



World Association for Psychosocial Rehabilitation

BULLETIN

Association Mondiale pour la Réadaptation Psychosociale

Vol 12, No 2, July 2000

Editor's note:

Welcome to some changes in our *WAPR Bulletin*! With this issue the editorship passes to the US Branch of WAPR, the American Association for Psychosocial Rehabilitation. All of us in WAPR are grateful to Anna Pitta, Willians Valentini and the Brazilian branch for their enormous effort in producing the bulletin from October 1998. They built well on the decade put in by past president Gaston Harnois, who edited it from Montreal. He had taken over from Oliver Wilson who succeeded Parameshevara Deva. Having just done this ourselves in New York we can appreciate all previous efforts even better as we move from sympathy to empathy.

1. **electronic transmission:** the bulletin is being transmitted electronically to the board and national secretaries and to any member whose e-mail addresses we have. In the USA this means hundreds of copies will be received instantaneously without any postage costs. We shall send it in WordPerfect, Microsoft Word, and as a very long e-mail without attachment. We do this because few people have Adobe Pagemaker, in which the Bulletin was previously formatted so beautifully for printing. There is some sacrifice of complicated format. Anyone is free to print the bulletin and to distribute copies is widely as possible, since the bulletin is a calling card for WAPR Printed copies of the bulletin will still be made and mailed to the board and national secretaries with hope that they will be photocopied undistributed is widely as possible. We shall fax the Bulletin free anywhere on request.
2. **WAPR content:** Previous editors, all humble and decent as well as gifted, sought feature articles and news of other organizations as well as WAPR. But covering WAPR well leaves room for little else. We shall try to reflect WAPR's efforts by including some of the many reports of officers, national branches, committees, etc. the WAPR Board receives. All reports have been requested in electronic form for speed of distribution and to avoid retyping. The calendar will continue to welcome announcements from other organizations, especially those concerned with the same issues as WAPR, but we shall also give first

priority to do WAPR meetings. We hope that our members will see problems in a global perspective and appreciate the innovative solutions carried out by many of our members and national associations. We hope this will encourage international visiting as members attend WAPR meetings in various countries. This change is a bit bumpy so far and has delayed this July issue and resulting in incomplete coverage of both reports and the Seventh World Congress, a great scientific success held in Paris from May 7-10, 2000. But both these will occupy the October and December issues you should receive shortly. In this issue we include a project proposal for Africa to which interested members may wish to contribute or steer towards funding. As decided in the Board, we regret that we will not carry requests for funds of non WAPR projects (having received more than 50). Another feature introduced in this issue is carrying some of the statements of personal background and plans for WAPR offered by the candidates in this year's election. We shall continue this feature for several issues until all members of the board have had a chance to be known by the membership. Other content is on the website: <http://www.wapr.de/>

Copy for the bulletin can be sent anytime to taintor@nki.rfmh.org and (please use both addresses) taintz01@med.nyu.edu. Don't worry about deadlines - we'll use any late items in the next issue.

While I shall yield the President's report to Jacques Dubuis, who I succeeded at the Congress, I doubt it will be possible to succeed his record of hard work. However there should be no delay in keeping praise on him, Dr. Gilles Vidon and to the French association for their Herculean efforts in bringing off the Congress off. **-Zeb Taintor for the AAPR**

Rapport d'activité du Président, 7 Mai 2000

Lorsque j'ai été élu à Hambourg je m'étais fixé trois objectifs 3 objectifs pour mon mandat

1. Organiser les relations et le travail du Secrétariat permanent à Hambourg,
2. Proposer un amendement de la constitution préparé par une commission composée de MP Deva G Harnois Z Taintor et moi même.
3. Préparer un rapport sur la collaboration entre les groupes d'usagers, les associations familiales et les professionnels (E. Hauff, D. Johnson).

A ces premiers objectifs deux autres se sont rapidement ajoutés ;

Celui d'encourager la création de nouvelles branches de l'AMRP (cela avait déjà été le souci premier de mes prédécesseurs) pour parvenir à l'équilibre financier des finances de l'association. Seule manière de garantir la pérennité du secrétariat permanent à Hambourg et bien entendu également de renforcer ainsi l'association au niveau international.

Celui de contribuer à créer une branche française forte qui devait aider à organiser le congrès mondial à Paris, dans de bonnes conditions.

Je n'imaginai pas à ce moment que l'organisation du congrès mondial mobiliserait l'essentiel de mon énergie, parfois au détriment du développement de l'association au niveau mondial.

I) L'organisation de la branche française :

Le succès du congrès mondial passait évidemment par l'organisation d'une branche française forte, c'est à dire nombreuse, compétente, représentant l'ensemble des professionnels dans leur diversité, allant des associations familiales aux usagers en passant par les représentants de la société civile.

Grâce à l'initiative de Denis Leguay entouré de quelques uns d'entre nous, ce premier objectif a pu être atteint. Le congrès d'Angers a été un franc succès qui a donné une bonne image de notre groupe et de l'association mondiale dans notre pays et une bonne image de ce que nous pouvions réaliser comme réunion scientifique d'envergure.

J'insiste un peu sur cette étape moins pour qu'elle serve d'exemple, car nous en verrons bientôt les limites, mais parce qu'elle me paraît une condition qui demeure essentielle dans tous les pays, pour assurer le développement de l'association, mais aussi pour disposer ainsi d'un comité scientifique et d'un comité local d'organisation suffisamment solides et disponibles, pour organiser un congrès mondial. C'est une condition qui n'est cependant pas suffisante.

Cette étape franchie, et alors que tout semblait devoir se dérouler normalement, les difficultés n'ont cessé de s'accumuler.

La fragilité financière de l'association n'arrange pas les choses. Celle ci, très dépendante des finances du comité local d'organisation et /ou de son organisateur professionnel, et n'est pas en position de force pour imposer ses conditions. D'autre part, la nécessité d'assurer le financement du secrétariat permanent nous condamne à un succès financier lors de chaque congrès mondial.

