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Association Mondiale pour la Réadaptation Psychosociale.

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WAPR Bulletin

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Errata: It was incorrectly reported in the October issue that Dr. Ida Kosda was Regional South-Asia Vicepresident. In fact, Dr. Kosda is WAPR Vice-President. Dr. Lorraine Barnabi was also incorrectly reported as Vice-President; instead, Dr. Barnabi is Regional Vice-President for Las Americas.

Les Défis de la Réhabilitation Psychosociale dans le cadre de la Santé Publique.

Angelo Barbato. WAPR President.

On peut dire que l'Association mondiale pour la réhabilitation psychosociale (AMRP) est un nouveau venu dans le domaine de la santé mentale. Elle fut établie en France en 1986 et célébrera donc son vingtième anniversaire lors de son neuvième congrès, qui se tiendra cette année à Athènes du 12 au 15 Octobre. Sa croissance continue au cours des dernières années illustre bien l'importance croissante de la prévention et de la réduction des handicaps sociaux comme fondement pour le soin communautaire des personnes atteintes de troubles mentaux sévères. Notre association travaille de près avec l'Organisation mondiale de la santé, avec le Conseil économique et social des Nations Unies ainsi qu'avec le Bureau international du travail. De plus, elle maintient une collaboration étroite avec la Commission européenne, l'Institut africain de réhabilitation et plusieurs autres organismes de par le monde.

Soulignons d'abord que l'adhésion à l'Association est accessible non seulement aux professionnels de la santé mentale mais aussi aux chercheurs dans diverses disciplines, aux administrateurs, aux personnes responsables du développement des politiques, aux usagers et à leurs proches et aux groupes revendicateurs. L'AMRP est donc à la fois une société scientifique, une organisation professionnelle multidisciplinaire et un groupe revendicateur. Et ceci parce que son but premier est d'offrir à toute personne et à tous les groupes un lieu constant pour une discussion des sujets d'importance pour les soins à long terme en matière de santé mentale. De plus, l'AMRP, en sa qualité d'organisme non gouvernemental international, s'est engagée à développer une atmosphère propice

à des relations multi nationales dont les fondements sont l'égalité dans les partenariats et la collaboration au-delà des frontières culturelles, politiques, religieuses et linguistiques. Notre but est de rejoindre un auditoire mondial, surmontant les limites des échanges scientifiques trop souvent limités aux professionnels des pays prospères de l'Ouest.

Entre nos congrès mondiaux, nous considérons très important de promouvoir les initiatives qui se poursuivent à travers le monde, d'établir des liens entre nos associations nationales et de chercher à faire se rejoindre les activités qui se tiennent au niveau local et celles qui s'étendent au plan mondial. Dans cette perspective j'ai le plaisir d'accueillir dans l'AMRP les associations nationales du Japon, de la Jamaïque et du Canada, qui ont décidé récemment de se joindre à nous. Je profite de l'occasion pour envoyer mes vœux de bon travail aux amis canadiens, qui sont en train d'organiser leur colloque, qui se déroulera à Chicoutimi du 24 au 26 Mai. Je rappelle des bons exemples de stratégie de partenariat international dont j'ai été témoin dans ces derniers temps:

- La création du Forum du Sud-est asiatique pour la santé mentale et la psychiatrie, grâce aux efforts de nos représentants dans cette région. Le Forum a convoqué avec un grand succès deux rencontres au Sri Lanka en septembre 2003 et en juillet 2005.
- La réunion régionale à Lahore, organisée par nos amis pakistanais en septembre 2004, où j'ai été ému de voir des psychiatres indiens et pakistanais travailler ensemble pour la première fois depuis nombre d'années.

- La conférence internationale consacrée au mouvement des consommateurs de services en santé mentale, organisée en partenariat avec l'Organisation Mondiale de la santé, qui s'est déroulée à Milan en juin 2005. Cette conférence a présenté une perspective mondiale sur le mouvement des consommateurs, en offrant un forum pour la présentation des points de vue et des opinions des consommateurs sur de nombreux points importants. On a eu l'occasion pour une clarification mutuelle et un débat ouvert entre les consommateurs, les professionnels et les proches, où on a souligné les enjeux communs et les perspectives différentes.
- La conférence organisée à Madrid par notre chapitre espagnol, avec la participation de plusieurs représentants des pays européens.

La réhabilitation psychosociale a pris sa place et ne peut plus être perçue comme la Cendrillon dans le monde de la santé mentale. Il est grand temps de contempler à la fois le passé et le futur, de revoir ses fondations originales, ses développements passés et son avenir. C'est ce que nous ferons lors de notre prochain congrès mondial où nous explorerons trois domaines importants: la recherche, les pratiques et les politiques.

Il y a déjà dix ans, un exposé conjoint de l'Association mondiale de la santé et de notre Association définissait la réadaptation psychosociale une stratégie qui cherche à accroître les possibilités pour tout individu atteint de problèmes de santé mentale afin qu'ils puissent trouver leur fonctionnement maximal dans la communauté, tout en améliorant les compétences des individus et en favorisant des changements environnementaux.

Aujourd'hui, nous devons placer la réhabilitation avec décision dans le cadre de la santé publique en rapprochant la rigueur scientifique, la perspective humaniste, la sensibilité au contexte socio-

politique, l'expérience des soins quotidiens et la prise en charge de leur destin par les personnes aux prises avec des problèmes de santé mentale.

Au besoin, nous devons nager à contre-courant, en nous opposant au réductionnisme biomédical et technique qui pose un danger, même lorsqu'il est pratiqué à bon escient. Malheureusement, nous savons que la route de l'enfer est pavée de bonnes intentions.

L'évolution présente du domaine de la santé mentale exige que l'AMRP renforce ses relations avec les sociétés scientifiques dont la mission est semblable à la nôtre, par exemple, l'Association mondiale pour la psychiatrie sociale et la Société internationale pour le traitement psychologique de la schizophrénie. Enfin, le rôle de plus en plus important des usagers (ou clients, consommateurs, survivants, etc) à titre de protagonistes actifs en réhabilitation exige de nous tous que nous portions une attention particulière au mouvement des consommateurs, à leurs besoins, à leurs perspectives, leurs buts et leurs demandes. Dans ce but, est très importante la participation de l'AMRP au projet de l'OMS de réaliser l'Atlas des mouvements des usagers dans le monde.

Nous avons parcouru un court chemin, mais la route qui reste encore à parcourir sera beaucoup plus longue. Nous invitons à se mettre en route avec nous tous ceux qui désirent combattre les handicaps liés à la santé mentale et améliorer la qualité de vie des gens qui cherchent à trouver leur santé et leur juste participation sociale.

