



## The Child-Friendly Paediatric Health Care Model

**Prof. Dr. med. Jochen H. H. Ehrich, D.C.M.T. (London)**

Department of paediatric Kidney, Liver and Metabolic Diseases of Hannover Medical School, Germany.

This article focuses on vulnerable children with chronic diseases and on the role of paediatricians, teachers and other stakeholders in today's complex health systems.

Paediatricians are not aiming at creating a monopoly; instead they favour the team approach of all caregivers.

Paediatrics is characterised by the **diversity, variety and heterogeneity of health care offered in the 51 European countries with more than 200 million children aged less than 18 years** and with more than 200.000 paediatricians. Paediatrics respects the rules on child development which state that an adolescent is not a young adult, a school child is not a small adolescent, an infant is not a small child, a neonate is not a small infant and a premature newborn is not a small neonate. Paediatricians care for both healthy and sick children. Health care management differs according to where: inpatient care in hospitals, outpatient care in hospitals or in private practices, homecare and rehabilitative care in special rehabilitation units. Paediatric health care focuses on the patient and not on diseases; however children with acute diseases need a completely different case management than children with chronic diseases. Special care is given to underprivileged and marginalised children such as children with chronic diseases and disabilities, children with a migrant background and poor children. Approximately 20% of the child population suffers from a chronic disease and with a few exceptions, almost all these chronic diseases are rare diseases with more than 1.000 different disease entities. Rare diseases mean affecting less than 1 patient per 5.000 people. Children have by far a longer period to cope with their chronic disease or disability than adults. The transition from paediatric to adult medical care is a multi-factorial challenge. Children have no voice in society and their caregivers do not speak with one voice, which has led to considerable inequity of health care in many European countries.

The Council of Europe has recently developed “**the Child-Friendly Health Care Model**” which will be presented to 47 Ministers of Health on the occasion of the Ministerial Conference to be held in September 2011 in Lisbon. The preamble of this health-care model reads: Sustainable development fulfils the needs of the present generation without endangering the needs of future generations. The aim is to create a virtuous cycle to improve children's health in Europe with the dictate of the “4 Musts”: **Protection, Prevention, Provision and Participation.**



As the child-friendly health care model should be applicable to all age groups of children and to all disease groups affecting children, this manuscript selected **children with chronic kidney diseases and transplantation** to show how this design in terms of references may be applied to help stakeholders in improving paediatric health in different European countries.

**Protecting** children with kidney diseases means eliminating nephrotoxic substances from the environment of children, for instance, heavy metals and nephrotoxic drugs thus fulfilling the criteria of primary prevention. There is also a need for the avoidance of over and under diagnosis of urinary tract diseases which may harm children, and the same holds true for over and under treatment of urinary tract diseases. Last but not least, a lack of education must be avoided.

**Prevention** of kidney diseases includes genetic counselling of at risk families. Secondary prevention will include cost-free mass screening of all children to identify urinary tract diseases using urinary dip sticks and ultrasonography or, if the cost-benefit ratio is negative then secondary prevention should be offered to risk groups only, i.e., prematures and small for gestational age newborns. Most chronic kidney diseases start early in life and many of them remain undetected because of a lack of clinical symptoms and signs. Early diagnosis of kidney diseases is required and, once diagnosed, treatment should aim at halting the progression of chronic kidney disease and reducing extra-renal comorbidity by adequate therapy thus fulfilling the criteria of tertiary prevention. Pedagogic counselling must be offered to risk families and to teachers as well as all persons involved in vocational training of transplanted patients.

Adequate nephrological care includes the **provision** of adequate, affordable, accessible, available diagnostic and therapeutic renal care as well as equity, efficacy and efficiency of renal care including modern supportive technology. National health care systems must provide adequately trained teams of caregivers including specialised paediatric nephrologists, nurses, dialysis teams, pharmacists, psychologists, teachers, dieticians, career advisors, physiotherapists and others. These human resources need training, accreditation, continuous medical education and supervision to guarantee high standards of medical care. Health ministries must provide a sufficient number of child-adequate children's hospitals with a renal unit, dialysis unit and kidney transplant unit which fulfils the criteria of paediatric centres of excellence. Child-friendly renal replacement therapy means that transplantation is more adequate than peritoneal dialysis and peritoneal dialysis is more child-friendly than haemodialysis. One of the most recent challenges has turned out to be the provision of a basis for rational use of essential drugs, their safety and distribution. The off-label use of drugs which are not tested in a paediatric population exposes children to additional risks. Paediatric nephrologists must provide evidence-based practice guidelines which are based on pure scientific findings, however their national application may depend on country-specific priorities influencing appropriate use and updating. Paediatric nephrologists represent around 1% of all paediatricians and they should provide interaction, communication and referral with primary paediatric health caregivers. This



could be a paediatrician or a general practitioner depending on the different primary paediatric health care systems in Europe. Paediatric nephrologists must provide a guided transfer of adolescents into adult renal care. **All caregivers must respect the children's rights and children must be asked, children must be heard, children must have a voice before taking a final decision on further diagnostics or therapeutic intervention. All stakeholders should aim at increasing children's families' trust in caregivers and institutions.** Improvement of the health education of patients and their families and offering culturally appropriate counselling will lead to an improved participation of patients. Accept non-adherence as a fact which cannot be attributed solely to patients and their families but also to all caregivers. Therefore unavoidable non-adherence has to be taken as an imminent behavioural challenge requiring special attention, prophylaxis and treatment. Provision of adequate, affordable, accessible, available educational care as well as equity, efficacy and efficiency of educational care has to be guaranteed. Adequately trained teams of teachers must cooperate with all other care givers. Teachers need training, accreditation, continuous medical education and supervision.

The right to health does not mean the right to be healthy, nor does it mean that poor governments must put in expensive treatment, but it does require fair-play in offering care when concerning age, gender, ethnicity, culture, socioeconomic status, religious beliefs, political beliefs, or other ideologies of patients. The priorities of medical care given to children may differ from country to country, however, equal health opportunities should be given to all age groups in a given country. Cross border care should be improved and organisational pathways must be developed if there is no adequate treatment available in a given country.

The following federal and regional policy makers should be represented in **national health care programmes**:

I. **Ministries** of 1. Health, of 2. Labour and Social Affairs, 3. for Family Affairs, 4. of Transportation, Building and Urban Affairs, 5. **of Education and Science**, 6. of Food, Agriculture and Consumer Protection, 7. for the Environment;

II. **Health insurance companies;**

III. **Non-governmental (NGO) health care providers such as HOPE;**

IV. **Parents' organisations;**

V. **other.**

**The CFHC mode is universally applicable however, the emphasis is different and its application differs according to age groups (fetus, newborns, infants, preschool children, schoolchildren, adolescents, young adults) as well as to healthy children and to children with different disease groups.**



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The challenge in **international social responsibility** with respect to **children with chronic diseases** includes the following:

1. The **child-friendly health care model** should be applicable to all paediatric subspecialties in all European countries.
2. The lack of **demographic data** on the diversity of paediatric health care in Europe **including the differences in health education** needs to be compensated by following the path: 1. Research, 2. Evaluation of quality and of priorities, 3. Recommendations.
3. Initiate a strategy for further **communication in the “triangle” of patients and patients’ organisations, medical care givers and teachers** to stimulate cooperation and consensus of all opinion-makers when improving well child care.
4. There may be a need for a specialised **European agency for chronically sick children** offering both a scientific and social network for all stakeholders.