

### ISPS Newsletter - Autumn 2023

#### Dear ISPS colleagues,

Any communications these days must begin with an acknowledgement of the difficult time the world is going through. Wars and atrocities fill our newsfeeds, seemingly worse every day, and that is following on a recent world-wide pandemic, which is not quite over. We members of ISPS are very well aware that today's horrors don't end for the people who experience them, but can live on in their psyches, and in the psyches of generations yet to come. It is chilling to witness this mental health crisis in the making, over and above the daily news of the wars.

I can only wish all our community the grace to survive these terrible times, whether you are experiencing them first hand or at a distance, whether you are in the middle of a conflict or hearing these experiences and fears from your friends, family or clients.



To transition to the more usual topics of the president's letter:

Klaus Lehtinen and his team in Finland are hard at work on the next international conference to be held right outside of Helsinki June 5th-8th, 2024. The call for papers has gone out, see elsewhere in this newsletter for information on submitting your proposal. The Executive Committee is looking forward to seeing you all in the Land of the Midnight Sun next June!

Related to this, the EC will be conducting a fund drive to gather donations so that we may offer partial scholarships to those who would otherwise have difficulty attending. International conferences are of course very expensive to put on, even when held at universities such as Aalto University, rather than upscale hotels. ISPS's super power is that we include the voices of people with lived experience, family members, clinicians, and researchers, all together in our big tent. With that in mind, our fund drive will hopefully make the conference available to more of our members. More on this soon, and please consider donating via the link below, if you are able.

Another initiative of the EC, of which we are feeling especially proud, is the development of new ISPS chapters. Elsewhere in this Newsletter you will see a brief announcement of EC members travel to, and support of, a new ISPS chapter in Armenia. The next newsletter will include a more in depth report on this recent trip. We are also excited about a new chapter in India, initiated by a large and enthusiastic group, including professionals and family members. We hope to include a report from them soon.

Now I am off to the ISPS-US conference, "Humanity in Solidarity: Sharing the Journey Through Psychosis and Extreme States," to be held at the University of Delaware. This will be my first in-person conference in years.

Julie Kipp Chair, ISPS

#### **Donate HERE**

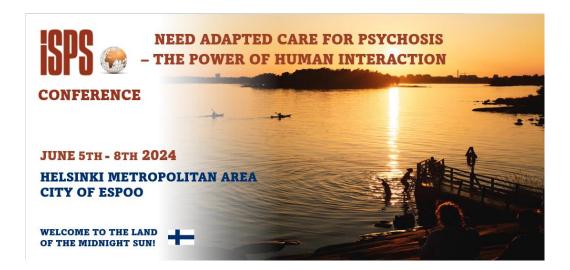
if you wish to contribute to a fund to assist people on low incomes to take part in ISPS Helsinki 2024.

Suggested donation: \$5-50, according to your means.

Please add the note "ISPS 2024" when donating.

The fund is to support the participation of people who would not otherwise be able to do so for financial reasons, in particular people with lived experience, their family members, students, and/or people living in developing countries.

Thank you



## ISPS Helsinki 2024

**Call for Abstracts** by 30th November 2023

Read about our Plenary Speakers <u>HERE</u> #isps2024 #ispsinternational



**News from Regional ISPS Groups** 





Jen Kilyon, Alf Gillham and Ludi Van Bouwel of the EC had the wonderful opportunity to travel to the growing ISPS Armenia local network thanks to the invitation of Elmira Hovhannisyan and Hayk Khachikyan. It was a honour for all of us to represent the EC and a very exciting experience. We are convinced that it will be a start of a rich cooperation and perhaps act as an example for future developments of ISPS.

Armenia's ISPS group had offered to host the next ISPS International conference, which unfortunately had to be postponed because of unrest in that part of Europe and the difficulties members might have had in attending.

The people in the picture (Left to right) are: Alf Gillham, Elmira Hovhannisyan, Jan De Lepeleire, Ludi Van Bouwel, Jen Kilyon, Yeva Adamyan and Hayk Khachikyan.

