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WAPR HEAD OFFICE.

Zografu Community Metal Heath Center. Davaki-Pindou 42. 15773 Athens. Greece. Tel/Fax.: +30 210 7481174 madianos@nurs.uoa.gr

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Edited in Hospital de Dia Madrid. c/ Manuel Marañón, 4. 28043 Madrid (Spain). Tel. ++34 91 7596692 Fax. ++34 91 3003355; guinea@hdmadrid.org. www.hdmadrid.org

World Association Psychosocial Rehabilitation
Editorial
WAPR

Models in Psychosocial Rehabilitacion: Adoption or adaptation[1]?

Madianos M.G.
Professor of Psychiatry University of Athens.
President, WAPR.

In psychiatry, and especially in the field of community mental health and psychosocial rehabilitation, we have been witnessed since the eighties, the development of series of evidence-based models of psychotherapies, biological therapies, crisis intervention techniques and psychosocial rehabilitation programs. These models, mainly developed and tested for their effectiveness by mental health experts mainly in Anglo-saxon countries, are widely spread all over the western hemisphere and elsewhere.

The possible explanation of the Anglo-saxon dominance in the proliferation of their models of mental health programs is 1) the hegemonism of English language in medical sciences, through the numerous publications in international scientific journals. There are examples of national scientific journals (Acta Scandinavica Psychiatrica) or international (European Psychiatry) or even specialized (Social Psychiatry/ Psychiatric Epidemiology, International Journal of Social Psychiatry) published only in the English language, 2) the wide reputation of the English language Universities and institutions in the area of mental health research, attracting English speaking young scholars who later will become the "messengers" of the gained scientific knowledge in their home countries, 3) the eclecticism of British and American schools of Psychiatry compared to the strong psychoanalytical influence of the francophone Psychiatry and 4) the National policy of USA and Great Britain in funding of mental health research.

Madianos M.G.
Professor of Psychiatry University of Athens.
Presidente, WAPR.

The cultural framework of a model: Cultural specificity or rigidity.

Copying or adapting a model of treatment in psychiatry and mental health care (including psychosocial rehabilitation) from one culture to another, brings out dilemmas or criticism. Firstly it is clear that social, economic and cultural factors are always influencing the expression of psychopathology through objective and subjective underlying mechanisms. The most illustrative example is the somatization of anxiety symptoms

manifested by patients in Southern Europe and Latin America versus the so-called psychologication of anxiety by patients living in northern countries. Secondly in the case of help seeking, the fear of stigma and other cultural barriers could cause significant delays in the appropriate treatment for severe mental disorder. Culture can affect familial attitudes and rituals towards openness and causing problems in public's awareness and care delivery. Culture could also influence chronicity in schizophrenia causing institutionalism in the community. Thirdly cultural and socioeconomic factors could be considered either negative or beneficial on the course of a mental disorder. The International Pilot study of Schizophrenia by W.H.O reported that patients living in villages in developing countries (Africa) had better outcome in community adjustment compared to patients coming from urban areas in western metropolitan cities. The community support in the villages played beneficial role in the community survival of these patients.

In psychosocial rehabilitation practice there are several programs and techniques proven to be effective in one country and in many cases these programs are adopted by professionals in other countries. In Lahore, Pakistan, the late Professor Chaudhry and his colleagues developed a model service based on the Fountain House model of New York in a modified version. Expressed Emotion Technique was applied in India, Japan and in other non- western countries. Another clinical example is the inappropriate use of foreign language in the exploration of psychotic psychopathology. Marcos in 1973 reported that when a patient, suffering from schizophrenia, is examined not in his/her native language, the semiology of psychotic symptoms is hidden. Falloon's Optimal Treatment of Schizophrenia was tested in various countries of different socio-cultural background. Assertive Community Treatment is another example of a widely spread model of rehabilitation in various cultures.

The basic issue for a model of mental health care and rehabilitation, is sociocultural responsiveness.

The example of expressed emotion with the "famous" critical comments of family members was designed and tested in English patients and families. How can it be measured in patients and families coming from southern European countries where personality characteristics are different compared to the emotionally inhibited behavior of persons living northern countries?

It is difficult for a model for a model of psychosocial rehabilitation program proven to be effective in a London borough to be adopted by a mental health team in a lower class borough in an urban area of a country in a different geopolitical area.

The issue is not adoption but adaptation. There are principles of community mental health such as comprehensiveness, continuity of care, sectorization, basic components in the development of community-based services, but there are also special requirements to meet the needs of local community mental patients.

In the recent years the waves of immigrants from Africa, Asia, Eastern Europe, coming in urban

areas of major European cities cause the crucial necessity for culturally responsive mental health and rehabilitation programs and services. It is difficult to decode the content of a delusion of an African patient, suffering from a psychotic illness, and a design a therapeutic intervention when the therapist's cultural background is so different from that of the patient. Another example is when the culture and the religion of non-western patients are barriers in their participation in recreation activities in a rehabilitation program of a community-based service in a western urban area.

Every model of psychosocial rehabilitation intervention has several stages and components with strong social and cultural background, which must be compatible to that of the participating patients in order to be effective.

Adaptation or development of new models of services or programs. The paradigm of a Community Mental Health Center a greater Athens, Greece.

In 1979 a small team of mental health professionals developed the first Community Mental Health Center in Greece in a lower social class area, in two boroughs of greater Athens. The team faced the dilemma in the choice of development of a model-service following a typical American urban model or constructing a new model of service.

The team inspired by the leadership being very sensitive in respecting the local sociopolitical and cultural environment gradually developed a model service compatible with the local community.

The Byron and Kessariani Community Mental Health Center was developed in line with the local sociopolitical environment and soon provided a full spectrum of effective mental health care and rehabilitation services and programs in the community (the two boroughs of Athens) with the use of the local community socioeconomic and cultural resources related to accessibility of the mental health care in response to community awareness in help-seeking, as well as the community survival and the integration of severely mentally ill patients, community residents, (including housing and employment), through volunteering and the support by the local agencies. Cultural and socioeconomic differences within the same catchment area were found confirming the need for cultural specificity of the mental health care. This Community Mental Health Center soon provided indices of effectiveness related to the decrease of crises and later in the reduction of hospitalizations of local residents in psychiatric institutions. The Center is now serving as a model service in Greece. It becomes apparent that the adaptation of any model of mental health care service and rehabilitation has to be compatible with the local culture and social economy. Adoption of a model of mental health-service is an easy solution, although the development of a brand new model culturally responsive to meet the specific mental health needs of the community is the desirable one.

Madianos M.G.
Professor of Psychiatry University of Athens
President, WAPR

(Footnotes)

[1] Modified version of presentation in I Congreso de Federación Española de Asociaciones de Rehabilitación Psychosocial, Madrid 24-25 Noviembre 2005.

