

European Network of Users and Ex-Users in Mental Health

The Second European Conference
of Users and Ex-Users in Mental Health

The International People's College

Elsinore, Denmark
May 26th - 29, 1994

Report

CONTENTS

Preface		5
Chapter 1	Founding of The European Network of Users and Ex-Users in Mental Health.	7
Chapter 2	Programme and events.	9
Chapter 3	The World Federation of Psychiatric Users.	11
Chapter 4	Co-ordinating committee and taskforces, '91-'94.	15
Chapter 5	Self-determination, social integration and welfare.	21
Chapter 6	Legal issues, human rights and compulsory treatment.	26
Chapter 7	Alternatives.	37
Chapter 8	Structure and organization.	41
Chapter 9	Other proposals and decisions.	46
Chapter 10	Declarations and petitions.	48
Chapter 11	Election of the board.	50
Appendices		52

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December 1994

European Network of Users and ex-Users in Mental Health

1994

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CONTENTS

2	Preface
7	Introduction: The European Network of Users and ex-Users in Mental Health
9	Chapter 1: The European Network of Users and ex-Users in Mental Health
11	Chapter 2: The European Network of Users and ex-Users in Mental Health
13	Chapter 3: The European Network of Users and ex-Users in Mental Health
21	Chapter 4: The European Network of Users and ex-Users in Mental Health
26	Chapter 5: The European Network of Users and ex-Users in Mental Health
32	Chapter 6: The European Network of Users and ex-Users in Mental Health
41	Chapter 7: The European Network of Users and ex-Users in Mental Health
46	Chapter 8: The European Network of Users and ex-Users in Mental Health
48	Chapter 9: The European Network of Users and ex-Users in Mental Health
50	Chapter 10: The European Network of Users and ex-Users in Mental Health
52	Chapter 11: The European Network of Users and ex-Users in Mental Health

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European Network of Users and ex-Users in Mental Health

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Preface

The Second European Conference of Users and Ex-users in Mental Health was organized in Elsinore, Denmark by a Danish/Swedish committee of psychiatric users/survivors, representing the Danish Association for Mental Health, Sind; Galebevægelsen (a Danish network of psychiatric survivors) and The Swedish Association for Social and Mental Health, RSMH.

On behalf of the European Network of Users and Ex-Users in mental Health, the Organizing Committee wishes to express its gratitude to:

- the Danish Ministry of Social Affairs;
 - the City of Elsinore;
 - the Commission of the European Union/DGV-E3, Integration of Disabled People, within the framework of the Helios II-programme;
 - the Danish Ministry of Foreign Affairs / Demokratifonden
- 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 and the Nordic Association for Social and Mental Health for their support.

The Organizing Committee especially wants to thank the two chairpersons Jan Dirk van Abshoven and Peter Campbell. Further thanks go to the staff from SIND for their work before and during the conference and the people of the International College for the catering and technical support. Additional thanks goes to the former Co-ordinating Committee and to René van der Male and Jan Dirk van Abshoven from the European Desk for supporting the Organizing Committee.

Finally we thank all the delegates and other participants to the conference and we wish the Network, the board and the members of the taskforces good luck in the future.

Karl Bach Jensen

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1. Founding of The European Network of Users and Ex-Users in Mental Health

In the 1980's people from the user/survivor movement in Europe gradually started to meet in the corridors of big, expensive conferences. People from Britain came to Holland and vice versa to exchange ideas. At a certain point the Working Group International Contacts of the Dutch Clients Union thought to have enough energy and money to organize a European conference in 1991. Prior to this two European meetings were held, in London and in Amsterdam, to get to know each other, exchange ideas and plan the conference. People from 7 countries were involved in this.

October 1991 people from 16 countries met in Zandvoort, the Netherlands. The European Network was founded, a Co-ordinating Committee, workgroups (taskforces) and a European Desk were installed.

In Zandvoort common interests were discussed at length and the conference laid the ideological ground of the network by stating the following general aims:

The European Network is against any unilateral approach to and stigmatisation of mental and emotional distress, madness, human suffering and unconventional behaviour. The European Network should support users autonomy and responsibility in making their own decisions (self-determination).

In order to implement the above statements priority will be given to three main areas:

1. Influence and change present treatment in psychiatry;
2. Create and support new alternatives to the psychiatric system;
3. Act against any discrimination in society of people who have been subject to the psychiatric system.

These areas will concentrate on the following issues:

ref. *psychiatric treatment*

- abolishing compulsory treatment;
- increasing users' influence on their own treatment (e.g. demanding the right to describe or define their own case, the right to refuse professional 'aid', the right to correct their own record);
- ensure that users receive adequate information (stating the right to receive written information about all possible risks of the treatment, the users' right to establish independent advocacy).

ref. *alternatives*

- support and promote the right to professional drugfree care;
- support of user groups creating alternatives to medical psychiatry;
- support and promote the right to establish user controlled initiatives inside and outside psychiatry.

ref. *discrimination*

- fight psychiatric stigma;
- get jobs for proper salaries;

- fight for proper housing;
- monitor European and national legislation.

To carry out any work we need to focus on:

- *users and user-organizations;*
- *politicians (politics);*
- *public (by means of the press);*
- *professionals in psychiatry;*
- *psychopharmaceutic companies;*
- *allies.*

Some special tasks to tackle first are:

- *Introduction of the psychiatric will*
- *Gathering information on psychopharmaceutic drugs*
- *Spreading information on and fighting the increase of electro- and insulineshocks*
- *Allocation of fundings.*

The structure of the Network was also discussed at length and the conference agreed on the following:

- *The Network is (ex)user-only, i.e. all delegates need to be or to have been involved with psychiatry as user, client, patient.*
- *Each country is responsible for the composition of its national delegation i.e. all national delegations are self-composed.*
- *Communication will go through national contact persons.*
- *The meeting accepts the task-oriented, bottom up structure. This structure deals with communication rather than with power. People in the task co-ordination group will have to work rather than to exert power.*
- *A legal entity, abiding to the business laws of the relevant country, should be established, e.g. to apply for funding.*
- *The people who make up this legal entity should not have more responsibilities than the people in the co-ordination group.*
- *The bi-annual conference is the highest authority within the Network.*

On the basis of these decisions in Zandvoort and the work done by different groups in two and a half years time, the 'Second European Conference of Users and Ex-users in Mental Health' took place in the old town of Hamlet: Elsinore in Denmark.

2. Programme and events

- For the detailed programme see Appendix I -

OPENING

The participants were welcomed by the deputy mayor of the host city Elsinore.

The mayor, Ole Lützhöft expressed a very positive attitude towards the idea of users/ex-users in Europe meeting and discussing the conditions of people with mental health problems. He wished that the conference and the network would succeed to improve these conditions.

Also the principal of the International People's College welcomed the participants. He mentioned that the college where the meeting took place, was build soon after World War 1, aiming to promote international understanding and peace by bringing people from different national, social and cultural backgrounds together. While promoting human rights and fighting injustice against minority-groups are very important issues of the college, he felt very glad and proud to welcome European Users and Ex-users in Mental Health to the college.

The Conference was opened by Karl Bach on behalf of the Organizing Committee. He informed about the preparations of the conference and showed his gratitude towards authorities and organizations sponsoring and supporting it. He expressed his hope that the conference would go on in a positive, loving and confident spirit.

Later Thursday evening every participant had the opportunity to introduce her/his organization and her-/himself. Every delegate was asked in brief to tell in which way he/she felt to be a user/ex-user of mental health.

PROCEEDINGS

The speeches on friday morning, of Mary O'Hagan of the World Federation of Psychiatric Users and of the former Co-ordinating Committee, have been summarized in the next chapter.

The idea of a programme consisting of the 5 lectures, the consecutive working groups and the plenary discussions was to share experiences and views on developments in the different European countries, and to reach consensus on how to reinforce and widen ideology, policy, organization and structure of the Network.

When working groups were composed and started Friday afternoon, group 2 (Legal issues, human rights and compulsory treatment) and group 3 (Medical model, diagnostics and treatment methods) decided to join into one single group.

Lectures, reports from working groups, plenary discussions and decisions on each of the 5 main topics of the Conference are summarized in four separated parts of this report. The lectures (speeches) have been shortened by the speakers themselves.

Thanks to the chairpersons Peter Campbell and Jan Dirk van Abshoven, the Conference got through the programme according to plan.

During the conference two social events took place outside the college.

Friday afternoon the city of Elsinore offered a reception in one of it's drop-in and activity centres for people with mental health problems. Users and employees at the centre made the

visit into a nice and interesting experience for the participants of the Conference.



Saturday evening the conference visited a very different user-run drop-in centre in Helsingborg, Sweden. Users of the centre met the guests, who spend a very pleasant time.

In Helsingborg friends from RSMH had arranged a party for the European guests. Many Danish and Swedish users/survivors took part; musical and dramatical performances by Swedish users/survivors gave a strong impression. All in all it was a great opportunity to meet and talk under very relaxing conditions.

After three days of hard work, a lot of talking, laughing, exchanging experiences and ideas, agreeing and disagreeing, the Conference was closed by Maths Jespersen on behalf of the Organizing Committee. In his closing speech he thanked the two chairpersons, the people from SIND and the people of the International College.

Personally he thanked his fellow members of the Organizing Committee for a splendid cooperation between Swedish and Danish user-organizations, he hoped for the cooperation to continue in the future. Finally he thanked all the delegates and other participants to the conference and wished the Network good luck in the coming years.

3. The World Federation of Psychiatric Users

3a SPEECH OF MARY O'HAGAN, CO-CHAIRPERSON OF WFPU

Good morning. My name is Mary O'Hagan and I come from New-Zealand. I used mental health services in New-Zealand for a number of years and I found it a very distressing experience, I'm sure everyone here had it or does. I thought the services I used were not helpful. So when I became stable again I was determined to try and do something to change the situation. I've been working in the survivor-movement for the last eight years.

Today I wear two hats as we say in English, the first one is that I'm the co-chairperson of the World Federation of Psychiatric Users (Paolo del Vecchio from the United States is the other chair-person), which was formed in Mexico at the world-congress for mental health in 1991. I'm also boardmember of the World Federation for Mental Health.

The World Federation of Psychiatric Users or WFPU is described in the newsletter that I've handed out to you. WFPU's biggest problem is that we don't have much money. Users in Europe, the USA and Japan have been fundraising but so far without any success. Some of the European members plan to give support to users and user-groups in poor countries or in countries, where users' and survivors' human rights are even more abused than in some other countries. Although Japan is not a poor country, we feel the need to support users and survivors in Japan because the human rights are very much abused in that country.

It's very difficult being stuck in the bottom of the world like I am to try and keep an organization going like this one. It's very difficult for people who have jobs and lots of commitments locally to actually put in time. But if you do have any enthusiasm for putting in time to WFPU, it would be very welcome indeed.

In the newsletter there are two inserts, one is the draft set of by-laws for the legal structure for WFPU and if you have interest in by-laws and legal structures please send your comment to us by the 30th of September. We also have a position-paper prepared by Paolo del Vecchio, the co-chairperson, and we will also welcome your comments on that.

There are different working groups in WFPU, for instance fundraising and finance, in which René van der Male is a member; the contactperson for the third world users-supporters is Carl Axel Ringsparr.

New-Zealand is the focus for the newsletter and administration and we have one other: the political action working group, co-ordinated by Paolo Delveccio; Judy Chamberlin wants to give support here as well.

Another thing I want to draw your attention to in the newsletter is that we are looking for a new name for the organization. There has been a lot of dissatisfaction with the name World Federation of Psychiatric Users. So if you do have any ideas for a new name, please send them to us.



- TOMORROW IN MADRID -

The other hat I wear today is of boardmember of the World Federation for Mental Health. This is not an easy role. The role I see for myself in the World Federation for Mental Health is highlighting the agendas that we as users and survivors have, making sure that they are put on the table so to speak. I think also that we need a much more genuine attempt for the World Federation to include users and survivors. I'm concerned that many users, particular in the United States and Europe, feel that the World Federation is not a friend to our movement and if you have concerns about the World Federation I would very much like to hear those, so I can take them to the boardmeeting in Madrid which starts tomorrow. I want to make sure that there is good user-representation on World Federation committees. For instance there are a couple of committees at the moment to do with legal issues and mental health and the abuse of psychiatric drugs. I think that it's very important that our views get strongly heard in those committees.

For those of you who don't know much about the World Federation for Mental Health, it's an organization that started nearly fifty years ago after World War II and it's really made up of mental health-associations and non-government organizations from around the world, although there are a sort of statutory organizations involved as well. They congregate every two years, I've mentioned the congress in Mexico '91. The 1993-congress was in Japan and the next one will be in Dublin.

The last decade has shown an improvement in the user/survivor input into the congresses and by now we are a theme of our own. Users and survivors get up, give their speeches and so on. But, until this moment the organizers for the 1995 world-congress in Ireland are not involving us at all. I wrote to the organizers, they have not written back to me, and I would like to be able to offer them the services of the European Network in helping them to organize the congress for next year.

Finally, being both member of WFPU and the WFMH, I'm very concerned about the users in what we call 'third world countries' (a name I don't like), and in countries where the human rights are much more abused than in western countries. I think it's terribly important that we actually give support to users and survivors in these countries and that is one thing that I would really like to see happening through the World Federation of Psychiatric Users. If we just focused on that, I think we would be doing a good job.

3b QUESTIONS AND COMMENTS TO MARY O'HAGAN

Matthias Seibt says it be a very important task for this world-wide network to support psychiatric survivors in the third world, but there is hardly any money on the account. Does that fit?

Mary O'Hagan: These things don't fit together until there is more in the bank. Although there are certain things we can do, mainly through newsletters and correspondence to people and giving out information. I think there is quite a lot we can do without much money.

It is very difficult to get money at the international level, the bigger your scope of work the harder it seems to get. It seems that if you try to get money for a specific project it's easier to do than for running costs. Support of users in third world countries could be a very worthwhile project, a focus for the WFPU fundraising over the next year or two.

Edna Conlan asks that more users of mental health must be heard and represented at the next conference in Dublin.

