EUROPEAN NETWORK OF (EX-)USERS AND SURVIVORS OF PSYCHIATRY

THIRD CONFERENCE

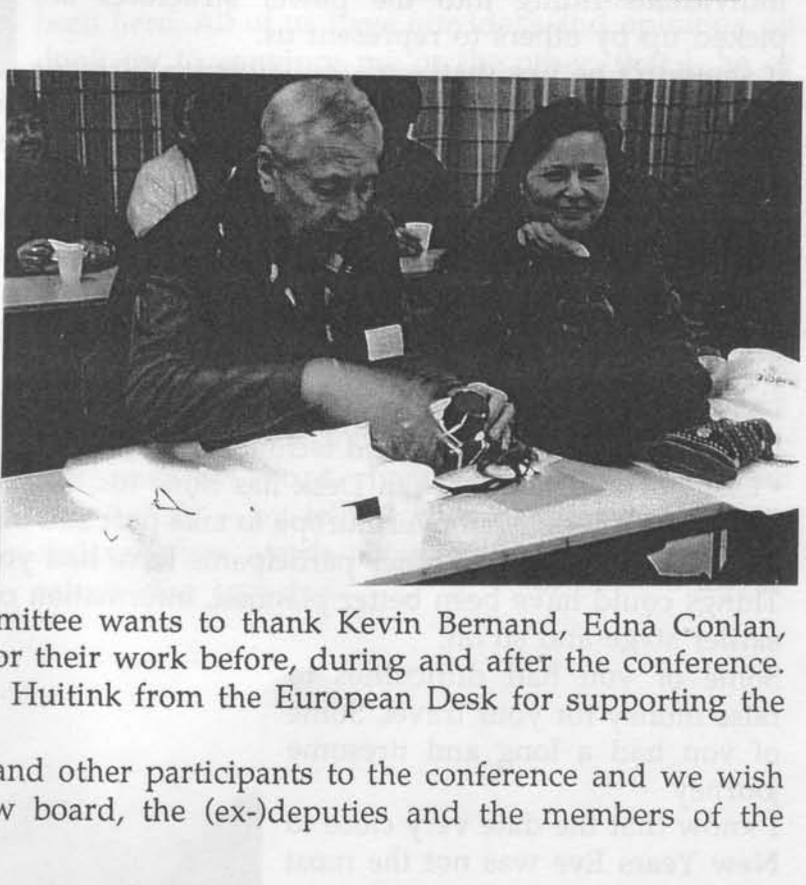
READING, ENGLAND
1997, JANUARY 3 – 6

REPORT

Contents

Colofon
Editorial department and layout: Peter Lehmann, February 1999
Pictures: Clemens Huitink, Maths Jesperson
Production: European Desk

Preface



The third European Conference of (ex-)Users and Survivors of Psychiatry was organised in Reading, England, by a British committee of (ex-)users and survivors of psychiatry, representing Mindlink, Survivors Speak Out and UKAN (United Kingdom Advocacy Network).

On behalf of the European Network of (ex-)Users and Survivors of Psychiatry, the Organising Committee wishes to express its gratitude to the

- Clientenbond
- Sainsbury Centre for Mental Health
- University of Reading

for their financial support, thus making the conference possible.

We also want to thank the European Regional Council of the World Federation for Mental Health for their support, as well as the Hamlet trust for financing the travels for a lot of (ex-)users and survivors of psychiatry from the ex-stalinistic states. We were very glad to have them in our midst finally.

Further more the Organising Committee wants to thank Kevin Bernand, Edna Conlan, Ethna Kilduff and Don McAngus for their work before, during and after the conference. Additional thanks goes to Clemens Huitink from the European Desk for supporting the Organising Committee.

Finally we thank all the delegates and other participants to the conference and we wish the Network, the old and the new board, the (ex-)deputies and the members of the taskforces good luck in the future.

Karl Bach Jensen and Peter Lehmann

Opening speech

by Karl Bach Jensen

Since the founding of our European Network in 1991, a lot of politicians and professionals have spoken and written about the importance of user-influence, empowerment etc.
But when it comes to reality – when decisions, crucial to the future and destiny of our people are made – then the attitude mostly is like if we the users, ex-users and survivors of psychiatry had no voice at all.
Very often we are expected to feel happy just because we are allowed to take part as a passive audience. Individuals fitting into the power structures are picked up by others to represent us.
It shouldn't be like that!
For the third time we succeeded on our own to prepare and organise that psychiatric users, ex-users and survivors could meet on an European level.
That our Network stayed alive for these many years, that our organisation, although still very immature, still is growing and developing in itself proves that we are able to organise, to speak on our own, to empower the powerless.
A lot of efforts have been done to make this conference a reality:

- Board members spent many hours to discuss and decide about what should happen these days.
- The British organising committee has done a very big and difficult job to raise money, to arrange a lot of practical and technical details.
- Clemens at The European Desk has done his utmost to write, mail and answer letters, inviting delegates all over Europe to take part and being well informed.

You the delegates and other participants have had your trouble I am sure:
Things could have been better planned, information could have been passed to you at an earlier stage and so on.

Some of you had difficulties to raise money for your travel. Some of you had a long and tiresome journey.
I know that the date very close to New Years Eve was not the most convenient – it was chosen because of practical reasons. The rooms where we stay these days usually accommodate the students of this university.
Unfortunately a few countries that took part in our former conferences are missing today: Rumania, Greece, Iceland. But also new co-

untries joined us: Estonia, Bulgaria, Slovakia, Luxembourg. Two delegates from Albania planned to take part, but did not get there visas in time.

Still we are in lack of representatives for users/survivors in Spain, Portugal, Ireland, Latvia, Lithuania, Russia, Ukraine, Moldavia, Belarus, Macedonia, Croatia, Bosnia-Herzegovina and Malta. Hopefully more countries will take part next time we meet.

Anyway: a big and warm welcome to all of you. Later on my colleague Edna Conlan will go through the programme of the conference.

The former secretary at the European Desk of the Network, Jan Dirk van Abshoven mentioned when we met at our first conference in Zandvoort, the Netherlands, in 1991 something like:

»All of us are strong minds. If not we wouldn't have been here. All of us have our ideas and opinions, so don't try to convince me or the other, that I, he or she am/is wrong. We must agree to disagree.«

From that point I think we always have to start, also at this conference.

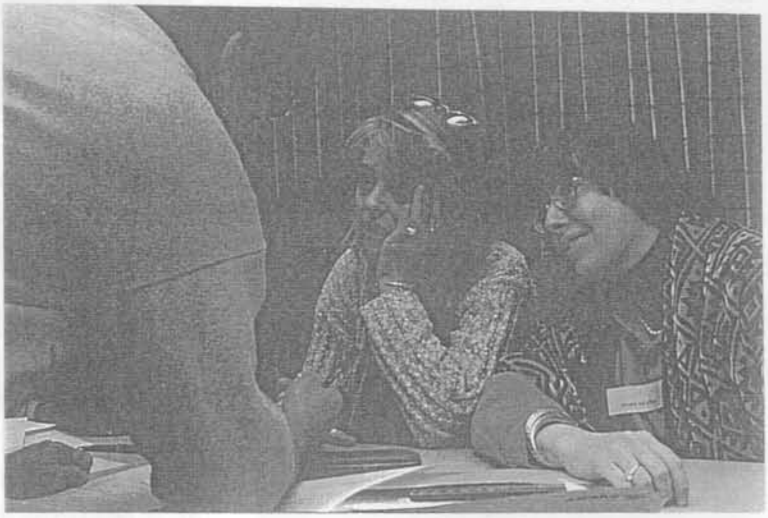
But to develop this Network, to get closer to our goals about getting influence and have our rights met properly, we need some agreement.

Not forgetting our diversity as an important strength, we also must deal with unity and compromises.

I officially declare this conference to open by giving each of you a chance to introduce yourself very briefly – by telling your name, your country and very few words about who you are. But please: no long speeches.

Report of the workshop 1: »Criticism of psychiatry in theory and practice. Medical model, drugs, ECT, coercion, advocacy«

Facilitators: Edna Conlan, Peter Lehmann
Reporter: Edna Conlan (deputy-report by Peter Lehmann)



In the working group about psychiatric drugs there was a discussion about the risks of electroshock, neuroleptics and antidepressants, especially of fluoxetine (trade names: Prozac, Fluctin). Critic was expressed about genetic theories in psychiatry. Information was changed about different forms of advocacy for 'users' of psychiatric drugs, about will declarations in advance to protect yourself from forced treatment (for example the psychiatric will, which is used in Germany). Further on there was an expression of sorrow about the growing legal possibilities to be treated by force in psychiatry, and there was clearness about the necessity to criticise psychiatric treatment and theories in a scientific way to strengthen the legal status of (ex-)users and survivors of psychiatry.

Report of the workshop 2: »Alternatives. Selfhelp, hearing voices, holistic approaches, runaway-houses, user-run projects«

Facilitators: Ron Coleman, Iris Hölling
Reporter: Ethna Kilduff

Speech by Ron Coleman

First I would like to thank the organisers for inviting me to speak at the conference today. I always enjoy speaking at conferences; most of the time it is at conferences run by and for professionals. In fact today will be the first time I have spoken to a user only conference and I feel both honoured and humbled by this. 14 years ago I was Diagnosed as having schizophrenia, 5 years ago that was changed to chronic schizophrenia, just over 3 years ago I gave it up and went back to being me. Ron Coleman psychotic and proud of it.

I have been asked to speak about alternatives, the first question that I would like to raise is alternatives to what. For it would appear to me that there is two ways to look at this. The first is that we look for the present system in our countries to offer alternatives to its present love affair with drugging everyone or using ECT. Or we look elsewhere perhaps even to ourselves to find answers the system has failed tot deliver.