World Association Psychosocial Rehabilitation
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The development of community psychiatry in Hungary. What can we learn from the developed countries in Europe?

Judit Harangozó MD, Andrea Bodrogi MD
Semmelweis University of Medicine, Centre for Community Psychiatry, Budapest

Abstract del editor.
Este artículo describe la situacion de las reformas del sistema de atencion a enfermos mentales en Hungria en la era post-comunista y se plantea que tipo de experiencias innovativas pueden ser incorporadas de las experiencias de otros paises. La autora refiere la situacion en que los expertos tienen la posibilidad de ejercer influencia pero encuentran dificultades relacionadas con la "autoestigmatizacion" de sentirse en desventaja con otros paises desarrollados y la resistencia de parte del sistema a aceptar las reformas necesarias. Se describe la situacion actual, la tentativa de instaurar una metodologia basada en el concepto de "Programa para el tratamiento óptimo" basado en principios generales de la Rehabilitacion Psicosocial. Se redfiere como desde el año 2000 la psiquiatria comunitaria ha pasado a formar parte del programa de los residentes de psiquiatría. La autora describe la dificultad de tasformar las prácticas clasicas hacia servicios basados en evidencia.

The following article intends to clarify the current situation of mental health reform in a post-communist country, Hungary, and, also, find the best ways of learning from research evidences and experiences of other countries.

Hungary, which is a country under social transition, has recently joined the European Union. While the establishment of laws garanteeing human rights and changes in the economic system is completed, health and social care systems still show the 'old socialist' standards:

- Low cost-effectiveness,
- Less sensitivity towards evidences, human rights and needs of clients,
- Institution-based financement,
- Doctors and bio-medical approach are dominant,
- Cliens show a mostly dependent behaviour with doctors and institutions,
- Lower representation of NGO's and private practice;
- Education did not change the paternalistic attitudes of professionals;
- Decision-making is not evidence-based either.

Mental health services have just started to go through changes: nowadays, we are in the exciting period of a reform process. Experts are able to influence this process, but we also have difficulties in finding out how to do it. *Should we try to implement programs, service models from the developed countries or should we find out our 'own ways'?*

Most of the people living in this part of the world are characterized by 'self-stigmatization'. We feel somehow 'inferior to the developed countries. We indentify ourselves with our unfortunate history – this is similar to how our patients interiorize stigmatization coming from others. As one of our politicians said recently: 'Germany is a happier country than Hungary. People have better hope for the future...'

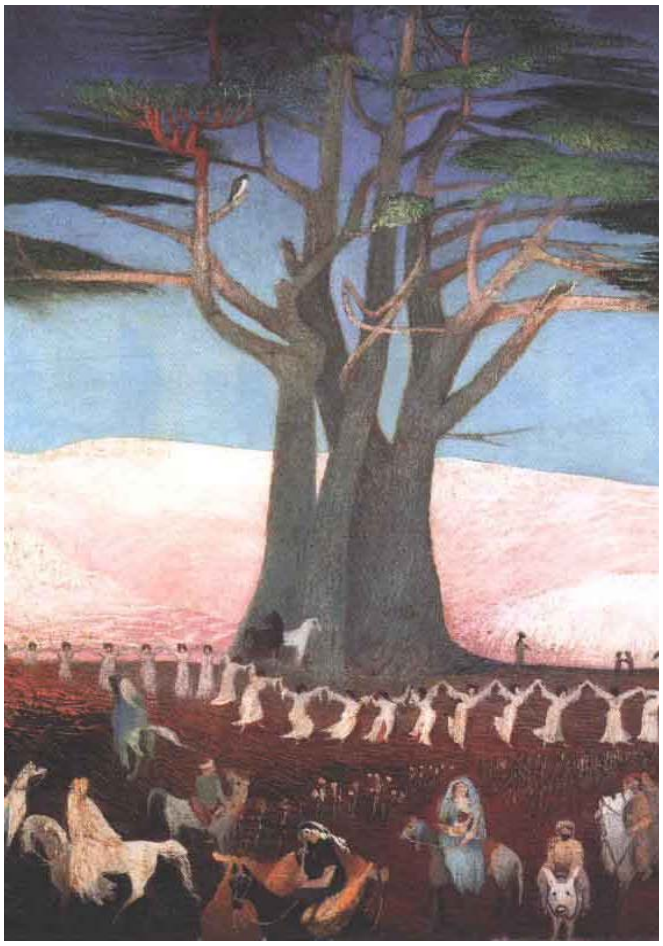
I think, we have to overcome this attitude. At first it is important to assess our advantages and disadvantages when planning mental health reforms. If we do so, we can see that besides a lot of disadvantages including lower resources and fewer traditions in the fields of human rights and need-based approach, still there are several advantages related to the traditional situation and attitudes. What are these?

- There was a well-functioning system of foster families before WWII.,
- Community based outpatient services were developed from the 1920s and from 1950 a nationwide system of these services was set up, now 130 of these serve a 10 million population.
- Inpatient care is usually provided in general hospital wards.
- Therapeutic communities provided an 'alternative' approach from the late 70s implementing the culture of new attitudes and therapies.
- There is a tradition of psychotherapies and a well-designed and developed system of training programmes for a wide range of mental health professionals.

It is also an advantage that the methodology of community psychiatry has been disseminated nation-wide and it is part of the post-graduate curriculum for both psychiatrists and social professionals. Our team, on a university and also an NGO basis, started to develop the various evidence-based forms and methods of community psychiatry in Hungary from 1995. We were also involved in the establishment of other NGOs: our foundation was the founder of Mental Health Interes Forum, the first nationwide users' advocacy organization and also helped the first family organization to start.

Our goal was to build up cooperations with experts who represent the highest international

The first author, Judit Harangozó, with a family.



Symbol of the Comm. Psych. Section of the Hung. Psychiatric Ass. Painting of T.K. Csontváry, a famous Hungarian painter who lived with schizophrenia. He started to paint when the voices said: 'You will be the greatest paintor in the world'.

quality. Ida Kosza, the vice president of WAPR helped us a lot to find the right direction. We joined to the Optimal Treatment Program by IRH Falloon, and organized an advisory board including Agnes Rupp, Leonard Stein, Benedetto Saraceno, Marianne Farkas and others in order to learn evidence-based methods of practice, education and research. We also implemented Supported employment program published by Drake and others. In a pilot project we set up an evidence-based community service in Budapest, trained professionals first on an NGO basis (supported by grants and pharmaceutical companies) and also published the standards and the (excellent) results. In a few years we also established the Community Psychiatry Section of the Hungarian Psychiatric Association. At the beginning of this process, the general opinion of psychiatrists was mostly against our approach. At this time, our NGO, Awakenings Foundation helped us to keep our independence. We were able to win EU grants for NGO's to start the work. In the past few years the acceptance of professionals has increased a lot.