II) Le prochain congrès mondial de l'association.

Pour la première fois dans l'histoire de l'association nous ne pouvons annoncer avec certitude le prochain congrès . Au moment où je rédige ce rapport, 4 semaines avant le congrès nous n'avons pas reçu de proposition écrite d'Israël (Dr Y.Bar El) ni de New York (M.Itzkovitz).

Un dossier de candidature a été préparé par le secrétariat permanent à Hambourg et adressé aux candidats.

III) Le bulletin.

Le bulletin a été édité par A.Pitta et W.Valentini au Brésil. Au nom du Board je les remercie pour leur travail. Cependant des problèmes de coordination n'ont jamais pu être réglés et la publication n'a jamais été régulière.

La réunion du Board à Athènes a permis d'envisager d'éditer le bulletin à New York. A. Pitta et W.Valentini sont d'accord. Malheureusement depuis aucune proposition écrite ni chiffrée ne m'est parvenue mais Zeb Taintor s'est engagé sur cette question et traitera cette question.

IV) Le développement de l'association.

A. *Les branches nationales :*

Je dois faire un bilan contrasté de la création ou du développement des branches nationales de WAPR.

La branche française restera ébranlée par la préparation de ce congrès .

La branche allemande reste un projet.

La branche anglaise n'existe toujours pas.

La branche hollandaise n'a pas été réanimée par l'organisation il y a un an du congrès sur l'évaluation et la recherche dans la réhabilitation.

Par contre la Grèce a réussi un magnifique départ grâce a l'initiative de M.Madianos et S. Stylianidis. Nous entendrons avec plaisir leur rapport sur cet événement.

L'Italie, le Brésil, le Portugal, les USA etc. ont des branches très dynamiques qui organisent régulièrement des réunions scientifiques.

L'Inde, la Chine, s'attachent désormais à créer des centres de recherche ou de formation des professionnels de la réhabilitation.

On trouvera plus de détails dans les rapports produits par ces pays.

B. *La collecte des cotisations par le secrétariat permanent de l'association :*

L'organisation de la collecte des cotisations reste un gros problème malgré le travail de liaison avec les différentes branches par le secrétariat permanent. Les versements restent irréguliers et surtout ne couvrent pas les besoins du secrétariat. (voir rapport d'activité du secrétariat permanent).

V) les comités :

Le bilan est encore plus contrasté en ce qui concerne les comités de l'association.

G.Harnois a fait un travail magnifique au comité sur le travail des malades mentaux. Il a réalisé un travail de liaison important pour alimenter le réseau GLADNET. Il a aussi poursuivi l'organisation de l' INMH.

M.Farkas a pu publier le résultat de son travail.

C.Mercier et H.Martinez ont poursuivi leur travail considérable sur la Ç qualité de la vie È et les Ç droits de l'homme [separate article]È.

Mais beaucoup de comités ne font rien et/ou ne remettent pas de rapport.

Au début de mon rapport je faisais l'énumération de mes projets de départ : la constitution, le rapport sur la collaboration, qu'en est-il aujourd'hui ?

VI) L'amendement de la constitution :

Il a été rédigé par Z.Taintor.

VII)Le rapport sur la collaboration entre les professionnels les usagers et les associations familiales :

Usagers, associations professionnelles, et professionnels de la Réhabilitation se sont saisis eux même de cette question et ont préparé un premier document qui a été traduit en Anglais et en Espagnol et qui vous a été adressé.

P.Bantman le coordonnateur vous présentera ce document, que nous souhaitons avec votre accord, proposer à l'assemblée générale. [adopted -see below]

VIII) Le secrétariat permanent :

Seules des raisons financières peuvent nous conduire à renoncer à l'aide du secrétariat permanent à Hambourg et ce serait bien regrettable. C'est cependant une éventualité que nous ne pouvons pas exclure, et le Board devra se prononcer sur cette question. Il est possible également que nous devions faire face un jour au départ de la secrétaire, ce qui poserait certainement un problème pour la continuité.

IX) Le rapport de consensus sur l'utilité et l'usage des médicaments antipsychotiques de seconde génération :

Ce rapport à l'initiative de l'Association Mondiale de Psychiatrie (AMP/WPA) a été commenté par plusieurs membres de la WAPR qui ont largement contribué à son amendement. Ce type de collaboration, peut être ultérieurement à conduire par l'intermédiaire de l'INMH, doit servir d'exemple.

X) Des projets pour les membres de la WAPR :

Le travail sur la collaboration, à tous les niveaux, des professionnels de la santé mentale avec les associations d'usagers, et les associations familiales, doit être repris.

Un des aspects de ce travail se situe au niveau clinique et concerne l'informations des

malades et des familles, sur la maladie ses étiologies, l'usage des médicaments et l'observance du traitement. De nombreux programmes de formation existent désormais. Les problèmes techniques scientifiques voire éthiques que posent leur usage dans les équipes psychiatriques méritent une étude approfondie une évaluation à laquelle notre association devrait contribuer.

Jacques Dubuis

President's activity report 7 May 2000

When I was elected in Hamburg I had set myself three objectives for my term of office:

1. Organising the work and relationships of the Permanent Secretariat in Hamburg
2. Proposing an amendment to the constitution, drawn up by a commission composed of MP Deva, G Harnois, Z Taintor and myself.
3. Preparing a report on the collaboration between user groups, family associations and professionals (E. Hauff, D. Johnson).

Two other objectives were rapidly added to these first objectives:

4. that of encouraging the creation of new branches of the WAPR (this was already my predecessors' main concern) in order to balance of the Association's finances. This is the only way to guarantee the continued existence of the Permanent Secretariat in Hamburg and, of course, to thus strengthen the Association at international level.
5. that of contributing the creation of a strong French branch that should help with organising the World Congress in Paris in good conditions.