Going down the first route that of expecting the psychiatric system to offer real alternatives would be the ideal, but we all know that would amount to a real delusion on our part if we really believed that this would happen. Not going down this road would tantamount to us putting the sheep clothing on to the wolf. What would happen would be the iron fist in the velvet glove, everything would be okay as long as we did as we were told but step out of line and they would revert to their old ways of forced treatment. Some users would argue that this might not be the case that the leopard can change its spots. This argument appears valid on the surface and it would be easy to fall into believing that it could work. If this was to happen then we would be failing to learn the lessons of history. In the last century in a city called York a young Quaker was murdered in the state hospital. The response by the Quakers in York was to open their own psychiatric unit called the York retreat. This unit operated on the basis of treating people as people: an holistic approach. The British Government, after an inquiry, was so impressed that it ordered the Quaker model to be adopted by all psychiatric institutions; and it was but oh for such a short time. For the reality of what happened was not that all the institutions became like the York retreat but that York retreat became an institution.

If we cannot learn from history, what can we learn from, can it be the case that we learn from ourselves, in the hearing voices network we work together, not to get rid of voices, but to learn to live with voices. Self help is not a therapy it is a way of dealing with our experience that allows us to maintain control over our lives. For at the end of the day psychiatrists do no own our experience, psychologists do not own our experience, nurses do not own our experiences, social workers do not own our experience, family and carers do not own our experience. Not only we can own our experience and I believe this more than I believe anything else, it is only when we own our experience we can own our recovery.

For surely it is recovery that we seek no treatments or therapies that have in the past been of little or no help to us. We know that 50% of people with psychosis still experience so called psychotic symptoms, even on medication. We know that 33% is the recovery rate in schizophrenia using medication. We know that the recovery rate in schizophrenia was 33% before medication was introduced. We know that most psychiatrists become psychiatrist because they are useless at another medical discipline. Can we trust psychiatry to offer us alternatives when in Britain the Royal college of psychiatry was the only organisation that called for compulsory treatment in the community, the answer must be no. Let's face it, conference at present we may have little pockets of alternatives, some even being provided by the system but it impacts on so few that one could argue that alternatives within the system do not exist in any meaningful way.

If this is the case, then we must seek out our own alternatives. If services need to be provided then we should seek to provide user run services indeed perhaps the time has come to set up the anti-system. I have always believed that users have the ability to run a service, dealing with people's mental distress that would be both better and different. My personal vision would be of a service that users ran that was based on the principles of choice, no cohesion and dignity that would seek to meet peoples physical, spiritual and mental needs. A service that would indeed be an asylum, a place of safety for ourselves. I do not believe that the debate should be about reform of revolution, rather it should be about reform and revolution. We should be seeking to reform the present system which holds imprisoned many of our friends and at the same time be building our own revolutionary system. Again we must learn the lessons of history. Revolutions cannot work in a single or a small block of countries. For us to create a new system run by ourselves, it would require that all of the European countries be involved; as an international organisation we must have a common agenda for change, not only based on what we think is achievable, but also based on our aspirations, our dreams our visions and our needs as users.

I said earlier that my vision was one of user run services and so often I think of that being something that may happen in the future, but as I thought about today I realised that it was already happening: throughout Europe people are coming together in self-help groups. There are groups for people with eating disorders, alcohol problems, drug addiction, manic depression, hearing voices, compulsive behavior, anxiety, depression and many other so called illnesses.

It is in these groups that we find the foundations of an alternative system. It is in these

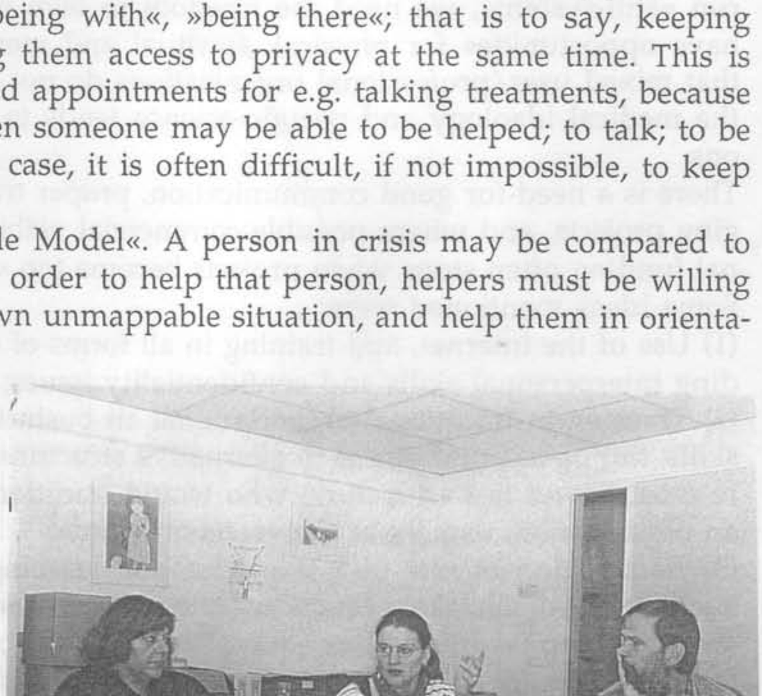
groups and in the wider user movement that we have got off our knees and fought back and it will be in these groups that we can achieve the main alternative. I believe we all seek that is freedom. Together we can move on to reclaim our freedom. The freedom to be, who we are, for me the freedom to be Ron Coleman, the freedom to be psychotic and proud...
Thank you.

Report

Under the title of »alternatives« it was agreed to look at alternative services; »therapies«; ways of defining our own experience; opportunities for work and other activity; information networks; methods of expression (e.g. through the arts); structures of organisations. It was decided to look at alternatives:
within the system
outside the system.

1) Within the system

Included as »within the system are non-user-controlled voluntary sector organisations.
It was agreed that developing alternatives within the system means collaboration with professionals, and therefore usually an unacceptable level of compromise. Projects are often unambitious and inappropriate for users' needs. It is very difficult for professionals, and also often users themselves, to understand that traditional methods and approaches can be both ineffective and damaging.
We agreed that it is necessary for users to own our own experience. Therefore, in order for alternative strategies to be effective in helping users, it is necessary for the helpers to recognise and respect that every individual has her/his own reality and needs.
Ron Coleman raised the point that professionals should be trained in »radical non-intervention«. One of the most effective ways of helping persons in crisis, including psychosis, is simply what Iris Hölling terms »being with«, »being there«; that is to say, keeping company with the person, but giving them access to privacy at the same time. This is much more effective than programmed appointments for e.g. talking treatments, because it is impossible to predict exactly when someone may be able to be helped; to talk; to be listened to; to listen to others. In any case, it is often difficult, if not impossible, to keep appointments when in crisis.
Maths Jesperson presented the »Jungle Model«. A person in crisis may be compared to someone who is lost in the jungle. In order to help that person, helpers must be willing to enter the jungle, the individual's own unmappable situation, and help them in orientation and navigation, to accompany them on their journey; it is finding a way out of the jungle together. This does not necessitates full understanding of their thoughts, emotions and experience, which is in any case impossible, but requires a basic willingness to accept and try to understand.
Instead of doing this, what professionals have traditionally tried to do is to build a wall around the lost person, to protect them from the jungle. This often has



the effect of making it very difficult, even impossible, for the person ever to find their way out.

Ron Coleman compared the Jungle Model to others called »Mapping the Maze« and the PIE model, »Play it by ear«, which means spontaneous reaction to events as they happen. We examined a model of a Hierarchy of Needs, presented by Ron Coleman, which was compared to Abraham Maslow's model. The point was made by other participants that users have the same needs as everybody else and it was agreed that in any case we are the experts on our own needs.

There was general agreement that the biggest problem is how to get professionals to accept these ideas. It was suggested that we should do what they often do to us, which is taking over their best projects and adapting them for ourselves, in accordance with our own perspectives. However, they will not usually approach us, or accept our non-medical models easily, and, as one participant put it, »Never the twin shall meet« (the two will never meet).

However, even despite these difficulties, many of us still have a commitment to working within the system, for various reasons, including a lack of resources to develop our own alternatives. One workshop participant, Peter Relton, is employed as a Service User Development Worker in a Home Treatment Service, which was set up to give people in crisis an alternative to hospital admission. It is his job to present user perspectives to professionals working within and outside the team, which has a broad commitment to social models of mental distress. He also made the point that radical non-intervention in the community would be impossible in his own work environment.

It was generally agreed the users working within the system may be able to create change, but that this is very difficult, a long job, and perhaps not worth the effort where possibilities exist to develop our own alternatives.

2) Outside the system

It was agreed that to have effective and viable alternatives outside the system, a user-run »anti-system«, we need the freedom to own our own experience and recovery, and have opportunities for physical, spiritual and mental asylum. Most participants agreed that mixed user/professional organisations do not properly address users needs, because the medical ideology and pseudo-science tends to have precedence over other perceptions.

There is a need for good communication, proper training for those working in and managing projects, and where possible commercial viability and self-sufficiency, because external funding often stops when projects become too »alternative« for professionals' comfort. Some ideas mentioned were:

(1) Use of the internet, and training in all forms of communication and networking, including interpersonal skills and confidentiality issues;

(2) Training in traditional organisational an business
skills, but open-mindedness to alternative structures, e.g. the »bottom up« approach, where most power lies with those who would traditionally be seen as being at the bottom of an organisation, usually at the »receiving end«.

(3) Recognition of our own expertise and learning from the experience of others, both successes and mistakes. Maths mentioned a project where, in recruiting staff, each year spent in hospital counted as equivalent to a year of university education.

