



I am Turning into a Barnacle

By Michael Eigen

M.E: So there is transformation, at least change going on.
D.N: You must be kidding. You can't mean it.
M.E: You detect a note of irony?
D.N: I fear sincerity. Sincerity is a cage.
M.E: So you live in water without being caught?
D.N: I am made of shells within shells.
M.E: Yet...
D.N: Yet my sensors are growing inside you. I am inside you.
M.E: Absorbing nourishment with your sensors?
D.N: Quietly. You can't feel me, see me, hear me.
M.E: But we are talking...
D.N: I mean my sensors inside you, quietly feeding ...
M.E: Do I mind?
D.N: You will vanish without knowing. Only a shell will be left.
M.E: Did someone feed on you? Eat your insides?
D.N: But my sensors are still here. I still have my sensors.
M.E: You are eating my insides. Am I eating yours?
D.N. You backed me against a wall.
M.E: I don't think I meant to take away your room. I'm sorry if I did.
D.N: You reach me when you say things like that. No one talks to me that way.
M.E: And how do *you* talk to you?
D.N: I feel you know there is a monster that turns me into a shell.
M.E: Thank God for sensors. How is it possible they survive?
D.N: That's a mystery. Shells with sensors, sensors with shells.
M.E: We are very sensitive. We are almost pure sensitivity.
D.N: Even with shells.
M.E: Sometimes shells make us more sensitive.
D.N: I'm afraid we are running out of time and I haven't told you how awful it is to be eaten by a monster inside the sensors.
M.E: Everything is in jeopardy.
D.N. Yes, everything.
M.E: I feel like making a psalm for the living sensors, even with monsters within.

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President's Column

By Jessica Arenella



ISPS-US has formed several new committees in order to grow the organization. The Diversity Committee has begun exploring strategies to provide a welcoming space for people of all ethnicities, races, genders, sexual orientations, and abilities.

We also have an Awards Committee to recognize current members for their contributions and achievements. If you are interested in joining either of these committees – or the Education, Family, Student/Early Career Professional, Lived Experience committees – please e-mail Karen Stern at contact@isps-us.org.

We had a tremendous conference in Portland, Oregon where I was excited to see so many new faces! It was our most successful annual conference held on the west coast to date, and I want to thank Dr. Khaki Marino and her planning committee for doing such an outstanding job.

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I am Turning into a Barnacle

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D.N: Have you felt worms inside your head?
 M.E: Bad thoughts?
 D.N: No, more. Worms.
 M.E.: Like in a corpse?
 D.N.: You're getting closer.
 M.E: Closer to what it feels like being you?
 D.N: Yes.
 M.E: All the time?
 D.N. Almost all the time. Once I would have said yes, all the time. But it is not all the time now.
 M.E: Thank God.
 D.N. Not sure who to thank or how – moments of life.
 M.E: With all the monsters, shells, and eating oneself alive.
 D.N: With all the worms eating my insides.
 M.E: And mine. I am thankful for some better moments wherever they come from.
 D.N: I am thankful too, even if they come and go. Something comes up. I want to say thank you.
 M.E: Thank you too. It sometimes is good to be together.
 D.N: It can be.

* * *

Michael Eigen, Author, "The Psychotic Core, Contact with the Depths, Flames from the Unconscious: Trauma, Madness and Faith"

Letter from the Editor

By Marie Brown



Welcome to the Winter/Spring 2018 issue of the ISPS-US newsletter! This issue features very interesting articles by our members at ISPS-US: Michael Eigen offers us a fragment of a psychotherapy session in "I Am Turning into a Barnacle"; Kevin Healey discusses how movies can help change conversations around what is commonly called "mental illness"; Isabelle Butcher offers us a review of a first-person account of psychosis and recovery titled "The Girl in the Mirror"; Gregory Shankland continues his next installment of understanding the phenomenology of voice-hearing; Mohiuddin Ahmed offers his thoughts on using movement in psychotherapy; and Satu Beverly writes about Open Dialogue from the viewpoint of "The Girl in the Mirror." Finally, Diane Inda talks about assumptions in mental health treatment. And, as always, our newsletter opens with a word from our President, Dr. Jessica Arenella.

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Blog: isps-us.org/blog/

President's Column

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Re-uniting each fall to see ISPS-US members in person is a celebration in itself, like a family gathering of sorts. Upon reflection, it can be summarized kind of like a wedding. We had:

Something Old – Our eldest member, centenarian Joseph Abrahams, was also not only in attendance, but presented as well.

Something New – Record number of new attendees at an ISPS-US meeting! Through our partnership with EASA, many members of early intervention programs in psychosis from across the country learned of ISPS-US.

Something borrowed – Our keynote speaker, Gogo Ekhaya Esima, and our Honoree, Narsimha Pinnitti, shared their wisdom of their cultural heritages. Ms. Esima shared her journey from suicidal psychiatric patient to Sangoma healer. Dr. Narsimha Pinnitti applied the Buddha's five factors of the mind and yogic practice to decrease the suffering from psychosis while acknowledging its origins in human experience.

Something blue—We honored three of our members who died prematurely. There were memorial posters for Matthew Stevenson, who was very active on our listserv and in the recovery movement, and also for Paul Peacock, who created our Debategraph map and was instrumental in bringing this forum to our organization. A memorial scholarship was created in honor of Rodney Waldron, a peer specialist of color who presented at ISPS-US.

The scholarship will be used for conference fees and toward travel and accommodation costs for two people of color to attend Annual Meetings of ISPS-US. If you would like to donate, use this <http://www.isps-us.org/donate.php> online form and indicate the purpose of the donation when prompted.

The Call for Proposals has gone out for the Philadelphia meeting, so please send in your presentation ideas in order to present. You will not be disappointed by our Keynote Speaker – Berta Britz – who is a powerful orator with a message you will want to remember. I am excited to meet our Honoree, Krista MacKinnon, who has done a lot of excellent work educating families about how they can better support their loved one who is struggling with extreme or unusual experiences. So, register early and bring a friend, colleague, or family member with you. I look forward to seeing you in the fall.

Peace,

Jessica Arenella, PhD

Three Movies, One Dialogue

By Kevin Healey

Maybe we can we eradicate “mental illness” with tweets?

In Canada each year, Jan 31st becomes “Bell Let’s Talk Day” when people load the northern Twitter-verse: each use of the hashtag #bellletstalk on Canadian networks raises 10c and \$2m annually in a community fund for grassroots initiatives. Of course, it also generates – for Bell – huge brand awareness and good will, plastering the country with their logo; and it smokescreens a series of lawsuits, Bell workers’ complaints of how they are treated, leading them to struggle in ways they become diagnosed with “mental illness” and which the company would rather we didn’t talk about very much at all.