At that point I did not think that organising of the World Congress would take up most of my energy, sometimes to the detriment of the development of the association at worldwide level.

1) Organisation of the French branch:

The success of the World Congress was obviously due to the organisation from a strong French branch, this is to say with competent associations, representing the diversity of all professionals, ranging from family associations to users and including civil society representatives.

Thanks to Denis Leguay's initiative, and with help from some of us, we were able to reach this first objective. The Angers Congress was a clear success that gave our group and the Worldwide Association a good image and a good image in our country and a portrayed a positive image of what we could achieve in terms of a large-scale scientific meeting.

I am dwelling slightly on this stage not so much because it serves as an example - as we will soon see the limits it has - but more so because it seems to me to remain an essential condition in all countries for ensuring that the Association develops and also for thereby having a scientific committee and a local organisation committee at our disposal that are strong and available enough to organise a World Congress. It is a condition which is nonetheless not sufficient.

Having completed this stage, and although everything appeared to be unfolding as normal, the problems continued to mount up.

G. Vidon and myself will later give evidence of the problems in various letters.

The Association's financial vulnerability does not help matters. It is heavily dependant on the finances of the local organisation committee and/or its professional organiser, and is not in a strong position to impose its conditions. On the other hand, the need to ensure the financing of the Permanent Secretariat means we should try to ensure financial success at each World Congress.

II) The Association's forthcoming World Congress.

For the first time in the history of the Association we cannot announce the next Congress with certainty. As I write this report, 4 weeks before the congress, we have not received a written proposal from Israel (Dr Y. Bar El) nor from New York (M. Itzkovitz).

A candidate file has been prepared by the Permanent Secretariat in Hamburg and sent to candidates.

III) The Bulletin

The Bulletin has been published by A. Pitta and W. Valentini in Brazil. On behalf of the Board I should like to thank them for the work they have done. However, the coordination problems have never been resolved and publication has never been regular. The Board meeting in Athens enabled us to consider publishing the Bulletin in New York. A. Pitta and W. Valentini are in agreement. Unfortunately since then I have received no written or costed proposal but Zeb Taintor has committed himself to this issue and will handle it.

IV) Development of the Association

A. National branches

I must provide a contrasting summary of the creation or development of the national branches of the WAPR.

The French branch will remain busy with the preparation of the congress.

The German branch is still being established.

The English branch does not yet exist.

The Dutch branch has not been revived by the organisation one year after the congress on evaluation and research in rehabilitation.

However, Greece has got off to a flying start thanks to M. Madianos' and S. Styliandis' initiative. We look forward to hearing their report on this event.

Italy, Brazil, Portugal, the USA etc. have very active branches which regularly organise scientific meetings.

India and China also now intend to create research or training centres for rehabilitation professionals.

More details can be found in the reports produced by these countries.

B. *Collection of membership fees by the Association's Permanent Secretariat:*

Organising the collection of membership fees remains a major problem despite the Permanent Secretariat's liaison work with the different branches. Payments remain irregular and, above all, do not cover the Secretariat's needs (see the activity report from the Permanent Secretariat).

V) The Committees

The report is even more contrasting on the Association's committees.

G. Harnois has done some magnificent work at the committee on work on the mentally ill. He has done considerable liaison work to fuel the GLADNET network. He also followed the organisation of the INMH.

M. Farkas was able to publish the findings of her committee's work.

C.Mercier and H. Martinez have been very active chairs [see separate article]

But many committees are doing nothing and/or are not submitting reports.

At the beginning of my report I listed my initial projects, namely the constitution and the report on work done, and what has become of them?

VI) Amendment to the constitution

This was drawn up by Z. Taintor

VII) Report on work done with professionals, users and family associations

The report has yielded the superb manifesto published below.

P. Bantman, the coordinator, will present this document which with your agreement we hope to submit to the Assembly [where it was approved]

VIII) The Permanent Secretariat

Only financial reasons can lead us to dispensing with the assistance of the Permanent Secretariat in Hamburg and this would be a shame. However it is a possibility that we cannot rule out and the Board will have to give its opinion on this issue. It is also possible that we may have to face up to the departure of the secretary one day, which would indeed pose a problem in terms of continuity.

IX) Consensus report on the utility and usage of second generation antipsychotic medicines

The report based on an initiative from the World Psychiatry Association (AMP/WPA) has been commented on by several members of the WAPR, who significantly contributed to amending it. This type of collaboration, which subsequently will perhaps be managed via the INMH [presidents of international mental health associations], must serve as an example.

X) Projects for members of the WAPR

Work on collaboration at all levels between mental health professionals and user associations and family associations must be reviewed.

One of the aspects of this work is at clinical level and concerns informing patients and families about the illness, its aetiology, the use of medicines and patient compliance with treatment. Several training programmes now exist. The technical scientific problems or even ethical problems their usage poses for psychiatric teams are worthy of a detailed study and our association should contribute to this evaluation.

Jacques Dubuis

MANIFESTE du 7ème CONGRES DE L'ASSOCIATION MONDIALE DE REHABILITATION PSYCHOSOCIALE, 7-10 MAI 2000, PARIS (France)

Les participants à la conférence ont résolu ce qui suit :

Nous accordons notre plein soutien à la Déclaration Universelle des Droits de l'Homme qui doit également garantir les droits des personnes atteintes de troubles psychiques, et leur entourage.

La fin du deuxième millénaire doit être l'occasion pour les états de (re)définir une pratique de Santé Mentale garantissant les droits des usagers et des proches en matière de Santé

Mentale.

Un certain nombre de résolutions antérieures ont déjà exprimé des garanties dans ces domaines que ce soit dans le cadre de WARP ou d'autres Associations Internationales.