Peter Campbell: My question for the WFMH and Mary is: Is this going to be a useful use of our energy or are we simply going to actually end up in the same position, putting energy in and actually not having any real control over what happens at the congress in Dublin in two years time.

Mary O'Hagan: I don't know the answer to that, because I don't know the people involved well enough. Fortunately the past few congresses have included us in the preparations, insuring that there is a separate theme in the conference solely for talks and discussions by users and survivors. Though I think that it wouldn't take too much energy to put the pressure on the organizers in Madrid and give them a fairly strong message. We then must review things after that.

Carl-Axel Ringsparr proposes to adopt a resolution which very strongly states that we must be involved in a correct manner, just like we did it in Japan and Mexico because that is something which we will need in the future. We must ask Mary to take that message with her to Madrid.

Judy Chamberlin: I have very mixed feelings, as we have expressed before, about whether we should be putting our energies into WFMH, but I think Mary is right that any organization that says to be concerned with mental health and with the welfare of the patients, needs to be reminded by us, we have a moral obligation there. We are the ones that you are talking about and it's arrogant to proceed without listening to us.

So I think that, although it's certainly much more satisfying to be here among our friends, we also have to go out among our so-called friends who are often our enemies.

Specifically about the organization of the meeting in Japan and the following meeting in Ireland, I want to say this. When we have a separate track for users, in one way that's very good because we are among ourselves, we got a lot of work done in Japan in terms of the organizational structure, but I don't know how much impact we have on the conferences as a whole. Because I know for myself I didn't go to one single workshop except for the users track and I know that there were many workshops where outrageous things were said that we would have wanted the opportunity to object to. It's a very important decision to make as to whether to have this separate track that meets for the entire conference or to infiltrate the rest of the conference.

Bjørn Hæhre: I entertain the philosophy that where ever psychiatry is mentioned, we should be present, because we live with prejudices and in solitude today. We've got to show the flag. We've got to show who we are. If we don't get benefit from the conference itself we can pursue lobby activities by being present. That is valuable, that's my philosophy throughout.

We must talk to our enemies, if that is the expression you want to use. We need to be able to talk to people who are there. That is why it is important for me to be where it happens.

Mary O'Hagan: Basically at the moment there are two ways that decisions are made in the WFPU. They are made at the two yearly meetings at the world congresses, but at the last one there was a real awareness that the people present didn't want to make decisions without consulting the membership. So what is happening is that if you look at this newsletter there are several opportunities for people to have input into the position paper, the draft bylaws and the naming of WFPU. I have to say that because it's such an embryonic organization, there aren't a lot of decisions to be made. These are the major ones that are before us. We're asking for your input into these decisions.

The meeting in Japan agreed that if money-funding did come through for users and survivors to go to world-congresses, the co-ordination-group of WFPU would make a decision about which countries should be represented at the congress. I very much doubt if there will be any funding available to take anyone to the congress in Ireland. It just so happens that Japan is a far richer country and they were able to get sponsorship much more easily and we were able to get about 8 or 9 users and survivors to that congress.

I think it is a very good idea to have an alternative conference in the same place, before, after or during the congress. If people want to explore that further I'd be happy to take peoples view on that.

Jan-Olof Forsen: We have to build up our own organization before we can do anything. This WFMH has existed for 50 years and we only exist since 1991, this is our second conference. Though I think we should help the weak countries, we must keep in mind that we can't be present everywhere. We must think of all our comrades who are not with us here today and we must work to strengthen our own organization more than anything else. This is not about some organizations being richer and some of them being poorer, what we need to do is organize at grassroots level so that we become a force to present ourselves.



Mary O'Hagan: Most of what goes on in our movement is at grassroots level and that's the way it should be. I'm involved in grassroots-activities in my own country. But there is a tendency meeting the same faces everywhere. If you want your face to be seen in those conferences, the best thing to do is to become active in WFPU, do some work and show yourself as a valuable contributor. In this way you'll certainly be seen as someone who can represent WFPU at congresses.

René van der Male: I would like to ask Mary O'Hagan a question for WFMH preparing the conference. Is it possible that users participate or are represented in each workshop, so they can report back to the user-meeting? And I want to ask for separate rooms where users can meet and discuss the findings of the conference.

Mary O'Hagan: I think this is in line with Judy's point and I think it's possible to organize users to go to strategic workshops, where our views are particularly absent, and to give their views and to feed that back to WFPU.

4. Co-ordinating committee and taskforces, October 1991 - May 1994

4a THE CO-ORDINATING COMMITTEE

René van der Male presents an outline of the history of the European user-movements and the European Network.

The Co-ordinating Committee as it functioned since Zandvoort consists of 5 people: Matthias Seibt, Carl-Axel Ringsparr, David Warner, Roberta Graley and me, René van der Male.

The Zandvoort conference left us nothing but ideas and agreements, compiled in the conference report; we had hardly any resources. It took some time to start and to develop concepts.

For the last two years I've been working to set up the European Desk, a full-time, non-paid job. The Co-ordinating Committee not only has very little money, but also a limited amount of time. We had to be very creative to put into practice the ideas that were agreed on in Zandvoort.

In the mean time the Danes promised to organize this conference and the Organizing Committee almost independently organized and worked out this whole conference. I'm extremely glad and happy that they succeeded to organize it and it gives me a lot of faith and trust that we know how to continue and how to proceed.

However, when we leave this conference we should be aware that we have enough ideas and agreements to continue, because the funds we have are limited.

I will give you a short description of what kind of rules we would stick to, the last two years.

First of all travel expenses needed to be covered by the people themselves, or by their organizations, so they had to ask locally for funding.

We would meet every six months. Each committee member ideally would have a deputy, to replace him/herself if unable to attend. Also each committee member would be the host of at least one meeting: the obligation to accommodate people during Co-ordinating Committee meetings, which usually took two days. This was roughly the way we worked. The whole idea was based on gathering information and then spread it out again, gather, collect and target it in a specific direction.

Before we specify the several taskforces I would like to ask David to give an outline on what we have been doing in those Co-ordinating Committee meetings. They were held in Carrara, Bochum, Nottingham, Utrecht and most recently in Copenhagen.

- MINUTING THE MEETINGS -

David Warner, taskforce co-ordinator for the Alternatives project, took notes and wrote the minutes of these meetings:

At times mistakes were made in writing the notes, therefore the minutes never were published. We circulated these notes between us. Every meeting had roughly 8-10 pages of notes taken.

There often were discussions, but we also formulated the actions to be taken, categorising them in the minutes to be sure to have a follow up on everything that we promised ourselves to do. Smaller things were writing letters or responding to people that had written, asking specific questions or asking for information - for us a way to keep up with the outside as well.

Financing and future fundraising were other actions for the Desk to be taken, how to apply to the Helios project, to the Horizon project.

The newly re-introduced drug Clozapine was a subject, which resulted in the report produced by the University of Utrecht. The research was meant to find out about the true risks of this Clozapine medicine, the results were not as bad as we thought, but doubts still remain. We will have to obtain a better point of view concerning this controversial medicine. We set up lines of communication with the WFMH, made structural decisions regarding the Desk. Also we made preparations for a computer network.

In all, we talked about 12 to 15 different actions every time we met, of which roughly 90 % was carried out.

René continues:

This Network is to meet every two years, and you present here are to set out the lines for the Co-ordinating Committee to follow in their work. Thinking about getting done any work, one soon gets to consider money. This will be an item during the workshop 'structure of the network' at this conference. For now, the shortage of funds forces us to be both creative and realistic.

I hope that during this conference some delegates will take up responsibility for the next bi-annual conference, I invite you all to consider this.

Now, in more specific detail about what we have been doing so far. Each taskforce will present themselves. Proposals for the future are warmly welcomed in the workshop on structure.

4b PRESENTATION OF THE TASKFORCE 'MEDICATION AND PSYCHIATRIC WILL'

Matthias Seibt:

A psychiatric testament or will is a prior determination which somebody makes, as long as the psychiatrist considers one a normal human being. In the will one describes the type of treatment that is or is not acceptable when being treated against ones will. It is a decision, irrespective of what some people say, like psychiatrists or their assistants.

To make this kind of will has been practice in Germany for some time, and it has not been clarified in legal terms whether this must be respected or not. This is still an outstanding issue, but it works in practice. Psychiatrists don't want to run the risk of treating somebody who has made such a will.

Originally the idea stems from the US and in the mean time it has been translated into Danish and Swedish. I don't know about particular experiences in those countries.

The other subject for our taskforce concerned psychiatric drugs. I want to recommend the book 'Toxic Psychiatry' by Peter Breggin, and there are two other German books that are fairly good. I don't know the situation in other languages.

Perhaps it would be worthwhile to have these translated.

And I've got here two shorter texts, these are recommendations concerning ways in which one could leave behind these drugs, how to fight this addiction.

Peter Lehmann informs that an English text is available, 'Unconventional approaches to psychiatry', in which some explanation can be found on the psychiatric will.

We also have prepared forms in Austria and a beginning is made in Switzerland. In Germany the psychiatric will is very well known, the magazine 'Der Spiegel' published about it.

The psychiatric will is not yet subject of any legal action, because all legal experts say that it is

actually in force and the psychiatrists would not have the guts to go against this. A number of judges already have confirmed that this is in fact a document which has legal force.

It also has a preventive effect: already having thought about what's going to happen, people have a stronger individual attitude to psychiatry later.

Karl-Bach Jensen informs that Galebevægelsen in Denmark have issued a book with translations of Thomas Szasz' original article concerning the will, and an article by Peter Lehmann. A Danish lecturer in criminal law has given comments and explained the psychiatric will and how in the long run it could be incorporated into Danish legislation.

Theresja Krumenacher explains that they are trying to introduce a psychiatric will in Switzerland, although the institutions are very much against it.

Angelo Gigliotti says that since the conference in Zandvoort the psychiatric will has been copied in Italy. It is very difficult to implement this in Italy, since the will is associated with a document which determines what should be done after you die. Therefore a kind of crisis-card has been developed for people who need psychiatric care and it applies in the social context. It has been used as a kind of model, as a way of protecting against psychopharmaca and compulsory treatment. It protects minors as well as adults.

Annika Malmqvist informs that in Sweden a document is available about the will. It contains a list of the historical background, and a number of examples on how you could formulate it. In Sweden it is not called a will, because we don't want it to sound as if we were dead. It is available for our members and so far there has been a lot of interest in it.

Roberta Graley explains that the psychiatric will is not in use in Britain, but a crisis-card is very well used throughout the U.K.

Peter Campbell adds that the work on a translation of the psychiatric will, as published in Germany, has begun but is not yet completed.

4c PRESENTATION OF THE TASKFORCE 'EUROPEAN ENQUIRIES'

Roberta Graley:

Our task was to find out how to initiate a European enquiry (e.g. about electroshock, ECT). Andy Smith, who was in Zandvoort with me, actually did most of the work on this. To initiate a European enquiry may be fairly simple, the wording has to be very precise.

Some demands are:

- The European Network has to back a request and the enquiry has to be pan-European.
- The enquiry should be able to promote the benefits of the Network to the EU.
- The enquiry should promote the idea of EU wide standards of care.

If an issue doesn't meet these criteria, one still can enforce an enquiry. Any individual can actually put forward an enquiry, although if it doesn't meet these criteria you cannot ask for the European Network to back it.

The one thing I would like to stress again is that in order to make it work you have to make sure that your wording is right. So in other words you cannot say: "please would the parliament stop electroshock". What you have to say is: "please would the parliament investigate the use of electroshock in the countries of the European Union, and compare the evidence of the adverse effects in these countries where it is banned with the evidence of the positive effects from those countries where it is legal for coherence across the union". It means that we really have to be careful when we initiate an enquiry.

There are several people from Britain here today. What we would like to do is to propose that

the European Network takes this one stage further. We in Britain have done the research, we know how to initiate a European enquiry. We think now is the time to test this.

We are asking you today to give us the go-ahead to take the subject of electroshock before the European Council, to co-ordinate all the evidence, for and against electroshock and to ask them to give us legislation that electroshock cannot be given compulsory, that it can only be given with the users' consent.

Judi Chamberlin wants to offer some caution regarding the official enquiry in the United States around ECT, although the situation in the United States may be different to Europe.

This enquiry was dominated, not just by psychiatric interest but primarily by the interest of those who promote ECT, which made it very difficult for any of us and specially among survivors of ECT to have any input.

So the official report in the USA has found that ECT is 'a wonderful thing. Be very careful not to give the ECT-promotors a weapon while trying to disarm them.

Roberta Graley: I do know about electroshock in America. I went over there and was amazed to find that they actually have maintenance electroshock-treatment in America.

What I am hoping to do is to gather enough information to put before the European Committee from the user networks around Europe, that we will have enough information about the adverse effects as well as the 'pro' effects, which the professionals tell us are there. We are not at the stage yet that we can actually ask them to ban it. But what we can do is ask to give some kind of guidelines where it can be used and where it cannot be used. That is how far we are at the moment, if we are realistic.

The chair indicates that the first step to be taken in fact is this enquiry. A comparative study, because if in some countries ECT is banned while in other countries 5000 to 6000 people are being treated with ECT, one of the two kinds of practice must be wrong. There is no middle course: either it is very good or it is very bad. That is why we want this enquiry.

4d PRESENTATION OF THE NEWSLETTER-TASKFORCE

Carl Axel Ringsparr:

The period from the first meeting in Zandvoort was followed by the reality of the day. We had the same feeling with our newsletter. For the first issue we had material and articles, to make the following issues was more of a problem.

What has been the problem. Firstly to get to the readers. It took time and hard work to build up contact. Sometimes the articles were too long or about too complicated subjects or about subjects not in our field: psychiatry and the mental health area.

Another problem was that people sent articles without their names and addresses and we can't take the risk of printing an anonymous article. And also the mailing and collecting the right addresses has been a problem and still is, because people are moving to other places. New members entered our mailing list.

We have learned about preparing and printing a newsletter. We now understand what it is to be responsible for the newsletter: have a group around you and articles in stock for at least two extra issues. This is long term planning, necessary for a good result. Now we know, late alas for the past issues.

