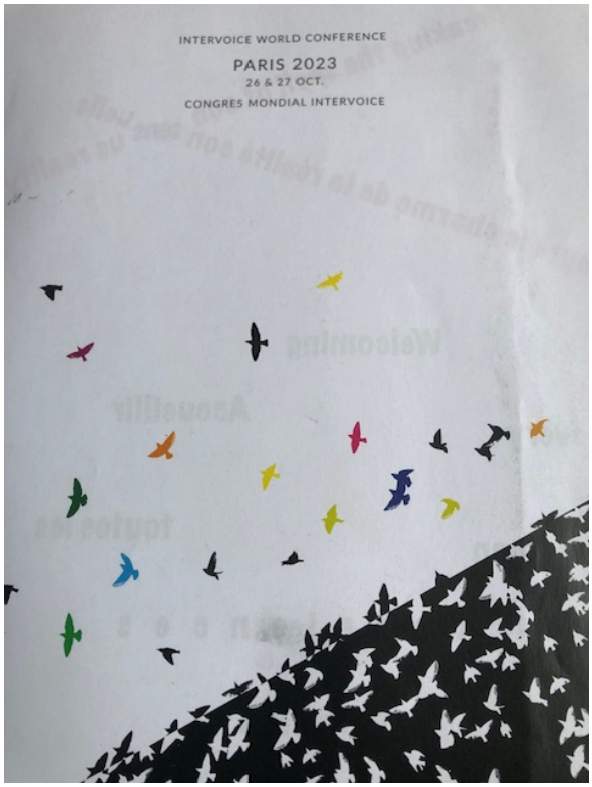
Transition from the clinical to the community context

Voice hearing groups as part of a process of permanent deinstitutionalisation and community development

Reflections on my professional experience on occasion of two recent Hearing Voices events held in Paris and Florence



Pino Pini

Psychiatrist in Italy and the United Kingdom,
Mental Health Europe board member

In my professional experience I have witnessed various significant moments in the mental health sector. Below are some reflections on my relationship with the voice-hearing movement inspired by the work of Marius Romme, and on projects for the development of psychiatric self-help. I was given the opportunity to present a contribution at two hearing-voices events held in Paris and Florence, in October and November 2023, respectively (see *Acronyms, Bibliography and Sitography* section). The time to which I am referring, and which ranges from the period of deinstitutionalisation (1960s-70s) to the current one, is characterised by very different, if not even opposing, positions relating not only to the mental health sector, but also to society in general.

The period of deinstitutionalisation paid particular attention to overcoming the Global Institution (of which the psychiatric hospital was a significant example), believing that it was necessary to operate above all on a collective level to help people develop their individuality (the individual proceeds from the social). The current period instead focuses predominantly on the individual, believing that this can help the community to develop adequately (the social proceeds from the individual). In the field of mental health, these positions translate, in the first case, with the prevalence of relational and social work, and, in the second, with a greater emphasis on the approach to the individual as it is considered a priori in need of specific individual interventions. Therefore, opposite orientations are both useful for the knowledge of human things and for overcoming the various problems that naturally fill our daily lives. For this reason, both excessive polarisations on one or the other side, and flattening on a single side, that cancel out the different ways of thinking and operating must be avoided.

Voice hearers and psychiatry in the last hundred years: different opinions

Eugene Bleuler (early 20th century) states that voices are not a fundamental symptom of schizophrenia, while for Kurt Schneider (mid 20th century) voices are first-rank symptoms of schizophrenia. Marius Romme (80s, 20th century) instead considers voices not as symptoms of a mental illness, but as a physiological way of functioning of the mind in certain circumstances. This last author will contribute significantly to the promotion of close collaborative work between Experts by Experience (*EPE*), Experts by Profession (*EPP*), people who attend and do not attend the services; therefore, a work aimed at breaking down the barrier between "us" and "them". Currently, the *DSM* and *ICD* diagnostic systems consider voices as a typical component of schizophrenia with positive symptoms, linking them again to the idea that they are a manifestation of an underlying illness.