Angelo Barbato

Rehabilitation and self determination.

Centres for Psychiatric Rehabilitation promote recovery and social inclusion.
5th National Conference in Italy of the Network of Day Care Centers in Psychiatry.
Paola Carozza.

The 5th National Conference of the National Day Care Centers in Psychiatry was held in L'Aquila (Italy) from 10-12 November 2005. The theme of the conference was "Rehabilitation and self-determination - centres for Psychiatric Rehabilitation promote processes of recovery and of social inclusion". The conference was attended by about 400 representatives of various professions (psychiatrists, psychologists, social workers, therapists in rehabilitation, teachers, nurses, psychology students, medical students specialising in psychiatry), users and their families, associations of volunteers, politicians and civic dignitaries.

The conference represented an opportunity to meet the training needs of the many workers who deal with people with psychiatric disabilities and to affirm the role of psychiatric rehabilitation in promoting processes of recovery, of empowerment and of inclusion in the community, which ought to be the main objectives of the whole system of mental health services. This view reflects recent changes in the conceptualisation of mental illness. In fact, the traditional assumption, according to which mental illness blocks growth and development and prevents people from being complete citizens, is disappearing for good. This change is due partly to a number of important studies, conducted in the last thirty years, and partly to the spread of effective treatments for helping psychiatric patients to gain valued social roles. Together, these factors have begun to break down the conviction that a serious psychiatric impairment means living without purpose, or enduring lifelong disability. There are, therefore, well-founded reasons for revising the prognosis for people with serious mental illness.

It follows that greater attention needs to be paid to the tools and methods with which to counteract the disabling effects of mental illness on the individuals that suffer from it. Thus, psychiatric rehabilitation, by emphasizing the treatment of the consequences of the pathology,



WAPR Meeting in Milan. June, 2005.

rather than the pathology itself, has contributed to reducing not only the impairments and the related symptoms, but also the functional limitations, the disabilities and the handicaps associated with mental illness.

In view of such considerations, the conference focused on the followings topics:

- The need use an accredited method that will confer on psychiatric rehabilitation the dignity of an established technique, and overcome the widespread belief that using a specific method and behavioural guidelines nullifies the creative and human component of the treatment. Technique is a word that is often misunderstood and maligned, but it can be defined simply as the application of scientific knowledge to the solution of individual and societal problems. In the case of psychiatric rehabilitation, technique can be thought of as a human technique.

- The need to overcome the tendency to identify rehabilitation with the physical places where it is carried out (day-centres, supported



housing, therapeutic communities, etc.) — a tendency that is probably a hang-over from the days when rehabilitation was carried out in mental hospitals. Indeed, psychiatric rehabilitation is not a specific type of programme, such as “day treatment for people with serious mental impairments” or “24-hour treatment for chronic and untreatable patients”, nor a specific kind of vocational programme. Psychiatric rehabilitation is a general approach that can inform all programmes aimed at increasing people’s independent functioning, in any of setting.

- The need to improve treatments aimed at helping users to choose, get and maintain valued social roles. Unfortunately, many people with psychiatric disabilities, despite living in the community, do not manage to work, are not able to take up their studies again, or to live independently. This increases the number of in-patients, improperly hospitalised and institutionalised, or of “stabilised” outpatients, who are actually de-socialised.

- The need to build a partnership between families and professionals. Since a large percentage of people with psychiatric disabilities live with their family (more than 60%) and most patients who live by themselves have frequent contacts with their parents, the family both strongly influences the outcome of rehabilitation and plays a crucial role in the recovery of their relatives..

- In the past, the only types of data about rehabilitation that were collected were those related to recidivism, employment outcomes and total days in the community. These early studies suggested the need

for more refined measures of all the different outcomes of interest. As outcome measurements in psychiatric rehabilitation studies are becoming more refined, i.e. assessing degrees of improvement over time rather than partial situations at one point in time, the findings with respect to psychiatric rehabilitation treatments are becoming more targeted and specific. Consistent with psychiatric rehabilitation’s emphasis on an individual’s direction and choice, studies have confirmed that a person with a psychiatric disability can be a primary and direct source of information about the effectiveness of the programme, which suggests that in future, research ought to be carried out by mixed groups of official researchers, consumers and relatives (Participatory Action Research).

- The existence of many factors that contribute to the development of chronicity, among which the role of the mental health services themselves must be investigated. This knowledge has led to ever greater doubts concerning the assumption that chronicity is an inevitable outcome of schizophrenia, but rather it is the result of a combination of various factors, some of them inside, and some of them outside the individual.

- The need to train workers to cope with psychiatric disability and to make them competent to help disabled people to gain valued social roles and to develop processes of recovery.

A further stimulus was provided by talks given by two well-known users/survivors, Judi Chamberlin and Ron Coleman, who spoke about their experience of recovery, as well about its relationship with the processes of psychiatric rehabilitation and empowerment.

At the end of the Conference, the WAPR Board member Antonio Maone has been elected as chairman of the Network.

Paola Carozza
Head, Center for Psychiatric Rehabilitation
Department of Mental Health,
Chieti, Italy

WHO / WAPR consumers' views.

Sylvia Caras, PhD.

Intervention in Milano, June 2005

Ciao. I'm delighted to be with you, my first visit to Milan. I live in California, near San Francisco. In addition to what you just heard, here's my consumer credential: I have four diagnoses, have been in six hospitals, three times against my will; I've been handcuffed, electroshocked and chemically restrained. For me, the path was finding others, getting and giving support, and then turning from victim to advocate. I've been invited to talk here about organizing in the United States, and to comment on the report from the World Health Organization report which we have just heard.

I've prepared some general remarks and then will make some specific comments about WHO's work. And I've put links to a few resources and these remarks on the web for you at peoplewho.org. Select the WAPR link.

I'll start with 90 seconds of history.

In the twentieth century, as some societies moved from manufacturing to service, in the developed world the self help movement and the human rights movement parented the mental patient movement. This new movement inherited the self-help principles of volunteering, mutuality, valuing the experiential, and deflating professional privilege, along with the civil rights focus of other disability rights, gay rights, and women's movement groups and was nurtured by the politics of empowerment in an increasingly self-help oriented society.

In the 60's, the mental patient movement challenged psychiatry's hold on explaining behavior but remained separatist. By the 80's, diagnosed people were changing the mental health system from within. Some groups maintained a strong anti_psychiatry ideology; society was urged to increase social acceptance of human diversity. Some groups developed institutional collaborations or at least interactions - partnerships.