The small Armenian team that prepared the trip, under the guidance of Elmira Hovhannisyan and Hayk Khachikyan, is strong and inspiring. They have a clear goal in mind and, in doing so, are asking for the support and mandate of ISPS International.

In 4 days, we visited:

- 1) the Department of Psychology of the Russian Armenian (Slavonic) University
- 2) Noubarashen Psychiatric Clinic outside the city of Yerevan
- 3) Avan Psychiatric Clinic in the centre of the city of Yerevan
- 4) the Rehabilitation City of Heroes in the hills at the border of the city of Yerevan.

In each presentation, first Elmira gave some general explanations about ISPS. Jen, Alf and Ludi each spoke of their own personal experiences (of being with psychosis) and what they gained and learnt from being part of ISPS. Each committee member told something about their attraction to ISPS and how this came about.

Elmira and Hayk guided us also to some important cultural places in Armenia. The visit of the Museum of the Memorial of the Genocide of 1915 on the Armenian people made a deep impression for us all and it was very important to understand more about the current history and the conflicts which are still going on between the Armenian people and the surrounding countries (Turkey and Azerbaijan). History is, we know from the current situation in the world, so important to understand.

This trip by EC members of ISPS has taught us about the mental health problems in Armenia due to the country's difficult history, but especially the recent problems with the Nagorno-Karabakh conflict.

The existing initiatives and channels of help for mental health problems in Armenia cover a wide spectrum of initiatives: from elements strongly linked to former Russian politics to small-scale, innovative and refreshing models of care. They coexist.

The support of ISPS International is very important in this transformation process that is underway. It should be explored in what form it can best take. For instance, preparing an ISPS congress in Armenia within a few years, could be considered. We hope that in the future people with lived experience of psychosis and family members can be included in the organisation of mental health and of ISPS Armenia.

For the ISPS EC members who undertook this trip, a deeper knowledge of the geo-political history in that broad region was immensely instructive and relevant. In a world where geopolitical conflicts are developing as never before (Ukraine, Israel-Hamas, Nagorno-Karabakh), resulting in a marked increase in the number of refugees certainly in Europe.

ISPS International can learn a lot from the experiences and expertise around the professional reception of refugees and war victims in Armenia. This country as a 'border area' between many worlds (Europe-Asia, Christianity-Islam, caught between the Ukrainian and Israeli conflict) can be from this perspective, an interesting example for us to learn from.

During the visits during this journey, the local ISPS team was able to physically reach over 140 people to outline and clarify the objectives and framework of ISPS. We would really have liked to meet those with their personal experiences of psychosis and to include family members, but in Armenia this seems very new. A leaflet was created and was presented to all the people who attended our visits and social media is already being used to spread the word. There was quite a lot of interest.

The ISPS team personally felt very safe in Armenia, despite initial concerns. Armenia is a country with a rich culture and a friendly, dynamic and proud population.

We will provide a fuller account of our visit for a later issue of the ISPS Newsletter.

To quote the English poet William Blake:

"the eye altering alters all"

And we hope that for Armenia and ISPS this will be so.

## **Appreciation to the ISPS Executive Committee members from Elmira and Hayk**

The visit of Ludi, Alf and Jen is highly important for the development of the ISPS Armenia regional group. Strategically it will have a significant impact on both the engagement of new members, and promotion of goals and values of ISPS in Armenia. In total, we had 110 participants in the events organised, including: psychiatrists, psychologists, chief nurses, social workers, students, lecturers, leaders of mental health field of Armenia.

After all four events we got mainly positive feedback from hosts. They mentioned about the level of professionalism as well as the interesting and informative speeches of both speakers. The Head of Psychology Department of Russian Armenian (Slavonic) University speaks about readiness for further cooperation in studies and projects. The psychiatrists of Noubarashen expressed an opinion that state regulations are needed for the improvement in the mental health field. Also, the founder of Rehabilitation City of Heroes Suren Areents welcomed the further cooperation, not only in educational programs but in development of the centre as well. Their appreciation was also expressed in the issuing of certificates (seen in the photo).

