

## **Detailed report of the ENUSP activities within the Community Action Program to Combat Discrimination (2001/2002)**

### **Desk**

Due to a lot of unexpected changes, the board of ENUSP had to face a lot of problems, which made it necessary to change the planned activities. The former secretary Clemens Huitink decided to change his working place. The changing of the desk brought some problems and unclearness about responsibilities, with the results, that the ENUSP Desk had to move to Germany and Peter Lehmann became the new Secretary. For a short time an additional room had to be hired in Central Berlin, where volunteers could sort all the desk's stuff Peter Lehmann had fetched from Utrecht.

The secretaries did the typical work: writing letters and mails from anybody, answering letters and mails, organizing board-meetings and telephone-conferences, gathering topic for board-meetings, writing minutes, fulfilling the decisions of the board, negotiating with other organisations, making book-keeping, writing new applications, sorting material.

Severe financial problems of ENUSP, mainly coming from unsolved balancing-problems with the EC-grant 1998/1999 made it necessary, that the Interim-Secretary got an advisor at his side, the educated businesswoman Kerstin Kempker, who is experienced with the solution of financial problems.

### **Adding value to the objectives and activities of umbrella networks which deal with the same grounds of discrimination as ours**

ENUSP attempted to influence policy at a European level and maintains contacts with other international organisations active in the mental health field and in human rights issues. Contacts and collaboration have been set up especially with:

- CEFEC (February 2001), preparation meeting for Berlin conference, representation of ENUSP at the meeting and CEFEC board meeting. Then representation of ENUSP at the CEFEC conference CEFEC. Being contact person for CEFEC.
- Council of Europe: Meeting with the Human Rights Commissioner, Budapest (June 2002)
- EDF. Collaboration with the EDF Disabled Women's Committee, presence at different meetings, as well as the EDF Committee on Human Rights.
- EPF (European Patients Forum, before: Public Health Forum), presence at the meeting in 7/2002 in Luxembourg, then declaration of the membership.
- European »Network of Excellence« about information technologies and communications in psychiatry: Contacts and positive decision about the membership
- European Social Platform of NGOs: Contacts for membership failed, because this platform seems not interested in a ENUSP-membership
- EYPD-Preparation: Presentation of a paper on social exclusion at the European Congress on People with Disabilities in Madrid (March 2002). Declaration of the membership at EYPD. Application for a grant to EYPD. Meeting with the referent of the German "Behindertenbeauftragten" to prepare a Pan-European reading in EYPD 2003.
- Hamlet Trust: Participation and contribution to the Hamlet Regional Workshop in Slovenia, October 2001: Gozd Martuljek, with about 90 participants of East Europe
- MDRI (Mental Disability Rights International): September 2001: One week fact finding mission to psychiatric institutions in Kosovo (each kind of abuse of patients in psychiatric institutions). Participation at the International Human Rights Symposium (October 2001). Letter to Kofi Annan
- MHE: (Failed) Negotiations about a common organisation
- Nordic Forum for Social and Mental Health: Membership
- WAPR: Participation in the organisation of the conference (May 2002): "Rehabilitation of the people with mental health problems" in Ljubljana for professionals, (ex-)users and survivors of psychiatry and relatives of UK, Croatia, Spain, Italy, Bosnia, Romania, Slovenia. Representation in the board of WAPR.

- WFMH (July 2001) Conference in Vancouver, Canada, "Respecting Diversity in Mental Health in a Changing World", participation and presentation: "Modern anti-psychiatric positions and their practical implications"
- WHO: September 2001: Participation at the Patients' Rights Conference of WHO-Europe, Budapest. October 2001: Participation at the Conference "Coping with stress and depression related problems in Europe", organized by the World Health Organization, the European Commission and the Federal Ministry of Social Affairs, Public Health and the Environment (Belgium).
- WNUSP (April 2001), founding conference working group preparation meeting in Odense, Denmark. July 2001: Preparation meeting of first General assembly, founding conference, and later founding conference and general assembly, Vancouver. Organisation and facilitation.

### **Mechanisms of consultation and information between the organisation members**

4 **board-meetings**, prepared in cooperation with MHE, have been held. The secretary and the newsletter-editor have been present.