The annual Tweetfest is bittersweet for many, since it mostly amplifies the usual single-story “mental illness” messaging without acknowledgement of the accompanying dangers inherent in any such powerful single story. So, we get the hyped-up celebrity-driven empathy blitz about the brokenness of those who struggle, the celebration of how we are still only ten years away from major scientific breakthrough that will save us all, the invocations to end stigma without once addressing the acts of stigmatisation that generate the stigma; and we get mass encouragement to join in the moralistic coercion of those of us who struggle to step out from the shadows, get diagnosed, and take our magic pills.

If only all we needed were more of the same then, in Canada at least, we’d have tweeted “mental illness” to extinction a few times over every Jan 31st.

Indeed, many of us wish we could have one day a year when we *don’t* talk about “mental illness,” or at least one day in which we can talk about it differently – and how about #letslisten?

“What we call ‘mental illness’ is one of the most talked about, complex, and least understood challenges facing our culture.”

Starting a different kind of conversation

So how do we find ways to start different kind of conversation?

Well, movies can be a great way to start conversations, and showing a movie for free is a way to bring people together. When a movie addresses what we call “mental illness” from very different perspectives than we are typically treated to then we get to start very different conversations.

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Three Movies, One Dialogue

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ISPS-US recently invested in screening rights for member groups and branches to show three such movies. Each movie by itself is excellent, takes a different perspective – or perspectives – and each is very good for starting very different kinds of conversations about the kind of struggle we call “mental illness” and especially the kind of experiences that get called “psychosis.”

Community collaborations and blurring boundaries

The Toronto branch of ISPS-US is working with **Grad Minds**, the mental health committee of University of Toronto’s Graduate Students Union, to offer a series of movie screenings using these rights and also using access to the excellent screening room of U of T’s Robarts Library.

The aim is simple, to offer access to movies that folks might not otherwise be able to see, to start a dialogue, and to blur the boundaries between campus life and community life. This series is only one step we are taking together, we began with speaking invitation at Grad Minds’ annual Mind Matters 2018 conference and also work together to offer workshops on campus open both to the community and with subsidised placed for grad students.

We started in January with PJ Moynihan’s *HEALING VOICES* and continued in March with Phil Borges’ *CRAZYWISE* and again in April with the made-in-Toronto-by-Jonathan-Balasz *THEY HEARD VOICES*.

The Girl in the Mirror by Lumi Winterson

Book Review by [Isabelle Butcher](#)

Isabelle Butcher is a PhD student at the University of Manchester examining the relationship between life experiences, attachment style and symptoms of schizophrenia in particular social withdrawal, emotional withdrawal and lack of motivation. Isabelle’s PhD is funded by the Medical Research Council. Prior to conducting her PhD Isabelle conducted her undergraduate and master studies at Cardiff University, UK and Leiden University, the Netherlands before working in an inpatient hospital in south Wales, U.K. Isabelle is part of the Manchester branch of the 70/30 campaign which aims to reduce child maltreatment in the UK by at least 70% by 2030. <http://www.70-30.org.uk/isabelle-butcher-ambassador-manchester/>

This book tells the story of Lumi Winterson, who was born and grew up in Australia, through her own eyes.

Lumi’s life experiences have shaped who she is today. Lumi during her early life experienced psychological and sexual abuse. Examples of chapter titles include ‘puberty blues’; ‘they all fall down’ and ‘lunacy.’ Lumi’s life also included various admissions to hospitals, and each time she was admitted to hospital her experience of being in a hospital differed; with some staff being more caring than others. Lumi towards the end of the book describes her Dad, and the relationship they had in addition to his own personality. The author states that he may have had Schizophrenia or Schizotypal Personality Disorder. The chapter ‘Daddy dearest’ explores both positive and negative thoughts about her Dad and Lumi clearly reflects on him. Lumi summarizes what a diagnosis of schizophrenia means and the different symptoms both ‘positive’ (hallucinations, delusions) and ‘negative’ (lack of motivation, lack of enjoyment in things that used to bring pleasure). Lumi describes how she experiences these things. Throughout the book there are several poems which serve to illustrate Lumi’s feelings. The poems help Lumi’s story flow and illustrate Lumi’s creativity. Lumi highlights the impact of her friends and family in her journey in life to date; through her relationships with her parents we see the role that they play in her journey and the impact that her friends have had on her. In Lumi’s own words there are friends whom she has come to know and who have played an integral role in her recovery. It is lovely to hear and gain insight into Lumi’s feelings throughout her life and towards the end of the book Lumi refers to feeling happy and full of hope.

Within the book Lumi makes reference to the type of medical support she received, including pharmacological and psychological interventions; Electro- Convulsive therapy, Dialectical Behavior Therapy, and the drugs clozapine, Abilify and Effexor. Lumi particularly reflects on the importance and usefulness of DBT and credits this in addition to support from professionals as being instrumental in her recovery. Lumi does not state that one treatment is better than another; she does highlight that medications only make up part of the treatment. It is however eye opening and sad to read of Lumi’s experiences in some of the hospitals where staff seemingly did not cope well with individuals experiencing psychosis.

The book is also illustrated with pictures that have been drawn by Lumi and highlight her journey.

This book is a must read for anyone; particularly anyone whom has an interest in psychosis. Despite Lumi’s horrific experiences this is a story of beauty from ashes and recognises that recovery is a process but there is light at the end of tunnel. It is a huge privilege to be able to have had insight into Lumi’s mind and life to date.

MADSense Article 4: The evolution of a MAD quest to Make A Difference – a MAD experience.



By Greg Shankland, with respect for the experience of others.

Madness is a scary, confusing and complicated experience that significantly compromises the quality of life.

Early on, I observed the behavior of voices, took them at face

value and found a way to respond directly more or less as I would to other everyday stimuli. The difference was I could not walk away from, nor physically remove them – they were bullying and cruel, so that was the obvious (but unavailable) choice. Instead, I had to rely on reducing their significance, interference and impact in my life. The basic technique I applied is derived from my practice of neuro linguistic programming (NLP), which was to interrupt the flow of information and emotion that they provoked and replace it with something of my own choosing. I took charge of my response as best I could.

This gave me space to be more objective and in time it became clear to me that a few concepts, if available as psycho-educational material, would have helped me anticipate and mitigate many problems. If someone had been able to coach me through it, to offer practical support that made sense instead of psychoanalyzing me, the journey through madness would have been simpler and less traumatic.

Prevention of psychosis is possible.

So, having made some progress, I set out to create something along these lines. Having a sense of what was needed was one thing. Finding good answers and presenting them usefully and credibly was a much bigger job than I realized. Voices got in the way, deliberately and creatively.

The journey became a quest to make a difference in the hearing voices field.

- ***“You are the perfect man for the job!” voices declared. What exactly that meant was made a little mysterious – and later, threatening, as voices embroiled me in a battle between good and evil, invoking themes of religion and conspiracy to prevent me from getting the job done.***

And so it has been a slow journey. Understanding took time, with voices gleefully inserting confusion through deceit and manipulation, keeping me stuck in the detail. Gaining the clarity and language to describe it to others

took even longer, with voices adding layer upon layer of complexity and interference. Moreover, voices were downright cruel and proud of it and tried to bludgeon me into submission to scare me off. It isn't easy to be rational and clear when emotions run high.

