

Education of children and adolescents with medical needs in hospital or at home

A HOPE - Survey (2007 – 2008)

Summary, Identified Barriers, Examples of Good Practice

HOPE (*Hospital Organisation of Pedagogues in Europe*) as an INGO (International Non Governmental Organisation) of the CoE (*Council of Europe*) has asked the European Parliaments to collaborate in working towards a common strategy to guarantee continuity in the education of children and adolescents with medical needs, whether in hospital, at home or in a rehabilitation centre. It was our intention that these answers and our HOPE Charter may be a good start for a discussion aiming at finding a common strategy to safeguard continuity in education of pupils that are also patients.

In October 2007 HOPE sent a letter to the then listed addresses of all Ministries of education in the 47 member states of the CoE. We received 33 replies to the four questions which you will find below together with a general summary of the answers for each question.

1. Is there any legislation in your country that guarantees the educational rights of the child or adolescent suffering from illness be they at home or in hospital? If so, and if possible please include a copy of the legal text or a summary in English.

In general, European school laws promote and respect the right to access to ‘Education for all’ (Salamanca Statement and Framework for Action, World Conference on Special Needs Education: Access and Quality, Salamanca, Spain, 1994). But even so we know from reports from our network of hospital teachers in Europe that the implementation of the legislation is deficient both on national and local levels.

2. Is there any regulatory body that oversees the implementation of this law? How does this body ensure that the objectives are met?

It is not always clear from the answers that hospital schools are being inspected even if there is a system of inspection for ordinary schools. The Scottish Government sent an example of Her Majesty’s Inspectorate of Education from 2007 when it inspected the Hospital Education and Home Tuition Service.

3. Would it be possible for you to send us any statistics relating to numbers of pupils who have had to stay an extra school year because of illness or because of lack of continuation in their education?

Only San Marino and Liechtenstein stated that no child has ever had to stay an extra school year because of illness.

Although statistics regarding repeating a school year could not be presented the UK (Access to Education), Niedersachsen, Sachsen in Germany and the Swiss cantons of Aargau and Geneva included numbers of children and adolescents that required education because of illness or injury. Number of children/youth: UK (100 000), Niedersachsen (1 446), Saxony (7 708), the canton of Aargau (30), the canton of Geneva (100). However the lack of statistics shows that there is no general interest to really find out how our pupils fare in the educational systems in Europe. Adding to this there are no answers from e.g. Russia, France, Italy and Spain wherefore we can assume that there is a sufficient number of pupils throughout Europe warranting that countries in Europe collaborate to adopt a common strategy to ensure educational provisions for pupils and students with medical needs.

4. Is there any specialized education for teachers, both working in hospital or in mainstream education in your country? Please forward a curriculum.

With Austria as an exception there are no regular specialised courses for hospital teachers.

The Fachhochschule Nordwestschweiz, Pädagogische Hochschule offered a course with relevance to hospital teachers for children younger than six years in autumn 2007.

Slovakia mentions somatopedy as a field of study included in Special Pedagogy at the pedagogical faculties.

Wales is providing a bi-lingual e-learning course for teachers and support staff on special educational needs.

Barriers identified to continuity in education.

These also include examples from the biennial reports that are requested by HOPE from each of the committee members and which provide information on the current status within each country. Examples are also taken from seminars and congresses on education for students with medical needs.

- ***Regulations***
No regulations for education at home or unclear policies of responsibility for the education of the absent student.
- ***Criteria***
Stipulations relating to the length of time that a child or adolescent needs to be out of school before any educational intervention can start causes unnecessary delays.
- ***Consent***
in all forms from parents, medical team or school authorities cause delay to the

education process. This includes legislations where the doctor's consent or dissuasion alone can put the patient/pupil out of the general education system.

- **Communication**

No contact between the mainstream school and the hospital school.

- **Environment**

Hospitals do not always offer a proper learning environment as there is no proper legislation that places the responsibility of offering class rooms with them.

- **Specialised Training**

No special education or further education for hospital teachers.