(4) Development of user-controlled businesses and »care« facilities. Iris is involved with an association against psychiatric violence and a »runaway house« in Berlin, where professionals are brought in only when thought necessary by users and others in the house; Maths mentioned a hotel in Sweden, a villa, a second-hand shop, a cafe and a youth club, run entirely by and for users; Elisabeth Larsen from Denmark mentioned a »mad movement« of psychiatric survivors which has 15 hours' »air time« per week on local radio,

but the external funding will finish next year. Ron Coleman mentioned his publishing house, bookshops and cafe projects. It was agreed there was a necessity to distinguish between cafes fun for profit and those acting as a drop-in service for users. Working users should be properly paid.

(5) A widely expressed need for user-controlled advocacy services. We are the experts and know best how to help other users empower themselves.

(6) Much more widely available information on alternative »therapies« to dangerous psychiatric drugs and electric shock treatment, e.g. herbs, plants, minerals, vitamins, hormones, massage, reflexology, psychic healing, Chinese medicine, light-boxes, light rooms, exercise, tobacco, alcohol, sex, drugs and rock and roll(!). We are all individuals and need to find ways of looking after ourselves without psychiatry which are best for ourselves as individuals. »Leisure« activities can also be survival strategies.

All the workshop participants agreed that we could have continued to explore these ideas with more time available, and it had been very useful to hear other perspectives.

There were five proposed tasks for the Network:

1) To develop David Warner's work on the Directory of Alternative (Humanistic) Housing and Employment Structures. Delegates would investigate their own countries and report back to the European Network Desk, where a database would be held. This database/directory would be primarily of user-controlled services, etc., but a second category of services would be those which are not user-controlled, but useful and important to users. The definition of user-controlled is that the majority of those in the organisations with decision-making power (in all areas, at all levels) are (ex-)users/survivors.

2) To similarly develop a database of alternative models of theory and practice, the problems encountered and solutions found, especially concerning finance.

3) To develop directories of alternative concepts of our own experiences and self-help methods.

4) To develop a database/directory of alternative and complementary »therapies«, including how to overcome problems of withdrawal from psychiatric drugs.

To improve communications within the Network.

The »Jungle Model« (presented by Maths Jesperson)

Person lost in jungle.

Helper enters jungle to assist with navigating a way out.

Professionals traditionally tried to build a wall to protect the person from the jungle.

A »'Hierarchy of Needs'-Model« (Ron Coleman)

(There was some disagreement about the exact place which some categories should assume in the hierarchy. It was recognised by participants that although we may have similar basic needs, other priorities are different.

houses – safe environment
economic viability
self definition – right to choose
activity
education – information
company
liberty

Report of the workshop 3: »Employment, training. Social integration, international recommendations«

Facilitators: Kevin Burnand, Mary Nettle
Reporter: Kevin Burnand

Needs of people with mental health problems

The current rate of unemployment for people with mental health problems is 70 – 80%. This, I feel, is not because people do not want to work but current work structures are not flexible enough to accommodate the up and down nature op peoples emotional life.
Prejudice (stigma) and ignorance means employers reject people with a history of mental illness, this causes people to lie about their medical history and therefore have no support if they need time off work and they can be dismissed from their job.
Particularly in northern Europe the Social Security system provides a minimum income for people unable to work but the rigid inflexible way in which the rules are enforced can lead to what in the UK is called the Benefit Trap. This means that if you are able to get a job you have to give up all your benefit which may be worth more than the job pays, and, if you find the job is to stressful and have to give it up you spend a lot time of waiting, often with no money at all, to be able to get the level of benefit you had before.
In Canada people with mental health problems can be eligible for a disability pension, this is paid regardless of whether you are working or not. I feel that such a pension, guaranteed for life, would be a great help in reducing the stress levels associated with returning to work. It would not a 'scroungers charter' as the pension would only be awarded to people who have been in the mental health system for some time.
In the UK we have a Disability Discrimination Act which specifically includes people with a history of mental health problems. The act in the USA includes people with psychiatric disabilities. There is a debate within the mental health user movement as to whether we should consider ourselves to be disabled. My view is that you are disabled if society treats you differently and there is no doubt this happens to us because of our mental illness label.

The Workshop

Participants for all or most of the sessions.
Daniel Bestun – France
Kevin Burnand – England (scribe)
Stefania Dei – Italy
Milena Gheorghiev – Bulgaria
Tiit Kabrits – Estonia
Mary Nettle – England (facilitation)
Manuel Turmes – Luxembourg

The workshop split into two areas of discussion:
1. A highlighting of the different approaches in different countries to employment prospects for people with mental health problems

2. A discussion of whether it is best to be described as 'disabled' to gain work or whether the label is an hindrance and particularly whether the European User Network should remain as a member of the European Disability Forum.

Employment issues

On reviewing, from the delegates present, what the different employment prospects were in each country it became clear that there was a wide variation of expectation. In Luxembourg and Denmark there were government schemes that helped people back to work in a positive way, giving them a decent salary and training. This also provided a number of careers in the workplace as well as having very good pension/benefit provision for those not able to work.

However, in other European nations there was a different story. In England there is little valued work or training opportunities and the position in some Eastern European countries was impossible as their overall economy was in a terrible position. In Italy there are some opportunities for work in government self help schemes but here paying the high cost of living was difficult on the moneys paid to people, especially in regard to housing costs. Overall the chances of valued employment for people with mental health problems were felt to be small and dependant on the country the person lived in.

Although most countries have either discrimination legislation or quotas for the employment of a certain number of 'disabled' people these legal methods of providing employment were either ignored or very weak resulting in only menial jobs being available. In fact the idea of those already working, or in most nations those seeking work, stating that they had a mental health difficulty was thought to be a guarantee of losing your job.

The forthcoming conference on Employment sponsored by the International Labour Organisation be held in London in February has four statements to be examined with regard to employment for people with mental health problems. The group felt that the ideas were very good but that they were perhaps merely good statements with little or no chance of being realised in the countries of Europe.

Although we tried to be positive about employment – i.e. schemes in Slovene or Luxembourg which employed some people, it was felt that if you had a mental health problem you were at the bottom of the pile when it came to distributing the fewer and fewer jobs available in Europe.

The disability issue

There was a long discussion on the question of whether we should describe ourselves as disabled – should we ask for 'normal' consideration of special measures which describe us as disabled? The facilitator pointed out the United Nations definition which places the onus on the individual and not society when it comes to responsibility for discrimination and that there was a difference between experiencing discrimination and being disabled. The group felt the idea of being a victim of discrimination by society was more valid than being seen as a lesser person. Some participants however, felt it was good to have a recognised medical condition as this opened doors to, other things – employment schemes, benefits, pensions, etc.

There was such a variation in experiences that to state we are disabled in public in all European nations would be impossible. There were some advantages to the label in some western countries but to 'come out' in certain eastern states could result in terrible consequences for the individual. Therefore we felt we could not recommend a specific course of action for the whole of the European network when it came to the issue of 'are we disabled' and should we remain part of the European disability forum. (Please see Mary Nettle's contribution for an extension of this point)

Feedback by Mary Nettle, Mental Health Consultant

Should The European Users Network consider themselves to be a network of people with disabilities?

The criteria used to define disability varies according to individual experience. The way this experience is described varies from country to country.

Within the European Network the definition of service user is left to the individual, this can be the same for a definition of disability.

The view of the workshop is that individuals are disabled by their psychiatric label which means they are treated differently, that is disabled, by society.

The issue of working with other disabilities in the Independent European Disability Forum was discussed. This forum currently includes organisations of and for people with mental health problems and only involves the fifteen European Union member states. Each member state has, or is working towards, a national disability council which will send representatives to the European Forum.

The current role of the European Users Network is as one of the European non governmental organisations seeking to influence the work of the Forum as part of a consortium led by the European Regional Council of the World Federation of Mental Health. It is intended to make links and eventually to be influential enough to have a place on the Forum in our own right.

It was agreed, after much debate, that it was very difficult to come to a consensus. A compromise resolution was put to the conference and passed which will enable the Network to continue working with the Forum.

The European User Network took part in a conference on employment in Sweden in October 1995, this is being followed up by a conference in London in February this year.

Four principles were agreed:

1) People experiencing psycho-social disabilities should enjoy equal opportunity and treatment in respect of access to, retention and advancement in paid employment which corresponds to their own informed choice and takes account of existing skills. In this principle, the rights of men and women experiencing psycho-social disabilities should be respected.

2) Equality of opportunity for persons experiencing psycho-social disabilities shall extend to all levels of work organisation and management. This calls for respect for confidentiality of personal information.

3) Every workplace should conform to standards established by the social partners ensuring a healthy and empowering workplace.

4) Special positive measures such as wage subsidies and supported employment schemes shall not be regarded as stigmatising nor discriminatory against other workers.

It would be very useful to debate these principles in the employment workshop and see if we need to add them or make them easier to understand. The European Users Network has been asked how we can help get these principles adopted in our countries and would welcome ideas to take to the London conference.

Report of the workshop 4: »Multiple oppression. Developing policy on equal opportunities – Experiences of ethnicity, gender, social class, poverty«

Facilitators: Peter Fleischmann, Jasna Russo

Peter Fleischmann talked about the over-representation of ethnic minorities in UK mental hospitals by a factor of three. Homosexuality was regarded as an illness in the UK until 1973. In Denmark much mental illness includes homosexuality as part of the diagnosis.
Peter Fleischmann said we should celebrate the diversity of human life rather than discriminate against it.
Many said that many ethnic minorities in Britain, such as ? and Jewish people were still not properly considered by the user movement.
Sharon said that homosexuality was often hidden in the psychiatric system.
Erik referred to the wealth of human diversity and a European law that states that people should not be committed to psychiatric hospitals of race, sexual orientation etc.
Roberta said that Afro-Carribeans in England were frequently diagnosed schizophrenic compared with others and that this diagnosis was often because of their culture is seen as illness by psychiatrists.
Erik talked about how psychiatric diagnosis was relative to particular societies' norms and the question as to whether psychiatry was really social ? or treatment for 'real' illness was opened ?. A strong consensus developed that we were proud to be 'mad' or belonging to an ethnic minority, gay or lesbian.
After a long discussion about what was normal emerged the important basic human right for the mentally ill to procreate. One person said that she had been refused IVF, because of her mental history.
Erik talked about the special laws for the mentally ill, e.g. that if an ordinary person is thought in danger of committing a crime they have to actually do it before they are arrested. Whereas for the mentally ill, the suggestion that they may commit a crime is enough for them to be forcibly detained.
Roberta said how people spent many years in closed psychiatric institutions in the UK for having committed offences that ordinarily would have resulted in only a few months imprisonment.
The issue as to whether we waited to define ourselves as disabled was discussed at length and the issue whether we wished to join or be affiliated to disability organisations was

also discussed. It was felt that we should be able to define ourselves as individuals and that we need to strengthen our own collective identity before joining other organisations. The following statements were agreed by the group to be taken forward to the plenary session:

No-one should be compulsorily treated or detained in a psychiatric hospital for reason of race, belief system, religion, sexual orientation, cultural or family background, hearing voices, age, lifestyle, physical disabilities or learning disabilities, language or gender, drugs use or behaviour considered immortal by society.