As you can see, the voices I hear set out to make it impossible to understand them. To make help seeking difficult. To make attempts to describe or expose them hard to believe, or accept as true. To make it difficult to respond. They threatened me for every action that I took to explain their behavior. They constantly worked to create a trap for the mind from which escape seemed impossible. They declared war. Then declared my progress, every small achievement, a threat to them and therefore to me.

- ***“You must know evil greggieboy!” voices threatened – and delivered by imposing phenomenology as torture, by distorting my perception and by encouraging and leading me towards believing in a frightening view of the world we live in.***

This is what makes madness a scary, confusing and complicated experience.

Fear and paranoia are the primary cause for the need for care and support – instead of helping people feel safe and secure, we are declaring **them** to be dangerous and forcing care upon them, aggravating the problem. It is voices that are proactively and creatively cruel and I am encouraged to see avatar studies aimed at helping people face bullying voices, an idea that I myself apply:

[http://www.thelancet.com/journals/lanpsy/article/PIIS2215-0366\(17\)30427-3/fulltext](http://www.thelancet.com/journals/lanpsy/article/PIIS2215-0366(17)30427-3/fulltext))

Getting help is equally scary, confusing and complicated.

Confusing and complicated because there are no clear answers – only an array of beliefs fiercely protected by different stakeholders. Scary – because none of what was on offer accounts for or comes close to matching the experience – “help” more often looks like another burden than it does a solution.

I had a great life before I suddenly heard voices. When people probe my past psychological or psychosocial causes, I am pushed to defend my childhood, my mental strength, when I know they are not the problem. Moreover, it ignores the fact that hearing voices is by far the most traumatic thing I have experienced, worse than I could have imagined possible. Hearing voices IS the trauma.

MADSense Article 4

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The idea that a chemical imbalance is the cause, now thoroughly discredited, does not begin to describe the cruelty of voices, how they deploy phenomenology as torture and to make threats. The idea that voices might represent parts of my personality that need to be integrated, is insulting. What is there to integrate? I reject evil and bullying out of hand, why should I compromise the principles I live by to respond to voices any differently, to accommodate or appease them?

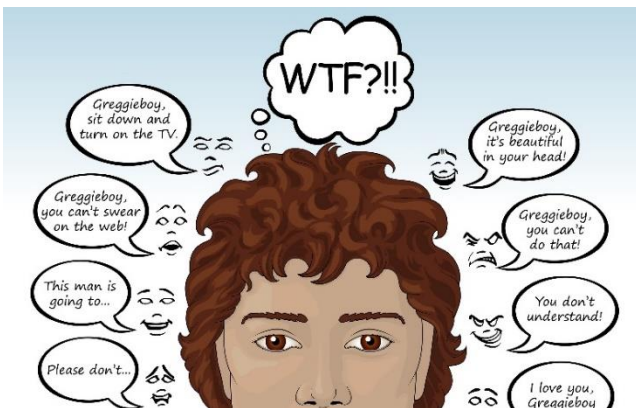
This complete mismatch between the ideas on offer and the phenomenon and the experience of it makes help seeking very difficult. As long as we continue to ignore this, the models of understanding and care will not match the experience of it nor will they address the root cause – and people will be reticent to come forward and non compliant.

A wicked problem needs creative thinking unfettered by established beliefs.

Ed de Bono is renowned for his teaching of creative thinking by a method he calls Provocation, in which people are encouraged to adopt an outlandish statement about a topic as true, to force a paradigm shift in thinking. The crazy (and now funny) thing is that when you look at the ‘voices’ phenomenon as a malign entity that has bl@@ped with our minds for millennia, provocative as that seems, it simplifies the understanding of it. So many more things make sense because it matches what we are able to observe in our interaction with the phenomenon – and what we can do to counteract the effects on our ability to lead lives of our own choosing is radically simplified.

This is the approach I adopted. Aided and distracted by voices Provoking my mind, to solve *everything* they threw at me, lol. The process, made into a quest by how voices engaged me in distractions, was revealing. In particular, it showed that...

Everything flows from the phenomenology.



When you understand the phenomenology and how it provokes (stimulates) our predictive mind processing, the emotional and interpretive outcomes we observe can be understood in terms of natural, functional mind processes, working as they should.

It is the stimuli that are weird and a form of self-directed mind stimulation therapy is at the core of solutions – the psychologists theoretical form of what I practice as NLP.

Fast forward almost ten years and MAD-Sense is finally on YouTube answering some of the “What the bl@@p?” questions that madness provokes.

I say ‘finally’ because it is a major milestone in a journey into and out of madness, during which I lost and regained my sense of humor and zest for life more than a few times. And I say ‘finally’ because my emotional systems are rebalanced and my sense of humor is readily accessible even for touchy topics that I can now address with a sometimes-irreverent tone – including cruel voices, religion, conspiracy, politics and sex! All topics that voices forced on me as a distraction from and dramatization of my quest, lol.

In my style, I adopt a technical approach and dispense with some political correctness because I think directness is required if we are to understand this phenomenon properly. I am sure you will understand.

- **“You are the cutest man,” my voices say, encouraging me to say what I think. Or making me their enemy by virtue of likeability. They like to keep all nuances of interpretation open.**

What is on the channel? (MAD-Sense Teaser | <https://youtu.be/hQhZbrPepgw>)

MAD-Sense shines a light on the phenomenon and experience of voices by stripping away our beliefs and interpretations to look at how brain:mind processes respond to weird stimuli. This **process view** allows us to account for the variety of experiences, beliefs and interpretations that we observe.

The idea is to help us make better informed choices based on new insights. To help us prevent psychosis rather than analyze it. To help us live a good life of our own choosing.

Although the videos on the YouTube channel are organized differently (for a future book), understanding these four themes from psycho-educational material would have helped me to relate to my experience, to anticipate the emotional journey, to get the help needed and to gain the inspiration and confidence to learn to navigate my way through madness and live a life of my own choosing.

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MADSense Article 4

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1. A **structure** for having a pragmatic and constructive conversation about the experience.
 - I struggled to describe what was happening to me, for myself and others. When people ask “What is it like?”, we end up describing voices – when, in fact, the experience is our reaction and response to the phenomenon, our interpretation of it, which unfortunately invites psychoanalysis given our “mentally ill” paradigm. The experience evolves as we adapt and voices engage with us in new ways. Since we have no common understanding, explanations, hypotheses and experiences are described in terms of personal beliefs – a level at which we are unlikely to agree. I had no way to suggest what others could do to help and it was too easy for the beliefs of others to dominate.