Des moyens financiers importants doivent également être mis en œuvre pour la Santé Mentale, par les états concernés, afin de permettre la lutte contre la stigmatisation et la discrimination pour des raisons de troubles psychiques, et, le développement de mode d'assistance et de réhabilitation, en dehors de l'hôpital psychiatrique.

Projet de rédaction d'un manifeste pour l'établissement d'un dialogue soignant-usager -famille

En ce qui concerne les patients et les usagers

1. Le droit à l'auto-détermination

Chaque personne a le droit de prendre les décisions concernant sa propre vie , incluant le fait d'accepter ou non un traitement , et quel sorte de traitement .

2. Le droit à la non discrimination .Le droit d'être un citoyen égal aux autres citoyens d'un pays et de ne pas être discriminé ou exclus par un problème de santé mentale mentale .

3. Les usagers souhaitent également le droit d'être représentés eux-mêmes dans tous les forums dans lesquels la politique de santé mentale et les pratiques sont discutés , et pas d'être représentés par d'autres à leur place. En ce qui concerne la planification , la politique en Santé Mentale et l'organisation des soins , les usagers de la Psychiatrie doivent être impliqués d'une manière significative dans les prises de décisions.

4. Toute personne a droit à une assistance et à des soins appropriés en matière de santé mentale , spécifiquement adaptés à son cas et à ses difficultés en cas de nécessité. Assistance et traitements doivent être garantis dans la loi.

5. Cette assistance peut s'exercer quelque soit le lieu de résidence de la personne (hôpital, logement familial, logement personnel ou thérapeutique , patient sans domicile .La Psychiatrie communautaire constitue le courant d'idées et de pratiques le plus approprié pour réaliser ce droit à une diversité de services .

6. Autant que possible , le traitement de même que tout changement de traitement , sera établi en accord avec la personne qui présente une souffrance psychique. Des formules alternatives animées par des usagers , peuvent proposer aux patients qui le souhaitent une prise en charge en articulation ou non avec le système de soins officiel.

7. On ne peut priver les sujets présentant des troubles psychiques de leur liberté , que si leur condition est telle qu'une hospitalisation et un traitement forcés sont jugés nécessaires pour protéger leur santé , leur sécurité et celle de leur entourage. Il ne peut y être procédé que sur la

base d'un code juridique garantissant tous les droits humains fondamentaux .Seul une instance judiciaire peut prendre une telle décision.

8. Les personnes présentant des troubles psychiques doivent garder le contrôle de leur finances et de leurs biens aussi longtemps que possibles .Ils ne peuvent en être privés qu'au titre de dispositions juridiques spécifiques .
9. Toutes les dépenses de traitement de soins et de réhabilitation doivent être couvertes par un système de sécurité sociale garanti par la loi .

En ce qui concerne les familles

1. Les soignants intervenants en psychiatrie se doivent d'élargir leur perspectives dans le soin et la prise en charge du patient, a toutes les personnes qui composent son environnement et en particulier sa famille.
2. La famille doit être aidée et parfois relayée dans les problèmes qui se posent vis-a-vis du patient, en particulier dans le cadre du projet thérapeutique et dans celui de la réinsertion - réhabilitation.
3. Il est important de garantir une aide par la mise a disposition des familles d'informations et des moyens de communication sur les ressources existantes pour prendre en charge les personnes présentant des problèmes de santé mentale .
4. L'aide apportée a la famille ainsi que les soins aux patients ne doivent pas s'arrêter sur le refus du patient. Dans les situations difficiles les familles doivent être aidées sur l'attitude à avoir vis- - a-vis des patients dont les comportements posent problèmes , tout en respectant la confidentialité du dossier médical .
5. Les usagers et leurs familles doivent être informés sur les traitements appliqués, sur les résultats à attendre de ce traitement et sur les effets gênants possibles des médicaments , de même que des diverses possibilités de soins offertes par le service .
6. Soignants et familles doivent aussi collaborer à la mise au point et à la réalisation des divers aménagements sociaux nécessaires à un accompagnement adapté aux patients dans la cité , incluant par exemple des structures d'hébergement .
7. On attirera l'attention des usagers et des membres de la famille sur l' existence d'organisations de relation d'aide. Il en existe dans la plupart des pays occidentaux (Association d'usagers, Association de familles de patients...).
8. A cet égard les initiatives d'associations Internationales destinées à réduire la stigmatisation et la discrimination , quotidiennement endurées par les personnes diagnostiquées schizophrènes , doivent être stimulées et relayées sur le plan national.
9. L'amélioration de la communication vers le public, pour permettre une meilleure

compréhension et tolérance de la maladie, sont des éléments clés de cette action.

MANIFESTO from the 7th CONGRESS OF THE WORLD ASSOCIATION FOR PSYCHOSOCIAL REHABILITATION, 7-10 MAY 2000, PARIS (France)

Establishing a dialogue between professionals, patients and families.

Concerning users and patients

1. Self-determination. The right to make decisions about one's life, including whether or not to accept treatment and what kinds of treatments to have.
2. Non-discrimination. The right to be a citizen equal to all other citizens of one's country and not to be discriminated against or segregated because of a psychiatric diagnosis.
3. People also want the right to represent themselves in all forums in which mental health policy and practices are discussed and not to be represented by others who claim to speak "for" them. Involvement in policy, planning and service delivery. People who use services should be involved in meaningful ways and in representative numbers with regards to making decisions about the design, operation and evaluation of such services.
4. All recipients of care persons are entitled to appropriate assistance and care specifically adapted to his or her case and syndrome . Assistance and treatment should be legally guaranteed .
5. This assistance can be exerted some is the place of residence of the person (hospital, family housing, personal or therapeutic, patient housing without residence).
6. Self-help alternatives. User-run alternatives, designed, staffed and run by users exclusively, should be available (and adequately funded) as alternatives or adjuncts to the formal system. It should be up to the individual whether to use such services and, if used, whether they are used exclusively or in combination with professionally-run programs.
7. The recipient of cares can only be subjected to deprivation of their liberty if their condition is such that enforced hospitalisation and treatment are considered necessary to safeguard their health and their safety or that of their environment .This can only be done on the basis of a basic legal code which guarantees all fundamental human rights.
8. The Recipient of cares must have complete control over their finances and possessions for as long and as much as possible . They may only be deprived of control in accordance with specific legal provisions.