What are the methods of our pilot program? They are based on the 'Optimal Treatment Program' mentioned above which uses evidence-based strategies:

- Asserive outreach with case management by multidisciplinary teams.
- Family and community based services.
- Care is based on personal goals (needs) of users and family members.
- Optimal biological treatments.
- Psychoeducation with the assessment and monitoring of early warning signs.
- Stress management including crisis management by problem-solving strategies and communication skills training .
- Social skills training.
- Other CBT strategies

From 2000, community psychiatry became part of the training programme of psychiatric residents. Community services started to develop from 2000 in the whole country when the minister of Social Affairs – a former psychiatrist – established community care and day clubs for mental patients as an obligatory and state-financed social service. Now 110 new services work in the country. Professionals of these services are trained for case management, team-work, family care, skills training, psychoeducation, stress-management, relapse prevention, drug monitoring strategies, compliance training, etc. These strategies are similar to those used in our pilot program and put down in psychiatric protocols. Though it was a great step, the current situation is quite controversial. The new services are not integrated to the medical system. Some social services defined themselves to serve people 'who don't want psychiatric treatment any more'. Antipsychiatry found its place as a social community psychiatry service. Many of the social professionals have an interest in the desintegration and also in

serving clients with less severe psychiatric problems. New services at many places do not serve the most disabled clients who overuse institutions. The waiting lists for long-term institutions did not decrease at all. As quality control is weak and social professionals can do what they 'feel needs to be done' the strategies we teach them are not really implemented in the every day practice.

It is a difficult question now, how to go on? What can we learn from the other European countries?

When looking out to the more developed parts of Europe we can be disappointed as well. National mental health policies are not evidence-based (nor on the level of practice, services and decisions), while a lot of money is spent on 'learning and studying the best practices' which are far from being best practices at all. The typical European culture of traditions and consensus works against changes in minds and/organizations as well. The emphasis on 'values' and trans-cultural differences all support the concept of 'being slow in real changes'.

200 of people living with schizophrenia in Hungary expressed their needs in a public survey in 2000. Their most important need was to recover from psychiatric illness. We have to know that the major value for them is this and all of them have the right to get the best treatments. Our services should provide community-based, need-based and family-based services with strategies supported by research evidences. Individualized therapies based on assessed needs can overcome most of the 'transcultural ' problems. New services should also focus on 'revolving door' and other severly handicapped groups of patients to provide accessibility for those who never get (good) services. New services should also be cost-effective. Hungary should avoid the practice of many developing and developed countries in Europe and other parts of the word where community services provide new resources for patients for whom the former services are efficient and sufficient still keeping the most severe patients unserved and stigmatized. Unfortunately this practice is typical. This way 'community psychiatry' is more a political slogen or fashion than a change in paradigm. There is no future for a development which is not cost-effective: waste of money is unethical and has no perspective for the future, either.

Will Hungary be able to overcome all these obstacles? Will Europe be able to change the traditional paradigm?

Budapest. Hungary.

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The Christian Meaning of Health in the Age of Globalisation.

Rev. Péter Szakács
Hungary

Abstract del Editor:
Esta ponencia fue presentada en el Congreso Hungaro de Rehabilitacion de 2006. Se propuso al autor examinar la cuestión de como puede interactuar la la creencia religiosa (en este caso, cristiana) en la conservación de la salud. El autor revisa el concepto de la OMS de Salud y analiza la importancia de la dimension espiritual en el concepto de salud como "estado de bienestar", en interacción con las dimensiones somática, psicológica y social. El autor plantea que en la era de la globalización, la dimension de la espiritualidad cristiana puede ser un elemento que contribuya a la salud y a la recuperación ayudando a la persona a situarse en una escala de valores, y tomar responsabilidades sobre si mismo.

My personal impressions on the congress in Budapest.

This was the first time I participated in a WAPR congress, and it made such a positive impression on me that I am taking the liberty to share with you readers some of my reflections. What I found most remarkable was the fact that apart from the high academic level of the lectures, there was an unmistakable, constructive, open atmosphere at the congress. It is clear that the WAPR team is more than a well-organised working group; it is a real cooperative team that supports its members with a communitarian spirit. For me, as a priest, it bespeaks not only a high level of academic work but also tangible human authenticity.

I would like to express my gratitude for the cultural and interdisciplinary openness shown in inviting me as a Catholic theologian. It was a great experience to give my presentation in a session together with Prof. Afzat Jahved who talked about the relationship between religion and mental health from the Islamic perspective. In my opinion, this WAPR congress offered a unique possibility to promote the dialogue between religions and cultures, thereby fostering dialogue between Islam and Christianity with mutual respect.

Globalisation was one of the main topics dealt with at the congress. I believe that it is thanks to the endeavours of the members of the WAPR International Scientific Committee that we could witness a global unity between the different nationalities. So this required a wide horizion, not only because of the picturesque views of Margaret Island, but also because the congress gave us an open and renewed intellectual vision, that in my opinion, is invaluable for the Hungarian academic world. This is also profoundly valuable because psychiatric rehabilitation was quite neglected and had struggled in isolation for a long time without being shown adequate appreciation. I would like to congratulate the vice-president Ida Kosza who organised the congress.

I would like to give you the abstract of my lecture which dealt with the relationship between the Christian concept of health and globalisation, along with some aspects of the psychosocial rehabilitation. My presentation was rather theoretical, focusing on the anthropological

foundations of the concept of health with less clinical experience than the preceding lectures. I intended my ideas to be thought-provoking seeking to inspire practical solutions in the future.

Introduction

In my introduction I raised the question: Can Christian belief contribute to the question of human health, and if the answer is in the affirmative, in what respect is this so? This vision is particularly pertinent in the changing socio-cultural context of our globalised world of present scientific improvements? What health model can Christianity offer to psychiatric rehabilitation that could be followed in the process of the rebuilding of a personality?

Some basic concepts in the Christian meaning of health.

According to the classical WHO definition that was created in 1946, health is a state of complete physical, mental and social well-being; on the basis of the Ottawa Charter, 1986, it may be defined as a dynamic equilibrium that enables an individual or group to identify and to realize aspirations, to satisfy needs, and to change or cope with the environment dynamically and harmoniously. Christian theological and philosophical anthropology also starts from the basic dimensions of human nature when it seeks to define health. Together with medicine, psychology, social studies and ecology, Christian anthropology accepts this definition of health but enriches it with an explicit reference to the spiritual dimension of health that points to the relationship between the human person, the transcendent world and God, the Creator and Saviour. The Church has a special vocation and competence to nurture this spiritual dimension. As we know, the relationship between spirituality and the quality of life is not alien to the WHO, since in its quality of life questionnaire (WHOQOL) it is dealt with as a separate dimension. The Christian approach adds to this spiritual dimension a complex moral value scale where health is regarded as a basic human value. Christian morality strives to create responsible health behaviour by motivating the free decisions of the individual's conscience from

Budapest. Hungary.

different angles. During this process the somatic, psychic, spiritual, and moral dimensions, as well as the social and ecological ones of the human person, should support each other in mutual harmony to enhance the global health and self-realisation of the individual and the community.

