

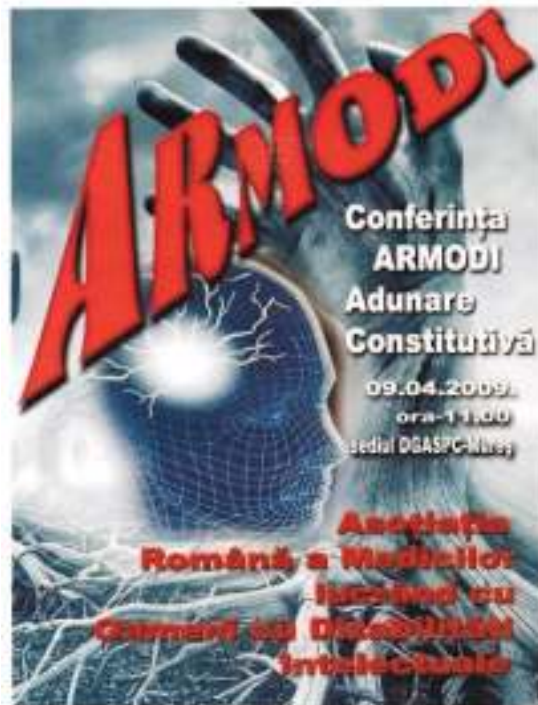


Newsletter May 2009

Dear members,

There is good news to tell:

A new association has been formed, ARMODI in Romania, the general meeting has been planned, the preparations for the conference next year in Bristol are made, a contribution to the "European action to reduce health inequalities" has been given and a visit to Bulgaria has been made. Let's start with the developments in Romania and Bulgaria.



ARMODI

It was a great pleasure to represent MAMH in Targu Mures, where 35 doctors from different places in Romania (Targu Mures,

Bucuresti, Sibiu, Satu Mare, Brasov, Zalau Cluj Napoca, Brancovenesti and Reghin) established a Romanian Association, called ARMODI (Asociatia Romana a Medicilor lucrând cu Oamenii cu Dizabilitati Intelectuale).

All participants expressed feelings of not being taken seriously as doctors for people with intellectual disabilities and even being marginalised. They were happy with the initiative taken by Dénes Barabas, Maria Kalakatroni, Marietta Szilagy and Talitha van den Heuvel. Dénez Barabas is the first president of the association, Vinereanu Arina vice president, Atila Kosa secretary, Adelbert Cichi and Emil Farcas members. In May 2010 they will organize the next conference.

I also visited an institution for 300 intellectually disabled people, some group homes and a day centre for intellectually disabled children, a day centre for intellectually disabled adults and an institution for visually disabled people (among them some intellectually disabled, but also people who are studying at high school and university).

What I saw was of good quality; people do the best they can with a lack of qualified caregivers and financial means. Schooling seems to be paid for by the government and people with disabilities can get money (minimal social payment) for 'personal assistance', very often earned by the parents. All the 'extras' they need however, (daily activities, treatment of speech therapists, physiotherapists etc) seem to be luxury and are most of the time dependant on non-governmental organizations and sponsorship, sometimes supported by a local government when one is lucky enough to have a mayor on his side. It is important that such activities should be regarded as rights for people with intellectual disabilities and should be funded by the State.

This is one of the issues that the new association may work on.



Some of the participants of the Targu Mures conference

In *Romania - 2005 Comprehensive Monitoring Report (COM (2005) 534 final) of the European Commission* I read the following passage:

“The disabled and mental health care system

Despite positive developments, the situation in homes for disabled adults, psychiatric clinics and homes for the mentally disabled requires continuous improvement. Romania has started to tackle reform for the disabled as part of a larger social sector reform. The main focus is now on developing an inclusive strategy that aims at closing and restructuring large residential institutions by developing alternative community-based services, support to families and smaller residential units. One of the main pillars of the reform has been an administrative overhaul of the system: residential institutions have been transferred from local to county level, something which will result in a more coherent reform and provide better financing. The directorates for social protection have now under their responsibility the social services for disabled people. A public campaign is under way with a view to raising awareness of the rights of the disabled. Although reform in the sector is still very much in its early stages, it is on the right track.

As for the psychiatric care, living conditions for inmates are poor and budgetary resources allocated are limited. Although staffing levels have increased, they remain insufficient. Serious

overcrowding and lack of activities or medical services can be noted. Reports of violence and ill-treatment continue to be quite common. The 2002 Law on Mental Health and Protection of People with Psychological Disorders is still not being implemented because of the failure to adopt the regulations necessary for its enforcement. However, the government has begun to tackle this issue, and a structural reform has begun with a view to remedying the lack of strategy at national level, improving living standards in the institutions, and providing appropriate budgeting and specialised training”.

Dr Roger Banks, our Board member from the UK is currently involved in a WHO-Europe initiative to produce a declaration and action plan for the care of children with intellectual disabilities in Europe; the Romanian government being a key instigator and supporter of this development.

BULGARIA

In March I visited two day centres for intellectually disabled children and adults, a rehabilitation centre for children, a centre for people with visual impairments and I spoke with authorities of the municipality, of the Regional Public Health Centre City of Varna, and of the Medical University.

These are some of my findings:

1. In Varna there are no institutions for people with intellectual disabilities. Integrated care is the official policy. There still remain institutions in the country, which I was not able to visit.
2. There are several day centres for children and adults but there are people on a waiting list and I could not clearly establish its length. I am not sure, therefore, whether every person with an intellectual disability gets the care and support they need.

