



Newsletter December 2008

Dear Members,

The end of the year is coming fast; a year in which progress has been made including progress in memberships (Swiss and Romania) and in contacts within the European Union. We had an inspiring General Meeting in Zürich at which we adopted a Strategic Plan. With new plans and full of energy the board will continue to work on the goals of MAMH.

We wish you and your families nice Christmas days and a happy new year.

The General Meeting 2008

It was an inspiring meeting in Zürich on November 22nd. We redefined the main goal of MAMH (reducing inequalities in medical care for people with intellectual disabilities) and we established a Strategic Plan.

Frans Scholte and Maria Arvio are re-elected as president and treasurer of MAMH, Thomas Dorn is elected as a new board member.

For the execution of the Strategic Plan, every member of the board will take responsibility for a part of it. Maria Arvio: good practices, leaflets on medical issues, Peter Martin: under- and postgraduate training in intellectual disability medicine, Frans Scholte: contacts with key politicians, policy makers and organisations on a European level, Roger Banks: profiling MAMH throughout the countries of Europe, Thomas Dorn: connections with the membership of

MAMH, all: to promote intellectual disability medicine as an element of health service provision wherever appropriate.

The minutes of the meeting and the Strategic Plan will be sent to you separately.

Contacts in Romania

Frans Scholte and Talitha van den Heuvel, a Dutch physician, who temporarily lives in Talmu Mures, have visited some institutions in Sibiu and met several physicians there. We experienced a warm welcome and had open discussions with our Romanian colleagues. Compared with the shocking images we had in mind from television programmes some decades ago, the care was certainly improved. We noticed warm loving care for children and adults who were well fed and properly clothed. However, there was a lack of daily activities and bedrooms were often shared with two or more persons. We saw children with enormous hydrocephalus and adaptations for serious physically handicapped persons that were not always adequate. We did not see adults with multiple and complex disabilities, they seem to live in special institutions.

We did not see adults with glasses; correction of visual impairment is not done because of fear of damage to the eyes. There are difficulties for the physicians working in institutions. They are dependent on family doctors for referring patients to hospitals and they are dependent on psychiatrists in treating persons with challenging behaviour; they cannot prescribe psychopharmacological treatments themselves.

We noticed that there were no young physicians in the institutions.

This was the first time that the physicians in Sibiu had met each other and they expressed the intention to meet more often to exchange knowledge and experiences.

There is another development in the province of Mures, where Talitha van den Heuvel lives. Talitha has distributed

information on MAMH, which was translated into Romanian, among physicians and organisations.

Physicians for the care of people with intellectual disabilities intend to establish a Romanian Association; Dr. Denes Barabas being one of the initiators of this plan.

The EU

As previously reported, on January 18th we met in Brussels with Mr. Johan ten Geuzendam, head of the EC Unit for Integration of People with Disabilities, Directorate-General for Employment, Social affairs and Equal Opportunities. On October 10th Frans Scholte and Roger Banks met with Mrs Fiona Kinsman, EMPL G/2, (Equality, Action against Discrimination, Legal Questions) and Ms. Nathalie Chaze, European Commission Directorate-General for Health and Consumer Protection, Unit C5 (Health strategy and health systems).

The European Union often works with recommendations for national governments, more than with legislation.

We put to them the following considerations:

Reducing health inequalities is one of the main goals of MAMH.

Some Relevant Facts:

1. People with intellectual disabilities experience health inequalities. For example: morbidity and mortality rates are higher in people with intellectual disabilities (People with learning disabilities are 58 times more likely to die before the age of 50 than the general population, Hollins et al 1998), sensory impairments are seriously under-diagnosed (according to the Dutch study Van Splunter et al. 2003, visual impairment in people with intellectual disabilities is present in 14 % of the cases , out of which 40 % was unknown prior to this

study); gastro oesophageal reflux disease (GORD) is often not recognised as the cause of anaemia, eating disorders or behavioural problems; psychiatric disorders are more often present in intellectually disabled people, but there is a lack of psychiatrists with interest in these kinds of patients;

2. People with intellectual disabilities cannot always properly express their medical needs or describe their symptoms.
3. Mainstream health services are currently unable to provide adequate health care to people with intellectual disabilities. Health professionals show a lack of knowledge in the specific health needs of this group of patients together with a lack of interest. (In the United Kingdom, the national charity MENCAP published a report “Death by Indifference” which highlighted 6 cases of people with learning disabilities who had died through alleged lack of appropriate care and treatment. The report suggested that health services may be guilty of institutional discrimination and this led to the establishment of an independent inquiry under the chairmanship of Sir Jonathan Michael, the conclusions of which have recently been published in the report Healthcare for All – Department of Health, London).
4. In official documents of the European Commission no distinction is made between people with physical and people with intellectual disability (often in combination with physical impairments). However, people with intellectual disabilities have different, specific health needs. It is important to recognise this in order to be able to reduce inequalities adequately.

What can be done to reduce health inequalities in people with intellectual disabilities?

In the education of health professionals

1. Pay attention to the specific health needs of people with intellectual disabilities in the general educational training programmes of all health professionals.
2. Develop specialised training programmes for health professionals who want to gain competencies in health issues of people with intellectual disabilities (intellectual disability medicine as a specialty). See the situation in the Netherlands, Finland and the United Kingdom.
3. Develop post-graduate training programmes in intellectual disability medicine for health professionals.
4. Raise the accessibility to these training programmes, especially for health professionals in Eastern European countries.
5. Encourage dialogue and support through networks of organisations involved in supporting people with intellectual disabilities to raise awareness of health issues.
6. Publicise simple guidelines for doctors and other health staff on how to ensure that they meet the needs of people with intellectual disabilities more effectively. (see MENCAP – Getting it Right campaign www.mencap.org.uk)

In daily practice

7. Develop or strengthen the use of mainstream health services by people with intellectual disabilities.
8. Health Services should identify people with learning disabilities at first contact in order that their progress and outcomes can be tracked and audited.

9. Guarantee the specialised support for mainstream health services dealing with intellectually disabled people. Health professionals who are specialised in the specific health needs of individuals with intellectual disabilities should be available as a back-up to mainstream health services. These professionals could diagnose, treat specific medical problems or take over (a part of) the medical care for people with intellectual disabilities.

How could the European Union possibly contribute to the reduction of health inequalities of people with intellectual disabilities?

1. Plan a study on the inequalities (of treatment and of health outcomes) of intellectually disabled people in the EU.
2. Pay attention to the reduction of health inequalities in people with intellectual disabilities in all recommendations concerning activities against discrimination of people with disabilities.
3. Support the above-mentioned solutions financially.

We asked the representatives of the European Commission to give us the opportunity to comment on draft versions of legislation or recommendations concerning health care for persons with disabilities.

In a letter to all members of the European Parliament Committee on Environment, Public Health and Food Safety and to Mrs Liz Lynne, who is vice president of the Disability Intergroup of the European Parliament we asked the same. Finally we asked Mrs Lynne to invite us to a meeting of the Disability Intergroup, to give a presentation on the current state of health and on inequalities in healthcare for people with intellectual disabilities.

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