9. All expense for treatment, care and rehabilitation should be met by a statutory based social security system.

Concerning families

1. The professionals working in psychiatry must extend their view in the care of and in their responsibilities to patients, to all those around the patient and in particular the patients' families.
2. The family must be assisted and sometimes involved (note: like taking the place in a relay race) in the problems which are posed in connection with the patient. In particular involved with the therapeutic team and in the efforts to re-assimilate and rehabilitate.
3. It is important to guarantee that assistance is made available to families - assistance in the form of information and means of communication with the resources which exist to take responsibility for those with psychic problems .
4. The assistance given to the family, as well as the care to the patients must not cease if the patient refuses. In such difficult situations, the families must receive assistance to address the attitude of patient whose behaviour/actions presents problems.
5. We draw your attention to the way of overcoming and gaining acceptance of the problem.
6. The patient and the family must be informed over the treatments used, about the results and expectations of the treatment and the possible bad side-effects of the medication.
7. Professionals and families must also collaborate at the debugging and the realisation of various necessary social installations adapted to the patients in the city including, for example, structures of lodging .
8. We draw to the attention of the patients and the members of the family, the existence of organisations which provide help. These exist in most of the western countries. (Organisations of service users, of families and of patients).
9. In this regard, the initiatives of international associations to reduce stigma and the daily discrimination experienced by those with schizophrenia must be encouraged and included in national plans.
10. Improvement in the communication with the public to allow a better understanding and tolerance of the psychic problems is a key element of this action.

MANIFESTO DEL 7º CONGRESO DE LA ASOCIACION

MUNIAL DE REHABILITACION PSICOSOCIAL, 7 - 10 MAYO

2000, PARIS (Francia)

Resoluciones de los participantes a la conferencia :

Acordamos solemnemente nuestro apoyo a la Declaracion Universal de los Derechos Humanos, la cual debe garantizar los derechos de las personas afectadas de trastornos psicicos, asi como los de sus familiares.

El termino del segundo milenio deber ser la ocasion para los Estados de (re)definir una practica de Salud Mental que garantice el derecho de los pacientes y de sus familias en materias de Salud Mental.

Buen numero de resoluciones anteriores han sido objeto de garantias en este dominio, tanto en el marco de la WARP como en el de otras Asociaciones Internacionales.

Los Estados implicados deben avanzar los recursos financieros necesarios para la aplicacion de estos proyectos en el campo de la Salud Mental, con la finalidad de seguir luchando contra la estigmatizacion y la discriminacion que sufren los pacientes psiquiatricos, asi que favorecer el desarrollo de otras modalidades de asistencia sanitaria y de rehabilitacion fuera del ambito del hospital psiquiatrico.

PROYECTO DE REDACCION DE UN MANIFESTO PARA ESTABLECER EL DIALOGO MEDICO-ENFERMO-FAMILIA.

Concerniente a los pacientes y otros demandantes

1. Auto-determinacion. Derecho en la toma de decisiones acerca del modo de vida, incluyendo la aceptacion o no del tratamiento, asi que sobre el tipo de tratamiento en cuestion.
2. Indiscriminacion. Derecho a ser un ciudadano como los otros ciudadanos del pais, y no ser discriminado o segregado por causas referentes al diagnostico psiquiatrico.
3. Derecho personal de los pacientes a representarse por si mismos en las reuniones cientificas que traten de la politica y practica de salud mental, y no de ser representados por otros que los defiendan y hablen "por" ellos. En la politica, la planificacion y la deliberacion de servicios. Los pacientes que utilizan los servicios deben ser involucrados de forma significativa, y de forma numericamente representativa, en la toma de decisiones.
4. Toda persona tiene derecho a una asistencia sanitaria adecuada en salud mental, a su situacion, a sus dificultades, cuando lo necesite.
La Asistencia y el tratamiento deben ser garantizados por ley.
5. La asistencia debe ejercerse independientemente del lugar de residencia de la persona (hospital, domicilio familiar, residencia terapeutica), incluso para los pacientes sin domicilio.

6. Dentro de lo posible, el tratamiento asi como las modificaciones ulteriores, sera establecido con el acuerdo del paciente. Otras formulas alternativas, a la iniciativa de los pacientes, pueden proponer otras formas de ayuda terapeutica, articuladas o no con el sistema sanitario oficial.
7. No se debe privar a los pacientes de libertad, condicion fundamental de los derechos humanos.
8. Los pacientes deben poder guardar el control de sus recursos financieros y de sus propiedades el mayor tiempo posible. En caso de imposibilidad, solo pueden ser privados en el marco de las disposiciones juridicas especificas recogidas en la ley.

