moment as the most important area for therapeutic intervention, a focus which he believes will bring individuals towards their life goals – rather than keep them stuck in the past.

We then have the third instalment of Gregory Shankland's exploration of the phenomenology of voicehearing. In this article, Shankland talks about why voices are so hard to ignore and what makes them compelling to the listener. Based on his own experiences of hearing voices, Shankland discusses the ways in which voices can become embedded into the listener's personal narrative through the brain's natural tendency to seek

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Peace,

Jessica Arenella, PhD

### Letter from the Editor

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meaning or explanations for experiences. Although voices are impossible to ignore, Shankland offers practical strategies for minimizing their impact.

Finally, new ISPS-US member Andrew Field talks about what he believes is a strong trend in ISPS-US to vilify medication and psychiatric care. Field, himself a person with lived experience, believes medication was invaluable for his own recovery from psychosis. Field states that ISPS-US is important, in that it brings together people with shared experiences; however, the tendency for some members to express an anti-psychiatry perspective can be seen as irresponsible. Field calls on us to be aware of our biases, and recognize that recovery is not "one size fits all."

I believe it is a testament to our strength as an organization that we can make room for all these varying perspectives. Psychosis is a complex phenomenon, and each of us comes to ISPS-US with our own emphasis and past experiences. One of the best places to dialogue with others is at our conferences. The theme of our conference this year is diversity – what a perfect place to continue these rich conversations!

#### How to Start a Hearing Voices Café

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What stayed with me powerfully from my own experiences in these encounters was that the differences were not so much in the *experiences* themselves as they were in the *language* used to describe them.

"Exile," and the many ways we can experience exile, was one of the recurring themes explored in the exhibition, and it struck me how our language is often a tool with which we use to exile others or by which we can become or feel exiled.

When I first met Dora in the summer, to plan for her exhibition to take place in the fall, I had expected that she would have a clear idea of what we might do together – and was surprised to hear her say "what do you want to do?"

She explained to me that her approach was to include "actors" from the local community. I also learned that it is also a policy of The Powerplant to work with local community groups – bringing them into the space and their art out into the community, so the art, the gallery, exhibitions become parts in a dialogue with community.

The idea for the "Saturday Encounters" came from a previous experience of mine as a human book in Toronto's public library service, the world's busiest

urban library system. Connected with the international project, anyone with a library card could book me and "borrow" me for a conversation for 20 minutes. It was a great experience; I was the most-booked and -borrowed human book on the day.

So we took that idea and turned it into a small group conversation – not one person sharing their experience, but whoever comes, whatever they experience, and sharing in whatever language they chose. I was but one of a handful of people who would sit in the middle of the vast gallery space in intimate circle sharing and inviting to share experiences that we don't normally talk about with others.

Some would be quite surprised at what they had joined in with; everyone who did come stayed, listened, and joined in. Many who came shared how they had experienced things they had no words for or didn't talk about because they did not know what words to use.

Others would talk of loved ones or people they knew who had similar experiences; or of their own experiences and reflections on the exhibition and their response with it.

#### Art?

The "Saturday Encounters" I attended were very much like Hearing Voices groups – in the middle of the biggest gallery in Canada's premier contemporary art space.

In our first meeting as we bounced some ideas around, Dora told me about the first Hearing Voices Café in Hamburg – part of a larger exhibition – and of how it had been inspired by a trip to Utrecht, one of my favorite places.

Something that was difficult for me at first was language; artists, like any other oeuvre, have their own lingo, jargon, and talk of "installations," "performance." So the act of visiting the gallery is "performative," engaging with whatever is going on the space is performance, installation.

Thinking of a Hearing Voices group in a galley as an "installation" is a bit weird, and perhaps unsettling, but it is really just language about how the space is being used to bring something from outside into that space to change it and also to invite us to think about how we interact in it.

For me, this was an interesting challenge, an unmissable opportunity to take into public view what is normally

#### How to Start a Hearing Voices Café

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required to be hidden away: taking "the asylum into the community."

We simply invited whoever was in the gallery to come together in circle, speaking to their own experience in the language of their own choosing – talking and listening with each other.

We sat together in this giant room surrounded by the exhibits, transient part of the space Dora had created, to create a new space open to whatever came into it. A place for everything and where anything can find its place. Still now from time to time, like right now, I see and hear the words Dora Garci a left me with... "I love the cosmology of it all."