The network should strive to contact and work alongside disability groups but maintain its independence and identity without affiliating to other organisations. The network should be aware of the diversity of the regions and not dominated by any one region and promote equality of opportunity for all individuals.

Every human being should have the right to have children. No person can have their children taken away on the basis of a psychiatric diagnosis.

The network should campaign for equality before the law for all.

No person should be sterilised and no pregnancy should be terminated on the grounds of a psychiatric diagnosis.

No-one should be denied medical services (including fertility treatment) with special reference to people detained in psychiatric hospitals.

Report of the workshop 5: »Structure and name of the network. Laws and bylaws, spirit and future«

Facilitator: Karl Bach Jensen

At the founding of this network we defined ourselves to deal with information and communication more than decisionmaking and power.

At our last conference in '94 we agreed to strengthen the structure of the Network by replacing a co-ordinating group with a board with some power to make decisions on behalf of the Network but in the spirit of the conference. We did not at that time decide any legal structure, no statutes or laws for the Network – but a few house-rules about board-activities.

Since then the board decided some more detailed rules about how to plan our meetings and how to make decisions.

We also felt the need for a legal body to give the Network and not only the European Desk, the opportunities to administer its own finances.

The first secretary at the desk and the board therefore worked intensively on establishing a foundation according to the Dutch law. However the problem is that a foundation is not a democratic body – democracy can only indirectly be build into it.

The final steps to establish such a foundation were never made, but the paper-work that was done has now been reedited. The draft statutes and by-laws which now are distributed amongst the delegates are a result of this process.

These draft statutes are not perfect. We tried to answer the questions such statutes have to deal with. The workshop and the conference probably will find some of our answers wrong. Please feel free to change and add. But keep in mind that some craters have to be met according to the Dutch law.

But why decide to change the Network into a legal body – into a European Federation – into a genuine NGO?

Some of the reasons are:

1) Defining membership, giving a clearer picture of who we are.
2) Specifying members' rights and level of democracy.
3) Getting closer to decisionmaking bodies and power-centres on a European level.
4) Seek funding to finance our activities and deal with finances.

When building a legal body we should not forget to balance between a bottom-up structure actively involving as many users/survivors as possible and the need for some centralisation to reach the goal = become and be recognised as THE European NGO of users, ex-users and survivors of psychiatry.

Other and stronger organised groups already try to make it seem like they represent us on a European level. With no legal structure we in the long run could be totally ignored by international authorities.

Another important balance to keep in mind in the future is to represent the views of on the one hand users/consumers accepting psychiatric treatment and on the other hand survivors not wanting any treatment at all.

In my view the real spirit of this Network is to go on to accept that we have different experiences and different views.

It is crucial that neither survivors with more or less radical views nor consumers less critical towards psychiatry would end to leave this network.

Competing parallel structures between consumers/users and survivors/ex-users combating each other on a European level would not help us at all.

Name change

To make the name of the Network more precise, giving all members a chance to identify themselves with the name and not changing the name to much, the departing board suggests the name to be:

EUROPEAN NETWORK OF (EX-)USERS AND SURVIVORS OF PSYCHIATRY (ENUSP)

European Mental Health Service User Network

For and against psychotropic drugs

Proposal as position-paper for the European Network of (ex-)Users and Survivors of Psychiatry [1]

Speech by Peter Lehmann

Assessing the administration and taking of psychotropic drugs is an especially controversial issue. Taking neuroleptics, antidepressants, lithium, antiepileptics (administered as psychotropic drugs), psychostimulants (administered to children in order to subdue them) and tranquilizers can lead to apathy, emotional deadness, depression, suicidal states, paradoxical agitation, confusion and delirium, intellectual disturbances, loss of creativity, lack of concentration, memory problems, epileptic attacks, weakening of the immune system, hormonal and sexual disturbances, chromosomal and pregnancy damage, blood damage, disturbance of body temperature regulation, heart problems, liver and kidney damage, skin and eye damage, parkinsonian disturbances, hyperkinesia, muscle cramps, movement stereotypy, or much more. On the other side, many individuals made the experience, that they cannot exist in their life-conditions now without taking these psychiatric drugs.[2]

It is up to every individual to decide for herself or himself if, for whatever reason, they want to take these substances. However, the following arguments do not reflect a context conducive to free decision-making nor do they speak for a care-free liberal attitude:

1. The treated individuals are usually not informed of the risks – neither of those which exist nor of those which are possible or cannot be excluded. The treated individuals do not know that substances are banned from the market in some countries but sold without restrictions in other countries. For example, penfluridol (brand names: Cyperon, Flupidol, Longoperidol, Longoran, Micefal, Semap) is banned in certain countries as a possible carcinogen, remoxiprid (brand name: Roxiam) because it is associated with blood damage, and triazolam (brand names: Apo-Triazo, Dumozolam, Halcion, Novidorm, Novodorm, Novo-Triolam, Nuctane, Nu-triazo, Rilamir, Somniton, Songar, Triasan, Triazoral) in connection with amnesia and black-outs.

2. Those who decide about the admission of these risk-connected substances onto the pharmaceutical market are profit-oriented companies, doctors who are either dependent on or sponsored by such businesses, or federal health bureaucrats who have yet to prove that the health of the treated individuals by psychiatry or other recipients of tested drugs play a central role for them in their deliberations. 'Patients'-groups and other related

groups are not part of the decision-making process concerning the admission or banning of psychotropic drugs.

3. In court cases concerning damages, the burden of proof lies entirely on the shoulders of the treated individuals by the substances. It is not the financially secure company which needs to prove that the hazardous substances which it produces does not cause the damages in question, but rather the usually financially insecure person suffering the damages who, in drawn-out proceedings, has to prove that specific damage can be directly and exclusively traced to the administered drug.

4. Psychotropic drugs are often administered forcibly. An especially criminal example is the forcible administration of psychotropic drugs to women of child-bearing age without possible pregnancy being taken into account.

5. More and more defenseless older people are administered these substances as a way of chemically managing their care-taking. More and more children – who do not have the possibility of making their own decisions – receive psychotropic drugs in order to adapt them through chemical means to an environment hostile to children. More and more women receive psychotropic drugs to chemically neutralize their disruptive reactions to silencing and restrictive patriarchal living conditions. More and more people who come into conflict with the law receive psychotropic drugs in order to keep them quiet in prisons or to break their resistance to deportation.

6. The vast spectrum of inter- and intraindividual effects make it impossible to predict the effect of a specific dosage of a substance. All known damages associated with all types of psychotropic drugs have appeared independent of the dosage and within a relatively short amount of time, sometimes even after taking a small dosage only once.

7. More and more people receive combinations of different psychotropic drugs. Their effects on each other as well as their combined effect is unpredictable.

8. All psychotropic drugs create dependency, although prescribers of the substances deny the dependency-forming effects (except in the case of tranquilizers). They also remain silent concerning the possible withdrawal effects, rebound effects, hypersensitive reaction of the receptors and irreversible damage which can appear after one stops taking the drugs, or they even redefine these effects as new symptoms. Examples of damage caused by psychotropic treatment which can appear during the treatment as well as while coming off of the drugs or even after one has stopped using them altogether include: chronic fear after long-term administration of antidepressants or tranquilizers, chronic brain damage after the combined administration of lithium and neuroleptic drugs, tardive dyskinesia (dystonia, movement sterotypy, and hyperkinesia) as well as tardive psychosis after the administration of neuroleptic drugs.

9. There are hardly any in-patient treatment facilities to support those dealing with the effects of coming off of psychotropic drugs.

10. At present there are attempts being made by psychiatric associations, pharmaceutical companies and family-member organisations (which are either ideologically influenced or financially supported by these companies) to enforce and compel the taking of

psychiatric drugs, especially the life-long consumption of the drugs. These attemps are being made through legal measures, perfecting surveillance and enforcement in such institutions as intermediate-care living projects, and developing new forms of drug administering.

11. There exists neither the right to psychotropic-free treatment nor non-psychiatric crisis facilities or financially secure self-help and user-controlled centers.

12. None of the named psychotropic drugs solve any kind of psychological problem which is of a social nature. As a rule, they make it harder to solve these problems, regardless of whether one has worked on the problem through individual self-help, group-support or paid psychotherapy. After one has stopped taking the psychiatric drugs – if it ever actually comes to that point – the conditions are usually worse than before, making it even more difficult to solve the problems which originally led to the implementation of the psychotropic drugs.