Either way, there is a shared user value base of self_determination, dignity, hope, reciprocity, witnessing, spirituality, diversity, ... and personal competence is connected with a desire for and a willingness to take public action. (1)

But in the United States, we have no national consumer organization. There are at least five federally funded bodies (2) that sometimes serve as substitutes. The family voice is well-funded and very strong, often presenting loved ones as objects of pity, as public safety hazards unless medicated. Consumers can act when the danger is sufficient. The threat of increasing unconsented interventions in New York and California mobilized many, but unsuccessfully. Progressives fear the United States is moving away from democracy in our political, social, and health practices.

In California, for twenty years we have had a now state-funded client network which joins with other social justice and provider organizations to



WAPR Milan meeting. June 2005.

advocate for housing and choice. However, the network has been slow to develop across the state and it's recognition in the capitol is not matched at the local level.

In my community, in Santa Cruz, we have a county-funded peer-run drop-in which is vibrant, providing support and personal enrichment and sometimes advocating around county budget issues.

There are other groups and other voices, a patchwork that is often fringe and that generally doesn't ally with each other or with the cross-disability or social justice community.

So that's the United States.

The World Health Organization stated in 1978 at Alma-Ata (3) that health is holistic, biopsychosocial, and I would add spiritual, and that "the people have the right and duty to participate individually and collectively in the planning and implementation (organization, operation and control, and I would add evaluation,) of their health care," and that a target is a "socially and economically productive life."

Mental health has been failing on all counts - though users and survivors are beginning to be included, that inclusion is not yet meaningful and effective. Partly because there is a pervasive assumption of our disorder; a cloaked process, a lack of transparency about how the system works; and an unwillingness to shift to a more-than-medical understanding. I hope that this convening will signal a change in direction.

Now, about organizing

There are three things that I think are preventing us from finding each other, each other, money, and shame.

About each other, when we are together, some are timid, some bully, arguments become about each other instead of about actions, we resent those who gain power or collude, we challenge each other for political correctness. At first when I began to give presentations at meetings, I was afraid of the professionals, afraid everything I said would be seen as a symptom and labeled - grandiose, paranoid, litigious ... and I would shrink into myself. But lately I'm more afraid of the critique and challenge of my colleagues, that my views and behaviors are inadequate because they don't match some one else's views. WHO has noted in prior reports

that in much of the developing world, patient/consumer movements are embryonic and there is little community or self-perception of consumers or carers as partners in the mental health policy development process. If we don't learn to put personal agendas second to the networking and rights work that needs doing, policy will continue to be about us, without us. Can we join in our shared pain and outrage and move on to make changes that will serve us and better our life quality.

The second obstacle: About money: the strong US local consumer organizations are dependent on public funding, and many consumer leaders earn in the public system. One can be risking one's job security by trying to make change from within. But there are ways to organize without much funding, using technology and volunteer energy. Start by thinking local and small, then linking with the group in the next city, then the next, - soon there is a network.

And lastly about shame: many have internalized the dependence taught by the medical model, that we have a disease, that doctor knows best, that we must defer to medical authority, and that we must show gratitude so the enforcers won't feel guilt about the indignities imposed on us. It's hard to stand tall when we are positioned as a threat by those who say they are on our side. Our sense of shame inhibits social participation, creates painful loneliness, deprives us of belonging, prevents us from finding each other.



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Therefore, organize.

A peer network provides a touchstone, a place of acceptance and safety for the self, for the soul. We give each other a sense of the possible.

But we need a business model that is based on mostly in-kind resources; we need role models; and we need goals. Users and survivors need to ask ourselves the hard questions - What do we care about? What are our responsibilities? How do we carry them out? What kind of a community do we want within our organization? And in the place where our organization is, what kind of a community there? How do we know if we have been successful in our organizing? What's the biggest obstacle?

We need to stop being reactive, distracted by wheel-spinning discussions about what we call ourselves and anti-stigma campaigns that only embed negative stereotypes. We need to be proactive, advocates for ourselves. And we need to emphasize mutuality and connection as much as action and opposition. So far we have no clear sound-byte message. I'm anticipating today and tomorrow listening to your ideas.

What we do have is the World Network of Users and Survivors of Psychiatry, WNUSP, doing dazzling global human rights work, and you are the base. Your local group. Your state group. And we have at least two other groups represented here which are doing international work, David Oaks from MindFreedom Support Coalition International, and People Who, the internet resources I maintain. So, how leverage all this work? I'm interested in information and communication technology and building e communities and would like to exchange email addresses with all of you who like email. 20 million Italians use the internet. If you use email and can speak and write basic English, I'd be pleased to be in touch and I, and I expect others here, could even come to your cities for a few days to help you get started. Let's join together towards a first goal — that all medical interventions must have full and informed consent. Internationally, this goal is embedded in the concept that all people have legal capacity.

As much as we need to find our own identity, we need equally to create coalitions – the disability community understands the indignity of forced interventions and disrespect; the social justice community understands



social exclusion. Once we are able to move past our own pain, move towards the mainstream, we have natural allies who will join with the motto of the disability world: Nothing About Me Without Me.

End notes:

1. Extracted from *Owning Madness*, www.peoplewho.org/sylvia/om
2. CONTAC, Clearinghouse, NEC, SOCSI, NACSMHA
3. euro.who.int/aboutwho/policy/20010827_1
4. This presentation was informed by e conversations with several US leaders. Sheila Cooper made this point.

“Mental Health: the View of Users”

(About the international conference: Observations and proposals of “Young Minds Group”).

Stefania Bussolotti, Simone Castellucci, Francesca Cirrincione, Davide Stefanizzi, Alessio Tellatin.

We are some users of PROGRAMMA 2000 and since March 2005 we have been organizing ourselves into an association called “Young Minds Group”.

PROGRAMMA 2000 is the first Italian program of identification and early intervention in the mental illness at its beginning and it is realized in the Mental Health Department of Azienda Ospedaliera Ospedale Niguarda ca' Granda, Milano. It is addressed to people between 17 and 30 and it is led by a group of operators that plan and realize personalized treatments for each one of the 89 users, who are at the moment followed by the program.

These treatments can include individual psychotherapy, social support (school, job, computer and music lessons), support to the families, therapeutic groups for anxiety handling and social competence. The users are involved in each phase of the project. The “Young Minds Group” is one of the activities of PROGRAMMA 2000 and it has the following aims:

- To improve the service interacting with the staff of PROGRAMMA 2000;
- To organize and manage aggregative and social events for patients and operators;
- To spread information about early intervention in mental illness;

As a group of users we participate in the international WAPR congress “Mental Health: the View of Users”, which took place on 10 -11 June 2005 at the Science and Technology National Museum of Milan.

