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THE MYTH OF THE SPLITTING OF THE BRAIN OR THE NEED FOR RENAMING SCHIZOPHRENIA

Michael G. Madianos MDMPH DrMed FEPA
President, WAPR

The history of terminology of schizophrenia is dated back in 1818 when the German Physician Johann Christian Heinroth used the term “psychosis” to describe cases with severe psychopathology now called Bipolar disorders (1). The German Emile Kraepelin introduced in 1896 the term “Dementia Praecox” for categories of insanity such as hebephrenia, paranoia and catatonia emphasizing the poor long term prognosis (3).

In 1911 the swiss Eugen Bleuler (2) in his famous book “Dementia Praecox or the Group of Schizophrenias” showed that this syndrome is not always ending with dementia. It then could be called “schizophrenia”. Bleuler introduced this term of Greek origin, following the tradition of descriptive medical terminology. The term is implying that a splitting (schizein) of the brain (phrene) is taking place. Within the next decades, this term has become synonymous to severe psychopathology of chronic course, poor diagnosis and deterioration.

However, recent advances in psychobiology, neuroimaging psychopharmacology and Community Psychiatry, as well as, in the field of Psychosocial Rehabilitation have changed dramatically many of the clinical and psychosocial aspects of the nosological entity called “Schizophrenia” (4). On the other hand, the use of this term has long been linked to labeling, prejudice, discrimination and stigma (5).

In many occasions this term used as a diagnostic answer to the family, is serving as a cruel reality confrontation, causing enormous pain, mystification, fear, pessimism or hopelessness among the family members of the suffering individual along with the phenomenon of subjective and objective family burden (6). Negative attitudes or rejection by the community of the suffering individuals from schizophrenia, are often expressed by the general population (7). It is needless to say that Greek psychiatrists are usually facing strong ethical dilemmas and serious problems by the application of the term “Schizophrenia” when they are dealing with the family’s demand for a diagnosis and for this reason, it is often avoided,



Michael Madianos. President WAPR.

being replaced by the term “psychosis” or “psychotic syndrome”. In Eginition University Hospital of Athens in the sixties and seventies, it was commonly used the term “Bleuler’s syndrome” as “hidden” diagnosis synonymous to Schizophrenia.

In other languages and cultures this term seems to be as “exotic” but with a rather terrifying connotation. Despite all these negative implications no efforts were made in the academic community to replace it until recently. Additionally, in medicine and psychiatry there are examples of renaming of medical terms linked with social stereotypes and burden. The term leprosy was replaced by “Hansen’s disease”, tuberculosis by “Koch’s disease” and the mongoloid idiocy by the “Down’s syndrome”. In psychiatry, dementia, manic-depressive illness and hysteria were named as “Alzheimer’s

disease”, “bipolar” and “dissociative disorders” respectively. In the case of schizophrenia few dedicated scientists in the field of mental health dared to propose a change in this terminology. Altschule (8) in 1967 proposed the term “Pinel-Haslam syndrome” naming after Philippe Pinel and John Haslam of Bethlem London who have made the original descriptions of the syndrome described as Dementia Praecox by E. Kraepelin. The late Ian Falloon¹ twenty three years later used the terms either “Bleuler’s and Kretschmer’s syndrome or Schneider’s syndrome” as an alternative “with the advantage of removing prognostic implications whilst associating the disorder with the diagnostic criteria now employed” (9). Falloon’s proposal on the need for a new name was based not in the descriptive or aetiological mode of diagnosis, but the naming is after the scientists delineated the syndrome e.g. Bleuler’s or Schneider’s or Kretschmer’s syndrome.

This type of diagnostic approach was neutral and “painless” and there are no reasons for not accepting it. However, it would be questionable whether the introduction of a new term for scientific purposes, according to the descriptive approach is not appropriate.

Invited by Ian to respond, I proposed the term “dysphrenia” (10) composed by the Greek words “dys” and “phrene” meaning dysfunction of the mind a concept closer to the findings of the eighties and the nineties accepting the definition of the illness as a progressive neurodevelopmentally derived “misconnection syndrome” based on a unitary model, involving neuronal synaptic connectivity between cortex and cerebellum, through thalamic pathways, supported by neuroimaging findings and psychoendocrinology (11).

The word “dys” has no specific negative connotation not related to malformation (splitting) and is commonly accepted and commonly used in psychiatry and psychology e.g. dysthymia, dysphoria, dyslexia, dysphasia etc.

In 1996 WPA launched the Global Programme against Stigma and Discrimination because of Schizophrenia related disorders (12). This programme was developed in 19 countries in different geopolitical areas. Although this anti-stigma campaign was very

effective in many occasions, the possibility of change of the name of schizophrenia was never introduced.

The major breakthrough came from Japan when the Japanese Society of Psychiatry and Neurology changed in 2002 the old term “Seishin Bunretsu Byo” (mind-split-disease) into the new term of “Togo Shitcho Sho” (integration disorder) (13).

This major change was triggered by the pressure of users’ and families’ associations and social groups.

In 2002 in a regional conference of the World Association for Psychosocial Rehabilitation organized by the Italian Branch in Rome, in a specialized symposium, it was the first time in the recent years that the need for a change of the name of schizophrenia was discussed extensively.

Lately, in the British Medical Journal (14) J. Liberman and M. First, published an editorial on renaming schizophrenia. In this editorial the opinions expressed by the authors stating “unfortunately changing the name of the condition (or even abolishing the concept) will not affect the root cause of the stigma—the public’s ignorance and fear of people with mental illness. Renaming may even have the unintended effect that the person, rather than the illness is blamed for the symptoms” provoked thirteen responses.

Liberman and First focused on the semantics of the term (renaming schizophrenia would not change the stigma attached to the underlying condition) ignoring the fact that semantics are the message diffused to the public. In one of few experimental studies on labeling, Penn and Nowlin-Drummond have shown that the use of politically correct labels e.g. consumer of mental health services, was associated with less negative reactions by the public, compared to the label of a person with schizophrenia or schizophrenic patient (15).

The editorial of Liberman and First in BMJ provoked a series of letters by mental health professionals many of them wondering whether the change of the term will reduce stigma and five responses openly challenging the name change.

In the Schizophrenia Digest (Fall 2006, www.szdigest.com) an article of Stacie Z Berg reported decades of suggested alternatives for

Table 1 Proposed new names for Schizophrenia.

Author	Year	Title
Altschule	1967	Pinel-Haslam syndrome
Falloon*	1970	Bleuler’s syndrome
Madianos*	1990	Dysphrenia or Dysprenic syndrome
Japanese Neuro-Psychiatric Association	2002	Integration Disorder
Anonymous	2006	Psychotic Spectrum disorder
Anonymous	2006	Perception Dysfunction disorder
Anonymous	2007	Dopamine dysregulation disorder
Stark*	2008	Cognitive disorder
Guinea*	2008	Psychosocial dysfunction syndrome

* WAPR board members.

schizophrenia many of them meaningless (16). The World Fellowship for Schizophrenia and Allied Disorders, initiated a series of contacts with professionals to open a discussion about renaming of schizophrenia. In table 1 different proposed new names for schizophrenia are presented by the author and the year.

In sum the pros and cons of renaming schizophrenia are the following:

The Cons

- Changing the name, stigma will remain since it is resulted from the distractive psychotic behavior of the suffering persons
- Schizophrenia is useful and almost valid but semantics are the problem.

The Pros

- Schizophrenia's semantics are the metaphor of distraction
- Schizophrenia is a scientific anachronism
- Schizophrenia is linked with stigma and pessimistic clinical prospective
- Schizophrenia has a demoralizing connotation
- Changing the name of Schizophrenia would be beneficial because it would be an indicator of change rather than the change.

Finally in the DSM V task force including a user's representative, there are voices for the review of the terminology². Nevertheless, whatever a new name is going to replace the anachronistic and cacophonous term of Schizophrenia, the time for a change has come.