From the closure of psychiatric hospitals to work with communities

The 1970s were a period of deinstitutionalisation with strong international influences such as those of French sector psychiatry and therapeutic communities in the Anglo-Saxon world. Dynamic, systemic psychotherapies and other approaches that enhance both subjectivity and external relationships were spreading. Artistic activities and open informal meetings were multiplying both within the hospital and in local services. Furthermore, the excessive use of therapeutic interventions (both pharmacological and otherwise) and the scarcity of moments of social inclusion, claimed as the right of every human being, were criticised. In this effervescent climate, the closure of psychiatric hospitals in Italy was ordered (Basaglia law 180/1978), but how do we effectuate a transition from the hospital to the territory? What is the relationship between the services and the community? Should the clinical approach extend to the community services, or should it take an innovative approach to build relationships?

Political experience, self-help groups, and mental health associations

In 1980, service users and family members requested that open meeting moments were transferred from a territorial service in Florence to the Casa della Cultura, an association headquarters in the surrounding area, as meeting in a neutral location allows you to develop relationships as equals. Among the various participants were operators, users, family members and citizens, all of whom were interested in a variety of ways. A collaboration was formalised between the mental health service, the neighbourhood council, and the university (Psychology) in order to verify the effects of these meetings in relation to the participants themselves, the service, and the surrounding community. Furthermore, contacts were established with mental health associations and user networks in Northern Europe and North America (*Mind, Mental Health Europe -ex ERC/WFMH-, Mindfreedom,* etc.).

Overcoming the "us and them" relationship seemed feasible in this new context. Individual discomforts were seen as human experiences and not as symptoms of more or less complex diseases. It was about communicating using the language with which people naturally express themselves in their daily context and avoiding inducing them to use technical terms. We wanted to do something beyond the codified therapeutic relationships and therefore it was underlined that in

this context we did not intend to provide therapy, even if we believed that each participant, including operators and people without mental health problems, benefit significantly from attendance at such meetings. As Romme would say, prevention is achieved by listening to the complaints before they develop into symptoms and therefore before being sent to the clinical specialist.

I was elected neighbourhood councillor in the same area of the city where I worked as a psychiatrist, which was quite usual among my colleagues at that time. This experience allowed me to forge further peer relationships within the community as a citizen involved in public affairs. This political position, which I held for ten consecutive years, was an important training on both a professional and human level.

In 1980, the same year in which I decided to dedicate myself entirely to the psychosocial perspective, the *APA* published the third edition of the *DSM* on a global scale, bringing the focus of mental health back to illness. The distance between the biological approach and the psychosocial one would gradually become greater and greater.

Experts by Experience (*EPE*) and Experts by Profession (*EPP*): Towards a new organisation of both services and the community

Between the 80s and 90s, national and international conferences on psychiatric self-help were organised in Prato in collaboration with services, local authorities, universities, *Mind, MHE, IMHN*. We decided to opt for the so-called non-separatist self-help/self-advocacy (*Survivors speak out*) which has a relational and social vision, is critical of the disease model, but also admits professionals with administrative and facilitation functions, provided they behave as equals. However, self-help for diagnosis is excluded as it is not critical to the disease model and is mostly guided by professionals.

I put an end to my political career to dedicate myself more to associations. In the early 1990s the Italian Association for Mental Health (*AISMe*) was established as a full member of the *MHE,* with the aim of facilitating the spread of psychiatric self-help. Other mental health associations and groups oriented towards self-help were formed both in Tuscany and in other parts of Italy.

In these same years, Romme's method (*EPE and EPP*) made its appearance in Italy, strongly supported by mental health associations and user networks (*MHE, ENUSP and AISMe*) as well as by a growing number of operators from different countries, and in 1998 the Voice Hearers Group in Prato was formed. In 2000, an international conference on Recovery was organised in Prato together with the *IMHN*. The concept of Recovery was also introduced in Italy, and was understood as a path of personal re-appropriation, in which the protagonist is the user put in the position to choose both the people with whom to relate and the methods of support.