#### Language

Finding shared-enough language to describe what was intended to happen proved difficult. What was being carefully brought together would fly apart, just when we thought we had got there. It was far from easy to find a form of words that satisfied all the different languages, understandings, and worldviews of people who would be involved in the encounters. At least twice it looked like we would not be able to do so, but we did.

#### In Community

For the Toronto exhibition, I SEE WORDS I HEAR VOICES, there was no funding to "install" a café in the community as part of the exhibition. As is so often the case, lack of funding leads to creativity. Involvement with the exhibition became catalyst, created the opportunity to start the HV Café out in the open, in the community, even in the neighborhood in which I live, in same the café in which I work from my laptop, writing this right now.

We originally intended to run for four months, for the duration of the exhibition, as a trial, a pilot, to learn. It was so successful we decided we wanted to continue. We attracted spontaneous attention from media: *CBC radio, Globe and Mail,* and *Toronto Star.* 

#### Sounds Like Such a Cool Place

One Saturday morning, when we were featured in *Toronto Star*, I was in the café having breakfast and overheard a woman from New York talking (loudly) on her phone proclaiming "I'm in Toronto! I came to the Hearing Voices Café because it sounded like such a cool place."

It seems that there's something about the idea of the Hearing Voices Café that sparks curiosity in people who ordinarily would not think about this stuff. I don't know how to start yours, but this is how ours started.

#### **Toronto Hearing Voices Café**

Our café runs once each month – the first Monday, 6pm to 8pm. That's what suits me and suits the café owners and suits the people who come.

We also have a full-charter Hearing Voices group, now almost seven years old. The cafe allows us to meet different needs – the HV group can remain intimate and private in the way those who come value, and anyone else comes to the café. Some come to both, of course.

When people first approach me now, asking about the Hearing Voices group, I tend to suggest they try the Café first; it's often a much easier introduction.

We have found it is important to accept and respect that for some people the idea of coming to a Hearing Voices group is daunting and the Café seems much less so. Sometimes people come with their worker. Sometimes a worker will arrange an outing for a few members of a supportive housing agency to come together.

#### So, who comes?

In short, anyone who wants to.

We now have a bunch of regulars, each of whom will come often, we get some people who come every now and then, and we seem to get a steady influx of new people every month.

We often get family members coming to find out more about resources or ideas they can share with a loved one. We sometimes get whole families turning up.

Often these people are exhausted after years of dealing with a system they thought was there to help, but which so often offers little worthy of that name. We get peer workers, workers, and psychologists. And we get people travelling as much as 100km to come.

#### What do we do?

We follow the values of Hearing Voices Network: we encourage people to speak to their own experiences.

There is no program, no selling of any approach; what we talk about is what the people who come want to talk about. Sometimes we'll have a topic or theme or watch a movie or videos together and talk about our response to that.

It being Toronto, we get people who have moved to the city from many different parts of the world and want to share different worldviews and ideas and practices from different cultures.

#### How to Start a Hearing Voices Café

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We do try to keep it so that we don't talk in ways that box people into categories. We don't tell people what they are experiencing or what to call it, and we don't tell people what to do. Mostly we listen with each other.

We do have some very lively conversations and learn from each other, sharing stories, resources, and insights and connecting with others.

It is a community – just like in any other lively café.

Our Hearing Voices Café is based on a very simple premise, that:

#### We can talk about difficult experiences in ordinary language in ordinary places. So we do.

For me it's the simplicity that creates the space and generates curiosity, but mostly it's because we do it in the open without palaver or artifice or anyone feeling responsible for what happens or might go wrong – humans gathering and talking and listening with each other about their experiences of being human. It's what coffee shops are for...

As Matt Galloway, presenter on CBC Radio – Toronto's morning show – said, introducing a segment by Reporter-Editor Mary Wiens, who has been a great ally:

#### "Many social movements have their origins in coffee shops, and that includes... the Hearing Voices Café."

The café is in a prominent place, in a residential neighborhood, has a whole wall of windows, is welcoming and friendly. Many people come here to work, meet neighbors, meet friends, or connect with friends round the world through their laptop; many groups use it as space to meet up.

There is a partition – the space we use at one end can be partitioned off, and we do that because we can get a bit noisy, but we're in full view and earshot, and anyone can come in. Our first time, we had thirty-two people squeezed in there. Typically, now we get a dozen-plus to twenty-something, often with folks sitting on the floor to get in.

We are now very much part of the Toronto landscape.

#### What makes it work?

Well. I don't know, but here's what I think...

