



Newsletter November 2006

Dear members,

How time flies for hard working people! Summer sped by and the holiday season is rapidly approaching. What has happened since the last newsletter? There was the conference in Maastricht, with the Health SIRG IASSID-MAMH round table about education of medical students in intellectual disability medicine, we have had our own meetings and we have made some new contacts.

Richard Newton, who has been a member of the board from the start (1991) and was president of MAMH from 1998 till 2002, had to step down. MAMH owes him a lot of gratitude.

Round table

Helen Beange of Australia chaired this meeting about **Education and Training for Doctors in Intellectual Disability Medicine**. Peter Martin (different models), Bob Davis and Marijke Meijer (the Australian and the Dutch approach respectively) introduced the subject.

In December 2005, in preparation for this meeting, a questionnaire was sent to doctors in different countries. Its aim was to get an impression of the present situation and the future plans in this field. The overall conclusion was that training in intellectual disability medicine is very limited for medical students. In most of the countries involved training is optional and there is only some indirect reference to intellectual disability from general subjects

such as psychiatry, genetics and paediatrics. Sometimes there are opportunities for an internship or a course on ID-medicine and in some cases contact with people with intellectual disability is organised.

Participants at the meeting agreed that a higher level of knowledge in ID-medicine is required and that education on this subject should be compulsory in undergraduate curricula. Several suggestions were made on how to achieve the goal of better training in ID-medicine.

It was decided that a statement should be produced, that can be presented to governments and policy makers. The outcome needs to be as good for people with ID as for any person and needs to be implemented all over the world; it is therefore important to record the differences and differing resources for each country.

A working group was established, the members of which will be responsible for input into the discussion about this subject from the perspective of their respective countries.

These representatives are:

Marijke Meijer	The Netherlands
David O'Hara	United States
Peter Martin	Germany
Rachel Forrester-Jones	United Kingdom
Mark Scheepers	United Kingdom
Monica Björkman	Sweden
Bob Davis	Australia
Helene Ouelette-Kuntz	Canada
Sally-Ann Cooper	Scotland

General Meeting

Unfortunately the president had to send apologies for absence due to personal circumstances; Peter Martin therefore chaired the meeting. Richard Newton had to step down as a member of the board. There were no other candidates at that time; the board is looking for candidates, especially from Eastern European

countries, who can stand for election at our next general meeting in 2007.

The General Meeting again agreed on the most important new activities for MAMH, namely closer contact with members, regular newsletters, renewal of the website, current medical information via our website sent to all members etc. All activities need to be strengthened.

Introduction new member from Turkey

Mrs. Muruvvet Gumus Banaz introduces herself:

I am a general practitioner. I graduated from the Aegean University Medical Faculty, Izmir, in 1998. After graduation I worked in primary health care centres in different parts of Turkey. I am interested in public health and I want to specialise in this field. I have written an article about immigrant women and their utilisation of health care centres; I conducted this project in one of the primary health care centres in which I was working.

My connection with MAMH began with a survey that reached me by e-mail. Through that survey, I encountered the new terminology of Intellectual Disability Medicine. In Turkey, there has not been a specific medical department for intellectually disabled people's health; there are some individual studies about intellectually disabled people's health in different disciplines.

As the organisation wanted me to write about the situation in my country, I realised that there were so many things that must be done for intellectually disabled people and I am interested in the public health aspect of this field. I used the Turkey Disability Report 2002 in my article (see: www.mamh.net) but I think that we need more detailed epidemiological research which can determine the expectations that people and their families have of the health centres and also the difficulties that they have experienced. We need team-work in order

to improve so I am trying to introduce MAMH to my colleagues in my country."

Sincerely,
Muruvvet Gumus Banaz

Royal College of Psychiatrists (UK), conference in Prague.

I (FS) was invited by the Faculty of the Psychiatry of Learning Disability of the Royal College of Psychiatrists to give a presentation at their annual residential Conference, which was held on the 5th and 6th of October 2006 in Prague. The subject of my lecture was The European Manifesto and other activities of MAMH; the audience very much appreciated the presentation. The conference was very interesting and I met a lot of colleagues, who are as dedicated to medical care for people with intellectual disabilities as we all are. I met **Dr Roger Banks**, currently Honorary Secretary of the Faculty, who is willing to strengthen the board of MAMH. I also met **Dr Jana Janotová**, who is a psychiatrist from the Psychiatric Hospital in Prague. Dr. Janotová gave a presentation about "the care of mentally retarded people in the Czech Republic: the current situation and treatment". She is interested in the activities of MAMH and promised to send us her presentation for publication on our website.

In our next newsletter she will introduce herself.

Eastern European countries

One of the main goals of MAMH from the outset was to support doctors in eastern European countries in their efforts to improve the quality of medical care for people with intellectual disabilities. It proved to be very difficult, however, to make contact with doctors who are involved in caring for these people in those countries. From Jana Janotová (see above) we learned why it is so difficult to find such doctors in these countries: they do not exist! For physicians, the need of

intellectually disabled people is just a small part of their work.

We have recently sent letters to a doctor and to an organisation, Pentru Voi, in Romania and to an organisation called Open Society Mental Health Initiative. Their goals are to finish institutional care and to start improving supported living in eastern European societies.

We also made contact with MDAC, Mental Disability Advocacy Centre, a non-governmental organisation, active in eastern European countries and based in Budapest.

European Union

In February 24th 2006 we sent a letter to Mr K. H. Florenz, president of EP Committee Environment, Public Health and Food Safety of the European Parliament.

In his eventual response Mr. Florenz included a resolution of the European Parliament on “improving the mental health of the population – towards a strategy on mental health for the EU” (2006/2058(INI)). This resolution was adopted by a huge majority of the Parliament in September 2006; the report now has to be adopted by the Commission. Mr. Florenz suggests that our association could provide a valuable contribution to the discussion and the best way to do this will be through liaison with the rapporteur, as soon as he/she is appointed following the Commission’s expected adoption of the strategy.

The resolution however is almost 100 % about mental health and mental illness. Only in points 0 and 44 are there references to people with intellectual disabilities:

0: *“whereas in most European Union countries there has been a move from long-term institutionalised care, both for children with developmental and behavioural problems which jeopardise their normal development, particularly in the educational sphere, and for adults with chronic and severe disorders and for those*

with learning disabilities, towards supported living, but whereas this had been without proper planning and resourcing of community services”.

44: *“..., but acknowledges that greater efforts must be made to convince the public of the better results achieved when people with severe mental or learning disorders receive care in the community”.*

The board will monitor the developments in the European Parliament and will make contact with the rapporteur in due course.

MAMH Meeting next year

Next year, at the end of September, a conference will be organised by MAMH and the German association of physicians for people with intellectual disabilities (Bundesarbeitsgemeinschaft Ärzte Dienste für Menschen mit geistiger oder mehrfacher Behinderung (BAG)).

The subject will be cerebral palsy.

The meeting of the board and the General Meeting will take place at this conference, which will be held in Potsdam. We hope, of course, to meet you there.

Finally we send you all good wishes for Christmas and the New Year.

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