Shared Experiences and Local Mental Health Systems

In the early 2000s, the Shared Experiences and Local Mental Health Systems (SE*&SLSM*) project was launched in Prato. The aim was to give a more precise location, and some coordination, to the different groups (eventually 30 groups, in the Prato area) formed in the wake of the projects for

psychiatric self-help in neutral environments of the community, and outside the service setting. The idea of an intermediate area between the services and the community was conceived. This intermediate area is able to help different groups to develop sufficient autonomy with respect to the services, local governments, and other organisations. In this way, it is thought to activate a permanent deinstitutionalisation mechanism. Furthermore, Basaglia foresaw that the closure of psychiatric hospitals would only be the first step in deinstitutionalisation. Between 2001 and 2004, the annual international *SE&SLSM* conferences were held in Prato with the involvement of many local, national, and international organisations including *MHE* and *ENUSP*.

Shared Experience: This is a collaborative project on equal terms between the association sector, the services, and local government. Participation through personal involvement is necessary. The project, implemented outside the service headquarters, is democratically co-created and responsibilities are shared. Examples of shared experiences are self-help groups, voice-hearing groups, sports activities, art, education, research, work, community integration, support for independent living, etc. Facilitators are expected to be present at the group, but they do not behave as therapists.

Intermediate Area: This is the tool that guarantees autonomy and development to shared experiences with respect to possible inappropriate interference by services, local government and other organisations. It also helps to balance global and local knowledge.

Local Mental Health System: This is the system that includes all community subjects (including services) involved in mental health issues.

Tetralog

Basic unit of communication that distinguishes the EC&SLSM project.

The following four subjects, when involved in shared activities, communicate with each other through equal relationships and share responsibilities:

1. EPE

2. EPP

3. Family member/Carer

4. Member of local government (civil society)

It is important to underline how local government (civil society) is one of the indispensable key subjects in each shared experience.

Development of groups of voice hearers in Tuscany, from community services

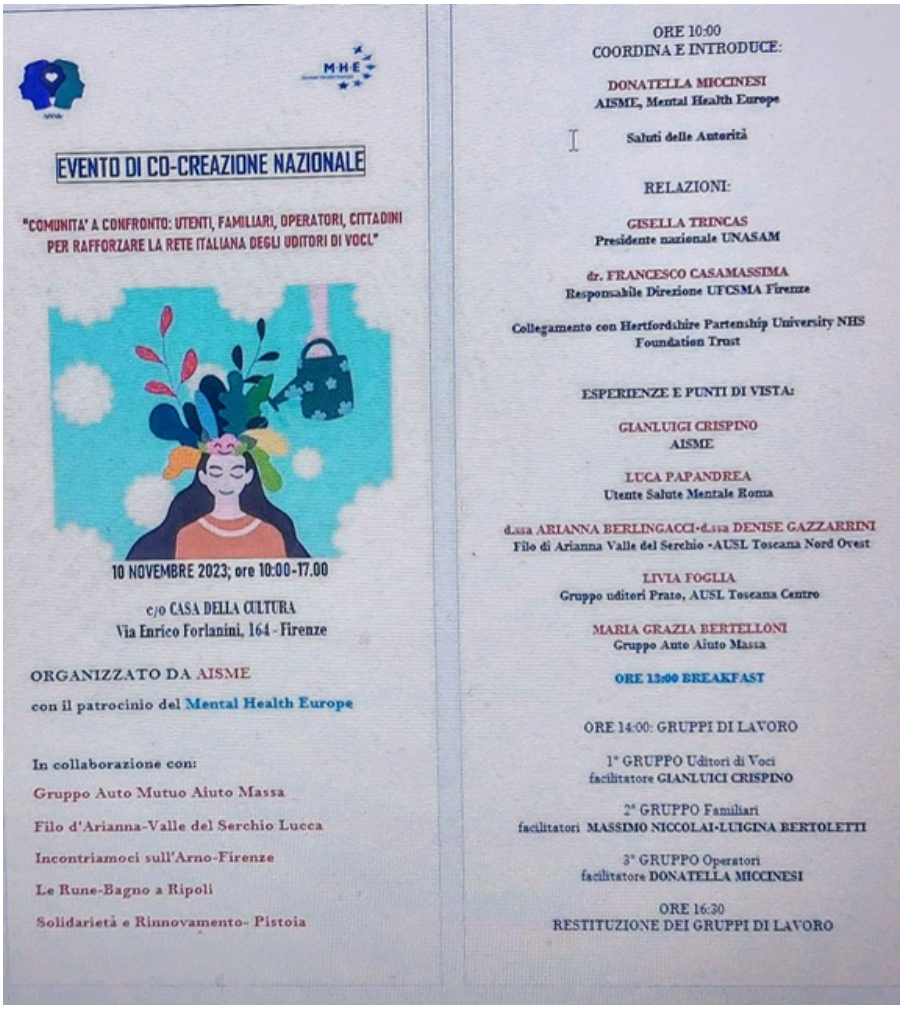
On the occasion of the *WMHD* 1994, Marius Romme was invited to Florence, which led to a close and long-lasting collaboration (translation into Italian of the books “Accepting Voices” and subsequently “Making Sense of Voices”). Several meetings and conferences were organised in Florence, Prato and elsewhere, both in Italy and abroad, which contributed to the establishment of *INTERVOICE*.