Among the several topics discussed during the conference, we would like to stress the most important for us and for every user:

- The declaration of World Health Organization in 2003, stating that we are facing a “global emergency” of human rights violation into the mental health system.
- The still existing use of electroshock employed against the patient’s will and without anaesthesia.
- The need for the patient to be informed and agree to each type of psychiatric treatment and the idea of creating a mental health system totally based on patient’s will.
- The need to set a humane and respectful relationship between operator and user to better the mental and the emotional condition of people approaching a psychiatric therapy.
- The urgency to implement some initiatives and projects in defence of human rights into the mental health services.

WAPR meeting was very interesting and constructive but too less attention was paid to a theme that in our opinion is really essential: the early intervention in mental illness.

As they say, “Prevention is better than cure”. Speaking of already suffering people, prevent means do something as early as possible. Early intervention has an essential role, as it can stop the person from getting irremediably worse and give him a chance of complete recover.

A mental illness usually spoils one’s adolescence and youth but with a proper therapy is possible to live a fruitful present and also have a future, avoiding the heavy influence of the disease on following periods of life.

In conclusion, we think that in the conference there was the right scope for criticisms and claims but not enough for the “sane” aspects of psychiatry. Also the Australian users association, in its project, remarks the importance and utility of early intervention.

Referring to another topic discussed during the congress, the problem of stigma, we want to underline the role of means of communication. In our opinion mass media should improve the knowledge on mental illness because only some correct information can help people to understand what a mental trouble is and prevent prejudice. Unfortunately, nowadays we are still far from this, because these matters are considered only when a very serious news story occurs.

We think that a different message should reach every single person in the society. In this view, an important contribution comes from the projects carried on by the users as a proof of their various experiences and of the existence of services able to provide help and proper support.

Caregiving for people with severe mental disorders in China.

WAPR Editor. (Report based on *Family Caregiving Of Clients With Mental Illness In China*, articles featured in www.psychosocial.com by K. Yip)

In the People Republic of China, it is estimated that there are 16 millions of adults with mental illness; 30 millions of adolescents and children with emotional and behavioral problems and numerous old people with dementia and mental problems

It is estimated that over 90% of persons with schizophrenia live with and are taken cared by their family members. The burden of family caregiving in the People's Republic of China is further intensified by its unique social, cultural and legal contexts.

In the recent 20 years, China has gradually regained its momentum on economic development and modernization. Related welfare and social services examined their deficits and weaknesses and in 1987, the Council approved a formal document. 'Opinions about Strengthening Mental Health Work'.

Drastic economic development in the People's Republic of China brought along not only change in industrial production and urban life but also commercialization of welfare and medical services. China government began to withdraw funding from mental hospitals. In 1990s, staff in hospitals run by the Ministry of Public Health had to find 30% to 50% for their take home pay from

the charging of admitted patients. In 2000, many hospitals have to run on a self-sufficient basis. For those deprived and poor clients with mental illness, they had to be admitted by mental hospitals run by the Ministry of Civil Affairs.

As a result, many family caregivers are left unattended in an endless struggle with family members with mental illness. Facing all these challenges, some recommendations have been made in different means to create opportunities to improve family caregiving of clients of mental illness: supporting family to support clients, relative mutual support group and locality support network, professional training and commitment, and culturally sensitive family counseling.



Psychiatric Reform and Psychosocial Rehabilitation in Brazil.

Alice Hirdes.

Psychiatric Nursing Teacher, researcher. alicehirdes@gmail.com

The law that deals with Psychiatric Reform in Brazil (no. 10216) was sanctioned on April 6th, 2001. In the 90's, the Ministry of Health, Alice Hirdes, introduced vast legislation that would govern all actions concerning an adequate treatment for people suffering mental disorders. Since more than 10 years have passed, the process of implementing Psychiatric Reform should have already consolidated all over the country. However, there are important differences regarding the structure of the services in the Brazilian states, as well as in different regions in each state, despite advances that took place. Whereas some cities have a net of services in mental health, others transfer people suffering mental disorders to specialized hospitals as a solution for acute and chronic cases.

In the last decades, in the Brazilian psychiatric reform, it can be noticed that we have had periods when discussions were intensified and new services and programs were implemented and periods when the process was slow. Historically, we can consider the 80's and the 90's as significant periods regarding the discussion about the re-structuring of psychiatric assistance in our country. The elimination of psychiatric hospitals is supported by the Brazilian health policies, whose main theoretical and political turning points were the Eight National Conference on Health (1986), the First National Conference on Mental Health (1987), the Second National Conference on Mental Health (1992), and the Third National Conference on Mental Health (2001). An important historical moment for the mental health sector in Brazil - which led to changes carried out by the Ministry of Health - was the Regional Conference on the Re-

structuring of Psychiatric Assistance that was held in Caracas, Venezuela, in 1990.

After these conferences, more attention has been given to the implementation of services to replace specialized hospitals, such as: a net of services to deal with mental health, Centers for Psychosocial Attention (CAPS), psychiatric rooms in regular hospitals, therapeutic workshops/meetings, and therapeutic houses, according to the particularities and needs of each community. Funds are provided for these communities by the Ministry and local management is in charge of the services; the aim is to use the funds for alternative services rather than psychiatric admission. So, there will compatibility between the procedures for actions in mental health and the assistance model.

Historically, costs of psychiatric assistance had always referred to expenses with admissions in psychiatric hospitals because they constituted the main form of treatment for people suffering mental disorders. Therefore, cost reports always referred to the hospital admission. Ten years after the Ministry of Health (Law no. 189) changed the way funds for mental health services were distributed, there is still a disconnection among the policies and expenses with admissions in psychiatric hospitals and community services. However, the tendency is to eliminate the model of psychiatric hospitals.

Nowadays, an important fact that is meaningful in the history of mental health in our country is the inclusion of actions concerning mental health in a governmental program called Programa de Saúde da Família (PSF), a program carried out in public health that aims at assisting families. According to the data collected by WHO/PAHO, arriving at effective solutions means that mental health is approached by the concept of public health. Another governmental

initiative is a program called Programa de Volta para Casa: it aims at socially re-integrating people suffering mental disorders after having spent a long time in hospitals; it includes some pension for psychosocial rehabilitation. Both initiatives privilege attention given in the community that is consolidated by local services.