REFERENCES

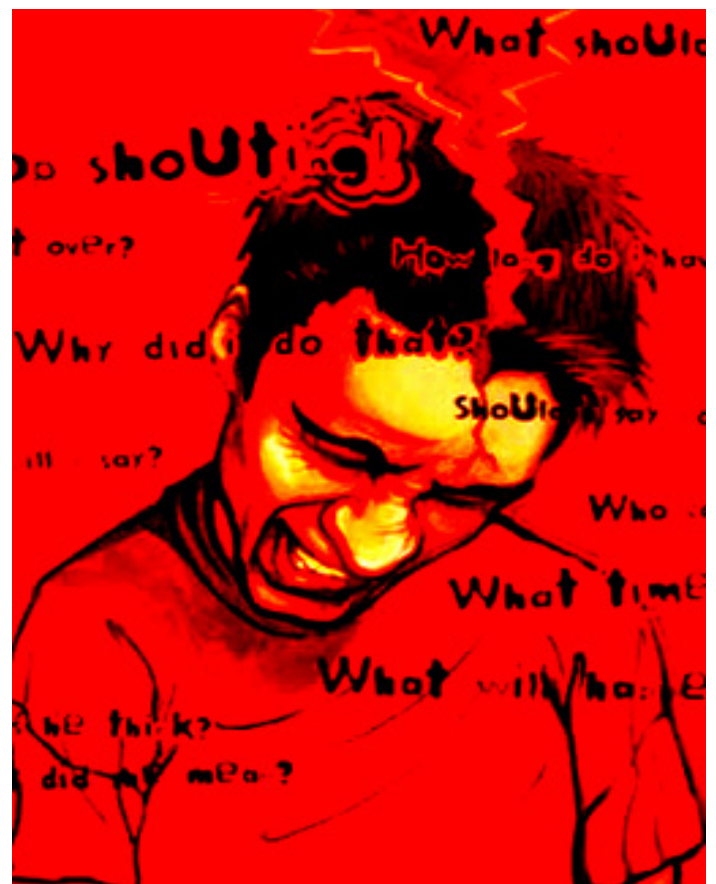
1. Zilboorg G (1941) A history of medical psychology. New York, W.W. Norton.
2. Bleuler E (1911) Dementia Praecox oder gruppe der Schizophrenien. Leipzig, Deuticke.
3. Kraepelin E (1913) Klinische Psychiatrie, 3rd edition. Leipzig, Barth
4. Tsuang MT, Stone WS, Faraone SV (2000) Towards reformulation the diagnosis of schizophrenia. American Journal of Psychiatry, 157:1041-1050.
5. World Psychiatric Association (1998) Fighting stigma and discrimination because of schizophrenia. Geneva, WPA.
6. Madianos M, Economou M, Dafni O, Koukia E, Palli A, Rogakou E (2004) Family disruption, economic hardship and psychological distress in schizophrenia: Can they be measured? European Psychiatry, 19: 408-414.
7. Madianos M, Madianou D, Vlachonikolis J, Stefanis C (1987) Attitudes towards mental illness in the Athens Area: Implications for Community Mental Health Intervention. Acta Psychiatr. Scandinavica, 75: 158-165.
8. Altschule MD (1967) Schizophrenia, or the confused past, ambiguous present and dubious future of the schizophrenia concept. Journal of Schizophrenia, 1:8-17.
9. Falloon I (1990) Schizophrenia: Do we need a new name? (Unpublished manuscript).

10. Madianos M (1990). The Schizein of the phrene: From anachronism to innovation (Unpublished manuscript).
11. Andreasen N (1999) A unitary model of Scizophrenia: Bleuler's "fragmented phrene" as schizoencephaly. Archives of General Psychiatry, 56: 781-787.
12. Sartorius N and Schulze H (2005) Reducing the stigma of mental illness: A report from Global programme on the WPA. Cambridge, Cambridge University Press.
13. Sato M (2006) Renaming schizophrenia: a Japanese perspective. World Psychiatry, 5: 54-56.
14. Lieberman JA, First MB (2007) Renaming Scizophrenia. BMJ, 334: 108.
15. Penn D, Nowlin-Drummond A (2001) Politically correct labels and Scizophrenia: A rose by any other name. Scizophrenia Bulletin, 27:197-203.
16. Berg ZS (2006) Changing the "S" word, is there a better name? Schizophrenia Digest, 4:30-34.

(Footnotes)

¹ Ian Falloon's article was supposed to be published in a new American journal entitled "Community Psychiatric Practice" which was never came out for economical reasons.

² In previous DSM revisions Bipolar disorder replaced the term manic and depressive illness.



NATIONAL CONFERENCE Mental Health
**Methodology, organizational levels and outcomes within
the services systems.**

Ravenna (Italy), 28th/ 29th November 2008.
Paola Carozza. Director of Psychiatric Rehabilitation
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The approval of the new mental health law, called “Law 180,” in 1978 marks the “Italian Revolution” in the mental health field. This initiated the development of a radical process of change in services delivery: from guardianship to the beginning of the patient’s deinstitutionalization. Let me try to summarize the main points of this change.

First, the law stated that the citizens’ mental health had to be promoted through of three levels of intervention, all deeply integrated: prevention, treatment and rehabilitation. Secondly, the law confirmed that citizens with psychiatric disabilities had the right to receive efficient treatment in their own social environment. The objective was to reduce hospitalizations as well as to strengthen family and social support networks and prevent marginalisation. Thirdly, the law established a comprehensive network of services in order to meet the needs of both of citizens with mental illness and their families (crisis intervention, environmental and social support, treatment, rehabilitation etc). Finally, the law introduced the concept of social inclusion as a result of a range of interventions focusing on helping the person with psychiatric disabilities to achieve valued roles in the community. Unfortunately, these objectives have not been accomplished sufficiently. In some areas of Italy mental health public services are in fact non-existing, and they have gradually lost their importance on organizational as well as professional levels. Many politicians and professionals claim that the lack of resources to be the main reason of inadequate services. However, this is simply not a problem of insufficient or fragmented resources, but also a consequence of inappropriate services.

The process of deinstitutionalization, the spreading of community mental health centres throughout our country and the growing interest of psychosocial interventions, particularly in the field of psychiatric rehabilitation, laid the foundation of a new paradigm placing recovery from mental illness as the guiding vision



Paola Carozza.

of mental health services systems. In establishing a mental health service organisation, it is essential to consider and define ways of implementing the standards and management systems of a recovery oriented practice, of empowerment and of social inclusion in the community, which should be the main objectives of a comprehensive mental health service.

In this perspective it is inevitable to wonder whether these new mission programs and actions are being implemented in our country and if the reason for the repeated attacks on Law 180 refers to the remarkable delay of recovery paradigm development. The need for placing recovery from mental illness as the overall goal of community mental health services stems from the evidence that many services systems are mainly oriented to manage crisis, to prevent deterioration and to stabilize the persons. The mental health systems developed over the last century and still exist today have been built on the mistaken assumption that serious mental illnesses are almost universally associated with a poor prognosis. Besides, in Italy, psychiatric rehabilitation has been and still is, more regarded as a technique than a perspective and

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way of helping people to have a meaningful and fulfilling life in their community. In the last twenty years, in fact, and unlike physical rehabilitation, psychiatric rehabilitation has held a marginal role and an ancillary function if compared with treatments. In general persons with severe mental disorders have been placed in a role of chronicity, condemned with the expectations of progressive deterioration. They have been referred to psychiatric residential facilities, often reproducing a disconnected and isolated way of living, being deprived of citizenship, being disempowered and with the risk of increasing internal stigma. It seems that a fragmentation of the psychiatric hospital into many small residential facilities has occurred, where the person with mental health problems are admitted once seen as “stabilized”. In these places one finds the same monotonous activities being repeated again and again in the same way with limited personal significance for the service users. Moreover, discharge from these places is rare and life long stay is typical, as a strong dependency on the place as well as the practitioners easily develops making the persons more helpless and “disabled”.

As community psychiatry has developed and hospitalization rates decreased, the traditional treatments, medication and crisis interventions revealed inadequacy in order to meet the various needs of people with psychiatric disabilities and insufficient in strengthening the persons skills and abilities to function in the real world. In fact, in order to be completely included in the community, people with psychiatric disabilities have to re-learn and to practice the daily living activities. As a consequence it is crucial to pay a greater attention to tools and methods that counteract the disabling effects of mental illness on the person. In this aspect, psychiatric rehabilitation, in focusing on the consequences of the pathology rather than the pathology itself, has contributed to reduce not only the impairments and related symptoms, but also the functional limitations, the disabilities and the handicaps.