We, the Armenian team, are proud of having such a great opportunity to introduce our country, history and current challenges, both overall in Armenia and in the mental health professions. During these days we felt your valued friendship, partnership and professional support. We are really grateful for your significant contribution in the enlargement and development of the ISPS Armenia Regional group!

With best regards, Elmira and Hayk

Review of the ISPS Sweden Conference 
"Trauma and Psychosis - shifting perspectives"





ISPS Sweden organized (with support from ISPS Norway and ISPS Denmark) a very successful two-day conference with the theme "Trauma and Psychosis - shifting perspectives" in Malmö 28-29 September 2023. There were 14 high quality speakers, 11 from Sweden, Norway and Denmark, Iceland and three international ones. Brian Martindale from the UK and Michael Garrett and Nancy Mc Williams from USA.

The conference opened with a musical performance where patients from an outpatient clinic of psychosis in Southern Sweden showed their joint work with music and words from the last year. This theme – the importance of non-verbal expressions as an important part of recovering - returned throughout the conference. Other important topics that were thrown light upon during the conference were modern understanding of the phenomenon of psychosis as a response to stress, the fundamental aspect of the importance of a good relationship and early forms of

communication as well as hands-on techniques when working with patients who isolate themselves, as well as psychotherapeutic aspects of psychotic symptoms. Other themes that were embraced were, generational trauma, violence and trauma, integrating CBT and psychodynamic theories and the importance of working with the family system. The finale of the conference was Nancy McWilliams' speech on Trauma and Personality and she "tied the knot" of the conference's theme as she made an acclaimed singing performance at the very end.

The participants (almost 200 people) were very satisfied, and the two days had a friendly and generous atmosphere.

During the conference we also promoted ISPS International's upcoming conference in Helsinki in June 2024 and ISPS Norway's conference in April 2024.

Sverker Belin and Lotten Romanus ISPS Sweden

#### Photos by Jens Roved

Photo 1: Lotten Romanus, Cecilie Brövig, Sverker Belin, Bent Rosenbaum and Tobias Landström

Photo 2: Nancy Mc Williams performing "Crazy" by Patsy Cline

#### **ISPS US Conference**

#### The ISPS-US 2023 Conference is almost here!

As the excitement builds, we want to share some reasons why you should consider attending virtually. Here's what you can look forward to:

 Flexibility to Watch at Your Leisure: All conference sessions will be recorded and quickly accessible on our online <u>platform</u>, allowing you to tailor your experience and watch sessions at your convenience, even after the conference ends.



- Access up to 17 Sessions Per Day:
   Enjoy both morning plenary sessions featuring renowned keynote speakers and engaging panel discussions, along with up to 15 daily breakout sessions that cover a diverse range of topics and perspectives.
- 3. Interactive Engagement with Speakers: Engage directly with session speakers. We have two dedicated virtual breakout rooms and three hybrid rooms with a moderator to ensure virtual attendees are included in discussions.
- 4. Cost-Effective Attendance: Experience the full breadth of the conference at an affordable price point, with virtual attendance starting from just \$25 for a one-day ticket. Join us virtually and access an array of valuable insights and discussions without breaking the bank.

Celebrating our 25th year as an organization and our 22nd conference, we are thrilled to witness the remarkable progress that technology has enabled in bringing together individuals from around the globe. With your attendance, we are excited to foster a truly global conversation on the future of mental health care

We look forward to seeing you online!

#### ISPS Israel News update

The Israeli ISPS group has been busy organizing our international conference, for the first time in the last five years. The title of the conference, that was chosen a few months ago, is **"Psychosis in a Mad World".** We sent out a call for papers and received more than 80 proposals - mostly from Israel but also from international speakers - clinicians, people with lived experience, researchers, family members, and others. We build a very rich and special three day program and were preparing to open registration on October 15th

But sadly reality surpassed any imagination - and Israel is now more than ever a Mad world... We are all facing now much darkness, brutality and pain. But we are trying to deal with it by supporting our suffering friends and clients, in any way we can.

We are hurting for all the victims of violence, for all the people that have witnessed violence, and all of those that are related to them. It seems that the tragedy is reaching every home.