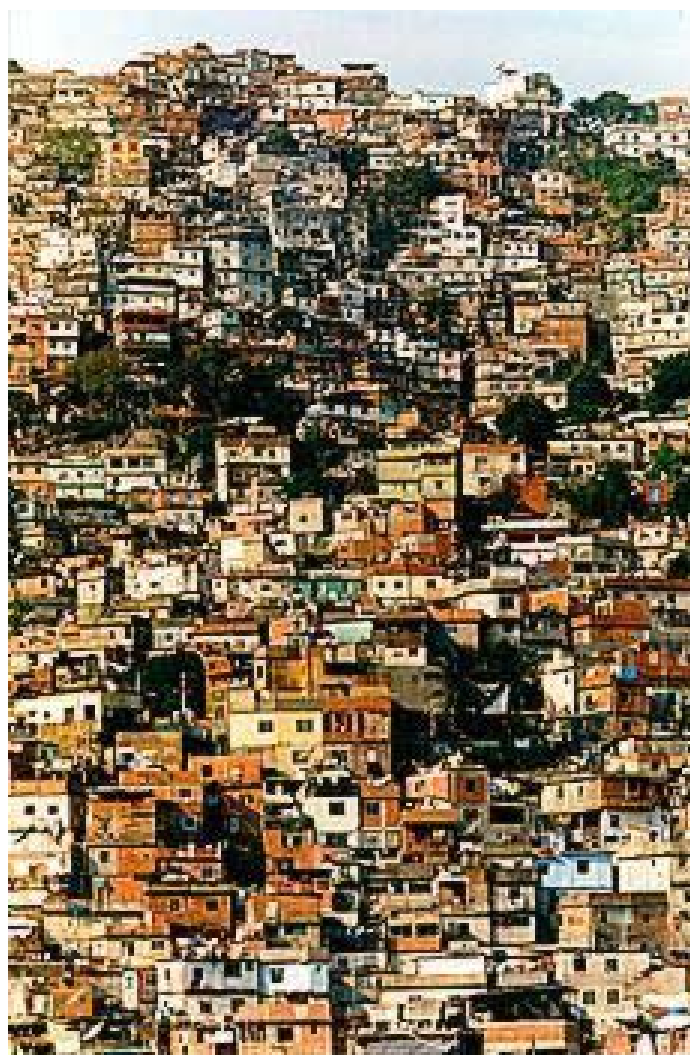
The insertion of actions related to mental health in the PSF demands that professionals be prepared and that concepts of a broad clinic be accepted, so that there can be a change in the paradigm. Adopting some beliefs that can be applied to our national reality and that supply our demands and the structure of the services (such as the inclusion of mental health care in public health services) can considerably change the scenario of mental health assistance. Below, I have listed some concepts that can be considered a methodological synthesis:

- the patient is a citizen, in spite of his/her psychopathologic situation;
- physical and mental suffering cannot be dissociated – environmental, social, and mental conditions are part of inter-related ecologies;
- psychosis, and experiences related to sufferings and violence take place in certain areas: in the family, in the community, in people's existential universes.
- the patient is the whole family; observation, listening, and research must be family-oriented;
- families that are more vulnerable and have more difficulties must be given primary attention;
- professionals must abandon the term "unstructured family" and try to understand the different ways each culture has to deal with suffering and overcome it;
- Partnership is fundamental to operate psychosocial rehabilitation. To do that, the whole sanitary organization must be involved and priority must be given to associations with public policies and with the resources the community can offer.

The principles above serve as a guide to actions carried out in community mental health. The emphasis given to actions in mental health in specific places in the community is the essence of psychiatric de-institutionalization. The insertion of actions in mental

health in the Programa de Saúde da Família (PSF) is a strategy adopted by the Ministry of Health to re-orientate the model of working with mental health. This is a very important initiative because, by emphasizing actions in the community, it privileges the social reintegration of psychotic patients, the follow-up of patients who have left the hospitals, the use of community resources, the attempt to eliminate the stigma attached to mental disorders. However, these actions must go beyond the centralization of actions in a biomedical model, or in the disorder itself by using an approach that links treatment and psychosocial rehabilitation.

I believe that many advances have taken place due to the experiences with de-institutionalization. However, I think that, despite the fact that many services use the shield of



Favelas, Rio de Janeiro. Brasil.



Rio de Janeiro. Brasil.

psychiatric reform in our country, there is constant need to observe and question current practices so that new services follow the proposed references, in our case, the Italian psychiatric reform. We also have to keep in mind that services such as CAPS must be temporary solutions and that a critical review must be regularly done; otherwise, the tendency is for new services that work on the psychiatric reform to become institutionalized. To avoid this, it is crucial to teach professionals who work with health and mental health (so that they get the tools they need), to sensitize people involved in health management, and to permanently analyze the quality of the services.

The Brazilian psychiatric reform, through the implementation of new programs in mental health as well as the insertion of actions concerning mental health in public health, allows that new approaches, principles, values, and attention to people suffering mental disorders be considered. Thus, more adequate forms to deal with mental disorders will be found in the family, and in the social and cultural environment. In our vast territory, we have several cultures, several Brazilian countries, in fact, but some characteristics are common to all: the affection of our people and the adaptation to difficult situations. It means that reform implementations are not homogeneous – practices are carried out according to the theoretical conception the professionals have. I see there are general principles that orientate the work, but, ultimately, they are subordinated to specific settings where those practices

happen. In this context, to make people participate and become subjects of their own history must be the professionals' primary commitment.

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CEDEP Seminair Paris 3-5 June 2006.
www.vvvgg.be/CEDEP

Instituto Jose Germain. 20 años de reforma psiquiátrica en el Área metropolitana de Madrid.

Report from WAPR Editor. Madrid (Spain)

Summary.

The old Leganes Psychiatric hospital reform started twenty years ago. A wide reform was expected to change the care of a wide metropolitan area, with more than one milion inhabitants, taking in account the principles of equity, universality and accesibility. Now, the old hospital has been completely closed and a new network of comunity services and faclilities provide wide medical atencion, residential care,suported labor and social inclusion.



New mental health facilities in Leganes, Madrid (Spain).

Hace ahora 20 años, en diciembre de 1985, se inició un proceso de reforma psiquiátrica, que partiendo del viejo Hospital Psiquiátrico de Leganés, iba a cambiar la forma de atención a la salud mental de más de un millón de habitantes del sur metropolitano de Madrid. El objetivo era el cierre del viejo manicomio y la creación de una red alternativa, comunitaria, de atención psiquiátrica que posibilitará una atención a los

problemas de salud mental de la población más eficiente y digna; una asistencia anclada en los principios de equidad, universalidad, descentralización y desinstitucionalización que meses después promulgaría la Ley General de Sanidad y que, en el terreno de la enfermedad mental, permitiera romper la extrema marginación a que se veían sometidos estos pacientes.