In 1998 the Group of Voice Hearers (HV) of Prato was started in the premises of a neighbourhood council. Since 2000, the HV Group has been one of the 30 shared experiences groups that have developed over time in the Prato area and is an integral part of the *SE&SLSM* project.

From 2005 onwards, the *AISMe*, in collaboration with other Tuscan associations, assumed the leadership of the aforementioned project. Many events on the topic of hearing voices are organised, especially in Florence (Casa della Cultura), with the participation of experts such as Marius Romme, Sandra Escher, Ron Coleman, Karen Taylor. The importance of staying outside the service premises, on an equal footing with the service operators, is reiterated, for a different vision of mental health and for the development of appropriate personal recovery paths. We distinguish between personal recovery and clinical recovery as the latter sees services in a prominent position and often with one-way indoctrinating characteristics. Relationships are nurtured between voice hearers who frequent the services and voice hearers who lead a normal life without the support of the services. In this regard, inspiration is taken from Romme's famous Dutch television experience in the early 80s, which started the movement of voice hearers freeing them from the relationship with the services.

Pino Pini and Marius Romme

The Prato hearing voices group, the first of its kind in Italy, inspired the development of other groups of voice hearers in various parts of Italy. A network of Tuscan associations, supported by the Tuscany Region, continues to promote the development of new groups of voice hearers. The aforementioned meeting in Florence bears witness to this, which was organised by *MHE/AISMe* at the Casa della Cultura. Presentations regarding developments in Tuscany will be given at various meetings and annual Intervoice conferences, internationally. I recently participated in those held in Paris and Florence, in October and November 2023.



EVENTO DI CO-CREAZIONE NAZIONALE

"COMUNITA' A CONFRONTO: UTENTI, FAMILIARI, OPERATORI, CITTADINI PER RAFFORZARE LA RETE ITALIANA DEGLI UDITORI DI VOCI"

10 NOVEMBRE 2023; ore 10:00-17.00

c/o CASA DELLA CULTURA
Via Enrico Forlanini, 164 - Firenze

ORGANIZZATO DA AISME

con il patrocinio del Mental Health Europe

In collaborazione con:

Gruppo Auto Mutuo Aiuto Massa

Filo d'Arianna-Valle del Serchio Lucca

Incontriamoci sull'Arno-Firenze

Le Rune-Bagno a Ripoli

Solidarietà e Rinnovamento- Pistoia

ORE 10:00
COORDINA E INTRODUCE:

DONATELLA MICCINESI
AISME, Mental Health Europe

Saluti delle Autorità

RELAZIONI:

GISELLA TRINCAS
Presidente nazionale UNASAM

dr. FRANCESCO CASAMASSIMA
Responsabile Direzione UFCSMA Firenze

Collegamento con Hertfordshire Partenship University NHS Foundation Trust

ESPERIENZE E PUNTI DI VISTA:

GIANLUIGI CRISPINO
AISME

LUCA PAPANDREA
Utente Salute Mentale Roma

d.ssa ARIANNA BERLINGACCI-d.ssa DENISE GAZZARRINI
Filo di Arianna Valle del Serchio -AUSL Toscana Nord Ovest