Concerniente a las familias

1. Los profesionales de la salud mental deben abarcar en la estrategia terapeutica respecto al paciente, a otras personas del entorno y en particular a la familia.
2. La familia debe ser ayudada en sus dificultades con respecto al paciente, particularmente con la inclusion en el proyecto terapeutico y en el de la reinsercion y rehabilitacion del paciente.
3. Necesidad de garantizar una ayuda a través de la informacion de las familias y facilitar la comunicacion sobre los recursos disponibles respecto a las necesidades de los pacientes.
4. La ayuda facilitada a la familia asi como al paciente no deben interrumpirse en caso de rechazo por parte del paciente. En las situaciones dificiles, las familias deben encontrar una ayuda especifica de las dificultades encontradas con el paciente.
5. El paciente y la familia deben ser informadas sobre el tipo de tratamiento, sobre los resultados esperados y sobre los efectos secundarios del mismo.
6. El personal sanitario y las familias deben colaborar en la realizacion y elaboracion del proyecto terapeutico, incluida la asistencia social y la facilitacion del acceso a la vivienda, o a otras estructuras de albergue.
7. Despertar el interes de los pacientes y de la familia por las organizaciones y asociaciones no gubernamentales que pueden ayudarles. Estas organizaciones existen en gran numero de paises (Asociaciones de familias y de enfermos, etc.).
En este sentido, debe estimularse la creacion de nuevas Asociaciones Nacionales e Internacionales destinadas a reducir la discriminacion y segregacion que sufren los pacientes psicoticos.
8. Mejorar la comunicacion con el publico general, afin de facilitar la comprension y la tolerancia de la enfermedad son los elementos clave de esta accion.

Ce projet de manifeste à été rédigé à partir de propositions , remarques et suggestions exprimées par les personnes suivantes , ainsi que par consultations des sites internet d'association d'utilisateurs ou de familles

d'usagers :

This manifesto was generated by the following, with their respective groups:

Paul Morin (Collectif de défense des droits de la Monterégie -Canada)

Luc Vigneault (Association des groupes de défense des droits en santé mentale du Quebec)

Claude Finkelstein (Fédération Nationale des Associations d'(ex)Patients en Psychiatrie)

Dr Antonio Garcia (France)

Judi Chamberlin (USA)

Marianne Farkas (Center for Psychiatric Rehabilitation-USA)

Susan Kirkwood (Eufami -Great-Britain)

The Anti-Psychiatrie coalition (USA)

National Association for Rights Protection and Advocacy (USA)

J.Walcke (Union Nationale des Familles et Amis des malades mentaux) France)

Bertrand Escaig (Unafam France)

R.van der Male (Straatadvocaat Basisberaad GGZ Rotterdam -Nederland)

Consumers and survivor movement (Madnation-USA)

Consumor/Survivor Information Resource Center of Toronto

Internet Ressource for people with disabilities (Grande Bretagne)

National Schizophrénia Fellowship (Grande Bretagne)

Die Psychiatrie-Erfahrenen Homepage (Allemagne)

Support group in Australia

Manifeste de la Première Conference Européenne des Familles de malades mentaux (De Haan-Belgium, 7-9 juin 1990)

Manifeste de Barcelone (2éme Congrès européen des associations des familles de malades mentaux)

Deuxième Congrès de la WARP(Barcelone 1989)

A National Branch Report:

WAPR ITALIAN BRANCH REPORT OF ACTIVITIES JUNE 1999 - MAY 2000

In 1999 members in good standing have been 45. The activities of Italian branch covered four areas:

- **Projects:** The Partnership project has been developed over the last months. It involved a consensus-building process on quality of mental health services among professionals, users and family members. The project took place in several community services in Milan and Rome. Methodology and preliminary results will be presented at the Paris Congress.
- **Relationships with other associations:** Relationships with family associations steadily developed, thanks also to the efforts of the Board member dr Muggia. WAPR has been instrumental in laying foundations for users associations in Italy. Small local groups are slowly growing. Representatives of Italian users will participate in the symposium of WAPR Italian branch at Paris Congress.
- **International Cooperation:** Italian branch sponsored through a grant of US\$ 1,500 the South-East Asian conference on Disability caused by mental illness held in Bangalore (India) in September 1999.
- **Meetings:** National Congress of Day Care Centers Association, supported by WAPR, has been organized in Rome in November 1999. WAPR officers Giuseppe Ducci and Antonio Maone led the scientific and organizing committee. The Congress, which enjoyed a great success, had among its keynote speakers, leading international figures of WAPR, such as dr Barbato and dr Gittelman. A seminar on " Psychosocial Rehabilitation for elderly people" has been organized in Padua in December 1999 by dr Storti. WAPR sponsored the International Congress of Cognitive-Behavioral Therapy held in Naples in November 1999. dr Meneghelli, member of the Board of Italian branch, was in the scientific committee. Respectfully submitted, Germana Agnetti, National Secretary.

A Committee report: PSYCHOEDUCATION GROUP REPORT

The psychoeducation group has been working for the past two years to extend training in the educational approaches to rehabilitation (consumer education, stress management training, living skills training, specific cognitive behavioural strategies) in many parts of the world. The most important initiative began with a joint meeting with the Board of the World Fellowship of Schizophrenia and Allied Disorders in Christchurch, New Zealand in September 1998,. A set of principles for family-based psychoeducation was developed, led by Julian Leff, William McFarlane, Rada Shankar, Tilo Held, Ian Falloon, Diane Froggatt, Dale Johnson, Jim Crowe and Margaret Leggatt, and others. This was followed by a joint WSF/WAPR presentation at the Congress in Hamburg.

A workshop for trainers was held in Umbria in October 1999 with consumers and professionals from Argentina, Australia, UK, Russia, Uganda, Kenya, South Africa,

US, Canada, New Zealand, Sweden, Italy and South Korea. This initiative hopes to use a cascade approach to train workers in these and other countries. Other training workshops have been conducted in many countries. An international symposium has been organised for June in Tokyo to develop further initiatives. It is clear that one of the major impediments to improving access of patients and their carers to highly effective psychoeducation strategies is the untrained professional workforce. The model of partnership between professionals and consumers helps to improve training, as well as ensuring that the content of education programmes is based on the practical and emotional needs of consumers, not merely on research-based psychological and social theories. Much has been learned from our friends in developing countries, where the partnership model an essential aspect of all services.