Los viejos pabellones de crónicos, donde se hacinaban varios centenares de pacientes, fueron cerrados a finales de 1991. El manicomio dio paso al Instituto Psiquiátrico Servicios de Salud Mental José Germain¹, una red ambulatoria de centros de salud mental, hospitalización parcial, hospitalaria de rehabilitación y de atención a la urgencia y al ingreso breve hospital general (figura 1), que atiende desde la visita domiciliaria a la atención residencial. La demolición de sus muros e edificios no históricos, convirtió los jardines manicomiales en jardines públicos y, hasta hace un par de años, uno de los pabellones abandonados en el Centro de Atención Primaria de los barrios adyacentes. “Voy al pediatra al manicomio”, se podía escuchar a los vecinos.

En el trascurso de estos 20 años, la red de servicios, los programas de atención, la plantilla (ha

pasado de 200 a 400 profesionales), y por fin, la apertura del Hospital de General de Fuenlabrada, municipio dentro del área de referencia del Instituto, y la ampliación del Hospital General de Leganés (del Severo Ochoa) en el año 2005, ha permitido la creación de unidades de hospitalización psiquiátrica en ambos centros, con plantilla facultativa del Instituto, con lo que se completa la red. Una red pública, integrada, en el territorio, comunitaria, que permite una atención de calidad, tanto a pacientes agudos, como crónicos, y sin demoras importantes. Una red que cuenta con la participación de usuarios y familiares a través de la Asociación Salud y Alternativas de Vida y con la colaboración en

programas de reinserción laboral y apoyo comunitario de los ayuntamientos del área (fig 2).

La red de servicios que constituye el Instituto se organiza como unidades de gestión clínica, rompiendo la estructura piramidal de divisiones médicas, de enfermería y de gestión.

Por otra parte, se han iniciado las obras de remodelación de los viejos edificios abandonados (Capilla, fachadas neomudejares), donde se habilitarán dos centros de atención primaria y los nuevos espacios de rehabilitación y hospital de día, lo que terminará de configurar el centro de este municipio del área metropolitana de la Comunidad de Madrid.



Old Leganes Psychiatric Hospital, before the reform. Courtesy Manuel Desviat.

I Congreso FEARP: Documento de conclusiones

Madrid, Noviembre de 2005.

Federación Española de Asociaciones de Asociaciones de Rehabilitación Psicosocial.

www.fearp.org

Ricardo Guinea.

Summary

There are solid social and scientific reasons to agree that Psychosocial Rehabilitation' principles and strategies should be a priority for public mental health systems. An emerging consensus gathers around the idea of recovery oriented services: services conceived on the idea that recovery is a long qualitative process, based on the client perspectives and priorities, respectful with his values and civil rights.

Aunque resultaría demasiado ambicioso pretender resumir en un breve documento de *conclusiones* los tres intensos días de trabajo, la multiplicidad de puntos de vista presentados y la riqueza de las exposiciones, se puede, no obstante, intentar rescatar algunas de las líneas maestras que pudieran resultar más o menos comunes y puedan representar las *tendencias* contemporáneas del pensamiento de la Rehabilitación Psicosocial actual.

Existen razones epidemiológica y socialmente consistentes, avaladas por consensos científicos y por organizaciones internacionales, para pensar que la rehabilitación psicosocial debe ocupar un lugar fundamental entre las prioridades de los sistemas públicos de salud y de servicios sociales.

Constituye un consenso emergente que un objetivo realista y posible de la RPS sería ofrecer a los usuarios la oportunidad de “recuperarse” de su enfermedad. Aunque el concepto de “recuperación” (“recovery”) se ha definido de maneras distintas, se lo podría resumir como una *situación en la el usuario, aunque no se encuentre totalmente asintomático, ha encontrado la posibilidad de reorganizar su vida a pesar de las consecuencias de la enfermedad, goza de un nivel significativo de independencia personal, cuenta con una red social razonablemente estable, cuenta con alojamiento adecuado y estable, puede disfrutar del ejercicio de algunos roles socialmente valorados,*



Users Workshop. I Fearp Congress. Madrid, Spain. 2005.

mantiene ocupaciones remuneradas durante al menos una parte del día, - o al menos, actividades que ocupen su tiempo de manera útil y socialmente valiosa - y, por último, pero no menos importante, tiene la posibilidad de intervenir en la toma de las decisiones que le afectan y de vivir en un marco social normalizado que tiene en cuenta sus preferencias personales.

La intervención profesional en rehabilitación se contempla entonces como un repertorio de intervenciones, servicios y sistemas de soporte

social orientados hacia la “recuperación”. Ello implica que deberían estar centrados en el usuario, que buscan (porque la *necesitan*) la participación de éste, que deben ser tan prolongados en el tiempo como sea necesario, y que pretenden ayudar al sujeto en su proceso personal en función de los tiempos y plazos que el sujeto necesite (y no a la inversa, en función de plazos predeterminados determinados por las necesidades internas de los servicios).

Las intervenciones profesionales que componen la rehabilitación constituyen otras tantas formas de ayuda al proceso de recuperación, que deberían comprender el proceso individual de recuperación de cada sujeto, y ponerse al servicio del proceso, y no comprenderse como finalidades en si mismas.

La búsqueda procedimientos y formas eficaces de ayuda profesional a los pacientes sigue siendo una prioridad, así como la búsqueda de procedimientos de valoración y de establecimiento de consensos profesionales. Sin perjuicio de los procedimientos de evaluación objetiva necesarios para saber si la gama de intervenciones que componen las posibilidades de intervención profesional o de evaluación de los procedimientos de gestión resultan adecuadas (es decir, efectivas, eficaces, o eficientes), se asume que la rehabilitación contiene igualmente elementos cualitativos que deben comprenderse y manejarse como tales. En este sentido pueden comprenderse algunas de las reflexiones que han aparecido en las exposiciones de numerosos ponentes, en algunos casos retomando conceptos de los años '60 o '70 (Maxwel Jones y las “comunidades terapéuticas” para pensar los dispositivos residenciales) o el recurso a conceptos epistemológicamente “no lineales” (como el de “complejidad”), o el uso de terminología adecuada para el análisis grupal o los fenómenos de carácter subjetivo y cualitativo (como por ejemplo, el concepto de “rol social personalmente valorable”, etc.)