The Hungarian word for health (egészség) is closer to the English "wholesomeness". This expression derives from the word "whole", which implies that all dimensions of a human person are in unity and harmony in a healthy state. This truth expressed by the Hungarian language is in perfect accordance with the perception of the Church. The health (wholesomeness) of a person implies the harmonious balance and cooperation between biological, psychic, spiritual-moral and socio-ecological dimensions.

Different scientific fields are competent in the examination of the role of the different anthropological dimensions in health: medicine (somatic dimension); psychology (psychic dimension); social studies and ecology (socio-ecological dimension); philosophy, theology and ethics (spiritual and moral dimension). We know that these four dimensions are in constant interaction with each other in a person. For this reason, the different scientific fields dealing with the varying dimensions should try to accomplish an interdisciplinary cooperation so as to enable us to get a real picture of the individuals' and communities' quality of life, or else influence it adequately.

Every discipline naturally focuses on its own field, but the competence of other disciplines cannot be ignored. We know how one can arrive at a false diagnosis if one follows the reductionist biomedicinal approach (fortunately, nowadays this is rarely seen, at least on the theoretical level), which treats the patient only from a biological aspect irrespective of the fact that several physical illnesses relate to various negative psychic processes that manifest somatically. There could be another – also reductionist – psychological approach that uses an exclusively psychic approach in treating the patient's spiritual conflicts, even though the patient has obvious problems with his or her world-view, or a religious/ moral crisis in the background, which then emerge even on psychic levels. It is a similar mistake to emphasise exclusively the religious involvement – although religion has a predominantly positive effect on health – in somatic and psychiatric illnesses which might lead to the omission of effective medical interventions.

Applying the four-dimensional model mentioned above to a particular example, it is possible that a person who is confined to a wheelchair but is spiritually well-balanced and who has come to terms with his or her limitations, is a healthier person globally than somebody who is unimpaired physically, but spiritually empty and demoralised, psychically frustrated, and injured in his or her social relationships. Similarly, if we look at the field of rehabilitation, we can reach better tendencies in recovery if we pay attention to more anthropological dimensions in rebuilding the personality of the patient. At this point I would like to refer to the frequent experience of involving energies of the moral and spiritual dimensions, which helps patients who take part in the rehabilitation programmes in coping with their physical or psychic difficulties, or aids in the positive integration of their permanent impairments into their personalities. At the same time a health problem usually raises or strengthens the patient's interest in the final, transcendent questions of life, and this growing spiritual openness during the healing work cannot be overlooked.

Some correlations between the Christian meaning of health and the globalisation process

The challenges of globalisation

The scientific-technical and the socio-economic improvements gave way to the globalisation process which offers numerous new possibilities in the cooperation of humankind, even in the field of health promotion. The work of the WHO is an excellent example in this regard. The Church itself has a global missionary self-awareness, as it tries to gather the believers from different nations into one community. Through the Pontifical Council for the Pastoral Assistance to Health Care Workers, the Catholic Church makes several efforts even on a global level for the human health; one of the emphasized criteria of its activity is the close cooperation with the WHO.[1]

At the same time, the context of globalisation brings serious challenges and this is being pointed out even by the WHO in the Bangkok Charter in 2005. These challenges put persons of this era on trial especially in psychic and spiritual ways. As a consequence of the fast socio-economic changes there can be an increase in the disturbance of the sense of personal identity, a feeling of defencelessness and loneliness, the occurrence of the anomic depressive symptomatology, whilst the individual's sense of coherence could decrease, all of these being very important psychic factors in the state of health. On the spiritual level, wide social

strata are threatened by impersonalisation, loss of identity on different levels, a spiritually superficial and rootless life meaning, as well as by the depletion of spiritual energies. The absence of objectives in life and a wholesome world-view can lead to moral indifference and value crisis. A grave temptation of globalisation is to build the global unity of humankind unilaterally on economic interests. The Bangkok Charter explicitly mentions the dangers of "commercialisation". Because of the growing importance of economic factors human capital (this includes also social, moral and spiritual capital)[2] can be overshadowed. Globalisation has several positive aspects on the social level. However, while the social macro-structures are gaining strength, its micro-structures could weaken: first and foremost, the basis of the structures, i.e. the human person together with his or her four-dimensional harmonious unity, as well as the family, the smaller communities, and the national and social identity.

What can Christianity offer to the human person longing for health in the age of globalisation?

The Christian approach can contribute positively to the improvement of the state of health in many ways.

It supplies the person with spiritual power, and this spiritual health-resource energizes the other three human dimensions from the spiritual dimension.[3]

The Christian perception of health gives health a fundamental position on the value-scale. With this value-scale it provides a stable point in a world that is increasingly full of uncertain factors, it gives meaning and direction to life and helps to process the events of life properly. It is well-known that religious exercises, especially prayer and the participation in religious services, are efficient in dealing with conflicts, and that they have a coping strategy feature.[4] In a word, the Christian faith augments the so-called spiritual and moral capital of the person.

This moral horizon stimulates personal responsibility in one's health lifestyle, and gives a motivation for responsible cooperation with health promotion projects organised on different levels, which are spreading as a positive effect of globalisation.

This responsibility taken for one's health and that of others enhances the experience of self-efficacy and coherence-identity, and this increased social role-taking supports the believers' social identity.[5] The enhancement of the personal and social identity is of key importance in the era of globalisation. Through its moral norms it motivates health behaviours and the forms of behaviour that avoid detrimental actions to health.

In our globalised world that is threatened by impersonalisation – what Durkheim described as an anomic state on the psychosocial level – the Christian faith represents a global worldview that is contemporaneously human-centred by its personal and loving picture of God and an anthropological view that is based on the dignity of the human person. So it gives believers the experience of personalisation whilst offering effective social support. One of the significant possibilities for this personalisation is the doctor-patient relationship.

We believe that this global health meaning, promoted also through a Christian anthropology (either by the global anthropological approach that covers all dimensions of the human person, or by the increasingly global work of national and international health structures), can contribute to the fruitful cooperation of different disciplines, and to the realisation of a more complete and wholesome quality of life.