The administration and usage of psychotropic drugs is, for all these reasons, to be judged with great scepticism. Nevertheless, the individual's decision to take psychotropic drugs should be respected. This is especially the case if the individual, making his or her own thought-out decision can, by taking as small, low-toxic and low-risk a dosage as possible for as short a time as possible, survive an otherwise hopeless situation which would lead to being put at the mercy of the violence of institutionalized psychiatry and the conflict situations it entails. It is also important to respect individual decisions to take psychotropic drugs regardless of the reasons, the dosage, the time-span and how informed the individual is or is not. Those who especially deserve understanding are those who, because of pychiatrogene nerve damage, are forced to continue taking these drugs in order to survive. This group of individuals make it clear how important it is to avoid as far as possible ever taking psychotropic drugs to begin with.

We need to reflect on the tension between, on the one hand, the needs of the individuals in question who have a right to define their own conflicts, needs and risk threshhold, and, on the other hand, the power of biological psychiatry, irresponsible politicians, family-member associations which get involved in internal family conflicts, and profit-oriented pharmaceutical companies. While the needs of the individuals need to be respected, the power of these institutions needs to be restrained. This tension can only be reduced on a long-term basis if consumers of psychotropic drugs as well as those who are administered these drugs forcibly are guaranteed the following: 1) diagnosis-independent human rights[3]; 2) easy access to financial compensation when necessary; 3) a right to psychotropic drug-free help; and, 4) appropriate alternative non-psychiatric help.

Footnotes

1) This paper is a translation of the shortened last part of my résumé in my (German language) *two-volume book »Schöne neue Psychiatrie« (»Brave new psychiatry«)*, Vol. 1: »Wie Chemie und Strom auf Geist und Psyche wirken« (»The effects of chemistry and current on mind and psyche«), Vol. 2: »Wie Psychopharmaka den Körper verändern« (»How psychiatric drugs change the body«), Berlin: Antipsychiatrieverlag 1996.

2) This sentence I added as a result of the Reading discussion.

3) Meant: It should not be possible to dispense a human (or civic) right because of a psychiatric diagnosis.

After the discussion the assembly decided to publish this proposal-paper in the European Newsletter. Commentaries should be sent the editorial department (Maths Jesperson).

The 12-Point-Programme

The European Network of (ex-)Users and Survivors of Psychiatry has formulated a 12 point programme for the next two years:

1) Strengthen communication between members and between the board and members.
2) Produce, publish and distribute more and improved written documentation about aims, structure and work, and to promote better public relations.
3) Make use of new technology, E-mail, internet and to create a WWW homepage at the European Desk.
4) Build links with and help to develop and consolidate the user/survivor movement in countries with no or a few organised groups.
5) Seek funding to finance networkers with language skills to travel in certain countries like Spain, Portugal, Greece, Romania, Ukraine & Russia, aiming to build links and support user/survivors to get together.
6) Help to raise finances and support national/regional parts of the network to take part in the activities and to run their events, e.g. seminars, conferences, summer camps.
7) Collate knowledge about law and practice concerning compulsion in psychiatry.
8) Plan and run mutual actions against compulsion, for the right to get the help needed.
9) Collect and distribute information about certain themes like ECT, Psychiatric Will, alternatives etc.
10) Strengthen knowledge and relationships with European authorities like EU, European Court, Council of Europe and UN bodies like WHO, ILO etc.
11) Build new structures of mutual co-operation between the network and European NGOs allies.
12) Fight to directly represent (ex-)users/survivors in the international arena.

The European Network of (ex-)Users and Survivors of Psychiatry

(actualised addresses, February 1999)

Secretariat

EUROPEAN DESK
Clemens W. Huitink
Postbus 645
3500 AP Utrecht
The Netherlands
Tel. +31–10–254 1808
Fax +31–10–254 1157

Newsletter co-ordinator

Maths Jesperson
Ostens Undéns gata 24
22762 Lund
Sweden

Delegates

AUSTRIA

Margarete Aulehla
Hafnerg. 5 / 10
1020 Wien

Ingrid Machold
Petrusg. 8 / 5
1030 Wien

BELGIUM

Jan Boeykens
Verlatstraat 13
2000 Antwerpen

Jan Kuypers
Goudstraat 8
9000 Gent

BULGARIA

Milena Ivanova Gueorguieva
Mercy
Mramor Boulevard Block 4
3500 Berkovitza

Penka Kolarova
80 Patriarh Evtimi Blvd.
Entr. A
1000 Sofia

CZECH REPUBLIC

Eva Feiglová
Sládkovicova 67
byt c. 69
14200 Prague

Jan Gottwald
Zvonsrova 6
13000 Prague 3

DENMARK

Anders Bungard
Frueloekke 2
6200 Abenra

Erik Olsen
Bentzonsvej 13, 1 tv
2000 Frederiksberg C

ENGLAND

Manny Lalani
Flat 6, 26 Bignor Str.
Cheetham
Manchester M8 OSE

Bev Mills
12 Links Green Walk
Gosforth
Newcastle NE3 5JH

ESTONIA

Maimu Kaasik
Mai 23 – 53
3600 Pärnu

Tiit Kabrits
Parnu Mnt. 66-24
Tallinn

Juta Rahu
Hiiela tee 10
0021 Tallinn

FINLAND

Christer Sundqvist
Metsäkuja 10
21600 Parainen

Virpi Vesterinen
Puistokatu 8 B 37
20100 Turku

FRANCE

Marc Lalvee
c/o AFTOC B.P. 35
59790 Ronchin

GERMANY

Kerstin Kempker
Zabel-Krüger-Damm 183
13469 Berlin

Peter Lehmann
Zabel-Krüger-Damm 183
13469 Berlin

HUNGARY

András Adoryan
Bimbo u 11
1022 Budapest

Gábor Gombos
Klauzál u. 31.f.6
1072 Budapest

ITALY

Stefania Dei
Via 10 Maggio N. 63
59100 Prato (PO)

Angelo Gigliotti
V. Vanchiglia N. 3
Torino

Oswald Pertramer
Kravoglstr. 6
39020 Marling

LUXEMBOURG

Roger Conrardy
3, Inip. Prince Henri
9047 Ettelbruck

Manuel Turmes
16, rue A. de Musset
2175 Luxembourg

THE NETHERLANDS

Marijke Holleman
St. Pandora
Postbus 75622
1070 AP Amsterdam

Jan Schlärman
LPR
Meerkoethof
3582 Utrecht

Louis Zwarts
LPR
Kuyperweg 18
2613 XE Delft

NORWAY

Nils Johan Rodal
Postboks 298
3701 Skien

Sigrun Tømmeras
Ole Brumms vei 20
0979 Oslo

POLAND

Wójcik Boguskawa
ul. Lenartowicza 16/14
43-300 Bielsko Biala

Grazyna Kusnieruk
Akacjowa 10 m 13
02-534 Warsaw

SCOTLAND

Melanie Kyle
c/o SUN
18/19 Claremont Cres
Edinburgh EH7 4QD

George Ronald
6 Norley Lane
Studley
Nr. Calne
Wiltshire SN11 9LS (England)

SLOVAKIA

Zuzana Ebringerova
Kalovesta 26
84105 Bratislava

Katka Molakova
Hlavna 1308
92522 Velke Ulany otr. Gatanta

Noro Soukup
Kyjersta 5
83102 Bratislava

SLOVENIA

Irena Movrin
Jakceva 5
1000 Lubljana

Peter Murko
Krziniskova 8
1215 Medvode

Peter Zamuda
Azbetova 34
2000 Maktbor

SWEDEN

Jan-Olof Fonsén
RSMH
Box 15094
10465 Stockholm

Frederique Magnusson

SWITZERLAND

Theresja Krummenacher
12, rue Crespin
1206 Genève

WALES

Sue Stevens
10 Ashwood Court
Elm Street
Reath
Cardiff CF 2 3RH

Other conference-participants

Maija Bäckman (Boardmember 1995 – 1997)
Uotinkuja 3
38200 Vammala
Finland

Kevin Burnand
United Kingdom

Sharon Chadwick
United Kingdom

Claude
France

Ron Coleman
United Kingdom

Edna Conlan (Boardmember 1995 – 1997)
51, Perran Avenue
Milton Keynes
United Kingdom

Stephen Craine
Idlocs House
4 Stanley Road
Aberystwyt SY23 1LS
United Kingdom

Paul Fijn
Mecklenburgstr. 2
7415 RJ Deventer
The Netherlands

Peter Fleischmann
Quendra Burimore per Shendetin Mendor
L 9 RR »Gjon Muzaka« Nr. 40
Kutia Postare 2930
Tirane
Albania

Roberta Graley (Chair 1995 – 1997)
Training Research Surveys
Fax +44–181–5023132
United Kingdom

Rinus de Groot
Mertensstraat 64
3067 CL Rotterdam
The Netherlands

Iris Hölling
Bergmannstr. 9
10961 Berlin
Germany

Piotr Iwaneyko
Krolewska 19
Krakow
Poland

Karl Bach Jensen (Deputy-chair 1995 – 1997)
Langelinie 7
6000 Kolding
Denmark

Ethna Kilduff
England

John Lantrill
England

Elisabeth Larsen
Stoebyvej 3, st. t.h.
2650 Hvidovre
Denmark

Michael Maagaard
Hjortevaeget 12
6000 Kolding
Denmark

René v. d. Male
Basisberaad GGZ
Postbus 21078
3001 AB Rotterdam
The Netherlands

Don McAngus
England

Mary Nettle
73 St. Mary's Road
Evesham Worcs WR 11 4EG
England

Jasna Russo (Boardmember 1995 – 1997)
Novalisstr. 13
10115 Berlin
Germany

Edmund Schönenberger
Katzenrütistr. 89
8153 Rümlang
Switzerland

Matthias Seibt (Boardmember 1995 – 1997)
Landgrafenstr. 16
44652 Herne-Wanne
Germany