Constatamos que las intervenciones de nuestros ponentes nacionales han aportado calidad y creatividad, de manera que, sin olvidar la idoneidad de una actitud científica de apertura a las novedades e informaciones de las autoridades científicas de todo el mundo, podemos también confiar en el trabajo de nuestros profesionales y merece la pena estimularlos a la reflexión teórica, a la investigación y a la innovación.

La Rehabilitación, además de ser un campo abierto a la validación científica de procedimientos y de búsqueda y establecimiento de consensos profesionales que nos orienten hacia la excelencia profesional, es un campo donde tienen importancia primordial los valores, esto es, los consensos sociales que establecen lo que consideramos colectivamente como los derechos de los usuarios, las leyes, los factores que afectan a su imagen social, etc.

Forma parte de la estrategia social de la rehabilitación la constitución de cauces de cooperación con las asociaciones de familiares, y de usuarios, y en particular, el apoyo a aquellas formas de participación en que los usuarios puedan ejercer, individual o colectivamente, sus derechos civiles y su autodeterminación personal.

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Madrid. Spain.



I FEARP Congress. A workshop.

THE BRASILIA PRINCIPLES

Guiding Principles on the Development of Mental Health Care in the Americas

The Ministry of Health of the Federative Republic of Brazil, the Panamerican Health Organization (PAHO) and the World Health Organization (WHO)
(Summary) (Full text in www.wapr.info/wapr_news)

THE PARTICIPANTS, RECALLING

That the Caracas Declaration was the result of a critical analysis of the state of mental health care in the Americas, that made unavoidable its reform; That the Caracas Declaration stated that the improvement of mental health care was possible through the replacement of the service model based on the psychiatric hospital with community alternatives of care, and through actions to safeguard the human rights and the social inclusion of persons affected by mental disorders; and That the Caracas Declaration was endorsed by all countries of the Americas. (...)

NOTING

That new developments have taken place in the last 15 years that enabled countries to advance in the restructuring of psychiatric care; That the Resolutions of the Directive Council of PAHO/WHO in 1997 and 2001 strongly support the principles enshrined in the Caracas Declaration; That PAHO/WHO Member-States adopted the Declaration of Montevideo (September 2005), which includes new orientations on Primary Health Care, such as the creation of health systems based on social inclusion, equity, health promotion and the quality of health care; and That WHO has developed guiding principles aimed at advancing mental health care reform at the global level. These principles were included in the World Health Report 2001, and in other programs and initiatives. (...)

OBSERVING

That mental health services need to face new cultural and technical mental health challenges that

have become more evident in the last 15 years, such as:

1. The rising psychosocial vulnerabilities of selected population groups, e.g., indigenous communities and individuals coping with problems resulting from the chaotic urbanization of the large metropolis;
2. The increasing magnitude of both the morbidity and of psychosocial problems affecting children and adolescents;
3. The increasing societal pressure to make available effective measures for prevention and management of suicidal behavior and alcohol abuse, and
4. The increment of different modalities of violence that require an active involvement on the part of the mental health services, with special emphasis on the care of the victims.

To this effect,

THE CONVENERS OF THIS CONFERENCE HAVE DECIDED TO JOIN EFFORTS:

1. To work towards a call for a Regional Meeting of Ministers of Health to formulate a Regional Plan of Action with precise aims and goals;
2. To raise the awareness of governments regarding the need to increase investment in mental health care to confront the dramatic burden resulting from both the morbidity and disability of mental disorders;
3. To collect, document and disseminate experiences of mental health care that have used indicators and standards promoted by PAHO and WHO, and
4. To foster inter-country collaboration with regard to programs of service development, training and research.

World Association Psychosocial Rehabilitation

Events

WAPR

- WAPR Canada. XIII Colloque de L'AQRP. Saguenay, 24 au 28 may 2006. (<http://scribi.net/aqrp/colloque>)
- WAPR North West UK Branch meeting. Manchester, April 8th. 2006. (www.wapr.info/wapr_events.htm)
- American Psychiatric Association 2006 Annual Meeting. Toronto. May 21th 2006. (www.wapr.info/wapr_news.htm)



WORLD CONGRESS OF PSYCHOSOCIAL REHABILITATION
ATHENS 12-15 OCTOBER 2006

CONGRES MONDIAL DE RÉADAPTATION PSYCHOSOCIALE
ATHÈNES 12-15 OCTOBRE 2006

CONGRESO MUNDIAL DE REHABILITACIÓN PSICOSOCIAL
ATENAS 12-15 OCTUBRE 2006

ΠΑΓΚΟΣΜΙΟ ΕΤΗΣΙΟ ΠΡΟΨΕΧΩΝΟΜΙΧΕ ΑΝΟΙΚΤΑΕΛΕΙΧΕ
ΑΘΗΝΑ 12-15 ΟΚΤΩΒΡΙΟΥ 2006

FINAL ANNOUNCEMENT

WORLD ASSOCIATION FOR PSYCHOSOCIAL REHABILITATION
ASSOCIATION MONDIALE POUR LA RÉADAPTATION PSYCHOSOCIALE

ASOCIACIÓN MUNDIAL EN LA REHABILITACIÓN PSICOSOCIAL
ΠΑΓΚΟΣΜΙΑ ΕΤΗΣΙΑ ΠΡΟΨΕΧΩΝΟΜΙΧΕ ΑΝΟΙΚΤΑΕΛΕΙΧΕ

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www.wapr.2006athens.gr

SPONSORED BY THE HELLAS FOUNDATION

WAPR World Congress.

Athens, october 12-15th, 2006.

Final announcement.

Full information in

www.wapr.info
www.wapr.2006athens.gr

Mar. 10th. Athens Congress. An agreement between WAPR and the Athens congress organizers specifies that a fund is available to allow the participation of consumers or persons from low income countries.

1. Various levels of support will be available. maximum support will be half of travel expensens, free accommodation and free registration.
2. Travel expenses will be reimbursed in Athens.
3. Everybody asking for support must send to Madianos and me a brief information about him / herself and an abstract of a presentation (oral or poster).
4. We will review all the requests, we will ask the advice of Board members or national secretaries, if necessary, and we will inform in due course the applicants about our final decision.
5. We will do our best to fulfill as many requests as possible, within the constraints of our budget.

March 3th. The French and American Psychiatric Associations will be co-sponsoring a session (#S9) on “Rehabilitation in France, Canada and the US: From Science to Recovery: Vive la difference!. More information in www.wapr.info/wapr_news.htm

Feb. 9th. A. Barbato reports that the association “Psychosocial Rehabilitation Canada /Réadaptation Psychosociale Canada”

officially informed me about its decision to be affiliated to WAPR as Canadian branch. You can find information on its activities in the website: www.psrrpscanada.ca/main_english.htm.