I do think an important factor is that the Hearing Voices Café is actually in a café, and one in which it just fits with how the space, the café is already run.

When I first approached Sue, the owner, to share what I was doing with Dora and that we had this idea to run a Hearing Voices Café out in the community, "do it here" was her response. I didn't even need to ask.

Later, when I came to asking if it was ok if we continued after the initial period, she said:

"I didn't know you were going to stop!"

#### Not the first, not the last

We were not the first, some of that story you've just read; there's more at Dora Garcia's website (see links below). The story was also told in the first "Saturday Encounter" and also transcribed, so it now forms part of the archive. We were the first to become a regular ongoing feature in the landscape of the city. Others followed: Valladolid, Paris, London, and now Oshawa.

Recently, in June 2017, we were very pleased to be invited to help folks in the Durham region (to the east of Toronto) start their own Hearing Voices Café.

We'd spent time there earlier this year, training over fifty people, workers from all parts of the "mental health system" who now felt energized and wanted to bring change to their community.

They came together, they found a cool place to hold it, and talked with the owner – and started.

So that, basically, is how you do it.

The world changes when we change the part of the world we occupy. What are you waiting for?

#### Some resources

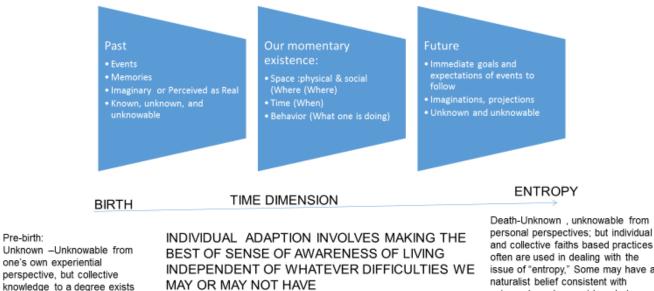
- Hearing Voices Cafe
- <u>Hearing Voices Café on the radio</u> <u>https://www.youtube.com/watch?v=\_hfHB8inhVQ</u>
- <u>Hearing Voices Café, Hamburg</u>
- I HEAR WORDS I HEAR VOICES
- Photo essay: I SEE WORDS I HEAR VOICES
- <u>Hearing Voices Café Toronto Pamphlet</u>

## **Existential perspectives, Positive Redirection, and other Personal Reflections in working with people exhibiting "Persistent Psychosis"**

By Mohiuddin Ahmed, PhD

Pre-birth:

#### OUR LIVING EXPERIENCE IS DETERMINED BY TIME AND SPACE AND DIRECTIONALITY



Mohiuddin Ahmed. Ph.D. April 2017

We are all information-processing living beings, always trying to figure out how best to respond to the current existential moments of our conscious life that spans all phases of our life spans, whether we are two years old or adults or 90 years old. We operate within the framework of a Unidimensional Time Flow where the Present, in one sense, is the only Reality that we experience consciously. Our past memories and future goals and projections, although they may appear to be important, but from an existential perspective of our present living existence, they do not exist except in our own mind or unless we choose to make them important to us. The Flow of Time is an existential reality and a mystery; much of it remains, and will perhaps remain, Unknown and Unknowable to the Human Mind.

"Adaptation" involves that we, all of us, as living human beings, try to make the best to our present-life conditions reducing any personal and social distress, irrespective of our past histories. Our focus on our past is useful to our understanding of our personal and social history, and has guided us in the present living, and has provided us with future directions. It has been the foundation of our various knowledge systems and it is the engine that drives the advancement of our civilizations. But at the

and collective faiths based practices often are used in dealing with the issue of "entropy," Some may have a naturalist belief consistent with science-based current knowledge personal level, for a variety of reasons, when people

develop persistent mental health problems over course of their life, any incessant focus on our past relating to these specific behavior patterns can have iatrogenic consequences. In trying to repeatedly understand one's past over many years, in order to establish a linear causality by our own self-reflection or in the process of mental health service delivery, year after year, as it does happen for many, may in fact reinforce the habit of being "prisoners of the past." There may be less acknowledgement that awareness of the Present, freeing oneself from Past, can also promote "new self-identities" with time flow, in terms of highlighting what a person is doing now in the present time frame and projection about a positive future. This may promote therapeutic goals for recovery and development of positive self-image for many.