Rev. Péter Szakács
Hungary

(Footnotes)

[1] Cf.: Pontificio Consiglio della Pastorale per gli Operatori Sanitari,Piano di lavoro, Cittá del Vaticano, 1998, pp. 25, 46.

[2]Kopp Mária – Skrabski Árpád, «A magyarság társadalmi és erkölcsi tõkéje», in Confessio, 2003/1, pp. 39-47.

[3] Cf.: Kosza Ida, «Népbetegség-e a depresszió? », in. Kórház, 1998/ 10, pp. 15-16.

[4]Pikó Bettina, «A vallás és egészség kapcsolatának szociológiai értelmezése», in. www.mtapti.hu/mszt/19993/piko.htm, consulted: 2006. 09.15.

[5] SKRABSKI ÁRPÁD – KOPP MÁRIA – RÓZSA SÁNDOR – RÉTHELYI JÁNOS, «A koherencia mint a lelki és testi egészség alapvetõ meghatározója a mai magyar társadalomban», in. Mentálhigiéné és Pszichoszomatika 5(2004)1, pp.7-25.

World Association Psychosocial Rehabilitation
Collaborations WAPR

Involvement of Experienced People in Mental Health

Report on a two year EU-funded project 'EX-IN' (Experienced Involvement), developing training programmes for people with experience of using mental health services to work as trainers and peer supports.

Jorg Utschakowski,
Initiative for Social Rehabilitacion, Bremen. Germany.

WHY EXPERIENCED INVOLVEMENT?

The project has been developed on the premise that a person with experience of mental health problems can use that experience to understand and support others with similar difficulties. Mental health care and research has a long history of dealing with users as an object of scientific enquiry – creating knowledge that has been developed from an outside position. Knowledge of mental illness and care from the inside, acquired through experience, is subjective and thus by comparison scientifically weak. And people as patients are traditionally viewed as limited in their capacity to make a meaningful contribution. This has led to a one-dimensional view of mental disorder, stigmatisation and professionally determined treatment.

Many aspects of what helps people recover are not addressed by a care system derived from this perspective and many users are not satisfied with the service they receive. People who experience mental health distress and use mental health services bring a vast source of knowledge about supportive attitudes, methods and structures, which is still not recognised sufficiently in the existing range of mental health care.

Many studies have shown that the involvement of experienced people in mental health services and in counselling leads to greater empowerment, development of social networks, improved social activities, more responsibility, extended coping and problem-solving skills and, critically, a sense of hope. The service offered becomes more flexible, providing more choice and concrete, practical information that is more orientated on recovery (Davidson, Chinman, Sells, Rowe 2005; Hardiman, Theriot, Hodges 2005).

Involvement of experienced people enables a better understanding of processes and experiences of mental distress and a better knowledge of how and why people recover. Experienced involvement also has the potential to improve the content and delivery of training for mental health professionals, and to improve mental health service outcomes that better reflect the service users' needs.

A growing number of training bodies, universities and services are involving experienced people. The problem is that in many cases the users have, due to the lack of structured training for their work, no acknowledged status. To improve the involvement of people with lived experience, to strengthen their abilities and to develop a base for an appropriate employment, the project is developing a curriculum that reflects the specific situation of users, and imparts the necessary skills.

WHAT IS AN EXPERT BY EXPERIENCE?

'The concept of "expert by experience" in healthcare is someone who has active

> experience with illness, handicaps and/or mental health problems and who has gained specific expertise in living with this illness, handicap and/or mental health problem and also with socio-cultural and institutional contexts where the illness, handicap or mental health problem gets significance'. (van Haaster, Koster 2005).

The focus of involving "experts by experience" is to actively draw upon personal experiences as a resource. For that reason people must be able to reflect on their experiences and their coping. This is connected with the competence and the willingness to communicate personal experiences as part of this self-reflection. (Wildwasser, Weglaufhaus „Villa Stöckle", Tauwetter 2006).

To avoid a perspective which is exclusively orientated on individual experience, beliefs and values;

> 'to become an "expert by experience" it is demanded that one reflects about ones own experiences and shares experiences with others who have same kind of experiences. It is demanded that the experts test their own experiences related to a variety of other experiences in different situations and of other persons' (van Haaster, Koster 2005).'

THE EX-IN PROJECT

The number of mental health services and training institutions that actively involve experts by experience is slowly growing in Europe. There are some countries such as the UK and Netherlands that have a longer tradition in this area, and thus have more practice in experienced involvement. Most European countries are just at the beginning, so the number of training and qualification opportunities for experienced people are even less.

To share and to package the different experiences of qualification and practice of experts by experience, a two year (to October 2007) European project funded by the Leonardo da Vinci programme was developed. 10 organisations from Norway, Sweden, the Netherlands, UK, Germany and Slovenia were chosen which have a special expertise in experienced involvement. In the frame of the EX-IN (Experienced-Involvement) project experienced people, mental health professionals and trainers are working together to develop and test a curriculum. This will include a core programme of modules for experienced people to become qualified to work as experts in mental health services, or as experts in training measures.

To avoid reproducing traditional knowledge and expectations, the project has the clear task of developing a training that is based upon personal experience.

The first step is to work from the experience of the individual participant. By reflection and structuring this experience he or she can develop an experiential 'I-knowledge'. If we take into account that it is necessary to develop a shared perspective of what are helpful attitudes, methods and structures for someone who experiences mental health distress, it is necessary that the participants also exchange their experiences to develop a 'We-knowledge". Thereby the experience of unusual mental experiences or distress is understood in both an individual and collective sense.

Alongside this approach it is important that the EX-IN qualification supports the improvement of skills, abilities and application of methods. In the transfer of this knowledge the focus is again to reflect theory on the basis of the experience. For example, if people are to work as teachers, then it is important that they know what content and what methods support a process where people learn to understand the perspective of experienced people.

On that base the following modules have been developed in the EX-IN project:
Basic modules:

- Experience and Participation (Netherlands)
- Empowerment (Slovenia)

- Trialog between experienced people, carers and professionals (Germany)
- Recovery (Norway and Sweden)

Specialised modules:

- Peer Advocacy (Norway)
- Assessment (UK)
- Health promoting attitudes (UK)
- Hearing Voices (Netherlands)
- Peer Support (Germany)
- Teaching (Germany)

Beneath that a handbook, an interactive game and a film will be produced.

The EX-IN project will enhance the contribution of the knowledge and capabilities of experienced people to mental health service provision. It will contribute to greater user and recovery orientation, and less discrimination and demeaning provision of mental health care. The project will also contribute to an improved status of experienced people. In establishing a qualification we expect to improve the employment opportunities with an adequate salary for experienced people.

PROBLEMS?

Of course the project also raises some difficult issues. The first is the question of whether a qualification of experienced people carries the risk of distorting individual experience. The training must be organised in a very respectful and sensitive way to maintain participants individuality.