LIVIA FOGLIA
Gruppo uditori Prato, AUSL Toscana Centro

MARIA GRAZIA BERTELLONI
Gruppo Auto Aiuto Massa

ORE 13:00 BREAKFAST

ORE 14:00: GRUPPI DI LAVORO

1° GRUPPO Uditori di Voci
facilitatore GIANLUICI CRISPINO

2° GRUPPO Familiari
facilitatori MASSIMO NICCOLAI-LUIGINA BERTOLETTI

3° GRUPPO Operatori
facilitatore DONATELLA MICCINESI

ORE 16:30
RESTITUZIONE DEI GRUPPI DI LAVORO

Synergy between the SE&SLSM project and the Hearing Voices group

The *SE&SLSM* project aims to establish a strong bond with the community and a new shared language; this is necessary for a permanent deinstitutionalisation process. The HV Group deals with profound personal experiences that must be considered as human experiences and, as such, the community is called to know and understand them without automatically delegating them to mental health specialists. In this way, the community is enriched with new skills that are useful for the development of more integrated social contexts. Furthermore, permanent deinstitutionalisation and community development emerge as two important, inseparable, moments for the renewal of mental health services and society itself.

From Italy to the United Kingdom

Law 180/1978, still in force, provides clear indications in a psychosocial sense, but Italian services, like most of those in Western countries, are gradually focusing on the disease model. This fact appears linked to a globalisation process driven by political and financial issues. A lot of money comes from the sale of ever new technological remedies (especially drugs), which often have dubious effectiveness. The mass media bombards people by making them believe that science and related technological applications are capable of discovering both new diseases (about 100 in the aftermath of World War II and more than 300 today), and new specific remedies for those suffering from mental health problems. Indeed, local voluntary mental health organisations risk becoming too dependent on powerful organisations such as governmental organisations and the pharmaceutical industry, if they want to survive.

However, will it be so simple to free ourselves from serious suffering through increasingly specific clinical interventions? Among mental health workers themselves, critical voices are raised precisely towards the scientific validity and reliability of psychiatric diagnoses, as well as the related remedies aimed at the individual, not to mention the fact that these remedies can cause unpleasant side effects.

For those who believe in the psychosocial approach it becomes increasingly difficult to continue to operate in such a situation. Hence my decision to retire a little earlier than expected and to understand how things were progressing in the United Kingdom, the country that had particularly inspired the Italian psychiatric reform in the 1970s.

It was known that in the UK (especially in England) mental health services were changing due to neoliberal policies oriented more towards the individual dimension than the collective one. Greater emphasis was given to the disease as an individual fact and to all the negative aspects related to it, including dangerousness. This change inevitably had considerable influence on other countries.

Towards the end of the 90s, some colleagues, with whom I had shared innovative psychosocial projects for a long time, had created the Critical Psychiatry Network (*CPN*) in England. The aim is to curb the excessive use of compulsory hospitalisations, the use of diagnoses and treatments aimed at the individual. It seemed to me that there were spaces, albeit a minority, to further develop projects similar to those I had dedicated myself to in Italy.

My experience in UK public services

For almost ten years I have spent most of my time in the United Kingdom where I have had the opportunity to work in various services, both hospital and community.

In England, mandatory interventions are numerically eight times greater than in Italy (*MHE 2017*). Psychiatric hospitals have been reduced in size and modernised, but they still play a central role compared to the rest of the mental health services, which unfortunately are very fragmented and communicate poorly with each other. The budget for mental health is approximately three times larger than the Italian one.

In recent years, things have regressed significantly compared to the openness towards social issues of previous periods, and there is a lot of dissatisfaction among professionals, users, and carers. The

disease model has absolute prevalence over the psychosocial one. Work in the community means, above all, an extension of the clinical approach (therapeutic, rehabilitative, and psychoeducational) and a control of the administration of drugs. If you are not taking the drugs and are on a CTO regime, you may be subjected to compulsory hospitalisation in a psychiatric hospital with an abbreviated procedure. Safety, understood above all as the social dangerousness of patients, permeates the entire mental health system which is regulated by the Mental Health Act. The psychosocial, relational, and cultural perspective is not widespread enough in the services. I often wondered what I was doing in the UK; perhaps it would have been better to remain in Italy and continue to propose operational models linked to social issues in a legislative context that, at least in theory, allowed them!