We hope you give us confidence and credibility for a new period, we will deliver to you a better product. Because we have learned from our mistakes and will not make them again. The

user and ex-user movement in Europe needs a newsletter and we need creative information about what's going on.

Over 100 copies of the last issue have been sent to the persons on the address list, the number of each edition being over 150. The budget is sufficient for reaching all people present.

Judi Chamberlin expresses her appreciation for the fact that there have been produced newsletters. Unless people have worked on a newsletter themselves, they don't realise how much work it is.

Peter Campbell indicates the need for persons who can give information from their countries or their group of countries to the RSMH. These persons could serve as correspondents for the newsletter.

Maths Jespersen would like these contact persons to copy and distribute the newsletter in their own country. It is printed so that it could be copied easily.

René van der Male is very pleased that the RSMH has guaranteed to produce newsletters in the two years to come. Voting will decide whether RSMH will be doing so in the next period.

4e PRESENTATION OF THE TASKFORCE 'ALTERNATIVES'

David Warner:

A fair amount of information from about five or six countries was sent in. More information is needed though.

I started from the wrong end by trying to ask questions about what works or doesn't work in a particular activity. All that I needed to do was to ask for information and then criticisms, whether they'd be positive or negative. These criticisms would naturally and inevitably accompany the material sent.

I did not know how to organize. I needed something more than superficial, but still digestible. So I came up with the idea of an abbreviated directory and I sent out a letter on the 6th of May entitled 'European network of users and ex-users in mental health task group alternatives' with my name and address. It basically asks for information.

It asks for five different items, names of activities, addresses, a brief description of activities which contains comments on user involvement, a brief history which is not so important and also who could be contacted for more information. There you could name yourself or the name of the activity itself or any other source. Judgements are quite helpful since I saw they do come out naturally in the information sent to me.

I received, for example, comments on a German restaurant which is supposed not to be an alternative at all. It is good that these kinds of judgements are discussed in the open.

This directory of mine could be divided into different topics such as co-operatives, crises-, refuge-centres and runaway houses in one category. Housing structures was another. Then restaurants, bars, theatre groups etc..

In the meantime I built up a nice collection of material and I think it needs to be kept in access to you all and to anybody who needs it. We need to decide whether it will be kept at the Desk or I keep it or whether the next co-ordinator keeps it.

Though I do not wish to be alternative co-ordinator in the upcoming years, I'm interested in seeing this project continue and whether it gets approval. We'll work on seeing it move ahead.

Edna Conlan was rather worried when David suggested that the name of the person making comments should be published. In her experience many people find it difficult to speak out.

Even about alternative services, when they are named. It is good when they want their name to be published. But if they do not then this should be respected.

4f PRESENTATION OF THE TASKFORCE 'EUROPEAN DESK'

René van der Male:

When we left Zandvoort three organizations took up responsibility for the European Desk. The first thing to do was to raise money. Raising money is difficult and it takes long. Splitting the work and responsibility between the three organizations so far has been partly a success.

We managed to obtain some money from the municipality of Amsterdam for a period of three years. But that amount of money is just enough to make phone calls, rent office space and send letters. Of that three years already two have passed, so only one year is left. We continued looking for additional funding with these three organization, which we managed later on.

Meanwhile the three got some problems between themselves. How this will develop in the future is not foreseeable.

The Client Union, as one of the three organizations, took the responsibility to carry on with the European Desk and one month ago they hired Jan Dirk van Abshoven for a period of six months to work as an employee at the European Desk. So far I've been working two years to do the preparatory work, setting up an office, organizing contacts, raising funds, contacting other organizations in Europe. I also went to conferences to announce that there is something like a European Network.

Another thing done was the Clopazine report. We must now consider the results of the research and decide whether and how to proceed.

THE CONTACTS.

The European Desk was to make links with Europe. The European Regional Council of the World Federation for Mental Health has a seat in the Disability Forum. The ERC-WFMH is to use us as an advisor for issues we want to take up.

So far we didn't manage to have a clear legal structure. In Zandvoort the idea was to make a foundation in order to be a legal body. However, the two other partners didn't agree on this. So we had to find another way to implement the European Desk.

The "Basisberaad GGZ", a grassroots organization of users in mental health care in Rotterdam offered help. So far this assistance has not been needed.

Jan Dirk is going to work at the European Desk for the next six months and we hope we can come with a very firm guideline for him to work. And also to guarantee future funding so we can secure the European Desk as a point where information is distributed and will be received.

5. Self-determination, social integration and welfare

5a SPEECH BY HANS BERGSTRÖM

First of all a short description of myself before I talk about influence. I have to do that because my story is the reason why I am here with you at Elsinore.

I am trained as a social worker, who in the seventies worked with compulsory treated girls of the age of 16-21. They were criminal and also drugs addicts. As a social worker I often had to send the girls to the mental hospital for compulsory care. I didn't reflect much about the mental hospital system at that time.

But as time went by I got more and more depressed over my own incapability to make the girls adjusted to the society again. I also started to mistrust the compulsory treatment of young people in Sweden. My depression became deeper and deeper and I had no one to talk to about my frustrations. I saw no other way than to take my life. So I took 60 pills of a sedative kind and took my car and drove to the countryside. This was in December and it was pretty cold. 36 hours later I woke up and drove home again. Then my boss came and took me to the hospital for intensive care.



After my body had got rid of the poison, I was asked by an intern doctor to go voluntarily to a psychiatric clinic. So I did and there started my career as a user of mental health care.

This was in 1972. I was lucky to get quite a good psychiatric treatment. The ward was divided in groups and every group of patients had different responsibilities. We cleaned our own rooms and also the common rooms. We had general meetings and as patients we wrote our own journals. But I met a lot of friends who mostly met oppression, compulsion, keeping and degradation. My lifeline back to life was when we, patients, organized and formed a patient-union. We applied for membership in The National Association for Social and Mental Health (RSMH).

For myself the door was closed to get jobs as a social worker. During 1,5 year I applied for 75 jobs and didn't get one. As a former user of Mental Health I was stigmatised.

Finally I applied for a job as director at The National Association for Social and Mental Health. I got that job because they know how useful it was to have been a patient in mental health care, and here I am. During the years I have been employed in the bureaucracy and also four years as a full-time politician. Now I'm working with a housing and occupation project together with the peer movement in Sweden.

- OPEN CARE -

What happened during those twenty-two years that I have been a member of RSMH.

In Sweden in the seventies we users of mental health care mostly tried to get organized and to raise our voices in our struggle to a worthy life. Most of the care was taking place inside large mental institutions as mental hospitals. We also had a debate about the harm that the total institution could cause a person, suffering from different psychiatric diagnoses. So at that time we started to build up the open care unit. They were meant to replace the twenty-four hour care in a psychiatric hospital.

In Sweden as well as in the rest of the western world a large number of former mental patients have been discharged from the mental institutions. In Sweden we have reduced our hospital beds with 75% since the sixties. The leap from a six-bedroom at the mental hospital to a lonely flat was too long. The total outsidersness was a fact, nobody cared about your quality of life. The only events that broke the absolute gloominess was a visit to the open care unit for a depot-injection in your ass. Sometimes the home-care also made a visit in your flat. There was nothing between the six-bedroom and the lonely flat.

Our group became the real losers of welfare. No network and no strong voices or lobby-groups that fight together with us for our right to a worthy life and for our right to be members of the society.

And all this happens with the worst recession in Europe on our hands since the last world war. Twenty million people are unemployed. They don't have any so called defects as mental illnesses. The European governments are struggling with big budget deficits. We already know how the different governments in Europe are cutting down budgets for care, social welfare, school, housing and so forth. We as users of mental health will be the last in line that will get what maybe is left when other strong lobby-groups have taken their parts and we know there will be nothing left. The so called mental illness is the last shameful disease, even aids has got a face when well-known people as artists, sport-idols step forward and speak out in different medias. They even arrange gala performances for the aids victims. When do we get our first gala performance for users in mental health?

Now we must go out in the society to fight for our rights.

- * To a worthy living.
- * To jobs and occupations.
- * To decent treatment, where the staff treat us as subjects instead of objects and not to be looked upon as diagnoses.
- * To live our own life and make our own history.
- * To influence our own treatment and care.

Therefore we must

- fight the prejudice among the public against users in mental health;
- raise a voice for those of our companions who don't dare to speak out;
- be a strong lobby-group that politicians and decision-makers listen to.

Most of all it's about our right to influence. An influence that deals with the individual, but also about influence on the local as well as regional level. It's about influence on a national level and extremely in this connection international influence and above all on the European level. We must be given the right to make the decisions regarding users and ex-users of mental health and our rights to a worthy life.

- WHO MAY PARTICIPATE? -

What I now say might offend somebody. But this is not a personal matter but a matter of principle.

Recently we had a debate at the board for the Nordic Association for Social and Mental Health about what should determine who could participate, and who could not, in a conference for users in mental health. My point of view is that delegates are people who have once or more been treated for a psychiatric disease. It doesn't matter if that is several years ago.

It is not necessary to have been in a 24 hour-care clinic; an open care treatment or psychotherapy are sufficient.

That does not mean that we cannot cooperate with engaged people who do not share our experience of psychiatric care. But this is the only occasion that we, from different countries in Europe with different cultures, gather with one thing that joins us: we shared the mutual pain of being users in mental health.

There are a lot of conferences and seminars throughout the world where groups of different staff are gathered and have discussions what they can do to fight the struggle for a worthy life for mental patients. But when we are having a user or ex-user conference the arena should be our own. We don't need any spokesman in those contexts however benevolent they are. For me it's a matter of believing in your own power. We can never again afford to let a large number of people be forgotten and hidden in society. We must raise our voice so that the decision makers hear the roaring from the users and ex-users of mental health. Nobody than ourselves will fight the struggle for our rightly demands to a worthy life. We must now be a voice in the EU-parliament in Brussels.

I am from a country that is known for the way it's people join in all kinds of associations, labour unions and so forth. I quote the Swedish labour union leader Joe Hill after his emigration to America: 'Don't mourn! Let's get organized!'

And I end with words of the French existentialist Albert Camus:

'Don't go in front of me! I can't keep pace. Don't go behind me! I don't dare to meet everything first. Go beside me and be my friend.'

5b WORKING GROUP 1

Hans Bergström gives the report.

It was hard work in this group because so many new people came from Eastern Europe and they did not have a long experience in building up organizations for users and ex-users. First of all we presented ourselves to each other and we spoke of our organizations and the difficulties in our home countries.

The group that consisted of many participants from Eastern Europe agreed that the main point for them right now is to organize and to try to build up nation-wide organizations.

We agreed that influence means a lot of things. Influence on an individual level as a private person, his/her right to a decent treatment whenever you get mentally ill e.g..

It's also about influence on a local level, where the local authorities are responsible for the well-being of the members living there. Then of course the regional and national level. And of course for us here it is a question of social integration, self-determination and welfare on an European Level.

We talked about the right to decide about one's own treatment. That means that we as users and ex-users would like to see contracts made up between our doctor and ourselves in periods of well-being. That contract should be about the treatment, which we have the right to get when we fall ill.

We want a case manager, a support person, ombudsman at the side of the user that helps one to get one's rights when ill. Case managers were already introduced in the United States and in Great Britain.

We agreed that on a local level the politicians should make up three year plans on a local level for support of the mental health user.

Meetings in local hospitals where we as members in user organizations can be a part in the local boards. They must listen to our voices and our demands as users.

We had a long discussion about jobs, because jobs are the best way to get rehabilitated back to life again. The group agreed that it should be illegal to neglect giving jobs to people just because they have a mental illness. In Poland e.g. when applying for a job past illnesses are checked, and you will not get the job when they find you've been mentally ill. The group concluded that a charter for the right to have jobs should be made up.

More working co-operatives run by users and ex-users should be established. We have examples of working co-operatives in Italy and Sweden where we are working on a self-help basis.

On a national level hearings or mental health tribunals should be held every third year about the state for users and ex-users in mental health. But most of all it's about agitation and organization.

Hans Bergström proposes that a working group be formed which will work on the subjects of self-determination, social integration and welfare. That group should consist of members from both Eastern Europe, who have no long experience and other countries like Scandinavia and Great Britain, who have a long experience of organizing so we can help them to integrate in the society and set up their organization. Delegates from Eastern European countries want and need help in order to be powerful and well organized. The better organized they are, the more influence they will get. In many countries in Eastern Europe there are several organizations for users in mental health. It would be a good thing if we could assist them in making nation-wide organizations that work together and speak with one voice.

5c PLENARY 1

Jirí Farny adds that more (ex-)users in e.g. his country should be mobilised and urged to join existing organizations in order to become a bigger force.

Viktoria Tóth stresses that the Eastern-European countries do not always need the help that is offered to them. Eastern European structures and problems are of a radically different nature and western methods do not always apply. On the other hand she stresses the value of the experiences already undergone in these countries and that we need to listen before we offer help.

Jasna Russo indicates that a great way to help Eastern-European User-groups is to create publicity for them, send delegates from other countries who will speak openly about their experiences as survivors, since openness about 'mental illness' is still lacking.

René van der Male would like to see this conference put into practice a plan to get the experience of Eastern-European User-groups out in the open.

Many of the delegates talk about problems related to work: work as a human right, as a quality of life versus work/employment as therapy, as means of controlling and disciplining people.

The chair puts it to the conference if people are interested in making a charter on the rights to jobs.

René van der Male would like that short term goals be attached to such a charter, bearing in mind that European funding is available.

Judi Chamberlin points out that work can bring on the one hand dignity, income and a sense of purpose in life. On the other hand work is very often exploitation, under-payment, damaging our spirit. Therefore we have to bear in mind that not all (ex-)users will want to give up their pensions.

Bjørn Hæhre emphasizes the importance of defining work: sheltered work or ordinary work; sheltered work under which conditions. Like others he talks about the importance of links to the trade unions and draws attention to the problem of people being ostracized/expeled from workplaces because of bad work environments, lack of rules/acts in this field, high rates of unemployment.

Neil Ward points out that he would rather see work in terms of (equal) opportunity and (equal) access to opportunities. That includes voluntary work, other activities beneficial to the individual concerned.