▪ **“You can’t understand”, my voices mocked.**

Eventually, I developed a model I call “My Story” – a variation on Maslow’s hierarchy of needs. It is a ‘life coaching’ style framework that uses simple life themes against which we can map our phenomenology, beliefs and relationship with voices to show their impact in our lives. It helps us put our relationship with voices into perspective and offers an interpretive anchor from which we can describe variations in experience using common language. The same framework is used to craft the story we want – to set objectives and evaluate progress.

2. A description of the **phenomenology** of “hearing voices”. There are so many special effects that the term “hearing voices” is totally inadequate.
 - The special effects amount to a form of body language which sets the scene and signals the intent of voices in ways that shape our beliefs about what voices are and their influence in our lives. The phenomenology is not static – voices deploy it creatively. If only I’d had some idea of what to expect, it would not have been so scary. The professionals mostly dismiss this with a few cursory questions – even though this is the *one thing* that had changed in my life. I was suddenly receiving weird stimuli that were inexplicably attacking me – inconceivable to others, as it would have been to me without the experience of it.

▪ **“It’s unbelievable, no-one will understand”, my voices mocked.**

I experienced a wide range of phenomenology from which I developed detailed descriptions of the weird ‘special effects’ showing how they train the brain to be hypervigilant and provoke the mind in particular ways. The stimuli exaggerate our emotions in a display of theater – soap/cosmic opera.

(Watch this video which maps the phenomenological complexity in my first eight weeks of hearing voices. Notice how the information voices presented led to specific delusions, to predictable paranoia and panic and trapped me in a catch 22 story – presenting a fake problem (if only I knew) with no accessible solution: <https://youtu.be/7s--ldk-5bw>)

3. Suggestions, or better still, **instructions for how to respond to voices** in the moment.
 - It was pretty obvious that it was the reaction/response that voices provoked in me – my attempts to explain, my assessments of the implications of their threats and assertions – that produced “extreme states”. *Thinking* itself became scary, a tough concept to grasp that is the crux of the experience. Regardless of my beliefs or interpretations, voices found ways to make the interactive experience of and with them miserable. It is transactional, with predictable interpretive outcomes. Not knowing how to respond created a sense of dread because I had no way to anticipate, to be ahead of the game.
- **“You can’t fight us greggieboy, you can’t escape,” my voices mocked.**

I needed to own each transaction. I needed to own the relationship with voices and the relationship with self that they distorted. Interpretation was simply a by-product of the transactions, that I could interrupt and dismiss, to avoid delusions and limiting beliefs forming.

This simple technique developed into a suite of six mind strategies applied preventatively and in the moment. The NLP is designed in and manages voices while developing healthy thinking habits that mindfully engage our reward progression to form positive beliefs and experiences and a balanced view of the world we live in.

(Watch this video, which talks to diagnostic, recovery and mind strategies: <https://youtu.be/GHXbduh9RRQ>)

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MADSense Article 4

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4. A **prognosis**. Not of my condition, but of **how the experience of voices might develop**.
 - The total lack of any insight into the journey of voices living in my head caused major problems. I refuse to use the term “accept and live with”, lol, since they are not invited. Voices proactively engage us in stories that have a particular structure to them – which gives them power. It’s tough when you realize that you are stuck with it. I came close to suicide. We look ahead – much drama and despair could have been prevented if I had been coached through critical points of the journey with some useful insights.
 - **“We have front row seats in your life, greggieboy, we’re not going anywhere”, my voices threaten.**

I have learned to shape my journey. I “acknowledge and deal with”, to minimize harm and get on with my life – and anyone can. Knowing that people do recover creates hope. Knowing the emotional trajectory gives me strength. Knowing how to navigate through it brings a sense of agency and progress. That’s what we need.

(Watch this excerpt which highlights turning points in the emotional journey through madness, which we can anticipate to avoid the worst of the lows:

<https://youtu.be/qKTvxyGXWNk>)

What next?



The quest will continue. This first iteration of videos can be simplified – and will be, hopefully in conjunction with service delivery and research partners. There is a book to be written, an app in early development. And many more videos to come. I hope you find it useful.

Me, looking fierce! Be well, Greg aka greggieboy.



MAD-Sense

MAD-Sense offers insights and training for mental health professionals grounded in a deep understanding of the well mind and MAD phenomenology and experiences.

I am a business strategist and consultant – here to help mental health professionals and researchers improve the services they offer.

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Rationale for the Use of Movement Experience as adjunct to Psychotherapy and Counseling in Working with Clients Across Life Spans

By Mohiuddin Ahmed, PhD

As living beings, we are always experiencing some level of movement, and navigating our body movements in our physical and social space. Awareness of movement of one’s own body and in other living and non-living beings in our social and physical surroundings is taken for granted by most of us. It affirms our own and others continued conscious living experience at various stages of our life. For most people, the use of varied movement activities involving doing daily chores and work, and other physical activities including playing sports, or engaging in routine physical exercises that many people do, are often performed without any affirmation of one’s awareness of conscious living existence, as movement awareness of being alive is implied and is taken for granted without needing any conscious reflection on our part.

Typically, engagement in varied physical and play activities are a part of our childhood growing up process as preparatory training of skills for adulthood. It is universally so, to a varying degree, across various species. Such play activities in childhood promote adaptive skills acquirement involving paying attention to one’s current activity and to one’s physical and social surroundings, and having the experiences of concentrating on a task, goal attainments, trial and error learning and from successes and failures, and handling frustrations, anger, and joy that are associated with play. More importantly, it helps in identifying one’s own “self-boundaries” and respecting “others’ boundaries” as one navigates in social and physical environments. All of these are important skills to be acquired for social and physical adaptations as one grows older into adulthood and in later life.

In our adulthood, physical exercises are often promoted in various communication media to enhance our personal and mental health. Such exercises promote mindfulness, increased focus on the “Here-and-Now Reality” in the Unidirectional Time Flow of the Present Moment our Existence. It also promotes goal attainment experience as when completing a particular set of exercise, and in the practice in the use of positive redirection strategy to ward off our “negative feelings and thoughts” – all of which facilitate our optimal adaptation to our present life circumstances.

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Rationale for the Use of Movement Experience

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In people with history of “mental illness” or with people who are experiencing psychological and behavioral difficulties at various age levels, the importance of promoting movement exercise may have such manifold benefits. Integration of such exercises, at the beginning and at the end of the therapy sessions may make clients more receptive to discussion of therapeutic issues relating to one’s personal problems as well as continued reflection on what was discussed in therapy following the sessions. When presenting rationale for such exercises also have therapeutic benefits on its own in terms of its generalized benefits of the skills training involved to one’s everyday functioning. Its incorporation in one’s day routine may also promote adaptive functioning for clients outside the therapy sessions. For those clients having difficulties in controlling aggression involving “physical and social boundary violations,” this type of exercises may specifically benefit them by learning experientially how best one needs to navigate one’s “boundary” and enhance their respect for boundaries of others as one moves in social and physical space, thus addressing “aggressive acting-outs” involving “boundary violation” issues.

