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## **Submission**

### **Re CRC General Comment on the right of the child to the enjoyment of the highest attainable standard of health (art. 24)**

#### **Brief**

Whether the child's right to health as stipulated in article 24 of the CRC is fully implemented by States Parties can only be judged in the context of how the needs of sick children and their families are met. The most important points are:

- A health care system accessible to all children from age 0 – 18, regardless of status, cultural background, illness or disability, that ensures the highest attainable standard of health care, provided by specifically trained paediatric staff within the necessary infrastructure and environment.
- Parents are considered by the caring team as partners who are as much as possible involved in the treatment of their child. The responsibility of parents for the care of their sick child is acknowledged by States Parties by regulations that allow paid leaves and compensate parents for all costs directly related to a child's illness, disability or stay in hospital.
- Children are treated in children's hospitals or wards by specially trained paediatric staff in an environment adapted to the needs of children of different ages and stages of development.
- Children are not admitted to adult wards with non-paediatric staff and in an environment unsuitable for children. If for rare examinations, surgery or treatments not available in a nearby children's hospital, children are exceptionally admitted to adult wards, they are transferred back to the children's ward as quickly as possible. Doctors or specialists from the adult ward visit child patients in the children's ward and not vice versa.
- Hospitals where children are treated provide trained staff and organizational frameworks to mitigate children's fear, pain and distress. Restraint should be avoided in case of invasive procedures, procedures requiring immobility or minor, but painful procedures (life threatening situations excepted). Restraint is an unacceptable technique in direct contradiction to the child's right to protection from all forms of physical or mental violence.
- Children's hospitals are fully reimbursed for non-medical care of children by professional staff (such as Hospital Play Specialists, Teachers, Psychologists, Social Workers, etc.). The right to therapeutic and recreational play and education during a hospital stay is a basic requirement for the wellbeing of children.
- Due to the enormous success of scientific research in the field of paediatric medicine many once fatal children's diseases can now be cured, great progress has also been achieved in the rehabilitation of disabilities. Many of these children nowadays enjoy a life as healthy adults and are fully valid members of society. They earn their own living and pay taxes. States Parties therefore need to understand that the cost of a holistic health care system for children is not lost money, but an investment in a society's future. The present trends in the health care market as described below do not solve problems but create new ones.

#### **I. Introduction**

Beginning in the late 19th century and throughout the 20th century huge progress has been achieved in the medical treatment of child specific illnesses and disabilities. At the same time hospitals exclusively for the treatment of children were founded, staffed by doctors and nurses with special paediatric training.

On the other hand, until the 1960s parents had no or only limited access to their hospitalized child, which resulted in long-lasting traumatic experiences for many children. Alarming scientific studies by psychologists and paediatricians became known in the 1950s.

In order to improve this situation parent's associations were founded in many European countries to promote the unrestricted presence and the participation of parents in the treatment of their children. The first such association, the National Association for the Welfare of Children in Hospital (NAWCH), was founded in 1961 in the UK, other European countries followed in the 1970s.

In 1988 a first international conference of associations from 12 European countries met in Leiden (The Netherlands). Based on experiential learning the **Charter for the Rights of Sick Children** was drawn up and adopted. The Charter consists of 10 points representing the most basic principles to be considered with regard to the treatment of all sick children before, during and after a hospital stay.

In 1993 the umbrella organization EACH European Association for Children in Hospital was founded in order to strengthen the exchange of information and experiences and to promote the implementation of the Charter in all European countries.

In 2002 the member associations of EACH adopted the Annotations to the Charter (Enclosure 1) to illustrate the scope of applications for the Charter and to explain to a wider audience the meaning of "family centred care". The Annotations take into consideration the standards to be met with by the national health care systems to comply with the requirements of the child's right to health.

Today National Associations and 8 individual persons from 19 European countries are members of EACH as well as 1 association from Japan (see on the last page list of members endorsing the present submission).

## **II. Health related articles of the CRC and the EACH Charter for the Rights of Sick Children**

The CRC promotes the child's right to health and the measures to be taken in this regard, and it requires from States Parties "to ensure that the institutions, services and facilities responsible for the care or protection of children shall conform with the standards established by competent authorities". However, as described in the above history of EACH and in view of current political developments all over Europe, such "institutions, services and facilities" need to be looked at from the perspective of the sick child and his family. A few decades ago hospital staff, the scientific audience and health care ministries were convinced and took it for granted that hospitalized children in their countries benefitted from the best possible care and that everything was done for their wellbeing. It did not cross anybody's mind to ask the children concerned and their families.