The integration of East-European members in decision processes and the difficulties to finance their travel costs to meetings were one more factor of delay. The originally planned board-meetings had to be postponed, and these changes made it necessary to change the meeting-places, too. Severe health problems of the board-member Paul Fijn made the change of one meeting place necessary, because he was not allowed by his doctor to fly. Health problems of Gloria Brown and Bev Mills made it necessary to invite deputies, who took over the role of board-members (Paul Fijn, Richie Butler). Due to the poorer becoming contacts to the French/Spanish/Portuguese speaking region, Claude Finkelstein became an adopted board-member to enhance the contacts. Due to the loss of the contacts to the English speaking region, Mary Nettle became an adopted board-member to re-establish he contacts. Due to health problems of the Austrian Michael Chmela (deputy of P. Lehmann's deputy Iris Hölling), Ulrike Burgstaller had to be his deputy for the board-meeting in Vienna.

- Nov 2001: Board-meeting in Poljce, Slovenia. The main task was to plan a membership-meeting in April 2002. The minutes of this board-meeting and all following ones are published on [www.enusp.org/minutes.htm](http://www.enusp.org/minutes.htm), the ENUSP web site.
- Jan. 2002: Telephone conference: The expected funding from Open Society will not come; only Hamlet Trust and Slovenian government would have given money. Contacts with subsidising institutions in the Netherlands to get the next conference of European (ex-)users and survivors of psychiatry financed failed.
- April 2002: Board-meeting in Utrecht
- June 2002: Board-meeting in Vienna
- August 2002: Board-meeting in Berlin

At the board-meetings special attention has been put to non-discrimination actions, to meet regional groups and to care for enlargement of ENUSP.

**Actions against discrimination** has been done, for example:

- Planning of an action against the new law on involuntary sterilization of women called mentally ill
- Statement against the new dangerous "England and Wales Draft Mental Health Bill 2002")
- Planning of an action against the Belgium Euthanasia Law: »chronically mentally ill« persons can decide to be killed, no control-commission is available. Organisation of the law text via Uilenspiegel to discuss it within the mailing-list.
- Discussion the Dutch 'Week of Psychiatry' (spring 2002) with the theme: "Conceptualisation in the media about psychiatric patients" and its book about bad examples of discrimination and good practises
- Negotiations with the German State's Secretary Dr. Volker Beck to take action against the "White Paper on the protection of the human rights and dignity of people

suffering from mental disorder, especially those placed as involuntary patients”, composed by the Working Party about psychiatry and human rights, a subordinated institution of the Steering Committee on Bioethics of the Council of Europe” and juridical discriminating people with psychiatric diagnoses

**Meeting with groups:** At the board-meetings meetings have been arranged with Paradoks in Ljubljana, with the board of the Klientenbond, with the Vienna FAPI, with the Berlin “Für alle Fälle (For all cases) e.V. and a meeting with the residents and staff of the Berlin runaway-house. Meetings, congresses, education, support and all many other forms of contacts to national, regional and local groups of (ex-)users and survivors of psychiatry have been discussed and planned, for example:

- September 2001: Ljubljana, Round-table for users of Slovenia: »Advocacy which we need« with about 200 participants of Slovenia
- September 2001: Key-note speech at the National Conference on Mental Health Training in Brighton, UK
- September 2001: Participation at the National Conference on Psychiatric Rehabilitation, Szeged, Hungary (anti-discrimination)
- September 2001: Participation at the board meeting of the Mental Disability Advocacy Centre, Tallinn, Estonia
- September 2001: Workshop for social-workers of Slovenia Community care for patients, Majcni – Slovenia
- October 2001: Organisation of the National Conference on Human Rights Monitoring in Psychiatric Institutions, Budapest, Hungary
- October 2001: Meeting with users of Bosnia in Slovenia (Ljubljana, Sežana), and discussing possibilities for co operations
- November 2001: Participation at the meeting of the Dutch LOIB (National Policy Board on International Affairs).
- November 2001: Ljubljana- Paradoks Workshop: Women and their mental-health problems. 16 participants, users and professionals of Slovenia.
- December 2001: Human Rights Monitoring in Kosovar psychiatric institutions,
- December 2001: Different performances for children of users of Ljubljana and Christmas and New-Year's presents for them.
- December 2001: Participation at a joint mission of the Dutch Mental Health Organisation in Slovakia
- Since January 2002: Work on Centres for Social work (in all Slovenia are 66 of them) with the people with mental health problems, and Custody. Organisation of two round table for users of Slovenia and other professionals
- January 2002: Contribution to the Mental Disability Rights Seminar in Sofia, Bulgaria
- January 2002: Start of an research together with the University of Utrecht whether the doctors describe now more antidepressants instead of benzodiazepines
- February 2002: organisation of a symposium at the German conference of the Deutsche Gesellschaft für Verhaltenstherapie in Berlin with international speakers about self-help and empowerment
- February 2002: Establishment of FORUM NGOs of Mental health of Slovenia
- March 2002, Ried, Austria: Organisation of a regional meeting of (ex-)users and survivors of psychiatry together with Austrian (ex-)users and survivors of psychiatry
- April 2002: Meeting with North Italian members of Marienthal in Venice: Social Co-operatives, discuss possibilities of employment of (ex-)users and survivors of psychiatry
- May 2002: Human rights monitoring in Slovakia
- May 2002: Trainer and representative of ENUSP at a human rights training in Slovakia, organised by the Mental Disability Advocacy Centre
- May/June 2002: Co-organisation and training of the human rights education in Hungary, organised by the Mental Disability Advocacy Centre