Feb. 8th. The World Federation for Mental Heath announces the first call to celebrating World Mental Health Day. This year, this campaign focuses on “Building awarenes - Reducing risks: suicide and mental illness”. More information in www.wfmh.org/wmhd2006.htm

Jan. 31th. International Amnesty publishes report on death penalty of mentally ill offenders. The report focuses in the situation in USA, but many of the conclusions can be extended to other countries that are curently using death penalty.

Full report in www.wapr.info/wapr_news.htm

Jan. 9th. First announcement CEDEP (Comité Européen : Droit, Ethique et Psychiatrie) Seminair to be celebrated in Paris (France) 3-5 juin 2006. www.vvvgg.be/CEDEP

Sept. 2005. Mr. Dejan Stevanovich appointed as WAPR representantive for Macedonia. More information in www.wapr.info/wapr_news.htm

Dec. 7th. WHO Press release on violations of the human rigths of people with mental health disorders urges countries international organizations, academia, health sector and others to take action to promote and protect their rigths.

November 9th. 2005. The Ministry of Heath of the Republic of Brazil, the Pan-American Heath Organization (PAHO) and the World Heath Organization (WHO) convened the “Regilonal Conference on Mental Health Reform - 15 years after the Caracas Declration”, and delivers a new statement: the “Brasilia Principles” www.wapr.info/wapr_news.htm

Sept. 22. “The New England Journal of Medicine” publishes the first release on CATIE Research Group on efectivenes of antipsychotic drugs in patients with cronic schyzophrenia. Some preliminar conclusions sugest that the new atipic drugs are nor clear winners. New result and analisis will be published on this controversial issue. More information in www.wapr.info/wapr_news.htm

AFRICA

Dr. Angelo Barbato,

It is our considered view that consumers in Sub-Saharan Africa should join efforts with the rest of the world in preventing and reducing social disabilities as a frame work for community care for consumers.

According to W.H.O's World Health Report of 2001, it states that three-quarters of people affected with mental health problems are living in less developed countries where programmes of caring for the affected are non-existent e.g Zambia. This means that many of the affected people in the world are not being reached with these wonderful programmes/initiatives in the fight against social disability.

As a network of young adults with mental health problems in Zambia, we are of the view that these programmes/initiatives reach the affected people in our region and this can be achieved if there is an effective way of acquiring the relevant knowledge concerning the community care method. In this new era of scientific knowledge, as consumers we are looking forward to participating and contribute to the development of community care by being proactive in information gathering and dissemination.

As W.H.O. is championing for mental health reforms, Africa will sooner than later, undergo a revolution as govts are being urged to reform their mental health sectors through development of policies and laws that will promote good practices and human rights of consumers in mental health care. This in itself is a rare opportunity for consumers not to miss, so that we can participate in the reforms.

Our prime aim is to advocate for the promotion of the two sides of mental health care; being: the medical and non-medical. Going by our findings during our Focus Group Discussion with Consumers, Family members and Health professionals in the mental health care, it was evident that there is need to consider the promotion of non-medical care as well, if consumers are going to be visible people in our communities. The non-medical care should aim at promoting our abilities and also fight barriers that hinder community participation. It is for this reason that we are requesting

for recognition as you promote organization of rehabilitation services and training in Africa. Like the first meeting I attended in Milan, it was an eye opener to the good works of WAPR and such more are needed especially for Africans, to also develop to the level where such programmes / initiatives should benefit consumers and enhance the social well-being in our communities.

Kindly advise on how to benefit from your wonderful programmes.

Regards, Sylvester Katontoka.

Sylvester Karontoka is Member of The Mental Health Users Network of Zambia.

usersmentalhealth@yahoo.com

ATHENS CONGRESS

Dear Board members:

I agreed with Michael Madianos the following procedures to select the consumers and participants from low income countries to be financially supported for the Athens congress:

1. Various levels of support will be available. Maximum support will be half of travel expenses, free accommodation and free registration.
2. Travel expenses will be reimbursed in Athens.
3. Everybody asking for support must send to Madianos and me a brief information about him/herself and an abstract of a presentation (oral or poster).
4. We will review all the requests, we will ask the advice of Board members or national secretaries, if necessary, and we will inform in due course the applicants about our final decision.
5. We will do our best to fulfill as many requests as possible, within the constraints of our budget.

I am asking all of you to circulate this information to everybody interested.

All my best .

Angelo Barbato. WAPR President.

New WAPR Website

www.wapr.info

Ricardo Guinea. WAPR website webmaster.

WAPR website www.wapr.info has been completely rebuilt and updated. Surfing through it, you can find easily the regular information: a welcome from WAPR President, Angelo Barbato, and the full list of the Board of Directors, including post address, telephone contact numbers and e-mail addresses. But some new sections have been added and are expected to widen their information.

A new section makes available recent and relevant documents and statements: **Kobe Declaration** (Japan, 2004), declaring the need to work with WHO and NGOs to advocate to make psychotropic drugs accessible, stimulate research in developing countries in order to reduce mortality; The Brasilia Principles (Brasilia, 2005), updating the **Caracas Declaration** (1990), in order to call for a Regional meeting of ministers of health of the Americas, raise awareness of governments on regarding the need to increase the investment on mental

health, collect and disseminate experiences and foster inter-country collaboration.

The “**links**” section includes many updated links divided in different categories: WAPR national Branches, documents on psychosocial rehabilitation, relevant international agencies, families and users organizations, scientific organizations websites, and “action and campaigns”.

Next, “**WAPR Events**” provides the available information regarding upcoming WAPR events all around the world, such as the next Canada, Manchester (UK) and Athens meetings.

All the recent issues of the **WAPR Bulletin** (from April 1999) can be visited, and downloaded to be printed and disseminated freely.

And last, a “**News**” section gives flashes on relevant and actual news, such as international agencies press releases, policy initiatives important scientific novelties.

WAPR website intends to be an instrument for exchange and information for all, WAPR particular or organizations members, and citizens. It is open to collaboration, sending your information to the webmaster, as indicated on the site.

Collaboration is accepted in all the three official languages: English, French and Spanish. All collaborations are welcome, and will make possible to count with a good exchange tool all around the world.



World Association for Psychosocial Rehabilitation.
Asociación Mundial de Rehabilitación Psicosocial.
Association Mondiale pour la Réadaptation Psychosociale



Last WAPR Conferences: Milano (Italy) and Madrid (Spain).



(Full Information in www.wapr.info)

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