To provide a holistic view on the implementation of the CRC and the EACH Charter, the concept of family centred care and the differing needs of children depending on age, individual development and illness or disability requires a broader perspective. The EACH Charter was drafted to address the problems that sick children or children with disabilities and their families encounter.

## **III. CRC articles relating to health and experiences of EACH members**

For the implementation of the right to health, resp. the rights of sick children not only art. 24, but also the following articles of the CRC need to be considered and should make part of the CRC General Comments on art. 24:

### **CRC Definition of the age of a child**

The CRC defines children as from the age of 0 to 18 years.

In quite a number of European countries the upper age limit for children admitted to children's hospitals and wards is 16 years in some countries as low as 12 years. In recent years the age limit has been increased to 18 years – but it is not yet a general standard.

For children and adolescents needing psychiatric care many children's hospitals do not provide appropriate infrastructure, and they are inadequately treated in institutions for adults. Even in well-resourced countries, such as Switzerland or France, psychiatric services with staff specifically trained for the care of children of different ages are not sufficiently established and funded. This applies especially to adolescents who need their own space away from smaller children but also away from adults (an increasing problem e.g. with regard to the rising numbers with anorexia, depression or suicide attempts among adolescents).

**CRC Art. 3** (see EACH Charter Points 1-3, 6-8)

In our opinion this is the most important article for implementing art. 24. To our regret we are observing in all European countries a rising tendency to continuously reform health care systems with the aim to cut costs in general (and regardless of the ultimate long-term outcome for the public health). Much too often the result are ill-conceived regulations and laws that severely reduce the rights of children to specific paediatric care.

The step-by-step privatisation of health care and raising the profitability of hospitals by focussing on high-tech medicine completely neglects the social responsibility of States Parties with regard to the care of sick children in hospitals or in their community. As a result all over Europe specialized independent children's hospitals are closing down or are downgraded to children's departments within an adult hospital. Likewise in many European countries the specific education of paediatric staff has been abolished in favour of a so-called generalist education.

In countries, such as Germany, many children's hospitals were closed following the introduction of the DRG-reimbursement system and more than 50% of the children are now treated in adult hospitals not specialized for the treatment of children. The care children need in addition to the strictly medical treatment is not reimbursed by the DRG-system and many children's hospitals had to close down due to insufficient income. In France where a similar system exists (Tarification à l'activité or T2A) most hospitals even the big university hospitals have a budget in deficit.

It is important to note that those payment systems (DRG-T2A) consider only the technical aspects of medical care and leave by side the time spent in the relationship work as well as the time for the necessary information to children and parents, which are both so important in children care.

As children in Europe are a minority of approx. 20% of the population, all statistical data show percentages, which are too small to regard them as substantial specialised fields of medicine. There is an overall trend to minimize the number of hospitals and to allocate specialised medical fields (e.g. coronary surgery or bone transplants) to one or two hospitals per country (where children are treated by non-paediatric staff). Distances of 300 km and more are considered as bearable for the patients. What this means for the families of sick children does not need much imagination.

The small percentage of ill children explains also the problem encountered with paediatric medications. Many of them used daily are not adapted for children and as a consequence, negative side effects appear when those medications are used to treat children (the problem is important when treating cancer or rare diseases). In spite of a European regulation (2005), the pharmaceutical companies are not very active in this field for financial reasons (high cost of the studies for a small number of patients), and States Parties do not seem very concerned about the problem.

On the other hand, there is scientific evidence at hand that e.g. anaesthesia introduced by non-paediatric anaesthetists results in a higher death risk for children. Even if there are regulations that children should be transferred after surgery from the adult hospital to the adjoining children's hospital this is quite often not done for profit reasons. Not everywhere adult hospitals indicate in their statistics the age of their patients so that no specific data is available.