5d DECISIONS 1

The proposals put forward by Hans Bergström that there should be a working-group set up to do work in the areas of social integration, employment, self-determination and welfare, were accepted with a large majority.

The chair suggests to include two themes among the tasks of the working-group: the area of work, employment and occupation, another area should be on how to support user/survivor/patient controlled organizations in other countries, particularly in Eastern-Europe.

Sunday morning Hans Bergström announces he would like to work on the fact that many users and ex-users in mental health are living in the community.

Peter Campbell offers to work with Hans Bergström on the issues from this working-group.

The chair points out that anyone else interested in the taskforce can contact Hans Bergström.

6. Legal issues, human rights and compulsory treatment;
The medical model, diagnostics and treatment methods

6a. SPEECH BY JAN WALCRAFT:
Legal issues, human rights and compulsory treatment in mental health

The European Convention for the protection of Human Rights and Fundamental Freedoms lists 10 fundamental rights.

1. The right to life.
2. Prohibitions on torture and slavery.
3. Right to liberty and security of person.
4. Right to due processes of law.
5. Right to privacy.
6. Freedom of thought, conscience and religion.
7. Freedom of expression.
8. Freedom of assembly and association.
9. Right to an effective remedy at law.
10. Right to non-discriminatory application of these rights and freedoms.

Another relevant piece of international legislation is the UN Declaration on Protection of all persons from torture and other cruel and inhuman or degrading treatment or punishment - 1975.

This declaration defines torture as:

'Any act by which severe pain or suffering whether physical or mental is intentionally inflicted by or at the instigation of a public official on a person for such purposes as obtaining information or a confession, punishing him for an act he has committed or is suspected of having committed, or intimidating him or other persons.'

These rights apply to all, including criminals. Yet every one can be overridden if we are diagnosed mentally ill. The law in most countries allows psychiatrists to deny freedom of thought, expression, privacy, liberty, and freedom of association; and subject us to torture and even the risk of death through high doses of toxic chemicals, anaesthetics and electric shocks, without an effective legal remedy.

Psychiatric treatments are often experienced as torture as defined by the UN. They are frequently inflicted for the purposes of punishment or intimidation, and can cause severe mental and physical suffering. As patients, we are often aware of being punished for being unhappy, emotional, angry or different. Yet the public are taught to see these abuses of human rights as humane, life-saving and necessary.

- MENTAL HEALTH LAW AND HUMAN RIGHTS -

Mental health laws emerged during the Industrial Revolution to control the poor, the unwanted and the different. 19th Century British Lunacy laws made it legal to remove people to asylums. In the 20th Century, the status of doctors rose dramatically. Psychiatrists benefited from the prestige of scientific medicine by re-defining their tortures as medical treatments. This trick was successful, and by the 1930s, pauper-lunatics had been redefined as patients, with little improvement in their treatment. The 1959 Mental Health Act officially recognised psychiatrists as judges of behaviour and arbiters of competence.

Psychiatric hospitals still do not provide a service many would choose to use. The most powerless groups - women, ethnic minorities, the elderly and the poor still get the most coer-

cive treatments, while little is done to deal with the social problems which cause or worsen distress.

People considered sane have the right to refuse medical treatment, and to take risks with their health and safety. However, for those judged mentally ill, the right to refuse treatment is overridden by the right to be treated, even without consent.

In fact, the first of the United Nations Principles for the Protection of Persons with Mental Illnesses states:

'All persons have the right to the best available mental health care, which shall be part of the health and social care system.'

Civil, political, economic, social and cultural rights for persons diagnosed mentally ill come only fifth in the UN document. Psychiatric treatment by its nature may remove these rights or make it impossible to exercise them.

The UN document also permits removal of the right to self-determination, on the grounds of incapacity, without any absolute right for the individual to choose a representative to contest the decision. National and international mental health law therefore contravenes human rights.

Inevitably, because of the legal obligations on psychiatrists, the psychiatric system is used to enforce social norms, despite the humanity of many doctors and nurses.



- THE STRUGGLE IN BRITAIN AGAINST COMPULSORY TREATMENT IN THE COMMUNITY -

In Britain, human rights groups have campaigned for many years to replace large asylums with community services. However, post-industrial governments are more concerned with saving money than providing services. The resulting hospital closure programme has satisfied nobody, leading to a backlash against community care, particularly from 'SANE' a small organization with strong backing from Rupert Murdoch's media empire. Their scare campaign resulted in a series of proposals from the Royal College of Psychiatrists (RCP) and the Department of Health.

The first, in 1986, was the RCP's 'Compulsory Treatment in the Community' proposal, aimed to enforcing medication on people with 'acute psychotic disorders', who 'relapse when they choose to discontinue treatment after they leave hospital' according to the RCP. Medication was the only treatment mentioned. Nursing unions and patients' organizations joined to oppose and defeat the plan.

The second, in 1993, resulted from the publicity after Ben Silcock, a young man diagnosed schizophrenic, jumped into a lion's cage and was badly hurt. This time, the RCP proposed 'Community Supervision Orders'. Again the purpose was to enforce medication, on the assumption that medication controls 'schizophrenia' and that psychiatrists can correctly identify and treat the disease. These assumptions are controversial. Research shows that many people recover from 'psychotic disorders' without medication and that with social support, many more can reduce or discontinue medication.

Ben Silcock expressed his own point of view clearly, saying:

"Psychiatric care is very cruel. Medications are psychiatric straight jackets that in the long run make things worse, and tie the mind up until it becomes frustrated. There is a stigma and an

illusion about victims of modern psychiatry. They are often people whose minds don't co-ordinate with modern thinking. They're put on drugs, locked up and their minds get like caged lions. The fact that I climbed into the lions' den is not a sign of my insanity. It is more a reaction to seeing my fellow beings locked up".

Clearly we may have good reasons for wanting to change, reduce or come off medication. Legal measures to force us to continue with medication in the community takes away our right to self-determination. But for the first time in history, psychiatric survivors are finding a collective voice. I was one of several survivors who gave evidence to a Government committee which helped to persuade them that no new legal powers were necessary. Supervision Orders were dropped.

However, the Government now plans to introduce Supervised Discharge powers to ensure that patients discharged from hospital comply with their treatment plans. Not doing so could lead to their recall to hospital. Once again, the aim is to enforce medication.

Meanwhile, a Civil Rights Bill that would have outlawed discrimination against disabled people and former psychiatric patients was defeated in Parliament.

It may be ethical to keep someone in safety for a few days to save their life or prevent them from hurting others, but forced treatment with chemicals and electric shocks infringes human rights, while ensuring that little effort is made to address the problems that cause people to break down. If legal coercion was removed, services would have to provide the range of holistic therapies, counselling and practical help that we consistently call for.

We must campaign for an end to all forced treatment.

6b. SPEECH BY PETER LEHMANN:

The medical model, diagnostics and treatment methods

The medical model, the psychiatric diagnostic system included, is a question of faith. People may believe in it or not. The concrete risks and dangers of psychiatric treatment seem more important here.

- DANGERS OF NEUROLEPTICS -

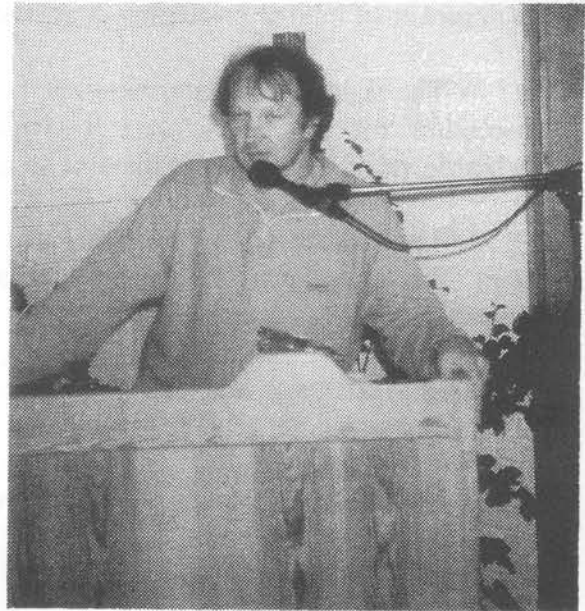
The main psychiatric reply to mad behaviour and feelings are neuroleptics. These neurotoxic psychodrugs lead to a reduction of the absorption of oxygen of the brain cells, the hormone system and the transmitter system are blocked; there is an organic disease of the brain, identical to the symptomatology of encephalitis lethargica. You can read about all these things in detail in my book 'Der chemische Knebel' ('The chemical gag') or in Peter Breggin's 'Toxic psychiatry'. Healthy people who are considered mad are made organically ill. Under neuroleptics about 90% suffer from brain atrophical states, brain cells die; 90% suffer from movement disorders; 30% from fever attacks; up to 100% from pathological changes of the electroencephalogram; 50% from inflammation of the gums, often combined with loss of teeth; under continued administration of neuroleptics about 80% from liver disease, 40% from diabetes, 43% from obesity. In addition to this, there are sterility, absence of menstruation, impotence, pigment deposition in the eyes and in the heart muscle; there is a significantly increased amount of breaks and splits of chromosomes, which may lead to identical mutations as caused by thalidomide (Contergan). Psychic deadening (called zombie-effect) loss of will, states of desperation and danger of suicide, dizziness and delirium are other dangers; this is by no means exhaustive.

In the USA since 1978 information sheets from neuroleptic-drugcompanies must include the warning that all neuroleptics can cause neoplasms (tumours) in the breast glands of rodents, if those animals are treated with doses that are normal in continued psychiatric treatment. In the German speaking countries, maybe in whole Europe, this danger, too, is not told to the 'users'.

Another severe damage is tardive dyskinesia; David Hill, psychologist in England, wrote 1993 in Clinical Psychology Forum, that world-wide meanwhile about 86 million people suffer from irreversible tardive dyskinesia, a choreatic-like muscle disorder; it can be developed after few months or years under all typical neuroleptics, and sometimes is recognised only at withdrawal or afterwards. There is no treatment for this disease; only further administration of neuroleptics may reduce the symptoms. Tardive dyskinesia correlates with shortened life expectancy. All these disorders are caused by all neuroleptics, low and high potent, by low and 'therapeutical' doses, by short and prolonged duration of administration. It is an illusion to separate dangerous doses from harmless ones. Even minidoses, one time administered, can lead to extremely dangerous dystonic attacks, i.e. means people might die of suffocation.

Furthermore, especially in the case of the so called atypical neuroleptics, there will be changes in the receptors' system; when neuroleptics first block the receptor system, especially the dopamine-receptors, the organism will react and built new receptors, which may not disappear after withdrawal, and then there is an imbalance of transmitters and receptors, as if an agent is implanted in the nervous system, that makes people irreversibly crazy. Finally, after prolonged administration, there might be a vegetative dependence, which may lead to severe withdrawal symptoms - sleep disorders, stomach problems, nervousness, circulatory collapse, withdrawal-psychoses etc.

Electro- and insulin-shocks are still in use; they are just as bad or probably even worse. Neuroleptics like these shocks lead to an artificial brain-organic psychosyndrome. Electroshocks cause epileptic fits. There is an internal damage to the brain cells by electrical current and by bleedings in the brain; nerve cells are damaged and die. Of course, there are also positive effects of these drugs and of shocks. These agents may suppress unpleasant feelings, you may have temporary relief, which may be more important than the risk of being damaged. On a short or medium term basis you might be able to adjust to your surrounding world, if you do not have to deal with ambitious tasks. Shocks will kill the brain cells, where memories are stored, and some bad memories will disappear too, and this may make you indifferent.



- CONSEQUENCES -

There are two trends as for psychiatric treatment:

People who, on principle, are in favour of the treatment, or who may demand better drugs, a better psychiatric net, being better understood by psychiatrists, more talks, more services to use, better cooperation. These people accept the concept of mental illness. The opposite side fights against compulsory treatment, the absence of information about risks and damages, etc.

Its adherents fight for autonomous and user-controlled alternatives to the psychiatric system, for self help, for money (less and less money for psychiatry, more and more for organized victims and survivors), for legal equality with (medical) ill and healthy ones, for legal protection (psychiatric testament (psychiatric will), for informed consent or rejection, compensation), and for free choice of doctors and therapists.

If we, users on the one side and victims and survivors on the other side, can deduce joint consequences from the risks and damages by means of psychiatric treatment we will have to act together and we have to try not to offend one another. How can we complain of psychiatric mistreatment if we only use the concept of users? Because this implies that psychiatry is something which is useful for all of us: for people who have been electroshocked, treated by force, developed tardive dyskinesia, perhaps died from neuroleptic malignant syndrome e.g.

On the other hand: If we equate psychiatry and torture, we ignore the needs of people going to psychiatrists by their own decision. If we want to base ourselves on a common factor, it might be the relationship to the human rights. They seem to be our immediate joint basis. I can see four issues here that are important:

- The right to remain unwounded, bodily:

Forced treatment only in cases of prior informed consent. Ban of damaging treatment methods (by proven brain- or genetic damages, by suspicion of tumor-building). Compensation and criminal prosecution of law-breakers.

- The right to medical, therapeutical and social help:

Development of harmless methods and of relievers for damages, caused by neuroleptics. Development of ethical principles in psychotherapies.

- The right to self-determination:

Prosecution for psychiatric assault. Right of self-definition, right to look into the own psychiatric records, to correct them or to get them handed over. Free choice.

- The right to self-organization and to self-representation of our own interests:

Money for user-controlled alternatives and for projects run by users. Patient's-councils, advocacy.

6c WORKING GROUPS 2 AND 3

Jan Walcraft gives the report.

We came up with three tasks which we would like the Network to consider for the forming of taskgroups.

Task 1:

Aim: to eliminate ECT in the long term

Short term measures:

1. To campaign for ECT to be classified as a high-risk treatment so that procedures for giving it are complicated and difficult (as is the case for lobotomy).

2. To continue collecting information on ECT, on its usage in different countries, its damaging effects and people's experience with ECT (which Jan Dirk has started).

3. To circulate information about ECT amongst our own organizations and more widely in order to generate press reports and change people's opinions. To circulate information about places like Alabama, where it is very difficult to give ECT, given the many restrictions.