In light of the changes of the mental illness concept over time, the traditional assumption of mental illness as preventing human growth and development and preventing the individuals from becoming real citizens, is definitely disappearing. This change is partly due to a series of important studies conducted in the last thirty years and partly due to the dissemination of effective rehabilitation and treatment programs aiming at the achievement



valued social roles rather than remaining a psychiatric patient.

In the last decades, three main knowledge- bases, based on the empirical works of many researchers as well as on published user experiences, have contributed to questioning and criticising the belief that mental illness has a deteriorating lifelong course, or at the best a course requiring maintenance:

- 1) Dissemination of the biopsychosocial model claiming that recovery from mental illness is the result of an integrated approach consisting of well-coordinated clinical, cognitive and social interventions, offered in a comprehensive community support system.
- 2) More thorough understanding of the total impact of severe mental illness, as conceptualized in the rehabilitation model (impairment, dysfunction, disability, handicap).
- 3) Dissemination of the concept of recovery that means growing beyond the catastrophe of mental illness and developing new meaning and purpose in one's life, taking charge of one's life even if one cannot take complete charge of one's symptoms (Anthony, 1993).

Implementing such knowledge in clinical practice means that services and treatment must reorient the approaches towards emphasizing resources and strengths and minimizing peoples deficits on all levels in the mental health services systems. This



implies that the community support system perspective (i.e. programs providing a great variety of settings and a wide range of support levels) becomes a part of the thinking of many system planners, administrators and professionals.

Following the reflections and perspectives outlined above, the mental health department of Ravenna, with the support of Emilia Romagna Region, Local Health Agency, Association of families of users and with the sponsorship of WAPR Italia, organized the national conference “Mental Health: intervention methodology, organizational levels and expected outcomes within the services systems”, in Ravenna, Italy, 28th - 29th November 2008. The objective was to stimulate a critical review of the relationship between methodology of intervention, organisational models and expected outcomes, inviting a variety of discussants; not only professional authorities from other countries (Ricardo Guinea, deputy Secretary WAPR) and Italy (Roberto Mezzina, Trieste, Arcadio Erlicher, Milano, Angelo Barbato, Milano, Giovanni De Girolamo, Bologna), but also service users, providers, researchers, family members, politicians (local and provincial authorities), administrators and no profit and profit entrepreneurs. The conference was attended by about 300 representatives of various professions (psychiatrists, psychologists, social workers, rehabilitation therapists, teachers, nurses, psychology students, medical students specialising in psychiatry), users and their families, associations of volunteers, politicians, administrators and civic dignitaries.

The main themes discussed were:

1. Nowadays, is the services system able to define a shared vision that indicates how the service users will benefit from treatment and what the person-centred outcomes are expected to be?
2. What are the organizational models that support the achievement of the expected outcomes?
3. How can cooperation between different professionals (psychiatrist, nurses, social workers, psychologists, etc.) and different components of Mental Health Department (Mental Health Centres, Day Hospitals,

in-patient settings, residential facilities, drop-in centres, etc.) be promoted?

4. How does the service system deal with the stakeholders and with other any non –professional subject involved in the processes of social inclusion of the users (local authorities, provincial administration, associations of volunteers, no-profit entrepreneur, teachers and employers)?
5. How does the service system deal with no-profit and profit entrepreneurs?
6. How does the service system deal with recruitment and selection of staff and promote the development of professional competence (knowledge, abilities and attitudes)?
7. What are the ingredients of the selected technical and organizational models that foster or hinder consumer goals’ achievement?

At the end of two-days meeting, the representative of Emilia Romagna Region (Angelo Fioritti) have highlighted some perspectives for the future with emphasis on:

1. To define the mission of the overall Mental Health Departments, not only of the single different services (ie continuity of care).
2. To adopt a holistic approach, according to which the users, before being defined as sick, cases or diagnosis, are regarded as unique persons, each of them with three closely connected dimensions: biological, psychological and social. Thus greater attention needs to be paid to the biopsychosocial model, the only approach that counteracts the risk of fragmentation of interventions and, therefore, of the person.
3. To adopt values and evidence based practices, to measure the outcomes and supply the personnel with effective tools, through a continuous learning process (intensive training in the workplace and regular supervisions). The need to train professionals to cope with psychiatric disability and to support them to become competent in helping citizens with mental illness to gain valued social roles and to initiate and





emphasise processes of recovery. The importance of recruiting skilled and motivated practitioners (including psychiatrist), has also often been highlighted. It is well-known how the negative attitudes of the professionals influence the consumers' outcomes.

4. To recognize that the mental health services system is not self-sufficient, but must develop and implement integration strategies with all the stakeholders. These actions are critical both to reduce the dependence of the service users on the mental health system and to acquire the appropriate resources (jobs, houses, leisure facilities, educational opportunities) that are essential for the social inclusion in the ordinary community environments .
5. The need of the development of a new type of leadership, beginning from the thesis that many, if not most, of the fundamental differences between organizations are due to differences in the quality and effectiveness of the leadership (Anthony, 2008). Serious and committed leaders are required in order to transform our current care system, founded on stabilization and deterioration prevention paradigm, to one founded on a rehabilitation and recovery paradigm. It must be taken into account that currently the leaders are stressed simultaneously by different perspectives, concepts and procedures: renewed interest in the advantages of asylums and a much stronger focus on community integration; increasing emphasis on involuntary procedures and, at the same time, focus on consumer choice; emphasis on more quality services and, at the same time, more stronger pressures to contain costs (Anthony , 2008).

The above-mentioned principles and purposes have been chosen by Local Health Authority of Ravenna to re-orient the whole Mental Health Department and to spread the culture and the practice of psychiatric rehabilitation in every dimension of the system. In order to develop this process of change in the current system of services delivery, a specific psychiatric rehabilitation service has been established, designed as an essential component of the Mental Health Department. The function of this new service is to develop effective programs for people with severe mental illness that hopefully will strengthen their skills and capacities to live independently and meaningfully in the community. Four main goals will be pursued: improving the quality of the services; reducing the practice with psychiatric residential facilities; increasing the number of persons discharged from the psychiatric residential facilities by using the supported housing programs, and containing and taking control over the costs of long term psychiatric residential facilities and increased hospitalizations owing to lack of rehabilitation.

Paolo Carozza

References

- W. A. Anthony , "Recovery from mental illness: The guiding vision of the mental health service system in the 1990s", *Psychosocial Rehabilitation Journal*, 16, 11-23, 1993.
- W. A. Anthony, *Toward a Vision of recovery*, Center for Psychiatric Rehabilitation, Boston University, 2008.
- W. A. Anthony, K. A. Huckshorn, *Principled Leadership in Mental Health System and Programs*, Center for Psychiatric Rehabilitation, Boston University, 2008.
- W.H.O, *International Pilot Study of Schizophrenia*, Geneva, 1974

English version kindly revised by M. Borg.

10th festival EURO-PSY Rehabilitation: The Merry – Go – Round of culture, Slovenia

Barbara Dolni. Festival coordinator. ŠENT – The Slovene Association for Mental Health.
Bernard JACOB. Vice-President of Europsyrehabilitation. Member at Large of WAPR - AMRP

After Pamplona in Spain, this year ŠENT – The Slovene Association for Mental Health had the opportunity and honour to organize 10th festival of EURO-PSY Rehabilitation. ŠENT joined the organization EURO-PSY Rehabilitation in 2007. The idea and proposal of organizing the festival in 2008 in Slovenia was given first by Bernard Jacob who was visiting our organization in July 2007. Then the board meeting was organized in Slovenia in November 2007, where ŠENT represent previous work and experience with organizing international congress and other similar events in international and national level. The members of board and ŠENT agreed that the festival 2008 will be held in Slovenia. Then all the organization begin with finding the suitable place, raising money, working on program and so one. In all times and all the phases of organization ŠENT involved all tree parts: users, relatives and professionals to create a common event.