Igor Spreizer (Boardmember 1995 – 1997)
Grabloviceva 28
1110 Ljubljana
Slovenia

Adrienne Szokoloczy-Grobet
10 Argousiers
1255 Veyrier/Genève
Switzerland

David Warner
Via San Giuseppe 42
19034 Casano di Ortonovo
Italy

Boardmembers 1997 – 1999

Stefania Dei, Italy
Region 1: France, Greece, Italy, Portugal, Slovenia, Spain

Gábor Gombos, Hungary
Region 2: Albania, Belarus (White Russia), Croatia, Czech Republic, Hungary, Macedonia, Poland, Romania, Russia, Slovakia, Ukraine, Yugoslavia

Iris Hölling, Germany
Region 3: Austria, Belgium, Germany, Luxembourg, Switzerland

Peter Lehmann, Germany (Chair)

Bev Mills, United Kingdom (Co-chair)
Region 4: England, Ireland, The Netherlands, Northern Ireland, Scotland, Wales

Virpi Vesterinen, Finland
Region 5: Denmark, Estonia, Faroer Islands, Finland, Iceland, Latvia, Lithuania, Norway, Sweden

Deputies

Edna Conlan, United Kingdom (Deputy-chair)
Paul Fijn, Netherlands / Melanie Kyle, Scotland
Milena Ivanova Gueorguieva, Bulgaria
Marc Lalvée, France
Eric Olsen, Denmark
Manuel Turmes, Luxembourg

The European Network of (ex-)Users and Survivors of Psychiatry

Memorandum and Statutes of Association

(Translation from the Dutch original text. Corrected version from June 9, 2003)

Today, the twenty-eighth of May nineteen hundred and ninety eight, the following people appeared before me, Mr. Anne Pera, Notary in the municipality of Zelhem (the Netherlands):

1. Mr. Paul Jan Francois Fijn, cook, born in Heerlen on the ninth of October nineteen hundred and forty five. (Passportnr. N29011173), living Mecklenburgstraat 2, 7415 HJ Deventer, unmarried.
2. Mr. Clemens Wilhelmus Huitink, secretary, born in Winterswijk on the third of April nineteen hundred and fifty five (driving licence no. 3123564748), living Middelweg 52, 7413 RZ Deventer, married.

The appearers have declared to set up a federation (vereniging) with the following statutes:

Name, Residence, Duration
Article 1

The federation is called: European Network of (ex-)Users and Survivors of Psychiatry.
The federation resides in Utrecht in the Netherlands.
The federation is established for an indefinite period.

Aims
Article 2

1. The aims of the federation are:
   - to define, promote and improve the rights of (ex-)users and survivors of psychiatry in Europe.
   - to create and support new alternative programs to the conventional psychiatric system.
2. The federation tries to achieve these aims by, among others:
   a. supporting autonomy of (ex-)users and survivors of psychiatry and their responsibility in making their own decisions.
   b. offering (ex-)users and survivors of psychiatry a means to communicate with one another, so that they may exchange opinions, perspectives and experiences and so that they can support each other most effectively in their personal, political and social struggle against isolation, injustice and stigma.
   c. contesting any kind of discrimination towards people who are, or who have been, subject to the psychiatric system.
   d. supporting the development of organisations of (ex-)users and survivors of psychiatry in all European countries.
   e. influencing policy making institutions on a European level, with an emphasis on legislation, human rights issues, de-medicalising psychiatry and supporting alternatives to conventional psychiatry.

The federation is opposed to any unilateral approach to and stigmatisation of mental and emotional distress, madness, human suffering and unconventional behaviour.
Where the term (ex-)user and survivor of psychiatry is used, it refers to people who are or who have been recipients of psychiatric services, according to their own definition.
The federation does not intend to make profits.

Membership
Article 3

Individuals, national and European based organisations of (ex-)users and survivors of psychiatry may apply for *membership as well as mixed organisations with a considerable number of* (ex-)*users and survivors of psychiatry*. Only the (ex-)users and survivors of psychiatry are entitled to influence the policy of the federation.
Applications for membership shall be considered for approval by next meeting of the board after application.
There is a maximum of 3 members per country.
The board may consult similar organisations and individuals of the region concerned before approving/disapproving the application.
In countries where no organisations of (ex-)users and survivors of psychiatry exists, or where those organisations are not members of the federation, individuals may become members.
Organisations are obliged to lay down their level of democracy. Applications for membership have to be send to The European Desk.
If the board approves or rejects an application, the General Assembly shall have the opportunity to overrule the decision of the board.

Admission
Article 4

1. Organisations applying for membership shall include a description of their level of democracy.

2. Applications shall be sent to The European Desk.
3. Applications for membership shall be reviewed and considered for approval at the next meeting of the board after application. Similar organisations of the concerned region must be consulted, as well as the member of the board that represents the region concerned.
4. The board can accept individual people as members from countries where no organisations of (ex-)users and survivors of psychiatry exists or if such an organisation does not participate in The Network.

Termination of Membership
Article 5

1. Membership comes to an end:
   a. By the death of a member.
   b. By liquidation of the member(organisation).
   c. If a member resigns from the federation.
   d. By termination by the federation. This may occur if the member does not abide by the statutes of the federation, does not meet his or her obligations and also if the federation cannot reasonably be expected to continue the membership.
   e. By dismissal. In case a member acts contrary to the statutes, rules or decisions of the federation or harms the federation in an unreasonable way.
2. Termination in the name of the federation is effected by the board.
3. Termination of the membership by the member or the federation can only occur by the end of the federation year and not later than November 30th. However membership may end immediately if the federation cannot be expected to continue the membership.
4. Termination contrary to as stipulated in the previous paragraph makes the membership terminate on the earliest date possible following the ordinary date.
5. A member is not entitled to exclude a decision by which the financial obligations of the members are made heavier, by virtue of such termination of his membership.
6. Dismissal is effected by the board.
7. If termination or dismissal is determined by the federation a written statement describing the reasons of termination shall be sent to the member as soon as possible. The member may submit a written appeal to the General Assembly. For the time between the termination by the board and the decision of the General Assembly the member is suspended from membership.
8. If the membership terminates in the course of the year, full yearly contribution remains liable.

Composition of the Board
Article 6

1. The board is composed of a minimum of five people, who are elected by the General Assembly through regional nomination. Election or re-election takes place out of (ex-)users and survivors of psychiatry and people 18 years old at least.
   The Chair and his/her Deputy are elected in function by the General Assembly.
   The board nominates remaining boardmembers.
   In both the nomination and the election process, a gender balance shall be achieved.
   The board can nominate from their midst a deputy for each board member. A board member may assume more than one function.
2. The delegates of each of the appointed regions shall elect the remaining boardmembers. These boardmembers nominate the Deputy Chair from their midst.
3. The delegates of each region shall choose a deputy board member, who may take over the responsiblities of such board member if so indicated.
4. Only (ex-)users and survivors of psychiatry shall be boardmembers. Board members may serve a maximum of three consecutive terms.

End of board membership, periodical membership, suspension
Article 7

1. Every board member, including when appointed for a limited period of time, may be dismissed or suspended by the General Assembly. A suspension which is not followed by a dismissal within three months, ends by the course of that term.
2. Membership may end:
   - at the end of the term in which the boardmember was elected;
   - by resignation of the boardmember;

  - as a result of being discharged by the General Assembly;
  - in case of being committed or bankruptcy;
  - · by the member's death.

3. Every boardmember retires not later than three years after his appointment. The retiring boardmember is immediately eligible for re-election. A boardmember assuming the responsibilities of a predecessor shall do so only for the remainder of the term of the predecessor.
4. Suspensions, discharges and resignations must be done by registered mail.
5. Boardmembers must be (ex)patient and 18 years old at least.
6. Boardmembers shall not receive salaries; they may receive expenses allowances to accomplish their activities. Any payment of expenses shall be a unanimous decision of the board.

Boardmember Functions
Article 8
Bylaws may give further rules according to meetings and decisionmaking of the board.

Task of the Board – Representation
Article 9

1. The board is responsible for:
   - a written notification of the General Assembly to all members as is described in article 15
   - the agenda
   - a report of the proceedings
2. Except for the limitations stated in the statutes, the board manages the federation and is responsible for the realisation of the aims just as decided by the General Assembly.
3. If the number of boardmembers drops under five, the board remains competent. However, the vacancy must be filled as soon as possible.
4. The General Assembly chooses a Deputy Chair, who will take over the responsibilities of the Chair whenever the Chair so decides.
5. The board may make decisions concerning agreements to obtain, to alienate, and to encumber registered property. However, the board cannot agree contracts in which the federation might become liable as a surety for the debt of a third party.
6. The federation may be represented in and outside a court of law by:
   a. the board;
   b. the Chair, together with another boardmember.

   The board can give a general or a special authorisation to one of the boardmembers to represent the federation. Such authorisation shall be registered in the register of the federation at the Chamber of Commerce where the federation is registered.

Chairship – Minutes
Article 10

1. The board shall meet twice yearly as a minimum. The Chair or at least two other board members may call a meeting. The Chair or the board members concerned shall convene the board members by giving a minimum of seven days advance notice, excluding both the date of the meeting and the date of the meeting's announcement. Notice of a meeting should include the proposed agenda of the meeting. The secretary of the European Desk and the editor of the Newsletter should also be invited to attend.
2. The Chair of the board chairs the boardmeetings. When absent the board appoints one of its members to chair the meeting.
3. The secretary of the board or a person designated by the Chair shall record minutes of every meeting. These minutes shall be confirmed as a true record and be signed at the next board meeting.

Board-Decisionmaking
Article 11

1. The board may only make decisions if the majority of its members(quorum) is present. If a quorum is not present, the members of the board who are present may decide to convene a new meeting in accordance with Article 10. This meeting should be held at least fourteen , but no more than twenty-eight days, after the first meeting. In the second meeting, decisions will only be valid if agreed by at least two thirds of the members present who are entitled to vote.
2. If the statutes do not stipulate otherwise, the board takes its decisions by a simple majority of votes.

3. Outside of a boardmeeting, the board may make decisions. However, such a decision may only be acceptable when all boardmembers declare themselves in favour of the decision by written letter, telegram, telex, fax or any other written form of communication.