4. Possibly organize a conference on ECT, although it might be costly and take up a lot of energy.

Task 2:

Aim: Finding a way to sue psychiatrists/companies for damage done by psychiatric treatment

Possible actions are:

1. Collecting information via the European Desk and the Newsletter about where successful damage-claims have been achieved, or where attempts have been made to sue psychiatrists so we can learn from these attempts.

2. To gather material to support any legal cases that people want to bring in their own countries, so we can support people who are trying to sue psychiatrists for damages.

3. To try to find sympathetic lawyers, who would be able to help people bring cases.

4. To find out what the European regulations are on giving information about the side-effects of medicines.

Task 3:

Aim: To work for a ban on all compulsory treatment

1. To separate compulsory commitment from compulsory treatment. While there may be arguments in favour of temporarily removing people to a place of safety, that is very different from forcing treatment upon people. We believe that compulsory treatment violates human rights.

2. To find out what the European Court of Human Rights says about compulsory treatment. To get legal advice on how to work towards a ban on compulsory treatment.

3. To campaign for drug-free care in hospitals (as it exists already) and to collect information about drug-free care and to publicise research that shows that drug-free care is effective and what people want.

4. To make a petition against compulsory treatment and to take it to the European Parliament.

6d PLENARY 2 & 3

Debate task 1: On eliminating ECT.

Judi Chamberlin adds that the State of Texas passed a law last year that was spear-headed by a group of ECT-survivors which bans ECT for children and which makes ECT for adults

procedurally difficult. She informs that some useful US-models can be found in regards to the suing of psychiatrists for damages. There have been successful damage actions both for drug side-effects and for deprivation of liberty.

Peter Lehmann offers more detailed information on the required procedures for ECT treatment to anyone interested. In Alabama quite a number of measures need to be taken and several authorities need to be involved before ECT can be administered. In accordance with a verdict in the court Electro-shock is a treatment measure which can only be used with the agreement of the following people concerned: the patient, the psychiatrist who made the diagnosis, a second psychiatrist, the medical director of the institution and a so-called extraordinary-treatment committee which has been appointed by an Alabama court of law. This committee is established by means of adding a fourth psychiatrist, a neurologist and a lawyer, another lawyer who can represent the person in question. If it is assumed that this person cannot evaluate what is in his best interest Electro-shock treatment can only be used if a judge has made a verdict to that effect. Since this is so complicated there has been no further Electro-shock treatment since the introduction of this arrangement.

Carl-Axel Ringsparr suggests as a strategy not to accept even difficult ways of using ECT, *we should instead say that our objective is the long-term aim to eliminate ECT all together.*

Viktoria Tóth points out that the entire working-group was in favour of the complete abolition of ECT, but we find that this is a step in the right direction.

The chair adds that since secrecy surrounds the administration of ECT, to bring the discussion again out in the open will have great effect.

Debate task 2: On compensation for damage by psychiatric treatment.

Jolanda Tillner states that we need to speak on behalf of the people who have been abused by the medical experts. There are experts e.g. that do not know too much about it, and there are false diagnoses made by these experts. I think therefore that the theme is of the utmost importance.

Alfred Deisenhofer would also be interested to work with this working-group. In Germany there are some cases where court cases have been brought and a lot of publicity has surrounded these cases. Although difficult that should not prevent us from dealing with this theme.

Maths Jespersen suggests to organize these working-groups in such a way that one country or one user-group takes the responsibility for one task or one working-group.

Peter Lehmann in contrast proposes that we form a working-group consisting of people who would specialise in this field. It is a very difficult field, especially reading legal texts in a foreign language. It is very important to get information from other countries, therefore the group should consist of people from a number of countries. He adds that he would be willing to participate in the work and to provide materials he can get from his connections.

Judi Chamberlin informs the conference that a lawyer named Eric Rosenthal, has a funded organization called 'Mental Disability Rights International'. He is particularly interested in contacting people in different European countries to start projects looking at human rights in psychiatry. Some of his projects are already running. He could be a very useful contact for some of these efforts.

Viktoria Tóth would also advocate a small international efficient working-group for this theme. This is a subject with which we can work in practical and pragmatic terms. She has a number of experiences in this field. In her canton in Switzerland e.g., doctors are covered in terms of responsibility by the law, which is quite outrageous.

Janos Vargha expresses his strong willingness to work in such a working-group, especially because such activity to improve this field in Eastern Europe may be joined to the general

harmonisation of the Eastern-European countries' legal system to the legal system of the countries of the European Union. In Hungary as well there are cases in which we can start law-suits.

Peter Lehmann explains that he is a member of a Swiss association called 'PSYCHEX', and in that capacity is connected to sympathetic lawyers who are also members. He would like to suggest that one of these lawyers is invited to join our next conference. Since it is a matter of principle to invite people who are not victims or users of psychiatry to participate in our conferences, this should be decided upon (the chair will include it in the voting procedures).



Debate task 3: On banning compulsory treatment.

Maths Jespersion remarks that one thing is to bring a person in against his/her will because he/she is considered dangerous or suicidal. Another thing is to give a person treatment against his/her will. Since these two things are so different in terms of degree of intervention a distinction should be made. It is bad enough to be locked up against your will, but it is certainly much worse to have people intervene into your body and mind. In the workshop people agreed to be against all compulsory treatment, whereas some thought that compulsory commitment could perhaps be accepted in some cases.

Theresja Krumenacher points out that in Switzerland no distinction is made. Hospitals take the view that where people are committed against their will they must receive treatment as well.

David Warner sees a major difference since the society will detain 'disruptive' people to guard the 'sanity' of society itself. Until there is an understanding of madness, society will always opt to separate mad, psychotic people from people who are 'tranquil, normal'. In such cases treatment does not apply, people are merely detained.

Erik Olsen insists that legislation should be the same for everybody. We should fight for the equality of the 'mentally ill' and the 'not-mentally ill'.

Judi Chamberlin adds that if for some small number of people social control is a necessary function, we should be honest and call it social control, and not pretend that we are doing it for this persons own good.

Tanja Lamovec states that mental illness should not be the reason for compulsory confinement, it should only be applied after a person has committed some 'undesirable' act.

Angelo Gigliotti points to the problem of minors being submitted e.g. in Italy to compulsory treatment and the use of neuroleptics. They should not be forgotten in this regard.

The chair asks for practical suggestions about the campaign for drug-free care and the collecting of informations.

Neil Ward indicates that he has access to large databases, so he can offer practical help in getting virtually any published material in England on subjects as ECT etc.

Judi Chamberlin also offers her assistance in this regard, and adds that people should give her their E-mail addresses, since this media offers the fastest, easiest and cheapest way of communicating any information.

Maths Jespersen advises to lobby among politicians to promote drug-free wards, since he had success in Lund, Sweden in getting support from politicians. It also creates a debate in the media, which is very helpful.

Caia Garupi warns that drug-free care does not guarantee good treatment. It is therefore vital that we define more precisely what treatment we want. In Denmark some alternatives ended in disappointment because psychiatrists were still the ones to decide on treatment.

The chair asks Edna Conlan and Viktoria Tóth to write a declaration on compulsory treatment which will be voted upon in the Sunday morning session.

Debate on neuroleptic drugs and human rights.

Erik Olsen presents a draft declaration to the Council of Europe, in response to the report on psychiatry and human rights (by Mr Stoffelen, march '94), in which he finds lacking something concerning medical treatments.

He proposes to accept the following declaration:

The Second European Conference of Users and Ex-Users in Mental Health declares:

- We consider psychiatry's use of neuroleptic drugs a violation of Human Rights and the freedom of thought (even a violation of the freedom of movement in the case of massive medication)

Jolanda Tillner elaborates on the side-effects of neuroleptics. In drug textbooks it is said that thoughts are prevented by means of neuroleptics (it prevents e.g. mathematical thinking from taking place), and therefore we can say that freedom of thought is prevented. This is one of the most serious infringements of Human Rights to enter people's minds and take away their freedom to think what they like and feel what they like (since neuroleptics prevent emotions from taking place as well).

Neil Ward point out that there are people who find value in drugs, and that that is their personal preference. On the other hand if we are to argue effectively against the use of neuroleptics (which I would certainly do, speaking from experience), our arguments have to be out of the domain of medicine, as the medical model is very limited.

Judi Chamberlin stresses that the issue is not the use of drugs per se, but force in the use of drugs. Therefore people should have the choice to take drugs if they wish to take the risks involved. On the other hand, given the conditions under which psychiatry operates it's almost always used, if not given with actual force, then certainly without informed consent.

Caia Garupi informs that in Denmark neuroleptics are used on very small children, who have no possibility of objecting to the treatment, and considers that to be one of the most criminal acts one can think of. Since the use of neuroleptics is so wide-spread, people have become addicts and cannot turn to alternatives soon, we should ban the use of neuroleptics on the first admission to hospital.

Peter Lehmann suggests that all treatment be considered forced treatment in psychiatry. Certain damage caused by neuroleptics would lead to a ban if it concerned any other drug, taking into account the chromosome damage, the genetic damage and hormone formation damage. The Network should consider the question of who decides whether drugs will be allowed or not.

Eva Feiglová suggest that patients who are given neuroleptics be given little booklets by their doctors in which an outline is given on the side effects and the danger of addiction.

The chair postpones the voting on the final wording to Sunday morning.

6e DECISIONS 2 & 3, ON LEGAL ISSUES AND MEDICAL MODEL

Task 1: The Network should aim to eliminate ECT in the long term and enforce the short term measures ('short term' defined as the time between this and the next conference.)

The points referring to 1. campaigning for ECT to be classified as a high risk treatment, 2. collecting information on ECT and 3. circulating information about ECT, were accepted unanimously as tasks for the taskforce.

Point 4. possibly organizing a conference on ECT was accepted by majority of votes.

Later Sunday the new taskforce on ECT reported that it will be co-ordinated by Erik Olsen, in co-operation with Jan Wallcraft and Jan Dirk van Abshoven at the European Desk. Erik Olsen calls upon everyone to collect as accurate data as possible on the use of ECT in the individual countries and to send it to the office of Galebevægelsen in Copenhagen. Furthermore he asks anyone interested in joining the group to contact him.

Peter Campbell, who works closely with Jan Wallcraft in the UK is interested in being involved and will help to send information.

Angelo Gigliotti and Neil Ward offer to send informations gathered on ECT to Erik Olsen.

Task 2: The Network should aim to find a way to sue psychiatrists/companies for damage done by psychiatric treatment.

Vote: To set up a working-group on legal matters including people from different countries, who would specialise in this field: accepted by acclamation.

The chair does not feel the need to vote on the necessity to collect informations and to inform

the network through the Newsletter since that is obvious.

Vote: To invite a lawyer specialist to come to the next conference (being a non-user):
accepted by acclamation

Sunday afternoon the new **taskforce of legal problems of damages caused by psychiatry, drugcompanies and others** requests information from all countries about:

1. Cases or casestudies, documents of ½ - 1 page, abstracts in English (condensed, accessible documents)
2. Legal situations and legal possibilities for compensation in different countries
3. Contact addresses of persons, especially lawyers, or experts in law and groups involved or interested in the topic

Documentation can be sent to Neil Ward's address in Hull where information shall be processed (also E-mail: n.j.ward@msd.hull.ac.uk).

Task 3: The network should work for a ban on all compulsory treatments.

Vote: To make a distinction as pointed out between compulsory commitment and compulsory treatment.

Proposal accepted by majority of votes.

Vote: The taskforce shall have as a priority to work for a ban on all compulsory treatment. Accepted by acclamation.

Since no taskforce-group was established at the conference on the task, it will obviously be a task to be worked on by the board or by other networkers with this as their special interest. If interested contact the European Desk.

Sunday morning the following **declaration** was proposed:

- *We, the Second Conference of Users and Ex-Users in Mental Health, demand the banning of any compulsory treatment.*
- *We also demand the banning of the use of neuroleptics or electro shock on people who are not of an adult age.*
- *We call on the European Parliament and national governments to put these demands into law.*

The declaration was accepted unanimously.

Later Sunday the chair proposes to continue to support the implementation of the Psychiatric Will and the interest in gathering information regarding medication under the **guidance of the board**, since these subjects are no longer incorporated in any of the taskforces.

Accepted by majority of votes.

7. Alternative(s to) psychiatry

7a SPEECH BY JUDI CHAMBERLIN

Because our movement opposes coercion in psychiatry, it is important to demonstrate that there are practical voluntary ways of providing help to people who are in great distress. The psychiatric system is based on a so-called medical model, which proposes that distress comes from biochemical or genetic causes that are divorced from the circumstances of everyday life. Psychiatrists must be challenged when they call this the medical model, because coercing people, putting them in institutions, and give them drugs against their will is really a social control model.

If distress isn't biochemical or genetic, where does it come from? Distress is real and painful, to the individual and to people around them. Behavior has meaning in the context of the person's history and current life. We try to put the behavior into context, while the psychiatric model calls it a "symptom" and rips it out of context. We also look at the economic, spiritual, and family dynamics aspects of peoples' lives. People are obviously going to be in emotional distress when they are poor, homeless, hungry, or undergoing a moral dilemma.

The psychiatric model frequently ignores family dynamics, yet many people end up diagnosed as mentally ill because they come from families in which they have been physically, emotionally, or sexually abused. It is not surprising that family organizations stress biochemistry and genetics instead!

It is important that our alternatives do not slip into replicating the psychiatric system. We may say: "John isn't feeling well now, but I know what he needs." We may talk of people in terms of diagnoses or 'symptoms'. We may develop hierarchies and say some of us who are 'well' know how to help others who aren't well. Some segments of the U.S. consumer movement take the position that it is necessary to commit people under certain circumstances. I have spent more than twenty years helping to develop alternatives and their philosophical basis, and yet in some 'alternatives' people are being committed. To me this is tragic.

-BOSTON, ITHACA, NEW JERSEY, VANCOUVER -

In our models, people in distress can also be helpers, moving from one condition to the other, sometimes in the course of a single day. People have the ability to change and grow, and to define what they themselves need.

The most common user-run programs in the U.S. are drop-in or day activity centers, places where people can come for a social life, recreational activities, discussion groups, and meals, which help to ease social isolation. In the U.S., where the level of pensions is low, people don't have the money to enjoy ordinary recreational opportunities, which further isolates them.