The programme committee consisted of 10 members; (users, relatives, professionals from the NGO, working in the field of mental health, professionals form Psychiatric clinic of Ljubljana, laymen, persons from the field of culture) prepared the content and the final programme of the event. Furthermore the programme committee provided contacts of all collaborating persons in the programme (mentors of the workshops) for the needs of the organizing committee. The organizing committee consisted also of 10 members (professionals, users and relatives from ŠENT) and was responsible for all activities related to the realisation of the event, promotion of the event and fund raising. And than after all the hard work, September was a time to finally be in the hosting role.

The festival took place in Debeli rti, Youth Spa and Holiday Resort in Ankaran, Slovenia from 22. till 26. of September 2008. There were all together 231 participants from 8 countries: Slovenia, Belgium, Spain and Canarian island, Great Britain, France, Austria, Croatia and Netherlands.

The participants were visiting different sports and relaxation activities, culture and art workshops. Due to the fact that 2008 is the year of Intercultural dialogue there was a special part of the festival dedicated on the presentation of Slovenian culture and ethnographic characteristics. In these workshops participants learned some basic Slovenian words, something about Slovenian history, find out about one of Slovene handicraft (products from straw), learned to cook Slovenia food, and visit the local cities at Slovenian costs.

There were all together 20 workshops (from 31 workshops from which people can choose from), which finally take place during the festival: Journalism and Photography, Literature, Handcraft, Impro Theatre, Graphics, Ex-Tempore Painting, Circus, Holiday Postcard, Gymnastics and Oriental Dances, Laughing Therapy, Horse Riding, Expressive Dance, Cycling, Kayaking, Swimming, Hiking and Orientation Hiking Trips, Istrian Cuisine, Straw Produce, Slovenia and Research Workshop.

The mentors of the workshops were people who are temporary working with ŠENT in daily centres, ŠENT employees, external co-workers, users and relatives. They all have at least one (depending of the number of people in the workshop) volunteer to help them with translation and workshop activities.

The festival started with welcome party on Monday 22th of September, where all the groups from different countries prepared short presentation program. It was a nice opportunity to meet for the first time, before the official opening of the festival.

The next day, on Tuesday 23th September 2008 in the official opening ŠENT invited some of very special guest. Among us there were: Slovenian ombudsman dr. Zdenka ebašek Travnik, mag. Janez Jug the director of Foundation for financing humanitarian organizations and organizations for disabled, Marjeta

Ferlan Istini, from Ministry of Labour, Family and Social Affairs, mr. Vojko Gašprut, painter and member of AMFPA - Association of Mouth and Foot Painting and ambassador of the the Kingdom of the Netherlands , H.E. Mr. John C.M. Groffen.

The festival was opened by president of EURO-PSY Rehabilitation Jo Maes who welcomed all the participant and wished them a nice time during the festival. At the end of the opening ceremony director of ŠENT Nace Kova thanks all the members of organization and program comities for good work and in the name of ŠENT welcome all the participants in Slovenia.

The next two days were in the spirit of workshops and at evenings there were organized different theme nights. The first day the journalist and writer mrs. Renata A•man represent her experience with depression and represent her book Depra, after that the local folklore group have a short program with local dances and songs. The next evening the games without frontiers were organized. There was a lot of fun and at the end the group from Canarian Island ware the best.

At the last day on Thursday 25th of September round table “Users, relatives and social services providers - collaboration in shaping and implementation of programs” was organized for all the participant and other visitors. The speakers exposed the problematic of collaboration in shaping and implementation of programs, which is a topic that is often discussed in our organization. On the round table we try to answer the question: on which way and how much relatives and users are contributing to the optimal performance of programs and services. The speakers were: Mag. Edo P. Belak, relative; president of Relatives’ forum of Slovenia; Andreja Štepec, user, president of Šent users’ forum, Jasmina Jakomin, Counselor Šent’s Living community in Tolmin, ŠENT; Marija Perkovi , director of Centre for Social Work Koper – Capodistria; Ivna Buli Vidnjevi, psychologist, University Psychiatric Hospital Ljubljana; Doc.dr. Liljana Rihter, Faculty of Social Work, University of Ljubljana.

The final conclusion was that in all countries participants in the festival users are dealing with two problems who need special attention: poverty and housing problem. The users expect that there would be more support to the work of NGO and especially to the program’s who are already carrying out.

The afternoon was time for visiting local cities and learn something more about Slovenia. Participant were visiting 3 different excursions and they visit Slovenian seaside.

The final event was held on Thursday 25th of September in the evening when all the workshops were represented in life or by power point presentation. All of the participant receive the festival newspaper and a small present to remember the participation, ŠENT and Slovenia. President

of EURO-PSY Rehabilitation Jo Maes, executive director of ŠENT Nace Kova and ŠENT member Joc Podlesnik closed the festival and invite all to the next festival in 2009. The evening continued with dance and party for all participants, mentors, volunteers, organization team and other people who help with the festival.

Final evaluation and thanks:

The organization of the festival was a very complex project and as a festival coordinator I would like to thanks all members of program and organization committee, all volunteers, mentors, special guest, EURO-PSY board members, previous organizers and all the participants for their visit and festival spirit. Very special thanks go to all the sponsors and donators who supported the 10th festival of EURO-PSY Rehabilitation in Slovenia. They are listed below.

Positive respond of the participants and other stakeholders about the festival is revealed through evaluation report. We have also received many praises and commendations of the participants after the event. Many articles about the festival were published in the local and also national newspapers, radio and TV stations.

This kind of festival was organized for the first time in Slovenia and also it was the first time that somebody from Slovenia was among the participant. So for all the participant, but especially between Slovenian the festival and his main concept was really very well accepted and we will try to be a part also in all the next festivals. Thanks again to EURO-PSY Rehabilitation for this unique opportunity.



Encuentro de Usuarios en Cabra (Spain) CREANDO REDES DE COMUNICACIÓN ENTRE LOS GRUPOS Y ASOCIACIONES DE USUARIOS Y USUARIAS DE ESPAÑA.

Juan Carlos Casal.

Vicepresidente Asociación Alonso Quijano.

En Cabra (Córdoba- España), el 18 de Octubre, junto con la celebración del II Campeonato Mediterráneo de Salud Mental Fútbol 7 se ha celebrado un encuentro para enriquecer y fortalecer el Movimiento de Usuarios y Usuarias del Estado español. El encuentro se celebró en el Teatro el Jardinito desde el día 16 al 18 de octubre.

Ha sido el primer encuentro Europeo, con representantes de ENUSP, Erik de Copenhague (Dinamarca) y Frank Fallan de VOX de la región de Escocia (Reino Unido). Ha sido convocado y organizado por nosotros, usuarios y usuarias, hemos presentado trabajos e ideas en comisión plenaria, hemos trabajado en grupos, y nos hemos divertido y participado en las actividades culturales de la localidad de Cabra. Resaltó un concierto de música Andalusí celebrado en el Teatro “El Jardinito”. Con el respaldo del [Ayuntamiento de Cabra](#) (Córdoba) y de diversas instituciones la Comunidad Autónoma de Andalucía.

Un nuevo hecho histórico para la consecución de una verdadera representación de las mujeres y hombres que están promocionando la salud global del colectivo de personas que han padecido, padecen o pueden padecer un proceso de enfermedad mental. Unas auténticas Jornadas en el Estado Español de Usuarios y Usuarias. Se elaboraron conclusiones de los grupos de trabajo donde se trataron temas de autonomía personal, inserción laboral y de humanización de los aspectos clínicos.

Llegue al pueblo de Cabra hacia las cinco y media de la tarde con un taxi me desplace al Cortijo de Frías, Un alojamiento rural, rodeado de olivos. Recorrer la carretera que lleva al cortijo por la noche me causaba una sensación novedosa y gratificante, me di cuenta que estaba en la Hispania de los Fenicios [Oryctolagus cuniculus](#), En la región Cordobesa la tierra de Séneca, Averroes, Maimónides, de Don Luís de Góngora y de Julio Romero de Torres. En la Córdoba milenaria del cruce de culturas, del aceite y del azahar. Siglos de cultura Musulmana, Judía y Cristiana impregnan estas tierras.