- June 2002 Welcome-words at the congress of the self-help organisations of the Bundesland Brandenburg (Germany)
- June 2002: INTERNATIOOL CAMP OF ART IN ŠTANJEL. 10 days with (ex-)users and survivors of psychiatry and volunteers of Slovenia, Češka, Slovakia, Finland, USA
- August 2002: Presence on the Carst NGO VEZI opening of a new Day center and Home group by the government's president, what brought good reports in the media with a lot anti-discrimination note.

Further on there have been many direct contacts, for example visits), to national members, for example Mindlink, Klientenbond, Uilenspiegel, BPE, to groups of (ex-)users and survivors of psychiatry in Estonia, Lithuania, Portugal, Czech Republic, Slovakia, Poland, Romania, Ukraine, Russia, Italy. International contacts have been enhanced, French (ex-)users and survivors of psychiatry started to try to get money to learn English.

At board-meetings **information-exchange** on literature-research on the effects of modern atypical and anti-depressants has been done:

Information has been gathered, from libraries, mailing-lists, magazines, books, drug company's information sheets; the information is available at the desk. Atypical receptor-changes, in particularly changes of the Dopamin-D1- und -D4-Receptors, found our attention, it was decided to monitor them further on, as well as the enhancement of the prolactin-level, leading to enhanced risk for breast-cancer in women, and cases of tardive dyskinesia in risperidone. Homocide and suicide as possible effects of SSRI were discussed. Special attention the ENUSP board put on the market's withdrawal of some new but very dangerous psychiatric drugs in single countries (remoxipride, sertindole) because of deadly effects. Discussion was done how to spread the information between the member organisations without having the risk of being sued for compensation or terrifying users of these drugs. It was decided, that the original documents about risk-information should be spread via the ENUSP-mailing list and that ENUSP-desk should go on gathering material and have it available for a publication. As there are some reports of (ex-)users and survivors of psychiatry, coping better with the modern neuroleptics and antidepressants, this issue should be one of the main issues at the next general meeting again.

### **Discussion and creation of homepage incl. mailing-lists**

A domain-address was bought, own space at a provider was hired. The website was done, worked over and, after asking the mailing-list participants and discussion in the board, a new design was agreed. People have been asked to translate the welcome page and the self-representation of ENUSP in all European languages, Dutch and German translations are available already, other translations are in work. Mailing-lists were developed, implemented and supervised. Email-addresses of European organisations of zzz and active people were gathered, the people were invited to join the lists:

The ENUSP Discussion List is the electronic arm of ENUSP. The purpose of this list is to communicate, to exchange opinions, views and experiences in order to support each other in the political and social struggle against exclusion, injustice and discrimination and to foster the inclusion at all policy levels of members and friends of ENUSP.

The ENUSP Individual Mailing List is the list for communication on more personal issues whereby the responses go only to the original writer, and not to the whole list. The purpose of this list is to seek information and provide individual support.

The mailing-list have been accepted by the members at once and are used to spread information. The desk uses the mailing-list to announce every interesting news, board-minutes included, to ask for topics for board-meetings and activities etc.

### **Newsletter**

Problems with electronic data communication made it necessary to change the Newsletter editor and the foreseen publication dates of publication. Two newsletters have been produced, printed as well as put into the internet:

- April and August 2002 (added)