Annual Report and Accounting
Article 12

1. The federations year extends from 1st January until 31st December.
2. The board is obliged to maintain updated accounting records of its property in such a way that its rights and obligations are transparent.
3. The board presents its annual report and accounting statements in a General Assembly within a period of six months after the year end. If this is not accomplished, the board must present the issue to the General Assembly and request an extension. After expiration of the extended term, any member may demand a copy of the accounting report. The secretary shall present an annual report on the activities of the federation during the past year at the same meeting in which the treasurer will present his/her financial report. In case of approval of the accounting report by the board, the treasurer is discharged.
4. The annual accounting report shall be audited by an accountant. The board is obliged to provide to auditors all information requested, including bank statements etc.
5. The General Assembly has the right to adopt the annual reports of the secretary and the treasurer.
6. The board is obliged to keep the records, mentioned in paragraph 2 and 3, for ten years.

General Assembly
Article 13

1. The General Assembly has full authority within the federation, including authority beyond the commission of the board according to the law or statutes.
2. The General Assembly has the authority to establish committees and task forces to execute special tasks. The board or the General Assembly should appoint a survivor or (ex-)user of psychiatry to co-ordinate each committee or task force.
3. Every second or third year a General Assembly is held as a part of a European Conference or at the written request of at least ten percent of the members. If no action is taken within two weeks, the members calling for the assembly may proceed to convene the assembly themselves in the way as described in article 15.
4. The General Assembly is composed of delegates from European countries, elected by members of the Network in their own country, with a maximum of three delegates per country.
5. In special cases the board can limit the number of invited delegates.
6. The members of each country are responsible for ensuring their delegation is selected in a democratic way.
7. Only (ex-)users or survivors of psychiatry shall be delegates.
8. The General Assembly determines the federation work plans and budget for each year.
9. The General Assembly has the right to approve or disapprove the annual reports from the secretary and the treasurer.
10. Board decisions may be overruled by the General Assembly.
11. The General Assembly is responsible for the election of members to the board.
12. The board manages the federation and is responsible for the implementation of General Assembly decisions.
13. The General Assembly determines the number of regions in which the represented countries are divided.

Admission and Voting Rights
Article 14

1. Decisions are determined by a majority vote.
2. All members of the federation have the right to be present at the General Assembly subject to a maximum of three people per country. Suspended (board) members cannot attend the General Assembly. However, a suspended (board) member has the right to be present at the meeting in which the decision to suspend is considered and is allowed to address such meeting regarding the possible suspension.
3. The General Assembly decides about admission of other people than the people as described in paragraph 2.
4. Each member of the federation who is not suspended has one vote. The boardmember who is not a member of the federation has an advisory vote.
5. A member may designate someone else to vote by written proxy only.

Convocation of the General Assembly
Article 15

1. General Assemblies are called by the board. The written convocation is sent to the addresses of the members according to the list of members, with a minimum period of at least four months advance notice.
2. The convocation must include a notification of the subjects to be considered, without prejudice of article 17.

Decision-making by the General Assembly
Article 16

1. The opinion of the Chair, expressed at the General Assembly is decisive. The same applies to the contents of a taken decision as far as has been voted upon a not written proposal.
2. However, if immediately after expression of the opinion of the Chair the validity of his/ her opinion is disputed, a further vote takes place if the majority of the Assembly wishes. A new voting also takes place if the original voting did not occur a head or scriptural and a present person entitled to vote demands so. The new voting overrules the original voting..
3. As far as the statutes or the law do not stipulate otherwise, all decisions of the General Assembly are determined by an absolute majority of votes. Abstentions are considered to be not given votes.
4. If, in the case of the election of individuals, none of the candidates has gained an absolute majority, or in case of a binding recommendation, a second vote between the recommended candidates, takes place. If again nobody has got absolute majority, revotings take place until either one person has got absolute majority or voting between two people has taken place and votes has come to a draw..
   At revotings mentioned above (in which the second voting is not included) each time the vote is between the people on whom at the preceding vote a vote has been taken, except the person to whom at that preceeding vote the smallest number of votes has been given.
   If at that preceeding vote the smallest number of votes has been given to more than one person, it is decided by lot to whom of those people no votes can be anymore at the revoting.
   If, in case of a vote between two people, the votes are equally divided, it is decided by lot, which of both people has been elected.
5. When votes on a proposal, other than on individuals, are equally divided, the proposal is rejected.
6. All votings take place by show of hands, unless the Chair or one of the voting members demands a vote by a confidential (unsigned and closed) ballot. Decisionmaking by acclamation is possible, unless a voting member demands show of hands.
7. A unanimous decision of all members, even though not fully in attendance at an assembly, has the same legitimacy as a decision of the General Assembly, provided that the decision has been taken with the advance knowledge of the board.
8. In a General Assembly, as long as all members are present or are represented, legitimate decisions can be taken, provided that they are taken unanimously, concerning all matters coming under discussion - therefore also a proposal to change the statutes or to dissolution- even though no convacation has taken place or if the letter has not taken place in the prescribed way or if any other regulation concerned is neglected.

Changing the Statutes
Article 17

1. No changes can be made to the federation's statutes nor can the federation be dissolved without a decision of a General Assembly, convened specifically for either purpose. The term to convene such a meeting is at least two weeks in advance.
2. Those who have made the appeal to the General Assembly to discuss a proposal to change the statutes, have to make available for perusal for the members a copy of the proposed change in an appropriate location at least five days before the relevant meeting is held. Furthermore a copy as meant above, must be sent to all members.
3. For a decision to change the statutes at least two thirds of the votes is needed in a meeting in which at least two thirds of the members are present or represented. If two thirds are not present or represented, a second meeting will be convened and held within four weeks after the first in which a decision on the proposal can be made regardless of the number of present or represented members, provided that the decision is taken with a majority of at least two thirds of the votes.
4. A change of the statutes will not come into force, unless it has been notarised. To have the deed been drawn up, every board member is authorised.
5. The boardmembers are obliged to deposit in the office where the federation registers are:
   a. an authentic copy of the changing of the statutes;
   b. the changed statutes.
6. When the General Assembly decides to change the statutes, two boardmembers, acting together, are authorised to sign, on behalf of the General Assembly, the document in which the change of the statutes is recorded.

Dissolution
Article 18

1. The federation can be dissolved by a resolution of the General Assembly. The regulations of paragraph 1, 2 and 3 of the preceding article are equally applicable.
2. After the resolution to dissolve the federation the board has to settle the property of the federation, unless the General Assembly has appointed other people to perform this task.
   The liquidation has to take place under continuous control according to the demands of the regulation, laid down in section 2: 23 of the Civil Code. The board gives, after the liquidation, a destination to the eventual credit balance that agrees, as much as possible, with the objectives of the federation. After the settlement the annual reports and similar reports of the dissolved federation must be kept by a custodian, who has been designated for that purpose by the board; within a term of eight days after the settlement the custodian must have inscribed his keeping duty in the register of the Chamber of Commerce.

Assets of the Federation
Article 19

The assets of the federation may, among other things, consist of: donations, subsidies, inheritances and legacies;

- membership fee;
- the revenues of the federation's activities;
- the revenues arising from the assets themselves.

The federation is responsible for good stewardship of the assets.

Bylaws
Article 20

1. The board can lay down by-laws regarding its own functioning and the functioning of possible committees and task groups.
2. The by-laws may not be contrary to the law, also if the latter is not compulsory, neither to the statutes.

Stipulation of Non-Discrimination
Article 21

The federation is not allowed to discriminate concerning race, nationality, minority, sex and personal circumstances, and must not express opinions, believe in or carry out actions, political or otherwise, which indicate a preference for any form of sexuality. The federation is not allowed to co-operate with people or organisations, which in their objectives, politically or practically, endorse or practice such discrimination.

Closing Stipulation
Article 22

In all cases which the statutes do not provide for, the board decides.
For the first time the following boardmembers are appointed:

1. Mr. Peter Lehmann, living Peschkestrasse 9, 10961 Berlin (Germany);
2. Mr. Paul Jan Francois Fijn, above mentioned;
3. Mr. Gabor Gombos, living Klauzal u.81.f.6, 1072 Budapest (Hungary);
4. Mr. Clemens Wilhelmus Huitink, above mentioned;
5. Mrs. Virpi Vesterinen, living Puistokatu 8 B 37, 20100 Turku (Finland);
6. Mrs. Beverly Mills, living 30 Liddell Terrace, Bensham, Gateshead, Tyne and Wear NE8 1YN (Great Britain).

Of whom those mentioned under sub 1, 2 and 3 will have respectively the function of chair, secretary and treasurer.
The appearers are known to me, the notary. Of which a deed in original has been drawn up at Zelhem on the date which has been mentioned in the head of this deed.
After concise specification to the appearing people of the contents of this deed they unanimously declared to understand the contents of this deed and not to require it to be read aloud in it's entirety.
Thus, this deed, having had a limited reading, has been signed by the appearing people and by me, the notary.

Maths Jesperson
Östen Undéns gata 24, S-227 62 Lund, Sweden
Tel +46 46 323217, +46 42 123036 Fax +46 42 184049
Editor of The European Newsletter of Users and Ex-Users in Mental Health

Report from The Newsletter June 1994 - December 1996

At the Second European Conference of Users and Ex-Users in Mental Health in Elsinore, Denmark 26-29 May 1994 agreement was reached on some tasks, which we should work on until the next conference. These tasks were divided between various working-groups set up by the conference. One of these tasks was the Newsletter and I was elected as the editor of it.

At the outset I outlined some goals for the Newsletter. All of these goals haven't been reached. I feel a bit dissatisfied with myself because of this. On the other hand, I also feel a bit proud of all the goals, which really were achieved. In fact, the Newsletter and the Desk are the only tasks agreed upon by the last conference, which actually also have been carried out during this period.