What pushed me to continue was, and still is, the close relationship with organisations such as the *CPN, BPS, CARP, MHE* and the group of associations that collaborate with the *AISMe*.

I am increasingly convinced that, to change things even in the mental health sector, we need to deal with the Anglo-Saxon world. This, for better or worse, affects our lives and services at least in the Western world. Together with my psychiatric colleagues at the CPN it is possible for me to argue in a scientifically credible way the criticisms of the disease model, the excessive use of drugs (*BMJ 2023*) and many other individual interventions which seem to be producing more harm than benefit and a sort of new global institutionalisation. The British Psychological Society (*BPS*) has proposed a method of psychological treatment that dispenses with *DSM/ICD* diagnoses, while focusing on power relations between people. Not without some difficulty, the practice of Open Dialogue and therefore a relational approach is spreading thanks to groups such as *CARP*. The groups of voice hearers are quite numerous but relations with the services are sometimes problematic. Colleagues who immigrated to the UK from former colonies warn about the process of psychiatric colonisation that has been underway for some time, fearing the risk of cancelling local knowledge in the name of *Global Mental Health* projects, promoted with the contribution of supporters of the biomedical model and pharmaceutical industry. *MHE* and *AISMe* allow me a strong connection with the associative world which is decidedly psychosocially oriented and independent from the biomedical model.

Below are two experiences I am working on in the London area, where I found some services interested in re-proposing experiences similar to those of Florence and Prato.

The EC&SLSM project in Watford

Hertfordshire Mental Health Trust has been developing the Shared Experiences and Local Mental Health Systems (*SE&LMHS*) project in Watford for five years, along the lines of the Italian SE&SLSM project. The Project is made up of a guiding moment (steering group, held monthly, online), a group for the exchange of personal experiences (the so-called Common Sense Group, held every two weeks, in person at Watford central library) and a reflection group (held every two weeks, online). Participants are *EPE, EPP* and people from the services and the community. Watford Borough Council and local charities such as Mind are directly involved in the project, with support from the Service Users Council, the University of Hertfordshire, and other organisations. The project is progressing successfully, and funding has been granted through special innovation funds.

Proposal for a new voice-hearing group at Enfield Adult South Core Community Mental Health Trust

A Hearing Voices group is being set up at the service headquarters with the aim of transferring it after a few months to a neutral community location, with the involvement of local organisations and in line with the *SE&LMH*S project. The Maastricht Interview (Escher, Hage, Romme) was presented and discussed with various operators and users of the service.

Community organisations interested in establishing the new Hearing Voices group were invited to give their input. *EPE* have been part of the project since the beginning. A temporary steering group has been established to write the project for official approval by managers.

Conclusion

Mental health services should not only follow the clinical approach dominated by the biomedical model and *DSM/ICD* nosographic categories. This approach, useful in specific and limited circumstances, risks instead damaging/colonizing the communities themselves by stripping them of their natural resilience mechanisms, when extended inappropriately and out of context. Services should also be open to the social and cultural perspectives of the communities in which they operate and should play an important role in promoting collaborative activities (such as shared experiences) with all key stakeholders present in those same communities. These activities should not be the simple extension of diagnostic, therapeutic and rehabilitative paths, but something completely different as they are co-created from the beginning with the different subjects of the different communities of which the services themselves are part. For this reason, service operators should spend part of their working time outside the service premises "without scrubs", therefore free from pre-established therapeutic, rehabilitative, or psychoeducational attitudes.

The services should look to the community, and not the hospital, as the main actor in mental health. They should also encourage de-prescribing and de-medicalisation processes, avoiding relapses/ withdrawal syndromes. These paths could be combined with group activities of the *SE&SLSM* type. New relationships between *EPE* and *EBP*, such as those of the *SE&SLSM* project and the movement of voice hearers inspired by Romme, can contribute to breaking the distance between "us and them", and produce permanent deinstitutionalisation, de-colonisation, de-medicalisation, social inclusion, democratic participation, and new community development.