Cabra, es un pueblo moderno del siglo XXI, sensibilizado



J.C. Casal, Vicepresidente de AAQ.

con los problemas de salud mental, una ciudad Libre del estigma de gente amable y acogedora. Escribo esta crónica después de un mes de esa experiencia mis recuerdos son gratos, por el entorno por gente que he conocido y lo trabajado en las Jornadas. Estuvieron Erik y Frank, fueron muchas horas de viaje para estar con nosotros, los Usuarios y Usuarias de España. Me aloje en la casa denominada Fuente Tójar con otros compañeros de Badajoz, Barcelona, Palma de Mallorca y Oviedo. En las otras casas del cortijo estaban los compañeros de la Plataforma de Asociaciones de Usuarios y Usuarias de salud mental de Andalucía. Durante los tres días que duró el encuentro Tuvimos la oportunidad de intercambiar opiniones y de disfrutar de actividades culturales.

Tres años del Movimiento de usuarios y usuarias.

Desde el año 2005 hemos tenido diferentes contactos entre nosotros, como individuos y como integrantes en colectivos locales que luchan a favor a la salud mental.

En el año 2005, en el Colegio de Médicos de Madrid, en el marco del primer congreso FEARP, asistí junto con dos compañeros de AAQ, Vikie y José Luís, a un taller de Usuarios, fue en un salón. Coordinaba el taller Rene Van der Male. Con la luz baja y con un cañón se fueron proyectando temas de debate, preocupaciones de usuarios de diferentes partes de España. Entonces me llamo la atención el tema de la salud mental y su atención en las zonas rurales, y los problemas para el acceso al trabajo. No éramos muchos los que nos manifestamos como usuarios, la luz estaba baja, no sé si era para favorecer la participación, focalizar la atención de la proyección de los temas, resguardar la intimidad de los participantes o por cualquier otra causa pensada por los anfitriones. Me acuerdo que había público al final del salón. Casi era más numeroso que los participantes usuarios.

La expectación y la curiosidad de otros era máxima, parece que querían escuchar lo que teníamos que aportar los usuarios para resolver la compleja problemática de la salud mental. El estigma y la invisibilidad de la enfermedad mental estaba presente, el público asistía a algo histórico, o en la sombra nos estaba controlando.

La reunión fue bilingüe (español-inglés) y al final de la misma recogimos un listado con direcciones y correo electrónicos para seguir manteniendo el contacto. Los temas tratados se recogieron y en las conclusiones del Congreso se hizo una reseña al taller. Se empezaba a hablar de la necesidad de que la voz de los usuarios del Estado fuese escuchada.

En noviembre de 2007 fue la segunda reunión del movimiento de usuarios con el objetivo de crear una plataforma representativa en el ámbito estatal. Se realizó en el centro de zona de Escuelas Pías de Madrid –UNED con el apoyo de todo el movimiento asociativo de familias y usuarios, de profesionales y de los grupos y asociaciones independientes. Hasta entonces, la mayoría de los contactos habían sido por correo electrónico y por teléfono. A partir de noviembre de 2007, dimos un salto

cualitativo.

Nos hemos empezado a reunir físicamente compartiendo espacios y con encuentros más formalizadas. Se ha explorado la posibilidad de articular el “Movimiento de Usuarios”, como plataforma o como Asociación estatal (una Federación) y comenzamos a pensar en como poder facilitar la participación en primera persona de individuos no asociados a colectivos.

La Asociación Alonso Quijano (AAQ) con la Asociación Bipolar de Madrid (ABM), en la sede de ABM y con el apoyo del Colectivo Orate hemos celebrado numerosos encuentros. También en Madrid hemos mantenido los primeros contactos informales con la Asociación El Atardecer, y con la Asociación de Familiares del Área Cinco de Madrid AFAEM 5.

La reunión mas destacable, previa al III encuentro estatal del Movimiento de Usuarios fue la celebrada en Barcelona en Abril de 2008, con la asistencia de miembros de la Asociación Colectivo Orate, AVANTE de Cádiz, La Asociación ADEMM de Barcelona, ABM y AAQ de Madrid. De esta reunión parte un documento que luego con pequeñas modificaciones fue firmado por numerosos colectivos en la reunión de Bilbao 2008, un acuerdo para empezar a trabajar. En Cabra (Córdoba) dimos un paso más para superar la brecha de organización y participación que nos separara para tener representación y voz en todo lo que como ciudadanos nos concierne en comparación con otros países de nuestra órbita cultural (la Europa del Bienestar).

La situación a la que llegamos en este encuentro es poco alentadora por la dificultad para organizarnos, interaccionar e intercambiar experiencias, y que haya redes de comunicación. Nuestros grupos son pequeños y con pocos recursos, vamos a la rémora de otros colectivo, por ejemplo los de personas con Diversidad Funcional Física (discapacidad Física) que llevan años de visibilidad y de reivindicación y estan representados en todos los ámbitos donde se habla de ellos y de ellas. Nosotros no



tenemos puntos de encuentro, no tenemos nuestras jornadas, nuestros congresos para hacer este tipo de cosas. El colectivo de Usuarios y Usuarias Español no maneja las nuevas tecnologías, como el correo electrónico, que permitiría el encuentro regular en páginas webs, blogs o foros donde podamos intercambiar. Otros colectivos han podido comunicarse electrónicamente, nosotros aún no sabemos, o no podemos, tener una conexión a internet es algo muy caro, el ordenador y la conexión en casa es un lujo para nuestro colectivo. Otra dificultad es la casi imposibilidad de tener encuentros personales. La falta de recursos económicos y el escaso respaldo de las Instituciones Públicas y del Movimiento Asociativo de Familiares y usuarios de la red de FEAFES, situación mantenida durante más de 25 años, hacen que valore el encuentro de Cabra como lo mejor que ha sucedido hasta ahora para que los Usuarios y Usuarias podamos comunicarnos, y conseguir organizarnos, y tener representación en todos los foros, como otros grupos de otras regiones Europeas han conseguido hace años.

El grupo de trabajo en el que participé concluyó las siguientes líneas estratégicas:

- Promover la Acción Ciudadana,.
- No segmentar el movimiento asociativo con términos biomédicos-
- Reclamar prestación de servicios ajustados a las necesidades del colectivo.
- Que se tenga especial atención una especial atención al ocio y tiempo libre, como forma de inclusión y de participación social.
- Promoción de iniciativas de inserción laboral que parten de nuestros grupos.
- Promover y trabajar en favor de fórmulas de financiación.
- Debate en torno a las figuras de tutela y autonomía personal.
- Que la participación en las actividades de nuestras asociaciones no sea exclusivamente para los socios.

Ha sido un nuevo hecho histórico para la consecución de una verdadera representación de las mujeres y hombres que están promocionando la salud global del colectivo de personas que han padecido, padecen o pueden padecer un proceso de enfermedad mental. Unas auténticas Jornadas en el Estado Español de Usuarios y Usuarias, organizadas con la iniciativa de SAPAME (Salud para la Mente).

Mas informacion en

<http://sapame.blogspot.com>.
www.1decada4.es/volvamosapensar/eliminarestigmas/avancesnoinst/asociaciones/encuentrocabra/

Juan Carlos Casal Álvarez.

Vicepresidente AAQ

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Encuentro de Usuarios/as: Declaración de Cabra.