Alternatives crisis services can be provided in people's own homes or in a central location. Companionship, safety, and listening on a twenty-four hour basis are needs that are often unmet in the psychiatric model. A person in extreme distress may need to talk or cry at any hour, so we need twenty-four hour coverage, and a larger staff than the drop-in center does. Housing is another need. Far too often, former psychiatric patients live in segregated settings, although they may want to live in integrated living situations with neighbours who aren't former patients, and yet to have some support when they want it, so that they are not isolated.

We also need alternative employment. Working can be frightening, because of stigma and discrimination, because often we have not worked in a long time, and because people may lose economically because their benefits are cut.

An example of a drop-in center is the Ruby Rogers Center in Boston. It operates seven days a week and is completely run by the members, all of whom have received or currently receive mental health services. Most members have been hospitalized repeatedly, yet together can run a program, handle a budget, make decisions about activities, and deal with people when they become difficult. We have operated this program for more than eight years.

A crisis program is more difficult to develop. By its nature it is more expensive than a drop-in program, since it involves employing more people to provide support. It is also more controversial, because the psychiatric system believes it is their prerogative to deal with people who are in crisis. It has been difficult to get funding for alternative crisis projects.

One project that's in a start-up phase right now is in Ithaca, New York, and will provide a safe, voluntary, non-medical environment. At the point when people are facing admission into the psychiatric service, they will have a choice to come to this crisis house instead.

In New Jersey a survivor group has government funding to develop housing. No more than three people live in each house and they choose who they want to live with. The program is expanding by increasing the number of houses and neighbourhoods, so that people have real choices. If your living situation is unsatisfactory, it contributes tremendously to how you feel emotionally.

In the employment area there are a number of projects that are providing workplaces that are supportive, in which the fact that people have psychiatric histories is not held against them, but is seen as a positive asset. There are programs which employ former psychiatric users as counselors, case managers, residential case managers, and similar roles in which they and their clients are people who have been through similar experiences. People also need opportunities to work in non-mental health settings.

Some of our projects are now five or ten years old, and we need to make sure that we stay true to our ideological roots. It's very easy to become more concerned with the financial end of things and keeping the project going, and to lose the underlying values. I've seen this happen in Vancouver, Canada, to one of the oldest projects started by mental patients in North America, the Mental Patients' Association. It was started in 1971, and used to be a user-run project, but it has now become a professional organization, in which the clients are once again under the control of professionals.

It is a great danger that we always have to be alert for, or else we'll find that we have once again replicated a system that people will have to organize to free themselves from. If we can remain true to our roots, we will have developed truly supportive and truly liberating environments for people.



7b WORKING GROUP 4

David Warner gives the report.

In the working-group 15 participants from 12 different countries were present. In general we spoke about many model case examples on alternative structures, therapies and medicines. A list of 17 ideas was produced, on which not all agreed on all points (a majority did not want the list to be published).

Judi Chamberlin explains that the group put together this list of very diverse statements that do not cohere, because people felt they would not reach agreement and therefore took the easy way out.

7c PLENARY 4

The chair asks the delegates to point out which alternatives we would like to have endorsed by a future taskforce.

Neil Ward sees training by users and ex-users of psychiatrists, medical doctors and mental health professionals as a very effective way to move forward.

Caia Garupi suggests to pursue a campaign against medical psychiatry. We should demand that psychiatry be separated from the medical model. We must influence new ideas and new thoughts regarding psychiatry.

Peter Lehmann suggests that there should be no diagnoses and that the pharmaceutical industry should have no influence over training and practice. Psychiatry is morally wrong and should not be reformed but abolished as was slavery.

A number of people were against the reform of psychiatry as we know it, but instead would like to enforce the development of new kinds of institutions which may replace the psychiatric hospitals. Some are in favour of user-run alternatives. Others would be in favour of reform and against total abolition. It was stressed on the other hand that many other points were cause for fruitful debate and agreement.

The compilation of a directory of alternatives, as it was started by David Warner, was welcomed as a means to exchange the different models that can be drawn upon and adapted for local implementation. User-run alternatives and alternative models exist already in several countries, a number of delegates offer their support in providing the information for such a directory.

7d DECISIONS 4

Peter Lehmann says that the document produced by the working-group alternatives can be used as a basis for discussion internally, but he doesn't want it published in any way since too much criticism can be levelled against it.

The chair puts the proposal to a vote to keep the document internally. It is accepted by majority of votes.

The chair asks who would participate in a future working-group on alternatives.

Neil Ward offers to contribute.

Tanja Lamovec is interested in working with the issues from the list.

Proposal: To continue the project to create a directory of alternatives.

Vote: accepted by acclamation

Tam Graham offers to send in material on alternatives in Scotland.

Oystein Hansen would like to help out in this project.

Jan Wallcraft would also like to be involved to some extent.

Sunday morning **David Warner** gives an outline of the new structure for the taskforce Alternatives. 'Processors', who may come from different regions (though not necessarily), will be responsible for searching, applying for and collecting information, and will then process it before sending it to the information centre. The processing consists of condensing longer articles into short English descriptions (format outlined in original alternatives information request letter), which can be put into the *Abbreviated Directory*. The bulk of information can be kept at the information centre and from there it will be sent out on request.

Oystein Hansen offered to serve as one of the processing centres, as well as Neil Ward, David Warner and others. The European Desk would serve as the information center/library, and David Bonde Henriksen would serve as the co-ordinator and supervisor for the taskforce. David Warner spoke with a number of people who showed their interest in serving as a 'processor', therefore it will not be necessary to give responsibility to a small group of people. (A format outline is added in appendix V.)

Neil Ward points out that foremost the taskforce depends on the motivation of individual processors who will have to actively gather informations on alternatives. Processing these informations is then a next step. He considers the mere communicating of these informations will be highly effective.

8. Structure and organization

8a SPEECH BY ROBERTA GRALEY

- (NET)WORKING TOGETHER in the United Kingdom -

The three national groups MINDLINK, SURVIVORS SPEAK OUT and UKAN have been working together on several projects for the Department of Health/ Mental Health Task Force.

In December 1992 the Dept. of Health in England set up a Mental Health Task Force, this project is to run for two years ending in December 1994. It was set up to encourage the closure of the large institutions and to replace them with effective community services, identify good practice and to produce a "vision". It is divided into three working areas: consumer satisfaction, service modernisation, and public image. The task force also collects data, spreads good ideas (it has produced a series of videos on good practice) and it formulates policy. How are service users involved? Three people from each of the three national groups are part of a sub-group. They were given a remit and from that devised a work programme to be spread over the two years.

The programme consists of the following:

1. A national charter of rights for mental health service users. The group consists of members from all three national groups, pooling their own experience with that of a wider reference group of service users from around the country who have had experience in producing and implementing charters.
2. An advocacy code of practice, this takes into account different types of advocacy concentrating on peer advocacy and collective self advocacy. It also looks at the relationships between advocates and professionals.
3. A series of five regional training days held in different parts of England. Each training day had places for thirty service users. There were workshops on a variety of skills which service users may need to become trainers, the idea came from a joint training day which the three groups funded in 1990. This is now to be taken a stage further and a training pack is being produced from the material gathered from the five training days.
4. The Task Force wanted a list of ten negative and ten positive things about mental health services. To consult with as many service users as possible the sub-group decided to hold a series of ten user conferences in different regions around the country. At each of these conferences we have invited local managers to attend the afternoon sessions (Mornings are user only) so that together managers and users could confront local issues and develop a consultation process between them. We have also run workshops on the National Charter and the Advocacy Code of Practice as we want as many users as possible to have input to the documents before the final versions are published.
5. All of this work will culminate in a National Conference in November, when we will launch the Charter, the Code of Practice and the Training for Trainers pack. Also the ten good and bad things about services in England will be announced, and there will be a resource book of the conferences containing contact addresses of all the groups which took part.

I am sure that the three groups would agree that this has been an exciting, valuable and enjoyable experience working together!

8b SPEECH BY KARL BACH

- FUTURE ORGANIZATION AND STRUCTURE OF THE NETWORK -

Roberta and I agreed to prepare the discussions on future organization and structure. Roberta introducing network-experiences from the UK, and me explaining some ideas about organization and structure of the European Network in the nearest future.

In Zandvoort the structure of the network was decided to be a very flat and democratic bottom up structure. The co-ordination committee established was not given any mandate or power to decide and/or act on behalf of the network.

In a network only expected to deal with information and co-ordination this structure might be acceptable, even though the co-ordination committee in the last two and half year in fact made decisions and acted. They had to - just to make things function.

But if we in the network agree to act on the basis of a minimum of political and ideological unity, if we want to influence opinion, decisions and development - then a more strong and powerful organizational structure is needed.

I don't expect this conference to found a fully developed organization on a European level, but some questions should be discussed and answered.

(The following questions and possible answers were distributed on paper to the participants.)

Some questions

- How to safeguard/ensure user/ex-user control in/of the network?
- Membership - individuals, organizations - which kind and how? Allies?
- How to elect and compose a European leadership (board)?
- How to give this leadership mandate to decide and act on behalf of the network without giving it dictatorial power?
- How do we link the European Desk, the board (leadership) and the Newsletter to strengthen unity, solidarity and efficiency internal and external?
- How to strengthen national groups in fulfilling the tasks of the network for the benefit of the whole European Network?
- Who will be responsible for the planning and realisation of the third European Conference?
- How to finance future activities?

Some possible answers

- European Conference every second (third) year still to be the highest authority.
- Still only users/ex-users can participate (self-definition).
- Still national delegations to be composed by each country through national contact-persons.
- The conference still should decide about the main tasks of the coming period and give its mandate to groups to work on these tasks and ask them to raise finances for the activities.
- Still all individual and collective members of the network should share the responsibility to fulfil the other tasks of the network and to raise finances for the activities.
- A European leadership (board) to be elected on this conference and with a chairmanship or a collective chairmanship.
- When this board is composed we should consider that different countries, European regions

and both sexes are represented.

- The board should be given limited authority to decide and act unanimously on behalf of the network, with a duty to inform about this by newsletters and/or minutes.
- The European Desk and the Newsletter should function under the authority of the board, thus given the mandate to decide about the geographical localisation of the Desk and the newsletter and the responsibility to make these very important parts of the network function continuously.
- In the nearest future we should aim at involving each other in activities in the different countries by strengthening the international user-engagement in the conferences, seminars and campaigns. This implies invitations, overcoming of language-barriers and raising finances for travel- and participation-expenses, being aware that some few figure-heads ought not always be the ones to represent users/ex-users of Europe.

To these answers Karl Bach added, that an elected board/leadership before the next conference as one of it's duties should initiate a draft programme and draft by-laws to be prepared. This as one of the steps towards the European Network to change into a genuine independent NGO.

8c **WORKING GROUP 5**

Karl Bach gives the report.

At the opening day of the conference Karl Bach spoke on the questions and possible answers for adopting a new structure for the Network. These answers were accepted in the working-group and formed the basis for the discussion.

The working group proposes:

Structure:

- To make a board with 6 people. This will replace the Co-ordinating Committee. One chair is chosen directly by the plenary session (as well as a deputy). The deputy of this chair only will be active if the chair resigns. 5 regions are requested to nominate a representative. The second chair, or co-chair, is chosen among the other 5 board-members (each having a deputy as well). The two chairs will have direct responsibility for the Newsletter and the European Desk.

-The board must carry out decisions agreed at the biannual conference of the Network. An outline of these decisions are to be written in the conference report.

Board:

The chairs of the Board:

- take care of the agenda,
- arrange an extra meeting if and when needed,
- chair the meetings.

The board will have close contact with the taskforces. The taskforces will get support from the board and will feed into European Desk.

It is recommended that the board meets at least every 6 months. Boardmembers or their organizations have to pay travel-expenses themselves .

Further proposals

European Desk:

- The employee of the European Desk is hired for 6 months. Additional funding will be looked for as soon as possible. The board will direct the activities of the European Desk. The Client Union (Cliëntenbond) is the legal employer. It is proposed to make an independent legal structure for the future. The employee of the European Desk will attend the board meeting without voting.

Newsletter:

- As an important tool of the network to appear minimum 3 times a year.
- One country, Sweden has been named, should take the responsibility to edit and produce the newsletter under guidance of the board. A representative from the group producing the newsletter should attend the meetings of the board without voting.

The regions are divided as follows:

- Region 1 Sweden, Faroe Islands, Iceland, Denmark, Norway, Finland.
- Region 2 The Netherlands, England, Scotland, Ireland.
- Region 3 Belgium, Germany, Austria, Switzerland.
- Region 4 Poland, Ex-Yugoslavia, Czech Republic, Hungary, Romania.
- Region 5 France, Italy, Greece, Spain, Portugal, Slovenia.

Karl Bach adds that although not many decisions were made by the conference for the board to carry out, the board should work in the spirit of the conference. The spirit of the right to have different opinion, but also the spirit of common, basic interests.

8d PLENARY 5

Jan-Olof Forsen suggests that contact persons could meet region by region, and in that way save money on travel expenses.

Erik Olsen suggests that the board should draft a set of articles or statutes, which can be put to the next conference. The draft by-laws set up by the WFPU could serve as an example.

Caia Garupi suggests that as the Newsletter will be copied and distributed to users, usergroups and others interested around Europe, we could collect donations in support of the production and further public relations activities.

8e DECISIONS (5) ON STRUCTURE

The proposals on structure and organization, from working group 5, are voted upon in their entirety: The proposals are accepted by acclamation.

The chair thanks the participants of the workshop for their efforts, since they held extra meetings in the evenings and in the early morning.

Later Sunday **Maths Jespersen** indicates that Sweden has requested to continue to make the **Newsletter**, and that he would be glad to do so as the new editor. RSMH has the facilities and has reserved money in their budget for the Newsletter. They want to start very soon, and hope everyone will contribute.

Accepted by acclamation.

The former Co-ordinating Committee proposes:

- In regards to the relationship with the European Regional Council of the W.F.M.H., the Network chooses to have an independent observer at the E.R.C..