In an advanced society like ours, and in many others, our life is usually governed by the pursuit of "secondary needs," where appreciation of various things and activities that we like, arts, recreational activities, watching movies or reading fiction, practicing religious faiths or spiritual beliefs, engaging in physical activities, hobbies, social and family interactions, etc., all of which play

#### Existential perspectives, Positive Redirection, and other Personal Reflections in working with people exhibiting "Persistent Psychosis"

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important roles in our daily lives. The basic survival needs (e.g., food and shelter) for most of us are assured through our monetary compensation for our work or through social entitlement programs. Much of what we like is also influenced by our emotional attachments, our learned associations from our past history, and our imaginations and personal beliefs, where logical analysis and understanding may not necessarily contribute as to why one particular activity is more appealing to one of us and not to others. Diversity of our likes for different activities is reflected in our consumer-oriented society, where much emphasis is put on marketing various specific products to individuals and to specific consumer groups. Likes and dislikes are subjective values and may not be evaluated by an objective criterion with a specific common outcome, and often such subjective values may dictate what may appear to benefit us and what does not. This may also hold true in mental health service delivery, thus making use of a uniform outcome criteria difficult to establish or to put a value judgement as to what outcome is qualitatively better than others, questioning the validity of use of a widely accepted so called "evidence based practice criteria."

Awareness of consequences to one's behaviors affirming our sense of personal freedom and choice, are also the cherished set of values in Western societies, complementing our democratic ideals, and they have also been the guiding principle in various psychotherapy and counseling models in mental health services. While this approach is effective with many people exhibiting transient or everyday mental health issues for which people may seek professional counseling or psychiatric services, its application to people struggling with longterm and persistent experience of mental health issues who continue to experience "distress experience" including presenting "at risk status," with regard to one self or to others, such as "persistent psychosis" - may be limited. Many such "persistent behaviors" involving mental health service needs may also be influenced by underlying emotional cues of learned associations, and associated personal beliefs, and as such, may exhibit characteristics of "entrenched habits," which are obviously difficult to displace or dislodge by the current traditional intervention techniques, as the evidence of their persistency indicates. Increasing awareness of consequences or insight or understanding of one's dynamics of origin or providing knowledge may not

always translate as behavior change agents for many such people.

In our everyday life, we all manage occurrence of distressing feeling and thoughts by a combination of various strategies. When we are unhappy or upset, we may say or do things that we may not ordinarily approve of doing, or we are negatively affected by others when they do engage in such behaviors. But with our subsiding emotions, those behaviors and thinking patterns often change. We may also practice some activities that help us to reduce our stress-agitation experience, or do things that we like to divert ourselves from feeling "negatively" by engaging in activities of our daily life that we like, or thinking about our future goals and aspirations. These activities allow us to displace the experience of our negative thoughts and feelings, and thus help us to move on without eliminating those "negatively valued behavior" from our behavior repertoire, however much we may wish them to disappear. They may crop up again and again, but we "manage" to live with them, so to speak, minimizing their interference or our daily life, although many may use such negative experiences for creative productivity in life.

Often, the risk management consideration drives overutilization of mental health services, including "overmedication" or psycho-social interventions, including the need for people being placed in "supervised living situations." Very little is known as to what specific behaviors are associated with "at-risk status," as it can be associated with varied behavior features in society, with people exhibiting "normal" and "typical," as well "abnormal" and "atypical" behaviors. But historically, due to focus on social conformity in various cultures, "atypical behavior features" of persistent mental health problems, such as psychosis, inappropriately have been associated with "at-risk status" without evidence-based criteria in all conditions.

This opinion piece highlights need for integration of the normalization principle of use of positive redirection, increased acceptance of diversity of human behaviors, including "atypical behavior syndromes" that do not necessarily involve "risk management considerations," and use of existential perspective that highlights the present living experience and positive aspirations for the future (with identified goals and steps to reach goals), leaving the past, associated with painful memories behind, in working with people with persistent mental health issues such as "psychosis."

## MADSense Article 3: What makes it impossible to ignore voices?

#### By Gregory Shankland

In the previous MADSense article, we learned that many of the "symptoms" of the hearing voices experience are the result of the how the phenomenology and what voices say provoke our thinking – leading to unusual thoughts and explanations, some of which become problematic "beliefs" – both delusional and limiting.

Our brain (body) REACTS, our MIND seeks out a response. Everything flows from the phenomenology – the mere presence of voices leads to an involuntary reaction/response, not derived from our real-world environment. Each reaction/response is an exchange of information and emotions that moves the relationship between hearer and voices along – with both transactional and story components.