There is also scientific evidence available that the non-specialized transportation of newborn babies needing neonatal intensive care (Nicu) results in significantly higher death rates. Nonetheless hospital planners are requesting Nicu centres in a few hospitals only in order to intensify the specialization described above. The transport of such babies has to be combined with a highly specialized transportation system with trained paediatric staff (doctors and nurses). Furthermore, as several scientific studies show, the separation of baby and mother shortly after birth severely disturbs the important early bonding process.

Although the arguments in favour of highly specialized (meaning also highly qualified) hospitals are convincing at first sight one of the ultimate results will be that vast parts on the countryside will be deprived of general hospital care. According to our observations health care system reforms are resolved by politicians and parliaments without the slightest consideration of children's needs and the damaging long-term effects on paediatric medicine in general. "The best interest of the child" as required in Art. 3.1 is almost never a "primary consideration".

**Art. 5** (see EACH Charter points 2 and 3)

"The respect of the responsibilities, rights and duties of parents ..." has, according to our experience, greatly improved in many children's hospitals in Western Europe, to a lesser extent in the new Eastern EU countries. But the rights and duties of parents are jeopardized by new developments on the health care market as described above.

**Art. 9** (see EACH Charter points 2 – 3)

"... a child shall not be separated from his or her parents against their will" – Applied to sick children in hospital, the situation has greatly improved by the almost generally accepted "rooming-in" principle for parents. But there are still hospitals (in Western and Eastern European countries) which do not allow rooming-in for all parents due to lack

of space (especially in intensive care units, where parents are so necessary for the well-being of the child) or do not allow the presence of parents at special examinations, treatments or e.g. preparation of anaesthesia or ask the parents to pay for the night. The reasons differ from country to country, but are clearly in violation of CRC Art. 3.3.

**Art. 12** (see EACH Charter points 4 – 5)

Thanks to the efforts of promoting the CRC the right of the child to express his own view and to be heard gets much more public attention. It is, however, a process where adults in general as well as the staff in hospitals or other institutions still have a lot to learn. Especially in difficult or delicate situations it is not easy to find solutions appropriate to the age and development of a child.

In our opinion the training of hospital staff specialized in the care of children should put even more importance than up to now on the training of paediatric staff (doctors and nurses) to communicate with children.

**Art. 16 and Art. 30** (see EACH Charter point 10)

The protection of the privacy of a child and his right to be treated with tact and understanding is – although mostly undisputed – again an ongoing process and has to be part of the training of doctors, nurses and other persons specialized in the care of children.

In this connection migrant children and their families very often do not find the necessary acceptance of their different cultural backgrounds – mostly due to lack of knowledge or ignorance. The help of professional translators to overcome at least the language barrier is too rarely used. Especially in hospitals the awareness for and knowledge of differing cultural views and manners is of paramount importance.

**Art. 17** (EACH Charter point 5)

We see the child's right to access to appropriate information in conjunction with art. 12, especially when it comes to information and materials, which further the wellbeing and physical and mental health of children.

Starting at an early age, general information on health issues should be provided by parents for their children. This should continue on through primary and secondary school level and be complemented by information materials on specific diseases prepared and distributed by doctors and hospitals, and, in our multi-cultural societies in the most currently used foreign languages.

**Art. 18** (EACH Charter points 2-4)

The recognition of the responsibilities of parents for the upbringing and development of the child is a cornerstone for creating an environment where the child feels protected and safe. In hospitals and other institutions, facilities and services providing care for children the participation of families is of paramount importance (Art. 18.2). Transparency around the work and activities of the staff is essential to avoid mistreatment or abuse of children in such institutions.

There is an inherent risk that uncontrolled staff members misuse their institutional authority. As recent scandals show, children in institutions (foster homes, homes for handicapped children, boarding schools etc.) are not sufficiently protected under today's laws and regulations. As a result the child's right to health is severely violated.

Acknowledging the joint responsibilities of parents by States Parties would also mean that the financial burden of parents with sick children is recognized. Sweden is the only country in Europe that grants paid leave to parents when the child becomes ill (4 weeks per year). In all other countries parents only get unpaid leave, if at all. Mothers whose children are often ill risk losing their job if they are taking leave for this reason. When both parents are working, the accompaniment of a child during a hospital stay might be impossible due to financial reasons. For parents who live in a distance from the hospital the cost of transportation for daily visits may accrue to a quite important sum in case of a longer hospital stay; the same applies for costs in a parking lot. In many hospitals parents cannot stay with their child without cost. Further costs might be incurred for out-of-home meals and for the care of siblings at home by third persons. In case of children undergoing long-term treatment or with chronic diseases requiring repeated hospital stays parents have to bear a considerable financial burden not reimbursed by health insurances. Still too often, the only choice for parents, whose child has a long-lasting and severe disease, is losing their job and facing a dramatic change of income for the whole family.