Israeli society, each person in their own way and capacity, are recruited to try and contain these horrific events - to be present, to find meaning in this madness, to hope to minimize the mental injuries that the events will have, without doubt.

It seems that the conference will be delayed because of the ongoing war. But our conference - "Psychosis in a Mad World" - will still be very relevant, now more than ever. We will update our friends and colleagues from the international community when the time comes. We hope that when more peaceful times will come

you will be willing to join us, and will now - whatever the political views are - stand with us in supporting humanity and against violence.

Members of ISPS Israel

#### Freelance Administrator/Organiser Required for ISPS UK

ISPS UK is a charity which promotes psychological and social approaches to psychosis. We are looking for a highly organised and detail-oriented individual, with excellent communication skills, to provide organisational and administrative support from their own home or office base on a freelance contract basis. An interest in and knowledge of mental health are desirable.

In this role you will:

- Maintain our membership database, respond to telephone/email enquiries and manage renewals.
- · Communicate effectively to all our stakeholders.
- Attend and minute meetings of the committee and AGM.
- Manage and record financial transactions and maintain accounts.
- Help maintain our website and social media presence.
- Support planning and delivery of conferences and other events.
- Undertake other administrative tasks as agreed with the Chair of ISPS UK and the committee members.

You will have strong interpersonal and organisational skills, and a high standard of written and verbal communication in English. This is a mostly a work at home role and you will be able to be flexible with your working hours. You will be required to work in the London area for quarterly Board meetings, annual conferences and occasional evening or weekend conferences as and when needed. Travel expenses will be paid for work related activities.

You will be comfortable relating in person or on the phone to mental health professionals, mental health service users and family members. You will have use of your own telephone, computer and printer, and be familiar with Microsoft Office and bookkeeping software such as QuickBooks. You will be willing to sign a consultancy agreement contract. You will have experience of work in a similar capacity.

Pay: £20 per hour

#### How to apply.

Please write a cover letter explaining how you meet the requirements of the job role and person specification along with your CV including 2 referees for a reference. Please download and complete the equality opportunity form and send all the documents to <a href="mailto:admin@ispsuk.org">admin@ispsuk.org</a> by the 27<sup>th</sup> October 2023 deadline.

For further information about the post please contact Catherine Stone at <a href="mailto:admin@ispsuk.org">admin@ispsuk.org</a> For informal discussion please contact our present administrator Catherine Stone or Eamonn Flynn, committee member of ISPS UK, <a href="mailto:yamonn56@gmail.com">yamonn56@gmail.com</a>

Interviews will be held on Wednesday 15<sup>th</sup> November online via Zoom. If you are not invited for an interview please assume your application is not successful this time. This role requires the successful candidate to complete a Disclosure and Barring Check and the receipt of satisfactory references.

#### Other news - from ISPS members

Dear ISPS Colleagues,

Once again I make a plea.

#### Some reasons why we should drop the term "schizophrenia".

Below is a list of outdated terms for diseases and conditions, along with their more current names. Similar to what happened to "mental retardation," and "manic-depression," "schizophrenia" should also be retired to the annals of history. It is a term hopelessly encumbered with too many beliefs/myths which are highly stigmatizing and scientifically inaccurate. It is time for our field to have the courage to move on and stop clinging to familiar but traducing and anachronistic terms.

If you agree, please consider signing my petition to the WHO and APA to replace the term "schizophrenia" as well as sharing it with colleagues, persons with lived experience and their families, and friends. There have been many replacement terms proposed. Japan (the first country to replace the term "schizophrenia"), South Korea and Taiwan long ago dropped and replaced the term. So far, research in Japan demonstrated reduced stigma, greater willingness to engage with treatment/therapies, etc. Change is difficult and there are many complexities involved, but the countries leading the way have shown that it is not only possible, but is beneficial to all involved persons.