There is no reason why we should treat inputs from voices any differently than inputs from any human. If my voices were people, I would ignore them. Voices will not let me. Instead, I have to acknowledge their presence and find a way to "deal with" them, all day, every day. Knowing why it is impossible to ignore them is useful in guarding against the effects, including many that go unnoticed, such as limiting beliefs.

In my case, voices are indescribably malign, cruel and deceitful, and I reject what they say, out of hand. Their presence is offensive. Total rejection is the only way to be true to who I am. It's the only way to know that my emotional response is genuine, or "true." Acceptance of voices compromises the principles I live by and that respect others. The idea of integrating or "living with" them is anathema to me – there is no way to find meaning in or integrate a constant stream of threats, cruelty and distraction – it is vile and unthinkable. I find the notion that I *should* insulting, quite frankly.

Rejecting them is the only option that gives me choice – it allows me to own my response, even when the reaction that voices provoke often makes it difficult to do so.

In spite of choosing to reject voices because it is the right thing to do, why can't I "just ignore them" as I would like to do, and as many suggest? It is the phenomenology, as much as what voices say!

#### I have reached the most instructive simplification of this complex topic by asking myself the question: "What is it about the phenomenology that makes it impossible to ignore?"

When we focus on what voices say, we invoke our executive functions, and are naturally led to finding

meaning, since that is what we expect of our experiences. Our aware or exec mind has expectations which we seek to satisfy, deliberately, in our *response*, or find explanations when we cannot.

Our brain develops predictive programs from patterns in our inputs, which are presented to our aware mind for attention when necessary, usually when the prediction does not "match" or satisfy an expectation – this is our *reaction*. We are less aware of this process, since it only presents in the aware mind by exception.

We need to consider both to understand how the phenomenology AND content steal mindshare, to make better-informed choices in how we respond. To this end, I summarize phenomenological characteristics in four themes:

- Presence
- Intrusiveness
- Variety
- Content

#### Presence

A constant, or at least expected, stream of inputs creates a sense of presence. This is more than an ordinary environmental input; by being unusual and constantly presenting in the aware mind, it asserts a level of significance at least equivalent to a relationship – another entity that moves my story along without my consent.

In my case, my voices are speaking most of the time, and when they are not, I have a buzzing sound like tinnitus. I usually become unaware of them when I am actively engaged or engrossed in conversation – only to be actively reminded of their presence the moment there is a gap in conversation. Voices are the first thing I become aware of in every situation, with every change of context, at the beginning of every day, and often by intrusion in my sleep and/or dreams. This is my "aware" perception of their presence – the knowledge that voices are there, will be there tomorrow, and demand attention one way or another.

My automated perception of them is that my brain has created a "space" for them in my mind – a frame of reference that has established relational parameters with every other frame of reference in my life. Trained by the constant stream of assertions of influence and significance, my programmed processes of finding a satisfying response now always include a check on this unusual frame of reference, for both consequences and support – neither of which are real.

## MADSense Article 3: What makes it impossible to ignore voices?

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The effect is that voices have asserted significance of their inputs regardless of their true value – they have achieved a ranking that I actively verify or reject. Each time I notice the presence of voices, my brain asks a question: "is there anything I need to do, or what does this mean?" It is a prompt that leads my brain to question.

#### Intrusiveness

Voices are able to adjust aspects of the phenomenology in ways that increase the power of their ability to provoke a strong reaction. The more powerful the reaction, the more difficult it is to control my response. This is achieved through a combination of features – tempo, emotive qualities, and a sense of closeness or proximity that creates a sense of intrusion, of *forcing* a response.

I describe three modes that relate to the governance of the process of finding emotional equilibrium – the shift from reaction to response, which can be gradual or sudden depending on which emotional systems are engaged. They are:

- I can hear voices speaking to me, yet I can avoid reacting to them – I do, however, have to expend effort to ignore them. I experience this most often when I am trying to concentrate on something, such as writing this article.
- I can hear voices and my brain reacts, calling up associations in my mind that trigger a train of thought. My drive system is engaged and I can interrupt the provoked train of thought and replace with something else. Even though I have control of the flow, voices have chosen a topic of thought for me which I can at best redirect or cut short. Probably 80% of my interactions are in this mode I have trained myself to interrupt and replace automatically, to ensure that the transaction, if not the story, produces a pleasant emotion.
- I hear voices and the reaction is so strong that I am unable to control the train of thought until the reactive emotion subsides. This happens when voices provoke me on a topic to which I have developed sensitivities or when my threat system is engaged. Voices have managed to engage my threat system all too frequently – something that almost never happened before I heard voices.