Usually such movement exercises could be brief, less than five minutes or so. The exercise can be akin to Tai Chi movement exercise, with a firm grounding of both feet in slightly bended position as in Skiing, with stretched bended hands moving up and down in a rhythmic manner while accompanying deep breathing exercise of inhaling with closed mouth and exhaling through open mouth. This should be done with a specified counting of 10 or 15 to provide the experiences of goal attainment, anticipatory movement and planning, including a sense of beginning, identifying steps, and attaining goal fulfilment. The variation of this could be having the two hands coming closer in a clapping position but withdrawing the hands before touching. The key to the movement exercise as in Tai Chi, should be in the form of slow but continuous movement of a specific part of the body that is being the focus of exercise, thus promoting maximal attention and concentration on the movement and anticipatory planning. One can improvise infinite variations of this type of brief exercise for people with varied physical abilities, including bedridden or wheelchair-bound clients. In a simulated clapping scenario, the hands should move towards each other without touching while lying in bed, or one may be instructed to watch one’s hand smoothly move up or down. For some, it could be squeezing bed railings or wheelchair handle in a rhythmic fashion for a specified

counting period while accompanied with deep breathing exercise. These exercises are not a substitute for physical therapy or physical exercises to promote recovery of functioning or strengthen body muscles. For practicing self-control strategies for clients with a history of aggressive behavior or other forms of “boundary violations,” one can devise a two-person choreographed movement exercise simulating the experience of coming closer to each other or engaging in a shadow boxing without touching each other. This exercise can specifically be helpful in promoting awareness of ones’ own physical and psychological boundary as well as respect of other boundaries to promote adaptive movement in social and physical space. The therapist needs to role play by demonstrating such exercises and give rational as to how such exercises can be beneficial to client in dealing with one’s psychological and behavior problems, without necessarily engaging in any psychodynamic interpretations of their specific problems, but simply highlighting the universal practice and appeal for such activities to promote adaptive behaviors. One can vary the level of practice and discussion on rationale based on what appears to fit client’s receptivity and needs. The focus is primarily on psychological benefits and existential awareness of living and being alive. Besides, these are basic and very important adaptive functioning skills in any normalized routine of person’s day, but many people with “mental illness” or having persistent psychological and behavior problems for which they may seeking professional help may be lacking in practice in such experiences in their present life due to a variety of reasons.

Over a 40-year period of working in various clinical settings, I have used this type of brief exercises as part of counseling process by having observed that independent of any diagnostic categories or labels, people with “mental illness,” many such people exhibit a variety of deficits in attention, concentration, anticipatory planning, and in identifying steps for a goal attainment or experiencing goal attainments, including being mindful of the present moment of reality in their life. They many may be ruminating about their past or seem to be imprisoned in the past and often may not be aware of the existential time dimension and the reality of perspective of the present that we all have to deal with in human life independent of our varied life circumstances and histories. In some ways all of us, at different times or the day of our life, do engage in such past ruminations, but it is in the loss of ability or in the difficulty in redirecting oneself away from such pre-occupations that may result in the interference in one’s adaptive day routine or contribute to a loss of adaptive skills that characterize, what I believe, people with “mental illness” symptoms.

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Rationale for the Use of Movement Experience

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In my opinion, the traditional psychotherapy and counseling have emphasized heavily on the use of awareness of one's consequence to behaviors, a la operant conditioning model of learning, as the primary behavior change agent. This philosophy fits in with the Western accepted value and practice of emphasizing personal freedom and choice. There has been a less focus in counselling on the underlying emotional associations that often govern much of our daily behaviors, whereby just a mere change of our underlying emotional status, may radically change our thoughts and feelings, without the necessity of applying any reflecting thinking strategy, analogous to counter conditional technique a la classical conditioning. Often this approach has been maligned as social control countering personal choice and freedom. Much of our everyday behaviors are thus governed by associative learning processes involving emotional conditioning or faith-based practice applications where rational discourse and insights may have limited roles. Much of our behaviors are also governed by observational learning that involves social learning principles and our exposures to role playing a la social learning theory. I believe psychotherapy and counseling practice can be greatly enhanced by incorporating actively some of these principles of learning, specifically in working with people with challenging and persistent mental health issues.

Some of the scenarios of movement-based exercises and the rationale for their use have been presented in *Mind Stimulation Therapy: Cognitive Interventions for Persons with Schizophrenia* (Mohiuddin Ahmed and Charles Boisvert, Routledge 2013), and more scenarios and rationale will be presented in our upcoming book, *Visually Enhanced Psychotherapy* (Charles Boisvert and Mohiuddin Ahmed), which is in preparation for publication by Routledge, hopefully to be published in 2018.

Embracing Change – Open Dialogue: The Finnish Approach of Treating Psychosis

The THEMHS Conference 2017

By Satu Beverly

Roots of Open Dialogue

Open Dialogue was initially developed for treating early psychosis. In 1983 Finland was in the grip of huge

financial depression and the mental health budget of Western Lapland was cut by one third of what it used to be. At that time Keroputaa psychiatric hospital was bursting with chronic patients. The incidence of schizophrenia was the highest in Europe reported as high as 27 new cases in a year.

All young clinicians at Keroputaa hospital – psychiatrists, doctors, psychologists and social workers had family therapy as part of their initial professional training. The financial crisis pushed them to become creative in their treatment approach. They decided to lean on their family therapy training and started to embrace the family, patient's social support network as part of the treatment team. They started to avoid the use of antipsychotics and hospitalization in the treatment of early psychosis to bring the costs down.

Through innovative planning, trial and error, continuous monitoring of the outcomes they developed a new approach, now known as Open Dialogue, to treat not just early psychosis but any level of "mental illness". They developed a common-sense approach that suits any conflict situation where multitude of people share a common apprehension of problems, difficulties and challenges. The decrease of schizophrenia has been dramatic from 27 cases to 1-2 per year. As a side effect of embracing patient's family, social support network as part of the treatment team, the stigma decreased, and referral time was shortened from years to a few weeks/months.

I first learned about Open Dialogue on the Internet. To find out more I went to Finland in 2011 to meet Professor Jaakko Seikkula, the leader of Open Dialogue approach. I saw him with my daughter who had struggled with treatment-resistant schizophrenia for well over a decade. Afterwards she told me: "If I had this kind of treatment from the beginning I would not be as sick as I am now." I believed the same.

Then I spent four days at Keroputaa hospital in Lapland as a visiting psychologist from Australia. I participated in treatment meetings at homes, hospital and community. As I speak Finnish, it was easy to have discussions with staff, patients and family members. I had the freedom to move around and talk with everybody at the hospital. I became 100% convinced that this is the treatment we need for "mentally ill" people. I have been an Open Dialogue advocate ever since.

Open Dialogue does not try to depress the symptoms by medication but treats the mind through a psychosocial approach giving the body a chance to heal itself. Medications are not a taboo but are avoided if possible.

