



Newsletter December 2010

Dear members,

After our very successful congress in Bristol UK, in May of this year, we received a lot of very positive reactions which is very pleasing. Now we will have to continue the work that is directed towards the main goal of MAMH: reducing the inequalities in health care that people with intellectual disabilities experience. A very important step has been taken by a WHO-Europe initiative: the establishment of a European Declaration on the Health of Children and Young People with Intellectual Disabilities and their Families. In the Newsletters of January and June 2010 we informed you on this project. MAMH has contributed to this project through Dr. Roger Banks, being a member of the Steering and Drafting Groups and main author of one of the ten expert papers (priority 1: protection from harm and abuse) and through Dr. Frans Scholte, as a participant in the invited NGOs conference in December 2009, on the Draft version of the Declaration, and main author of the expert paper to support priority 5 (Ensure good quality mental and physical health care).

This WHO initiative, Better health, better lives: children and young people with intellectual disabilities and their families “aims to ensure that all children and young people with intellectual disabilities are fully participating members of society, living with their families, integrated in the community and receiving health care and support proportional to their needs.

The declaration should cover 4 key objectives:

- promoting and supporting good physical and mental health and well-being;
- eliminating health and other inequalities and preventing other forms of discrimination, neglect and abuse;
- providing support that prevents family separation and allow parents to care for and protect children and young people with intellectual disabilities;
- supporting children and young people in the development of their potential and the successful transitions through life”.

“The following ten priority areas are identified which need to be addressed as a matter of urgency, in order to realize our vision that children and young people with intellectual disabilities and their families are able to live healthy and full lives. We will:

1. Protect children and young people with intellectual disabilities from harm and abuse

All children and young people with intellectual disabilities, wherever they live, must be guaranteed to live free from bullying, harm or abuse and should not live in fear or neglect.

2. Enable children and young people to grow up in a family environment

Promoting secure attachments and improving family functioning limits the impact of intellectual disability. Ongoing support to families is essential.

3. Transfer care from institutions to the community

Residential institutions that have a negative impact on the health and development of children and young people should be replaced by high quality community



Dr. Scholte, in front

support. New admissions to such institutions should be stopped through the development of community services.

4. Identify the needs of each child and young person

Early identification and early intervention improve long-term outcomes.

Children and young people require repeated assessment of their needs and planned support to make seamless transitions at each life stage.

5. Ensure that good quality mental and physical health care is coordinated and sustained

Children and young people with intellectual disabilities need the same access to health care as other children but may also need access to specialist treatment and care.

6. Safeguard the health and well-being of family carers

In order for a child with intellectual disabilities to grow up and develop within a family, the health and well-being of the family as a whole should be supported. Enabling families to care for their child from the time of identification of intellectual disability through to adulthood

can prevent harmful family strain or rejection of the disabled child.

7. Empower children and young people with intellectual disabilities to contribute to decision-making about their lives

Children and young people with intellectual disabilities can and will make their needs and wishes known and contribute to their community, given appropriate support and a receptive environment. Family members and advocates also need encouragement and support to make themselves heard.

8. Build workforce capacity and commitment

The well-being of children and young people with intellectual disabilities is strongly reliant on the knowledge, skills, attitudes and commitment of staff in all settings and sectors.

9. Collect essential information about needs and services and assure service quality

Quality standards and adequate information systems are needed to monitor quality of care, with transparent responsibilities for all stakeholders.

10. Invest to provide equal opportunities and achieve the best outcomes

Ensure fair and, if necessary, preferential spending on services from which intellectually disabled children and young people and their families benefit” (citation of the Declaration).

These ten priorities are further elaborated in accompanying ‘expert papers’.



Dr. Banks, also as representative of the UK

The final version of the Declaration has been signed by all the 53 European member states, UNICEF and WHO-Europe, supported by family organisations, service providers and other non-governmental organisations at a conference in Bucharest, November 26th and 27th 2010.

By signing this Declaration the governments committed themselves to implement and develop action plans together with non-governmental organisations.

The board considers this Declaration as a major step forwards, that provides us with

possibilities to put pressure on our governments to initiate new activities in the improvement of the care, including the medical care, for people with intellectual disabilities. We ask our member organisations and our individual members to study the Declaration, the ten priorities and the expert papers. We also encourage you to ask your government what they intend to do with this declaration. A suggestion could be to propose that your governments establish a Steering Group, consisting of members of government Ministries, client and family organisations, service providers and health organisations (of general practitioners and of intellectual disability physicians for example) that should work out for each priority area: where do we stand now, where do we have to go, which steps do we need to take between present and future situations, what timetable do we need for that.

For the complete Declaration and the expert papers on the ten priorities, take a look on the website of WHO-Europe:

www.euro.who.int/

2nd Academic Chair on Intellectual Disability Medicine in The Netherlands.

We congratulate Professor Henny van Schrojenstein Lantman-de Valk, MD, PhD, on her appointment as Professor in Intellectual Disability Medicine at the University of Nijmegen. This is the second Academic Chair in Intellectual Disability Medicine in The Netherlands. Professor Heleen Evenhuis, MD, PhD was her predecessor (Erasmus Medical Centre of the Rotterdam University).

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

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