The experiential effect is a demonstration of voice intent – their ability to use phenomenology to spring surprises and impose consequences – a style of interaction that is or turns malign at any time.

#### Variety

Many studies of phenomenology speak to the variety of phenotypes observed – from thought intrusion to sounds to music to voices to somatic intrusions and visions. The variety extends way beyond those commonly described, and includes other "senses" such as pressure and temperature and a wide variety of what I call "special effects," from spatial qualities to clarity and orchestrated dramatic scenes.

I have had many, many hours of lying patiently in bed, hoping to go to sleep while my voices have put on displays of their phenomenology – bragging about it and trying their best to get me to comment on their theatrics. The phenomenology is delivered as a story designed to foster particular kinds of unusual belief or explanation. My voices have created visions of my parents, used to manipulate beliefs about or in the hereafter. They have been mischievous faeries, aliens, god, the devil and an evil god, each backed up with "special effects" of phenomenology designed to make their claims more believable.

The effect is to get and sustain one's attention. Without the constant "newness" or change of features, our natural ability to adapt, acclimatize and learn to respond in healthier ways, at the very least by trial and error, would render voices irrelevant in time.

#### Content

By content we usually refer to what voices say – and this is important because this is what we are led to focus on – and our natural response is to integrate what voices say into our story. I have over 40,000 hours of voices commenting on everything that I do and think – it is a huge distraction away from my own story.

Content attracts focus – it becomes a key component of the information we have to work with. However, it is of unverifiable and doubtful provenance, and since we cannot apply the usual standards of evidence checking, we end up working in a never-ending field of truth and doubt, in which unusual and limiting beliefs flourish.

Content gains significance by assertion, insertion, insinuation, implication, tone, and a host of other cues that are akin to "body language." Content is the sum of the features of the phenomenology and not simply what voices say.

Content moves our story along; each transaction is either pleasant, or not. We expect stories to have twists and turns. We expect characters to behave in particular ways, until they don't. This is why you find many hearers who talk about "loving" or "helpful" voices that change, or

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turn on them. These are examples of how voices encourage and discourage our processing of the information confusing our hierarchy of significance of information.

Voices change their spots all the time, and the transactional experience is no way to evaluate anything. It is only when we take the time to evaluate their impact on our life story that we may see the consequences.

Our default setting is to accept and "work with" the inputs we experience, because we choose the contexts we participate in. Voices are not inputs we choose, and extra vigilance is required to limit the damage they cause by asserting significance and demanding attention.

The fact that voices are difficult to ignore, does not mean that we must pay attention to them.

Greg Shankland is a voice hearer and business strategist. He is the founder of MADSense, bringing unique insights to the understanding of intrusive phenomena for those who experience unusual states, family/friends and



the professionals who support them, including researchers and academics.

Services include MADConsulting, research, seminars, talks and training workshops.

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## **The Dangers of Anti-Psychiatry**

#### By Andrew Field

I was listening to classical music while driving home from class, when I suddenly became convinced, as the music built to a poignant crescendo, and I was parking the car, that we were spirits, that the spirits of the dead still lived, that there were good and bad spirits. I was flooded with this intuition, as if drinking some intoxicating liquid. The song ended. In the silence that followed, I realized with dawning astonishment that the whole universe entailed a cosmic warfare of good versus bad spirits, like comets smashing into each other continuously, drawing color and sparks. Ideas started to connect; previous conversations began to cohere, become lucid and comprehensible, like ghosts made flesh; past actions suddenly loomed up with headshaking clarity and understandableness; and it all made sense, like a shining matrix of ideas that had taken me years to process, and which was now cascading upwards into a climactic waterfall realization about the spirit world, and about the nature of the universe. It was clear to me that I was a good spirit, that God wanted me on *His side to combat evil – all the fanged darknesses* around that you could only detect with your spiritual eye. It was like that part at the end of the Beatles "A Day in the Life", that resounding crashing finality of the piano chord. DA-DUM! I was suddenly a cosmic warrior, entrusted by God with the secret of the universe.