There is a major need for improving training materials. A new series of consumer guidebooks has been produced, and is now available in several languages. However, printing of written materials is expensive, and photocopiers are rare in many services. It is also worrying that the benefits of psychoeducational methods are being diminished by advocates of new medications, most of which show relatively small benefits when compared to those of psychoeducation. Where funds are short the clinical choice should favour the psychosocial methods, and it our group has been working to educate administrators to understand the logics behind this economic argument. Clearly we must fight to ensure that every improvement in treatment is provided in all parts of the world, but WAPR should focus on the promotion and implementation of psychosocial methods. We have much to learn from the WSF and other consumer groups, and it seems that closer collaboration with other associations and initiatives can greatly strengthen our work. Prof Ian RH Falloon, Psychoeducation Group Convenor

A Board Member: EDVARD HAUFF (now Deputy-Secretary General, formerly Deputy VP for Europe)

Edvard Hauff MD, PhD is the Director of Psychiatric Education, Ullevaal University Hospital,

and Professor of Transcultural Psychiatry, University of Oslo. He also serves as a Consultant for persons with immigrant background at Holmlia Community Mental Health Centre. Since 1993 he has been involved in training psychiatrists and establishing mental health services in Cambodia, and one of his main professional interest is the development of psychosocial rehabilitation in low-income countries.

Hauff's GOALS FOR WAPR

Priorities :

- Continue the development of WAPR as a forum for the development of a real partnership between users, their relatives and friends and mental health professionals, with the common objective of improved inclusion of users in the community

- Strengthen the support to low-income countries regarding the establishment of national branches, and the development of knowledge and skills in psychosocial rehabilitation in these countries, as well as support the establishment of users' and relatives' associations there
- Strengthen the struggle against violation of the human rights of mentally ill persons, especially in war torn and disaster stricken communities
- Participate in the development of an improved evidence base for psychosocial rehabilitation, and disseminate information about this developing evidence base through the WAPR congresses and other relevant meetings
- Review the WAPR committees and assess if the resources should be concentrated to the most relevant and active committees
- Work towards a closer collaboration and possible merger with other international associations working for persons with severe mental illness (e.g. the International Society for Psychological Treatment in Schizophrenia (ISPS)), and also strengthen the collaboration with other international mental health associations (e.g. WFMH) in the efforts to further the understanding of mental health and psychosocial rehabilitation in the international community.

A funding proposal from Africa: (there are later versions)

Botswana Association for Psychosocial Rehabilitation, P.O. Box 126 Lobatse,
Botswana Southern Africa

Contact: The National Secretary Mr. Stephen Tsumake Tel: (267) 330267 Fax: 332174

WAPR Regional Vice-President Dr. Paul Sidandi E-mail: paul.sidandi@it.bw

Community Psycho-education Project on HIV and AIDS for people with mental disabilities in Lobatse

Background information and project justification: The proportion of women in Lobatse is similar to the national profile of 52% women and 48% men. Children under 15 account for 45% of the population. The number of mentally ill patients currently admitted to Lobatse Mental Hospital on any given day is 240 on the average. Of these 29% (70) are women and 71% (170) are men. Women who are admitted come at a late stage because a woman has to be extremely disturbed before relatives agree to seek medical assistance. The experience of the Association is that women are referred to the hospital when the illness is advanced and is more difficult to manage.

The magnitude of mental illness in Botswana: Lobatse Mental Hospital which is the national referral centre for mental health with a catchment area responsibility for the

southern half of Botswana and Lobatse Town (Population estimate 35,000) admitted on average 906 cases a year from 1991 to 1996 with men accounting for 575 (64,5%) and women 316 (34,5%) of the cases. The number of admissions, which had been falling steadily over the years, have been on the rise from 1994 and this has been largely attributed to the HIV factor.

The risks of the problem of HIV/AIDS among women and children in the community: Since AIDS was first diagnosed in Botswana in 1985, the risk of infection can be estimated from the seroprevalence rates of HIV among pregnant women and by extension to their offspring. The latest sentinel surveys of HIV in Lobatse shows a rising seroprevalence rate rising from 17,8% in 1993 to 37,9% and 33,7% in 1997.

Prevalence of HIV among the mentally ill: The number of HIV positive cases among the mentally ill patients admitted to Lobatse Mental Hospital from 1991 to 1999 has shown a trend of a steady increase over the years. The number of tests reported as negative are also steadily declining and the cross over occurred in 1994 with more tests returning as positive than the negative. Of the 184 tests done over the period, 100 were positive and 84 negative. The gender breakdown of the 100 positive cases was 55 Female, 34 Male and 11 unrecorded.

The project is the first of its kind that will for the first time since HIV was diagnosed focus on the impact of HIV and AIDS on mentally ill patients and in particular women and children. The project seeks to empower patients with skills to prevent them from being infected with HIV. It will also provide to those patients who are already infected and are either in the mental hospital or on home based care.

Mentally ill patients in general and those suffering from schizophrenia in particular suffer a significant degree of co morbidity or co-occurring disorder. The condition increase the risk of HIV infection among individuals with severe mental illness because they have higher rates of HIV related risk behaviour such as unprotected sexual intercourse and risk of infection from the use of infected needles and blades in the hands of traditional healers. They are also vulnerable to sexual abuse as they are not in control.

Taking care and empowering the mentally ill patients is an important strategy in the continuum of prevention of the spread of HIV. Lack of serious support to this category of society could jeopardise efforts made in curbing the spread of HIV.

Different strategies to address the problems of HIV and AIDS, as they relate to mentally ill patients, needs to be found. Innovative approaches and care skills are urgently required. Examples are facilities that hold potential but temporary solution is the concept of the Halfway house in the community. The project will also focus on Information, Education and Communication (IEC) with special training strategies for both caregivers and parents.

This will help to reduce the current high number of relapses or reoccurrence of the illness as most patients return straight home as soon as they are discharged even when they are not actually ready for community or home based care.

Such patients need a Halfway house to consolidate their recovery. Care in the community also helps to reduce the stigma attached to mental illness.