Mental health needs to be free from instances of social control to which many services are inappropriately called upon to respond. National mental health laws in line with the *UNCRPD* should be promoted. A new balance should be developed between new technologies and human relations. The experiences of the *INTERVOICE* movement should be further disseminated, both within services and in society.

Acronyms, Bibliography and Sitography

AISMe Italian Association for Mental Health https://aisme.info/

APA American Psychiatric Association https://www.psychiatry.org/

BMJ, British Medical Journal https://www.bmj.com/content/383/bmj.p2873

BPS British Psychological Society Power Threat Meaning Framework https://www.bps.org.uk/member-networks/division-clinical-psychology/power-threat-meaning-framework

CARP Compassionate and Relational Psychiatry https://mentalhealthtimeforaction.org/campaign-for-compassionate-and-relational-mental-health-services-ccarmhs/

Casa della Cultura RAI 3 documentary, From the hospital to the community. The roots of the EC&SLSM.1984 project http://vimeo.com/user11913937/review/49815715/5d6ae25b69

Decolonization, Suman Fernando www.decolpsych.com

DSM Diagnostic Statistical Manual of the American Psychiatric Association (APA) https://en.wikipedia.org/wiki/Diagnostic_and_Statistical_Manual_of_Mental_Disorders

CPN Critical Psychiatry Network https://www.criticalpsychiatry.co.uk/

https://brokenmedics.com/the-myths-of-the-chemical-imbalance-and-the-chemical-cure-for-psychiatric-disorders/ podcast Joanna Moncrieff and Peter C Gøtzsche. October 5, 2023

CTO Community Treatment Order (mandatory taking of drugs in the community)

ENUSP European Network of Users and Survivors of Psychiatry https://www.edf-feph.org/our-members/european-network-of-ex-users-and-survivors-of-psychiatry-enusp/

EPE Experts by Experience EPP Experts by Profession

http://www.ecologiadellamente.it/articoli.php?archivio=yes&vol_id=2136&id=23144

Florence 2023 event on hearing voices https://drive.google.com/file/d/1BYzxUjTZKzcDA95W1bxRmB2qFFOyHvMw/view?usp=drive_link

*Global Institution https://en.wikipedia.org/wiki/Total_institution_*

Global Knowledge and Local Knowledge, https://philpapers.org/rec/BRAPMH

Global Mental Health https://www.tandfonline.com/doi/full/10.1080/09581596.2016.1161730

ICD International Classification of Diseases (WHO) https://www.who.int/standards/classifications/classification-of-diseases

IMHN see IMHCN https://imhcn.org/

INTERVOICE https://www.intervoiceonline.org/#content

Maastricht Interview https://www.improvingmipractices.org/application/files/9615/6924/4250/Maastricht.Mine.pdf https://www.dirkcorstens.com/maastrichtapproach

MHE Mental Health Europe https://www.mhe-sme.org/ Https://www.mhe-sme.org/mapping-exclusion/

MHE Mental Health Europe https://www.mhe-sme.org/ Https://www.mhe-sme.org/mapping-exclusion/

MIND https://www.mind.org.uk/

Mindfreedom https://en.wikipedia.org/wiki/MindFreedom_International

Pars October 2023, hearing voices congress https://www.paris2023.info/program-programme/

WFMH https://wfmh.global/

SE & LMHS (Shared Experiences and Local Mental Health Systems) project, 2017 - Brussels presentation (https://drive.google.com/file/d/1aRRA7ggjkplm0-K21n_6r8QfUqMpyFV5/view) https://www.criticalpsychiatry.co.uk/news/developments-of-the-shared-experiences-and-local-mental-health-systems-project-prior-to-and-during-the-covid-19 -pandemic/

Survivors Speak Out. http://studymore.org.uk/ssoweb.htm#:~:text=Survivors%20Speak%20Out%20was%20founded,who%20dissent%20from%2C%20society's%20norms.

UNCRPD United Nation Convention for Rights of People with Disability

WFMH World Federation for Mental Health https://wfmh.global/who-we-are/about-us

WMHD World Mental Health Day

For further information on my experience in Italy and the United Kingdom click on following link:

http://www.blog-lavoroesalute.org/lavoro-e-salute-settembre-2023/ (in Italian)