This experience happened to me in 2012, when I was enrolled in a master's program in English. I had gone off my medication, thinking that I didn't need it anymore it was in actuality working for me, and so it gave me the illusory idea that I was okay without it. But as time passed and I stayed off the medication, my thoughts and

feelings began to turn in bizarre directions. I had had a very prolonged psychotic episode in 2008, which led to two hospitalizations, and during that time period I had become obsessed with a book called A Course in *Miracles*. I would read the book hungrily, practicing the thought exercises in the back of the book; and over time I began to think that I was Jesus Christ and had the power to change the consciousness of other people if I operated from the stance of the Holy Spirit. Now, in 2012, off medication, I began to become obsessed with the book again and bought another copy. Because I was off medication, the distance between myself and my psychosis began to erode, and I forgot all the agony, terror and isolation of my earlier psychotic episode.

As I grew sicker, I began to become more belligerent to my classmates. After a few weeks of this, I was told to get a psychiatric evaluation before I could return to school. Because I was very sick by then, and unable to recognize that I was sick, I refused to get the evaluation and ultimately moved back home with my parents. By then, without realizing it, I had caused hurtful rifts between myself and my classmates and teachers, as well as between myself and my then girlfriend, who I believed did not understand my creativity and was only out to get me. Living with my parents was a nightmare, though probably more nightmarish for them than for me. I would shout at them, had no insight that I was behaving aggressively towards them, and had the delusion that they were emotionally abusive, though they were not. My illness had completely gotten in the way of my life: I was no longer in school, I wasn't working, and I was in the grip of a very intense psychosis. I was no longer

#### The Dangers of Anti-Psychiatry

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functioning as a sane person. I had incredibly grandiose ideas about writing a book about poetry that would change the academic landscape, and drove every day to Ann Arbor where I would work on the book at a library. I had constant and intense psychotic experiences when I drove to Ann Arbor, and would drive recklessly and dangerously, sometimes tailing people because I thought we had a secret connection. I was putting my own life, and the lives of other people, at risk. And when I finally realized that I was sick and needed to get back on medication, I crashed and fell into a very dark depression that was full of very intense shame. *All of these incredibly painful and disrupting incidents happened because of my decision to get off medication. They would not have happened had I stayed on the meds.* 

I am writing this piece because I've noticed in ISPS-US that there is a very large trend towards vilifying medication and romanticizing psychosis. We constantly hear that psychiatrists are in cahoots with big pharma, that medication ruins lives, that the experience of psychosis is spiritual, that there are psychological reasons that explain psychosis outside of the medical model. But all of these explanations do not fit the contours of my life or the content of my lived experience. I see a psychiatrist who is also a therapist, and I trust her expertise and help. She works hard to help me, and I find it paranoid and irresponsible, not to mention ungrateful, to think that she is a shill for the pharmaceutical companies. Medication has not ruined but saved my life. While my psychosis made me think that my experiences were spiritual, in reality they were delusions that kept me isolated and in states of abject terror. And while my family wasn't perfect, they have always been supportive.

I joined ISPS-US because I fell in love with the book Making Sense of Madness – especially its emphasis on the lived experience of madness. I remain committed to reading about and understanding the phenomenology of madness, because this makes me feel less alone with my own madness experiences, and therefore I hope it makes other people feel less alone as well. But this constant emphasis on the evils of medication is dangerous. It could lead others to forego medication and have the kinds of extremely distressing, alienating, and painful experiences that I had when I went off medication. I do not wish this for anyone. It is one thing to provide a forum for people to talk about these experiences something which is sorely needed. It is another to hear advice from professionals that could lead to more of these experiences. That is why I find the vilification of medication to be extremely irresponsible, and that's why I decided to write this piece.

## **Coffee & Psychosis: Podcast Review**



By Marie C. Hansen

My newest Internet discovery is a podcast from the UK called <u>Coffee & Psychosis</u>. The podcast was created by a young man with his own lived experience of psychosis and is described on the website as: "a collection of human stories around the subject

of madness. What society neatly calls 'mental health.' Should you lend your feet, the path is lit with curiosity for what lies behind the doors labelled: Schizophrenia, Psychosis, Bipolar, Depression, Anxiety – and so forth. This is an attempt to unearth a deeper humanity behind the sometimes-saccharine view of "unwell-being." The story behind the script. The death of metaphor. This has nothing to do with coffee."

Currently there are three episodes of the podcast, and it seems like it will have weekly installments (at least I hope

so!). The first two episodes follow the journey of Luke Sandifer, a college student who began to hear the voice of God after a time of intense stress. Sandifer and host look at his experience in a way that is at once humorous, informative, and completely genuine. The third podcast explores one woman's journey through an intensive supernatural or mystical experience. All three podcasts explore the topic of psychosis in rich and dynamic ways, bringing into the conversation opinions about how treatment can be improved, the meaning behind "symptoms," and tips for recovery. The host does an excellent job in allowing his guests to speak from their own perspectives while simultaneously drawing from his own experience.