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Embracing Change – Open Dialogue

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Schizophrenia develops from early psychosis if not treated well, or not at all

Our mind relates to the environment we live in and especially to people in our lives. Through our own reflections as we see and experience them we learn who we are and form our self- image. When these relations become too stressful or traumatic mind starts to struggle. We need new coping skills but we may be unable to ask for help. Left alone we may develop bad coping habits such as self-harm which help us in the beginning but on the long run are not good for us.

Lumi Winterson, in her book *The Girl in the Mirror*, talks about her need to appear normal throughout her childhood and teenage years, not to be labelled odd or crazy, different from others and be ostracized. Not knowing what is normal and what is not she hid her difficulties well. The warning signs were not detected. She did not get help needed and became “mentally ill.” When she learned in her thirties through Dialectic Behavior Therapy about emotional intelligence and living in the moment she also learned new coping skills. She thinks that these skills should be taught from early childhood onwards at schools, colleges and universities and people would stay healthier.

Ongoing research to Open Dialogue in Finland has shown excellent results compared to biomedical approach. The five -year study on early psychosis in 1992-1997 showed by the end of the study 85% had recovered. About one third were medicated at some stage. About 15% were on antipsychotic medication and/or disability pension. Their unemployment rate was lower than of general population. Stigma /shame of “mental illness” was disappearing and referral time had decreased from 2-3 years to 2 weeks – few months.

Psychosis in “mental illness” originates usually from some trauma for which there are not yet words to describe it. It is like a messenger from the past triggered by something the mind finds too much, too hard to deal with. The sooner the warning sign are detected and recognized for what they are help can be provided. In Open Dialogue, this happens through clinicians engaging the patient and his/her social support network as a vital part of the treatment team. In the treatment meetings every one’s voice is respected and heard.

Open Dialogue engages clinicians, patient and his social support network as partners in the recovery/ treatment process. They work together through the treatment network meetings to identify patients’ concerns, worries and anticipations. In each meeting main and most urgent concerns are identified and explored until the solutions

that meet the patient’s needs are reached. The responsibility for action is shared. The understanding of “mental illness” amongst the consumer and those closest to him /her is increased.

Main Principles

Most referrals come to one phone at the hospital clinic. It is manned by the most experienced clinician on duty and is always answered immediately. The assumption is that people call because they are in crisis. They are listened to and taken seriously. Having the opportunity to speak may be all that is needed, and if not, the first social support network treatment meeting is organized.

The keys to success on Open Dialogue is based on its main principles:

1. Immediate help – The first treatment meeting takes place within 24 hours of the referral;
2. Social network perspective – As appropriate, family /social network is included in every treatment meeting from the beginning though the entire treatment period;
3. Flexibility and mobility – Flexible treatment response is required to meet the varying and unique needs of each consumer /family;
4. Responsibility – Psychiatric units guarantee their responsibility by mobilizing a specific treatment team for each consumer;
5. Psychological continuity – The mental health team takes charge of the entire process for as long as necessary both inpatient and outpatient settings;
6. Tolerance of uncertainty – All members of the treatment team including health professionals must deal with the uncertainty caused by unknown in each network treatment meeting;
7. Dialogism – Open Dialogue is a conversation that values everybody's thoughts, feelings and ideas and encourages everybody to be heard including children of all ages.

Case Study – *The Girl in the Mirror*

Lumi was 19 years old, halfway through her nursing studies, when she tried to take her own life and was diagnosed with early psychosis. She was treated under biomedical model and developed treatment resistant schizophrenia.

She had been sexually abused when 5-6 years old. She did not tell anybody until in her late twenties because she was threatened by her abuser: “If you say anything your house will catch fire and your parents will die”. The abuser, her dad’s best friend lived around the corner and was a frequent visitor at Lumi’s home and his son was her close friend.

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Embracing Change – Open Dialogue

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Stigma and shame were overpowering. She had a huge need to appear normal, not to let others think that she was mad or crazy, different from others, not knowing what she had experienced was normal or not.

Warning signs were there, such as huge separation anxiety and fire from early childhood, increasing self-harming and mood swings from teenage years. However, when she was questioned about them, she always found acceptable explanations. There was also blindness to warning signs, lack of understanding of “mental illness” amongst those close to her including teachers and mental health professionals.

Because warning signs were not recognized, Lumi was not taught good coping skills to deal with her emotions and difficulties dealing with them from early childhood until she learned about Cognitive and Dialectic Behavioral Therapies, Art Therapy and had formed a trusting relationship with her ongoing treatment team. When all combinations of biomedical and electric shock therapies under numerous psychiatrists under the public mental health services had failed and her conditions continued to deteriorate she turned to the private mental health services. In the fourth private hospital, she established a trusting relationship with nursing staff, psychologists, art therapist and her current psychiatrist who recognized that with the biomedical model on its own her life will never get better.

The road to life worth living was opened when Open Dialogue principles, engagement of her social support network as a part of the treatment team, transparent communication and use of psychotherapies in addition to medication were adopted to her treatment.

Essential elements for Lumi’s staying alive have been:

- Love and hope / belief that things will get better;
- Being accepted unconditionally;
- Clinicians working in partnership with each other, her and her social support network as a treatment team;
- Finding a hospital where she feels safe;
- Being able to develop and maintain a trusting relationship with her treatment team;
- Little things matter, eg nurses being kind to her, showing that they care by listening and hearing what she has to say without judging her.

Stop severe “mental illness” from developing

The main points for stopping severe “mental illness” from developing are:

- Ability and opportunity to recognize the early warning signs when all is not right / OK followed by urgent appropriate action;
- Change of focus from diagnosis and medication to client’s real needs, what is happening in his/her life, what difficulties / challenges / apprehensions there are and mobilizing the help needed;
- Focus on each individual client’s needs, interests, what motivates them continuous support and assistance is provided;
- Having a trusted support network consisting of clinicians and the client’s social support network is vital;
- Treatment team meetings take place to discuss client’s difficulties / challenges and to decide what action is required and how the responsibility for actions that need to be taken is shared;
- Antipsychotic medications are generally avoided if possible and especially in the first few days of early psychosis. They are used only after careful consideration if possible in small doses for short periods in conjunction with alternative therapies, to avoid dependency on medication and development of chronic “mental illness.”

Research to open dialogue in Sydney

Sydney University established in collaboration with private benefactors a research chair at Sydney University to find out what elements in the treatment of “mental illness” enhance /produce recovery. Niels Boos accepted the position in the beginning of 2016. He decided to research Open Dialogue, which has produced amazing result in relation to recovery in Finland. Professor Boos had found the case to be the same in Denmark whilst he was researching Open Dialogue there.

By October 2016 the research plan had progressed to the point of having four research centers established, one in private and three in public mental health services in NSW:

1. Uspace at St Vincent’s hospital is experimental where some patients are offered weekly Open Dialogue meetings.
2. ARO – Assertive outreach team in Penrith is building Open Dialogue to their treatment model.

