

Accompanying letter to the power point, workshop 15, Amsterdam, October 2012

Already during the workshop in Munich, 2010 a participant of the workshop said that patients in the school age have a right to education when in hospital. Full stop. We just need to refer to the Universal Declaration of Human Rights and the Convention of the Rights of the Child. Yet we know that too many governments do their best to put in place procedures which postpone the start of the education when in hospital for so long that the patient is already discharged and sent home for convalescence before the school in hospital could even start.

Barriers to postpone education in hospital were listed in an old Survey I made in 2007. It is my impression that most of the incongruities found in that survey are already addressed in the Standard. But please check this. For your convenience the barriers are included in the PowerPoint. (Anybody interested in the specific answers from the governments who sent in answers may ask me for very unprofessional, but readable tables which put the answers in grids country by country. The HOPE website has a list of the governments that answered. Surf the worldwide web. Hospitalteachers.eu. Hit Current information, then workshops and workshop 15. A summary of the survey is there. Sometimes copies of the letters sent by the governments are also there. The website too is under revision☺. On the other hand some countries may by now have new school laws so facts might be outdated.)

Pupils as patients must be the only group of students with special educational needs whose educational rights have not yet been expressively addressed in the UNESCO Education for All Programme (EfA, start in Jomtien, Thailand in 1990).

In the power point I have made an effort to find support for “our pupils’” rights in paragraphs from conventions, agreements and statements which can come close to defining sick children’s need for special education and with focus on continuity and inclusion. Other paragraphs can surely be added. It is up to you to scrutinize, criticize or make best use of the ones I have mentioned. Use them for arguments sake or as a reference when binding (only conventions after ratification are binding. However it must be said that even after ratification the procedure of having them implemented into the national legislation takes time and varies from country to country. See more comments in the power point.) To some who might be interested in the development of the EfA-programme the power point may serve as important milestones. Even if many more documents from other meetings have been published within the EfA - programme, the Salamanca Statement and Framework for Action (1994) is to me still the most captivating document published on special needs education. It is not a diluted dishwasher agreement. The enthusiasm of the participants can still be sensed in the final document. What has happened in between? At least in my country schools (free schools and municipal schools) are rushing headlong into segregation and specialization. Few schools talk about “celebrating differences”.

The work that lies ahead of the workshop 15 is not just a revision or update of the Charter and the Standard. When ready and adopted both documents must be spearheads for the future. The following are groups of pupils/students who must be added to the Charter and the Standard.

- Well siblings to pupils/students admitted to hospital and children of adults in hospital.
- Cross border patients. Already now pupils are given treatment in other countries than their own.
- For pupils admitted to hospital recurrently we must ensure that the mainstream schools are well prepared to receive these students in between treatments.
- Rights of pupils with chronic diseases in the mainstream school. Pupils with chronic diseases and or disabilities should have full coverage in the Disability Convention. The disability convention must certainly be useful when we pin down the requirements for the adaptation of schools to receive pupils with disabilities and or medical needs.

I am happy to be able to include The Swedish School Nurses' Organization as observers in the workshop. Their expertise on inclusion as a partly "non-educational service" in schools is highly valued.

The HOPE Charter and Standard are very much needed. An effort must be made to have them adopted and recognized also by other organizations than HOPE, national and international. In the present working group there are members from New Zealand and Australia. They too are working on a Charter. Collaboration would be of benefit if at all we dream of having a globally adopted Charter and Standard for pupils and students with medical needs.

Problems may vary from country to country. If the participants in the workshop represent many countries it will be more likely for the Charter and the Standard to become as comprehensive as possible.

Gerd Falk-Schalk, Uppsala May 3, 2013