Another issue arises when we consider that many people using professional mental health care are not satisfied with the service they receive. What role can an expert by experience play in this system? Is it a kind of non-professional professionalism? Will professionals accept a colleague who has been or can be their patient? Will there be concurrence about which approach is better?

What we have to ensure is that the intention to intensively involve experienced people has to be accompanied by public awareness and debate. To support experienced people in their new role, networks have to be organised where people can exchange ideas and experiences.

We are just at a starting point of professional involvement of 'experts by experience', and we don't yet know all the answers. But the need for the improvement of mental health services and the potential positive impact of experienced involvement in care and training makes the journey into unfamiliar territory very worthwhile.

More information www.ex-in.info
or Jorg Utschakowski : utschakowski@fokus-fortbildung.de

Information about the author:
Jorg Utschakowski, 44, employed at the Initiative for social rehabilitation in Germany, Coordinator of several European projects for mental health, trainer for mental health professionals and experienced people, lecturer at the university of applied sciences in Bremen. M ervyn Morris, 48, is Professor of Community Mental Health at the University of Central England, and Professor II at University College Buskerud, Norway.

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World Association Psychosocial Rehabilitation
Editorial
WAPR

A call for action.
WAPR DECLARATION ATHENS 2006

Whereas,

Throughout the world there are 35 to 40 million persons with serious mental disorder; and,

Recognizing that half of the world's population survives on less than $2 per day and 1.2 billion persons on less than one dollar a day; and

Observing increasing recruitment of health and mental health personnel from developing countries to work in developed countries; and,

Whereas the lack of the above mentioned resources and primary health care has contributed annually to the deaths of millions of persons with severe mental disorders; and,

Cognizant of the World Health Organization's Global Priority Agenda for greater assistance and efforts to deal with HIV-AIDS,TB and Malaria;

Therefore;

The World Association for Psychosocial Rehabilitation, at it's World Congress in Athens, Greece, October 14th, 2006

Urges the adoption of policies to save millions of lives.

1. Recommends financial support and appropriate compensation to permit expansion of educational institutions in developing countries for the recruitment of their health and mental health personnel;

2. Urges increased education and appropriate training to provide for increased numbers of health and mental health personnel in developing countries;

3. Recommends the organization and strengthening of family and other associations, including industry and trade unions to promote the survival, employment and well being of persons with severe mental disorders and disabilities;

4. Calls the attention of the World's leaders, the public and health and mental health authorities to the urgent need to save the lives of millions and to include severe mental illness along with HIV-AIDS, Malaria and TB in the WHO Global Priorities Agenda;

Calls upon all NGO's,religious and lay leaders and professional associations to join with the World Association for Psychosocial Rehabilitation to alert the public to press for action to save the lives of the millions who are dying and advocate for the inclusion of severe mental disorder in the WHO Global Priority Agenda.

Approved by the Assembly.

The IX World Congress of Psychosocial Rehabilitacion, Athens 12-15 October 2006:

The Anniversary Congress 1986-2006.

A Final Report by The President, Michael Madrianos.

In October 12-15, 2006 the Board of the World Association for Psychosocial Rehabilitation (WAPR) and its Hellenic Branch organized the IX World Congress of Psychosocial Rehabilitation.
The Athens Congress followed the very successful Congresses held in Lyon 1986, Barcelona 1989, Montreal 1991, Dublin 1993, Rotterdam 1996, Hamburg 19998, Paris 2000 and New York 2003.
In Athens we celebrated the 20th anniversary of WAPR and the Congress was specially designed for this reason. The Congress venue was the International Congress Center of Megaron Moussikis. The Congress agency responsible for the organization of the Congress was AFEA Corporate Travel Consultants and Congress Services of Athens. The Congress was sponsored by the World Health Organization (WHO) and co-sponsored by the World Psychiatric Association, World Federation for Mental Health, the University of Athens, the Municipality of Athens and the Ministry of Health and Social Solidarity.

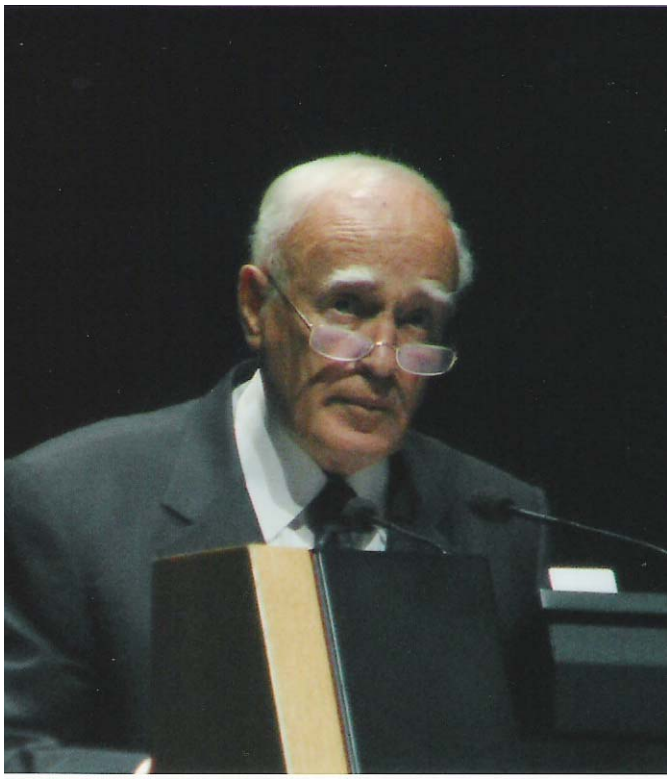
Michael Madrianos, WAPR new President and Lourdes Ladrido- Ignacio, WAPR President Elect.

Past WAPR President; Angelo Barbato's speech; .

The 9th World Congress was under the aegis of His Excellency the President of the Hellenic Republic Karolos Papoulias, who declared the Congress open in the Opening Ceremony. This Ceremony was brightened by the presence of the Minister of Health, the President of the Academy of Athens, the Rector of the University of Athens, the President of EUFAMI and other prominent foreign professionals in the field of mental health as well as by the orchestral music performed by the Municipality of Athens Symphonic Orchestra.