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Embracing Change – Open Dialogue

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3. EPI – Early psychosis intervention team in Penrith is totally embracing Open Dialogue.
4. Access team in Katoomba does Open Dialogue when possible, mainly the philosophy in network meetings. Katoomba is serviced from Penrith.

The fifth research center is in Victoria. EPI – Head space team at Alfred Health where Open Dialogue has been adopted service wide to the previous treatment team model.

Staff training started in these centers in October 2016 and the 3-year Open Dialogue Train the Trainer course at the Centre for Family Based Mental Health Care in November 2016. This course, imported from Finland has just finished in London with good results. The funding from a private source for this 3-year course was assured in the beginning of 2017.

Clinicians in Sydney centers had one-week pre-training instruction by two overseas trainers in January-February 2017. This was followed up by teaching and monthly supervision. Training in Alfred Health has been by professor Niels Boos and Kristof Mikes-Liu. In addition, Sydney University is setting up a new one-year Family Work and Open Dialogue course. The first unit of study is already running. It is hoped to be developed to a graduate certificate course with Kristof Mikes-Liu in charge.

Professor Boos is planning more training of clinicians in public mental health sector as well as a training package for peer support workers. Meanwhile he is exploring the concept of Open Dialogue in peer support and in the Australian system to find out what support is needed to fit Open Dialogue into these systems.

Conclusion

Research programs in Finland and Denmark as well as the 3-year training of staff in London on Open Dialogue are impressive advocates for change from the biomedical model to Open Dialogue and recovery. It also fits well with the requirement of psychosocial support as the key element for the eligibility of NDIS in Australia.

Open Dialogue is a win-win situation for people with “mental illness,” their families and friends, health professionals, the society in general and the government. Western Lapland is used as an example of successful treatment of psychosis and “mental illness” in general. Since Open Dialogue approach was institutionalized there, the incidence of new cases of schizophrenia has declined dramatically.

Open Dialogue increases the awareness of “mental illness” in the wider society through network meetings and hence decreases stigma. It is also effective, cost efficient and humane whilst it improves the quality of life for the consumer, those in his/her social network and mental health clinicians. The Finnish research shows that:

- Not many treatment team meetings are needed on the long run
- Very little drugs are used
- Home is the preferred place of treatment
- The majority of patients are never hospitalized;
- The majority of patents recover;
- The majority of patients become employed and/or go back to further study;
- 15% were on disability allowance after 5 years;
- The level of unemployment of recovered patients in Western Lapland is lower than that of the general population.

Open Dialogue is for people who want to open their minds to new ways of understanding and /or treating “mental illness.” It is time for change and to reform the out of date system used in Australia.

Satu Beverley, Retired Psychologist, Open Dialogue Advocate, Carer

The Assumptions We Make: Ambushed by Stigma

A mini-case study by Diane Inda, PMHNP

I practice in both a clinic and an urgent walk in setting in a state in Western America. I have less time than I would like to see, assess and evaluate my patients and offer them suggestions, resources and prescriptions that I think might be helpful. I struggle with educating my patients, their families and myself. On occasion I am reminded that fighting assumptions and stigma is always a work in process.

No matter how we try to avoid it, every one, human and animal alike; we all make assumptions in some sense (negative or positive) about what is going on. The therapy dog at my work hears me crinkle plastic and then the sound of crunching. He then sidles over to me, leans affectionately and looks up at me with the inevitable luminous “puppy dog eyes” because in his experience, those signs and sounds mean a potential treat. Unfortunately, today he is wrong. I offer him a carrot. He is not impressed.

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The Assumptions We Make

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I set aside my snack to consider the limited information I have on my next client. Paranoia, latency, history of refusing or discontinuing medications, refused to talk about substance use, seems twitchy and fidgety in the waiting room, history of many encounters with law enforcement, including some violence. Before I even walk out to the waiting room, I've already made a few guesses...assumptions. I'm thinking antisocial, I'm thinking meth, I'm wondering about how safe the family of this patient is.

I go out to the waiting room, and the security officer on duty tells me in hushed tones that the patient has "stepped out for a minute" a polite semi-code which means the officer is doubtful that the patient will return. The officer then gestures subtly to a young woman sitting on the edge of her chair, clutching her faux-designer purse in a white knuckled grip that is threatening to dislodge at least one of her artificial nails. Her hair is twisted in what was probably meant to be an artfully and seductively tousled hairdo, but the Hello Kitty butterfly clip looks a little out of place.

"His sister would like to talk to you." Before I can even ask, I'm told that the patient has signed a release of information instructing that she can be told "everything."

Wonderful, I think to myself, this could be someone willing to talk about things that the patient can't or won't mention. I invite her into my office and ask her how I can help, and is there anything she thinks I should know. She settles herself in a chair and looks relieved. "I'm so glad I can talk to you about this."

She tells me that her brother "hasn't ever been right, really" since he was very little, "only got a couple grades of schooling" that sometimes he is scary, that lately he gestures "a lot" and talks to himself "and then laughs, when ain't nobody there". She says that he's "smoking all sorts' o things", that he's been "in trouble with the law too many times" and that she is "kinda worried for my safety."

At this point I've mapped out a tentative picture in my head. I'm expecting a disheveled, malodorous, paranoid, possibly aggressive, likely underweight person. I suspect he's likely to be resistant to any medication I suggest, likely resistant to any suggestion of stop taking drugs...and to be honest, it's a constellation of things I've seen far too many times before. I'm thinking that she might have to get an order for protection. I'm thinking that if he is seriously using too many drugs, that he may try to steal from her or hurt her. Persons

struggling with addiction can do things to their family in the grip of drugs, or as part of the struggle to obtain them that they would never normally consider. Violence. Theft. Assault.

And then the security officer escorts the patient in and all my assumptions are shot to tiny bits. He's fairly well groomed. He's distracted, yes, but not the twitchy paranoia that I see too often in people whose primary difficulties are caused by intoxicants. He agrees he didn't attend very much in the way of schooling, but his diction and his vocabulary wouldn't be out of place in a college student. He reports "seeing things" but his descriptions don't match the usual psychosis I see in people whose instability is secondary to their drug use. They also really don't match the psychosis I usually see in patients with severe "mental illness."

Looking at him, I'm abruptly reminded of a conference I went to many months ago, where a lovely young woman gave a talk about a journey that began with "hearing voices" and ended with her finding that she had inherited, and now needed to be trained in, a gift that some cultures would call "second sight". She went the pills and therapy route, and nothing helped, and things got worse. A lot worse. When she finally sought training, from someone culturally prepared to teach her – she found that her "curse" and "mental illness" was a gift and a blessing, and now she is able to help others with the advice and support that she gets from the spirits she describes as her long-deceased ancestors.

I've had to totally re-evaluate what I think may be happening to this young man. I ask about a family history of "mental illness," and I also ask if anyone had "second sight". At the latter question he looks surprised. Something changes in his body language. She looks disparaging.