Los participantes en el Encuentro de Usuarios/as de Cabra (Córdoba, España), desean expresar su adhesión a los principios y valores recogidos en la Declaración consensuada en el Encuentro de Usuarios celebrado en Bilbao en junio de este año 2008, resumidos en :

- Defensa del ejercicio pleno de los derechos del colectivo.
- Compromiso activo de los colectivos firmantes a realizar todos aquellos esfuerzos que, en función de su capacidad operativa, les permita avanzar en la consecución de sus objetivos.
- Importancia de la adopción de responsabilidad de carácter representativo por parte de los propios afectados, que contribuya a una mayor comprensión de la sociedad y a un abordaje de calidad para con la persona

Y, por tanto:

1. Nos comprometemos a mantener cauces de comunicación que nos permitan seguir consolidando una estrategia conjunta para fortalecer nuestro Colectivo: trabajando en red, participando en encuentros y foros de intercambio y otras formas de comunicación.
2. Para ello, necesitamos disponer de un estilo de actuación común que nos identifique, con actitudes de moderación en la comunicación, de respeto entre las personas, de escucha activa con el deseo de compartir nuestra experiencia vital para avanzar en el crecimiento personal y colectivo.
3. Promover el respeto y la pluralidad de opiniones, evitando comportamientos individuales o de grupo que puedan coartar la libertad de expresión o estilos coercitivos que obstaculicen la cohesión del Movimiento de Usuarios/as.
4. Creemos necesario fomentar la participación de mujeres en puestos directivos de nuestras asociaciones y promover la inclusión de los jóvenes.
5. Somos conscientes de que la salud es un proceso de atención global a lo largo de toda la vida de la persona. Nos comprometemos a trabajar en la defensa de una atención integral de la salud mental infanto-juvenil.
6. Tenemos que buscar fórmulas para articular la participación y representatividad de quienes no forman parte de nuestras asociaciones.

Cabra (Córdoba, España), 18 de octubre de 2008.

Colectivos firmantes:

- Plataforma de Asociaciones de Usuarios de Salud Mental de Andalucía (Asociación Mente Sana (AMENSA) Motril – Granada, Asociación Salud para la Mente (SAPAME) Granada, Asociación ALFARALA Málaga, Asociación de Familiares y enfermos Mentales de la Costa del Sol (AFESOL) Marbella – Málaga, Asociación (TOPATÓ) Cartaza – Málaga, Asociación de Familiares y Enfermos del Valle de los Pedroches. Pozoblanco – Córdoba, Asociación Futuro. Sevilla)
- Asociación Balear de Usuarios Salud Mental. (ABUSAM) Illes Balears.
- Asociación de Enfermos Mentales para la Integración Social (AEMIS) Badajoz.
- Associació de Bipolars de Catalunya (ABC) Barcelona.
- Asociación Hierbabuena. Oviedo y Gijón – Asturias.
- Asociación Alonso Quijano. (AAQ) Madrid.

Acerca de la importancia de asumir riesgos razonables en los procesos de Recuperación

Alberto Fergusson MD

Director Instituto de Autorehabilitacion Acompañada.

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Son múltiples las secuelas que dejaron tanto en las personas diagnosticadas con enfermedad mental como en sus cuidadores, varios siglos de falsas creencias y mitos con respecto a lo que es la denominada “enfermedad mental”. Las diferentes formas de instituciones que se idearon durante siglos, por diferentes motivos forzaron en las personas diagnosticadas con “enfermedad mental” y principalmente con “esquizofrenia”, todo tipo de intervenciones escogidas por los “expertos” sin mayor participación de las personas estigmatizadas con estos diagnósticos. Fue en ese sentido que en nuestro programa y en general en el enfoque que denominamos como “Autorehabilitacion Acompañada”, concebimos lo que llamamos el “manifiesto filosófico”, el cual afirmaba y aun hoy afirma lo siguiente:

“Los denominados enfermos mentales han sido objeto de todo tipo de tratamientos forzados: forzados a hospitalizarse, forzados a desinstitucionalizarse, forzados a salir de sus familias, forzados a volver a sus familias, forzados a salir de sus comunidades, forzados a volver a sus comunidades, forzados a utilizar medicación psiquiátrica, forzados a dejar la medicación psiquiátrica, forzados a determinados estilos de vida, forzados a salir de otros estilos de vida y así sucesivamente. Muchas cosas pueden decirse con relación a lo anterior, pero basta con afirmar que precisamente el forzarse o ser forzado por otros a pensar, sentir o actuar en determinada forma es frecuentemente de acuerdo con nuestras observaciones, el origen inmediato de aquel estado mental denominado esquizofrenia. O de lo que nosotros preferimos denominar daño destrucción y descomposición psicológica”.

En efecto casi treinta años de trabajo con personas diagnosticadas principalmente con la llamada “esquizofrenia”, nos han enseñado a apreciar que son frecuentemente pequeñas cosas las que pueden generar grandes diferencias. Una de ellas, a la cual deseamos dedicar estas reflexiones, es la mayor o menor libertad que se tenga de asumir riesgos razonables e inteligentes. Son muchos los pensadores que han mostrado de que manera el asumir riesgos convierte la potencialidad de lo humano en realidad humana.



Alberto Fergusson.

La posibilidad de asumir riesgos parece estar mas o menos limitada tanto para las personas diagnosticadas con esquizofrenia como a sus cuidadores (profesionales de la salud mental, familiares, amigos etc.) Con el argumento de la real o supuesta fragilidad de algunas personas, se les impide a unos y a otros, asumir lo que podríamos llamar los riesgos naturales de la vida.

Nuestro programa fue por muchos años una especie de Comunidad Terapéutica. Desde hace algunos años tomamos la decisión de alejarnos en lo posible de cualquier forma de institución, con la convicción de que de una u otra forma, cualquier institución tarde o temprano tiende a ‘manicomializar’. Nos incrustamos entonces por así decirlo, en la comunidad “natural”.

Al dar este paso muchos cambios comenzaron a generarse por iniciativa comunitaria. Se creo por ejemplo, de manera bastante espontánea, un grupo que estudiaba lo que se llamaban los “residuos de discriminación” en la comunidad. Se buscaba en dicho grupo, identificar aquellas “pequeñas” cosas que continuaban marginando a quienes tenían o habían tenido un diagnostico de esquizofrenia y porque no decirlo, de manera



sutil, también a aquellos que los acompañaban en sus procesos de recuperación. Las personas “acompañadas” y “acompañantes” de acuerdo con nuestro lenguaje. Podríamos decir que se creó una especie de observatorio de pequeñas discriminaciones. Muy pronto uno de los participantes detectó un hecho sorprendente: La actitud frente al riesgo era diferente entre la población de personas acompañadas y acompañantes, con relación a lo se observaba en la población general. Mientras que en esta última se asumían diariamente todo tipo de riesgos, los diagnosticados con esquizofrenia y sus cuidadores evitaban los riesgos casi automáticamente. Esto resultaba para nosotros especialmente insólito en la medida en la que el rediseño de la vida diaria con toda creatividad, es uno de los postulados centrales de la Autorehabilitación Acompañada. Parecía que estaba proscrito tomar riesgos razonables. Parecía exigírsele implícitamente a las personas acompañadas un grado de prudencia que con frecuencia llevaba a la inmovilidad. No replanteaban su vida con libertad ingenio creatividad, y se mantenían en determinados estilos de vida a pesar de que dichos estilos claramente significaran para ellos un evidente daño psicológico. Parecían olvidar que el evitar tomar riesgos razonables e inteligentes es en sí mismo el peor de los riesgos.

En los últimos años se ha consolidado un enfoque positivo y progresista. Me refiero al denominado Modelo de Recuperación, el “Recovery Model”. De acuerdo con nuestras observaciones, no existe ninguna posibilidad de recuperación, sin tomar riesgos razonables e inteligentes por parte de todos los involucrados en los procesos de recuperación, o sea tanto por parte de las personas acompañadas como por parte de las personas acompañantes. En un

panel reciente en la Universidad de Boston, donde coincidieron varios miembros de WAPR, se planteó en uno de los talleres el análisis de aquellos casos que estaban ‘atascados’ en la ruta de la Recuperación. (“Those who are stuck on the road to recovery”). Alcance a plantear en dicho panel la idea según la cual, en principio, los atascados somos los cuidadores. Fue solo recientemente que el grupo que menciono en nuestro programa, detectó que muchos de aquellos que no se recuperan son precisamente quienes no asumen riesgos, bien sea porque ellos no se atreven o porque sus acompañantes los impulsan a que no lo hagan. Entre más atascado se este, más habrá seguramente necesidad de tomar riesgos. A partir de estos hallazgos, se creó un grupo que analiza en conjunto el riesgo, con el fin de purarlo por así decirlo y lograr que de esa manera se logre una mayor posibilidad de éxito en cualquier empresa riesgosa. Existía desde siempre en nuestro programa un viejo lema que dice lo siguiente : “El que piense recuperarse debe hacerlo con el que quiera apoyarlo, sin el que no desee apoyarlo y contra el que sea”. Con la nueva actitud ante el riesgo, dicho lema a recobrado plena vigencia.