**Art. 19** (EACH Charter points 8 – 10)

As pointed out with regard to Art. 18 the child's right to health is severely impaired, when children are not protected from all "forms of physical or mental violence".

In still too many paediatric wards, pain-control is not adequately provided due to a lack of training of nurses and doctors and an inadequate organisation of the ward.

The practice of restraining children, i.e. forced immobilization, during clinical procedures is still common in many countries. In many situations lack of experience or knowledge of other forms of intervention and alternatives are the

main reasons for this practice. Regarding invasive procedures (e.g. bone marrow puncture, endoscopy, extensive wound care), procedures requiring immobility (e.g. imaging) and other painful or stressful procedures (e.g. intravascular access, lumbar puncture, suturing of wounds, ENT and dental procedures, urinary catheterization) forcible restraint is an unacceptable technique in direct contradiction to the child's right to protection from all forms of physical or mental violence. It is not in the best interest of the child.

**Art. 23.3 and 23.4**

The principles of the EACH Charter for the Rights of Sick Children equally apply to children with all kinds of illnesses or disabilities.

In our opinion too little is done in most European countries to ensure the access of disabled children (especially in case of severe disabilities) to education, training, and health care services. We see many cases where families with disabled children are not adequately or sufficiently supported by social and health care systems in Europe. Mostly the financial support of such families is meagre, given the fact that parents with a disabled child are limited in their working careers and earn lower salaries. Various state insurances and agencies are responsible and endless discussions have to be carried out on whether a treatment is due to the disability or a "normal" illness. Apart from the 24h-care of their child parents are spending many hours repeatedly writing applications to obtain confirmation from doctors or experts in order to get reimbursement for necessary technical equipment, special clothes or articles of care. Services offering hourly or daily relief from care for such parents do not exist in many places and are mostly provided on a voluntary basis.

In this area only a holistic approach of family centred care can ensure the rights of children with disabilities.

**Art. 25** (EACH Charter point 8)

The child's right to periodic review of treatment oblige hospitals or other health care institutions to employ staff specifically trained for the treatment of children and with special expertise to independently review and evaluate a child's development and the best methods for his care, protection and treatment.

**Art. 28, 29.1 a) and c), Art. 31** (EACH Charter points 7 and 10)

Children of all ages, regardless of their illness or disability and regardless of their own culture, religion or language shall have full opportunity for play, recreation and education also in hospital. Play is an important factor for children to better cope with their experiences in hospital and the necessary, maybe painful, medical examinations and treatments.

In the UK the profession of Hospital Play Specialists (HPS) is well established. Hospital Play Specialists are trained to prepare children e.g. for surgery or a medical treatment and accompany children and their families during (and under certain conditions after) their stay in hospital. HPSs are integrated in the team caring for a child and they are highly appreciated by doctors, nurses as well as by parents. HPS are trained to observe the behaviour of children, to recognize possible anxieties or traumatic after-effects of a treatment and to evaluate and further the skills of a child to cope with the situation.

Apart from the UK, Sweden and The Netherlands no other European country has developed so far a similar professional care for hospitalized children. In a number of countries inadequate old hospital buildings do not provide enough space for playrooms, playing with children is mostly left to charity workers and school lessons are often provided by outside teachers. Play and education are not part of a hospital's budget and if not reimbursed e.g. by the ministry of education or private sponsoring, it may be abolished altogether. Again, this is a field where the DRG reimbursement system has a disastrous effect on the holistic care of children. EACH strongly recommends that the profession of HPS is introduced in all countries of Europe. (HPSs work in the US, Australia, New Zealand, Hong Kong, Japan).

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Dear Madam, dear Sir, we hope our submission will be helpful in drafting your General Comments on article 24. We are, of course, at your disposal for any further information or a meeting.

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**Enclosures:**

EACH Charter and Annotations (by post)

EACH Member Associations endorsing the submission