We have a long discussion about what he is experiencing, what I can offer as possible helpful options, and possible therapy, resources that I think may prove helpful. I've printed out the current schedule for a nearby holistic center whose "donations-accepted-but-not-required" list of offerings includes spiritual and meditative techniques from healers in various local cultures. I include a discussion about medications and what they might do (or not do) to help and several printouts of referrals. They head out to the lobby again.

Then she comes back in, wanting to get one question urgently asked. "D'you think he might have the Schizophrenia?" She says. "Because I don't wanna live with somebody that has the Schizophrenia. Those people are dangerous."

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The Assumptions We Make

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I tell her honestly that I think that if he chooses to use some of the options that we discussed today, that I think he will be able to do better, and to do more of the things that he wants to do in life. In a way, I am avoiding her

question, but I'm also being as honest as I can. And then over her shoulder, I see that her brother hasn't gone far. He heard her question, and he also heard my answer. He hefts the referrals I gave him, and gives me a subtle nod, a sad smile and a wink.

Rarely am I so very glad to have been so very wrong.



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Berta Britz offers consultation and training through Berta Britz Consulting. Recipient of the 2016 Intervoic Inspiration Award, Berta is on the board of HVN-USA. Her ministry, "Hearing Voices and Healing," is under the care of Central Philadelphia Monthly Meeting. Berta uses the liberation she experienced in the International Hearing Voices community and in Montgomery County Hearing Voices Network Taking Back Our Power Hearing Voices Groups to inform her collaboration for understanding the experience of living and working with anomalous beliefs and voices and growing compassionate communities. Her deepest passion is for creating spaces that welcome young people growing into their fullest selves.

Honoree: Krista MacKinnon

Krista MacKinnon is the Director of Families Healing Together, an online resource for families struggling with emotional distress. After working in the mental health system for fifteen years Krista, who was also a patient herself, understands deeply that families deserve access to a community that supports a recovery mindset. Deeply fascinated by exploring the intersection of wisdom and technology, Krista leverages tools of the internet age to create an online community that both supports and inspires. Krista is a mom of three, a Canadian expatriate to Costa Rica and California, and a lifelong student of yoga and breathwork.

DEADLINE: Submissions Due by May 21, 2018

As we gather together in this historic city of Philadelphia, we are aware that one of the central symbols of what is best in our country is the Liberty Bell, cracked and yet whole, stifled and yet resonant, emblematic of failure and of hope alike. When we look at the available resources for those who are struggling with psychosis and other anomalous experiences, we can both celebrate the supportive network of services, research and relationships that fill the spaces between us and bemoan the cracks in our communities and in our system of care, through which so many still fall.

In this, the ISPS-US 17th Annual Meeting, we welcome presentations that aim to fill the gaps -- to bridge the divide between where we are now and where we need to go, to connect people with optimal services, to bring us closer to one another through empathy and wisdom, and to make the spaces between us more liberating and alive. Join ISPS-US for a weekend of inspiration, support, and possibility as we work to transform the cracks in our communities, our continuum of care, and our understanding into fertile spaces where hope can thrive. Philadelphia, here we come!

We welcome proposals for presentations, papers, panel discussions, and creative or alternative formats focused on psychological and social approaches to psychosis or extreme mental states. We encourage interactive and experiential formats. A variety of perspectives and topics are welcome and we are interested in representing a diversity of voices. All professional disciplines, experts by experience, and family members are encouraged to submit proposals. Please share your knowledge, experience, energy, and hope.

Proposals must be submitted online by May 21, 2018.

See submission requirements at www.isps-us.org.

Registration will open in June. All members will be notified.

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ISPS-US would like to thank the following people for their generous donations (beyond dues) from September 2017 to May 2018:

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Petition to the World Health Organization and American Psychiatric Association to drop the highly stigmatizing, scientifically-challenged term "schizophrenia"

Please Share and Consider Signing the Petition

Supported by the International Society for Psychological and Social Approaches to Psychosis

The term "schizophrenia" has become synonymous with dangerousness even though it is a very small minority of persons with this diagnosis who violently hurt others and this may be explained better by the following factors: male gender, young adulthood, misuse of substances, homelessness, having been exposed to violence, sense of powerlessness, helplessness, stigma, etc. There is research showing social and communication disorganization if a person believes the person she or he is speaking to knows their diagnosis. The term is also associated with non-recoverability. Dangerousness and non-recoverability seem to be hard-wired into the diagnosis. The term encompasses a heterogeneous group of people with different symptoms, etiologies, course and outcomes. It is a static, traumatizing and stigmatizing term for those persons given it. It often takes away hope and a sense of agency because people are told that they have a genetic brain disease. Hope, ongoing social and peer support, and a sense of agency and self-efficacy are needed to facilitate recovery. Nine world outcome studies and the World Health Organization studies on "schizophrenia" demonstrate substantial recoveries. People have a better chance of recovery when given good care that is acceptable to them. Genes, epigenetics, neurobiology, body, mind and environment (including the environment of our ancestors), and the meanings given to our experiences all interact to contribute to a particular syndrome, whether it is "schizophrenia" or major depressive disorder. The brain is a biological organ embedded in and altered by a continuum of causes and effects.

Perhaps, many of the neurobiological findings in "schizophrenia," which are often non-specific and can not be used for diagnosis, could be better explained to be the result of chronic stress, relational and social traumas, social isolation/exclusion, social defeat, economic adversities, low self-esteem/shame, stigma, prenatal stress, migration (particularly from a non-white to a white environment), urban birth/living, low impact SNPs & CNVs (single nucleotide polymorphisms and copy number variants), epigenetic changes to gene expression, the effects of first and second generation antipsychotics (e.g., the Iowa Longitudinal Study), etc. African Americans are about 3-fold more likely than whites to be diagnosed with "schizophrenia." Social adversity can become biologically embedded and result in epigenetic changes to gene expression, which may be potentially transmitted across generations. Japan (integration disorder), Hong Kong and Taiwan (cognitive-perceptual dysregulation/dysfunction) and South Korea (attunement disorder) have dropped the term "schizophrenia" from their psychiatric nosology. Surveys in Japan have shown that service recipients and professionals alike are pleased with the change. Prominent psychiatrists such as Robin Murray in the UK and Jim van Os in The Netherlands have presented strong and convincing arguments as to why this term should be dropped. The editor of the prestigious journal Schizophrenia Bulletin has also recently wondered whether the term should be replaced. I believe the time is now to drop this stigmatizing, hope-disabling, scientifically controversial term which is saturated with various myths about non-recoverability and dangerousness.

Please consider signing my petition to the World Health Organization and American Psychiatric Association to drop the highly stigmatizing, scientifically-challenged term "schizophrenia."

Thank you,

Brian Koehler

<https://www.change.org/p/american-psychiatric-association-apa-drop-the-stigmatizing-term-schizophrenia/nftexp/ex35/v4/644737274>

Spanish translation thanks to Ana Sofia Rodriguez from Mexico:

<https://discapacidades.nexos.com.mx/?p=65>

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