A few comments in summary:

* The Newsletter during the previous period (November 1991 - April 1994) was only a small brochure. Each issue was only an A4 folded, which meant 4 pages in A5. And only two issues were printed during this period.

* I needed because of this some more precise guidelines from the board about what kind of newsletter they wanted. Should I carry on with the simple brochure from the previous period? Or should the Newsletter be more comprehensive? Should it be an internal one for members of the network only? Or should it be possible for others to subscribe to it? The board chose the last alternative, because one of the purpose of our network is to influence the outside world and not just to discuss matters in a closed circle of our own. But this means that the Newsletter had to be much more thorough than before.

* As a result of my discussion with the board I wrote a plan for the Newsletter. The periodicity of the Newsletter I thought should be four issues each year: Winter, Spring, Summer, Autumn. Each issue should consist of two A3 folded, which meant 8 pages in A4. These goals haven't been reached completely. The period has covered 2,5 years. After the decisions about the Newsletter at the first board-meeting in August 1994 the remaining quarters were 9, which means also 9 issues of the Newsletter. In reality the result is instead 5 issues. On the other hand, the last two issues have been in 16 pages instead of 8 pages, which means that they in fact are double-issues. And this means that I actually have produced 7 issues during the period. Compared with my original plan of 9 issues, the result is in fact fairly good. The periodicity has also been quite regular, although you don't think so when you loook at the dating printed on each issue. For example the issue called "Number 4 - Autumn 1995" was actually made in Summer 1996.

* My plans concerning the content were as follow:

Editorial
Reports from board-meetings
Reports from task-forces
Information about coming conferences and other meetings
Debate
Book reviews
Magazine reviews
Articles about user organisations/user groups
Articles about psychiatry (treatments, legislations, trends etc)
Articles about alternatives to psychiatry
Articles about users/survivors artistic manifestations
Information about user-run camps, festivals etc
Users/User groups seeking contact with other users/user groups
Information for travelling (cheap accomodation, user-run drop-in-centres etc)

Examples of most of these themes are actually to be found in the 5 issues of the Newsletter. One thing which surprise me very much is that very few contributions have come from people who have been directly involved in the network and its conferences (one exception is Mihai Marin in Bucharest, who has sent me many good contributions). From members of the board I've got only a few contributions and from the task-forces not any at all. Instead I've got many letters all the time from other users/survivors, who haven't been known to the network before. I think this is one result of my diligent travelling to conferences and meetings all around Europe, where I have spread more than 1000 free copies of the Newsletter to all interested persons I have met.

* The Newsletter was intended for users/survivors and interested subscribers (also professionals) in Europe. Now, as the European Network in fact is the only international psychiatric users/survivors network functioning at the moment, there is a big interest from users/survivors also outside Europe. Each issue is therefore sent also to a lot of subscribers in the US, Australia and New Zealand. I also send free copies to a user organisation in Japan and one in Brazil. The Newsletter seems to reach also the most distant corners of the world. Just recently I, for example, got a letter from the Ministry of Health at Bahamas and one from the Seychelles Disabled People's Organisation. All of this must also be a result of my diligent travelling to conferences all over Europe.

* Out of this, you understand that much of my work as the editor is about many other things than just writing the Newsletter. Actually these other things occupy very much of my time, which is one of the reasons why I haven't been able to make as many issues of the Newsletter as was my intention. Much time-consuming is my answering of all letters I get concerning the Newsletter. Going around on international conferences all the time is been much time-consuming too (usully I also make a presentation/lecture there, which I have to prepare at home beforehand).

* I hope you'll overlook some of the things, which haven't worked perfectly with the Newsletter during this period. If you still would like to entrust me with the task of editing the Newsletter also during the next period, I am prepared to do this. Also our national headquarters of RSMH in Stockholm is prepared to go on printing the Newsletter, distributing one free copy of it to the contact person in each country/user organisation and collecting subscribtions to it from others.

Maths Jesperson

European Network of Users and ex-Users in Mental Health

Secretariat:

EUROPEAN DESK
P.O. Box 84050
3009 CB Rotterdam
The Netherlands

REPORT FROM THE EUROPEAN DESK

In the past years the European Desk has operated as well as possible as an intermediary between the different european groups and the governing board of the Network.

This was a difficult task due to several changes in employees amongst other things.
The successor of Rene van der Male, Jan Dirk van Abshoven, was also succeeded by Rinus de Groot.
These employees all received half-year contracts because there was insufficient prospect of a permanent financing of the Desk.
Employees and the Govening board, however, always parted harmoniously.

Rinus de Groot was succeeded on June 1st 1996 by Clemens Huitink, the present seceratary. He also, initially, received a half-year contract but this was changed to an indefinate contract on December 1st 1996 so that the continuity of the Desk is secured for the time being.

In the meantime the Netherlands Clientenbond is the only agency that is formally responsible for the workings of the Desk.
The Netherlands Clientenbond however wishes to accentuate that they wish to share this responsibility with the governing board of the Network.

The contacts between the Board and the Clientenbond are excellent.

The Netherlands Clientenbond is being forced into a merger shortly with two other organisations in the Netherlands. What the status of the Desk will be in this merger proccess is still unclear.
The Netherlands Clientenbond will try its hardest to maintain the desk for the Clientenbond and thereby it will also remain for the Network.

The desk itself functions closely with the Board and trys to fullfill a coordinating and stimulating role. The accent is on the supporting of the Board with its activities although the desk itself also undertakes its own initiatives.

The initiatives of the desk are concentrated on promoting the knowledge about the Network.

A lot of work was undertaken for the making of the "Kolding Report" which would have been impossible without the help of many volunteers.
The preparation of the Board meetings was another facet of the work that received a lot of attention.

A worrying point is and remains the financial position of the Desk.
Untill now the desk is practically completely dependant on the support of the Dutch Government, The support which was requested for 1996 was fl, 48,500 , the actual support granted was fl. 35,000, Shortcomings in the budget were fulfilled with suport of fundings.

The situation for 1997 will not change dramatically from that in 1996 is the expectation of the Netherlands Clientenbond.
It is however clear that the financial dependance on only one government is not good for the operation of the Desk and Network.
There is more work to be done than the desk could reasonably handle,
This forces a better listing of priorities that will need to be created in cooperation with the Board.
Over this atunement there will need to be continuous dicussion, Continuous, but not endless !

Clemens Huitink.
December 16. 1996

EUROPEAN NETWORK OF USERS AND EX-USERS IN MENTAL HEALTH

THIRD EUROPEAN CONFERENCE, READING UNIVERSITY 3 - 6 JAN 1997

MAIN THEME : CHALLENGING THE ROOTS OF PSYCHIATRY

CONFERENCE PROGRAMME

FIRST DAY: FRIDAY, JANUARY 3

Conference participants arrive at the Porter's Lodge, Whiteknights Hall to collect their room keys and be shown to their rooms.

1200 - 14.00 REGISTRATION AT PALMER BUILDING.

14.30 - OPENING OF CONFERENCE AT PALMER BUILDING,
(PLENARY ROOM, FIRST FLOOR.)
WELCOME BY KARL BACH JENSEN,
CHAIRMAN OF BOARD, AND EDNA CONLAN,
CO - CHAIR, ON BEHALF OF ORGANISERS.

15.00 Report from the European Desk (Clemens Huitink).
Report from the Newsletter (Maths Jesperson).
Reports from the Task - forces.
Reports from the Chairs and Board Members from the five regions. Karl Bach Jensen, Edna Conlan (5), Maia Bachmann (1), Matthias Seibt (2), Igor Spreizer (3) Jasna Russo (4).

16.00 Coffee and Tea break

17.00 Regional Meetings in Seminar Rooms, facilitated by Board members.
Regions: 1 (SCANDINAVIA), 2 (GERMAN SPEAKING COUNTRIES), 3. (MEDITERRANEAN COUNTRIES),
4. (CENTRAL AND EASTERN EUROPE), 5. (NETHERLANDS, IRELAND AND U.K.).

18.00 PLENARY ROOM: Report back from regions.

18.30 END OF DAY ONE.

19.30 DINNER AT WHITEKNIGHTS HALL

20.45 " PERFORMING MINDS "
Theatre group from Bradford.

SECOND DAY: SATURDAY, JANUARY 4

8.00 Breakfast

9.00 INTRODUCTION TO THE WORKSHOPS
(PALMER BUILDING, PLENARY ROOM).

1 * Criticism of Psychiatry in theory and practice.
Medical model, drugs, ECT, coercion, Advocacy,
Psychiatric will or Advance Directive.
Speakers: Peter Lehmann, Edna Conlan.

2 * Alternatives.
Self help, Hearing Voices, Holistic Approaches,
Runaway Houses, User run Projects.
Speakers: Ron Coleman, Iris Holling.

3 * Employment, Training.
Social Integration, International Recommendations.
Speaker: Mary Nettle.

4 * Multiple Oppression.
Developing policy on equal opportunities.
Experiences of ethnicity, gender, social class, poverty.
Speakers: Jasna Russo, Peter Fleischmann.

5 * Structure and name of network.
Laws and Bye-laws, Spirit and Future.
Speaker: Karl Bach Jensen.

6 * Verbal and Non-verbal communication.
Music, Body Language, Dance and Pantomime.
Rene van der Male, David Warner.

10.30 Coffee and Tea break.

11.00 Workshops in Seminar Rooms.

13.00 Lunch at Whiteknights Hall.

14.00 Workshops

N.B! 16.00 Legal Seminar on " Human Rights ".
(Small theatre, first floor, Palmer Building).
Introduction of theme by Lawyers

15.30 Coffee and tea break.

N.B! 14.00 Continuation of Workshops directly after lunch.

18.00 END OF DAY TWO.

19.30 SPECIAL CONFERENCE DINNER AND PARTY.

(DISCO AND LATE BAR-00.30)