3. I was also unable to get a good insight into the financing of the care for people with intellectual disabilities. I heard different stories: The care for children with disabilities in a rehabilitation centre (Karin Dom) is free for the parents. The contribution of the government however covers just 10 % of the budget. The care in another day centre for intellectually disabled children (built with the support of the Twinning Foundation Dordrecht-Varna) is completely paid by the government. Schools are also funded by the State. For people with an intellectual disability, who live at home with their parents, sometimes one of the parents, most often the mother, receives a certain amount of money for 'personal guidance' of the individual with intellectual disabilities.
4. The therapies available in the day centre and the rehabilitation centre are similar to Western European countries: support of psychologists, physiotherapists, speech therapists is available. All centres have a sensory room at their disposal (for Snoezelen).
5. The role of the doctors in the centres is not quite clear: in one centre the doctor is just for first-aid medicine, in the rehabilitation centre the doctor also contributes to the personal plan for every client.
6. General medical care, provided by general practitioners, displays a lack of time, knowledge and special interest in people with intellectual disabilities. There is no specific training in intellectual disability medicine. There are no health watch programmes.
7. Contact is difficult since most of the doctors and the authorities do not speak English.

For the near future I think MAMH should continue to expand contacts with the universities of Varna and Sofia. The contacts with the authorities of the municipality and of the Ministry of Health may be helpful in developing future plans. I thank the board of the Twinning Foundation Dordrecht/Varna, for giving me the opportunity to join them in Varna and for opening doors to authorities and centres.

Note:

During my visit to Varna I did not see institutional care.

In the annual report of The Bulgarian Helsinki Committee (BHC), "Human Rights in Bulgaria 2008", a very bad picture is presented of the situation for institutionalised people with intellectual disabilities:

"It demonstrates the helplessness of the state institutions to deal with the situation in the closed institutions. This helplessness dooms thousands of people to live in a situation in which their human rights are severely violated. Given the seriousness of the situation of the people accommodated in institutions and of those under guardianship, on December 3 2008 the World Organization against Torture (OMCT) together with BHC and the Mental Disability Advocacy Centre (MDAC) submitted to the Bulgarian parliament an appeal to put an end to the violations of the rights of people with mental disabilities. The focus was placed, among other things, on the need to change the legal norms regulating the statute of placement under guardianship".

What you see is not always all there is.

ANNUAL GENERAL MEETING

Our General Meeting 2009 will be held **September 4th, 13:00-14:00**, in Amsterdam, during the Conference of EAMHID, September 3-5, in conference centre De Meervaart.

www.amsterdamcongress2009.org

The agenda will be sent to you later.

BRIDGE 2010

This will be the name of the conference which will be held in Bristol in the first week of May 2010. Dr Sylvia Carpenter is working hard on the programme and the announcements. In May the programme will be completed, and speakers and potential participants invited.

THE EUROPEAN UNION

In March 2009 we completed a response to the 'consultation paper, EU action to reduce health inequalities' of the European commission.

Citation 1: The size and scale of the differences in health of people living in different parts of the EU and between socially advantaged and disadvantaged EU citizens represents a challenge to the EU's commitment to solidarity and equality of opportunity. In this context, the European Commission has announced a communication on reducing health inequalities in the EU in its work programme for 2009 as an initiative on "Solidarity in Health".

Citation 2: As highlighted in the 2008 Joint Report on Social Inclusion and Social Protection¹ and the 2008 report² "Monitoring progress towards the objectives of the European Strategy for Social Protection and Social Inclusion" and others³, substantial differences in overall life expectancy at birth and in the years lived in good health (Healthy Life Years) can be observed across the EU Member States. People in many new Member States live shorter lives than their Western counterparts. For example, for women, the life expectancy gap between EU countries is 8 years. For men it is 14 years. Moreover, the gap in Healthy life years is even greater- for women it is as high as 18 years. The rates of incidence and mortality of diseases also vary widely across the EU. For example, ischaemic heart diseases kill over 10 times more women in Lithuania

than in France and there are 25 times more cases of tuberculosis in Romania than in Cyprus.

Large differences in health status also exist within EU Member States where there is a clear social gradient in health status⁴. People with a lower level of education, a lower occupational class or a lower level of income tend to die at a younger age and to have a higher prevalence of most types of health problems. For example, socio-economic inequalities in healthy life years can amount to more than 10 years for men and almost 5 years for women. Similar gaps exist in health between some ethnic and migrant groups and the general population. While overall levels of health have improved over the last 20 years the gap between the most advantaged and most disadvantaged has increased in many countries. Gender can also determine differences in health status, health risks and access to health services. Women live on average 6 years longer than men, but most of these additional years are lived with activity limitation due to bad health.

¹See

http://ec.europa.eu/employment_social/spsi/docs/social_inclusion/2008/joint_report_en.pdf

²See

http://ec.europa.eu/employment_social/spsi/docs/social_inclusion/2008/omc_monitoring_en.pdf

³See for example

http://ec.europa.eu/employment_social/spsi/reports_and_papers_en.htm for the annual reports of the European Observatory on Social Situation and Demography

⁴See for example

http://ec.europa.eu/health/ph_determinants/socio_economics/socio_economics_en.htm for various relevant links and publications.

In our response we have pointed out the specific health inequalities that people with intellectual disabilities experience. We offered our help in reducing these inequalities.

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