In this Congress in all the former Presidents of WAPR were given a commemorative award.
The topic of the Congress was: Psychosocial Rehabilitation coming of age in a globalized world:

Practices, policy, research. In the Congress almost all the most prominent professionals in the field of psychosocial rehabilitation were given lectures or workshops. There were approximate 400 scientific events including 30 key and special lectures, 40 special sessions, 128 free communications, 6 workshops and advanced institute and 155 posters. The total number of participants was 1045 including more than 100 users and families. The organizers provided 30 scholarships for young scholars coming from low- income countries. For more than 200 participants there was no fee in charge. The registered participants represented 45 countries: Greece (563), Australia (18), Austria (3), Belgium (5), Brazil (10), Bulgaria (8), Canada (28), Cyprus (5), Czech Republic (4), Denmark (3), Estonia (1), Finland (7), France (25), Germany (10), Ghana (2), Hungary (2), India (25), Israel (5), Palestine (2), Italy (65), Japan (6), Korea (8), Mexico (5), Netherlands (12), New Zealand (2), Norway (25), Pakistan (1), Philippines (9), Poland (2), Portugal (4), South



Mr. Karolos Papoulias,
The President of the Helenic Republic.

Africa (11), South Korea (8), Spain (50), Sweden (2), Switzerland (2), Taiwan (2), UK (10), USA (40), F.Y.R.O.M. (1), Egypt (1), Sri Lanka (1), Malaysia (1), Botswana (1), Jamaica (1), Serbia (1). In these numbers 85 invited speakers and members of the board should be added.

The topics of the Congress were the most crucial issues like deinstitutionalization and globalization, fighting stigma, human rights violations, alternatives to asylums, social psychiatry and rehabilitation, psychotherapies and rehabilitation in chronic mental illness, drug maintenance, family burden, alliances among consumers and professionals, models of care, children's rehabilitation.

In the Congress two very important declarations were unanimously approved related to human rights of persons suffering from mental illness.

It is commonly accepted that our anniversary Congress served very successfully as a global forum for exchanging ideas and experiences for the

Improving mental health care in developing countries.

15-19th February, 2007
Lahore- Pakistan.
WPA Section on Psychiatry in Developing Countries & South Asian Forum on Mental Health & Psychiatry

Establishing our Future Psychosocial Rehabilitation Goals Towards 2010 and Beyond.

20 – 23 march 2007
Brackenfell, Cape Town
Hosted at CAB Conference Centre by Mental Health NPO Stakeholders. (MHNS) and
www.mentalhealth.org.za

WPA - WAPR Regional Meeting

Apr. 20 (Friday), 2007
Lotte Hotel World, Seoul, Korea
www.wpa2007seoul.org
www.yonginwhocc.or.kr
Further Info: Tae-Yeon Hwang MD, PhD
Tel: +82-31-288-0206, Fax: +82-31-288-0363

Mental Health in Europe: the contribution of psychiatric nursing practice and science.

"Discover the field, enjoy the scenery"
22-23 March 2007
Congress Centre Hotel Haarhuis
Stationsplein 1, Arnhem, The Netherlands
Foundation Congress of HORATIO - European Psychiatric Nurses.

Emmanuele Lomonaco
In memoriam.

WAPR Italian branch has been badly struck by the untimely death of Emanuele Lomonaco. Emanuele was Head of the Department of Mental Health of Biella, in Northwestern Italy, and a Board member of WAPR Italian chapter.

Under his leadership Biella mental health department became in the last years an outstanding example of high standard service characterized by emphasis on prevention and social/vocational rehabilitation, in addition to clinical care, together with a strong community involvement and user participation. As a result of his interest in quality improvement and innovative approaches to mental health services evaluation, he introduced in Biella a pilot model of service accreditation by consumers. He planned to present his experience at Athens WAPR congress, but unfortunately he was unable to attend because of his ill-health. However, he managed to get funds to allow the participation of a large group of professionals, consumers and local authorities from Biella, who organized a symposium on *"The collaboration at local level between the department of mental health, the local authorities and the private sector"* .

We miss you, Emanuele, but we will remember you warmth and enthusiasm, as well as your commitment to the improvement of community care of mental disorders.

Emmanuele Lomonaco.

1986 - 2006

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

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Rehabilitación, Psicofármacos y Reduccionismo: lo que nos enseñan los estudios sobre psicofármacos.

José J Uriarte. WAPR Board Member.
jota.jota@telefonica.net

Hace un tiempo leí un artículo en el que se revisaba la situación actual y el futuro previsible a corto plazo del desarrollo de tratamientos farmacológicos para la esquizofrenia[1]. En el mismo, y entre otras cosas, el autor reflexionaba acerca de un modo frecuente y asentado de pensamiento, que aunque de un simplismo obvio, a menudo parece escapársenos a la hora de hablar de tratamiento y de rehabilitación: la tendencia al reduccionismo, tanto desde el campo de lo biológico como del psicosocial, enturbia a menudo el sentido común y complica sobremanera las recomendaciones terapéuticas y asistenciales. Así que Kane, autor de dicho artículo (un experto en psicofármacos más que en rehabilitación), termina por decir, literalmente:

Es bastante inocente asumir que una sola intervención vaya a conseguir el efecto deseado sobre la totalidad de los variados signos y síntomas (positivos, negativos, afectivos, cognitivos, conductuales) que se asocian a la esquizofrenia…

No parece que haya que ser un genio para darse cuenta de que, en el nivel de conocimientos actuales acerca de la esquizofrenia, y de la mayoría de los trastornos mentales, buscar remedios simples, basados en una intervención única, sea farmacológica o psicosocial, es muy inocente…o muy prepotente.

De forma similar, la reciente publicación de los resultados de estudios observacionales de efectividad a gran escala y con largos periodos de seguimiento de los fármacos antipsicóticos, está suponiendo un importante cuestionamiento acerca del conocimiento que tenemos de los resultados de nuestras actuaciones asistenciales (reflexión que no debiera limitarse al campo de los tratamientos farmacológicos). Lo más sorprendente es, precisamente, el escaso y contradictorio conocimiento que tenemos sobre la efectividad, en la vida real, de nuestras intervenciones y del impacto de las mismas sobre las personas que atendemos. Y el propio campo de la rehabilitación, un eslabón esencial en la asistencia a los pacientes más graves, no puede permanecer ajeno a este análisis y reflexión, que en muchos sentidos, tiene mucha más importancia que la que quizás se le atribuye a primera vista. Es evidente para mí que lo que llamamos rehabilitación, la atención integrada sanitaria y psicosocial a la enfermedad mental grave, no es un compartimiento estanco e independiente del tratamiento, sino que es el tratamiento en sí mismo de los pacientes más graves y con un curso más crónico. Pero en ocasiones parece que, cegados por nuestros propios prejuicios ideológicos, teóricos, formativos, e incluso intereses económicos y de poder, nos empeñamos en compartimentalizar el abordaje a nuestros pacientes en espacios y secuencias terapéuticas artificiales, lo que obliga a nuestros pacientes a adaptarse a nuestra oferta asistencial más que viceversa. La defensa de un modelo u otro de atención, de priorización de intervenciones y de organización del personal asistencial de los diversos servicios no es ajeno a intereses corporativos y luchas de poder en las que cada profesional trata de afianzar su rol. El riesgo es una creciente fragmentación de los servicios y de los componente fundamentales de la asistencia, lejos de los equipos multidisciplinares cuya Biblia, siempre, ha sido la de mantener la capacidad de proporcionar

tratamientos integrados, y en equipo, con continuidad de cuidados a largo plazo.