#### Do you want to sign the Petition? You can find it HERE

Ablepsy: blindness

Ague: flu-like symptoms likely caused by malaria

Apoplexy: stroke Biliousness: jaundice Black dog: depression

Blood poisoning: sepsis or septicemia

Breakbone: dengue fever Camp fever: typhus

Chalkstones: swelling with pain that probably was caused by rheumatoid arthritis or gout

Consumption: tuberculosis

Dropsy: swelling caused by fluid retention

Dropsy of the brain: encephalitis

Drug Addiction: Substance Use Disorder

Falling sickness: epilepsy French pox: syphilis

Green sickness or green fever: anemia

Grip, gripe or grippe: flu Leprosy: Hansen's disease

Mad cow: Creutzfeldt-Jakob disease

Nervous Breakdown or Neurasthenia: Anxiety or Mood Disorder Palsy: problems with muscle control, such as tremors or paralysis

Manic Depression: Bipolar Disorder

Mentally Retarded: developmentally or cognitively delayed

St Vitus dance: involuntary jerking movements now referred to as chorea. Huntington's disease

is an example

Swine flu: H1N1 virus

Two pernicious myths in particular seem to be hard-wired into the term "schizophrenia": dangerousness and non-recoverability.

First, research has repeatedly demonstrated that most of the violent crime committed in the US is not by persons given a diagnosis of "schizophrenia" -a significant majority of those persons do not commit a violent crime and they may often be victims of violence. The Epidemiological Catchment Area Study (Swanson et al., 1990) found that only 3% of the total violence reported was done by persons given a diagnosis of "schizophrenia." Other studies showed a range from 3-5%. In addition, violence may be explained better by the following factors: male gender, young adulthood, level of education, misuse of substances, homelessness, having been exposed to violence, sense of powerlessness, feelings of learned helplessness, stigma, etc.

Second, on the issue of non-recoverability, traditionally, many clinicians who saw people recover (a multi-dimensional construct to be derived with the significant input of people with lived experience) after being diagnosed with "schizophrenia," based on the never proven concept of Kraepelin's "prognosis confirms diagnosis," would begin to think the person was misdiagnosed. This fatalistic perspective had a corrosive effect on a person's sense of hope for her or his life to get better. Yale Professor Courtenay Harding, in her review of 10 world outcome studies, including the WHO studies, observed that people had a very good chance of significant improvement and recovery, even after being institutionalized for long periods of time (the 'Vermont Study'). Some of the socio-environmental factors that may and do impede recovery include: institutionalization, socialization into the patient role, lack of good therapeutic programs, reduced economic opportunities, social exclusion as opposed to social inclusion (social isolation), traumas, expressed emotion (i.e., hostile criticism), racism, poverty, migration especially from a non-white to a white neighborhood, urban birth/living, side effects of some medications and/or dosages, lack of clinician expectations for recovery and improvement, restricted access to good medical care, stigma, sense of despair, loss of hope and a sense of autonomy and agency.

In a remarkably little discussed paper published in the American Journal of Psychiatry "Identification of Distinct Psychosis Biotypes Using Brain-Based Biomarkers" Brett Clementz and colleagues (2015) noted:

"Multivariate taxometric analyses identified three neurobiologically distinct psychosis biotypes that did not respect clinical diagnosis boundaries" (p. 1). A concept of a single severity continuum using DSM diagnostic criteria did not map onto the distinct biotypes demonstrated in this research. The authors implicitly criticized the use of clinical categorization as opposed to the potential advantages of neurobiological indices.

I propose that we need to go much further in dialogue with all involved persons and refinement of indices, particularly including salient dimensional social and psychological factors already identified in research as relevant to the inception, continuation and outcome of what we still call "psychotic disorders."

Brian Koehler PhD, MS New York University

# DSM 5: ten years later

## International Colloquium

Friday December 15 and Saturday December 16 2023

Salle Quartier Notre Dame des Champs 92bis Boulevard du Montparnasse 75014 Paris (France)

organisation by Patrick Landman (Stop DSM Paris) and Marc Calmeyn (Bruges)
With a little help from renowned speakers, professionals and persons with lived experience and many round tables

#### from the Lowlands

Stijn Vanheule (Ghent University) Damiaan Denys (UMC Amsterdam University) Jim van Ds (UMC Utrecht University)