- **Hospital Teacher's Role**

The hospital teacher is not a full member of the caring team or there is no hospital teacher at all. This causes disruption in the education and a break in the chain of information about the learning capabilities and achievements of the pupil to the main stream school, the referral unit or rehabilitation centre.

- **Shared Values**

No shared set of aims, values and vision between school staff and health service staff regarding school, diminishes the quality of education of the patients/pupils and may cause the patient to become an unwilling drop-out.

- **Confidentiality**

Strict rules of secrecy that do not allow exchange of information between authorities that is for the benefit of the pupil.

Future Challenges

- Agreements on continued education for cross-border patients.
- Provisions for temporary inclusions of siblings in the hospital schools.

Examples of good practice highlighted from the answers received.

Regulations-Stipulations: Keeping track of absent pupils is not impossible for countries with a larger population. In the UK, for instance, every municipality has its Local Education Authority (LEA) to which all absent pupils are reported. The intervention for the education otherwise than in the home school must be put in place never later than after 15 days of absence.

- Every school must have an educational welfare officer (EWO) to manage school attendance for all its pupils.
- Pupils in all European countries must have a personal education plan with no restrictions of subjects taught. In the case of pupils with special needs the plan must be responsive to demands of continuous revision following their changing medical status.
- There must also be a transparent follow-up system after discharge if there are fears of late cognitive effects of the treatment given and even, if necessary after several years.

- Schools must send information to their pupil in hospital or if they are taught at home. It includes social events and initiatives to facilitate liaison with peers.

All examples are more or less quotations from the Guidance: *Access to education for children and young pupils with medical needs** sent from the UK. and the Welsh version *Access to education for pupils with medical needs*. These set out minimum national standards for the education of children who are unable to attend school because of medical needs. The Welsh version can be obtained from Rebecca Griffiths education.training@wales.gsi.gov.uk version ISBN 0 7504 8868 9 with the addendum “Indicators of Effective Practice” (LEA Officers)

Among the answers received the UK statutory guidelines are well worth being used as an example for a European common strategy and compare well to the European Charter for Children in hospital adopted by European Hospital teachers during the General Assembly of HOPE in Barcelona in 2000.

Communication: Improving communication may be one of the first steps to work towards a better cooperation between the child and the parents, the home school and the hospital teacher.

Specialised training: Hospital teachers throughout Europe form a special community of pedagogues that share the unique experience and expertise of teaching students with medical needs. (See Professional profile for Hospital Teachers, O.H. Mourik. copyright Ziezon, 2008 ISBN-978-90-810631-2-8) This community is little seen or recognised in many countries. It goes without saying that it would be most efficient to offer a European course for a minority group of teachers such as Hospital teachers at university level for a Masters degree. With especially the long experience of offering courses in Austria as a reference, HOPE will support and collaborate in any project between universities that aims at developing such courses.

Hospital teacher’s role: The school law in Niedersachsen is the only legislation, in the answers received, that stipulates that the hospital teacher must be a full member of the caring team. The hospital teacher is a link between the sick child, the parents and authorities. The hospital teacher knows about changes in the medical care and treatments and adapts the education plan to the changing circumstances.

All governments should therefore encourage and support national organisations for hospital teachers in order to have expert partners with whom they can have a dialogue and so keep up a modern standard for a continued education for children and adolescents with medical needs. If there is no national organisation, HOPE or if at hand the Committee member or Contact Person of HOPE in your country are ready to enter as dialogue partners.

Hopefully our survey gives enough evidence for any reader of this document to support our campaign with the final aim to formulate a common strategy among all the member states of the Council of Europe to ensure continuity in education for children and youth with medical needs be they in hospital or at home.

Finally I would like to express my sincere thanks to the governments that answered and took such an interest in sending extensive information, even beyond what was requested. In doing so one noticed an assurance of being able to present examples of good practice and a pride in the work performed by hospital schools in their countries.

Uppsala, October 23, 2009

Yours faithfully



Ms Gerd Falk-Schalk, President, HOPE

* At http://www.hospitalteachers.eu/winfos/activeprojects_master.php → Workshop 15.
you will find:

- Scanned copies of all answers received.
- Assessments of answers in tables
- “UK Access to Education” in pdf.