Estudios como el americano CATIE[2] o el británico y más reciente CUtLASS[3] concluyen sorprendentemente que los nuevos tratamientos antipsicóticos tienen escasas ventajas aparentes sobre los antiguos, o que al menos no suponen un impacto revolucionario sobre la evolución clínica de nuestros pacientes. Otros estudios han puesto en cuestión también la efectividad de muchas intervenciones psicosociales cuando se utilizan de forma aislada que parecen no ser capaces de obtener resultados espectaculares ni duraderos por mucho empeño, calidad técnica y entusiasmo que se ponga.

Así que a la espera de mayores conocimientos, y de mejores tratamientos, los mejores resultados se obtienen con un tratamiento integrado, una combinación de tratamiento farmacológico óptimo, un seguimiento cercano y asertivo y psicoeducación para nuestros pacientes y sus familias. O sea, lo que el recientemente fallecido Prof. Falloon proponía en su proyecto OTP[4].

O lo que concluye el propio Lieberman, director del estudio CATIE:

El potencial de los fármacos antipsicóticos requiere de una organización asistencial que favorezca el contacto con los servicios, el adecuado control de los problemas de tolerancia, la continuidad de cuidados, y la provisión de intervenciones psicosociales.

Obviamente.

José J Uriarte
jota.jota@telefonica.net

(Footnotes)

[1] *The Future of Pharmacotherapy for Schizophrenia. Kane JM, Malhotra A. 2003*

[2] *Lieberman JA, Stroup TS, McEvoy JP et al. (2005), Effectiveness of antipsychotic drugs in patients with chronic schizophrenia. N Engl J Med 353(12):1209-1223*

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[4]*Falloon IRH, OTP Collaborators. Optimal treatment for psychosis in an international multisite demonstration project. Psychiatr Serv. 1999;50:615 –618*

(Full Information in www.wapr.info)

President:
Michael Madianos
Zografou Comm Ment. Health C.
Davaki-Pindou 42
15773 Athens Greece
madianos@nurs.uoa.gr

President-Elect
Lourdes Ladrido-Ignacio
Manila Philippines
ignacio@ibahn.net

Secretary-General
Afzal Javed
Nuneaton. United Kingdom
afzal.javed@ntlworld.com

Immediate Past-President
Angelo Barbato
Milano Italy
dirba@tin.it,
barbato@marionegri.it

Past Presidents
Zebulon Taintor
New YorkUSA
taintz01@med.nyu.edu,
taintor@nki.rfmh.org

Jacques Dubuis
Cedex France
jacques.dubuis@ch-le-vinatier.fr,
jacques.dubuis@wanadoo.fr

M. Parameshvara Deva
Ipoh Malaysia
devaparameshvara@hotmail.com

Benedetto Saraceno
World Health Organization
Geneva Switzerland
saracenob@who.int

Martin Gittelma
New York,USA
gittem01@med.nyu.edu

Gaston Harnois.
Montréal, Québec
Canada
hargas@douglas.mcgill.edu

Oliver Wilson.
Scotland, United Kingdom
o.wilson@virgin.net

Vice Presidents
Ida Kosza
Hungary
kosza@mail.datanet.hu

Marianne Farkas
Boston. USA.
mfarkas@bu.edu

Representing Families
Ernesto Muggia.
Milano. Italy.
errnestomuggia@tin.it

Representing Consumers
René Van der Male
Utrecht The Netherlands
r.van.der.male@utrech.nl

Kobus Jordaan
Care Haven
South Africa
mental@iafrica.com

Representing Voluntary Organisations
Geraldine Marshall
British Columbia
Canada
gmarshall@lynx.bc.ca

Liaison to UN and Its Agencies
Humberto Martinez.
New York, USA
Dr44hlm@pol.net

Treasurer
Stelios Stylianidis
Athens. Greece
epapsy@otenet.gr

Deputy Secretary-General
Ricardo Guinea
Madrid, Spain
guinea@hdmadrid.org,

Regional Vice-Presidents and Deputies
AFRICA
Paul Sidandi,
Lobatse Botswana
paul.sidandi@it.bw

Leana Uys,
Durban South Africa
uys@nu.ac.za

Arouna Ouédraogo
CHU Yalgado Ouédraogo
Ouagadougou Burkina Faso
arounaouedraogo@univ-ouaga.bf

AMERICAS
Roger Montenegro.
Argentina.
rmontenegro@wpanet.org

Lorraine Barnaby
Kingston Jamaica
teneight8@aol.com

EASTERN MEDITERRANEAN
Haroon Rashid Chaudhry.
Lahore Pakistan
pprc@wol.net.pk

Ibrahim Murad
Jerusalem. Israel.
jamalmurad@hotmail.com

EUROPE
Edvard Hauff.
Oslo Norway
edvard.hauff@medisin.uio.no

Antonio Maone
Roma Italy
maone@tin.it

Marc Habib.
France.

SOUTH-EAST ASIA
Thyloth Murali.
Bangalore, India
mut47@nimhans.kar.nic.in,
reva_th9@rediffmail.com

Nalaka Mendis,
Columbo ; Sri Lanka
nalaka@sri.lanka.net

WESTERN PACIFIC
M. Parameshvara Deva
Ipoh Malaysia
devaparameshvara@hotmail.com

Tae-Yeon Huang.WHO Collaborating Center for Psychosocial Rehabilitacion.
Korea.
lilymh@dreamwiz.com

Members at Large

Naotaka Shinfuku
Fukuoka, Japan.
shinfuku@seinan-gu.ac.jp

Maria Economu.
Greece.

Dale Jonhson.
Huston. USA.
DLJOHNSON@uh.edu

Anjum Bashir.
Essex. UK
anjumDR@aol.com

Yair Carlos Bar-El
Har Adar, Israel
barel4@bezeqint.net

Gregory C. Bunt
New York, USA
gbunt@daytop.org

Anna Meneghelli
Milano, Italy
annameneghelli@tiscali.it

Bernard Jacob
Vottem Belgium
bernard.jacob@aigs.be

Gabriele Rocca
Milano Italy
garocca@libero.it

Michael Sadre Chirazi-Stark
Asklepios Westklinikum
Hamburg, Germany
m.stark@asklepios.com

John Talbott
Baltimore, USA
jtalbott@psych.umaryland.edu

José J. Uriarte
Bilbao. Spain
josejuan.uriarteuriarte@osakidetza.net

Marit Borg
Drammen; Norway.
maritbor@online.no