En un documento que se publicará próximamente, daremos ejemplos detallados de lo que llamamos riesgos razonables e inteligentes. Por el momento dejaremos planteadas cuales son las “excusas” más frecuentes que hemos encontrado para impedir que se asuman los riesgos que se requiere desafiar si se piensa realmente en la “recuperación”.

En primer lugar está el fantasma de las “crisis”. Al igual que la denominada amenaza terrorista a nivel mundial ha servido como excusa para coartar ciertas libertades básicas de la población, la amenaza de las “crisis” psicológicas constituye la excusa ideal para desestimular el que se asuman riesgos razonables y necesarios. En segundo lugar está el fantasma del suicidio con todos los riesgos legales para las personas acompañantes. En tercer lugar está la que constituye quizás la forma más sutil de censura al riesgo, la cual se genera a través de posturas más o menos moralistas abiertas o disfrazadas, frente a los nuevos estilos de vida que con toda creatividad y libertad deben diseñar y asumir las personas que estén en un proceso de recuperación. En este sentido cabe recordar otro lema que ha hecho carrera en nuestro programa el cual dice: En ocasiones hacer cosas que puedan ser juzgadas como “enfermas” por otros, puede ser la única forma de no ‘enfermar’ realmente.



THE AUSTRALIA - NEW ZEALAND BRANCH OF WAPR LAUNCHED IN MELBOURNE

Reported by R. Guinea.
WAPR Bulletin Editor.

In the course of the Indo Australasian Psychiatry Association (IAPA), the Australasian New Zealand branch of WAPR (ANZ-WAPR) was launched. The congress took place in Melbourne (Australia) in December 13th-14th 2008.

Dr. Russell D'Souza, first ANZ-WAPR president, gave a warm welcome to everybody wishing to assist in recovery, fight disability related to mental disorders, raise the quality of life and enhance the social inclusion of people with mental health problems. Dr. D'Souza stated that the *ANZ-WAPR is poised to bring together the health care professional, NGOs, Careers, Consumers, advocates, industry, administrators and government agencies in order that the disability, recovery, rehabilitation and full integration into community of people with mental illness in the Australian and New Zealand community are best achieved.*

B. Hocking, the ANZ-WAPR vice-president, stated that *the word recovery is increasingly used to describe a vision for guiding mental health services, emphasizing that it is possible a meaningful and productive life for people suffering from bipolar disease, schizophrenia or major depression, and encouraged to meet ANZ-WAPR to learn and put into practice good community programmes.*

The new branch of WAPR was greeted by Dr. Michalis Madianos, president of WAPR, who expressed WAPR's gratitude to the colleagues of Australia and New Zealand, and specially to Dr. D'Souza for their efforts spent for the establishment of this important branch in south Pacific. Dr. Javed, Secretary General of WAPR also addressed his welcome to the new branch, and said that it was an historic moment in the history of WAPR, and his hope that *the launch of ANZ-WAPR will be the scene for more collaboration and understanding among the professionals involved in this journey of bringing empowerment, confidence and hope to patients, services and careers.*

Umits Agis, the ANZ-WAPR Secretary General, submitted his first report, reporting that *whilst there was an awareness of the pivotal role of recovery in PSR in the treatment of mental illness, there didn't exist an organization that facilitated a focus on this area as a legitimate area of inquiry in research and inter-*



Russell D'Souza, Presidente ANZ-WAPR

agency collaboration; and that Dr. D'Souza and U. Agis consequently, attended the board meeting of WAPR in August 2007 in Goa, India, during the inaugural Asian Psychiatry Congress, where a formal proposal for the formation of the ANZ-WAPR Branch was presented by Dr. Madianos and Dr. Javed. This request was formally considered and approved at the WAPR meeting in London.

The Committee's initial meeting took place in January 17th 2007, via national telephone link up. The committee has been meeting bi-monthly since, and finalised its constitution in March 2008, and is now a fully registered organization.

Its formal inauguration took place in the WAPR Symposium in IATA Congress. Parliamentarians from the sitting of the Federal and State Governments, and stakeholder from major NGOs and vocational rehabilitation providers attended the formal inauguration.

The report points out the future directions of WAPR-ANZ:

- Increasing membership.
- Applying for research funding.
- Promoting recovery and rehabilitation.
- Informing governmental policy on the role of rehabilitation in

social inclusion.

- Greater collaboration between consumers, careers, NGOs, primary care providers, and pharmaceutical industry to enhance recovery and rehabilitation.
- Running a regional Asia Pacific WAPR meeting in 2010.
- Bidding for the 2012 WAPR bi-annual national conference.

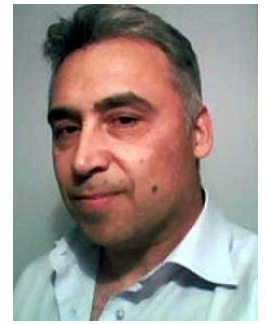
Finally, the report explained that WAPR-ANZ founding committee is committed and focused to place its vision on the map in the south pacific, and is motivated by the belief that WAPR provides the visionary framework through which we can do much to progress the needs and the issues confronted by consumers and careers in trying to overcome the disabling effects of mental illness.

In the course of the congress, the WAPR Symposium took place, sponsored by the Commonwealth Government's Rehabilitation services.

Prof. G. Gallop (Sydney), in his communication entitled "Anxiety, Hope and Politics", raised the issue of how climate change, international terrorism, global financial crisis have rattled the foundation of contemporary thinking and practice; wondered whether this changes will quickly go back to the old models of market and economic growth or not, and in this context, he proposed that a new approach to politics that is based on well-being agenda and a more balanced approach to public policy is needed, however contemporary politics seems to find difficulties in absorbing such complexity and deliver the required solutions.

G. Vaillant for USA presented a paper on the neurophysiology of positive emotions and its utility in psychotherapy. The importance of vocation rehabilitation was examined by P. McAlpine; it was explained how associated factors such as low levels of literacy, alcohol or drug dependence, social isolation or intergenerational unemployment, may disadvantage people in addition to the mental illness, and explained the experience of the Commonwealth Rehabilitation Services Australia.

Prof. R. Meares presented a paper called "Towards a Secu-



B. Hocking, Vice-President ANZ-WAPR, and U. Agis, Secretary General ANZ-WAPR.

lar Spirituality", examining the relationship of the experience of well-being with high level "mental synthesis" functions investigated with an event-related potential study. The author showed experimental links found among some event-related potential study results, and subjective well-being and some personal ways to achieve that outcome in interaction with the environment.

In a similar direction, Dr. R. D'Souza presented his paper on the necessity of fostering spiritual values and wellbeing in clinical practice, considering the interpersonal neurobiology of wellbeing, rather to merely fight disease and distress,

Prof. Berk from Melbourne presented his paper on oxidative stress and alterations of free radical defences in both bipolar disorder and schizophrenia.

Prof. S. Sundram presented a paper on drug-treatment resistant schizophrenia, and some subsequent hypothesis related to the better outcome obtained with clozapine, and its possible relationship with the role of epidermal growth factor in neurodevelopment and in mature CNS.

In the course of the meeting, the Asian Journal of Psychiatry was presented.



AFRICA

Mental Health Day in Lobatse, Botswana.

Paul Sidandi, Regional Vice President WAPR Africa sends M. Moesi's article, published in Botswana Daily News, that reports how was celebrated the mental health day in Lobatse, Botswana.

Caregivers of mental disorder patients should ensure that they follow treatment procedures as prescribed to avoid relapse, says Dr Keneilwe Motlathledi. She urged caregivers to ensure that 'drug fatigue' did not occur in their patients. Dr Motlathledi, who was presenting on drug compliance at the Mental Health Commemorations at the Lobatse Mental Hospital, urged caregivers to ensure that their patients did not smoke dagga and other recreational drugs as it could worsen their situation. She noted that a stable home environment was important for a mental disorder patient, adding that it was difficult to take care of a mental disorder patient.