Accepted by majority of votes.

The former Co-ordinating Committee suggests the following houserules for the newly elected board:

- The board should meet every six months.
- The report of the meeting should be published in the newsletter
- Travel expenses of the members of the board must be covered by them individually, or by their organizations. An exception will be made for the boardmember from Slovenia, in this case it will be the responsibility of the board to find resources to cover his travel expenses.
- Each member of the board will have one deputy. The deputy will replace the boardmember if he/she cannot be present at the meeting.
- Guests of the host-nation are allowed and warmly invited at the six-monthly meeting to observe during the presentation of the agenda point Taskforce/workinggroup reports.

The proposed houserules were accepted by a majority.

The conference puts it to the board to investigate the possibilities of a computer-network. Work in the Netherlands has started to set up a BBS for users and user-groups, which can serve the Network. A list of E-mail addresses shall be compiled and distributed.

It is further suggested that the board will consider two special fields of attention: women issues and minority issues. Eva Feiglová is especially interested in ethnic minority issues, and asks people to send her material on this. She hopes that in the future a group can be formed on this issue.

The former Co-ordinating Committee proposes to compile a list of people, who have expertise in a certain field and are available to speak at conferences when the European Desk receives requests for user-representatives. This way more people from the Network, and from various countries can get the opportunity to attend international conferences.

9. Other proposals and decisions

9a NEXT CONFERENCE

The chair asks the conference for suggestions where to hold the next conference of the Network. Great-Britain is suggested, and asked their position. The British delegation welcomes the suggestion. There are quite a number of organizations in place, and a good infrastructure, and they feel they can make a good job of it. The British acceptance is applauded.

9b NAMECHANGE

A proposal was submitted by delegates from Germany containing 25 signatures in their support of changing the name of the Network.

We propose that the name of the Network be changed to:

'The European Network of Users and Survivors of Psychiatry'

Argument in support is that there are enough people in this conference who do not comply with the word 'users' and define themselves as survivors of psychiatry.

Other arguments in favour:

In Zandvoort we didn't decide on a name, and we need a common name to cover the broad spectrum of opinion. With the terms Users and Survivors we cover both sides. We want to avoid a split. We accept that there are people who try to benefit from the psychiatric system, but they too must accept that there are many people who see psychiatrists as people who have outraged them in a brutal and violent manner. We appeal for mutual tolerance by means of this proposal. (Kerstin Kempker)

It would be such a pity if chaos would cause a split up of the network. The new name could last us many years. It would not be such a big change to use the name 'survivor' in stead of 'ex-user' if some 'ex-users' feel they identify themselves as survivors. Furthermore I see a positive meaning in the word 'survivor'. After all we did come out of psychiatry alive, unlike others before us in the middle-ages and during the Nazi-era. (Karl-Bach Jensen)

Arguments against:

At the Zandvoort conference we spent half a day's discussion on the matter already. Furthermore it would be confusing for the sponsors of these events to receive letters with different letter headings. We should stick to the present name whether people are ex-users, survivors or even presently using psychiatric services. (Thomas Graham)

The word survivor means that you fought a fight against something and you've lost it. I think our fight is still going on and therefore I don't see myself as a survivor. Sometimes you win some sometimes you lose some, but the fight continues. When we met in Zandvoort for the first time it was a dream coming true, and I hoped we would be practical, not continue to discuss ideology. (Angelo Gigliotti)

We must take into consideration the negative impact of the use of the word survivor to the outside world (professionals, psycho-pharmaceutic industry), and not be led by our emotions where our own experiences are concerned. We have responsibility to other patients, who cannot speak for themselves and future patients as well. Our fight must be a diplomatic one. (Eva Feiglová)

I think we should not rush, forcing a name change at this stage. There are many possibilities, more people should have the chance to come up with alternative names and people should have more time to think them over. We could then put a name-change on the agenda for the next conference. (Caia Garupi)

A majority votes against this proposal; it is not accepted.

10. Declarations and petitions

10a 'Declaration to the Romanian Government', proposed by Marin Mihai:

Because freedom of thought is the necessary and sufficient condition of dignified life,
because human nature is still free, and the loss of this freedom could be a crime against
humanity,
because individual freedom is the condition for justice and for the peace of society,
because those who have died in Romanian psychiatric institutions can't speak anymore,

We ask the Romanian State that by its legislative, judicial and executive power structure to
guarantee:

1.

The right of the human not to receive compulsory psychiatric treatment (biological, chemical,
physical, psychological or any other kinds of psychiatric compulsory treatments).

2.

The right of the human being to be informed about the fact that compulsory psychiatric
treatment is against his/her own interest.

Vote: the declaration is accepted unanimously

10b Petition to the German Government, proposed by the German delegation:

'The Second European Conference of Users and Ex-Users in Mental Health declares:

In Germany, like in most European countries, mental patients are not yet regarded equal to
other citizens. This is especially disturbing for victims of the 'Nazi'-influenced psychiatry
(compulsory sterilisation and compulsory treatment).

These victims haven't been recognised as victims of Nazi-Germany. This circumstance is
unacceptable and we urge these decisions bear no relation, and are not based on
'Erbgesundheitsgesetz' (1965: the last decision).

Victims of psychiatry want the same rights as other citizens: in the present and in the future.'

Judi Chamberlin appreciates this resolution very much, and points out the tragedy that it's
taken this long for us to organize in order for people to take notice of this fact.

Peter Lehmann points out that it was not the Nazi's who influenced psychiatry, but the other
way around, psychiatrist's influenced the authorities (Peter Lehmann wrote an article in English
on this subject; there is no time here to elaborate on the subject).

René van der Male requests to specify the era when this happened (1933-1945).

Jasna Russo requests that if the resolution intends to argue against compulsory sterilisation and
treatment in the present, some concrete formulation should be added.

Jolanda Tillner states that even today compulsory sterilisation occurs in Austria.

The chair asks the German delegation to make alterations to the declaration for clarification
purposes at a later stage, and asks to consider this a declaration in support of the German
delegation.

The declaration is accepted by majority of votes.

Text of the petition as altered by Ursula von Asseburg after the conference:

Petition to the German Government:

'The Second European Conference of Users and Ex-Users in Mental Health declares:

In Germany, like in most European countries, mental patients are not yet regarded equal to other citizens.

This is especially discriminating for victims of the "Nazi"-psychiatry (compulsory sterilisation and "Euthanasia"). These victims haven't been recognised as victims of "Nazi"-Germany.

This circumstance is unacceptable. We demand that all decisions, based on the "Erbgesundheitsgesetz", shall be delayed.

Victims of psychiatry claim the same rights as other citizens: in the present and in the future.'

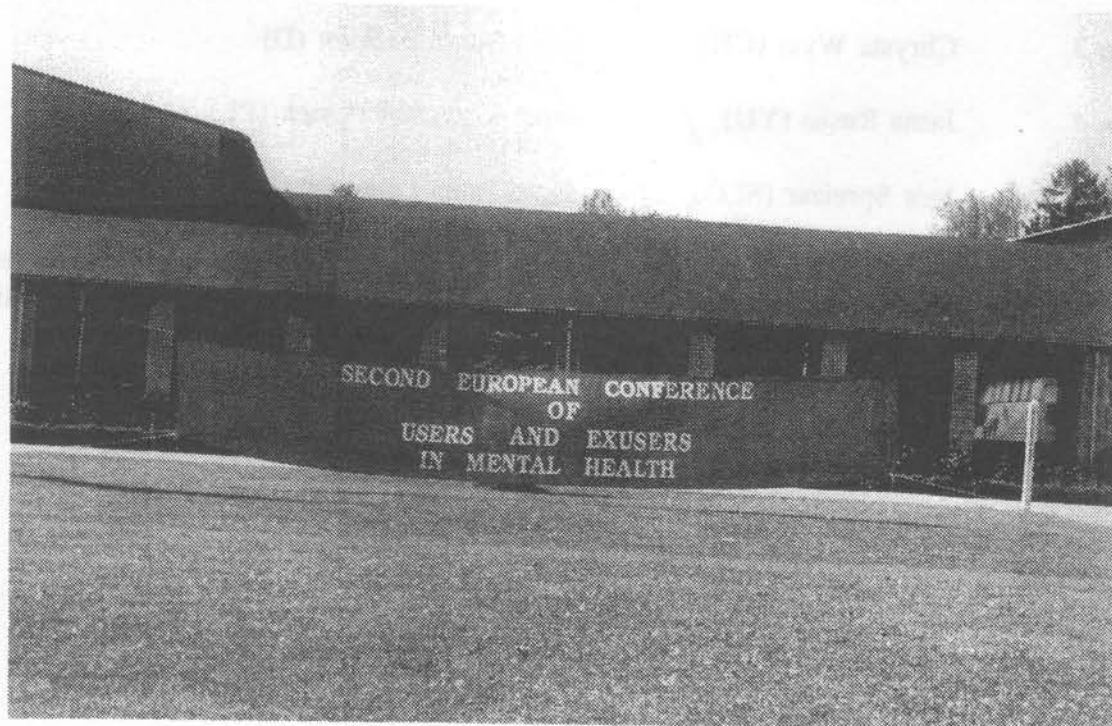
10c Petition proposed by the Scottish delegation:

'The Second European Conference of Users and Ex-Users in Mental Health, held in Elsinore, Denmark may 26-29 1994, supports the participation by the Scottish Users Network in a march to demonstrate against the deliberate sabotaging of the Civil Rights Bill, (1994), by the United Kingdom Conservative Government.

The march will begin on the 9'th of June 1994 at Kilmarnock, Scotland, and will finish in London, England.'

The purpose of this protest is to support people who are disabled, and to put mental health higher on the agenda.

The petition is accepted unanimously.



11. Election of the board

Sunday morning three candidates were put forward for the position of Chair of the Network. All but one accepted the candidacy: Roberta Graley from England. Several delegates thought it important that our chair should be a woman.

She is voted into the chair by majority.

Roberta Graley is accepted as our new chairperson for the next two years. (applause)

Seven candidates were put forward for the position of deputy chair, two accepted candidacy: Karl Bach Jensen and Peter Lehmann.

In an open ballot Karl Bach Jensen won the vote.

Karl Bach Jensen is the new deputy chair of the Network.

- DECLARATION ROBERTA GRALEY -

The new chair Roberta Graley thanks all the delegates of the second European conference for their support and their trust.

'I promise to work as hard as I can for our network, but I like to remind you that the board is there to carry out your wishes, so you must keep in contact with us. I look forward to the future and I believe that the Network can develop into a powerful influence over the rights of people who receive psychiatric treatment. And I personally will work as hard as I can to achieve this. I thank you all.'

The members of the board were elected by their own regions as follows:

region 1	Karl Bach Jensen (DK)	dep.: Maija Bäckman (SF)
region 2	Edna Conlan (UK)	dep.: René van der Male (NL)
region 3	Chrysta Wyss (CH)	dep.: Matthias Seibt (D)
region 4	Jasna Russo (YU)	dep.: Krzysztof Paszek (PL)
region 5	Igor Spreizer (SLO)	dep.: Tanja Lamovec (SLO)

At their first meeting held immediately after the closing of the conference, the 5 regional representatives in the board elected Karl Bach Jensen to join Roberta Graley in the chairmanship of the network.

The Second European Conference of Users and Exusers in Mental Health
International People's College, Elsinore, Denmark
May 26th - May 29th, 1994

PROGRAMME:**Thursday, May 26th**

- 14 - 18 Arrival, registration, coffee/tea
- 18 - 19 Evening meal
- 19 - 20 Welcome, official opening, background and aim of the conference
- 20 - 22 Mutual presentation of the participants

Friday, May 27th

- 8 - 8.30 Breakfast
- 9 - 9.30 Mary O'Hagan, chairperson of World Federation of Psychiatric Users presents WFPU.
- 9.30 - 12 Presentation from coordinating committee, followed by reports concerning the task forces of the European Network.

- 12 - 13 Lunch
- 13 - 14.45 Lectures on five main-topics - planned as introduction to working groups:
 1. Selfdetermination, social integration and welfare, Hans Bergström (Sweden)
 2. Legal issues, human rights and compulsory treatment, Jan Walcraft (U.K.)
 3. The medical model, diagnostics and treatment methods, Peter Lehmann (Germ.)
 4. Alternative(s) to psychiatry, Judi Chamberlin (USA)
 5. Future organization and structure of the network, Roberta Graley(U.K.)/Karl Bach(DK)
- 14.45 - 15.15 Coffee/tea
- 15.15 - 16.15 Composing and start of working groups, each of them concerned with one of the main-topics
- 17 - 18 Reception offered by the city of Elsinore on "Vandværket" - a drop-in and activity-centre for psychiatric users
- 18.30 - 19.30 Evening meal
- 19.30 - 21.30 Working groups continued.

Saturday, May 28th

- 8 - 8.30 Breakfast
- 9 - 10 Working groups finishing
- 10.30 - 12 Reports from working groups 1 - 4 and plenary discussions about political and ideological questions
- 12 - 13 Lunch
- 13 - 14.30 Plenary session continued
- 14.30 - 15 Coffee/tea
- 15 - 16.30 Plenary session continued
- 17.10 - 18.30 Buses leave for the ferry-boat to Helsingborg, Sweden
- 18.30 Visit to a user-run drop-in centre of RSMH
- 19 - 24 Social and cultural event in Helsingborg, musical and dramatical performances

Sunday, May 29th

- 8 - 8.30 Breakfast
- 9 - 12 Report from working group 5 and plenary discussion about future organization/structure. Conclusions, elections
- 12 - 13 Dinner
- 13 - 14 Closing of the conference

The conference is organized and planned by a Danish/Swedish organizing committee, guided by the Coordinating Committee of The European Network of Users and Exusers in Mental Health.

The conference is supported by SIND, Galebevægelsen, RSMH, NFSMH, WFMH/ERC.

Substantial financial support comes from the Danish Ministry for Social Affairs, The City of Elsinore, The European Union/Helios II-programme and The Danish Ministry of Foreign Affairs/Demokratifonden.