Alltogether, the podcast is not unlike a really great episode of <u>The Mighty Boosh</u>, (well, if The Mighty Boosh developed a penchant for talking about mental health in really amazing and unique ways). I highly recommended *Coffee* & *Psychosis* for anyone who has recently experienced firstepisode psychosis, as well as clinicians working with young people. Funny, cool and insightful, *Coffee* & *Psychosis* is a new and refreshing voice in youth mental health.



## Join us at the ISPS-US 16th Annual Meeting *Psychosis in Context: Exploring Intersections in Diverse Identities and Extreme States* November 17-19, 2017

University Place Hotel, Portland, Oregon Cosponsored by the EASA Center for Excellence at PSU Hosted by the ISPS-US Pacific Northwest Branch

## www.isps-us.org

Register by September 17 to receive early rates!

The Institute for the Advancement of Human Behavior (IAHB) is pleased to offer continuing education credit hours to counselors, psychologists, social workers, nurses, physicians, educators and certain other healthcare professionals for the ISPS-US 16th Annual Meeting. Please see <u>www.isps-us.org</u> for complete details.

## Keynote Speaker: Gogo Ekhaya Esima

Sick or Gifted? Bridging the Connection Between Mental Health Issues and Spirituality

## Honoree: Narsimha R. Pinninti, MD

Trauma, Psychosis and TIMBER Model to Treat Traumatic Psychosis

## ABOUT THE MEETING

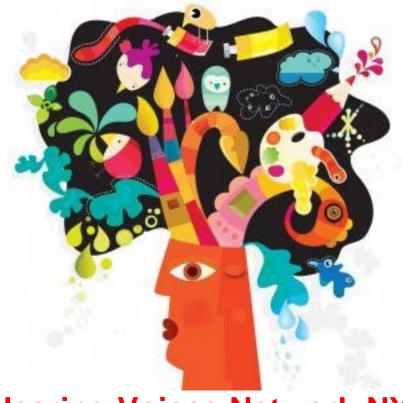
Extreme mental states and psychotic experiences occur within a context that includes a person's unique family story, ethnicity, religion, race, socioeconomic status, gender and sexual identity, trauma experiences, and more. The attempt to isolate these states and experiences from the soil in which they grow often results in diagnosing people instead of understanding them. Yet individuals' reactions and adaptation to the nexus of social constructs, cultural beliefs, and personal and collective histories that form the backdrops of their lives are sources of their strengths and their suffering alike. How can those who are struggling come more fully to appreciate the complexities of who they are, why they hurt, and what the possibilities might be for transformation? And how can helpers better understand the intersection of these layers of relevant factors so that assistance can be provided that truly fits the person?

ISPS has focused on psychological and social approaches to psychosis, madness, and extreme states of mind for over 50 years. The ISPS-US 16th Annual Meeting will feature a diversity of perspectives on psychotherapies, research on recovery, and theoretical developments. The points of view of experts by experience and family members will be highlighted. A main focus will be intersectionality or the interconnected nature of social identities as they relate to systems of discrimination and oppression. We hope to see you in beautiful Portland, Oregon!

This program will interest psychologists, psychiatrists, social workers, counselors, therapists, nurses, and other mental health professionals, students, academics and attorneys, as well as members of the lay public, including peer specialists, people with lived experience of psychosis/extreme states, and their families, who are interested in learning about the experience and treatment of psychosis and extreme states.



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## Hearing Voices Network-NYC Creative Arts Group

We are starting a free creative arts group for individuals who hear voices, see visions, and have other experiences often referred to as "psychosis."

The group will incorporate drama, movement, art and music as ways to externalize and concretize phenomena often difficult to put into words.

Meetings will be held weekly: Tuesdays at 4:30pm East Village Access (EVA) 242 East 2nd Street, between Ave B & Ave C

For more information, please contact Tami at tgatta@communityaccess.org

ISPS-US has signed the <u>Open Letter</u> endorsing the <u>Report of the United Nations Special</u> <u>Rapporteur</u> on the right of everyone to the enjoyment of the highest attainable standard of physical and mental health. The Open Letter is sponsored by Mental Health Europe and The British Psychological Society.

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