Dr Motlathledi said a compliance rate of 80 was considered good, adding that it was affected by among others the level of education of the patient and the kind of environment that the patient lived in.

Speaking on stigma and discrimination, the hospital's clinical psychologist, Ms Vonile Tladi, said the stigma surrounding mental disorders could increase feelings of loneliness and isolation of a patient. She noted that patients who were trying to overcome a mental health problem faced rejection and exclusion from the community, adding that the effect was the unwillingness of mental health patients to

seek help.

Ms Tladi also said nearly two thirds of all people with diagnosable mental disorders never sought treatment. In order to reduce stigma and discrimination, she said, the public needs to be educated on mental illness.

She argued that less discrimination would result in people with mental disorders becoming more honest about their illness which would result in early diagnosis, improved recovery and compliance.

Giving a keynote address, Dr Bazaraki Mayenga, the principal medical officer at Lobatse Mental Hospital, said about 60 000 people in Botswana were affected by mental disorders. She called on the community to advocate for the rights of people with mental disorders because they could not voice their feelings and needs.

Dr Mayenga urged the community to create awareness on the importance of mental disorders and develop strategies to seek services for these ailments.

Dr Paul Sidandi, a senior psychiatrist consultant at the hospital, denied allegations that patients were ill-treated and mishandled at the country's only mental health facility. He said that a patient who was forced to come to the hospital against his or her will and who resisted taking drugs could be seen as mistreated.

The commemorations were held under the topic: "Making Mental Health a Global Priority: Scaling up Services Through Citizen Advocacy and Action." .

*Summarised from M. Moesi.
Botswana Daily News www.gov.bw*



WHO - WAPR MEETING IN GENEVA, SWITZERLAND.

Reported by R. Guinea. Dep-Secretary General WAPR.

The announced WHO / WAPR meeting took place in Geneva, Switzerland, 5th December 2008. The main objective of the meeting was to explore the possibility of a revision of the WHO-WAPR Consensus Statement from 1996.

The meeting was attended by B. Saraceno, Director of WHO Department of Mental Health and Substances Abuse, S. Saxena and T. Yasamy from WHO, and M. Madianos, WAPR Presidente, I. Kosza, J. Dubuis, S. Styanidis and R. Guinea from the WAPR Board.

Saraceno gave a warm welcome to all attendants and reported that WAPR is in fact a NGO, in official status with WHO and consequently has the right to attend WHO governing bodies meetings and make statements.

When it comes to the issue of revising and updating the 1996 WHO/WAPR Consensus Statement, Saraceno explained WHO's position starting with some considerations. Saraceno explained that the present priorities of WHO are formally described in the "Mental Health Gap Programme" (www.who.int/mental/mhgap)

The main objective is to reduce the gap between those persons with mental health problems receiving treatment and those not receiving treatment. Special attention is given to citizens in low income countries, and with a particular focus on suicide prevention, substance abuse, alcohol, depression, mental disorders in childhood, psychosis and schizophrenia, dementia and epilepsy. Saraceno explained that WHO policy intends to promote very concrete actions to face the problems of people not being offered and not receiving treatment, especially in developing countries and in environments of limited resources.

In this context, Saraceno explained, WHO is developing some strategic lines of work, trying to find out the most efficient actions to be supported. WHO has very strict guidelines to assess the efficacy and effectiveness of the different available options (for more info, see "WHO Handbook for guideline development").

Regarding psychiatry, some particular factors should be taken into account. First, psychiatry is still regarded as the Cinderella of Medicine. Secondly, there is a very important bias in mental health and psychiatric research due to the fact that biologic research is given much more funding compared

to social research. WHO committees for assessment consider there is reasonable level of reliable research in primary and secondary levels of health care, but in the third level of care the evidence for interventions is considered limited by the responsible review committees. Saraceno underlined that "the lack of evidence" related to the interventions in the third level of prevention should not be confused with "evidence of lack of effectiveness", but it indicates more efforts are needed in order to assess the interventions made in tertiary level of health care and rehabilitation.

In Saraceno's point of view these circumstances give some practical consequences:

WHO will not revise the 1996 Consensus Statement. In the context of the WHO strategic work a revision would not have any practical consequences in the WHO programme.

WHO proposes three possible ways for immediate collaboration:

1.- Make contributions through the programme "Package of intervention", intended to build and assess programmes for direct intervention in the practice. This would be a very challenging pathway as the criteria for assessment on WHO is very strict. There would be two kinds of possible levels for this kind of packages: at the individual levels (specific initiatives) or at institutional level (institutional plans or programmes)

2.- To plan a common WHO-WAPR initiative in order to prepare a document regarding "Good practices in PSR", that should describe initiatives from the 6 regions of WHO. A consensus should be reached on how these good practices could be assessed.

3.- Participate on the XXI edition of the International Classification of Diseases. This would require the contribution of specialist in classification available to work in Geneva for some time.

M. Madianos, WAPR President, appreciated the information and the proposals, and reported on the initiative of changing the diagnostic label of "Schizophrenia".

Reported by R. Guinea.

Kindly revised by M. Borg and B. Saraceno.

The Situation in Gaza. WAPR Resolution.

Whereas:

The World Association for Psychosocial Rehabilitation is an advocacy organization for persons with mental illness and disability and is a Non Governmental Organization (NGO) in relation to the agencies of the United Nations; and,

Recognizing that:

The situation in Gaza impacts on the entire population: the disabled, the aged, children and the entire civilian population, and

Understanding that

The borders of Gaza are now closed to medical personnel and the delivery of medicines;

Therefor:

The WAPR resolves that all parties comply with the Geneva Conventions relating to issues of international conflict:

1. Persons disabled by physical and mental illness be permitted to exit Gaza, and
2. that medical and medical supplies be granted access in and out of Gaza.

Action to be taken

1. Transmission to all WAPR Board and members for comment, sign on;
2. Transmission of this resolution to all governing parties, agencies of the UN and news agencies, etc.

Athens, January, 12th. 2008.



Events

WAPR



WPA - CONGRESS Florence 2009.

*“Treatments in Psychiatry,
a new update”*

1 - 4 April.

Florence Congress Center.
Viale Strozzi. Florence. Italy.

www.wpa2009florence.org

In the course of the congress, it will take place the Regular WAPR-WPA Symposia:

“Recent advances in Psychosocial Rehabilitation”

- Assistant Prof. Marina Economou, Greece
 - Dr Antonio Maone, Italy
 - Dr Ricardo Guinea, Spain
 - Prof. Johannes Wancata, Austria
- Moderator: Prof. Michael G. Madianos, Greece.

WAPR WORLD CONGRESS BANGALORE 2009

12 to 15 November 2009, Bangalore.

*“One world:
quest for integration”*

Convencion Center.

National Institute of Mental health and
Neurosciences.
Bangalore. India.



www.wapr2009.org

Deadline dates:

Abstract Submission: May 15th.

Abstract acceptance & notification: June 30th.

Reduced Registration Fee: May 31st.





1986 - 2008.

**WORLD ASSOCIATION FOR PSYCHOSOCIAL REHABILITATION -ASSOCIATION MONDIALE POUR
LA RÉADAPTION PSYCHOSOCIALE -ASOCIACIÓN MUNDIAL PARA LA REHABILITACIÓN
PSICOSOCIAL**

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Dr Stelios Stylianidis, Treasurer, WAPR.
EPAPSY, 61 Grammou str, 151 24 Maroussi, Athens, Greece, Grèce, Grecia.
Tel: 0030 210 6141350, 6141351 Fax/Telecopier: 0030 210 6141352.

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Interest in Psychosocial Rehabilitation/Centre d' Interêts en readaptation psychosociale/Area de interés en rehabilitación psicosocial:

All money directed to WAPR should be sent by bank transfer to the following bank account/Tous les paiements addresses a l' AMRP doivent être deposes sur le compte à l' adresse suivant compte/ Todos los envíos de dinero para la AMRP deberán que ser enviados a esta cuenta:

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