Myrrhe van Spronsen (MD PhD person with lived experience)
Jean-Louis Feys (head doctor psychiatrist Saint-Bernard Manage)

#### from France

Clarisse Baruch François Gonon
Mireille Battut Nicolas Gougoulis
Ariane Bazan Pascal-Henri Keller
Guy Dana Éric Laurent
Bruno Falissard Bernard Odier
Tristan Garcia Fons Lisa Ouss
Bernard Golse Dominique Tourrès Landman

#### online conference with

Paul Appelbaum (Columbia University NYSPI, chair of the DSM Steering Committee)
Robert Krueger (University of Minnesota USA, Hi-TOP Consortium)
Nev Jones (University of Pittsburgh and person with lived experience)
Roberto Lewis-Fernandez (Columbia University NYSPI)

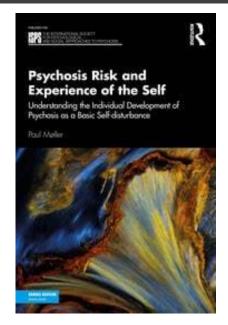
This event wants to break down the barriers between different approaches to mental disorders, and enable people to meet in a setting where the ethics of discussion will be preserved.

online registration is available on infotronique.fr/DSM5

COMETOGETHER, RIGHTNOW-THE BEATLES







# NEW! Recently published in the ISPS Book Series

Psychosis Risk and Experience of the Self: Understanding the Individual Development of Psychosis as a Basic Self-disturbance

#### By Paul Møller

This book sheds light on the inner aspects of psychosis and psychosis risk, and its core experiential phenomena as a method of understanding the individual early psychosis development.

The book details how such experiences might take shape in the human mind and how a better understanding achieved through detailed clinical conversations can lead to earlier detection and

improved interventions. Møller also outlines the subjectivity model (also called Ipseity Disturbance Model) and presents a broad review of different treatment approaches and settings, in which work with disturbed self-experience could be integrated, including psychotherapy, in-patient milieu therapy, supportive treatments, psychoeducational family work, local networking, and medication.

Psychosis Risk and Experience of the Self will prove essential for experienced and specialised clinicians as well as the more generally interested reader.

"This marvellous book shows us that going 'back to basics' (the central role in psychiatry of conversation and close listening) can point the way forward for developing a more satisfactory understanding of psychosis and what to address in treatment. The content and writing style will appeal to a broad audience-clinicians, researchers and interested general readers alike. This book is highly recommended"

Professor Barnaby Nelson, Head Ultra High Risk for Psychosis Program, Orygen, The University of Melbourne, Australia.

"Paul Møller offers here a superb synthesis of clinical acumen with theoretical precision. He lights a path for those seeking both to treat and to understand schizophrenia and related conditions—especially for those who recognize that treatment necessarily relies on understanding. This fine book also serves as a clear and exciting introduction to the phenomenological approach to grasping the lived-world of mental disorders"

Louis Sass, Ph.D. Distinguished Professor of Clinical Psychology, Rutgers University, State University of New Jersey, USA. Author of Madness and Modernism and The Paradoxes of Delusion.

Order your copy here

Find out more about the ISPS Series of books here

#### **Upcoming ISPS Events**

Looking for a webinar or conference to attend this year on psychosis?

Did you know that the ISPS has over 20 regional networks around the globe, many of which organise regular meetings, conferences and webinars?

Take a look at the list of forthcoming regional ISPS events

## Did you know ISPS has a YouTube channel?



Interview with Julie Kipp (ISPS Chair) and Brian Koehler Learn about ISPS in our #ispspioneer series of videos

#### Have you joined ISPS yet?

If not, here are 4 good reasons why you should join us today!

1) Members enjoy reduced delegate fees for ISPS conferences such as for ISPS Helsinki 2024.



- 2) Members enjoy access to the ISPS journal Psychosis and have full online access to all previous issues of the journal also.
- 3) 20% discount on books in the ISPS series published by Routledge.
- 4) By joining ISPS you can **connect with over 1,500 people around the world** who share your interest in psychosocial treatments for psychosis through our email discussion groups and regional meetings.

Join now



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