LIST OF PARTICIPANTS

The second European conference for Users and ex-Users in Mental Health
 The International People's College, Elsinore (Helsingør), Denmark
 May 26th - May 29th, 1994

Austria	Jolanda Tillner	D	Poland	Alicja Stokowska	D
Belgium	Jan Kuypers	D		Stanislaw Garbarz	D
	Jan Boeykens	D		Krzysztof Paszek	D
Czech Republic	Jan Gottwald	D	Romania	Alina Darowska	O
	Jirí Farny	D		Marin Mihai	D
	Eva Feiglová	D	Scotland	Tam Graham	D
Denmark	Jørn Sundahl Nielsen	D		Rosemary Burns	D
	Rasmus Skotte	D	Slovenia	Tanja Lamovec	D
	Lise Rahm	O		Bostjan Pogorelc	D
	Caia Garupi	D		Igor Spreizer	D
England	Edna Conlan	D	Sweden	Jan-Olof Forsen	D
	Neil Ward	D		Jimmie Trevett	D
Faroe Islands	Vildgerd Astridardóttir	D		Annika Malmqvist	D
	Margreta Poulsen	D		Anna-Lill Jacobson	O
Finland	Ulla Ylikotila	D	Switzerland	Christa Wyss	D
	Maija Bäckman	D		Viktoria Tóth	D
France	Jacques Lombard	D		Theresja Krummenacher	D
	Regine Barillon	D	Yugoslavia	Jasna Russo	D
Germany	Kerstin Kempker	D	Coordinating Committee	Roberta Graley	GB
	Ursula von Asseburg	D		René van der Male	NL
	Alfred Deisenhofer	D		Carl-Axel Ringsparr	S
				Matthias Seibt	D
Greece	Dimitri Livas	D		David Warner	I
	Phanasis Dimitrakopoulos	D	Invited Speakers	Peter Lehmann	D
Hungary	János Vargha	D		Jan Wallcraft	GB
				Judi Chamberlin	US
				Mary O'Hagan	NZ
Iceland	Rannveig Haraldsdóttir	D	Organizing Committee	Karl Bach Jensen	DK
	Anna Valgardsdóttir	D			Maths Jespersen
Italy	Massimo Belfiori	D		Hans Bergström	S
	Angelo Gigliotti	D		Niels Jacobsen	DK
	Mario Biggio	D		David Bonde Henriksen	DK
	Barbara Tozzi	O		Erik Olsen	DK
	Walter Stauder	O			
The Netherlands	Jaap Oosterhuis	D	Invited Chair-persons	Peter Campbell	GB
				Jan Dirk van Abshoven	NL
Northern-Ireland	Joe Brown	D	Interpreters	Claire Duvantier	
Norway	Bjørn N. Hæhre Øystein Hansen	D D		Lena Flugler	
				Antje Rösch	
				Hannelore Koob	
				Thomas Harder	
				Paolo Poggi	
				Aase Peerless	
	Hanne Aarup				

D: delegate-status
 O: observer-status

LIST OF USER ORGANIZATIONS

The European Network of Users and Ex-Users in Mental Health

SLOVENIA**"ALTRA"**

Committee for Innovation in Mental Health
 Drustvena 35
 61110 Ljubljana
 tel: +386.61.45.37.11
 fax: +386.61.13.37.011

SWITZERLAND**"Bly-Bly-Club"**

P.O.Box 1957
 8040 Zurich

"Irre am Werk"

P.O.Box 1957
 8040 Zurich

"Les Sans-Voix"

Solidarity movement for the
 protection of psychiatric patients
 Case Postale 235
 CH 1211 Geneve 17
 tel: +41.22.346.48.21
 (mornings)

ITALY**"Associazione "Gruppo-Auto-Aiuto"**

Massa Carrara
 P.zza Cesara Battista No.1
 54033 Carrara
 tel/fax: +39.585.75275

"Gruppo di Auto-Aiuto Merano"

Raffeingasse 1
 39011 Lana (BZ)
 tel: +39.473.564.396

"Ass. per la Lotta Contro le

Malattie Mentali"
 Via Vanchiglia 3
 10100 Torino
 tel: +0039.11.835.264

FINLAND**"Mielenterveyden Keskusliitto"**

The Central Association of Mental Health
 Venuksenkuja 2
 11130 Riihimäki
 tel: +358.14.725.985
 fax: +358.14.751.127

GERMANY**"Bundesverband Psychiatrie-Erfahrener"**

(BPE)
 Thomas Mann strasse 49a
 53111 Bonn

"Forum Anti-Psychiatrischer Initiativen"

(FAPI)
 c/o Mathias SEIBT
 Berggate 1
 44809 Bochum
 tel: +49.234.52.19.75

BELGIUM**"Kisjot Ombud Services"**

Goudstraat 8
 B-9000 Gent
 tel: +32.9.224.22.78
 fax: +32.9.223.85.02

"Flemish Survivors Movement"

P.O.Box 48
 Berchem 5

"Working group Morkhoven"

Gitschotellei 236/5
 B-2140 Borgerhout
 tel: +32.9.236.93.48

SWEDEN**"Riksförbundet för Social och Mental Hälsa"**

(RSMH)
 P.O.Box 15094
 10465 Stockholm
 tel: +46.8.772.33.60
 fax: +46.8.772.33.61

ENGLAND**"The United Kingdom Advocacy Network"**

Premier House
 14, Cross Burgess Street
 Sheffield S1 2HG
 tel: +44.742.753131
 fax: +44.742.700984

"Survivors Speak Out" Office

34, Osnaburgh Street
 NW1 3ND London
 tel: +44.71.916.5472

MINDlink

Granta House
 15-19 Broadway
 Stratford, London E15 4BQ
 tel: +44.81.519.21.22
 fax: +44.81.522.17.25

SCOTLAND**"Scottish Users Network"**

c/o EAMH
 40, Shandwick Place
 Edinburgh EH2 4RT

IRELAND**"Mental Consumers Association"**

Philipsburgh Avenue
 Fairview
 Dublin 3
 Fax: +3531.67.91.754

ESTONIA

Meelerahu
 c/o Juta Rahu
 Hiiela tee 10
 EE 0021 Tallinn

THE NETHERLANDS

"Clientenbond"
 Clients Union in Mental Healthcare
 Working Group International Contacts
 P.O.Box 645
 3500 AP Utrecht
 tel: +31.30.521.822
 fax: +31.30.541.157

"LPR"

National Patients Councils
 in Mental Healthcare
 Meerkoethof 48
 3582 48 Utrecht
 tel: +31.30.521.424
 fax: +31.30.543.889

POLAND

Klub "AMICUS"
 Str. Grottgera 25A
 Warsaw
 tel: +48.22.41.03.72

"BRATERSTWO SERC"

Plac Gen. Sikorskiego 2/8
 Krakow
 tel: +48.12.22.56.74/21.51.17

"PSYCHE"

Ul. Sobieskiego 67 lp.
 43300 Bielsko-Biala
 tel: +48.30.25.345

CZECH REPUBLIC

"Czech Association of Mental Health"
 Zvonsrova 6
 13000 Praha 3
 tel: +42.2.67.310.371

FRANCE

"Federation National des Associations
 D'(Ex)Patients PSY"
 (FNAP Psy)
 17, Rue Waldeck Rousseau
 94600 Choisy le Roi

"Group Information Asiles"

BP 172
 75622 Paris Cedex 13
 tel: +33.1.46.80.15.04

NORTHERN IRELAND

"Hollywell Patients Council"
 Holywell Hospital
 60, Steeple Road
 Antrim BT41 2RJ

NORWAY

"Mental Helse Norge"
 Postboks 298
 3701 Skien
 tel: +47.35.53.43.70

"Søkelyset"

Searchlight
 Etterstadsletta 87 A
 0660 Oslo

ICELAND

"GEDIJÁLP"
 The advocacy and psychiatric patients
 organisation in Iceland
 Öldugata 15
 101 Reykjavik
 tel: +354.125.990

FAROE ISLANDS

"Sinnisbati"
 c/o MBF
 Islandsvejen 10 C
 FR-100 Tórshavn
 tel: +298.7373
 fax: +298.6192

DENMARK

"Landsforeningen Sind"
 L.I. Brandes Allé 1
 1956 Frederiksberg C
 tel: +45.31.35.42.66

"Galebevægelsen"

Blågårdsgade 39
 2200 København N
 tel/fax: +45.31.35.77.50

GREECE

"Movement for the Rights of Mental Patients"
 ΚΙΝΗΣΗ ΓΙΑ ΤΑ ΔΙΚΑΙΩΜΑΤΑ ΤΩΝ
 "ΨΥΧΑΣΘΕΝΩΝ"
 Θεμιστοκλεους 11
 ΑΘΗΝΑ 106 77
 tel: +30.1.363.8411
 fax: +30.1.644.5140

SPAIN

ASAFES
 (Asociacion Alavesa de Familiares y Enfermos
 Psiquicos)
 Portal de Arriaga, 14 bajo
 01012 Vitoria - Gasteiz
 tel: +34.945.28.86.48

Contacts with users exist in the following countries,
 though no private addresses can be given:
 Ex-Yugoslavia, Hungary, Austria, Portugal, Ro-
 mania, Bulgaria, Albania.

LIST OF ELECTED AND APPOINTED REPRESENTATIVES

The European Network of Users and ex-Users in Mental Health
 In conference in Elsinore (Helsingør), Denmark
 Sunday May 29th 1994

Members of the Board:

Chair	Roberta Graley (UK)	dep.: Karl Bach Jensen (DK)
region 1 & Co-Chair	Karl Bach Jensen (DK)	dep.: Maija Bäckman (SF)
region 2	Edna Conlan (UK)	dep.: René van der Male (NL)
region 3	Christa Wyss (CH)	dep.: Matthias Seibt (D)
region 4	Jasna Russo (YU)	dep.: Krzysztof Paszek (PL)
region 5	Igor Spreizer (SLO)	dep.: Tanja Lamovec (SLO)

The regions are divided as follows:

- Region 1 Sweden, Faroe islands, Iceland, Denmark, Norway, Finland
- Region 2 The Netherlands, England, Scotland, Ireland
- Region 3 Belgium, Germany, Austria, Switzerland
- Region 4 Poland, Ex-Yugoslavia, Czech Republic, Hungary, Romania
- Region 5 France, Italy, Greece, Spain, Portugal, Slovenia

Appointed representatives:

Newsletter coordinator:	Maths Jespersion (S)
European Desk secretary:	Jan Dirk van Abshoven (NL)

Taskforce coordinators:

Taskforce ECT:	Erik Olsen (DK)
Taskforce 'Legal issues', damage claims:	Neil Ward (UK)
Taskforce Alternatives:	David Warner (I)/David Bonde Henriksen (DK)
Taskforce Selfdetermination:	Hans Bergström (S)

OUTLINE ALTERNATIVES

An abbreviated directory of alternatives to traditional psychiatry and alternative structures and methods used in Europe is being compiled. It should serve as an information source. The directory does not take a position on whether an activity is good or not. It will serve to communicate the facts and/or ideas through brief overviews.

A general description or any fragment of information regarding an activity is worth a lot in that it can give new ideas and possibilities into what is happening today and what can happen elsewhere in the future. Descriptions of pre-existing, yet now extinct activities are always welcome for their informative value as well.

Structure and abbreviation key:

1. Entries are to be grouped by Subject (abbreviated: Sub.)

- Sub. I Cooperatives.
- " II Crisis housing, refuge centers and/or runaway houses.
- " III Housing structures.
- " IV Restaurants, bars.
- " V Theater groups, ceramic studios, painting studios and the arts in general.
- " VI Daily drop in centers.
- " VII Alternative therapies.
- " VIII Runaway houses for children.
- " IX Groups/Associations.
- " X Critical information on neuroleptics and psychotropes.
- " XI Crisis intervention teams and telephone hot lines.

2. Due to the vastness of Europe, entries should be grouped according to their proximity to each other, so the entries under each subject are to be grouped by country and each country group is to be placed in alphabetical order by country name ie.: first ALBANIA and lastly ZIMBABWE.

3. Within each country group the various entries will be arranged alphabetically by:

- a. Name.
(with the following information)
- b. Address.
- c. Description.
- d. For more information who should be contacted.

Contributions should be mailed to :

David Warner
Taskgroup Alternatives
Via Carriona 36
54033 Torano di Carrara (MS)
Italy
fax: +39 585 752 75

Entry examples:

Sub. VII. Alternative Therapies.

Greece:

- a. "The Therapeutic Community" c/o The Open Psychotherapeutic Center (O.P.C.) of the Athens Institute for Group Analysis, Athens.
- b. Address to be obtained.
Tel. 6447533 or 6435980 (Athens).
- c. "The Therapeutic Community" has introduced many innovations in the direction of democratisation and flattening the authority pyramid (more information available c/o contact person: see d.). One innovation is the socio therapeutic groups conducted by members and patients. There are eight such groups where the conductor (who gets a 50% fee reuction in his therapy), changes every 3 months. An old member can create and conduct his/her own group, thus paying nothing for therapy. The group of conductors meets every week and discusses problems that come out in the groups.
- d. Contact: Dimitris Livas Tel.: 6435980 (Athens) or Yianna Katsouri Tel. 6447533 (Athens).

Sub. IX. Groups/Associations.

Slovenia:

- a. ALTRA, Association for Inovation in Mental Health.
- b. Drustvena ul. 35, Ljubljana 61110 Tel.: 386-61453711.
- c. "We started our work in 1988 at the international workcamp in Hrastovec where there is a total institution for psychiatric users. Our helplessness and the impossibility to help led us to to establish an Association which makes the political and media preasure the exsisting authorities. In the last few years we have developed several prevention programmes: Home group, Advocacy, Drop in center, Social network, Club, etc. and we are preparing some new programmes such as a Newspaper, Shelter, Information center, etc. In all activitiere the major roles are held by ex-users with the support of some alternative experts from University of Ljubljana and TEMPUS programme 'Mental Health in Society'. "We are sponsored by the city of Ljubljana, some foundations and others. We provide a part time service for more than 50 ex-users. Many students from our University and alternative artists also do voluntary work."
- d. Contact: Igor Spreizer c/o address for ALTRA or FAX to the High School for Social Work at: 386-611337011.