It is well known that HIV is not only lymphotropic but also neurotropic. Neuropsychiatric problems may be the first clinical manifestations of HIV infection. These manifest long before any other systems are involved. It is also known that certain mental illnesses such as Affective (mood) disorders can cause immuno suppression in their own right. This may result in a double impact on the immune system of a HIV/AIDS patient. Other mental illness such as hypomania, personality disorders, anxiety states, alcohol and drug abuse may give rise to behaviours that increase the risk of contracting HIV. Mental illness may pose a major barrier to pre-test and post test counselling by distorting the message, or through lack of co-operation.

The Association has observed in Lobatse Mental Hospital that the mentally ill tend to form relationships with other mentally ill patients. Contracting the disease can arise from this kind of relationship. The stigma attached to mental illness may magnify the stigma and isolation of the HIV patients even more. The chronic nature of most mental illness makes this condition difficult to manage in the community and therefore Community Health and Social Workers need skills for effective care.

The Botswana Association for Psychosocial Rehabilitation (BAPR) has been at the forefront of the efforts in the field of Rehabilitation Psychiatry.

It is leading efforts aimed at finding a suitable model for Psychosocial Rehabilitation (PSR), which can be implemented in Lobatse and has the potential of being replicated in other parts of the country, which have similar disease patterns and are in a comparable stage of development.

This project will also seek to find strategic ways of integrating the care and support of mentally ill patients infected or affected with HIV and AIDS into the general health care delivery system using a multisectoral approach in its implementation. Community Based Rehabilitation Services (CBRS) approach is a cost effective method of meeting the rehabilitation needs of families and individuals with mental disabilities. These are some of the strategies the project will work on with the aim of piloting them in Lobatse. If they are successful they form the basis of the project expansion in other areas.

Project objective The objective of this project is to find appropriate strategies that would empower the mentally ill persons to cope with their condition in their community. In addition the project will provide the patients with skills to minimise the risk of exposure to HIV infection.

Activities:

- i. Conduct baseline survey on the level of awareness of HIV/AIDS among the mentally ill patients
- ii. Conduct a survey on community support systems that assist and or prevent mentally ill patients from being infected with HIV through sexual abuse and rape as a result of their mental condition.
- iii. Develop strategies to empower the patients in preventing themselves from the risk of infection.
- iv. Identify the number of mentally ill patients that are already infected with HIV with the aim of providing special care.
- v. Develop a Halfway house for such patients.
- vi. Organise a workshop on the implications of HIV and AIDS on mentally ill patients with the aim of influencing the National AIDS Policy and Programme to take serious consideration on their care and support.

Project inputs:

Project personnel, research equipment (i.e. Computer etc.), communication equipment suitable for use by mentally ill patients, publications, posters, video cassettes, Half way house and funds.

Project outputs:

- i. Baseline report.
- ii. Inventory of community support systems for mentally ill patients with HIV and AIDS.
- iii. Proposed strategies for empowering mentally ill patients to prevent themselves from being infected with HIV.
- iv. A Halfway house in the community.
- v. A variety of publications and videos.
- vi. Recommendations for policy changes to cater for the mentally ill patients infected with HIV, or for the care of already infected persons and for the protection of others from infection particularly care givers.

Target groups:

Mentally ill patients especially women and children.

Implementation strategy:

The implementation of the project will start by conducting a baseline survey on the attitudes of mentally ill patients in the community and in the hospital towards HIV and AIDS. The project will collaborate with the Lobatse Multisectoral AIDS Committee and the Lobatse Mental Hospital.

The hospital in partnership with the Association is planning a research project on the mental aspects of HIV and AIDS. Other collaborating partners in this project will be Social and Health Workers in Lobatse.

The project will use the Kgotla (traditional community meeting place) to pass on relevant messages on psycho-education. It is envisaged that the project will also use drama in order to reach to the mentally ill persons, a group often considered difficult to reach using traditional systems of communication. The role and collaboration of Traditional Healers will be solicited as most patients are attended in the first instance by Traditional Medical Practitioners or Spiritual Healers and frequently also upon discharge from the mental hospital.

Project inputs:

Human resources, equipment, transport, stationery and a Halfway house.

Project monitoring and evaluation: The Association in partnership with other caregivers will monitor the implementation of the project. Evaluation will be based on the assessment of whether the project has achieved its objectives.

Implementation organisations The project will be implemented by the Botswana Association for Psychosocial Rehabilitation (BAPR), an NGO specialising on the care and support of people with mental disabilities and affiliated to the World Association for Psychosocial Rehabilitation (WAPR). The Association collaborates with the Lobatse Mental Hospital where it is also based. The members of the Association are volunteers and serve in various institutions. Also included are community members and patients.

Budget:

The anticipated budget for this project is P500,000.00 in the first year. (US\$125,000).

WAPR CALENDAR:

The **Indian** Chapter of the WAPR is organizing a two day workshop for seven states in the North Eastern Region in order to develop community based rehabilitation programmes there. This will be with full support and participation of the family. The Honourable Health Minister of Assam is inaugurating the workshop on 8th September 2000. Closing ceremony on 9th September 2000 will be attended by H.E. the Governor of Assam. Contact: tmurli : <mailto:tmurli@nimhans.kar.nic.in>

The **Hungarian** Association for Psychosocial Rehabilitation will meet* 28-30 September 2000. Patron is Oliver Wilson, WAPR PAST President. Contact Dr. Ida Kosza: Kosza@mail.datanet.hu

The **Phillipine** Association for Psychosocial Rehabilitation will have* its First National Conference on Psychosocial

Rehabilitation, "Towards Destigmatization, Supporting Families and Caregivers of the Mentally Ill" Manila, November 28-30, 2000 contact: felicitas soriano: zfelicitas@hotmail.com

*Z. Taintor to participate.

MEMBERSHIP: Join your national chapter of WAPR (see list on website) or use the form on the web site: <http://www.wapr.de/>